THE UNIVERSITY OF HULL

Adults with Intellectual Disabilities' Lived Experiences of Wellbeing and the Internet: A Descriptive Phenomenological Study

being a Thesis submitted for the Degree of Doctor of Philosophy

in the University of Hull

by

Gillian Helen Hebblewhite, BSc (Hons), BA (Hons) (The University of Lincoln)

February 2018

Dedication

This thesis is dedicated to the participants who took part in this study who, by sharing their experiences with such openness and honesty, have deepened and enriched my own understanding of the lived experience of wellbeing and internet for those with intellectual disabilities.

Acknowledgements

I would like to thank Emma Stevens for her support whilst I completed this Ph.D. and my supervisors, Dr Nick Hutchinson and Professor Kate Galvin, for their continuous support and expertise. Without them I would not have managed to complete this study.

I would also like to thank the members of my advisory group, all the organisations and individuals who took part in my study, Emily Woodcock for proof reading my thesis and all those who have supported and helped me during my studies.

Abstract

Internet usage continues to increase among adults with intellectual disabilities (IDs), but many are scared to use the internet or are denied access by those who care for them. The internet offers many opportunities, such as the ability to increase social networks and independence, and gain access to health information and support, all of which could contribute to the wellbeing of those with IDs. Due to the lack of qualitative research into the everyday lived online experiences of adults with IDs living in the United Kingdom (UK), decisions around adults with IDs' internet access and use are often based on reported stories in the media, those without IDs' experiences, and child-related internet information. This has resulted in an overly paternal and negative approach and a lack of understanding into how best to support adults with IDs' enjoyable, safe and independent internet use.

Taking a descriptive-empirical phenomenological approach, 8 participants with IDs aged between 19-62 from the Yorkshire and Humber region, were interviewed multiple times using semi-structured and adapted methods about their experiences of wellbeing and the internet. The qualitative data was analysed in two phases: data relating to the individual participant's context was analysed using inductive thematic analysis (TA), informed by methods set out by Braun and Clarke (2006, 2013), whilst data relating to the concrete lived experiences of the phenomenon was analysed using descriptive-empirical phenomenological methods set out by Giorgi (2009). The essential structure of the phenomenon: internet and wellbeing, was composed of seven constituents:

- The internet as a mirror.
- The internet enables visibility and invisibility.
- The internet as liberating.
- The internet meets unmet needs.
- The internet creates a decision maker and expert.
- The internet as friend and foe.
- The body connects to, and disconnects from, the internet.

The participants' sense of wellbeing, as well as suffering, was often integral to the internet experience and entwined with their offline context and ID related identities.

Table of Contents

List of Tables

List of Figures

List of Abbreviations

American Association of Developmental and Intellectual Disabilities - AADID

Artificial Intelligence - AI

Call of Duty - CoD

Department of Health - DoH

Down’s Syndrome - DS

Grand Theft Auto - GTA

Intellectual Disability - ID

Intellectual Disabilities - IDs

Independent State of Iraq and Syria - ISIS

Information and Communication Technology - ICT

Internet Gaming Disorder - IGD

Massively Multi-Player Game - MMO

Massively Multi-Player Games - MMOs

Massively Multiplayer Online Role-Playing Game - MMORPG

Massively Multiplayer Online Role-Playing Games - MMORPGs

National Institute for Health and Care Excellence - NICE

Profound Intellectual and Multiple Disabilities - PIMD

Reflective Lifeworld Research - RLR

Registered Learning Disability Nurse - RNLD

Speech and Language Difficulties – SLD

Thematic Analysis - TA

Virtual Environment - VE

Virtual Environments - VEs

Voice over Internet Protocol - VoIP

World Health Organisation - WHO

United Kingdom - UK

United States of America - USA

Chapter 1

Background to Intellectual Disabilities, the Internet and Wellbeing

1.1 The starting point for this study

The topic for this research study originated, initially, from my interest in globalisation (which the internet is a process of) and because of many conversations over several years with people with IDs, their families, carers, professionals and supporters. The subject of the internet, especially when combined with the idea of people with IDs independently accessing and using it, appeared to bring about strong opinions and feelings, especially from those without an ID. When those without an ID re-told their own or others' online experiences, which was often negative, this appeared to influence the listener with IDs', sometimes making them feel scared and apprehensive about the internet. Many did not know exactly what they should be fearful of and had not experienced the internet themselves to gain their own online experiences. I found it was common that older parents and/or paid supporters of an adult with an ID often acquired their information about the internet from secondary sources, especially the media and other parents and family members, rather than from their own lived experiences of the internet. To me, this group of people with IDs and their older parents/carers were missing online opportunities, which could contribute positively to many aspects of their wellbeing.

When talking to adults with IDs who had accessed the internet their experiences varied greatly. Some found the internet to be an altogether positive, enjoyable, entertaining and informative experience, whilst others had experienced online bullying, sexually inappropriate messages on social media by those they did not know, and verbal abuse centred towards their ID. The negative online experiences which had interrupted their sense of wellbeing either made them cautious of going onto the internet again (a decision often supported by those around them) or they had accepted these negative experiences as part of the whole of their internet experience and continued to use the internet. I encountered both these variations at a youth club for young people with IDs, although the latter was more common. For example, one young woman with an ID explained how she was currently being bullied on Facebook. She felt distressed and unsure of how to stop this from happening but wanted to continue using the social media platform. Her mother, who was unfamiliar with using the internet, was concerned and was trying to find ways to stop the cyberbullies targeting her daughter, including suggesting that her daughter should no longer continue to use Facebook. Both were unable to navigate themselves around Facebook to report or block the bullies, who were the young woman’s school peers. Facebook has subsequently simplified and made this process easier, but it still lacks (as do many parts of the platform) accessibility for those with IDs. Another young woman with Down’s Syndrome (DS) at the same youth club told me, in a matter of fact way, that she was regularly asked by men she did not know, via messages on social media, for ‘topless’ photographs of herself. She simply ignored their requests and continued to enjoy using the internet.

Internet use was common amongst the young people with IDs who attended the club and they accessed the internet at home, their school and on their own personal mobile phones with ease. They had grown up with the internet from an early age, it was embedded in their everyday lives and the term ‘digital natives’ (Oxford University Press, 2017) accurately described many of these young people I met. However those whose physical and IDs were significant enough to make accessing the internet difficult due to a lack of Information and Communication Technology (ICT) training and therefore skill level, adaptations, and a positive attitude towards the opportunity to access the internet and their abilities by those supporting them.

On the other end of the continuum, some people with IDs across a range of settings, often older and living in residential care, had no idea what ‘internet’ meant or knew of its existence. Others wanted desperately to access the internet but had no opportunities to do this. At a residential home for people with IDs, younger residents believed the internet could help them find out about the things that mattered to them, as well as offering them an easier way of communicating with their family and friends. It was sad to discover that one reason for staff denying an individual with an ID the opportunity to learn to operate and access the internet was that they would communicate more with their family, and their family did not want more communication with this individual. Even if a resident had the ICT skills and wanted to go online, they could not easily do this because there were limited computers onsite and these were for staff use only. No attempt was taken to provide the residents with alternative ways to access the internet. The staff’s reluctant to help the residents access the internet, beyond the simple lack of physical access to a computer, included: a fear of the risks the internet could pose to the adults with IDs, a lack of resources and time in their paid role to provide the required support to enable this, their own lack of knowledge in the area, or a conclusion that the internet would be too difficult or of no use for the adults with IDs to use.

Refering to internet-related literature, the consensus is that the internet will continue to increase its influence over our lives and provide ever more opportunities and threats (some complex and yet unknown) to all of us, including those with IDs. The exclusion of those with IDs from the internet is effectively ill-preparing them for the technological world they find themselves in, and this could mean that they will struggle to live independent and well lives as a result. At present, there is a lack of research into adults with IDs' everyday lived online experiences and wellbeing. Research that does exists is often unreflectively influenced by a non-ID perspective, one which is often paternalistic and risk-averse in its approach to those with IDs and the internet. Without access to balanced research (which includes the lived experiences of the internet accessed by people with IDs) media stories, non-ID experiences and child-related internet research will continue to be relied explicitly or implicitly upon to provide advice and guidance to inform decision making around internet use by adults with IDs and their supporters. However, it should be noted that many in the field are working towards a more balanced approach, for example, researchers who are cited in this chapter, and SaferNet charity and dimension, who provide internet advice that is created in partnership with, and for, people with IDs and those who support them. Although the internet and wellbeing are vast and growing areas in non-ID research, the background for this research topic, I felt, needed to be grounded in some exploration and understanding of ID, followed by discussion around the internet and wellbeing in regards to those with IDs, in order to decide upon the best approach for the research study.

1.2 Intellectual disabilities

1.2.1 Prevalence, causes and definitions of an intellectual disability

The estimated prevalence of people with an ID globally varies from 0.23%-3%, but, as those with IDs are often hidden populations across the world, it has been suggested that these percentages are an underestimation (Allgar et al., 2008; Harris, 2006, King et al., 2009; Gates et al., 2007). Whitaker (2013), drawing on the work of Zigler (1967) and Zigler et al. (1984), outlines two causes of an ID:

> Organic: ‘a single biological cause resulting in significant neurological or biochemical changes’ and
>
> Familial: ‘when there is no single factor causing the condition, but rather it is due to the same multitude of biological and social factors that determine the intelligence and adaptive ability of most people in the population’ (Whitaker, 2013:108).

However, for many people with IDs there is no identifiable cause for their ID (Whitaker, 2013). The definitions and views of an ID have been influenced greatly by the dominant theoretical perspective/s of the time, often derived from health/medicine and psychological, and the less dominant, sociological and anthropological disciplines (Gates et al., 2007). The ‘plethora’ of conflicting theoretical approaches and understandings of IDs makes the task of defining an ID, and all other terms used to describe an ID (learning disability, learning difficulty, mental retardation, etc…) problematic (Gates et al., 2007; Atherton, 2007). At present there are a number of widely recognised definitions for an ID, which include:

> ‘…a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired

> social functioning), and begins before adulthood, with a lasting effect on development.’ (World Health Organisation (WHO), 2017a:1);
>
> ‘A significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with:
>
> A reduced ability to cope independently (impaired social functioning);
>
> Which started before adulthood, with a lasting effect on development.’ (Department of Health (DoH), 2001a:14).
>
> ‘A disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18.’ (American Association of Intellectual and Developmental Disabilities (AAIDD), 2013:1).

There is sometimes confusion between certain terms used to describe an ID globally and nationally, including in the United Kingdom (UK) where the terms ‘learning disability’ and ‘learning difficulty’ are both used to describe an ‘intellectual disability’ in different settings and organisations (Holland, 2011). In the UK a learning difficulty, often used in special educational settings, is also used to describe a specific learning difficulty, which occurs independently of intelligence, is neurological rather than psychological, but which still ‘affects the way information is learned and processed’ (British Dyslexia Association, n.d.:1). In Mansell’s (2010) report, ‘Raising our sights: services for adults with profound intellectual and multiple disabilities’, the increasingly international term ‘intellectual disability’ was used instead of the term ‘learning disability’. This was seen by some as an early indication that there would be a change to the UK terminology but this has not been fully realised (British Institute for Learning Disabilities (BILD), 2017). However, the use of the term ‘intellectual disability’ and ‘intellectual disabilities’ is used throughout this thesis in response to this term becoming increasingly internationally recognised and to bring clarity to the reader. I am of the belief that people with IDs should be free to define themselves with the choice in their defintion to include a reference to their ID or not. Those with IDs, represented by People First, stated their opinion on such matters:

> ‘At People First (Self Advocacy), when we talk about people with learning difficulties, we mean ‘people labelled as having a learning difficulty’. This is one of the labels that society puts on us to mark us out as not being able to understand things the same as other people... We believe that people labelled as having a learning difficulty are disabled by society. We choose the term ‘learning difficulty’ instead of ‘learning disability’ to get across the idea that our learning support needs change over time.’ (BILD, n.d.:4, citing People First).

One universal term for an ID is difficult because those with IDs are not a homogenous population and therefore one term, if an agreement could be made, would not adequately describe each individual’s ‘own personal needs and aspirations’ (Gates et al., 2007:18). In fact, one term or label to describe an ID may increase the experience and occurrence of segregation and stigmatization for those with an ID and for those without an ID to lose sight that individuals with IDs are human beings first and foremost (Gates et al., 2007).

The current terms, definitions and benchmarks for the recognition/diagnosis of an ID have also brought about criticism and will continue to do so. One such criticism is the exclusion of those with autism, who do not currently meet the criteria set by the DoH (2001) in their definition of an ID. The dominant view of ‘disability’ and its subsequent definitions and classifications are ‘informed overwhelmingly by medicine’ (Drake et al., 1996:148). For example, although the WHO (2015a) acknowledge that the difficulties faced by someone with a disability require the removal of barriers created by the environment and society, disability is also described as ‘not just a health problem’ (:1), meaning, it is still in part viewed as a health problem:

> ‘Disability is thus not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives. Overcoming the difficulties faced by people with disabilities requires interventions to remove environmental and social barriers.’ (WHO, 2015a:1).

Lovell (2010) describes the role of medicine as one which aims to:

> ‘cure or rehabilitate people [that have become]… disabled following an individual tragedy…, returning them to the normal condition of able-bodied or as close as it is possible’ (:85).

But the ‘individualising and medicalising of disability’, as described by both Lovell (2010) and Drake et al. (1996), follows the ‘tragedy’, and is marked by diagnosis, assessment, and followed by impairments which received ‘medical curative or rehabilitation responses’. It is a view and process only possible when ‘able-bodiedness’ is seen as the ideal and ‘normal’ (Lovell, 2010:85, Oliver, 1990). Oliver (1990) related this ideal of able-bodiedness with the rise of capitalism and the marginalisation of those with disabilities due to their perceived lack of contribution to society, specifically within the labour market.

Alongside medicine, there have been other disciplinary approaches that have influenced how those with IDs are viewed in society. Psychology as a discipline, which has subsequently developed its view towards those with IDs considerably, has viewed an ID as ‘abnormal’ behaviour, defining it as a deviation from statistical or social norms, maladapted behaviour and personal stress, and as ‘restricted development’ (Gates et al., 2007:10;

Atkinson et al., 1990; Bijou, 1992). Anthropological and sociological approaches suggested that IDs were culturally defined and it was cultural differences that gave rise to this term (Edgerton,1975). An account by Gazaway (1969, cited by Gates et al., 2007), described young people living in a deprived area in the United States of America (USA) who were not able to participate in most activities and could not be taught to whistle, sing or hum a simple tune (Gates et al., 2007). The description is offered for consideration by Gates et al. (2007) because it also fits with what we think we know about those with IDs and the taken for granted cultural definitions:

> ‘Most of us, myself included, are sometimes guilty of writing (and perhaps believing) that the mentally retarded and their lives are simpler than they really are… since the retarded are by definition ‘simple’ and our accounts of them cannot be praised for their efforts to discover complexity.’ (Edgerton, 1975:139).

The exclusion of those with disabilities is based not on the individuals themselves but on how society is designed (and for whom it is designed for), alongside social, economic and political contexts (Swain et al., 1993; Pullin, 1964). Although internet accessibility and inclusion are improving, it’s design, which is often text-based, is seen as a good example of a flaw or exclusion which continues to create barriers for those with IDs as well as many other groups and individuals, such as those with physical disabilities/impairments (Harrysson et al., 2004).

If we are to take ID as simply a construct of society, as suggested by Edgerton (1969), Gustin (1963), Kurtz (1981) and Dexter (1958), then what is the construct of people with IDs by society? Edgerton (1969) already acknowledged that ‘simple’ (rather than ‘complex’) was his own (and societies’) construct of ID and Wilkinson et al. (2014) and Jahoda, et al.

(2010) highlighted the individual with an ID as being ‘childlike’. Kurtz (1981) listed two societal images of people with IDs held by the general population in the US: as a ‘sick person’ and as a ‘developing person’. He noted that ‘medical personnel’ were more likely to view a person with an ID as a ‘sick person’, whilst educators, psychologists and parents were more likely to take the view of an individual with ID as a ‘developing person’ (Kurtz (1981). Current dominant medical definitions of ID (WHO, 2017a, 2017b; DoH, 2001a; AAIDD, 2013) also portray similar societal images of people with IDs as Kurtz (1981) noted, alongside the view that someone with an ID is ‘limited’. Implicitly these limitations are often seen as the result of the individuals themselves, and/or their ID, rather than societal and environment.

Terminology used to describe an ID has added much to the past and current constructs of ID and the stigma experienced by this population. The current UK term used is ‘learning disability’, which was introduced in 1991 by Stephen Dorell (Minister of Health) in a speech given to Mencap. ‘Learning disability’ replaced the term ‘mental handicap’, a term seen to negatively portray this group (Emerson et al., 2001; Gates, 2007). The widely used term ‘mental retardation’ has been under debate for some time because it:

> ‘…has expanded from a diagnostic label embedded in both legislative and social norms to a pejorative, stigmatising term that is increasingly offensive to a large group of individuals’ (Schalock, 2001:4).

This led to the ‘American Association on Mental Retardation’ to change its name to AADID (Gates et al., 2007), but this term is still used to describe an ID, especially in the US. Looking further back, Atherton (2007) gives examples of other terminology which was used to describe an ID:

> ‘subhuman organism, menace, unspeakable object of dread, object of pity, holy innocent, diseased organism, object of ridicule and eternal child’ (:46).

These examples, which were once accepted terminology and descriptions for ID at the time, are now seen as derogatory and altogether inappropriate and have been replaced. But they have not completely disappeared and still exist: ‘childlike’ and ‘object of ridicule’ through media reporting, especially on ID-related hate crime, and as a ‘diseased organism’ through bio-medical perspectives and healthcare structures (Atherton, 2007). The replacing of old terminology used to describe an ID, and those with IDs, with new terms, conveniently hides the unpleasant origins and history associated and bound up with this older terminology and the implications it had on the lives of those with IDs. As previously discussed, the obvious answer is to create a term from the opinions and descriptions of those with IDs, but as well as people with IDs being a varied population they also have little ownership over the definitions and descriptions of IDs, which continue to be part of their history and story. These are commonly re-accounted and constructed by those without an ID:

> ‘What history they [people with ID] do have is not so much theirs as the history of others acting either on their behalf, or against them… [they are] hidden from history as they are from the rest of life.’ (Ryan and Thomas, 1987:85).

Argyrou’s (2013) work on the ‘economy of thought’ (:6) and ‘political economy’ (:7) argues that for someone to invest themselves to knowledge, including the re-accounting of another‘s history and story, they have to be ‘interested’ in the knowledge and that is derived from what they can take from this ‘interest’, be it the prestige of coming up with ideas that no one else has previously thought of, the subsequent publication of these ideas, the career progression that may be initiated from such activities, or the guardianship acquired over having an ‘interest’ in such knowledge. This idea is particularly important, but also uncomfortable, for all those (including myself) who do not have an ID who take such an ‘interest’ in those with IDs, who are not represented in dominant structures as those without an ID are. Without considering and reflecting on their own gains, Argyrou (2013) argues that those who have an ‘interest’ may feel they are giving but they are taking far more: the independence, autonomy and power over those they are speaking on behalf of. This, I feel, is a re-occurring feature of the history and research of those with IDs and for the purposes of this study requires further exploration.

1.2.2 The history and context of people with intellectual disabilities

As previously discussed, an ID can be viewed or defined in a variety of ways: abnormal, developing, a sickness, medicalised, and socially constructed, in that an ID only exists because it differs from a ‘culturally defined ‘normal’ learning ability’ and behaviour (Holmes and O'Loughlin, 2014:4; Gates et al., 2007). An ID is ‘historically and culturally bound’ (Chadwick et al., 2013:230) and has been:

> ‘a source of speculation, fear, and scientific enquiry for hundreds of years [and] has in the past served as a way of segregating this group from society’ (Clarke, 1986:9).

Beart et al. (2005) and Burns (2000) highlight that ID as a term and a label can be so powerful that it becomes that individual or group’s primary social identity. Although those with IDs are a diverse group, they share a rich but at times difficult history, where they have experienced stigma, segregation, exclusion from society (commonly in the form of institutionalization and sterilization), abuse, and in some cases death (Price-Jones and Barrowcliff, 2010; Gates et al., 2007; Atherton, 2007; Lucardie and Sobsey, 2005). Their history is often hidden and not spoken about and both Read and Bowler (2007) and Doka (2002) have stated that this lack of personal history and heritage may influence people with IDs’ identity and overall wellbeing, especially when experiencing loss and transition. Atherton (2007) also suggested that the history of those with IDs that are re-accounted by others and medicalised definitions have led to people with IDs to become ‘depersonalized objects of institutional action’ (Bredberg, 1999:85). This has resulted in individuals and groups of people with IDs being subjected to unethical treatment, abuse and death within health and research contexts. For example, ‘ineducable’ children were given large amounts of sugary food and sweets in order to study the relationship between the consumption of sugar and tooth decay at the Vipeholm Institution in Sweden between 1945 and 1953 (Gustafsson et al., 1954; Krasse, 2001), and ‘retarded’ children at Willowbrook School in the US were deliberately infected with hepatitis to study the progression of this disease in the 1950s and 1960s (Krugman et al., 1962). During World War II, adults and children with mental and physical disabilities, including those with IDs, were viewed as ‘useless eaters’, burdens on society, and ‘unworthy’ of life. As a consequence of these views they were subjected to a well-planned, systematic and rationalised euthanasia programme by the Nazis (Atherton, 2007). Officially 70,273 adults with disabilities were murdered in gas chambers and/or used in experiments to find effective mass killing solutions. These murders and experiments were supervised by doctors and nurses within hospitals, asylums and medical facilities as part of the T-4 euthanasia programme (Proctor, 1988, 1992; Friedlander, 1995; Burleigh, 1994; Gallagher, 1990; Mitscherlich and Mielke, 1962). As part of the child euthanasia programme, which took place between 1940 and 1945 in Austria, approximately 789 children with intellectual and physical disabilities were murdered by doctors and nurses at Steinhof psychiatric hospital. The historical accounts showed the 'extreme fear and pain they experienced daily' (Atherton, 2013:16; Neugebauer and Stacher, 1999; Meissner, 2010).

Although it is argued that we have moved on from subjecting people with IDs to this type and level of abusive treatment, Atherton (2013) found that some contemporary views within health and social care academia in the UK still bore a resemblance to the Nazi euthanasia programme's objectives: the view that someone with an ID is worthless or has a worthless life. Examples include publications by Guibilini and Minerva (2012a, 2012b) and Payne (2006) and within the media (British Broadcasting Corporation News, 2008, 2009). In their study Lucardie and Sobsey (2005) looked at the murders of people with IDs reported in the media from the 1980s onwards and found that children and adults with IDs were still being killed by military personnel, governments, and those who were working in the institutions where the victims with IDs lived. In countries such as Rwanda, Bosnia and China, 'mass homicides' and 'mercy killings' took place because the lives of those with IDs were deemed 'worthless' and burdensome (a similar view taken towards those with ID in euthanasia programmes). However, it was the US that had the most media reported murders of children and adults with IDs compared to other countries across the world. Lucardie and Sobsey (2005) highlighted that all the murders they had included in their study were murders that had actually been reported and then subsequently communicated in the media. This leads to the conclusion that many more murders of adults and children with IDs could have happened across the world, but remain unreported, especially in countries where the media is more rigorously controlled.

Although adults and children with IDs in the UK are no longer killed in 'mass homicides' it is evident that abuse and neglect, that has sometimes led to death, still continues to occur. At times this is sensationally exposed and brought to the public's attention by the media. The abuse experienced by those with IDs living at Winterbourne View is a good example. Although the media is highlighted as often having a strong influence over the negative representation of those with disabilities (Barnes, 1992; Sedghi, 2014), in this case, without the media's intervention (or 'interest') this abuse may have continued unrecognized, or unchallenged as some of the residents with IDs and their families had already tried to speak out and initiate help but were not listened to (DoH, 2012). It is not only within institutions where people with IDs experience abuse, exploitation and feel threatened, they also experience a high level of hate- and mate- crime from the communities they live in (Mencap, 1999; Gravell, 2012). The agreed definition of mate cime is:

> 'When a person is harmed or taken advantage of by someone they thought was their friend' (Lincolnshire Police, n.d:1).

Dimensions (2017) highlighted that hate crime is ‘physically and emotionally destructive’ for people with IDs and those who support them, but this is not often recognised (:1). Davies (2013a) reported that 88% of people with IDs living in the UK had experienced bullying or harassment in the past year. 66% of these people reported that this was happening to them on a daily or weekly basis. 47% had experienced verbal abuse and 23% had been physically assaulted. 73% of these hate crimes had happened in a public place. Despite being a topic of reports, campaigns, initiatives and:

> ‘good intentions, children and adults with learning disabilities and autism, still, end up as the victims of bullying’ (Devine, 2017:1).

Reflecting upon and bringing together the history and treatment of people with IDs by those around them, past and present, and the pervasive dominant bio-medical view that a person with an ID is sick, abnormal, developing, childlike or ‘an administrative, medical, eugenic, educational and social problem’ (Clarke, 1986:9), holds important implications to this study and myself as a researcher. This thesis exists because IDs are seen as different from what society sees as ‘normal’. ID definitions are often socially constructed and based on dominant Westernised, academic and medical knowledge. Society creates barriers for those who are different and, as a result, people with IDs experience inequality in most areas of their lives and do not have the same opportunities as those without IDs. ID is viewed, debated and defined generally by those without an ID and who are in a position to create or influence such views, debates and definitions (a position not generally afforded to those with IDs). It is for this reason that I feel it is necessary to centre research on those with IDs’ experiences and find methods that allow those with IDs to influence and define themselves and their lifeworld. This leads to research that is centered around the concerns and issues of those with IDs, not those without an ID, to address the inequalities society generates for this population.

With IDs in the background I now focus on wellbeing, another important aspect of this study. Set alongside the exploration of ID, which has highlighted that bio-medical perspectives could threaten the view that a person with an ID can be a well being and can experience wellbeing much like everyone else, it is important to take a brief look at the term wellbeing to decide how best to set an individual with an ID, by default, as a well being.

1.3 Wellbeing: towards an existential meaning of wellbeing

The ‘blurred and overly broad definitions of wellbeing’ (Foregeard et al., 2011:81) are, as Dodge et al. (2012) describe, the consequence of the unresolved question of how wellbeing should be defined (Vernon, 2008). Thomas (2009) describes wellbeing as ‘intangible, difficult to define and even harder to measure’ (:11) and the ‘absence of theory-based formulations of wellbeing’ puzzled Ryff and Keyes (1995:719-720). Pollard and Lee (2003) describe wellbeing as:

> ‘a complex, multi-faceted construct that has continued to elude researcher’s attempts to define and measure’ (60).

However, the struggle to define wellbeing is not new. In ancient Greece philosophers were also equally perplexed with ‘wellbeing’: its complexity and intangibility, how it should be defined, achieved and maintained (Vernon, 2008). We continue to strive, as the ancient Greek philosophers did, to define and achieve wellbeing, indicated by a steady thriving economy which fulfils the demand for an apparent human need to achieve wellbeing, happiness and fulfilment (Vernon, 2008; Bradley, 2015). Within the growing body of research around wellbeing there has become a ‘greater necessity’ to define wellbeing, despite the known difficulties in defining it, in order to determine how to measure it to then determine how to increase or maintain it (Dodge et al., 2012:222). Wellbeing is also encompassed within and comparable with the terms ‘health’, ‘human flourishing’, ‘happiness’ and ‘Quality of Life’ (QoL) (Svensson and Hallberg, 2011; Vernon, 2008; Bradley, 2015; Morisse et al., 2013:2; Gable and Haidt, 2005). As such, a brief overview of these terms and their relation to wellbeing would be helpful.

In 1946 the definition of health by WHO was:

> ‘a state of *complete* physical, mental and social well-being and not merely the absence of disease or infirmity’ (:100; my emphases).

This definition, although hailed as groundbreaking in its attempt to overcome negative connotations and its inclusion of physical, mental and social health domains, was criticised for the use of the word ‘complete’. Using this term led to most individuals being classed as unhealthy, because their health (and thus wellbeing) was judged incomplete (Huber et al., 2011; Jahad and O’Grady, 2008). Huber et al. (2011) noted that as the search for a ‘complete’ state of health continued, and knowledge and technology developed, the definitions for health conditions were redefined and the thresholds for interventions lowered. Huber et al. (2011) suggested that this led to the ‘medicalization of society’, seen in the increase in expensive screening, the detection of health conditions (which were not previously considered as problematic), and the production of drugs by pharmaceutical companies for these (previously unproblematic) health conditions (:1). From a WHO discussion that proposed moving away from viewing health as a state, towards viewing health as a process or force (amplified in the 1986 Ottawa charter for health promotion), health was then defined as:

> ‘The extent to which an individual or group is able to realize aspirations and satisfy needs, and to change or cope with the environment. Health is a resource for everyday life, not the object of living; it is a positive concept, emphasising social and personal resources, as well as physical capabilities’ (Health promotion: a discussion document. Copenhagen, WHO, 1984:1).

Further definitions of health, like WHO’s (1984), also included notions of resilience and the ability to adapt and self-manage, for example Huber et al. (2011:2) and Vingilis and Sarkella’s (1997) definition of health as:

> ‘the capability of individuals, families, groups and communities to cope successfully in the face of significant adversity or risk’ (:159).

Alongside the term ‘health’, QoL is also associated with wellbeing and has been defined in a variety of ways, including:

> ‘The satisfaction of an individual’s values, goals and needs through actualisation of their abilities or lifestyle… An individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns… a broad ranging concept affected in a complex way by the person’s physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment’ (Emerson, 1985:282).
>
> ‘A conscious cognitive judgement of satisfaction with one's life’ (Rejeski and Mihalko, 2001:23).

In the 1960s two approaches to wellbeing emerged: the hedonic tradition which emphasised aspects of QoL, ‘happiness, positive affect, low negative affect, and satisfaction with life’ (Dodge et al., 2012:223; Bradburn, 1969;

Diener, 1984; Kahneman et al., 1999; Lyubomirsky and Lepper, 1999), and the eudaimonic tradition which emphasised ‘positive psychological functioning and human development’ (Dodge et al., 2012: 223; Rogers, 1961; Ryff, 1989a; 1989b; Waterman, 1993). Later, wellbeing became more commonly seen as multi-dimensional rather than hedonic or eudaimonic (Diener, 2009; Michaelson et al., 2009; Stiglitz et al, 2009) but terms like happiness and QoL stayed connected to mainstream views of wellbeing. For example, ‘happiness’ is also likened to, or seen to indicate, ‘good mental wellbeing’, as observed in mainstream health services online information from the National Health Service (2017:1). But the use of terms such as happiness, or the multidimensional aspect of wellbeing, is not without criticism. Bradley (2015) suggested that:

> ‘many philosophers deny that experiential happiness is sufficient for well-being… genuine well-being requires something else in addition to having certain experiences’ (:3-4; Svenaeus, 2000).

The rise of a number of diverse dimensions for wellbeing has also led to what Pollard and Lee (2003) described as a ‘confusing and contradictory research base’ (:2). In an attempt to create an acceptable definition for wellbeing Dodge et al. (2012) stated that ‘stable wellbeing’:

> ‘is when individuals have the psychological, social and physical resources they need to meet a particular psychological, social and/or physical challenge. When individuals have more challenges than resources, the see-saw dips, along with their wellbeing, and vice-versa.’ (:230).

Like ID, the definitions of health, wellbeing and QoL are often influenced by the leading approaches of the time, including research which often tries to make definite and simplify these complex terms. Health viewed through the bio-medical model, in its extreme form, sees the body as a machine to be fixed when broken. It emphasises treating physical diseases and does not accommodate mental and social problems, or indeed holds the view that an ID in itself is not healthy. It de-emphasises prevention and measures health by its absence, for example, through disease or death rates. In comparison, holistic approaches view wellbeing, health and QoL as broader concepts, often experienced by the individual, therefore making the term more difficult to define and measure and for some the definitions are too vague and unmeasurable. The success at which wellbeing, health and QoL are defined and measured depends on the viewpoint and approach used to judge what is and isn't successful. It is widely accepted that wellbeing is complex and elusive (Dodge et al., 2012), beyond this, wellbeing can also be viewed as invisible and a taken for granted state, only brought to our attention when it is disrupted (Vernon 2008; Galvin and Todres, 2013). Husserl (1970/1936) and Laing (1967) both described human experience as something that positivist scientific methods were ill-equipped to research (this is further explored within Chapter 3). Thus if wellbeing is seen as a human experience it becomes clear why and how wellbeing continues to elude and is beyond simplification, or easily set within simple models, scales and measurements (Vernon 2008; Husserl, 1970/1936). The McDonaldisation of health, described by Ritzer (2011), sees illness/suffering being increasingly approached and reduced to something calculable and predictable by health services and subdivided for efficiency and controllability. This opposes both the holistic and existential views of illness/suffering and wellbeing, which in practice means patient experiences of care (their clinical encounters) are:

> ‘multiple and unconnected…[meaning that patient needs are not always]…effectively met… [and this can] undermine the patient illness experience’ (Price and Walker, 2015:62).

Because of the experience of those who come into contact with health services and health practitioner’s views that ‘patients… [are] merely consumers of services’ (:39; Ritzer, 2011), Galvin and Todres (2013) advocate for a more existential understanding of wellbeing to protect against dehumanising patients. These views are not without resistance and this may indeed be linked to the increasing financial implications and demand on health services across the world (NHS England, 2017).

To understand what wellbeing is we have to understand what it is to be human and a ‘well being’. The work of Heidegger (1962/1927) and Merleau-Ponty (1962/1945) are important in understanding the existential possibilities of being human and wellbeing as an ‘experiential possibility’. Svenaeus (2000) describes wellbeing as:

> ‘experiencing wholeness in his being-in-the-world… it is a meaningful world. The person need not be happy – he might well be sad; but, in mood, we find an attuned understanding that transcends in a coherent way… This homelikeness of the healthy being-in-the-world’ (:100).

It is when wellbeing is disrupted or becomes absent that it is brought to our attention and when illness/suffering is experienced there is:

> ‘a closing down of our potential to exercise one’s engagement with the world and the future in all the ways that may beckon’ (Galvin and Todres, 2013:39; Svenaeus, 2000; Toombs, 1993).

Based on the philosophical view of being human and its ‘existential notions of freedom and vulnerability (:40), Galvin and Todres (2013) proposed wellbeing as vitality: movement and peace or mobility and dwelling, where meaningful life projects are ‘cornerstones’ to an existential and lifeworld-orientated view of wellbeing. Wellbeing, viewed as vitality, ‘encompasses the possibilities of movement and the possibilities of peace’ (Galvin and Todres, 2013:40), both of which are viewed as the other side of each other but are not necessarily ‘pure opposites’ of each other. The idea of movement, also referred to as existential mobility, arises from the work of Heidegger (1927/1962) and Merleau-Ponty (1995/1945, 1968/1960, 1987/1960) and is identified as:

> ‘the capacity for movement in a sense of being able to move into possibilities of engagement that connect us with others, other spaces, other times and other moods… [and] the existential ways in which we can move vitally into different qualitative spaces, different relationships with others, different embodied movements and different moods that colour the world in different ways’ (Galvin and Todres, 2013:40).

Smith and Lloyd (2006) derived a meaning of health which: ‘touch[ed] upon life as movement’ (Galvin and Todres, 2013:40) through the consideration of the phenomenology of vitality:

> ‘…the measures of vitality… from the perspective of the living, breathing, moving person who seeks wellness and a healthy and active lifestyle’ (Smith and Lloyd, 2006:263).

From this, health and wellbeing could be viewed as the ability to live and ‘carry out one’s major and minor life projects’ (Sheets-Johnson, 1999:40; Galvin and Todres, 2013:40). With respect to vitality and movement, wellbeing (and illness) could be viewed as:

> ‘[to] live rhythmically and in balance; we inhale and exhale, we open and close our eyes,… we are active and we seek stillness… while in illness, the movements may be broken, uneven, or just too slow or too quick’ (Galvin and Todres, 2013:40).

Peace, at the other end of the continuum from movement, is the:

> ‘notion of stillness whether… [it] means to be restful, accepting [,or even welcoming,] what is present at hand, or an experience of ‘letting-be’. Peace involves the full spectrum of temporality, although it is primarily present-centred… [it] does not exclude… coming to terms with ‘what has been’ (past), as well as ‘what might happen’ (future).’ (Galvin and Todres, 2013:41).

Metaphorically, Galvin and Todres (2013) suggest peace is the:

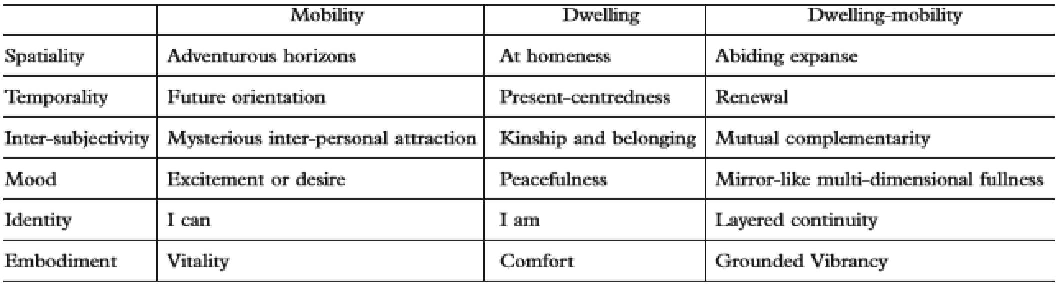
> ‘experience of ‘settling’ and ‘being at home’, where one comes to rest with present health conditions [or] … ‘how things are’, forgiving life its changes’ (:41).

Coming to terms with and forgiving how things are and changes that happen as part of life, is Heidegger’s (1966/1959) ‘letting-be-ness’. This is the potential for humans to let go of our: ‘wilfulness and to reconcile ourselves with whatever life is possible in spite of its limits’ (Galvin and Todres, 2013:42). Together, movement and peace, or dwelling-mobility, is wellbeing and is hidden, elusive and taken for granted:

> ‘[when] our bodies are healthy and strong [and] we meet the world unafraid,…we have a natural attitude [take for granted] to our subjective body… [a] harmony…[,] balance and the ability to achieve goals…[as a result of] a strong body… (Dahlberg et al., 2008:44-45).

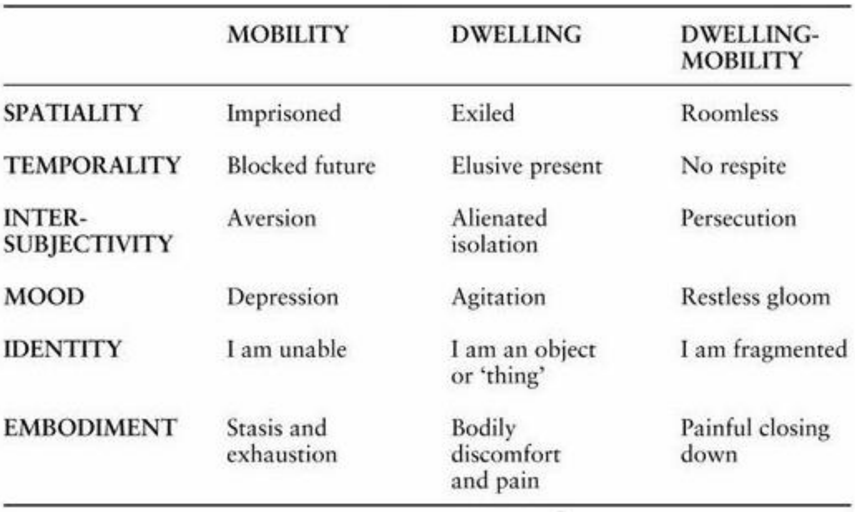
Galvin and Todres (2011), informed by ‘phenomenological-philosophical tradition’ in which Husserl, Heidegger, Merleau-Ponty and others have delineated fundamental lifeworld constituents that are implicated in human experience (Boss, 1979; Heidegger, 1962; Husserl, 1970; Merleau-Ponty, 1962), named a number of experiential domains in which wellbeing can be emphasised (outlined in table 1.1.)

Table 1.1 '"Dwelling-mobility" lattice' (Galvin and Todres, 2011:3)



	Mobility	Dwelling	Dwelling-mobility
Spatiality	Adventurous horizons	At homeness	Abiding expanse
Temporality	Future orientation	Present-centredness	Renewal
Inter-subjectivity	Mysterious inter-personal attraction	Kinship and belonging	Mutual complementarity
Mood	Excitement or desire	Peacefulness	Mirror-like multi-dimensional fullness
Identity	I can	I am	Layered continuity
Embodiment	Vitality	Comfort	Grounded Vibrancy

Table 1.2 'A framework for delineating different kinds and levels of suffering' (Galvin and Todres, 2013:99)



	MOBILITY	DWELLING	DWELLING-MOBILITY
SPATIALITY	Imprisoned	Exiled	Roomless
TEMPORALITY	Blocked future	Elusive present	No respite
INTER-SUBJECTIVITY	Aversion	Alienated isolation	Persecution
MOOD	Depression	Agitation	Restless gloom
IDENTITY	I am unable	I am an object or 'thing'	I am fragmented
EMBODIMENT	Stasis and exhaustion	Bodily discomfort and pain	Painful closing down

Illness, however, 'objectifies' itself and disturbs the individual's:

> 'easy and natural access [and relationship] to the world…[illness is the] bodily dissonance… a conflict of wanting and not being able to' [a disruption of harmony, balance and a loss of abilities as a consequence of] having a fragile body' (Dahlberg et al., 2008:44-45; Gadamer, 1996/1993).

Beyond 'symptoms, diagnoses and treatment' in illness, our immediate engagement in the world is affected, pain may be experienced, we may be weak and our abilities lost (Dahlberg et al., 2008:44). Our body, which Toombs (1993) describes as being broken down, becomes a barrier to our engagement with the world, resulting in a breakdown of life and effecting attachment with the world. An individual in this circumstance would experience ‘suffering’ (Galvin and Todres, 2013:98). For example, arthritis may lead to the inability to walk to a shop, and as such, this activity is ‘no longer within my bodily scope’ (Toombs, 1993:63). The individual’s ability to accomplish a project (shopping, or engaging with others whilst carrying out this project) is interrupted and suffering can be experienced across many many levels, an example of the different kinds and levels are put forward by Galvin and Todres (2013) in table 1.2. Galvin and Todres (2013) suggest that Heidegger’s (1927/1962) ‘homelessness’ is akin to suffering (‘homelessness’) and ‘homecoming’ to wellbeing (’homecoming’). They are always in relation to one another, but not in a linear continuum. If suffering is experienced wellbeing is not cancelled out and vice versa. It is anticipated that the phenomenon: wellbeing (and internet) will inevitably be set alongside suffering, as suffering is part of the continuum of wellbeing. The view of wellbeing as an existential experience and the frameworks offered by Galvin and Todres (2011, 2013) provide a good underpinning for a phenomenologically-based understanding of wellbeing for this study. Within Chapters 6 and 7 wellbeing and suffering are further discussed alongside examples from the constituents of the essential structure of the phenomenon: wellbeing and internet. I now briefly return to those with IDs and link wellbeing to this population.

1.3.1 People with intellectual disabilities and wellbeing

People with IDs’ experience of the lifeworld and the barriers it presents to them, as a result of societal views or an intellectually demanding environment (Whitaker, 2013) designed for those without an ID, is similar to Dahlberg et al.’s (2008) notion of ‘body dissonance’: ‘a conflict of wanting and not being able to’ (Dahlberg et al., 2008:45). There is a dissonance: a lack of harmony between the individual with ID’s body and the lifeworld, seen in the inequalities they regularly face. But an ID in itself does not make these individuals ill or mean they have an unable or fragile body which prevents access to the lifeworld. However, research studies show that those with IDs do experience more illness through other conditions and illnesses, and from the health inequalities they experience, more so than the general population. As a consequence they have an overall shorter life expectancy than the general population (Emerson and Baines, 2010) and studies worldwide have reported that those with IDs have higher rates of psychiatric disorders (such as schizophrenia), dementia, epilepsy, sensory and physical impairments, unhealthy teeth and gums, type 2 diabetes, gastro-oesophageal reflux disease and osteoporosis compared to the general population (Emerson and Baines, 2010; Hollins et al., 1998, Puri et al., 1995). In the UK coronary heart disease and respiratory disease were the most common causes of death for people with ID (heart disease 14-20% / respiratory disease 46-52%), higher than the general population (Hollins et al., 1998). Alongside those recognised and diagnosed health conditions, Baxter et al. (2006) and Deb et al. (2001) state there is also a higher prevalence of unrecognised and undiagnosed physical and mental health conditions in people with IDs. The DoH (2001b) has also highlighted that loneliness is a significant problem for people with IDs due to their limited social opportunities and lack of contact with others. This in turn prevents them from having the opportunity to be able to develop and maintain friendships (Mason et al., 2013). Friendship in itself has been seen to have a positive impact on an individual’s wellbeing and can be a preventative factor for mental and physical health problems (Duck, 1991, Chappell, 1994, Uchino, 2004, Brackenridge and McKenzie, 2005, Lunsky, 2008). Those with profound intellectual and multiple disabilities (PIMD) often face the most inequalities, which contribute to their experience of suffering. Often this is caused by communication barriers and the failure to view the individual as a human being. These individuals were less likely to receive support which could contribute to their sense of wellbeing (Sheehy and Nind, 2005). Wellbeing and those with IDs is an ever-growing area of interest, but is not ofter linked with internet access. But within the area of health and wellbeing the internet has become an increasingly important resource for many different groups who are experiencing an interruption to their wellbeing (suffering), including loneliness. Access to health resources and peer support are commonly cited as examples. It is interesting to note that a focus on wellbeing, internet and those with IDs is generally lacking and as such has not kept abreadth of online wellbeing and internet opportunties. The internet, like wellbeing, is another complex term which is constantly shifting and morphing before we have a chance to fix an opinion or view on it. It developed relatively quickly from something that just exchanged information to something ‘central’ to human and lifeworld interactions, now described as:

> ‘a stable foundation underpinning many aspects of daily life in the developed world… central to the ways in which we experience others and ourselves as well as the way we interact with all manner of

> cultural, social, economic, and political processes' (Power and Teiglan, 2013:1).

The internet is certainly an interesting area but some exploration on what the internet was, is, and could be, and how we as humans relate to it, is required.

1.4 The internet.

1.4.1 Internet: information abundance to raising questions of ourselves and our relationship with technology

In the late 1960s a programme to exchange information, developed by the US military and academia, became what is now known as the internet (Avni, 2014). Many of the earlier definitions of the internet almost all concluded that the internet was a global network of connected networks where information could be disseminated and retrieved: a space for a communication exchange (December, 1996; Leiner et al, 1997; Cox and Koelzer; 2003; Comer, 2000; Soh et al., 1997; Samiee, 1998; Zaheer and Manrakhan, 2001; Auger and Gallauher, 1997; Changsu and Galliers, 2004). Brock and Yu's (2005) three categories for defining the internet sum up many of these definitions/descriptions:

- '**Information pull** (active and passive)': referring to an organisation or individual synchronously or asynchronously pulling information from the internet, e.g. reading messages on newsgroups, browsing through web pages, retrieving information from databases.

- ‘**Information push** (active or passive)’: which involves pushing information onto the internet by sending non-personalised messages to newsgroups, mailing lists, or setting up a website.
- ‘**Interaction- interaction**’: which involves non-anonymous, asynchronous or synchronous personal exchange of information between known communication parties.

Doan and Bloomfield (2014) described the internet as having grown rapidly and was a place where information was in ‘abundance’. They identified the internet by the specific activities in which information could be exchanged and the spaces where this took place: websites, email, weblogs, instant messaging, social networking pages, chat rooms, bulletin boards, online tutorials and online classes. Doan and Broomfield (2014) noticed that some of these were open for all whilst others were only available to certain groups. December (1996) and Comer (2000) based their descriptions of the internet on its ability to facilitate communication through different online services: file transfer protocol (ftp), electronic mail (e-mail), newsgroups, internet relay chat, video conferencing and the world wide web (www). Wallace (1999) identified six different internet environments (which preceded definitions by Brock and Yu (2005) and Doan and Bloomfield (2014)): www, email, asynchronous discussion forum (news-groups), synchronous chats (Internet Relay Chat), as well as multi-user dungeons (MUD), text-based virtual environments (VEs); Metaworlds (3D MUDS), 3D VEs, and interactive video and voice (webcam). This brought together the internet’s ability to exchange information, facilitate interaction and communication, and to host text-based VEs which could be visited and inhabited by online users from economically developed countries from across the world. Although the internet was always created by humans, the initial human creators of the internet and its contents were relatively few in number and only those who had the skills, funding and ‘interest’ in such pursuits participated in its creation. When platforms were created that enabled users who were less skilled and often unfunded to generate their own content, the internet became more than simply a place to exchange information and communicate with one another. Later definitions of the internet accounted for this and started to focus on the meaning and impact this would have on internet spaces and users as they engaged, interacted and connected with each other and artificial intelligence (AI) in all manner of varied VEs (worlds and games). Although the main purpose of these spaces was to entertain, their ability to create rich places to inhabit became more than just entertainment and the behaviour of visitors to such places shaped the online environment and vice-versa:

> ‘[T]he most important mediator of behaviour in these Internet environments is the purpose of the people who visit or inhabit them’ (Wallace, 1999:5).

As the internet became something that was increasingly interconnected with and simultaneously a creation of the online users that inhabited the internet and their interactions with each other, ‘internet’ became an altogether more complex ‘thing’ for scholars to describe (especially as the internet has been rapidly growing and developing into new forms and offering new applications). VEs, such as Second Life, blurred the lines between what was ‘real’ and what was ‘virtual’ or ‘simulated’ and questions were asked about whether the virtual would ever be considered real and if people’s online presence could be considered meaningful and surpass the ‘real’ (Turkle, 2011; Boellstorff, 2008, Graham, 1999). Recent definitions increasingly demonstrate a new and interdisciplinary awareness of the internet as being inherently entwined with human relationships off- and on-line, for example Young's (2008) definition of the internet as 'a new, culturally valued cognitive tool' (:174) and Turkle's (1996) 'identity technology' where users can present their 'self' online and connect with others (:17). Riva and Galimberti (2001) suggested the internet could:

> 'be defined as a process by which a group of social actors in a given situation negotiate the meaning of the various situations which arise between them.' (:2).

Turkle's (2011) critical approach to our own relationship with, and our ever-increasing reliance on, the internet brings much to the understanding of the internet and where it is leading us. Turkle (2017) raises interesting questions around the connection between the internet, ourselves and our motivations:

> 'Human relationships are rich and they're messy and they're demanding. And we clean them up with technology. Texting, email, posting, all of these things let us present the self as we want to be. We get to edit, and that means we get to delete, and that means we get to retouch, the face, the voice, the flesh, the body -- not too little, not too much, just right.' (:1).

The internet is something that has been and can still be defined, at a basic level, as a communication exchange, but it has become much more. It is more complex than we perhaps realise at present and it may continue to lead to a deeper understanding about who we are and what we are becoming (Turkle, 2011, 2009). For the current and future possible experiences of the internet and our understanding of this phenomenon we perhaps need to look inwards and ask ourselves why we find the internet so appealing. Turkle (2011) states:

> ‘Technology is seductive when what it offers meets our human vulnerabilities. And as it turns out, we are very vulnerable indeed. We are lonely but fearful of intimacy. Digital connections and the sociable robot may offer the illusion of companionship without the demands of friendship. Our networked life allows us to hide from each other, even as we are tethered to each other. We’d rather text than talk.’ (:1).

It is important to note that whilst an importance is placed on the influence the internet has on humans, the internet does not influence all humans equally as there are some groups who utilise the internet and those who do not, which creates a digital divide. Those with IDs have been cited as a population which experiences this digital divide, but does this digital divide have any impact on their lives and wellbeing?

1.4.2 A digital divide for people with intellectual disabilities

ICT, television, cell phones and the internet have changed people’s daily lives: their environment and how they connect with and relate to one another, and reducing or even eradicating distances and physical barriers in a profound way. But this is not experienced by everyone throughout the world (Gutiérrez and Zaragoza, 2010). Financial, knowledge and skill factors have led to a lack of ICT and internet access and digital inequalities creating what is known as a ‘digital divide’ for some groups, including those with IDs (Gutiérre and Zaragoza, 2010; Chadwick, et al., 2013; Hilbert, 2015). A US study found that 54% of people with disabilities used the internet compared to 81% of the general US population (Fox, 2011). Within the UK, 36% of people with disabilities were accessing the internet compared to 77% of the general population (Dutton and Helsper, 2007). Evidence of a ‘digital divide’ for people with disabilities is evident in these and other studies but the lack of differentiation between physical and IDs in these types of studies makes it impossible to develop a clear insight into how many people with an ID may or may not have internet access and be using the internet (Chadwick et al., 2013, Fox, 2011, Dutton, Helsper, 2007, Kaye, 2000, Lenhart et al., 2003, McClimens and Gordon, 2008). Whilst recent indications of how many people with IDs use the internet are not available, Hoppedtad (2013) found that many individuals with IDs in his study, especially those with severe IDs, rarely used technology at all. The lack of access and use of the internet by adults with IDs has been related to a lack of necessary skills, training and support, economic and financial barriers, restrictions placed on internet access or use by parents, carers or professionals, and the 'cognitive inaccessibility' of the internet due to its design (which has received little input from those with IDs) (Chadwick et al., 2013, McClimens, and Gordon, 2008; Fox, 2011; Dutton and Helsper, 2007; Kaye, 2000; Lenhart et al., 2003; Carey et al., 2005; Emerson and Hatton, 2010; Emerson et al., 2005; Kennedy, 2009; Kennedy et al., 2010; Goggin and Newell, 2003; Wehmeyer et al., 2004). In a study by Palmer et al. (2012) over half of those with an ID did not have access to a computer according to their family member, even though the family member acknowledged that access to the internet could be beneficial to the individual with an ID. Both Chadwick et al. (2016) and Seale (2014) further highlighted that those who supported individuals and groups with IDs can create barriers by acting as 'gatekeepers' between those with IDs and their access to the internet, or by not giving one-to-one support to those with IDs in order for them to learn and develop the ICT skills needed to engage and use the internet. The prevailing societal view that people with IDs are just not able to use the internet or that they, by the fact that they have an ID, are ‘vulnerable’ and thus more at risk through using the internet, leads to less support (Chadwick & Wesson, 2016; Livingston and Haddon, 2009; Seale, 2007, 2014). In a study by Chadwick et al. (2016), which looked at individuals who supported people with IDs, the supporters indicated that they generally felt that the internet brought both a greater risk, than a benefit, to those with IDs. The perceived benefit was ‘personal online engagement’ (:30), but the risks cited included those with IDs they supported being:

> ‘bullied, threatened or harassed online, providing too much personal information to others and being susceptible to online marketing scams.’ (Chadwick et al., 2016:25).

There is, however, a wave of digital natives, young people (including many with IDs) who have grown up with the internet. Feng et al. (2008) observed that internet use was increasing among young people with IDs, specifically for learning and entertainment purposes. Despite this increase, there is a general agreement that people with IDs are still less likely than the general population to have access to computers and the internet, excluding them from popular activities such as social media (Guo, Bricout and Huang, 2005; Fox, 2011; National Telecommunications et al., 2013; Office for National Statistics, 2013). Research has shown that people with IDs can be supported to use the internet within their everyday lives and there have been innovations in social networking services, including sites specifically aimed at people with IDs (Hegarty and Aspinall, 2006; Näslund and Gardelli, 2012). These websites are typically considered, by those without an ID, as being safer and more accessible for those with IDs than websites that have been developed for the wider online community. However, this strategy does not consider the continued segregation of those with IDs from society and studies that indicate people with IDs want to use the internet like everyone else and connect with those online who do not have an ID (Löfgren-Mårtenson, 2008; Molin et al., 2015). Whilst the internet is seen as being able to offer a wide variety of opportunities to enhance the health and wellbeing of everyone globally, it is often only theoreticized that opportunities offered by the internet could increase the health and wellbeing of those with IDs (Duck, 1991; Chappell, 1994; Uchino, 2004; Brackenridge, McKenzie, 2005; Lunsky, 2008; December, 1996; WHO, 2015b; Tsitsika et al., 2009; Turkle, 1995). It is impossible to cover all aspects of the relationship between wellbeing and internet for the general population in this thesis and relate these to the ID population, but what follows gives a brief overview of a number of examples relevant to this thesis and study area.

1.5 Wellbeing, the internet and adults with intellectual disabilities

The internet has brought about many opportunities, as well as threats, to wellbeing and these are debated often owing to the many approaches and views taken on what wellbeing, health and the internet actually are. The most common notion of how the internet can contribute to wellbeing is that the internet is an important source of information regarding health. There are also numerous online tools which allow internet users to assess aspects of their own health (Akram et al., 2008; Fox and Duggan, 2013; Khoo et al., 2008). The internet is useful in that it stores data on its users and the analysis of health-related internet searches can provide valuable information on disease epidemiology and health behaviours, as examples. Moon et al. (2017) study suggested this could help guide health-related approaches, specifically helping to manage vitamin D deficiency. Cole et al. (2012) and Fox and Duggan (2013) found that at least 50% of those using the internet searched for health-related information on a monthly basis. The internet's increasing potential to offer convenient and accessible ways to access and disseminate health information is leading to what Garcia et al. (2005) describes as an 'unprecedented revolution' (:468). But the ease and capacity of the internet to disseminate and access information is giving rise to concerns over uncensored information that may not be accurate or lacking in quality, something that the general internet user is unlikely to check (Reichow et al., 2014; Eysenbach et al., 2002; Scullard et al., 2010; Silberg et al., 1997; Bernstam et al, 2005). Reichow et al., (2014; 2013) also noted a growing number of websites related to IDs and explored the likelihood of these to influence the decision-making process of parents of children with IDs, or parents who suspected their child had an ID. Previous studies found that online information on IDs varied in quality (Bussing et al., 2012; Chowdhury et al., 2002; Di Petro et al., 2012; Reichow et al., 2012; Stephenson et al., 2012). By sampling 300 websites, targeted by searching for the terms attention deficit hyperactivity disorder, autism, DS, learning disability and ID, Reichow et al. (2014) found that information differed across different countries, including the UK and Ireland. They concluded that those searching for such information should be 'vigilant and not use the internet as the only source of information' (Reichow et al., (2014:2298).

The internet can contribute to wellbeing and disrupt it in obvious ways, as a distraction contributing to road traffic accidents, and more complex ways.

One of the latter’s main concerns around the internet and wellbeing, currently, is the possibility of internet addiction. Those with autism have been cited as a group who may be more prone to internet addiction than the general population (Dunckley, 2016), although this is also disputed (Romano et al., 2014). Studies suggest that the excessive playing of online games can lead to an internet gaming disorder (IGD), which has a negative impact on the individual with IGD’s mental health. IGD has been linked to specific issues such as emotional disorders and substance and behavioural-related addictions (Sarda et al., 2016; Sigerson et al., 2017; Zhang et al., 2016). IGD or ‘gaming addiction’ has received criticism over whether it actually exists, and if the term ‘addiction’ or ‘disorder’ is indeed appropriate (Griffiths, 2014). But despite such criticism, IGD is now categorised in the Diagnostic and Statistical Manual of Mental Disorder as requiring ‘further study’ (American Psychiatric Association, 2013:795) and the effect IGD has on wellbeing is becoming more grounded in evidence from ongoing research.

Another highlighted wellbeing opportunity the internet can provide is its ability to connect people, which could potentially alleviate loneliness and thus contribute to the wellbeing of an individual. This is an important opportunity for people with IDs because they often have fewer opportunities, are often restricted, or find it difficult, to participate in paid work, meaningful activities, and form and develop relationships with others, including friendships and, in particular, sexual relationships (Hall, 2010; Eastgate et al., 2011: Brown and Thompson, 1997; Kerbage and Richa, 2011). Social media has been highlighted as having the potential to benefit those with IDs who experience offline social isolation and loneliness, or have small social networks which consist mainly of family, carers and health and social care professionals (Emerson and McVilly, 2004; Gravell, 2012; Robertson et al., 2001). Chadwick et al. (2013) believe it is possible that access to social media sites could enable people with IDs to increase the frequency and quality of their social interactions, develop meaningful relationships and therefore reduce feelings of loneliness. Social media has also been seen to play an important role in supporting the empowerment and participation of marginalised individuals and groups by enabling networking, engagement in online campaigning, and improving self-esteem (Moreno & Kolb, 2012; Bowker and Tuffin, 2002; Caton and Chapman, 2016).

There is a general lack of research into the benefits of internet use for people with IDs, but Chadwick et al. (2012, 2013a, 2013b), Dobransky and Hargittai (2006), Goggin and Newell (2003), Cromby et al. (1996), Braddock et al. (2004), Vanderheiden and Cress (1992), Cohen and Wills (1985), Fullwood and Wooton (2009), Cummings et al. (2002), Leiberman et al. (2003), Barak et al. (2008), Bannon et al. (2015), Livingston and Haddon (2009), Näslund and Gardelli (2013), Stendal (2012), Stendal et al. (2011), Shpigelman and Gill (2014) highlight that, mostly theoretically, the internet did present many health, wellbeing and QoL-related opportunities to this population. Many of which may be difficult for adults with IDs to achieve in the ‘real’ or offline world. These include access to online information, education and learning, skills, literacy, communication and creative development, social interaction with others online, identity development leading to an increase in participation, inclusion, a sense of belonging, connectedness, a chance to be heard, personal empowerment, physical and mental health benefits, increased self-confidence, wellbeing, independence, employability and a sense of control over one’s life. Despite these often theorised opportunities there appears to still remain:

> ‘a general lack of evidence and many of these potential opportunities and benefits remain assumed and empirically unverified for people with intellectual disabilities in the literature’ (Chadwick et al., 2016:22).

This may in part be due to the lack of trust around the internet and those who inhabit it. Over a decade ago the internet was viewed optimistically as something that would bring about a revolution in the way we worked, irreversibly changing our culture, creating active digital citizens, and acting as a safe places to explore our identities (Miller, 2011; Riva and Galimberti, 2001). Miller (2011), citing Rheingold (1993), stated that the continued development of internet would:

> ‘lead to the creation of alternative communities, worlds and even identities free from the prejudices of offline society’ (:1)

Although there are online spaces that certainly do offer identies free (as much as possible) from the prejudices of offline society, the disheartening realisation now is that the internet has lost its fundamental notion of trust, which was fostered by its pioneering creators and users. The internet is currently being shaped by it’s users who are afforded anonymity online and who are predominantly from ‘economically developed’ countries and do not have an ID. An internet shaped by its users is not necessarily an altogether negative state, as it brings many opportunities, but it also freely enables illegal, abusive and unethical activities which can often dominate media stories around the internet. It unsurprisingly highlights the internet as a potentially dangerous and risky place to be, especially for anyone deemed ‘vulnerable’, such as those with IDs, but so is the offline world. Statistics from Mencap (cited by Davies, 2013a) and Beadle-Brown et al. (2014) show that disability hate crime towards people with IDs offline is unacceptably high and the exploitation, abuse and murder of people with IDs, for example, Brent Martin, Steven Hoskin, Susan Whiting and Gemma Hayter, still continue. Sometimes their deaths are loosely linked to their use of the internet within media reports. Reporting on the death of Gemma Hayter, the Mail Online (Slater, 2011) wrote:

> ‘More disturbing… than her table manners were her liaisons with men, drawn in by her internet profile where she described herself as ‘big, bold and beautiful’’’ (:1).

Setting aside the negative discourse used in this report, in the public summary of the serious case review of Gemma Hayter, the internet was not cited as a tool used by the perpetrators, but rather Gemma’s human need for friendship and belonging (Warwickshire Safeguarding Adults Partnership, 2010). This is also echoed in Beadle-Brown’s (2014) report, where many of the victims described their perpetrator as a ‘friend’. Whilst media stories do bring attention to hate crime, including mate-crime, it also depicts a potentially dangerous and disturbing offline world to live if you have an ID. A question arises at this point: is the internet, or the ‘online’ world, any more ‘dangerous’ or ‘risky’ for adults with IDs than their current offline world? The internet, specifically social media, appears to be becoming the place of choice for others to befriend those with an ID, to enact mate-crime. As such, there is a call for funding to help tackle mate-crime online by organisations such as the Association for Real Change (ARC) (Rakusen, 2012). Rod Landman highlighted the case of a woman with an ID who was sending money to a person who had ‘befriended’ her online:

> '"The only reason that the people who provide services for her found out about this was because she had gone on to start undressing for him in front of her webcam."' (Rakusen, 2012:1).

Anecdotal evidence published online from a UK advocacy/support group (consisting of adults with IDs) offered, in part, an 'insider view' to the internet and the risk it posed by others with ID online. There is a lack of clarity as to how this piece of evidence was brought about and if it disregarded more positive experiences described by group members. But, importantly this was one of the first pieces of evidence I found online which relayed the internet and wellbeing experiences of those with IDs. The evidence read:

> 'People in the group felt worried that they would be targeted by aggressive or unkind people on social media. One of the panellists had agreed to meet a stranger in real life having been contacted by them on facebook, but (luckily) changed his mind on the way there' (Davies, 2013b:1).

Whilst research exists on both the internet and wellbeing of general populations and groups, such as young people, older adults, and those with physical disabilities (Gordon et al., 2007, McKenna and Bargh, 2000, McKenna et al., 2002, Shapira et al., 2007, Shaw and Gant, 2002, Obst and Stafurik, 2010, Gross, 2004, Cheatham, 2012), there has been no specifically focused research on adults with IDs' lived experiences of wellbeing and internet. It appears that without such research we will continue to rely on media stories, child-related internet research and the concerns and perceptions of those without IDs to make decisions that affect the lives of those with IDs. Without taking a balanced approach, free from non-ID pre-assumptions, we may not realise how the internet may be contributing to adults with IDs' sense of wellbeing or suffering. The next logical step was to conduct a systematic literature review which would not only to highlight the gaps in the research, but also strive to gather research papers that included adults with IDs explicit and implicit internet and wellbeing experiences. During the exclusion and inclusion stage it became apparent to me how many theories and methods used in the research papers had influenced the participant’s with IDs’ internet experience and wellbeing and I decided upon a more lengthy and in-depth meta-study approach, set out by Paterson et al. (2001), to the literature review which uncovered some surprising and startling themes.

Chapter 2

Literature Review

Considering the benefits, opportunities and threats the internet could, theoretically, bring to people with IDs health, wellbeing and quality of life (QoL) (Chadwick et al., 2013), this literature review's aim was to search for and bring together primary research that could answer the question: Does internet use affect the wellbeing of adults with IDs?

2.1 Methods

2.1.1 Search strategy

The terms, 'intellectual disability', 'internet', 'health', 'wellbeing' and 'quality of life' were defined to construct the inclusion and exclusion criteria and to ensure a comprehensive literature search across different disciplines. The definition for the term 'intellectual disability' was taken from the DoH's (2001a) definition for 'learning disability':

> 'A significant reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with: a reduced ability to cope independently (impaired social functioning); Which started before adulthood, with a lasting effect on development' (:14).

The term 'internet', for the purpose of this literature review, was defined as a computer-mediated global network of connected networks which facilitates synchronously or asynchronously interaction or communication exchange, and/or information that is actively or passively retrieved, collected or scanned, synchronously or asynchronously and/or information that is actively or passively disseminated (December, 1996; Leiner et al, 1997; Cox and Koelzer, 2003; Brock and Yu, 2005; Samiee, 1998; Zaheer and Manrakhan, 2001; Auger and Gallauher, 1997; Changsu and Galliers, 2004). This simple but broad definition and the range of search terms used for the ‘internet’, for example, ‘virtual’, ‘avatar’ and ‘social media’, aided the search for and inclusion of primary research that represented the full range of internet activities, online spaces and technology, for example, Voice over Internet Protocol (VoIP) and VEs, which can often be forgotten in internet-related literature reviews.

Wellbeing does not have a universally accepted definition (Dodge et al., 2012) and Svensson and Hallberg (2011) describe the holistic, modern definitions of ‘quality of life’ and ‘health’ as being increasingly encompassed within and comparable with the concept of ‘wellbeing’ (Gable and Haidt, 2005). To account for this, the terms ‘wellbeing’, ‘health’ and ‘quality of life’ were all used to construct a comprehensive list of keywords for wellbeing. The definitions for health, QoL and wellbeing were holistic and not indicated by the mere the absence of a perceived negative condition, such as disease or disability (Guerin, 2012; John and Wright, 2006; Seedhouse, 1995; Dodge et al., 2012; Thomas, 2009). This was important to this literature review in order to be aware and to prevent an ID or other disabilities being viewed as an illness in itself within the papers. For this study, wellbeing was considered using a lifeworld approach and as an individual or group: ‘to be able to’ live and ‘carry out one’s major and minor life projects’ (Sheet-Johnson, 1999:40), alongside Galvin and Todres’ (2013) existential mobility: mobility and dwelling.

Once the keywords were identified these were truncated to include all variations of the associated keywords and Boolean operators, ‘AND’ and ‘OR’, were used to search for the literature from the identified databases. The full keyword search can be found in Appendix A.1. Due to the full and comprehensive range of keywords, the abstracts of the literature, where possible, were searched initially prior to the full text. A limit was set for literature published between 2004 and March 2015. This was due to the rapidly changing nature, use, and increasing capabilities of the internet. Further limits included: peer-reviewed, and where databases allowed, primary research only and participants over 18 years of age.

14 databases across health, psychology, social sciences, education, media and internet-related disciplines were identified:

- Allied and Alternative Medicine (AMED)
- Academic Search Premier
- British Nursing Index (BNI)
- Cumulative Index to Nursing and Allied Health (complete) (CINAHL complete)
- ProQuest Dissertations and Theses A & I
- ProQuest Dissertations and Theses UK and Ireland
- International Bibliography of Social Sciences (IBSS)
- Medline
- PsycARTICLES
- PsycINFO
- PsycBOOKS
- ScienceDirect

- Scopus
- Web of Science (Web of Knowledge) Core Collection

Using the search strategy, searches were performed to find relevant literature and recorded. Additionally, OpenGrey was used to search for grey literature to find any new research relevant to the research question. This was in consideration to the internet as both a rapidly changing and developing area of research in itself, having the ability to proceed or bypass formal methods of publication and dissemination.

2.1.2 Inclusion / exclusion criteria

The following inclusion/exclusion criteria were set prior to the literature search. Literature to be included in the review needed to meet the following criteria:

Be a primary research study with a population, or a focus on a population, with an ID; who were aged 18 or over; who had experienced the internet; and where the internet was referred to as having influenced some aspect of their health, well-being and/or QoL.

Literature was excluded using the following exclusion criteria:

1. The population sample does not have an ID as defined by the DoH (2001a).
2. The population sample was aged under 18, thus not defined as an adult under UK law (Office of the High Commissioner for Human Right, 1989).

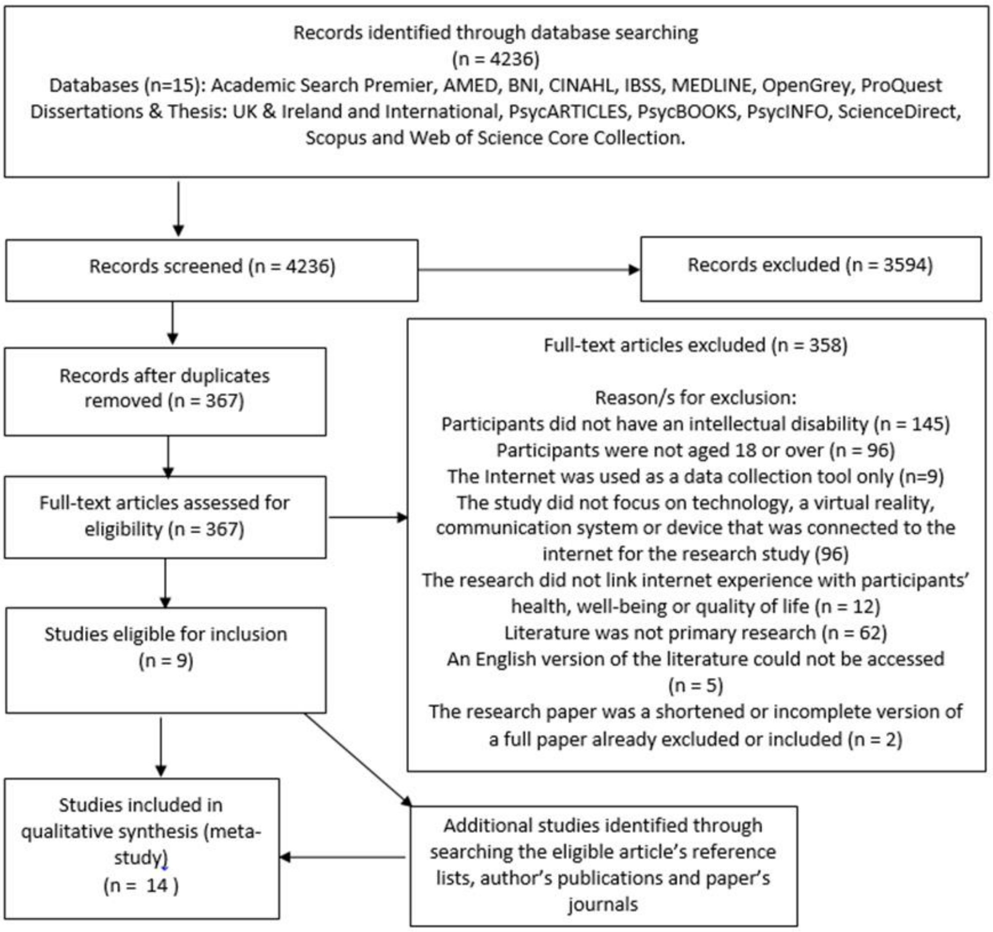
3. The internet was used only as a data collection tool for the researcher/s without the input, engagement or participation of adults with ID.
4. Literature that used any of the keywords for the term ‘internet’ but did not fulfil the definition used in this review.
5. Research that did not state any effects on the health, wellbeing or QoL of adults with ID using the holistic definitions for these concepts.
6. Literature that was not primary research, including literature reviews.
7. Literature where an English translation could not be found.
8. Literature that was a shortened or an incomplete version of a complete published research study.

A detailed rationale for each of the exclusion criteria can be found in Appendix A.2. All excluded literature was coded with each of the above numbers to indicate the reason for exclusion and represented in Figure 2.1.

2.1.3 Search process and eligible papers included in the literature review

Using the search strategy outlined above, 4236 papers were identified from the 14 databases and OpenGrey searched. The titles and abstracts of these papers were examined and 3594 papers were excluded at this stage using the inclusion and exclusion criteria, leaving 642 papers. 275 duplicates were then excluded at this next stage leaving 367 papers. The full text of the 367 papers was examined against the inclusion and exclusion criteria and 358 papers were excluded, leaving 9 papers eligible for inclusion.

Figure 2.1 Search Process and Results



Some of the research studies had mixed populations that could not be seperated, for example participants with IDs alongside participants with physical disabilities and/or health conditions, or participants with IDs aged over 18 with participants with IDs aged under 18. These studies were excluded as they would not fulfil the inclusion criteria.

At the penultimate stage 9 papers were eligible from the inclusion/exclusion process and several strategies were then employed to identify all possible eligible papers for this literature review by examining the 9 eligible paper's reference lists, author's other publications, and the journal the paper was published in. These are strategies Horsley et al. (2011) recommend as a supplement to systematic searches and this yielded a further 5 eligible papers. This made a total of 14 papers eligible for inclusion in this literature review. An overview of the papers is presented in Table 2.1.

Table 2.1 Included Papers: An Overview

Author/s/year/title/ country of origin	**Aims of the research study**	**Study design**	**Participants**	**Key findings**
Brewer, J. L., Taber-Doughty, T., Kubik, S. 2010 Safety assessment of a home-based telecare system for adults with developmental disabilities in Indiana: a multi-stakeholder perspective. / Indiana, US	Aim: to ascertain the perception from multiple stakeholders of the level of safety, security and privacy provided by a telecare model of service delivery for individuals with developmental disabilities during the overnight hours in place of on-site staff support.	Surveys (18 questions allowing for yes, no, or I don't know responses and two open-ended questions / adapted for participants with ID, and interviews with participants/clients with ID.	45 clients, aged between 19 and 72, with mild or moderate developmental disability / 23 volunteer advocates / 47 administrator participants / 12 independent case managers.	Overall, the telecare system was perceived to be as safe, secure and private as the conventional alternative of having staff in the home. The telecare system, overall, was a cost-effective solution to the rising need for the support of those with developmental disabilities.
Edler, C. & Rath, M. 2014 People with Learning Disabilities Using the iPad as a Communication Tool - Conditions and Impact regarding e-inclusion. / Germany.	Aim: to understand how people with learning disabilities use or deal with the challenges presented by a new type of tablets [iPads] including touch screen, voice output, voice input and camera.	Action research used as an approach to collect qualitative data: 'observations, interviews, questionnaires, photos, videos, and case studies'	16 people with learning disabilities (5 male, 4 female) aged between 19 and 35 / 12 assistants/supporters aged between 18 and 47.	Main results highlight the accessibility challenges still prevalent: poor level of awareness of the relevance of media-literate action for the target group; insufficient coaching/personal support; insufficient technical accessibility and assistance.

Author/s / year / title / country of origin /	**Aims of the research study**	**Study design**	**Participants**	**Key findings**
Hall, V., Conboy-Hill, S., Taylor, D. 2011 Using virtual reality to provide health care information to people with IDs: acceptability, usability, and potential utility. / UK.	Aim: to 'assess the acceptability, usability, and potential utility of a virtual reality experience as a means of providing healthcare related information to people with intellectual disabilities'.	Qualitative participatory research: working alongside people with IDs and their supporters in a community setting. Framework analysis technique used to analyse data.	20 people aged between 20 and 80 with mild to severe IDs.	The use of virtual reality environment showed the potential 'for experiential learning to aid retention of knowledge' in a variety of settings.
Hegarty, J. R., Aspinall, A. / 2006 The use of personal computers with adults who have a developmental disability: Outcomes of an organization-wide initiative. / UK.	Aim: 'to document examples of computer use by adults with developmental disabilities [and] to identify what staff members perceive to be organizational/managerial constraints around the implementation of ICT.	Ethnographic based 'service-evaluation research'/ 'qualitative program evaluation' with an emphasis on participant observation and describing the phenomena.	13-day services / resource centers / residential houses (all run by one organization) were visited to talk to service managers and to observe and talk to staff and service users.	'Despite constraints, many services were making use of computers for those service-users who wished to do so.' Supporting staff required necessary ICT skills and confidence to 'impart' these to service users.
Holmes, K.M. O'Loughlin, N. / 2014 The experiences of people with learning disabilities on social networking sites. / UK.	Aim: To highlight the negative and positive experiences of three people with learning disabilities using online social media.	Vignettes / case studies gathered from clinicians working in a community learning disability team.	3 female participants with mild learning disabilities (aged: 25, 30 and 28).	Raising awareness of online exploitation and effect on the mental health of those with ID. Offering people with ID rights and freedom online. The incongruence of the perceptions of participants and their family, carers and clinicians around risk and the internet.

Author/s / year / title / country of origin /	Aims of the research study	Study design	Participants	Key findings
Löfgren-Mårtenson, L. / 2008 Love in Cyberspace: Swedish Young People with Intellectual Disabilities and the Internet. / Sweden.	Aim: To find out the experiences and how and why the internet is being used as a social arena by young people with IDs and how they present themselves online. To find out the experiences and opinions of staff members at special schools and care services.	Qualitative / ethnographical approach using interviews.	10 young people with IDs (aged between 18 – 31, 10 males, 2 females) / 12 staff members.	Young people use the internet 'mainly for social and romantic reasons… [to be] "like everyone else"'. When presenting themselves they do not mention their disabilities. Staff worried considerably and focused on the risk posed by the internet to the young people.
McClimens, A., Gordon, F. / 2008 Presentation of Self in Everyday Life: How People Labelled with Intellectual Disability Manage Identity as They Engage the Blogosphere. / UK.	Through a blogging project to explore the potential of widely available computer-mediated technologies (CMT) in relation to their use by individuals labelled with ID and encourage the learning of new ICT skills. Uncover the participants' sense of self and how they presented themselves online.	Qualitative approach: 'Interactionalist variety of ethnography'. Observations, questionnaires, a structured focus group, and data from the blogs were used.	Group of participants with IDs.	Notions of authorship and audience from this study contributed to the debate around people with IDs sense of self, disability as a construct and their ability to navigate themselves around the 'virtual world of the web'.
McClimens, A., Gordon, F. / 2009 People with intellectual disabilities as bloggers: What's social capital got to do with it anyway? / UK.	To examine the data from a blogging project using the Social Capital Question Bank as a framework.	Data from a qualitative approach: 'Interactionalist variety of ethnography' (from 2008 study above) using Social Capital Question Bank as a framework	Group of participants with IDs.	Researchers concluded blogging had nothing to do with social capital and the study was limited. Issues arose relating to 'policy, daily life and who or what counts as friend'.

Author/s / year / title / country of origin /	Aims of the research study	Study design	Participants	Key findings
Moisey, S., van der, Keere, R. / 2007 / Inclusion and the Internet: Teaching adults with developmental disabilities to use information and communication technology. / Canada.	Aim: to explore ‘the immediate and possible future outcomes when adults with developmental disabilities are given access to training and appropriate online technologies to build basic skills in the use of…[ICT] particularly e-mail and Internet browsing’.	Multiple case study design.	11 adults with developmental disabilities provided with individualized training to learn email and ‘web-based’ (aged between 25 and 45) informational resources’.	Participants ‘gained basic ICT skills’ to further their inclusion into the ‘”global community”’
Molin, M., Sorbring, E. Löfgren-Mårtenson, L. / 2015 / Teacher's and parent's views on the internet and social media usage by pupils with intellectual disabilities. / Sweden.	Aim: To explore ‘what characterizes teachers’ and parents’ views on young people with IDs and their self-presentations on the Internet?	Semi-structured focus group interviews conducted. Thematic analysis used.	8 teachers in special schools for students with IDs. 5 parents of students with IDs from this school.	Parents suggested the internet could be an awareness-raising tool for students with IDs: around their own disability, and as a way of meeting other students. Teachers views were important as they were highly influential on the students with ID’s internet and social media usage.
Seale, J.K. / 2007 / Strategies for supporting the online publishing activities of adults with learning difficulties. / UK.	Aim: To explore the online publishing activities of adults with IDs (DS), and the strategies those who support them use in these activities, implications for adults with IDs’ empowerment and self-advocacy.	Not stated	15 home pages of those with IDs / DS analysed.	Home pages were used as part of a bigger family website, and supporters took sole or joint responsibility for writing these. This study raised questions about the ‘validity’ of online publishing activities of those with IDs / DS.

Author/s / year / title / country of origin /	**Aims of the research study**	**Study design**	**Participants**	**Key findings**
Shpigelman, C., Gill, C. J. / 2014 / How do adults with intellectual disabilities use Facebook? Disability and Society / US.	Aim: To find out how participants with IDs use Facebook, how they perceive Facebook, their experiences, and recommendations.	Online questionnaire.	58 respondents with IDs / (could be a mix of those with IDs or learning difficulties).	Those with IDs are using Facebook as much as non-ID users. Many respondents suggested they used Facebook with no assistance, but the text-based nature of this social media was difficult for some.
Taber-Doughty, T., Shurr, J., Brewer, J., Kubik, S. / 2010 / Standard care and telecare services: comparing the effectiveness of two service systems with consumers with intellectual disabilities. / US.	Aim: Comparing the effectiveness of standard care with telecare in the independence of completing tasks by adults with IDs.	‘Alternating treatment design with baseline and follow-up conditions in a single-case study.	4 participants with IDs living in their own apartments receiving ‘supported living assistance’ (aged 47, 55, 42 and 53).	The telecare system increased independence but lengthened the time taken for participants to complete the tasks. The telecare system was seen as something that could support those with IDs in their own homes.
Williams, P. / 2008 / Transition and people with learning disabilities. Reflections on the quality of content that emerges from the process of involving service users in information provision. / UK.	Aim: to describe the information content of websites developed by and for people with IDs around the theme of transition.	Content analysis approach to analysing the content of websites.	Websites, with contents created by people with IDs.	‘Hobby-related information dominated the websites’. The personal experiences the people with IDs had written ‘provided limited information of use to others’. The content created by those without IDs was sometimes too difficult for people with IDs to understand.

2.1.4 Methods used to critique, evaluate and synthesize the eligible papers

An interpretive approach, using Paterson et al.’s (2001) meta-study, was taken to structure the review and synthesis process of the eligible research papers. Meta-study moves beyond the practise of collecting and synthesizing data and findings by separately analysing the methods (meta-method), data/findings (meta-data) and theory (meta-theory), before synthesizing these elements together to form a meta-study of the literature. This is conducted to create:

> ‘meanings that extend well beyond those presented in the available body of knowledge’ (Paterson et al., 2001:4).

The majority of the 14 eligible papers were qualitative or used a mixed method approach, with one quantative study (Taber-Doughty et al., 2010). All these studies fit easily within the methods set out by Paterson et al. (2001) but a range of critical appraisal tools was used in response, not only towards the mix of approaches used in these studies, but to also address the study’s findings and conclusions which appeared to be influenced by the chosen methods, theories and researcher viewpoints. For example, the studies by Edler and Rath (2014), Hall et al. (2011), McClimens and Gordon (2008, 2009) Brewer et al. (2010), and Taber-Doughty et al. (2010) provided the internet experience as part of the research study or as a tool to provide care and support for adults with IDs. This often influenced the way the participants engaged with and experienced the internet (and those around them, the findings and how it contributed to the participant’s wellbeing. The critical appraisal tools used to appraise the 14 papers were:

- Methodology checklist: qualitative studies (National Institute for Health and Care Excellence (NICE, 2015).
- Criteria for the evaluation of qualitative research papers (Blaxter, 2003; 1996).
- Quality appraisal checklist – quantitative studies reporting correlations and associations (NICE, 2012).
- Mixed method appraisal tool (Pluye et al., 2011).

The methodology checklist: qualitative studies (NICE, 2015) was chosen because it was comprehensive and detailed, perhaps due to the authors bringing together and synthesizing a series of questions based on other checklists by Spencer et al. (2003) and the Public Health Resource Unit (2006). Although this qualitative methodology checklist by NICE (2015) was comprehensive and detailed, it lacked a critique of the participant experience in the research study. This was important because the participant's experience of the internet and wellbeing was the research study/process itself in some of the studies. To consider this element, Blaxter's (1996, 2003) Criteria for The Evaluation of Qualitative Research Papers was chosen and integrated within the Methodology Checklist: Qualitative Studies (NICE, 2015) to critically appraisal the method, theory, data, and the experience of the adults with IDs in the qualitative research studies. For the research study that was quantitative, the Quality Appraisal Checklist – Quantitative Studies Reporting Correlations and Associations (NICE, 2012) was combined with the Criteria for The Evaluation of Qualitative Research Papers (Blaxter, 1996, 2003) to appraise the quantitative element of the paper and to give an insight into the participants' online experience and wellbeing. To critically appraise the mixed method research studies, the Mixed Method Appraisal Tool (Pluye et al., 2011) was used and expanded in parts using the Methodology checklists for qualitative and quantitative studies (NICE, 2015, 2012) and the Criteria for The Evaluation of Qualitative Research Paper (Blaxter,1996, 2003).

After each paper was appraised, the meta-method, meta-data and meta-theory for each paper was coded, themed, and then synthesized into meta-method, meta-theory and meta-data themes for all papers. These themes were then further synthesized to create meta-study themes to include in the findings of this literature review.

2.2 Findings: The effect of internet use on adults with intellectual disabilities' wellbeing

2.2.1 Influences and interpretations by the researchers of the adults with intellectual disabilities' online experiences

There were several themes that arose from the meta-method and meta-theory analysis and, once synthesized together with the meta-data, revealed some influences on both the actual online experience of the participants with IDs, their wellbeing during and after the study, and the interpretations made by those without an ID. These included the researcher's control over the internet experience. At times this was arranged in an unfamiliar place for the participants with unfamiliar internet activities. This was problematic in many ways because the online activities were often not relevant to the participants. In some studies there were no acknowledgement or attempt to look at ways for the participants to continue their internet access after the study finished. Hall et al. (2011) ensured their study was set in a familiar place for the participants which could ensure continued supported internet access for the participants.

Researcher/s' reasons, approaches and viewpoints influenced the studies in a variety of ways. There was a lack of critique for terms such as 'intellectual disability', 'internet', 'friend', 'independence' and 'risk', and a lack of definitions for 'intellectual disability' and 'adult', which at times led to questions around the ID status of participants, how data was collected and interpreted, and the rationale behind the study. The lack of clarity and a reliance on researcher approach, rationale and viewpoint sometimes led to a negative interpretation of the participant's internet experience, including citing the lack of success of an internet activity within the study on the participants with IDs rather than on the design of the study or the researcher's choice of online activity. At times an overly positive interpretation of findings was recorded in the paper, despite the qualitative data from participants and those who supported highlighting some negative experiences (Brewer et al., 2010, Taber-Doughty et al., 2010). In some studies all participants with IDs, despite their level of skill and experience on the internet, were supported. In McClimens and Gordon's study (2008) it appeared that this was to ensure the participants stayed safe and did not publish anything inappropriate online, despite particpants having completed internet safety training.

The nature of a meta-study meant that many themes were created and the literature review became a significant piece of work. For this thesis, there was a need to focus on the meta-study's themes that answered the literature review's question, however the full text of 'Influences and interpretations by the researchers over the adults with IDs' online experience' and 'Others' influence and control over adults with intellectual disabilities' online experiences and the effect this has on their health, wellbeing and QoL is included in Appendices A.3. and A.4.

2.2.2 Using the internet: motivation, engagement, independence and the understanding of the internet by adults with intellectual disabilities

Edler and Rath (2014), Löfgren-Mårtenson (2008), Moisey and van der Keere (2007) and McClimens and Gordon (2008) observed that their participants were excited by the thought of learning how to use the internet and were highly motivated to want to learn the necessary skills. Where the research studies offered access to the internet, and the opportunity to learn, participants with IDs were observed not only making use of their own allotted time to learn and access the internet, but also the allotted time of other participants who had been unable to attend their allotted time slots (Moisey and van der Keere, 2007). Löfgren-Mårtenson (2008), McClimens and Gordon (2008, 2009), Shpigelman and Gill (2014), and Holmes and O'Loughlin (2014) attributed adults with IDs' motivation to learn and use the internet with their 'longing' to make contact with others, often those who did not have an ID, for interaction, to get feedback on their presented online ‘self’, and to develop friendships and in some cases sexual relationships.

In the studies by Edler and Rath (2014), Hegarty and Aspinall (2006), Shpigelman and Gill (2014) and Löfgren-Mårtenson (2014), it was noted that adults with IDs used the internet independently or with very little support. Young people with IDs in Löfgren-Mårtenson’s (2008) study living in Sweden had grown up with the internet and used this on a daily basis. They had learnt how to use a computer and access the internet from several sources including learning at school, by themselves, and from their siblings. They were already part of what Löfgren-Mårtenson (2008) described as the ‘net generation’ and had learnt, to a certain extent, internet smartness and netiquette rules.

The independent use of online technology was also observed by Edler and Rath (2014) when they gave their participants with IDs new iPads to use. The participants with IDs were described as not showing reservation. They independently and patiently tried out the iPads they were given and discovered new things. They quickly learnt and became familiar with this new technology and its applications only after a few repetitions. One participant, who was described as having ‘severe multiple disabilities’ and not able to communicate verbally, drew attention quickly from others around her by pointing at the Skype application symbol indicating she wanted to communicate with someone. The researchers described this participant as being almost completely independent when she used this application. She selected the person she wanted to communicate with and, through Skype video chat, communicated to another person through her own individual non-verbal behaviour and gestures. She rejected flexible picture communication systems (go talk now) when this was offered to her as this did not appear to meet her specific communication needs. In fact, Edler and Rath (2014) noted that the adults with ID's comprehension of the iPads were not significantly different from those without an ID who were supporting them. As the study progressed, the supporters decreased their coaching and support towards the participants with IDs. This resulted in the adults with IDs displaying social competences, such as peer support for each other, in response to the decreased support offered by their supporters.

In Shpigelman and Gill's (2014) study 82.8% of adults with IDs reported using Facebook with no support. However, the respondents in this study may not be completely representative of a population with IDs due to the unclear description given for an ID to potential respondents and the self-selecting sampling strategy based on this description. The online written survey contained 57 questions, which would require a level of concentration and literacy skills that not everyone with IDs who use the internet may possess to complete. The potential participants were also advised to initiate support from an 'other' if they needed help, but the limitations of the recruitment and data collection method may have resulted in more of the respondents having milder ID or having a learning difficulty, the latter does not impair intelligence and would not fit within UK and US accepted ID definitions.

The researchers who had reported the independent use of the internet by some of the participants with IDs in their studies had thoughtfully and carefully chosen the online activity to match the needs of their participants, or the participants themselves had chosen the online activity as part of their everyday internet use (Hall et al., 2011; Edler and Rath, 2014; Shpigelman and Gill, 2014; Holmes and O’Loughlin, 2014; Löfgren-Mårtenson, 2008). The high engagement and independence shown by many of the participants in the online virtual environment (VE), offered in the study by Hall et al. (2011), was attributed to information being presented in visual and audio format and the inclusion of familiar environments and landmarks, such as a hospital and Brighton seafront (which the participants all recognized and instantly engaged with because they lived in this area) within this VE, Second Life. Hall et al. (2011) were the only researchers that noted their participants (who had differing levels of IDs) understanding their online experience:

> ‘[They] knew they were interacting with a virtual environment through a computer because they were using the keyboard and mouse to access it [and] …engaged with the scenario [and experiencing] subjective sensation of feeling and behaving as if they were actually there’ (Hall et al., 2011:e91).

All participants with IDs instantly noticed their avatar and almost all: ‘thought it was ‘pretending’ to be them’ (Hall, et al., 2011:e91). Some referred to the avatar as ‘I’, others just used the avatar to navigate around the VE. Concern was expressed for the avatar by some participants when it was faced with potential danger, such as crossing a road. One limitation of the VE could have been that there was too much for the participants to engage with at one time. This was because Hall, et al. (2011) observed that the control the participants with IDs had over the avatar’s movement within the environment often resulted in a lack of interest with other VE content.

What was apparent in many studies was the importance of a good design or choice of the devices and/or online activities/applications for the participants, for example, VE, iPads, Skype, and social media, which not only made it easy for the participants to use but also fulfilled a common motivator among those with IDs: the opportunity to reach out and contact others online, which was noted by Löfgren-Mårtenson (2008), McClimens and Gordon (2008, 2009), Shpigelman and Gill (2014) and Holmes and O’Loughlin (2014).

2.2.3 Barriers and enablers to internet access and connecting with others

Many of the studies recognised that adults with IDs’ motivation to use the internet were so that they could make contact and communicate with others online. At times adults with IDs could not always access or use the internet to fulfil their need to contact and communicate with others. The barriers to their internet access could not be overcome necessarily by learning ICT skills and/or obtaining physical access to an internet connected device. Barriers encountered by the participants in the studies included the specific design, structure and predominantly text-based nature of the internet, which appeared difficult for adults with IDs to overcome (Hegarty and Aspinall, 2006; McClimens and Gordon, 2008, 2009; Löfgren-Mårtenson, 2008; Shpigelman and Gill, 2014). Despite acknowledging this barrier, 3 of the research studies used predominantly text-based online activities and data collection tools, such as blogging in the studies by McClimens and Gordon (2008; 2009) and an online written survey consisting of 57 text-based questions by Shpigelman and Gill (2014). In McClimens and Gordon’s

(2008) study one participant was quoted as saying: “I find it hard to write down but it’s easy to remember in my head” (:7) and some adults with IDs in Shpigelman and Gill’s (2014) study stated they felt overwhelmed by the amount of text-based notices and posts they received on Facebook. At times they did not understand what other online users were writing on Facebook due to the predominantly text-based communication being used. Even when websites were specifically created for other online users with IDs, Williams (2008) found that some of the text used was too difficult for adults with IDs to read and understand. Some researchers tried to overcome the difficulties adults with IDs faced with text-based online activities and communication by suggesting they seek support from another without an ID or provided them support rather than adapting the activity to make it more accessible for the participants to use independently (McClimens and Gordon, 2008, 2009; Shpigelman and Gill, 2014).

In Löfgren-Mårtenson’s (2008) study, adults with IDs were using text-based ‘cyber-language’ to communicate, connect and socialise with others online. ‘Cyber-language’ does not require a high level of literacy unlike other text-based communication such as email and many online social networking sites. Despite the young adults with IDs’ teachers appearing to place value on computer-mediated communication as a way for their students to learn how to spell, the internet community did not demand:

> ‘…correct spelling or grammatical reference. Feelings, needs and wishes may instead be expressed through symbols and so-called “emoticons”’ (Löfgren-Mårtenson, 2008:130).

It appeared that the ‘cyber-language’ used by online users without IDs was also accessible for adults with IDs as they too could understand and communicate in ‘cyber-language’, therefore enabling them to communicate on equal terms with other online users. Communicating using ‘cyber-language’ also meant that they did not have to automatically disclose their IDs to others online. This led to the participants in Löfgren-Mårtenson’s (2008) study to report feeling included and that they could be like everyone else.

In Brewer et al. (2010) and Taber-Doughty et al. (2010) studies, the type of computer-mediated communication chosen for the participants with IDs was not well suited to all participants with IDs that took part. Some participants were described as having hearing impairments or difficulties and it was noted in the studies that these participants struggled to hear the VoIP based communication. Moisey and van der Keere (2007) were the only researchers to specifically adapt and plan their online training sessions and activities to suit each of their participants with IDs’ individual communication and ICT skill level and needs.

When studies focused on internet use in the participant’s everyday lives and they were able to choose how to communicate online, adults with IDs’ often indicated a personal preference, one of which was email. Although email is text-based, Moisey and van der Keere (2007) and Löfgren-Mårtenson (2008) suggested that the preference towards this could be because an email has no time pressures and thus allows users with IDs to communicate at their own pace. An email also creates a single written record for later reference and does not include many of the subtle communication clues, which some adults with IDs can find difficult to interpret and understand. Moisey and van der Keere (2007) referred to Sohlberg et al. (2002) who also suggested that email was a preferred form of online communication by some adults with IDs. This was further collaborated by Shpigelman and Gill (2014) and Holmes and O’Loughlin (2014) studies, who also found that some of their participants with IDs felt more comfortable communicating through email rather than in a face-to-face situation.

Social media was cited as another preferred way to communicate and connect with others. In Holmes and O’Loughlin’s (2014) study, Facebook was described as providing one woman with IDs: ‘with a medium in which to increase her social circle without having to meet anyone’ (:5). Holmes and O’Loughlin (2014) provided invaluable context for this individual and her wellbeing. She had a limited social circle and experienced social anxiety that sometimes led to her refusing to leave her house alone. The internet provided her with an opportunity to connect and communicate with others in a way that made her feel safe (Holmes and O’Loughlin, 2014). Some of participants in Shpigelman and Gill’s (2014) study stated that Facebook, even though it was primarily text-based, was the only available way for them to keep in contact with friends and family. However, they wished that this site included pictures to communicate, not just text. This highlights how much or how little choice adults with IDs really have when they use the internet in their everyday lives and how they do, or do not, feel included in online communities.

The use of faceless online communication took the form of a faceless robot nurse in a VE in Hall et al. (2011) study and faceless online verbal communication through VoIP in Taber-Doughty et al. (2010) study. The latter was communication in the form of prompts towards the participants with IDs, which appeared to increase the independence shown by some participants when completing the tasks that were set for them. When Taber-Doughty et al. (2010) compared this with the offline communication between onsite staff, who used a variety of face-to-face verbal, gestural and physical prompts, the participants found that the faceless online communication was more successful for the participants' independence. Taber-Doughty et al. (2010) did not discuss in any further detail why their independence appeared to increase whilst the tasks took longer to achieve when faceless online communication was used. Perhaps just having one method of communication allowed the participants with IDs to better understand the instructions given to them. The onsite staff may also have been over-supportive when helping the participants to complete the tasks, and thus the online communication allowed the adults with IDs to demonstrate their actual level of independence when completing these tasks, even if it meant that the task took longer. However, whilst some adults with IDs appeared to be able to demonstrate their independence with the prompts from faceless online communication, others expressed that they did not engage well with this style of communication (Brewer et al., 2010; Hall et al., 2011). In response to the telecare system, which appeared similar to the system used in the study by Taber-Doughty et al. (2010), one participant with an ID in Brewer et al. (2010) study stated they wanted to: '"see their faces when they talk"' (:267). Staff also voiced their concerns about the participant's wellbeing when face-to-face communication was replaced with faceless online communication. This concern did not appear to have been discussed any further by the researchers.

In Hall et al. (2011) the faceless nurse ‘robot’, that resided in a virtual hospital environment, communicated to the participants with IDs through text in a dialogue box. The nurse ‘robot’ was not recognized as being a ‘nurse’ by the participants or indeed something they could communicate with (Hall et al., 2011). Some of the participants did follow the nurse ‘robot’ when she offered them a virtual tour, but Hall et al. (2011) noted that this appeared to be a low response considering the reported high level of participant engagement in the VE, especially towards their avatars. We cannot be sure that the lack of communication towards the nurse ‘robot’ was due to her not having a face, the text-based communication that she used, or the participants’ apparent concentrated engagement in their own avatars and the VE they were situated in (Hall et al., 2011).

Some research studies aimed to support their participants with IDs to connect with others outside their known on- and off-line social circles (McClimens and Gordon, 2008, 2009; Moisey and van der Keere, 2007). This was not successfully achieved in these studies despite participants receiving support, training, and in some cases online communication adaptations. In response to this lack of success, McClimens and Gordon (2008) speculated that the lack of outsider comments on the participants’ blog posts may be due to adults with IDs’ lack of literacy skills, not knowing what to do with words, and their use of descriptive language which: ‘stopped short of identification [and expression]’ (:9). McClimens and Gordon (2008) likened the display of words and images combined on a computer screen to printed media where appearances counted to a: ‘distant and anonymous audience’ (:10). The adults with IDs lack of ‘sophisticated linguistic acts’ (McClimens and Gordon, 2008:9) was seen by the researchers to have contributed to their failed attempt to construct and present an appealing ‘self’ within the blogosphere. They had, according to McClimens and Gordon (2008), given little material for others to interact with and to interpret in order to attract the attention of others online. Adults with IDs not being able to construct text online that could attract the attention of online users was also raised by Williams (2008) in his study that looked at text within transition-related websites created by adults with IDs and their supporters. Williams (2008) described the text as descriptive but not often relevant for other online users. There are alternative explanations for the apparent lack of success the adults with IDs had when they tried to connect with other online users in McClimens and Gordon (2008, 2009) studies which may not point to the attributes of the participants themselves. The internet safety training participants received prior to the study included the advice to not give out too much information about themselves whilst online. This may have inhibited what they wrote about themselves and their lives in their blogs. The researchers choice of the online activity in this study, blogging, may have led to unsuccessful connections with others online. The limitations blogging has with engaging, communicating and attracting others online was acknowledged by McClimens and Gordon (2008) when they cited Hafner (2004) who noted on the topic of blogging: ‘never have so many people written so much to be read by so few’ (:15). It was disappointing that McClimens and Gordon (2008, 2009) did not consider these factors when discussing the reasons behind the lack of success of the study rather than focusing on the attributes of their participants.

2.2.4 Connecting with others online, presenting an online ‘self’ and identity

As previously stated, one of the most valued aspects of the internet indicated by many of the participants with IDs, as well as some of those who supported them, was the ability (or potential) for them to connect with others online (Löfgren-Mårtenson, 2008; Shpigelman and Gill, 2014; Molin et al., 2015; Holmes and O’Loughlin, 2014). Despite some participants facing barriers to achieve this, many participants were indeed successfully connecting with others online. Many of the studies in this review also highlighted some interesting themes around who they were choosing to connect with online. However, in Brewer et al. (2010) and Taber-Doughty et al. (2010) studies, the adults with IDs did not have any choice over who they communicated with as this was with the telecare staff who controlled the VoIP installed in the participant’s home. The internet in these two studies was not used by the adults with IDs to connect with anyone other than the telecare staff, even though the presence of an internet connection onsite (in their homes), meant that the internet, theoretically, was available for them to do this. It appeared in these studies that the participants with IDs had very little say in who and how they communicated online and they also indicated, in Brewer et al. (2010) study, that they did not like the correcting nature of the communication from the telecare staff. These online experiences may have resulted in the participants with IDs having a limited and/or negative perception of what the internet was and it may have dissuaded them from using the internet in the future.

When able to freely access the internet, many adults with IDs communicated online with those they already knew and had previously met offline (Edler and Rath, 2014; Löfgren-Mårtenson, 2008; Shpigelman and Gill, 2014; Moisey and van der Keere, 2007). Shpigelman and Gill (2014) found that only 10.5% of their respondents used Facebook to connect with others online whom they had not previously met offline. Löfgren-Mårtenson (2008) also noted that many of her participants with IDs only had online contact with people they had initially met offline too, mainly through their school or job. They would occasionally contact others they knew offline but had not spoken to online, because they did not “dare” contact them in “real life” (Löfgren-Mårtenson, 2008:131).

As recognized by McClimens and Gordon (2008, 2009), Holmes and O’Loughlin (2014) and Shpigelman and Gill (2014), connecting with others online often involves presenting a ‘self’ through disclosing information about yourself: your likes, dislikes, hobbies and interests, to initiate interaction with others:

> “I use it [Facebook] to tell people about my artwork and show pictures. I like to share photographs” (Shpigelman and Gill, 2014:1609).

However, the label of ‘intellectual disability’ can be so powerful that it can dominate: ‘all other aspects of ‘self’’ (Holmes and O’Loughlin, 2014:4; citing Burns, 2000). It appeared that in the studies by Holmes and O’Loughlin (2014) and Löfgren-Mårtenson (2008) the internet could offer the opportunity for an adult with an ID to remain anonymous or free from the label of an ID so that they could then present and promote other aspects of their identity or indeed create a new identity or role. The creation of a new identity to present to unknown others online appears part of a growing internet culture, but Löfgren-Mårtenson, (2008) and Shpigelman and Gill (2014) discovered that many adults with IDs did not want to create a new identity for themselves. Instead, they wanted to convey a 'sincere and accurate' online identity to others (Löfgren-Mårtenson, 2008:129). One participant in Shpigelman and Gill (2014) stated: "I think it is nice to show who I am" (:1609). Löfgren-Mårtenson (2008) and Shpigelman and Gill (2014) also noted that many adults with IDs using the internet wanted to be viewed as 'normal' and to feel and lead a life like everyone else rather than being categorized as belonging to a group with IDs. In their offline world being viewed as 'normal' was not always possible and, whilst they wanted to convey an accurate and sincere online identity, many adults with IDs chose not to mention their ID to others online. Instead they concentrated on writing about other accurate and sincere representations of themselves: where they lived, their favourite foods, films, celebrities, poetry, leisure activities and their jobs (Löfgren-Mårtenson, 2008; McClimens and Gordon, 2008;2009). But McClimens and Gordon (2008) found that sometimes, even when an ID was not explicitly disclosed online, adults with IDs made references to their own support networks: 'other personnel' and activities, that gave other online users clues to them having an ID. For example, one participant wrote:

> '"I do different things at the university such as working with social work students. We explain about people with learning disabilities about how to work with us"' (McClimens and Gordon,2008:24).

One adult with IDs in Löfgren-Mårtenson (2008) described how they could use the internet fairly anonymously so that others:

> '"don't know who you are… what school you are attending. They don't really know you at all"' (:132).

The decision to present only chosen aspects of 'self' or remaining anonymous may have aided the initial connections with others online, especially those without an ID. Löfgren-Mårtenson (2008) noted that opportunities are limited when it comes to connecting with peers without an ID (beyond family members, paid supporters or professionals) because those with IDs often inhabit spaces that are often segregated from the mainstream. In Löfgren-Mårtenson's (2008) study, adults with IDs who wanted to make connections with online users who did not have an ID, sometimes gave specific reasons for their motivation:

> '"I'd rather have a boyfriend that hasn't attended a special school … I want one that has a steady job and a driver's license. Because I can't drive a car myself, I have a bad heart condition"' (Löfgren-Mårtenson, 2008:131).

Alongside the study by Löfgren-Mårtenson (2008), only two other studies, by Holmes and O'Loughlin (2014) and Shpigelman and Gill (2014), described adults with IDs successfully connecting with online users they had not met previously offline. In many cases, they had achieved this without the support from others. Some participants in Löfgren-Mårtenson's (2008) study described creating and developing important online relationships with others, with one participant describing that he had all his best friends and a girlfriend exclusively online without having met them, at any stage, offline. The value and importance of online friendship to the participants with IDs was often acknowledged in the studies, but at other times it was not. For example, McClimens and Gordon (2009) described online friends, specifically the number of online friends accumulated, as not being ‘an indicator of anything more relevant and certainly nothing real’ (:27). The lack of reflexivity around online friendship was apparent in this study as well as a fixed view of what online friendship meant to people with IDs. Throughout many of the studies there was evidence that the participants with IDs did find the internet, and the online friendships and relationships they had developed, very relevant, ‘real’, and something they actively sought out.

2.2.5 Searching for friendship online and wellbeing

McClimens and Gordon (2009) cited the work of Rheingold (1993) who believed the internet would ‘bring people closer together in virtual communities based on shared interests’ (:26). McClimens and Gordon (2009) thought that Rheingold’s (1993) beliefs may, in turn, be able to promote the benefits of the internet for adults with IDs’ wellbeing. But they were also clear to note, however, that whilst subscribing to an online group was relatively simple and straightforward, an online connection does not equal community and: ‘shouldn’t be mistaken for actually becoming part of a community’ (:26). McClimens and Gordon (2009) also commented that for everyone, having no friends, on- or off-line, is a negative and socially isolating position. Holmes and O’Loughlin (2014) observed that two of their client’s sense of self-esteem was inherently linked with how many Facebook ‘friends’ they had. The teachers and parents in Molin et al. (2015) study described some adults with IDs as being “a bit isolated in real life” (:26) and that the internet played an important part in their lives for them to experience social interaction. The importance and relevance of online friendships and relationships for adults with IDs were seen alongside their context which was included in some of the studies. Their lack of friends and inclusion in the offline world and their longing to create connections with others online had led to the view that the participants with IDs were making themselves, at times, vulnerable in order to obtain friendship and inclusion (Löfgren-Mårtenson, 2008; Holmes and O'Loughlin, 2014). In Holmes and O'Loughlin's (2014) study two women with IDs had experienced cyberbullying: hurtful and inappropriate messages, and had been harassed and targeted for sexual and financial exploitation. Holmes and O'Loughlin (2014) noted that these negative online experiences had resulted in these women feeling hurt, distressed, afraid, worried and upset. The researchers themselves had:

> 'witnessed the negative impact on these individual's mental health because of online exploitation' (Holmes and O'Loughlin, 2014:7).

In some studies the reason for a negative online experience, such as exploitation, was blamed on the person with an ID, specifically their difficulties in understanding the motives of a non-ID online perpetrator. The parents and teachers in Molin et al. (2015) study described that some adults with IDs found it difficult to 'detect what is true and what are other people's intentions' (:28). In Holmes and O'Loughlin (2014) study, the women with IDs did not appear to acknowledge the intentions of others using Facebook and their lack of understanding around the Facebook term 'friend', coupled with their longing for friends online, resulted in them accepting friendship requests from those they did not know. Molin et al. (2015), Löfgren-Mårtenson (2008), McClimens and Gordon (2008, 2009) and Holmes and

O'Loughlin (2014) all highlighted that certain perceived characteristics of people with IDs, such as their apparent naivety, gullibility, vulnerability and sensitivity, and how they presented themselves online, all led to their increased exposure to internet content and online interactions, which had resulted in exclusion, abuse, trouble, or dangerous situations. In Molin et al. (2015) one teacher explained:

> "They [adults with ID] probably use the Internet like everyone else, but it is much more naïve […] people in the nearest surroundings are well aware of you attending the special school programme, but through internet contacts outwards you relinquish that role – being like everyone else, and it creates a completely different identity […] my experience is that girls often meet boys and are being used" (:27).

These characteristics, Holmes and O'Loughlin (2014) suggested, had allowed other online users to target, bully or sexually/financially exploit some of their participants. Understandably, this had caused one of the women in this study distress, but it had also resulted in punishment (in the form of having her finances and internet use restricted). Although internet safety training was provided after the study, punishment was also used by professionals rather than supporting and educating the individual with IDs to use the internet safely. This would have also encouraged the individual to talk about further negative online experiences without fearing punishment or restriction. In this and other studies, the responsibility of the negative online experience was placed on the victim with ID rather than the perpetrator. Whilst Holmes and O'Loughlin's (2014) study highlighted that the women with IDs did not know how to effectively deal with negative online experiences, common in many of the studies in this review, in Molin et al.

(2015) study, set in Sweden, one parent described her daughter with an ID assertively dealing with a negative online experience:

> “[a Facebook friend] started to be very, insulting about sex and that kind of things. But then she deleted him right away and sad [sic] that she was not interested in him as a friend” (:29).

Putting aside the negative experiences reported in the studies when those with IDs sought friendship online, there were signs that friendship online was increasing adults with IDs’ wellbeing. Shpigelman and Gill (2014) stated that online friendship and inclusion could:

> ‘mitigate psychological and emotional distress for both non-disabled and disabled users.’ (:1612).

A few of their respondents also indicated experiencing positive emotions from using Facebook and engaging with other people online:

> “it’s a good place to be when you’re bored and lonely cause you get to talk to people”…”sometimes it’s a way to get emotions out” (Shpigelman and Gill, 2014:1608-1609).

2.2.6 Online negative experiences and wellbeing

Shpigelman and Gill (2014), McClimens and Gordon (2008) and Moisey and van der Keere (2007) all noticed that some adults with IDs did not view the internet very positively. The majority of respondents in Shpigelman and Gill’s (2014) study did not perceive Facebook as enjoyable:

> ‘“I don’t like it but it seems to be the only way to keep in touch with people from the past like school”’ (:1608).

The recent changes to Facebook’s timeline features on the respondents’ profile pages were seen as negative because it took a long time for the respondents with IDs to figure out how to learn how to use it again. They were also unable to reverse the automatic changes Facebook had made. These changes, that were out of their control, appeared to scare the respondent with IDs in Shpigelman and Gill’s (2014) study and impeded their use of Facebook. One participant with an ID, who was part of McClimens and Gordon’s (2008) blogging project, stated, after composing two lines of text, that she had had enough. When asked why, she explained that she found: “it hard to write it down but it’s easy to remember in my head” (:7). In this case, the text-based activity blogging appeared not to be accessible for this participant and it resulted in a lack of enjoyment or value in the activity, resulting in her disengaging from the blogging activity. Moisey and van der Keere (2007) also noted a lack of interest from one of their participants when he was using email. This was because it lacked value and purpose for him as he had no one to correspond with online.

Whilst Löfgren-Mårtenson’s (2008) participants with IDs rarely reported any negative experiences online, Molin et al. (2015) reported that teachers and parents had described that the connection young people with IDs had to unknown others online had been a negative experience for some. This had then subsequently:

> ‘“resulted in tragic or unwanted consequences, such as being humbled for clumsy statements or experiences of being forced into unwanted sex”’ (Molin et al., 2015:27).

The effect of these experiences on the young adults' emotional and physical wellbeing in Molin et al. (2015) study was not mentioned by the teachers or the parents. Holmes and O'Loughlin's (2014) study analysed how some of their female participants' negative online experiences, as perceived by the health and social care professionals and researchers, had affected the participants. The participants' negative experiences had started after they had accepted hundreds of Facebook 'friend requests' from users they did not know, had posted their contact number onto online social networking sites, and had given others their usernames and passwords. One woman with ID had become friends with a man online who began to send her sexual messages. She found it difficult to ask him to stop and had engaged in sexual conversations with him. He had asked her to send him sexual images of herself, which she had done. The woman was upset about this happening and was also worried that her parents may find out about this. Another woman with IDs, in the same study, had accepted anyone who posted a friend request to her through Facebook which resulted in her acquiring 600 Facebook 'friends' she had not previously met in person. Some of these 'friends' then started sending her 'hurtful' messages about her appearance and her activities on Facebook. But, because they were her 'friends' she did not want to block them. Löfgren-Mårtenson (2008) found that women with IDs often focused their time online with finding someone they could have a sexual relationship with, with the intention of moving this online relationship offline. This was also true for the women with IDs in the studies by Holmes and O'Loughlin (2014) and Molin et al. (2015), where they would often initiate contact, or respond to another's online contact with them, and then arrange to meet the other online user in person. The lack of firsthand accounts from the women with IDs themselves in these studies, and the paternal views and approaches by teachers, parents, and in some cases the researchers themselves, makes it difficult to understand what actually happened. The context behind these on- and off-line encounters and how these were viewed by the women themselves would have been useful. In Holmes and O'Loughlin's (2014) study it was clear that one participant's perception of her online experiences was quite different from how the health and social care professionals viewed them:

> 'Karen… saw no potential risk in her behaviour online and perceived her experience as positive and as opportunities to meet new 'friends'. This was incongruent with the perceptions of her family, carers and clinicians who felt that she had placed herself in significant danger by attending these parties and meeting unfamiliar people.' (:6).

2.2.7 Online experiences bringing enjoyment and sadness

Most of the research studies reported that many of their participants with IDs wanted to use the internet and when they did, enjoyed this experience (Edler and Rath, 2014; Hall et al, 2011; Hegarty and Aspinall, 2006; Holmes and O'Loughlin, 2014; Löfgren-Mårtenson, 2008; McClimens and Gordon, 2008, 2009; Moisey and van der Keere, 2007; Seale, 2007; Shpigelman and Gill, 2014). Through their observations of their participants with IDs experiencing a VE, Hall et al. (2011) stated that within five minutes 18 of the 20 participants had engaged immediately with the VE and 'maintained good concentration throughout' the internet experience (Hall et al., 2011:e91). The participants with IDs stayed voluntarily in the VE for 23 to 57 minutes and their level of engagement did not appear to depend on their age, level of ICT skills or cognitive function. The adults with IDs' ability to move the avatar autonomously, unsupported (or supported and encouraged) around the VE and engage with the virtual objects brought about a sense of achievement (Hall et al., 2011). They expressed enjoyment, wonder, and at times, amusement, which was observed by the researchers as participants:

> 'smiling, leaning forward into the screen, laughing and pointing… commenting and making jokes' (Hall et al., 2011:e91).

Enjoyment was still expressed by the participants with IDs who had not managed to improve their ICT skills and after the study finished most participants asked for further opportunities to engage with the VE (Hall et al., 2011). The staff interviewed in Hegarty and Aspinall's (2006) study described that 3 of their service users with ID were excited by the speed at which they received email messages. Holmes and O'Loughlin (2014) commented within their case studies that all 3 of their clients with IDs enjoyed using online social networking sites, with one specifically enjoying receiving messages and comments on her Facebook status. In McClimens and Gordon's (2009) study, one participant with IDs wrote in a blog that the online activity she was engaged in was fun and advocated that others should try it. In this study, a blogging project, all participants enjoyed getting answers to their blogs from the other participants, the supporters, and the researchers themselves. They also gained enjoyment from explaining to others what blogging was and what they were doing at the University (the setting for this research study) in their blogs. Additionally, Moisey and van der Keere (2007) reported that their participants enjoyed their one-on-one tutorial time and were eager to spend extra time on the internet when this was available to them. It was McClimens and Gordon (2009) who suggested that the enjoyment expressed by their participants, during their experience of the internet, may have been from: ‘the environment, the engagement and the participation in the study’ (:28), rather than just due to the activity of blogging. This could also be suggested as partly the reason for the reported participants’ enjoyment in other studies as well. In Moisey and van der Keere’s (2007) study, one participant with ID was observed arriving early to visit the receptionists, but once into the training session that formed the research study she decided to finish after only 5 minutes. Hall et al. (2011) noted that they could not tell if 3 participants, who stayed voluntarily in the VE for over 30 minutes, had enjoyed the online experience or not, due to the neutral expressions they showed throughout. They did not show signs of physical or emotional agitation and did not appear distracted. It could be concluded that these participants were engaged and may have enjoyed the activity but did not express this in a way the researchers’ noticed or could understand. But Hall et al. (2011) did not consider that these participants may not have known that they had an option to leave the study, or that they may have been copying the actions of other participants, supporters and researchers by staying seated at a computer and facing the screen. In this study obtaining or taking a base measurement of the non-verbal communication and behaviour, prior to the study, may have helped the researchers decide if the participants’ feelings towards the online experience was positive or negative, through their non-verbal communication. Alternatively, they could have recruited supporters who knew the participants well or found alternative ways to allow participants to express their enjoyment, or lack there of, in the VE experience.

The participants with IDs' online experiences appeared to have had a lasting effect on them in Hall et al. (2011) study. Two months after the study had finished the participants were described as still 'buzzing' about their online experience. The participants in this study were noted as being keen to become involved in future research and offered suggestions towards the development of the VE they had experienced. They also asked when they could participate again, with one participant stating: "Do it again – what date?" (Hall et al., 2011:e91). McClimens and Gordon (2009) and Moisey and van der Keere (2007) also noted that some of their participants were asking for further opportunities to engage with the online activity they had experienced as part of the research study. But unlike Hall et al. (2011) study, were there was a continuation of resources and support to allow the participants with IDs to continue accessing the internet, the participants in McClimens and Gordon's (2008, 2009) and Moisey and van der Keere (2007) studies faced the inevitable prospect of not being able to continue to access the internet after the study had finished. They expressed feeling sad and were upset at not being able to continue accessing the internet. Several participants planned to ask those who supported them to help them to continue to access the internet, but Moisey and van der Keere (2007) noted that only one of their participants continued to do so after the study had finished, and this was only to send email messages and an e-card to one of the researchers.

At the end of many of the studies the researchers felt that the participants with IDs had learnt not only about the internet but also about themselves too (Edler and Rath, 2014; McClimens and Gordon, 2009; Hall et al. 2011; Moisey and van der Keere, 2007). Williams (2008) suggested the process of thinking about one’s own life, using and representing this through ICT, and then viewing their own work online, had ‘tremendous value’ (:481) for those with ID and their sense of wellbeing.

2.2.8 The online experience as a form of surveillance and control

The telecare system used in Brewer et al. (2010) and Taber-Doughty et al. (2010) studies were meant to provide adults with IDs care and support, which was safe, private and secure, through remotely monitoring them in their own homes over the internet using a web camera and VoIP. This was particularly during the night and when the adults with ID were alone. Some of the staff in Brewer et al. (2010) study described the service users as wanting and needing face-to-face contact and social interaction:

> ‘“She is a very special person; she thrives on the one-to-one conversation with staff. She has to have someone to relay her feelings to.”’ (:267).

The participants noted the absence of the onsite staff and indicated that they were not able to see the faces of the telecare staff member when they communicated to them through the VoIP. The online faceless communication and surveillance was not always a positive experience for the participants, with one participant stating: ‘“they follow me, I don’t like people watching me”’ (Brewer et al., 2010:267). By interviewing the participants with IDs, Brewer et al. (2010) found that the online communication they had received from the telecare staff was being focused on correcting or restricting the participant’s behaviour, such as eating at night time. Brewer et al. (2010) suggested that if the onsite care staff was to also use correcting or restricting communication this may have resulted in a different and perhaps more positive perception by the service users, because there was a person delivering the message rather than a faceless voice. The positive stance Brewer et al. (2010) and Taber-Doughty et al. (2010) took towards the telecare system overshadowed the issues raised by the participants, onsite staff, and even the telecare case coordinators, around this model of care, who did not agree that the telecare system provided a more secure environment than the onsite care. They specifically raised their concerns over potential emergency situations which needed immediate assistance. Examples given were a client choking or if one client showed ‘extreme behaviour’ to another. These were scenarios that the telecare system’s remote and online communication and monitoring could not provide a solution to. In response Brewer et al. (2010) suggested that the telecare case coordinators lacked training and were removed from the day-to-day use of the telecare system for the clients, which had resulted in a lack of awareness over the possibilities this system could provide for the residents with IDs, specifically its ability to provide a secure environment. Surprisingly, Brewer et al. (2010) and Taber-Doughty et al. (2010) had not considered the impact surveillance or the lack of face-to-face contact would have on the adults with IDs’ wellbeing and their existing relationships with the onsite care staff.

2.2.9 The online experience increasing the ability for an adult with intellectual disabilities to make informed health-related decisions

Hall et al. (2011) had already drawn on previous research, particularly on studies involving patients with cancer, which had linked the use of gaming technology, motivation and the development of interventions, with an increase in patients' health knowledge. They also cited that VEs had also been used to provide skill-based training, rehabilitation, and participation in exercise and leisure activities. They also noted that many VEs, which were not connected to the internet, had also been used to support adults with IDs, providing them with a safe environment to practise and experience activities that they may not have been able to experience in 'real' life (Hall et al., 2011). Of course, the participants in Hall et al. (2011) study could have visited Brighton landmarks in 'real' life, as they lived near to Brighton and were already accessing resources in the community. With some planning by the researchers, they could have also visited a 'real' hospital environment, talked to a 'real' nurse, and interacted with 'real' hospital-related objects. But Hall et al. (2011) believed that the VE used in their study also provided the five elements needed for adults with IDs to make health care decisions and provide valid informed consent to health interventions. These were voluntarism, capacity, disclosure, understanding and decision. They discovered that the VE used in their study was an accessible way of providing health information and had the potential to positively influence the health, wellbeing and the QoL of adults with IDs by increasing their understanding and learning. It also gave them control over their own healthcare decisions and lives (Hall et al., 2011). In this study there was a high rate of engagement with this online experience and the participants remembered and recalled their experiences in the VE after the experience had finished. It also initiated participants to remember and discuss their ‘real’ healthcare experiences as well, which Hall et al. (2011) suggested could provide opportunities for adults with IDs to learn and initiate dialogue between themselves and a clinician. This could then aid the clinician to gather clinical information and ‘assess psychological concerns’ (:e91).

2.2.10 Perceptions of risk when accessing the internet

McClimens and Gordon (2009) noted that adults with IDs lived in a world dominated by ‘medical model thinking’ (:23) which often resulted in them having little ‘control and self-efficacy’ (:22) in their lives. This led to ‘others’, particularly in health and social care settings, viewing adults with IDs as needing to be ‘cared for’ which often crosses over into control, perhaps a result of the enduring history of institutionalisation which has created complex boundaries between care and control (McClimens and Gordon, 2009; Edgerton, 1971). At the heart of the complex interdependent relationship between adults with IDs and those who support them is online inclusion, independence and freedom, versus, risk and ensuring safety online. Löfgren-Mårtenson (2008) thought about ‘which risks [presented by the internet] are worth our concern’ (:136) and who should judge this. Few studies explored the concept, meaning and construct of the terms ‘intellectual disability’, ‘safety’, ‘independence’ and ‘risk’ despite the research topic and/or supporter’s views being heavily focused on these. Löfgren-Mårtenson (2008) noted that the supporter’s view of these concepts was often ‘predominant and controlling’ (:136) over the adults with IDs’ internet experience and explored internet ‘risk’ by drawing on Breck (2002) to further understand the concept, concluding that ‘risk’ is:

> ‘always the result of a social process and that it therefore always is a question of negotiation. How people view risk is determined in a large part by their social position’ (Löfgren-Mårtenson, 2008:136).

Adults with IDs generally occupy different places in society, often undervalued positions compared to those without IDs, and have different lifeworld experiences, which results in differing views on which situations are deemed risky. One participant in Löfgren-Mårtenson’s (2008) study stated that: ‘“the biggest risk is that nothing will ever happen to me!”’ (:132). Löfgren-Mårtenson (2008) used this quote to highlight that the young people with IDs based their decisions online on their longing for friendship and a romantic partner and did not:

> ‘assess the risk of getting into trouble as seriously as they assessed the risk of not having anything at all happen to them’ (:133).

In Holmes and O’Loughlin’s (2014) study it was clear that the views around the internet and risk by one woman with an ID in this study was different from the professional’s view. The young adults with IDs in Löfgren-Mårtenson (2008) study were conscious of internet risks, such as being defrauded out of money, internet addiction, online users misrepresenting themselves, and the dangers associated with dating strangers offline they have met online. They were able to describe different strategies that they should follow to avoid or deal with any of these situations if they occurred, indicating to ‘others’ supporting them a level of ‘internet smartness’. However, the adults with IDs, women in particular, did not follow their ‘internet smart’ strategies in reality. They disclosed personal information online and met strangers for dates in their own apartments. Löfgren-Mårtenson (2008) reasoned that ‘internet smartness’ and security strategies were set aside, often in the spur of the moment, and was overshadowed by their longing for a partner. A male staff member described how a female student with an ID met a man on a date and stayed with him over the weekend. He described how she was then financially exploited by him and that far from learning lessons from this incident, she did it again (Löfgren-Mårtenson, 2008).

Löfgren-Mårtenson (2008) was the only researcher who discovered that some adults with IDs were having to hide their negative online experiences or pornography consumption from ‘others’ in order to gain ongoing permission from those who supported them to use the internet (an activity they highly valued). It was also important that they convinced those who supported them that they were aware of online risks and knew the strategies they had been taught in order for them to keep themselves safe online, in order for them to continue accessing the internet. There may have been indications of this behaviour in other studies, such as Holmes and O’Loughlin (2014), where one woman with an ID, who had received messages of a ‘sexual nature’, found it difficult to stop this and ‘went along with the sexual conversations’ (:6). The researchers described that she found it hard to ask the man to stop and was also worried that the information would get back to her parents. Perhaps the reason the woman did not want her parents to know was based on the thought they may reactively restrict or stop her internet access to protect her.

2.3 Gaps highlighted by the literature review and an initial rationale for this study's aims and approach

Chadwick et al. (2013) have suggested many gaps and areas under-researched in the current internet and ID literature, which include finding methods of achieving digital inclusion for those with PIMD and exploring people with IDs vulnerability to cyberbullying, online addiction, scamming and fraud. The literature review highlighted some of the gaps already noted by Chadwick et al. (2013), but it also found new gaps in the literature. These are:

- Exploring the interdependency between adults with IDs and those who support them in regards to their internet access and use.
- Looking at the amount and type of support adults with IDs receive when using the internet, their online behaviour and how they present themselves online.
- Focusing on the online social networks of adults with IDs: how extensive they are, who they are in contact with and who they want to make contact with (whether these online users are known or unknown to the adults with IDs) and if online social networks are beneficial or not to an individual's wellbeing.
- Collecting adults with IDs' experiences of specific online activities such as virtual worlds, online dating, sex chat rooms, online shopping, online gaming or political engagement.
- Reviewing internet safety information for adults with IDs with regards to the accessibility and content of this, paying particular attention to

perceptions around risk and control of those with ID’s choices and decisions.

- Focusing on the online experiences and wellbeing of adults with IDs who have mental health conditions.
- Gathering the concrete lived experiences of online financial exploitation, including internet scams and online mate-crime.
- Looking at the content of posts and language used by other online users when they engage in cyber-bully or ‘trolling’ of adults with IDs.

Chapter 1 certainly adds to the list of gaps, one of which is to look at the influence of media reporting on the views and attitudes of adults with IDs and those who support them around the internet and risk.

The gaps highlighted are specific and may automatically direct the research into a predetermined area, forgetting that there is a general lack of lived online experiences of adults with IDs represented in research literature. A focus on adults with IDs’ experience of wellbeing and internet would provide a foundation for further, more focused, research that has it’s foundations in the concerns, experiences and needs of those with IDs. One of the main themes running through Chapter 1 was the lack of ‘voice’ people with IDs have over their own identity, history and role in society, and this was evident in some of the studies within this literature review. There is also differing views of the internet by those with IDs and those without, but it is the non-ID view that is often being represented in the literature. I conclude that the design of a study which focuses on wellbeing and internet needs to gather the concrete lived experiences of adults with IDs using methodology and methods which will allow the ‘voices’ of those with IDs to be heard and re-presented in a way which is free from the pre-assumptions of those without an ID, myself included. In response to this, the overall aims of this study are to:

- Explore the everyday concretely lived wellbeing and online experiences of adults with IDs (rather than set up unfamiliar wellbeing and internet experiences as part of the study design).
- Work in a way that respected and valued the involvement and contribution of adults with IDs in research, seeing this group as ‘experts’ of their own lives in order to produce research that can inform and shape internet guidance and advice for people with IDs.
- Approach the research topic with openness by exploring and bridling my own pre-assumptions around IDs, internet and wellbeing, in order to allow the phenomenon in question to reveal itself.
- Support participants and those around them, if required, to safely and independently access the internet.

The decision to use descriptive-empirical phenomenology as the methodology to answer a question that asked of the experience of a complex phenomenon: wellbeing and internet, was both exciting and daunting for two reasons. The first was that this methodology, as far as I am aware, had not been widely used to gather data from adults with IDs in order to illuminate many phenomena, let alone wellbeing or the internet. The second was the tantalising prospect of moving beyond the apparent standard research design and data gathered around this topic (as observed in the literature review) which often saw the researcher/s taking the participants out of their everyday context and/or deciding what the online experience should be. The Swedish based study by Löfgren-Mårtenson (2008) and Boellstoff's (2008) ethnographic study in Second Life, which incidentally did not meet the inclusion criteria for this literature review as it did not explicitly include any participants with IDs, alluded to people with IDs having a greater variation of internet activities and experiences than was represented in the general literature. Adults with IDs may be immersing themselves in online communities but had not had the chance to share their experiences within a research study. Much of the feedback during the recruitment stage, especially from gatekeepers, was that people with IDs were not using the internet, giving many reasons why this was occurring from their point of view. Prior to the interviews I was unsure if I could find people with IDs who were engaged independently on the internet, let alone inhabiting virtual worlds and navigating online communities. I hoped that by choosing the right approach and methodology I would not only gather new data to contribute to this field, but also demonstrate participants with IDs' high level of description and reflection, which is often doubted by researchers.

Chapter 3

Methodology

3.1 Phenomenology

Phenomenology has rich and interesting origins which have given rise to a varied array of approaches, which share some commonalities but are also marked by specific differences. After introducing phenomenology (it's origins and key concepts) I will focus on Giorgi's (2009) descriptive-empirical phenomenological (often referred to as descriptive phenomenology) method, which draws largely on the work of Edmund Husserl and Maurice Merleau-Ponty and inductive thematic analysis (TA), as set out by Braun and Clarke (2006). Together they both provided a firm foundation for this study's approach during the analysis stage and increased the depth and breadth of this study. Although not specifically used as methodologies for this study, other lifeworld focused phenomenological approaches, specifically Dahlberg et al.'s (2008) Reflective Lifeworld Research (RLR), was drawn upon to enrich the exploration and use of descriptive-empirical phenomenology.

3.1.1 The origins of phenomenology

> 'We need an imaginative, even outlandish, science to envision the potential of human experience… not just tidy reports' (Braud and Anderson, 1998: xxvii).

From 'ancient Greek thought and humanistic tradition' (Wertz, 2011:52) the ideas encompassed by phenomenology emerged and were initially developed as a philosophical method to investigate consciousness by

Husserl (1970/1936). His work subsequently developed into phenomenology practised today, albeit in varied ways, with their foundations in phenomenology’s old origins of ‘understanding the world and our experience of it’ (Dahlberg et al., 2008:30; Wertz et al., 2011; Finlay, 2008). Husserl (1970/1936) put forward the argument that humans have the capacity for consciousness whilst material nature does not, and therefore they are fundamentally different from each other. Husserl, therefore, concluded that the methods currently being used to study material nature were insufficient for investigating humans (1970/1936; Weertz et al., 2011). Husserl was not alone in this criticism, Laing (1967, citing Kierkegaard) also wrote:

> ‘It is tempting and facile to regard ‘persons’ as only separate objects in space, who can be studied as any other natural objects can be studied… one will never find consciousness by looking down a microscope at brain cells or anything else, so one will never find persons by studying persons as though they were objects. A person is the me or you, he or she, whereby an object is experienced’ (:20).

Husserl (1970/1936) concluded that because positivism was unable to separate science from the everyday world it had lost its connection with the lifeworld and therefore its relevance for the everyday person and the questions that concerned them the most:

> [M]erely fact-minded sciences make merely fact-minded people [who would never be able to answer]… precisely the questions which man, given over in our unhappy times to the most portentous upheavals, find the most burning: questions of the meaning or meaninglessness of the whole of this human existence (:6).

Laing (1967) and Husserl (1970/1936) were writing their concerns over mathematical-based natural science methods, being used to study human consciousness, in the context of the dominant positivist methodology of the time. These methods were viewed as not only superior, but the only real ‘scientific’ method that could discover the truth (Husserl, 1970/1936; Comte, 1979). In the *Crisis,* Husserl (1970/1936) claimed:

> ‘…that, despite the undeniable progress of the natural sciences, there was a critical disorder and distortion at the heart of the modern scientific enterprise itself.’ (:46)… [and Husserl himself] regarded the positivists as holding an essentially mistaken conception of science owing to their deliberate narrowing of the concept of reason: they denied the essential contribution of subjectivity and as a consequence had ‘decapitated’ philosophy” (Moran, 2012:70-71).

Husserl wanted ‘science’ to become a part of the world, rather than ‘holding an obscure and elite place in the world’ (Dahlberg et al., 2008:33). He warned that if ‘science’ could not ‘overcome the limitations of objectivism’ it would only serve to dehumanize society rather than bringing about the anticipated scientific knowledge, and from this, benefits to human kind (Weertz et al., 2011:52; Husserl, 1970/1900, 1970/1936, 1988/1913).

3.1.2 Introducing phenomenology

Heidegger (1998/1927) declared that phenomenology was simply: ‘the science of phenomena’ and stated that the word ‘phenomenon’, originally derived from the words ‘phainomenon’ and ‘phainesthai’, meant: ‘that which shows itself in itself’ or ‘to show itself’ (:50). As such, a phenomenon is a ‘thing’: an object or matter, as experienced by, or as it presents or manifests itself to, a subject (Dahlberg et al., 2008). Essence or the essential structure of the phenomenon is the:

> ‘style, pattern or way of being’ [They are what ‘things’, the phenomenon, are, and are]… Expandable and openly infinite, [which] can never be fully captured or explored (Finlay, 2011:127; Gadamer, 1995/1960; Dahlberg et al, 2008; Wertz, 2011).

Husserl (1970/1936) described the idea of phenomenology as: to go ‘to the things [the phenomena] themselves’ (‘zu den sachen selbst’) with the aim to ‘return to the things themselves’, ‘things’ being ‘the world of experience as lived’ and that which precedes knowledge (Finlay, 2008:1; Merleau-Ponty, 1962/1945). The essences of phenomena are often viewed as elusive and difficult to achieve, but not impossible, as long as it is acknowledged that an essence cannot be fixed and is fluid in nature. To achieve a return to the ‘thing’ the ‘researcher’ has to adopt phenomenological attitude, which requires openness, bridling, and ‘active reflection and questioning’ (Finlay, 2011:127; Gadamer, 1995/1960; Bengtsson, 1991; Dahlberg et al., 2008). Phenomena are experienced by the subject, with ‘Experience’ or ‘Erfahrung’ in phenomenology described as being the ’relationship we have to the world in which we are engaged’ (Dahlberg et al., 2008:32), or an:

> ‘…act of consciousness… [as] something real is given to consciousness as what it genuinely is.’ (Kockelmans, 1994:82).

Positioning oneself so that the ‘things’, the phenomena in question, can show themselves to us ‘is to return to embodied, experiential meanings’ (Finlay, 2009a:6). This is an overall concern of phenomenology and something the ‘researcher’ can achieve by valuing and remaining ‘faithful’ to the concrete everyday experiences: the descriptions and stories, their meanings, and what and how they are lived (Halling, 2007:3; Todres, 2005). Phenomenological attitude is essential for understanding human existence and, if this can be achieved, it will lay the ground for ‘a fresh, complex, rich description of a phenomenon as it is concretely lived’ (Finlay, 2009a:6; Todres, 2005; Halling, 2007). But phenomenology is not simply just about the phenomena, it is also:

> ‘consequently the science of the world and its inhabitants, the “things of experience” understood as the world of experience’ (Dahlberg et al., 2008:33).

This world of experience is lifeworld (lebenswelt) and is created from the objects that we perceive, take for granted, create meaning from, and that which surround us. Lifeworld is:

> ‘an inevitable structure of being… it is how our body and relationships are lived in time and space… [and the] intentional relationship between conscious, meaning making human subjects and the external taken-for-granted, meaning-giving world (Finlay, 2011:125-126; Husserl, 1970/1936; Finlay, 2009b; van Manen, 1990).

Husserl’s (1970/1936) lifeworld (our being to the world) theory was expanded upon by Merleau-Ponty (1995/1994) to become lifeworld phenomenology, an ‘understanding [of] human existence as an understanding of how we are to the world’ (Dahlberg, et al., 2008:37). Husserl’s lifeworld is ‘pre-reflective’ and ‘pre-scientific’ and it is ‘present whether or not we experience it…’ (Dahlberg et al., 2008:38). Although all phenomenological approaches are concerned with, and accept, the existence of lifeworld, lifeworld-based phenomenological approaches offer ‘a valuable orientation’ (Finlay, 2011:126) and argue that lifeworld is:

> ‘a necessary condition for knowledge… to know how the implicit and tacit becomes explicit and can be heard, and how the assumed becomes problematized and reflected upon (Dahlberg et al., 2008:36-37).

Descriptive-empirical phenomenology, as a method, ‘stay[s] close to what is given… in all its richness and complexity’ (Finlay, 2011:93) and this is important to a study into adults with IDs’ experience of the phenomenon wellbeing and internet.

3.1.3 Lifeworld fractions/dimensions

Lifeworld dimensions/fractions are elements of the lifeworld which add meaning to the lifeworld and a study which takes a lifeworld approach. Although a presupposition of the lifeworld appears to go against the phenomenological epoch, Ashworth (2015) explained that lifeworld is a 'necessary exception' (:23) and it would be difficult to bracket because:

> 'it would inevitably re-appear as soon as an experience was opened up for description… [,an] implication of Heidegger's (1962/1927) claim, when he names beings of the human kind "being-in-the-world": we cannot but be immersed in a lifeworld… [they] cannot but be expected to show themselves' (Ashworth, 2015:23).

The elements of the lifeworld, also termed dimensions, fractions or 'lifeworldly horizon of the phenomenon under study' are not 'strictly distinguishable', independent, or partitioned off with clear parameters, but are overlapping and interweaving (Ashworth, 2015:23). The whole lifeworld gains meaning from all these elements, with certain elements or fractions having particular relevance to a phenomenon, whilst others are set in the background, not disappearing but still part of the 'whole'. Ashworth (2015), specifically using the work of Merleau-Ponty (1962/1945) as a foundation, set out eight fractions of the lifeworld: self-hood, sociality, embodiment, temporality, spatiality, project, discourse, and moodedness (or mood as atmosphere).

The notion that an individual cannot access or find 'itself' unless they do so through the lifeworld is described by Heidegger (1988/1975):

> '[The individual] never finds itself otherwise than in the things themselves, and in fact in those things that daily surround it. It finds itself primarily and constantly in things because, tending them, distressed by them, it always somehow rests in things. Each of us is

> what he pursues and cares for. In everyday terms, we understand ourselves and our existence by way of the activities we pursue and the things we take care of.' (:159).

A phenomenological self, self-hood, is neither 'inner' nor 'a sense of ego to which intentional objects are presented, the subject of consciousness' (Ashworth, 2015:25): '...the person is in the world and only in the world do they know themselves' (Merleau-Ponty (1962/1945: xi). The self cannot be described by looking inside the self, but towards the world as it is experienced, a world which 'speaks' of the individual's selfhood. It is the individual's thought and activity directed towards the subjective world to which our thought and activity are directed. Self-hood or identity, as a fraction of the lifeworld, is the individual's lifeworld that speaks of their:

> 'interests, concerns, choices and priorities… [as well as]… The things ignored or forgotten or not done, as well as the things attended to or remembered or carried out' (Ashworth, 2015:25).

In this fraction, Ashworth (2015) suggests it is useful to ask questions about a particular experience:

> 'How does the lifeworld speak to us of social identity, our sense of agency, and a person's feeling of their own presence and voice in the situation?' (:25).

Other people inhabit an individual's lifeworld and this can influence selfhood and identity, often by others 'affirming or undermining' (Ashworth, 2015:26). This fraction is described as sociality or intersubjectivity. It is important to note the difference between people and inanimate things in the lifeworld and Husserl's Cartesian Meditations (1973/1950) provides the essential characteristics of the understanding of another person:

> ‘The other is a subject in the world, a minded being like myself. This is the assumption of the other as an alter ego.
>
> The world is, for both of us, an intersubjective one, there for everyone. So, for example, I and the other can share the same object of attention.
>
> There is reciprocity of perspectives such that standing in my position (and analogously, sharing my biographical standpoint) the other can take my mental perspective, and I can take theirs.’ (Ashworth, 2015:26).

In regard to sociality, Ashworth (2015) asks the question:

> ‘How are others implicated in an experience and does the situation effect relations with others?’ (:26).

Ashworth also highlights that the relatedness of one, and the other, must also include issues of power.

Ashworth’s next lifeworld fraction is embodiment based on the view that the body is inseparable from:

> who we are and what we do in the world… [The] body is the vehicle for experiencing, doing, being and becoming. We use our bodies before we think about it in everyday life activities. Through our bodies we perceive the world and relate to others, and – in the process – we learn about ourselves… person-body and others-worlds are intimately *entwined* … The lived body is an embodied consciousness which engages with its surrounding world (Finaly, 2011:29-30).
>
> ‘[I]t is through the body that we are able to pursue our projects… [our] purpose’ (Ashworth 2015:27 citing Merleau-Ponty, 1962/1945:82).

Temporality as a lifeworld fraction encompasses all that is experienced. All experience has a ‘temporal flow’ and is almost certainly ‘bound with the sedimented history of past experiences’ (Ashworth, 2015:27; Husserl 1991/1893-1917; Zahavi, 2005):

> ‘[E]ach present reasserts the presence of the whole past which it supplants, and anticipates that of all that is to come, and by definition

> the present is not shut up within itself, but transcends itself towards a future and a past.’ (Merleau-Ponty 1962/1945:420).

The lifeworld fraction of temporality inquires how ‘time, duration,… [and] biography’ (Ashworth, 2015:27), or historical flow, effects the experience (Schutz and Luckman, 1973, 1975).

The body is the existential vehicle and with body space (and time) moves in the fraction of spatiality. It is how the:

> ‘person’s picture of the geography of the places they need to go to and act within [which is] affected by the situation’ (Ashworth, 2015:28).

This fraction also interacts with ‘embodied nature’ and the geography considered in the lifeworld fraction of spatiality will not just be physical, there will be ‘social norms and a host of other meanings associated with places’ that need to be considered (Ashworth, 2015: 28).

Ashworth (2015) distanced his lifeworld fraction project from Sartre’s (1956/1943) project, as he considered Sartre’s an altogether too encompassing term for an individual’s activities and a ‘substitute for personality’ (:28). Ashworth (2015) defined project as a:

> ‘the person’s ability to carry out the activities they are committed to and which they regard as central? (The emotions of regret and pride, among others may relate to such pursuance of projects.) [and the activities to which we are associated have meaning]’ (:28).

Discourse, as a lifeworld fraction, is the linguistic part of the lifeworld and the words used to describe one’s situation. This fraction includes the terms used to describe the experience of interest, but it can also indicate other cultural forms that envelop the experience (Ashworth, 2003). However, Heidegger

(1976) commented that language was ‘the house of Being’ and, on looking at the work of Wittgenstein, found that language can limit the individual’s lifeworld.

Because ‘…we cannot but be immersed in a lifeworld’ (Ashworth, 2015:23), the use of these lifeworld fractions was taken into the analysis of the data for this study, not as an explicit framework but within the background as inevitable fractions/dimensions of the lifeworld that could not be bridled.

3.1.4 Intentionality

Merleau-Ponty (1995/1945) stated that lifeworld is a world of perception, but reminded us that:

> ‘perception is not a science of the world, it is not even an act, a deliberate taking up of position; it is the background from which all acts stand out, and is presupposed by them (:x).

An individual’s perception, which rapidly shifts, is directed towards ‘things’, they are ‘“about” something. It is this ‘aboutness’ that is often referred to as intentionality (Jordan, 2009). From Brentano’s (1874) theory of conscious intentionality, Husserl (1998/1913, 1992/1929, 1973/1939, 1977/1929) developed an epistemological concept whereby intentionality was viewed as:

> ‘the most basic mode of being [and is the] relationship between a person and the object or events of her/his experience, or… one’s directed awareness of an object or event’ (Dahlberg et al., 2008:47).

There is ‘always an intentional relationship with things’ (Dahlberg et al., 2008:49). When we experience something it has meaning for us, and we understand the ‘whole’ of a ‘thing’, explicitly or implicitly, even though not all of the characteristic qualities of the ‘thing’ are directly present to us or ‘immediately given’ (Dahlberg et al., 2008). They are beyond or transcend the ‘immediate given’ because the experience is of a ‘whole thing’. This involves intentional horizons which emerge from every perception and combine with that what is directly present: actual presentations, to make:

> ‘an existence in space and time possible, which our senses give to us as a whole’ (Dahlberg et al., 2008:50; Bengtsson, 1998; Husserl, 1970/1936, 1973/1950, 1977/1929, 1992/1929).

The transcendental quality of experience that creates a ‘whole’: a tangible reality that is of something beyond itself, is what Husserl (1973/1939, 1977/1929, 1992/1929) described as ‘apperceptions’ or ‘appresentations’ (Weertz, 2011, Bengtsson, 1998; Dahlberg et al., 2008). Appresentations are the psychological processes that illuminate the person’s world, including own and others experiences. For example, I see the face of a clock in a train station hanging down from Victorian cast iron structures (these are directly given to me). I check the time. I cannot see the platforms and the trains that are waiting, but I know they are just around the corner from the clock (these are the object’s outer horizons or immediate context). I know that the clock has a mechanism behind its face in order for it to keep its time, which I cannot see, but I know it is part of the ‘whole’ clock (this is the object’s inner horizons).

Husserl (1964/1928) also reminds us that every experience also has temporal presentations or temporal horizons, which endlessly move back and forth from the given present. Continuing with the example: when I experience the clock in the station (that which is directly given to me or present), I remember the last time I sat experiencing the station clock, watching the minute hand click slowly to the next minute, as it is doing now. I remember myself in the train travelling and I know that in the past I have seen deer, rabbits and pheasants whilst looking out of the train's window into the passing countryside. I remember and anticipate this again. I then think of my destination and the time and the darkness I will arrive in, even though the clock, which is directly present to me, is bathed in bright morning sunlight.

These are temporal horizons: the now-incidents that have been, the past train journey, and those which are to come: the future, the darkness I will arrive in when the train arrives, which occur as I experience the given present of the clock, and its inner and outer horizons (Husserl 1970/1936). These connections between the present, past and future are what Natanson (1973) and Merleau-Ponty (1991/1964, 1968/1960, 1995/1945) describe as an intended regenerative process. They are where understandings can expand, infinite meanings are considered and decisions can be made. Participant appresentations were also described and noted in Hall et al. (2011) study, when they experienced a hospital environment and part of their home city in a VE:

> '17 recognised Brighton seafront instantly. This led to a high degree of engagement, as the participants recalled previous experiences while in the virtual environment, expecting to see boats and go swimming, and even expecting to be able to locate their own home (Hall et al., 2011:6).

Participants brought in their past experiences of visiting an offline hospital whilst discussing their experience of the virtual hospital to the interviewer. However, this was viewed as a happy coincidence of the participant's experience in the VE. From a phenomenological viewpoint, the participants were clearly talking about the 'whole' of their VE experience, which included their appresentations. These did not appear relevant to the researchers and the participants' appresentations were described as 'made up':

> 'All participants reported some accurate memories, but the amount varied… parts of the interview elicited some made-up (confabulatory) information, or information that was added from their own experiences' (Hall et al., 2011:8).

3.1.5 Embodiment

Returning to consciousness, Merleau-Ponty (1968/1960) reminds us, through his 'flesh of the world', that although consciousness makes humans different from 'material nature' (as discussed earlier in this chapter) they are not separate from each other, but have an:

> 'ontological connectedness and mutuality; it is the idea that everything that is, is so because of everything else that exists' (Dahlberg et al., 2008:39, citing Merleau-Ponty, 1968/1960).

All of our experiences and thoughts, 'and the thoughts of others are caught up in the fabric of one sole being' (Merleau-Ponty, 1968/1960:110). 'Being-in the world', our personal space, in which our actions, behaviours and individual ways are played out, are only so because of our 'being-with others' in a shared world (Heiddeger, 1998/1927:155; Dahlberg et al., 2008). This is what makes individuals different from one another. Merleau-Ponty's (1995/1945) 'flesh of the world' helps to view the human phenomenologically because:

> '[the] silent', the mute' …[, and the] 'invisible'… fabric of meaning and background [gives a] necessary background to understand the phenomenological idea of humans as lived bodies (Dahlberg et al., 2008:39-40).

The lifeworld, according to Merleau-Ponty (1995/1945), is accessed through and is inseparable from our bodies:

> '[W]hen I reflect on the essence of subjectivity, I find it bound up with that of the body and that of the world, this is because my existence as subjectivity is merely one with my existence as a body and with the existence of the world, and because the subject that I am, when taken concretely, is inseparable from this body and this world' (:408).

A living body 'is the vehicle of being in the world' and it provides an anchorage (Merleau-Ponty, 1995/1945:82). Our connection to the world gives us a means of communicating with the world: 'constantly perceived and constantly perceiving' (Dahlberg et al., 2008:41). The lived body is what Finlay describes an:

> '*embodied consciousness* which engages with it's surrounding world… it opens up the world as a world of possibilities and potentialities' (:30).

The human body, as a subject-object, is different from objects, which can be moved around a room and which: 'we can turn away from' (Dahlberg et al., 2008:41). We do not 'have' a body, we are 'body', and we cannot:

> 'free ourselves from this embodiment, never come away from or stand outside ourselves as subjective bodies…[instead] we experience it from both inside and outside simultaneously [in natural attitude/unreflective awareness]' (Dahlberg et al., 2008:41-42).

Merleau-Ponty (1995/1945) suggested that the 'whole' experience, which integrates both appresentations with actual presentations, is only possible because of the body. Therefore objective 'scientific' methods, as critiqued by Husserl (1970/1936) and Laing (1967) in regard to researching human experience, can never allow a complete 'whole' understanding of human beings and their existence because it does not consider the:

> ‘perspective of their subjective experience, their lived viewpoint of body, health, knowledge and existence’ (Dahlberg et al., 2008:42).

All experiences have appresentations which help to create the ‘whole’ experience of an object or matter, and this is true for our experience of a human as well. When we experience a human we can only see one side, that which is present, as we do with objects and matter. By combining the present given with appresentations, we experience them as a ‘whole’ person. However, we cannot directly experience what that human is experiencing. We cannot access their perceptions or their emotions, but we can empathise with another human and this brings the possibility that we can understand another and their experiences (Elliston, 1977; Husserl 1977; Dahlberg et al., 2008). Elliston (1977), influenced by the work of Husserl’s Cartesian meditations (1973/1950), explored the experience of others and the possibility of empathy:

> ‘In the course of my everyday life I empathetically experience something which I take as another self. This empathy is now seen to mean (1) this other actual exists, (2) he is a physical thing, (3) he controls his body, and (4) he has a world to which he relates through sensory, cognitive, and effective experiences and upon which he acts’ (:217).

When we experience another we observe their behaviour and this reminds us of the things that we also do:

> ‘[It] conforms to my own intentions to such an extent, and designates a behaviour which has so much meaning for me, that it is as though I assume it’ (Merleau-Ponty, 1991/1964:43).

Although we cannot become that other person, we can become them intentionally, through bodily existence, and together a corporeal or phenomenological field (a field of meaning) is formed (Merleau-Ponty, 1991/1964; Gadamer, 1996). ‘All experience is of the world’, and of a subjective body (Dahlberg et al., 2008:47). Being part of and immersed in the everyday world and in one’s own existence is part of human existence and the world of experience: lifeworld. Husserl (1982) characterised part of human existence and immersion in the everyday world as ‘natural attitude’ (naturliche instellung):

> ‘[a] primordial position for the human being and consequentially also for scientifically orientated researchers [where we]… take for granted that the world is as we perceive it, and that others experience the world as we do…we do not critically reflect on our immediate action and response to the world, we just do it, we just are (Dahlberg et al., 2008:33).

Of course we need to live absorbed in the naïve, an uncritical and unaware ‘natural attitude’, to understand and have awareness of the lifeworld, but ‘natural attitude’ does not take into consideration all of the:

> ‘possibilities for each situation or phenomenon…[and is] too imprecise, weak and vague for scientific purposes’ (Dahlberg et al., 2008:34).

3.1.6 Phenomenological attitude

Merleau-Ponty described ‘natural attitude’ as a: ‘necessary condition for knowledge’ (1995/1945, cited by Dahlberg et al., 2008:37) for humans to effectively and efficiently navigate themselves through lifeworld, but it is ‘too imprecise, weak and vague’ for phenomenological research (Dahlberg et al., 2008:34). There are, however, two ‘facets’ to experiencing lifeworld: our view and experience of it in natural attitude and the present world we may or may not be aware of (Merleau-Ponty, 1995/1945). Husserl (1970/1900) suggested that a different ‘attitude’, one that would attend to the second facet: ‘the present world we may or may not be aware of’, was needed in phenomenology. Husserl (1970/1936) called this different ‘attitude’ ‘scientific attitude’. However, it was important for ‘scientists’ to understand both this pre-giveness: ‘natural attitude’, as well as ‘scientific attitude’, to achieve knowledge from what is concretely experienced, rather than from our ‘habitual’ ways of perceiving the world (Finlay, 2011; Finlay and Evans, 2009a). Once the ‘scientist’ was in ‘scientific attitude’, they could attempt to meet the phenomenon in an open and fresh way, through bracketing or bridling their pre-assumptions: that what is not ‘grounded in contact with the unique characteristics of its subject matter’ (Wertz et al., 2011:53). Once pre-assumptions have been bridled (set aside rather than eliminated), openness, which is curious and desires to see and understand, is created and is a state in which one can be:

> ‘surprised and sensitive to the unpredicted and unexpected… [disclosed] events and objects of the lifeworld… [which are] different from how they were assumed to be’ (Dahlberg et al., 2008:98).

So how can the phenomenological attitude or ‘scientific attitude’ be adopted in order to carry out a phenomenological inquiry? The answer to this question starts with Husserl’s phenomenological epochés (meaning abstention) which he developed to aid the ‘scientist’ to enter ‘scientific attitude’, thus enabling them to ‘return to the things themselves’ (Zurück zu den Sachen selbst) (Husserl 1970/1900-1901:252; Wertz, 2011). Husserl’s (1998/1913) epochés, or reductions, consist of:

- **eidetic**; a focus on the essence and a ‘meaningfully cohesive… [with] continuity… in favour over change’,

- **phenomenological, or phenomenological-psychological reduction**; which sets aside, interrupts or ‘brackets’ the taken for granted state or ‘natural attitude’, and
- **transcendental-phenomenological**; a combination of the eidetic and the phenomenological reductions.

Eidetic reduction is a focus on the continuity of the essence and Dahlberg et al. (2008) use the example of ‘redness’ to explain eidetic reduction: there is a continuity of ‘redness’ in the tomato, ball, tablecloth and book cover, but the ‘redness’ cannot be reduced to the red of the tomato as it ‘is more than these instances of red’ (:54). Eidetic reduction is essential for the analysis stage, specifically when constructing the essential structure of the phenomenon in question. Free imaginative variation, advocated by Giorgi (2009), is a method to aid eidetic reduction (which is discussed later in this chapter). Husserl’s phenomenological, or phenomenological-psychological reduction, epoché of natural science could be achieved by setting aside or ‘bracketing’/‘bridling’ prior knowledge. This knowledge could be theories, measuring instruments, prior research, and what is known of the phenomena under investigation. The ability to openly, as well as passively, approach the phenomenon, letting the phenomenon reveal itself and show itself as it is experienced, enables the phenomenon to be seen in new ways. This fulfils the fundamental aim of phenomenology, that:

> ‘knowledge must be grounded in contact with the unique characteristics of its subject matter’; ‘Zu den Sachen selbst’ (to the things themselves)’ (Wertz et al., 2011:53; Husserl, 1970/1900).

The isolation of unique characteristics or essence, Husserl (1970/1900) argued, would lead to the possibility of the creation of a distinctive structure of the phenomenon in question. But only at that particular time because phenomena do not remain still. Of course, descriptive-empirical phenomenology also requires the entering of and a commitment to ‘phenomenological attitude’ with which an openness is created. This leads to a willingness to see the experience of the participant in new pre-reflective ways, attending to how the phenomenon calls to be expressed as they present themselves (Finlay, 2011; Araten-Bergman et al., 2015; Ashworth, 1996; Vagle, 2014; Dahlberg et al., 2008; Husserl, 1970/1936; Heidegger, 1998/1927; Merleau-Ponty, 1995/1945; Gadamer, 1995/1960). It is clearly emphasised that these epochés aim to set aside, rather than to disbelieve or doubt, natural science and other knowledge (Dahlberg et al., 2008). Stepping out of ‘natural attitude’, temporarily, to attend to the ‘lifeworld’ (lebenswelt) brings a fresh view and one in which the ‘scientist’ is able to reflect on lived experiences or concrete examples of the chosen phenomenon by:

> ‘Looking forwards towards understanding, rather than looking backwards at… [bracketed] pre-understandings (Finlay, 2011:127; Dahlberg et al., 2008; Wertz, 2011).

Compared to other methods, phenomenology demands much from the researcher and is considered more than a method:

> ‘[It is] the expression of a way of being… in contrast to a dogmatic approach… [by standing] outside the positivist subject-object distinction…[openness becomes central to the] criterion of objectivity (Dahlberg et al., 2008:98; Palmer 1969).
>
> ‘[It] takes layers of reflection and critical concentration where the phenomenon is viewed with disciplined naiveté’ (Finlay, 2009b:476 citing Giorgi, 1985).

This was considered very early on in this study and a reflective diary started to be developed early in the research process. This is demonstrated and discussed in Chapter 5: Reflections. Whilst the literature review was being conducted I examined and scrutinised my own pre-assumptions, which were incidentally being expanded by doing a literature review, guided by questions provided by Dahlberg et al. (2008). This was in order to adopt and remain in phenomenological attitude for the duration of the research process.

3.2 The design of the study

As phenomenology calls for the concrete lived experiences of the phenomena to be gathered, the idea that ‘if you want to know how people understand their world and life, why not talk to them?’ (Dahlberg et al., 2008:171) was literally taken up in this research study. This appears obvious but within ID-related research, as highlighted by the literature review, asking those with IDs about their experiences is unfortunately not often ‘taken up’. The method of descriptive-empirical phenomenology to gather adults with IDs’ lived experiences has also not been particularly used in this field, perhaps owing to the suggestion/perception that people with IDs do not have the necessary level of skill to describe and reflect upon their experiences required for such a study, in order to generate rich data. But phenomenology allows for flexibility and adaptation. Dahlberg et al. (2008) highlighted that there are an unlimited variety and combination of methods and techniques which can be employed within phenomenology to gather rich and descriptive data: observations, interviews, written accounts, artwork, and poetry. However, some of these methods, written accounts as an example, may have created barriers for some people with IDs because of their level of literacy skills. Reflecting upon all the data gathering methods, interviewing was viewed as the most appropriate and immediate way to gain the lived experiences of people with IDs. Dahlberg et al. (2008) proposed that the researcher's task during an interview was to 'facilitate interviewees in telling their stories' (:184) of the phenomenon. In this case, wellbeing and internet. It was also anticipated that this may lead onto their experiences of having an ID, as this may link to their immersion in lifeworld, perhaps through their body, to which they experience the lifeworld. Openness is one of the key fundamental stances of phenomenology and is connected with what Heidegger (1998/1927) describes as the adoption of a 'goal free' listening by:

> 'Following, going along with, and privative modes of not hearing, resisting defying, and turning away…[This has the] potentiality for hearing, which is existentially primary, that anything like hearkening [Horchen] becomes possible. Hearkening is phenomenologically still more primordial than what is defined 'in the first instance' as "hearing" in psychology – the sensing of tones and perception of sounds. Hearkening too has the kind of Being of the hearing which understands' (:206-207).

The 'receptivity of the researcher to the subjects and the subject matter' is what Smaling (1995) referred to as the ability:

> 'to engage with a participant, establishing trust and confirmation and a level of nearness that allows the possibility of disclosure' (Dahlberg et al., 2008:100-101).

This initiated the design of a study that did not plan for a single, 'one-off', interview with the participants, which is something Flowers (2008) argues is the ‘staple means of data collection within most kinds of qualitative research’ (:24). Instead, a number of interviews over time was planned, and time was given prior to these interviews to build rapport, establish trust and connect with the participants. Multiple interviews allowed for ‘inter-action, a continual sharing and discussion’ on the topic between myself and participant and was what Kvale (1996) believed to be the true meaning of the term interview or ‘inter-view’ (Dahlberg et al., 2008:185).

The decision was made not to return the completed transcripts, or indeed parts of the analysis, to the participants to verify or validate. This may appear unethical or an act that could lead to the assumption of not viewing the participant as an ‘expert’, but this decision was based on Giorgi’s (2009) descriptive-empirical phenomenological methods and its grounding with Husserl’s ‘natural’ and ‘scientific’ attitudes. As most participants are usually unfamiliar with phenomenological attitude, they are describing their experiences in ‘natural attitude’, unlike the researcher in ‘scientific attitude’, and will not see the research in the same way (Finlay, 2011). This does not mean that participants with or without IDs are not ‘experts’ of their own experiences, they are, but they will be less clear of the meanings of these experiences (Giorgi, 2008a; 2008b). Language was the next consideration, especially with the formulation of the questions. The language used in phenomenology to ask questions had to be adapted in order for it to be understandable to all participants with IDs. The opening and following questions used by Araten-Bergman et al. (2015), as an example, to attain rich description and encourage reflection were: ‘Can you tell me about yourself and your illness? Can you share with me the story of the illness through the years? How would you describe your life with the illness through the years?' (:4). These may not have been understandable for all participants with IDs as they contained too many concepts and this was also highlighted by the advisory group used in this study. For this study a phenomenological opening question could have been: 'Can you tell me about an experience of wellbeing and internet?' or: 'Can you describe a time when your wellbeing has influenced your use of the internet?'. But for this study the opening question 'Can you tell me about the internet?' was used and further questions brought in additional concepts one at a time (the interview schedule is included in Appendix B.1.).

Data gathered was viewed as being needed to be carefully transcribed, verbatim, into text format and to include 'non-verbal information, such as periods of silence, sighing, coughing, laughing, crying and hesitations' (Dahlberg et al., 2008:234). Giorgi (1989) also added that non-verbal information should also include observed emotions. These were also seen as important for adults with IDs who may use slightly different communication styles, including non-verbal communication, which may give further understanding in the analysis stage. The option to transcribe verbatim was because I felt not transcribing verbatim would encourage interpretation, or the 'rounding up', of the participant's sentences to initially 'make sense' of the data and this would not have been suitable for descriptive-empirical phenomenological methods. But it is important to note that even transcripts which strive to be authentic are only a one-dimensional aspect, limited by language, of a once lived conversation, and which now, in the form of transcript text, lacks:

> 'the presence of those who were speaking [and therefore]… no longer exists… Instead of summoning our whole being, it does no more than

> touch us lightly by ear' (Merleau-Ponty, 1968/1960:65; Kvale, 1996; Dahlberg et al., 2008; Giorgi, 1989).

Prior to finalising the study design, advice was sought from people with and without IDs in the form of an advisory group and ethical considerations concerning the interviews and participants with IDs were explored. Existing studies, such as those by Crook et al. (2015) and McDonald (2012), which had looked into those with IDs' experience of being involved in research studies was also useful in the design of this study and often resulted in adaptations and specific approaches towards the participants to reduce barriers and minimise any negative effects. In Crook et al. (2015) study the participants stated that the barriers to participating in the research included:

- Unprepared researchers, who had not adequately adapted and made the research process accessible and understandable for them;
- Restrictions created by others (families and carers) over their independence by them being 'too busy, protective over those they care for, or who make decisions on the individual's behalf';
- A 'lack of transport or directions and inaccessible buildings' which made it difficult to access the place of research;
- Not being paid for involvement, as other non-ID participants often were, making them feel un-valued (Crook et al., 2015:133).

Negative experiences in participating in research studies were often as a result of poor ethical considerations and choices, such as including the name of a participant in the research report without his or her knowledge. This left the participant feeling angry and loath to participate in future research. Clinicians working with the participants from Crook et al. (2015) study also added that research that included people with IDs: ‘was important to help improve services’ (:130) and increased the participants’: ‘awareness of learning disabilities and the services they access’ (:133). The clinicians in this study often took on the role of ‘gatekeeper’, but this role often made them feel ‘uncomfortable’ whilst they aided the recruitment process. This was especially true if they thought their client with an ID was unsuitable for the specific study or would become upset or offended with the researchers or themselves. They also had concerns that their client’s participation would disrupt their existing relationship with themselves and the ‘undesirable consequences of research topics’ (Crook et al., 2015). The gatekeepers were also concerned if they were:

> ‘unsure of the study’s rationale… [or felt that the] research was being conducted ‘for the sake of it’’ (Crook et al., 2015:135).

These findings add to existing literature on the importance and the inter-relational issues of the ‘gatekeeper’ role, which can be facilitative, protective, but sometimes suspicious of the benefits of the research and the intentions of the researcher/s (Lennox et al,. 2005; Nicholson et al., 2013; Iacono and Murray 2003; Tuffrey-Wijne et al., 2008). It was also clear, from the experiences of those with IDs in Crook et al. (2005) study that some researchers were less than ethical in their research process and so it was understandable that ‘gatekeepers’ would be suspicious and aim to protect those with IDs. The clinicians also highlighted the ‘power disparity’ between the participant and ‘gatekeeper’ [and participant and researcher]’ and felt that some people with IDs had a ‘desire to please’ which may make potential participants feel as if they should participate (Crook et al., 2015:133). All of these points were very relevant to my own study and in combination with what the advisory group had also stated, decisions and adaptations (which were often then individualised for each participant) were made/created and used in this study. These are described in Chapter 4: Methods. There was a need for me to reflect on my own contribution and positionality and how this may influence the research and the participants. This is further reflected on in Chapter 5: Reflections.

3.3 Analysis of data: a two-phase analysis to pursue both sense-making breadth and lifeworld depth

Traditionally, qualitative research appreciates that information and knowledge are produced in specific contexts ‘by the participants who come from, and are located within [these] specific contexts’ (Braun and Clarke (2013). Context is important to qualitative research and is not seen as something that should be stripped from the research question or data (Braun and Clarke, 2013). Although Chapters 1 and 2, within this thesis, served to provide a broad context of those with IDs (their engagement in research and their wellbeing and online experiences as examples), the context of each participant in this study was seen as vital to the descriptive-empirical phenomenological study and what had been discovered as context outside this study in Chapters 1 and 2 needed to be set aside until analysis had been completed. In response to the success of analysing context and concrete lived experiences of the phenomenon in question, this research study was also approached in two phases. The first using inductive Thematic

Analysis (TA) to analyse the participant's context, and the second phase using descriptive-empirical phenomenology to analyse the concrete lived experiences of wellbeing and internet. Todres and Galvin (2005a) found that in their study of the experience of intimate caring for a loved one with Alzheimer's disease (Todres and Galvin, 2005b; Galvin et al., 2005), a two-phased approach to the analysis was not only complimentary but revealed:

> 'Two kinds of knowledge product (narrative identity and lived-through experiences)… constructively making sense of narrative identity as well as being constructed by the experiences lived through; the substantive "more" of the lifeworld that always exceeds capture by interpretation' (:10).

Similar to Todres and Galvin's (2005a) reasons for pursuing both sense-making breadth, to reveal narrative identity and lifeworld depth, the participants in this study were given the freedom to tell their own story, to choose in what order to place events and meanings, and what to prioritise. At times this took place before there was a focus on the participant describing in detail their concrete experience of the phenomenon. This was perhaps due to the opening question for the interviews being: 'Tell me about the internet?', which surprisingly initiated many different answers which were not always about the internet, but were, nevertheless, important to the participant's individual context and overall wellbeing, and subsequently to the phenomenon, adding valuable breadth to the study. Todres and Galvin (2005a) suggest pursuing breadth:

> address[es] the complexity of a phenomenon in an open-ended way… using] a "broad brush," whereby the boundaries and foci of an experiential phenomenon are not initially clear' (:5).

The opening question also allowed the participant to lead the interview and to retell their story in their own way, something many of the participants remarked they were not often given a chance to do in their everyday lives. Using TA as an approach to the participant’s context, which was uniquely varied, certainly gave a sense of ‘person-ness’ (Todres and Galvin, 2005a:5) to the experience of living with an ID, how it felt to be a male or female off- and on-line, and the experiences of loss and bereavement. TA also complimented the second phase (the descriptive-empirical phenomenological analysis). For example, one theme generated using inductive TA was the participant’s experience of spatial limitations and a lack of freedom offline, which became invaluable when a theme emerged from the descriptive-empirical phenomenological analysis of participant’s experience of an increase in spatial awareness and freedom online. Another example of what Galvin and Todres (2005a) describe as ‘useful transferable knowledge’ (:8) was Alex’s experiences of being verbally abused offline and also within the online games he played, and how he had subsequently isolated himself from the offline world and developed his own online tactics and a resilience in order to remain online, maintain his wellbeing, and combat the ‘trolls’. The TA of the participant’s context also illustrated the large variation between the participants which led to the decision to keep participant’s context as separate individual vignettes, rather than systematically synthesizing the participant’s themes as TA advocates in it’s later stages.

As the design of the study allowed for multiple interviews, gathering data that would reveal both narrative identity by pursuing sense-making breadth was easier because the participants were given time and freedom in their interviews to explore the phenomenon and their context. Neither the participants nor I saw the phenomenon: wellbeing and internet, as a ‘thing’ that had no context for the rest of their lives. In later interviews, to ensure lifeworld depth was addressed, I prompted the participants specifically about wellbeing and internet experiences they had already mentioned, often in a previous interview, because at the time I did not want to disrupt the participant’s retelling of their story.

3.3.1 Phase one: inductive thematic analysis method

As noted, this was a two-phase study and for the first phase inductive TA was used to inform and illuminate the individual participant’s context in relation to the phenomenon in question. This served to increase the sense-making breadth of this study. TA is defined by Braun and Clarke (2013) as:

> a method for identifying, analysing, and reporting patterns (themes) with data. It minimally organises and describes your data set in (rich) detail… [or] further than this, and interprets various aspects of the research topic (Braun and Clarke, 2006:6; Boyatzis, 1998).

The variety of TA used in this study was inductive (rather than theoretical) and is described by Braun and Clark as:

> a process of coding the data without trying to fit it into a pre-existing coding frame, or the researcher’s analytical preconceptions… the themes identified are strongly linked to the data themselves…[and] the analyst is not looking for anything beyond what a participant has said or what has been written (Braun and Clarke, 2006:12-13).

As such, inductive TA aligns itself well with the descriptive-empirical phenomenological approach described by Giorgi (2009). A benefit of TA methods is its flexibility because it is:

> ‘Essentially independent of theory and epistemology, and can be applied *across* a range of theoretical and epistemological approaches… which can provide a rich and detailed, yet complex account of data’ (Braun and Clarke, 2006:5).

Like descriptive-empirical phenomenology, the aim of inductive TA is also to set aside preconceptions or pre-assumptions and it also realises that the researcher cannot separate themselves from the lifeworld or:

> ‘…free themselves of their theoretical and epistemological commitments,…the data are not coded in an epistemological vacuum’ (Braun and Clarke, 2006:12).

However, TA has been criticised for its apparent flexibility, being seen as an ‘anything goes’ approach to critiquing qualitative research (Braun and Clarke, 2006:5; Antaki et al., 2002). This was addressed by Braun and Clarke (2006) when they set out a theoretically and methodologically sound ‘recipe’ and vocabulary for TA (:5). It is this ‘recipe’ that informed the first phase of analysis. What follows are a summary of the steps and how they relate to this phase of analysis and to the descriptive-empirical phenomenological analysis (the second phase):

1. Familiarisation with the data. This was similar to what was required for the second initial descriptive-empirical phenomenological analysis phase. Verbatim transcription was chosen specifically because, like descriptive-empirical phenomenology, it is not interpretive and it was seen as an act that would limit any interpretation through the rounding off or cleaning up of the participant’s sentences and words. This became even more important with participants who had speech and language difficulties (SLD).

2. Generating initial codes. The entire data set from each participant was worked through systematically and anything that was not a concrete experience of the phenomenon, but appeared interesting or was repeated (forming a pattern), was coded with a descriptor in the right-side column directly next to the data. Sometimes notes were also written, as well as potential themes that came to mind, in a separate document. For practical reasons text that was coded using inductive TA was highlighted in green, and text coded for the descriptive-empirical phenomenological analysis was highlighted red.

3. Searching for themes: Once the transcript was coded, these codes (with the data attached) were then arranged into potential themes for each participant. The themes were then arranged into tables with a potential name for the theme. Some became sub-themes for the participant and any common themes amongst participants, such as a lack of spatiality offline, was noted.

4. Reviewing themes: Once the themes were arrived at, they were reviewed and refined. Often themes were related and amalgamated. At this point, if it was clear data should indeed be in phase two (the descriptive-empirical phenomenological study, it was transferred over, and vice versa.

5. Defining and naming themes: The themes were defined for each participant and whilst the themes from each participant were not brought together systematically, commonly occurring themes that participants shared were made a note of: for example, the experience of losing an important person in their life.

6. Producing the report: The themes were then written up in the form of a vignette for each participant. These provided the sense-making breadth of the study and were referred to in the essential structures of the phenomenon in question set out in Chapters 7, 8 and 9.

An example of the TA of a section of Andrea’s context is included in Appendix C.4.

3.3.2 Phase two: descriptive-empirical phenomenological analysis

For phase two, Giorgi’s (2009) descriptive-empirical phenomenological methods were used to analyse adults with IDs’ concrete lived experiences of the phenomenon: wellbeing and internet. Unlike the first phase, which produced individual participant vignettes and pursued sense-making breadth, descriptive-empirical phenomenology does not aim to describe individuals’ subjective experiences. It is concerned with the general phenomenon as experienced and to work towards describing the essence or essential structure of the phenomenon and to pursue lifeworld depth (Finlay, 2011).

The descriptive-empirical phenomenological approach for use as a scientific and rigorous research method was developed by Giorgi (1985, 1997, 2009) and the Duquesne Circle in the 1970s (specifically from Husserl’s phenomenological reduction) and set out methods to search for, and extrapolate, the essential structure or essence of the phenomenon (Finlay, 2009b; Wertz, 2005). Giorgi's (2009) descriptive-empirical phenomenological methods were adhered to closely at the analysis stages to analyse the 'naïve' and lived experiences of wellbeing and internet in order to describe the essential structure of phenomenon without 'interpretation, explanation or construction' (Dahlberg, 2008:241). Only the 'lived' experiences of the phenomenon by adults with IDs can create:

> 'a pure description… nothing [should be] taken for granted about its "real" existence' by the researcher' (Dahlberg, 2008:242).

Phenomenological attitude was maintained during the research process, including the exclusion and bridling of any influencing theories, such as Bartle's (2014) player types model. Although Giorgi (1997) recommends a phenomenological attitude for the entire research process, it was at the data analysis stage where there was increased concentration on reaching and maintaining this open state. Only after the essential structure of phenomenon was finalised were pre-assumptions, often in the form of relevant theories and past research, brought in and included in Chapters 7, 8 and 9's discussions. Ashworth's (2015) fractions of the lifeworld were in the background during the analysis as a guiding influence, but not as a way to frame the analysis process.

The phenomenological descriptive method followed the following steps:

1. **Read data for a sense of the whole**: Whilst still remaining in phenomenological attitude, Giorgi (2009) recommends becoming familiar with the 'whole'. This was achieved, in this study, by listening to the audio recordings of the interviews and reading the transcripts, to get a sense of the

'entire description' (:128). A descriptive-empirical phenomenological approach is 'holistic' and there is a notion that:

> 'meanings within a description can have forward and backward references and so analysis of the first part of a description without awareness of the last part are too incomplete' (Giorgi, 2009:128).

Giorgi (2009) suggests that it is important at this stage, not to try and clarify or make specific the sense of the 'whole', but only to gain a general sense of the 'whole'. This stage was not so different from the first phase of Braun and Clarke's (2006) TA methods, and so both phases of analysis were achieved simultaneously at this point. Both phases of analyses did not start prior to getting a sense of the 'whole'.

2. **Determination of meaning units**: Once the data has become familiar, through reading (and listening) and re-reading (and re-listening), and a general sense of the 'whole' has been achieved, the 'whole' is divided into parts. This is because the descriptions of the concrete lived experience 'are [often] too long to be dealt with holistically' (Giorgi, 2009:129). The descriptions are read and, whilst practising phenomenological attitude and having the phenomenon in mind, a mark: '/', is used in the description 'every time one experiences a significant shift in meaning' (Giorgi, 2009:130). Subsequently, each part of the description, separated with this mark, becomes a unit of meaning. A unit of meaning can encompass one sentence, several sentences, or more. However, the start or end of a sentence does not have to mark the beginning or end of a unit of meaning. As Giorgi (2009) explains, 'a sentence is a unit of grammar and not necessarily sensitive to psychological reality' (:129). During this process one

still has to be mindful of the ‘whole’ and approach this task openly with a spontaneous manner and one that is:

> ‘more experientially determined rather than intellectually so [and without an]… establish[ed]… priori criteria for their determination.’ (Giorgi, 2009:130).

At this point, meaning units ‘carry no theoretical weight’, they simply make the descriptions more manageable for the next step (Giorgi, 2009:130).

3. Transformation of participants’ natural attitude expressions into ‘phenomenologically psychologically sensitive expressions’: The descriptions of the phenomenon, that have now been broken down into units of meaning, are now interrogated and:

> ‘expressed [,] in a more satisfactory way [with] the psychological implications of the lifeworld (Giorgi, 2009:131).

At this stage it is important that an:

> ‘epistemological claim [has] no speculative or non-given factor influenced the findings…[is justified by] a careful description of precisely the features of the experienced phenomenon as they are presented themselves to the consciousness of the researcher…, structures have the strength of facts, even though they are not pure facts.’ (Giorgi, 2009:130-131).

Importantly, Giorgi (2009) recognised that this needs to be expressed in phenomenological attitude and so there are no fixed psychological dimensions of experience, these are to be determined by the researcher. The phenomenologically psychologically sensitive expressions may not become apparent initially, they have to be ‘detected, drawn out, and elaborated’ on (Giorgi, 2009:131). The method of the transformation of meaning units into PPSE involves repeating the words of the participant, the first person expression, and transforming these into third person expressions. This is because:

> ‘one has to be sensitive to the viewpoint of another, but identity with the other is not the goal’ (Giorgi, 2009:154).

This process is specifically referred to in Chapter 5: Reflections, because at times my immersion in the data had slipped into identity and this, Giorgi (2009) explained, was not helpful to descriptive-empirical phenomenological methods.

Practically, Giorgi (2009) highlighted the use of a table format as a method of structuring and recording the transformations of the description, from meaning unit to transformations, and then transformations to phenomenologically psychologically sensitive expressions, which needed to be:

> ‘expressed more explicitly in language revelatory… of the lived-through experience with respect to the phenomenon being researched’ (:145).

At this latter stage Giorgi (2009) introduced the practise of free imaginative variation or eidetic analysis, or reduction, based on the fundamental question ‘How can we know such essences?’ (Wertz, 2011:127). This is to clarify what is essential to the essence in order to form the essential structure of the phenomenon. Eidetic variation, originating from the work of Husserl (1970/1900, 1998/1913), can be practised as free imaginative variation by:

> ‘[T]he given data… [being]… imagined to be different from what they are in order to ascertain higher level categories that retain the same

> psychological meaning but are not embedded within the same contingent facts' (:132)… [To] determine the most invariant constituents of the experience…[Would the structure]…collapse if a potential constituent were removed [?]. If it does, the constituent is essential' (Giorgi, 2009:199).

Giorgi (2009) notes that the procedure of free imaginative variation should 'not [be] pushed to the level of universality', as in philosophy, but only pushed to a level of 'generality' appropriate to this method (:132). Each description of the phenomenon is expected to be different for each participant, but the collective meaning of the phenomenon is generally identical. As such, the structure of the phenomenon is not limited to one participant, but based on several participants' descriptions of their experience of the phenomenon. Giorgi (2009) does not describe this step as easy and advises that the researcher needs to:

> 'dwell with the data, change and vary it imaginatively… [and this may involve having to] …write several versions before the desired expression.' (:132).

Giorgi (2009) also recommends that 'conscious processes' take place while performing this task, which is based on Husserl's (1970/1900) theory of meaning. This helps to identify an 'incorrect variant' and the identification of a 'correct variant' (Giorgi, 2009:132-133). But still, a correct variant, once identified, requires the need to return to the meaning unit and its place in the 'whole' to check that it 'truly comprehends all of the critical senses contained therein' (Giorgi, 2009:133). Giorgi (2009), like Dahlberg et al. (2008), sees the data, at all stages, as belonging to their context and any meanings derived from the data should not be separated from the context. They need to be 'seen as a phenomenon' and a 'harmony' of movement between the whole, the parts, and the whole, which will result in a ‘harmonic whole’ (Dahlberg et al., 2008:235-236; Gadamer, 1995/1960). This is necessary because phenomena are ‘complex, relational and embedded in the “flesh of the world”’ (Dahlberg et al., 2008:233; Merleau-Ponty, 1968/1960).

Once the meaning units had been transformed into phenomenologically psychologically sensitive expressions, these are read over to decide if they could be incorporated into a ‘single structure’ or if they are ‘so large that they ha[ve] to be designated as interstructural’ (Giorgi, 2009:166). Giorgi (2009) indicates that rarely:

> ‘is the unity a single idea. Rather, the structure usually consists of several key constituent meanings and relationship among the meanings is the structure… [The structures that are then written] depict the lived experience of a phenomenon, which may include aspects of the description of which the experiencer was unaware’ (:166).

To achieve this stage requires an ample period of dwelling with the data and varying it imaginatively. This is likely to bring about uncertainty and discomfort, which must be embraced to allow the phenomenon to show its meaning (Giorgi, 1989; 2009). Decisions, or the: ‘closing off of the phenomenon… [, should happen only] when one really has to’ (Giorgi, 1989:51). Additionally, Giorgi (2009) makes a note about the writing of structures, specifically about the language used:

> ‘the researcher has to be careful not to be too bound up with the language of the transformations. Sometimes such languaging can be carried over to the structure, but often it cannot because it is based upon partial analyses rather than an overview of the whole description.’ (:167).

Appendix C.2 shows an example of a section of transcript that was analysed using descriptive-empirical phenomenological methods.

Throughout the descriptive-empirical phenomenological analysis, Ashworth's (2015) lifeworld fractions were considered because they were 'inevitable structures of the lifeworld' (Dahlberg et al., 2008:194, citing Merleau-Ponty, 1995/1945). Finlay (2011) suggests that researchers need to still remain 'open to lifeworld experience as a whole' (:136) and if these structures or fragments do provide a framework they should not be used mechanically because they may inhibit or constrain the analysis. They should, as Ashworth (2003) advises, only be considered as 'analytical moments of a larger whole' (:151).

Giorgi (2009, 1989) provides research-based descriptive-empirical phenomenological methods, which he developed from pure philosophical work, witch still have firm groundings in philosophy and psychology. For this study these methods were crucial to illuminating the essential structure of the phenomenon: wellbeing and internet, as experienced by adults with IDs, whilst also considering the participant's individual context (the two-stage analysis pursuing both breadth and depth).

Whilst descriptive-empirical phenomenology has worked well in many research studies, whether it would work for a study with participants with an ID was still under question prior to the data gathering stage. An initial contact with the advisory group raised concerns over the use of descriptive-empirical phenomenological questions and the use of the term 'wellbeing' because in many cases most adults with an ID did not know what this term meant. But, as highlighted by Chapter 2, many of those without an ID also struggle with the meaning of the term wellbeing. It was, however, decided that asking questions that contained both the terms internet and wellbeing was viewed as perhaps too complex for all participants with IDs to understand. This was one example of how the study needed to be adapted for participants with IDs and I certainly learnt a great deal from this process and then putting these into practice. There was plenty of surprises and, as a result, flexibility was required. For example, the number of participants with speech and language difficulties (SLD) who took part in this study was pleasing but extra time and thought had to be given when first meeting the participants, and to reading and listening to their data straight after their first interviews, to increase my familiarity of the participants' speech and language style. The reason for many of the participants with SLD taking part in this study was because they had been previously excluded from other research studies, simply because of their SLD. Another factor for the participants' participation in the study was the lack of interest shown by those around them to their online experiences, including within online games and worlds, but these were exactly the experiences I hoped I could listen to.

The next chapter is a summary of the specific methods used, and decisions made, in this study. Although, it does not fully portray the full extent of thought that went into how to conduct this study ethically, nor all the adaptations and approaches that were considered, it gives a succinct and relevant account of, and rationale for, the methods used.

Chapter 4

Methods

4.1 Study overview

By using a descriptive-empirical phenomenological approach, this research study aimed to explore the question: What are adults with IDs' experiences of wellbeing and the internet? The inclusion criteria for the participants were:

1. An adult with an ID (self-selected).
2. Aged 18 or over.
3. That they had used the internet for longer than two months in the past two years.

The participants whose first language was not English and/or had a speech and language difficulty (SLD) were not excluded from participating in this study. The study aimed to recruit between 2 to 10 participants, as recommended by Giorgi (2009) and Dahlberg et al. (2008), based on the level of experience of the researcher and the nature of the phenomenon being studied. Multiple, semi-structured (aiming towards participant-led and open) and adapted interviews were conducted to gather participants' lived experiences of the phenomenon: wellbeing and internet. Participants were interviewed initially face-to-face for up to one hour and then, if they consented, given the option of up to a further 3 interviews. Analysis of the data was in two phases, the first used inductive Thematic Analysis (TA) methods (Braun and Clarke, 2006) to analyse the context, the second phase used descriptive-empirical phenomenological methods set out by Giorgi (2009) to analyse the lived experiences of the phenomenon in question.

4.2 Advisory group

Before finalising the design of the study and seeking ethical approval from the Faculty of Health and Social Care at the University of Hull, an advisory group was consulted. The advisory group consisted of 16 people: 9 had an ID and came from ID-related charities and health-related organisations and 7 did not have an ID but were studying, working and/or teaching in ID-related areas such as nursing/health, psychology, safeguarding or social work. Group and individual communication and discussion took place face-to-face and through emails with the advisory group members, depending on individual needs, preferences and availability. All advisors commented or contributed to aspects of the study, such as the need/relevance of the study topic, the design, methodology, the methods being proposed, participant information (Appendix B.2.), consent form (Appendix B.3.), publicity poster (Appendix B.4.) and internet safety information. The feedback from the advisory group was positive and offered constructive feedback which was utilised in the design of the study. Many felt this study was long overdue and was important in the lives of people with IDs and those who supported them. The advisory group felt that descriptive-empirical phenomenology appeared to be a suitable approach to the study, but highlighted that the data gathering method was need adapted to suit the needs of participants with IDs. This resulted in the need to break down a traditional phenomenological opening question, rewording all further questions, and having additional prompts (which allowed for participants who may have different understandings of the term ‘wellbeing’), including the creation and use of images and logos that represented general internet activities.

4.3 Recruitment

The decision was made to initially contact ID-related charities, advocacies and non-health-related organisations in the Yorkshire and Humber region. These were either previously known by myself or sourced from ID-related organisations' websites, for example Mencap. One of the reasons for this was to ensure that potential participants would already have an existing support network to help them make an informed decision about whether to participate in the study or not. Health organisations were not contacted because the focus of the research study was to elicit the everyday lived wellbeing and internet experiences of adults with IDs and their health status was not part of the sampling strategy.

Recruitment consisted of sending an email which contained a brief explanation of the study, the contact details of the student researcher, a link to the research project website, and the publicity poster as an attachment. On the research project website was text and audio recordings of the participant information sheet, consent form and the 'consent and making a choice' information sheet (Appendix B.5) for potential participants who required this. The email publicity was sent out on a Thursday afternoon, the best time of day to send an email and get a response (Andrzejewska, 2012) which was suggested to me by an ICT specialist. The email was sent to the named person of the charity, advocacy, organisation, or specific group, as shown online. If an email reply was received that showed interest in the study, the participant information sheet, consent form and making a choice information sheet was attached to an email reply. An offer was also made to meet potential participants who were interested, to explain the study face-to-face and answer any questions they had prior to any decisions being made about participating in the study. Often the gatekeepers invited me to travel to present the study to a group of people with IDs, which also gave them the chance to meet me in person and gave myself the opportunity to explain that they did not have to take part if they did not want to. All participants had received all relevant information about the study and met me at least once prior to deciding if they wanted to participate. They were advised to think about taking part before deciding. Many participants talked to staff about the decision and many took the information home with them to show to family members to discuss. Potential participants were advised that if they did want to take part they could contact me directly or, if they preferred, ask someone who supported them, often the gatekeeper, to do this on their behalf. Through this recruitment strategy 8 participants were quickly recruited from across the Humber and Yorkshire region.

4.4 Data gathering

4.4.1 Arranging interviews with participants and gatekeepers

All of the participants were, in various degrees, supported by a gatekeeper in their contact with me. Most gatekeepers were a positive influence on the recruitment and data gathering stages of the study. They helped with the arrangements of the interviews: making sure there was a quiet, confidential and familiar space for the participants to be interviewed, often at the ID-related organisations’ building, and securing these spaces. Some gatekeepers also prompted and reminded the participants that they had an interview the next day, often using text messaging to do this. Gatekeepers also liaised with families, specifically if the participant's travel to and from the venue was arranged by their family. In one instance, with the consent of the participant, a gatekeeper liaised with the participant's family to arrange a GP appointment for them after they had discussed medical symptoms in their interview which was of concern for the participant. The efforts by many of the gatekeepers, relevant staff and volunteers, and the support they gave to the participants, was fundamental to the success of this study and I am thankful for their help.

By the time arrangements were being made for the second and third interviews, many participants were keen and able to take the lead in organising when and where the next interview would take place. Conducting the interview at a familiar place for the participant enabled them to know where the interview was taking place, how to get there, and in many cases decreased the inconvenience for the participant, as the interview could be arranged on a day they were already visiting the ID-related organisation. Participants were reimbursed their travel expenses whether or not the participants were already attending the ID-related organisation, unless these expenses were already paid for by the ID-related organisation.

Prior to the first interview, I ensured that I spent some time informally talking and listening to the participants to build rapport and become familiar with their style of communication. This also included those I came into contact with who had decided not to participate. This was so any impact on their experience in their group was minimised and to ensure that they felt supported in their decision not to take part and not disadvantaged, for example, in their social interactions with the group or myself. The first interview was planned as a face-to-face exchange to ensure the participants consented to participating in the study and to complete the hard copy of the consent form. After the initial interview the participants were asked if they would like to be interviewed again. If they consented to this they were offered alternative ways of being interviewed other than face-to-face (email, Skype, or telephone). All participants specified that they preferred face-to-face interviews, with some stating that this was the easiest way for them to communicate. Therefore, all further interviews were conducted face-to-face.

All participants were assumed to have capacity in accordance with the Mental Capacity Act, which Jepson (2015) and Stevens and Hebblewhite (2014) highlight is not always assumed for those with IDs. Indeed in early stages of the recruitment some of the gatekeepers assumed the participants lacked capacity and started making the decision for them to participate on their behalf. This decision making was not considered ethical and these recruitment offers were politely declined. It was therefore important to give all the information to the participant and allow them to make their own decision. Prior to the first interview, a discussion was initiated around the contents of the participant information, making a decision information sheet and consent form, and the participant was encouraged to ask any questions. This was to ensure the potential participant was fully informed and understood what the study involved before consenting. Written and verbal consent was obtained before the start of the first interview and in subsequent interviews verbal consent was obtained before each interview.

4.4.2 Interviews

It was clear in the participant information, and also verbally stated face-to-face prior to the first interview, that, if the participant chose to they could bring someone into the interview with them for support, for example, a friend, family member, staff member or carer. None of the participants chose to do this, with some firmly declining this option. Once in the interview room, the participant was encouraged to rearrange the seating and the tables if they wanted to (which many participants did) and choose where they and myself sat.

The interview format was semi-structured, but a semi-open structure and participant-led interview was encouraged. The opening question/statement posed to almost all of the participants in their first interview, and sometimes at the start of subsequent interviews, was: ‘Tell me about the internet’ (the full interview schedule can be found in Appendix B.1). Occasionally the opening question was not used because the participant had already started talking about wellbeing and internet without being prompted with the first question, and was therefore encouraged to lead the interview. When required, often in the second interview, images and logos of internet activities were introduced if the participant was finding it difficult to remember all of the internet activities they had done. These images acted as prompts to elicit lived experiences.

After the first interview I listened to the audio recording of the interview to: ‘tune in’ to the participants’ communication style, identify anything that needed clarification, and areas of wellbeing and internet experiences that could be further explored in the next interview. Individual images to represent what the participant had talked about, for example, Grand Theft Auto (GTA), were created and if the participant responded well to the images as prompts they were used in the next interview to initiate further description of the experience.

After the final interview, all participants were asked if they would like to receive the study's easy read findings and a copy of the subsequent publication/s, once these had been completed. All participants stated this was something they wanted. All participants were also given gift vouchers, £10 for each interview that had taken place, and a letter to thank them for their participation in the study. The gift vouchers were not an incentive to take part in the study and this was not mentioned on any of the study's information that was given to potential participants, gatekeepers or organisations. Because people with IDs are less likely to be in full-time employment and may be in a position of lower socioeconomic status than the general population (Equality and Human Rights Commission, 2016), using the gift vouchers as an incentive was considered unethical, but it felt important to recognise the time the participants had given to the study.

During the data gathering stage two participants disclosed information that led the interviewer to encourage these participants to visit their GP. With the consent of one participant, a staff member of the participant's choice, was asked to support this. The other participant decided that she wanted to arrange this independently. Advice on both these participants was sought from both supervisors and all actions taken were documented.

4.4.3 Transcription and anonymising of the data

All interviews were audio recorded and transcribed verbatim. As soon as a potential participant had expressed an interest in taking part and an interview was being arranged, they were given a unique letter and number as a temporary pseudonym. This was used throughout the data gathering, transcribing, and early stages of analysis, until they were given names as pseudonyms based on something unique to them, but which would not identify them. For example, the pseudonym Leona, Latin for lion, was given to a participant who loved to watch sea lion shows on YouTube and the pseudonym Andrea was chosen because the version of GTA played by this participant was called ‘San Andreas’.

Some demographic information was collected from the interviews, but this was not specifically asked for unless it was appropriate to the interview, for example age, when the participant was referring to others online who were older than them or they had talked about others suggesting they acted or looked younger than they were. Participants often disclosed their disability status to the interviewer whilst discussing wellbeing, which sometimes led to the participant talking about their physical or mental health conditions. All participants were told that if they stated any names of people, places, or any other information which could identify them, these would be taken out of the transcripts. All anonymisation took place during the transcription phase.

Any words or sentences stated by the participant, or myself as the interviewer, that were not clear in the audio recording were left blank in the transcript. If what had been said sounded like a word or sentence, this was recorded in square brackets with the descriptor ‘sounded like ____’. During the interview information about pauses, length of pause if unusual, the participant’s or my own emphasis on words or sentences, observed body language, smiling, laughing, any external noises, the environment if applicable, and the images that either myself or the participant referred to were recorded contemporaneously after the interview had finished and then transferred onto the transcripts during transcribing. In some instances, the participants encouraged me to watch or look at something specific on the internet that they themselves had also experienced and this was also recorded on the transcripts. If I felt I was leading the participant in the interview this was also noted in the transcript and not used in the analysis.

4.5 Data analysis

The data analysis was in two phases: inductive TA for the participants’ context and descriptive-empirical phenomenological analysis to form an essential structure of the phenomenon: wellbeing and internet. After reading the transcripts and listening to the interview audio recording a number of times to get a sense of the whole, each participant’s transcript was then analysed for both the participant’s context relevant to the phenomenon (highlighted in green) and the concrete/lived experiences of wellbeing and internet (highlighted in red). Once the transcribing was complete and a sense of the whole had been achieved, data that was relevant context was highlighted green and a concrete/lived experience of the phenomenon was highlighted red. A descriptor was then placed in a separate column next to the green highlighted data (context). These descriptors were then transferred to a separate document and set out into themes, following inductive TA methods, for each participant. These were then summarised to describe the individual participant’s context, in a vignette, relevant to the phenomenon in question (Appendix D). Any themes that were common for more than one participant was also noted.

Data that was highlighted red, the concrete experiences, was divided into meaning units (using ‘/’ to separate each meaning unit) and an initial descriptor, stated in the third person, was placed in a separate column to the right of the corresponding data in the transcript. These descriptors were then transferred onto a separate document and further developed and arranged loosely into themes. The final themed descriptors were brought together to create individual participant’s essential structure of wellbeing and internet. Each of the participants’ individual essential structures were then brought together and arranged loosely and intuitively into clusters with the consideration of Ashworth’s (2015) lifeworld fractions in the background. These clusters were considered and rearranged several times before seven themes or constituents started to appear. However, these constituents were not set and allowed some amount of movement until they were settled on to enable the finalisation of the essential structure of the phenomenon.

Although the study design was well planned before the data gathering phase, flexibility was required and this fit well with a descriptive-empirical phenomenological approach. I started a reflective diary shortly after starting the Ph.D. program, which was not only invaluable for the progress of the research study (quickly highlighting challenges and encouraging dwelling of the study and data) but also personally as well. It helped to prepare myself to enter phenomenological attitude and to think about and make sense of my encounters with the participants, gatekeepers, supporting staff, volunteers, and maintenance people. I realised that no matter how well a study is planned and prepared for, things happen that are quite unexpected and could not have been anticipated. Selected aspects of the reflective diary are included in the next chapter, before Chapter 6: the essential overview of the phenomenon, and Chapters 7, 8 and 9 which consist of the findings. I feel the next chapter shows the importance of keeping a reflective diary during a qualitative study and how this aided the research process, specifically the analysis.

Chapter 5

Reflections

Willis (2008) suggested that good qualitative research should attend to specific attributes to ensure rigour whilst also ‘acknowledging idiosyncrasy and creativity in the research process’ (:150). Henwood and Pedgeon (1992) and Elliott et al. (1999) gave guidance on what specifically contributes to good qualitative research, many of which are discussed in other chapters within this thesis. For example, transferability, or situating the sample, can be found in Chapter 3, the integration of theory (coherence) in the analysis was demonstrated in Appendix C within a snapshot of data that had been analysed, and sensitivity to negotiated realities can be found in the discussion of the role and history of people with IDs in Chapter 1. This chapter, however, is concerned with reflection, researcher position (or positionality) and reflexivity across the research process, something that is required to be considered for qualitative research because of its effect on the research study and the findings (Grbich,1999). Observations, thoughts, reflections, positionality and reflexivity were recorded in a reflective diary which was kept during the research process. This chapter contains excerpts from this diary.

5.1 Reflection, positionality and reflexivity

Research is a process and represents a ‘shared space’, both of which are influenced by the researcher’s and participant’s roles and identities, which in turn shapes the inquiry (England, 1994; Bourke, 2014). Thus the researcher needs to be reflexive, and by this, Henwood and Pidgeon (1992) and

England (1994) meant to disclose, acknowledge and reflect upon the values and assumptions over the research process and their positionality. The philosophical foundation to descriptive-empirical phenomenology adds to the importance of understanding and practising reflexivity, specifically the acknowledgment of natural attitude, pre-assumptions, pre-understandings, and/or tradition, which form a context familiar to the researcher which is likely to either inhibit (but can also aid) understanding (Gadamer, 1995/1960). As discussed in the methodology chapter, being in natural attitude does not allow us to 'consciously analyse what one experiences' (Dahlberg et al., 2008:34). We are too immersed and lost in the activity and:

> 'thus [we have] fallen away from ourselves and "into the world" (:220). As a result, the things that we are closest to are the things that are most hidden from us' (Dahlberg et al., 2008:34 citing Heidegger, 1998/1927:220).

To overcome this problem we have to enter 'scientific attitude' in order to form a deeper understanding of lifeworld, but it needs to be remembered that as human beings, we never cease to be parts of, living and working through, the lifeworld (Merleau-Ponty, 1964/1946; Husserl, 1970/1936). Therefore, there is a need for 'scientists' who are making phenomenological inquiries:

> '…to understand how the lifeworld helps as well as hinders them to describe what they experience through their research' (Dahlberg et al., 2008:36).

Early in the research process I was able to identify, examine and scrutinise my own pre-assumptions and pre-understandings of, and position within, the topic under consideration and the research process using a set of questions suggested by Dahlberg et al. (2008). I attempted to bridle these to allow myself to approach the phenomenon with openness and ‘a true willingness to listen, see, and understand’ (Dahlberg et al., 2008:98). This then allowed the phenomenon in question to reveal itself and the process, which was documented in a reflective diary, added to the rigour of this phenomenological study. What follows is a selection of recorded reflections that stood out in this study and which demonstrate positionality, reflexivity, and the process of bridling.

5.1.1 Intellectual disability, interdependent relationships and learning disability nursing

As descriptive-empirical phenomenology demands, I needed to examine my own pre-understandings, pre-assumptions and positionality, and I felt, alongside the internet and wellbeing, this had to include IDs and learning disability nursing because of my own personal views, experience and positionality, which includes the dominant medical structure that surrounds myself as a Registered Learning Disability Nurse (RNLD) and student researcher. As previously discussed in Chapter 1, I approached this research study as someone who does not have an ID, therefore, I have no lived experience of having an ID. I am currently a student researcher engaged in the area of IDs, and an RNLD with previous experience of working with individuals and groups of young people and adults with IDs as a youth worker and art tutor. I have an ‘interest’ (Argyrou, 2013) in IDs which needs to be acknowledged as something that has rewarded me over the years with work, qualifications and a status, which has given me the power to conduct research into IDs, wellbeing and the internet as part of a doctoral program. But some of these rewards and statuses have developed into uncomfortable identities for myself, which I had to acknowledge and attempt to bridle. Other personal pre-assumptions and pre-understandings, for example, my own personal freedom and the important I place on freedom, also needed to be acknowledged and bridled during the data gathering and analysis stage as many of the participants experienced a lack of freedom offline. Any analysis and findings that related to my own pre-assumptions and pre-understanding were discussed with my supervisors to ensure I remained in phenomenological attitude. Despite examining and scrutinising my own pre-assumptions and pre-understandings, the research process did highlight further personal and professional values and feelings which I perhaps did not want to face, but needed to for this study (and, on reflection, for my own future). For example, having explained that I was doing a research study as part of a Ph.D. (which is part of the information given to the participant before they consent to their first interview), at the end of one interview, a participant asked why I had not become a ‘learning disability nurse’ after finishing my nursing degree. I replied that I still was a ‘learning disability nurse’ but one that does research rather than what he generally saw RNLDs doing day to day. However, I realised that whilst explaining and answering more of his questions (including when I would return to nursing), that I no longer felt like an RNLD. I had rarely used the term ‘learning disability nurse’ to describe myself since qualifying and I had distanced myself from this term since starting my Ph.D., actively taking up the more comfortable identity of a ‘student researcher’ instead. This de-identification had started during the later part of my nurse training, when I started to find the notion of ‘nurse’ alongside ‘learning disabilities’, at times, contradictory. I had also observed, what I believed were, some problematic relationships between ID-related professionals and organisations and their service-users/clients/patients with IDs. At times the professionals and organisations appeared to want to feel needed and valued by, or were paternalistic and controlling towards, those with IDs and, rather than increasing the individual with IDs' independence and independent decision making, professionals and organisations were often, knowingly and unknowingly, increasing the dependence of the individual with an ID onto themselves. This was also something I continued to notice during my research study and within the data I had gathered. Returning and reflecting upon Argyrou's (2013) concepts of 'interest' and 'guardians', who think and speak on others behalf (leading to the loss of autonomy of those being represented), it appeared unsurprising that this would be occurring because the professional's and organisation's 'guardian' positions are linked with financial rewards, identity, and status. Those with IDs sometimes viewed the professionals as 'friends' (also seen in the findings of my study). Often it was easier for the professional to be compliant to a friendship with the person with ID whilst working, perhaps because of the awareness that they may not have many friends. But when the 'friendship' was not continued outside work by the professional, and the friendship was stopped without explanation, this had a devastating effect on the person with an ID because they had seen this as a real friendship rather than a professional relationship. The professionals would often continue in their work unaware of the effect they have had on the person with an ID in these circumstances. Social media has further highlighted this area because many service-users/clients/patients with IDs can often find, contact, and request a friendship with the professional on social media. As more service-users/clients/patients turn to the internet for health-related support and information, professionals are forced to debate whether or not they should connect with those they work with online and in what circumstances.

I feel that these ID and non-ID interdependent relationships, in various forms, are not always equal and often have the potential to restrict and inhibit an individual with IDs' agency, but, I am also aware that my view could be based on the fact that I am someone who appreciates my own freedom and independence. As such, I struggled to fully understand or appreciate interdependency from an ID perspective. During the interviews and analysis, I soon came to realise that for many with and without an ID interdependency, the apparent lack of privacy for those with IDs, and decisions being made by those without an ID, appeared to be an accepted part of life by the individual with an ID and all those concerned. A clear example of this was during the data gathering stage of my study, when some of the gatekeepers and supporting staff would directly ask me (including when the participant was present) what the participant had said in their interview. This was never disclosed and the reasons for this were explained to the gatekeeper/staff member. On more than one occasion, staff members entered the interview room whilst an interview was taking place without knocking. One staff member (who had previously asked for details on what participants had said in their interviews and was refused this information) entered the interview room without knocking and was observed looking into an empty cupboard for some time. I too had looked into this empty cupboard, out of curiosity, as I set up for the interview. I assumed the staff member was trying to overhear the interview and I immediately stopped the interview and waited for her to leave. Once she had left, I explained to the participant that I had stopped the interview because what he said in his interview was confidential. He stated that he didn’t mind as long as they didn’t know what he did online, as this was private and a part of his life that was meaningful and important to him. It was the only part of his life that he could keep private from those who supported him and this was perhaps why the staff were so interested in obtaining this information. I also found that many of my participants had a different view from myself about what confidentiality was, with most participants (like the staff) assuming that I would share all their interview data with the staff that supported them, even though I had clearly stated both in the participant information and verbally that I would not. On realising that I was not sharing their data with the staff, many participants appeared to open up further in their later interviews, not only about their wellbeing and internet experiences, but also the frustrations and anger they felt around their volunteering roles, the staff that supported them, and the restrictions imposed on them by those without IDs. This strengthened my assumptions that a person with an ID’s life is often automatically open and available to the professional gaze and, not only did they lack privacy, but they often had to give up their privacy in exchange for status, identity and/or support from those around them. One participant spoke of his narrative (in nearly every interview) as one who had triumphed over the barriers presented to him as a result of his ID and, with the help of the health and social care professionals, how he was now involved in health and social care professional’s training by relaying his own experiences. This was repeated and emphasised in his interviews, even when the prompts were around the internet and other aspects of his life. It was clear that the participant had been encouraged and rewarded over many years to open himself up to the professional gaze and his wellbeing, specifically his identity, and was so entwined with this that at times he was unable to move beyond his ID status (now set within the medical domain) to develop meaningful friendships beyond those he had with health and social care professionals, or to embark on a sexual relationship (something he felt was missing from his life and made him feel sad that he had not been able to experience). As I sat and listened to this very familiar narrative from the participant, I was also sure that he felt that this was what I wanted to hear, because to him I was an ID-related professional, and we were, not only in the location of the interview, but also in our roles and identities, both surrounded by what Oliver (2009) describes as medical “professional dominance” (:45). As such, I was the ‘professional gaze’ that he needed to open up to, which, in a research interview, is exactly the aim in order to gather rich data. I had become aware of ‘professional dominance’ and ‘gaze’ in the lives of those with IDs before the data gathering stage of this study when I had reflected upon the notion of ‘learning disability nurse’, which, has no choice but to be contained within the dominant medical approach (despite often advocating a social model approach to disabilities). But this medical approach views a learning disability:

> ‘…[as something] wrong with them’ and hence the source of the problem…[The] issue of the distinction between illness and disability still has not gone away’ (Oliver, 2009:44).

Illness is different from a disability or an impairment. One difference is that disability, including an ID, cannot be ‘cured’ by returning the individual to the ‘normal condition of able-bodied or as close as it is possible’ (Lovell, 2010:85, DoH, 2001; AAIDD, 2013). Disability is caused by ‘social organization’ rather than being an individual’s problem (:4) because:

> ‘[a]ll disability can be eradicated by changes to the way we organize society… [W]e spend too much time and money searching for non-existent cures and not enough removing disabling barriers from the world in which we live’ (Oliver, 2009:44).

It is true that many people with an ID, alongside the general public, can become ill or acquire a long-term medical condition, such as epilepsy, diabetes, and/or respiratory, heart and mental health conditions, which may need the support of specialised health professionals. But if those with IDs’ health needs could be met by accessing mainstream health services, and we did not view an ID as an illness, then what is the role of a learning disability *nurse*? Of course, RNLDs are active in supporting those with IDs to access mainstream services, advocating on behalf of those with IDs and their families and carers, challenging societal views of IDs, and, at times, providing health services that are currently inaccessible or unavailable for those with IDs, for example, mental health services. But aiming for all those with IDs not to be medicalised (simply because they have an ID), and ensuring they are able to access mainstream healthcare (which would offer the best specialist heath services, excellent care and support, and which is available to the general public) should be the ideal long term goal to pursue in the interests of those with IDs. But this may mean a decline in, or a move away from, professions that medicalise those with IDs and an increase in ID-related training for all health professionals and other ID-related roles, such as advocates.

5.2 Reflections about wellbeing and internet during the data gathering and analysis stages

> ‘The things that we are closest to are the things that are most hidden from us’ (Dahlberg et al., 2008:34).

As one who holds an ‘interest’ in those with IDs and is set within the medical domain, I did not want to take the automatic view that the internet was something that was anymore dangerous or riskier to adults with IDs than to the general population (unless the data suggested otherwise). I also wanted wellbeing to be the presumed starting point for the participants in this study, as opposed to a person with an ID being viewed as ‘sick’, ‘abnormal’, ‘developing’, ‘childlike’ and/or ‘vulnerable’, as highlighted in Chapter 1. During the data gathering and early analysis stages, I found I had to revisit and reflect on my views around IDs, wellbeing and the internet many times, in order to bridle specific pre-assumptions and pre-understandings, so that I could remain in phenomenological attitude in order to re-present the participants’ experiences. One example of this was when a female participant expressed her disappointment when men, who she was matched with randomly when playing an online game, had not said anything of a sexual nature to her. When asked to give an example of the kind of conversations she had with these male players, she stated that they would often ask her what she was doing that evening: “What are you doing tonight?” to which the participant would answer honestly, that she was having her tea and planned on watching the soaps on television that evening. I initially assumed that the participant may not have understood the subtle sexual communication from the other player, but then I reflected on my pre-assumption that unknown male players online may only communicate with a woman with an ID in a sexual manner, because of my previous experience working with women with IDs and the cases I had read before this study. The question: ‘What are you doing tonight?’ could be a non-sexual or a sexual question. I realised that this could not be interpreted by myself as either sexual or non-sexual because I was not the one asking or experiencing this question, it was not my lived experience, and it was clear that the participant did not see this as a sexual question because she had expressed her disappointment at the absence of sexually-related conversations with the male players. Once my pre-assumptions were bridled this produced a different descriptor for this section of data, one that was descriptive rather than interpretive.

Another example of reflection on pre-assumptions, pre-understandings and bridling was around wellbeing and the notion of internet addiction when Alex described how much time he spent on the internet. “24/7” Alex stated before describing that both himself and his mother had suggested he was “addicted” to the internet. Alex described not having any friends offline and gave numerous examples of how the internet had negatively impacted on him, for example, disrupting his sleep patterns and increasing his lack of motivation to do activities offline. I initially started to equate the time he spent on the internet, these negative effects, and his lack of offline friendships (whilst knowing he also had online friendships) with a sense of suffering rather than a sense of wellbeing. With a view that the internet was pulling Alex away from the offline world. But once I started to dwell on Alex’s initial descriptions in phenomenological attitude and bridled pre-assumptions and pre-knowledge, I prompted him further on his wellbeing and internet experiences and he started to talk more about how he led a full social life online and gave more examples of internet experiences which were contributing to his sense of wellbeing. Although Alex had told me he was ‘addicted’, a label initially given to him by his mother, it was clear that his internet addiction was contributing significantly to his sense of wellbeing, whilst his offline world, which imposed restrictions and limitations on most aspects of his life, was contributing to his sense of suffering. When Alex could not access the internet he became agitated and sad, and no other offline activity appeared as inviting as re-connecting with the internet. I began to realise that any addiction Alex had was in fact an addiction to experiencing the lifeworld dimensions: identity, sociality, embodiment, mood, etc… which he was not often able to experience offline. We all need, seek, and are all possibly drawn and ‘addicted’ to experiencing aspects of the lifeworld. If we don’t experience them, sociality as an example, this can contribute to a sense of suffering (feelings of isolation and loneliness), and we may long for them. I started to wonder why the term addiction was so readily attached to the seeking of lifeworld experiences online which can contribute to a sense of wellbeing.

Another surprising theme that kept coming up in the participants’ interviews was the repeated description of themselves and their lives (and sometimes those who supported them) as being ‘busy’ and ‘very busy’. Participants described being encouraged to be ‘busy’ in their offline lives by those supporting them, often to distract the participant from negative thoughts or, in some cases, their ‘busy’ online lives, which others without an ID did not approve of. Being ‘busy’ focuses on existential mobility, described by Galvin and Todres (2013) as the striving towards the future through plans and pathways, rather than dwelling, which is placed at the opposite end of the wellbeing continuum. Both mobility and dwelling are seen as both important and equal components of wellbeing. I realised during the analysis stages that within ID services there is a focus on mobility rather than dwelling, and those with IDs are often encouraged to focus on mobility, or to be busy. As part of a professional's judgement and/or an assessment, if those with IDs are not busy this can become the focus for a professional, and plans are set to make sure the individual with ID is busy. Participants often recalled that they sometimes sought out online experiences to shut out their 'busy' and demanding offline worlds, which were often coordinated by those supporting them. John described spending time sat in a medieval feast in the online game Final Fantasy, sitting, talking and sharing stories with others. Andrea listened to music on YouTube and drove her car around in GTA, enjoying the freedom of driving anywhere she wanted without a set destination so that she could happen upon places she had not been to before. On an evening, Yvonne listened to music online whilst colouring in, or searching for poetry, in order to recover from her busy day and to dwell over the loss of family members and friends. For many participants, the internet offered the only chance for them to dwell safely whilst they still engaged in their 'busy' offline lives. As one participant explained, to just dwell offline, rather than keeping 'busy', held a fear that she 'may lose her mind'. Many participants had simply not been encouraged to dwell offline and as such, did not feel comfortable doing this. They, and those who supported them, only equated dwelling offline with a sense of suffering: loneliness, a lack of meaning in their life, or a loss of control or direction.

The openness brought to my data in phenomenological attitude and the continued reflection certainly prepared me for, and brought my attention to, what Gadamer (1995/1960) describes as many new understandings and surprises around the phenomenon wellbeing and internet as experienced by those with IDs. It is hard to represent a long reflective diary in such a small chapter, but I hope these examples give a flavour to the process of reflection, positionality, and bridling, which was immensely important to the research study and myself, helping me to develop into a more confident researcher, to decide what was important to me, and what direction to take after completing this Ph.D.

The next chapter presents the essential overview of the phenomenon: wellbeing and internet, before the phenomenon is presented in depth across Chapters 7, 8 and 9.

Chapter 6

The Essential Overview of the Phenomenon Wellbeing and Internet

1.1 Introduction

The aim of this research study was to gather rich data from adults with IDs to reveal the phenomenon: wellbeing and internet. It was hoped that the participants' experiences could be re-presented by using descriptive-empirical phenomenology, which included bridling (as far as possible) interpretations, pre-assumptions, pre-understandings and pre-knowledge: alternative methodology, methods, theories, models, frameworks, and those without IDs' views and concrete experiences. As touched upon in the earlier chapters, wellbeing has been linked with internet experiences in non-ID literature and, partly, in ID-related literature (but this is often theorised rather than derived from empirical evidence). However, adults with ID's concrete lived wellbeing and internet experiences have not been the explicit focus of any research studies. Within this study's findings, internet experiences were seen to be integral to the adults with IDs' sense of wellbeing in a variety of ways. Existential suffering was also experienced alongside wellbeing and internet and therefore also formed parts of the essential structure of the phenomenon, which was set out into seven constituents:

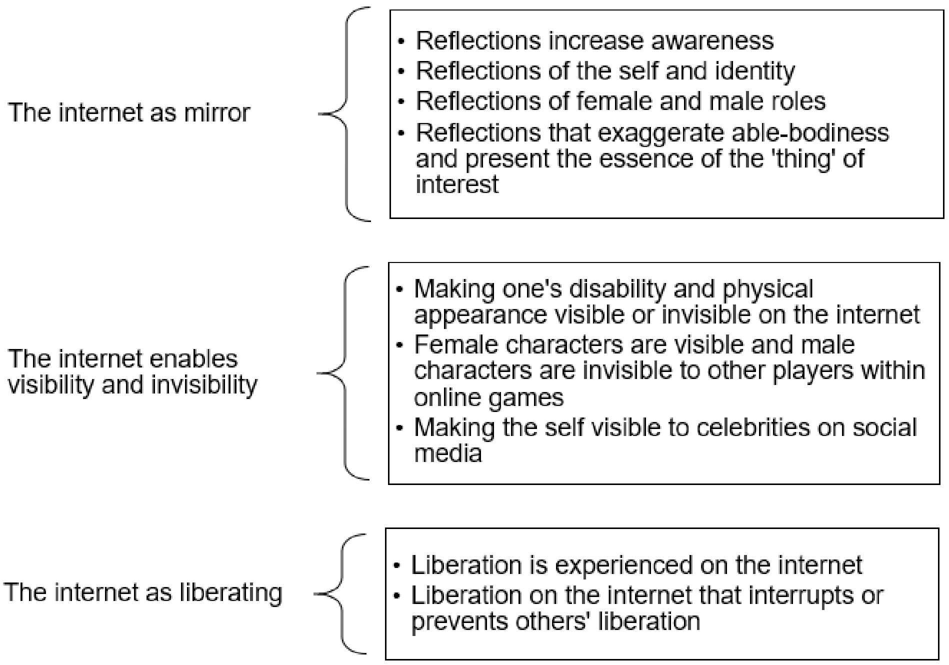
- The internet as mirror.
- The internet enables visibility and invisibility.
- The internet is liberating.
- The internet meets unmet needs.
- The internet creates an active decision maker and expert.

- The internet as friend and foe.
- The body connects to, and disconnects from, the internet.

Each constituent encompasses a number of subthemes which give examples of the participants' concrete lived wellbeing and internet experiences, which are further explored in the discussions. The constituents are set out across three Chapters, 7: The Liberating Nature of the Internet, 8: The Internet Simulates Aspects of the Lifeworld, and, 9: The Immersive Internet and Virtual Embodiment. Figure 6.1. provides a visual overview of the constituents and their subthemes under the chapter headings.

Figure 6.1 Overview of the Constituents and Subthemes of the Phenomenon Internet and Wellbeing

The liberating nature of the internet



The internet as mirror

- Reflections increase awareness
- Reflections of the self and identity
- Reflections of female and male roles
- Reflections that exaggerate able-bodiness and present the essence of the 'thing' of interest

The internet enables visibility and invisibility

- Making one's disability and physical appearance visible or invisible on the internet
- Female characters are visible and male characters are invisible to other players within online games
- Making the self visible to celebrities on social media

The internet as liberating

- Liberation is experienced on the internet
- Liberation on the internet that interrupts or prevents others' liberation

The internet simulates aspects of the lifeworld

The internet meets participant's unmet needs

- The internet meets the participants' unmet needs for identity, intersubjectivity, spatiality and project
- The internet meets the participants' unmet needs for mood/emotional support
- The internet meets participants' needs for consistancy, structure and an escape from conflict and everyday busyness
- The internet is not sought to meet a participant's needs

The internet creates a decision maker and expert

- The internet creates an informed decision maker and expert who can influence others
- The internet creates an expert in one's own and other's health
- The internet creates independence and the ability to plan one's own projects

The internet as friend and foe

- The internet as a perceived threat by those who support the participants
- Negative on- and off-line experiences
- The potential to meet those online in person

The immersive internet and virtual embodiment

The body connects to, and disconnects from, the internet

- The internet can easily to embed itself into a participant's life and contribute to their sense of wellbeing and suffering
- The monitoring and display of bodily rhythms on the internet
- Preparing and maintaining the immersion of the physical body within an online game
- The internet is hard to disconnect from and contributes to a sense of suffering

6.2 The range of internet experiences

There was a wide range of internet experiences described by the participants in this study, which contributed to both their sense of wellbeing and suffering. But some internet experiences appeared to not contribute to a sense of wellbeing or suffering, for example email, and were rarely discussed by the participants unless prompted. The participants described receiving volunteer, job, sports, news and offers/advertising related emails. Some of the participants' email accounts were shared with, or accessible to, a parent, whereas other internet experiences, such as online gaming, social media and YouTube, were often free from observation by a parent. It was these unobserved experiences that contributed to participants' sense of wellbeing/suffering. These are summarised as:

MMORPGs and MMOs, such as GTA, CoD, Final Fantasy, Fable, and Mine Craft. These were seen as high impact or immersive inter-relational internet experiences which offered a full range of online simulations of the lifeworld and, at times, transcended the limits of the offline world, for example, allowing a regeneration of a body after death.

Other online games, such as those played through social media (pool games, Criminal Case and Candy Crush) and other websites (Junior Vets on Call) often simulated sociality, temporality, project, and sometimes identity experiences. They provided the participant with the experience of connecting and chatting with others online (known and unknown) but they did not connect fully with an online community and the experience often centred on achieving tasks, 'levelling up', and gaining rewards. Compared to

MMORPGs and MMOs, these online games did not simulate all aspects of the lifeworld and were not as high impact or immersive.

YouTube offered the participants endless online experiences in the form of videos that had been uploaded onto this site, and the opportunity to follow specific YouTubers and their channels. The videos gave the participant a view of the lifeworld they may not ordinarily have access to, for example seeing the Northern Lights, and the opportunity to re-watch an offline experience, for example a dance performance or a sea lion show. Videos also included those that were funny, entertaining, amazing, weird, informative (including health-related information and advice), and news, celebrity and/or music based. Some participants used YouTube to learn about things that interested them and described this form of learning, or ‘research’, as being more accessible to them than their formal educational experiences at school and college. This was specifically highlighted by a participant who struggled to read and write, but who had a great deal of motivation to learn about astronomy and physics by watching videos on YouTube. YouTube was also used by some of the participants to display themselves to others online by recording their online characters and/or streaming their heart rate whilst playing within an MMORPG or MMO and uploading this for others to view.

Social media, specifically Facebook and Twitter, enabled the participants to connect and talk to friends, including ‘fan-based friends’, and their family members. They could keep track of and at times engage with pop stars, bands, sports players, and entertainers, by posting relevant photographs and images that could attract the celebrity’s attention. Facebook was a place for the participants to find out information about local and national events, view what others were doing and read others' posts, including others' opinions on world events and subsequent arguments. Social media was also used as a way to report problems with internet-related equipment or an online game, as this initiated a quicker response than emailing and was preferable to using a telephone.

Search engines, like Google, were used to search for a variety of things and, like YouTube, participants highlighted the unlimited choice of online experiences offered to them simply by the act of typing in a word or words into a search box and pressing 'search'. Participants used search engines to find images of themselves, poetry centred around losing a friend, their own and others' health conditions, houses that were for sale, job vacancies, cooking websites to find recipes, television guides, arena and theatre information, maps, weather forecasts, and information on items they wanted to buy.

Online buying sites, such as eBay and Amazon, were experienced by some of the participants, but they did not often buy items independently online because of the restrictions imposed on them by their families. Only one participant described viewing, bidding on and buying items on eBay, but this was still with the support of, and agreement, from her mother. Other participants experienced eBay as passive watchers of another family member who was searching for and viewing items of interest to them on this site. One participant described this passive experience as not being interesting to her.

Other internet experiences included unwanted sexual images appearing on their laptop screen due to a ‘virus’, online game forums, online video calling, and visiting downloading websites to view and download TV shows and films.

6.3 The range of wellbeing experiences entwined with the internet experience

MMORPGs and MMOs offered participants the chance to experience simulations of the lifeworld across all dimensions, which was integral to their sense of wellbeing whilst they inhabiting these worlds (and often times when they were not inhabiting the game). Within MMORPGs and MMOs participants experienced enjoyment, fun, and independence. They also felt they were valued, supported, and less judged by those online, compared to what they had experienced offline. The participants who had experienced MMORPGs and MMOs often had friends and romantic partners within these games and were part of a number of online communities. These connections felt comfortable to the participants and they described that others in these games understood them. They could complete meaningful projects and acquire a status based on their abilities within the game. This was enhanced by the fact that within MMORPGs and MMOs the participant’s disabilities and physical appearance, if they chose to, could be hidden from others online. Some participants stated that they feared rejection or negative consequences if they revealed their disabilities or appearance to others online. When a disability was disclosed to online friends this sometimes led to an acceptance by these friends, but at other times, this led to the participant being rejected by others online. Even though it was not always visible to the participant online, often because they did not actively search for it on the internet, the internet experience highlighted aspects of themselves they did not like and this brought about negative emotions and increased the negative perceptions and judgements they held or made about themselves. For example, having Down's syndrome (DS) or feeling unworthy of friendship, which resulted in a sense of suffering for some participants, feeling scared, overwhelmed, lonely and that their self-esteem had decreased.

MMORPGs and MMOs were generally experienced as liberating, comfortable and structured places for the participants to inhabit. The participants described a sense of freedom and mastery of the MMORPGs and MMOs which contributed to their sense of wellbeing and, unlike their offline world, anything was possible in these spaces. They no longer felt restricted, no long lasting consequences occurred for them, conflict could easily be resolved or avoided, and they could choose when to experience predictability and unpredictability. The chance to experience and become accustomed to unpredictability in the MMORPGs and MMOs was important to participants, specifically those with autism, as this was a way for them to learn how to build up their ability to cope with the unpredictability and busyness they encountered offline, which often resulted in an interruption to their sense of wellbeing.

Suffering was also experienced in MMORPGs and MMOs, especially within the lifeworld fraction/dimension sociality/intersubjectivity, for example, when an online marriage or friendship ended, or the participant was exiled from a community after a disagreement. This led to one participant feeling desperately sad and anxious (and not know quite what to do about this). They felt that others were spreading rumours about them and that they were being, or had been, betrayed by others online. This was then followed by feelings of loneliness and disconnection. For one participant, years of negative internet experiences in MMORPGs and MMOs from a young age had led him to feel upset, angry and worried. But he also stated that these experiences had contributed to the resilience he had built up towards those that verbally abused and threatened him online, ensuring his continued participation in these games, which he knew contributed to his sense of wellbeing across multiple dimensions.

Participants, specifically male participants, could view themselves through their online characters in the MMORPGs and MMOs. The strengths and abilities in their characters and their chosen roles, interactions, relationships with others and the projects they engaged in, gave these participants a sense of their preferred identities. These included being feared and/or respected by others, and being resilient, tough, skilful, big, a good fighter, powerful, helpful and protective of others. Through these online identities the participants felt valued, needed and admired by others. However, these preferred identities were opposed to their alternative and unwanted offline identities, which they and others had given to them, for example, ‘vulnerable’, dependent, or ‘wrong’ (medically). These participants gave little evidence of others offline validating their preferred identities, identites which they could view and/or enact online.

For one female participant, Andrea, the experience of playing GTA, specifically the act of driving her customised car, enabled her the spatial and temporal freedom she needed for her sense of wellbeing, but which was not available to her offline. When she felt upset about the loss of her grandfather, or experienced frustration and anger at not being able to get a paid job, driving in GTA contributed to her sense of wellbeing, particularly mood dwelling, as it brought her calmness and took her mind off, or distracted her, from thinking about the things she did not want to think about. But GTA was also a violent and unfriendly place for Andrea to inhabit, especially as a female character. Andrea stated that she did not choose to play a female character, the game chose this for her, and she would have preferred to play a male character for its ability to remain invisible to other players. The repeated attacks on her, as both a female character and female participant within this game, interrupted her sense of wellbeing by preventing her from driving along GTA's roads and motorways. She felt angry at male players who attacked her and felt helpless because she was unable to escape or defend herself against the attacks (due to not being able to work out how to do this in the game). Andrea's anger was also directed at females offline who attracted the attention of males by the way they dressed and acted, adding to the stereotype that females do not belong and are not welcome in a male orientated games like GTA. This view was also echoed by a male participant regarding the game CoD. Andrea also attributed, what she perceived as, some of her own weaknesses to being female and not male, specifically not having the concentration required to remain engaged within GTA for long periods, and the restrictions in her offline life and the interruptions to her driving activities in GTA because males, unlike females, could do whatever they wanted on- and offline.

The experience in MMORPGs and MMOs also contributed significantly to some of the participants embodied wellbeing, giving them an ‘adrenaline rush’ and the feeling that their heart rate was raised or stopping temporarily. In this experience they felt alert and had a sense of being on a “knife’s edge”. As a result of being verbally abused offline in public, by two men he did not know, Alex sensed embodied suffering: he felt tension deep within his body and his ‘bones’ from the anger he felt after this incident. But Alex found that CoD was a way for him to channel his anger and sense of embodied suffering towards defeating and triumphing over those who continued to uncaringly abuse himself and others. His online victories and status contributed to his sense of wellbeing, including embodied wellbeing. MMORPGs and MMOs were described as the most immersive internet experiences and one participant described how, in CoD, his own body became one with the online character’s body. He went to great lengths and rituals to increase his immersion, which included adapting his immediate environment, warming and cleaning his hands and fingers, drinking strong coffee with sugar in it, and imagining that he was physically in the online battle. If his character was shot, he would also feel he had been shot, and he imagined feeling the pain and suffering that would occur if his physical body had been shot.

Two male participants described themselves as being addicted to the internet, specifically to MMORPGs and MMOs. They stated that they approached these games very ‘seriously’ and at times they did not feel enjoyment because they had to invest a great deal of effort and time daily to continue to experience and maintain a sense of wellbeing (something they could not easily achieve from offline experiences).

Like MMORPGs and MMOs, other online games which involved sociality, project and, at times, identity and temporal experiences, were used to meet unmet needs: the need to talk to someone (through a social media hosted pool game) when this was not available offline, catching a criminal in the game Criminal Case, or curing an animal in Junior Vets on Call which met the need for a meaningful and purposeful job/project when this was not available offline. The latter examples also gave the participants hope that in the future they would be able to engage offline in a job or project of their own choice.

YouTube was often a place participants went to when they felt upset, frustrated or angry, because of the loss of a loved family member, not being able to get a paid job, receiving online verbal abuse and threats, or not being able to achieve what they wanted to within an MMORPG or MMO. Participants described that listening to music and watching informative/documentary videos often had a calming effect on them and this contributed instantly to their sense of wellbeing. Listening/watching YouTube videos was a way for participants to release their emotions and frustrations safely without damaging items in their rooms or incurring pity from others offline. One participant followed certain YouTuber's channels, describing that he felt connected to one specific YouTuber, who he watched when he felt stressed and upset because this made him feel happier. This contributed to his sense of wellbeing, specifically intersubjective dwelling and mobility.

Finding out about ‘things’ that may be hidden from them, ‘little secrets’ and conspiracies in YouTube documentary videos and watching/reading online news, increased the participant’s awareness of the lifeworld and their own spatiality. News about events that were happening, sports and celebrity news, brought about a sense of happiness for two female participants and one male participant described his awareness of the lifeworld from his experiences on YouTube and CoD as being a “good anxiety”. But increased awareness by experiencing YouTube, social media, games and online news, in particular seeing internet reflections of conflict, war, people fleeing war, terrorism, riots, violence, accidents, missing children and attacks by animals, contributed to the participants’ sense of suffering: they upset and worried three participants. Some participants also experienced anger, sadness, fear, and a sense they were helplessness and not in control of their lives as a result of viewing online reflections of an uncontrolled, conflict driven, and threatening lifeworld. The only time one participant felt he was back in control, and not helpless, was when he was playing in CoD, an experience he had mastered and had control of. In CoD he could eliminate conflict and threat by simply shooting the enemy. This internet experience went as far as being viewed by the participant as a way to prepare for worst case scenarios in the offline world, for example, if members of the Independent State of Iraq and Syria (ISIS) were to come to his home and start killing his family.

YouTube displayed videos that reflected all of the lifeworld, including bodies, and, at times, participants compared their own bodies with the bodies they watched on YouTube videos. For example, male bodies dancing, performing amazing feats like limbo-ing under fire and/or enduring painful acts without feeling any pain. This contributed to participants’ sense of suffering as they viewed their own bodies as uncoordinated, average, and/or un-masculine, in comparison to those they had viewed online.

Social media allowed participants to track and follow ‘celebrities’ and make themselves visible to the ‘celebrity’ in order to engage with them. When successful, the participants were happy and this process of making themselves visible contributed to their intersubjective dwelling and mobility. Many participants also felt happy that they could talk to their friends on social media and find new friends whom they had shared an interest with, an online game or the specific ‘celebrities’ they made themselves visible to.

Search engines where used to find images of the self in photographs taken of them in their preferred offline roles and identities. Like viewing their characters enacting roles in the MMORPGs or MMOs, viewing these photographs contributed to one participant’s sense of wellbeing, specifically identity, and opposed her unwanted offline identities, such as one who did ‘baby work’ and had DS. But the internet for two participants was seen as something which contained uncomfortable, scary, and upsetting aspects of themselves and others, specifically around having DS. Potential suffering was avoided by these participants by their refusal to search for DS, or any other aspect of themselves that they did not like or was not wanted, and not engaging with others online. Thus, a sense of wellbeing was maintained in their online experience. But, sometimes aspects of the internet could not be avoided. Whilst searching the internet, one participant experienced getting a virus on her laptop and sexual images started to appear on her screen. This made the participant feel embarrassed and she disassociated herself from these unwanted images, stating she would not do anything like that herself, and stopped using her laptop.

When search engines were used to find websites, which contained houses for sale, recipes, potential jobs, etc… this often increased the participants' sense of independence, it prepared them for the future (finding a partner, having a family, living independently and having a job), and it helped them gain control over their own life and influence others. Searching for their own and others' health conditions led to participants making offline decisions to visit their doctor, advising others on health matters, and no longer feeling like they may be a passive spectator of someone experiencing an uncomfortable aspect of their health condition, such as a seizure.

Generally, many participants felt safe on the internet and it had become their 'other world', especially when they did not feel safe offline and/or when they were experiencing a sense of suffering. For other participants, others online sometimes made them feel unsafe as they knew that others were, or could be, spying on them when they used the internet. They also experienced conflict with others online, and faced threats and criticism. To maintain their sense of wellbeing they often made themselves invisible online to prevent further attacks (being criticised, verbally abused, threatened and rejected) on themselves by others.

The internet experience gave participants dwelling and mobility opportunities to achieve a balance in their sense of wellbeing, often when their lives were mobility dominated, or as participants described, 'busy'. Even when disconnected, some of the participants' sense of wellbeing was still entwined with the internet and they sometimes experienced embodied and spatial suffering when they were involuntarily disconnected from the internet. Participants felt tired, bored and sad, and could do nothing but wait for the next opportunity to be re-connected (often labelled as a sign of an ‘addiction’ by themselves and others). When re-connection with a specific internet activity could not take place, sadness, regret, loneliness and quietness was experienced, even when they were inhabiting a similar MMORPG or MMO.

6.4 The essential overview of the constituents of the phenomenon wellbeing and internet

6.4.1 The internet as mirror

For this constituent it was important to consider the participants’ context, specifically their offline spatiality and primary identities being limited and/or controlled by others without an ID. Offline primary identities (disabled, dependent, wrong and vulnerable) given to them by others, were often unwanted by the participants and did not include identities they felt actually represented them or that they wanted to portray to others. However, the internet as mirror increased the participant’s spatial awareness of their lifeworld and self, which contributed significantly to their sense of wellbeing: identity mobility and dwelling, enabling them to experience ‘I am’ and ‘I can’ through the control and choice over their own identities. For example, rather than being one who has DS and an ID, Yvonne identified herself as being creative through her online projects. John, who described himself as a ‘vulnerable adult’ offline, was ‘strong’, valued, and a ‘protector’ and ‘healer’ of others in the online game Final Fantasy. Whilst the experience of the internet as mirror contributed to the participants' sense of wellbeing, specifically their sense of spatial mobility (making some of the participants feel more in control, happy and satisfied) as well as their knowledge of events and happenings, at times the reflections they saw in the internet mirror magnified, brought to their attention, and at times, distorted and exaggerated aspects of the lifeworld. This could be likened to the carnival mirrors at a fun fair which distort, in a variety of ways, the reflections of the self and the lifeworld as you look into them. The internet mirror was seen to reflect the desirability of the male body as able, strong and coordinated, with an ability to withstand pain, which left some participants to conclude that their own bodies were disabled, uncoordinated, average, or held unwanted feminine traits.

Whilst the internet mirror met the participant's need to re-experience the essence of the 'thing' they had seen offline (often initiated by the limitations encountered in their off-line world to be able to experience this again), it also drew attention to 'things' such as terrorism and criticism over the movement of people fleeing conflict and war. These online experiences brought about a sense of hyperawareness and formed the participant's perception of their lifeworld, which to them now appeared dangerous, scary, uncontrollable, threatening, and conflict driven. The experience of these reflections in the internet mirror brought about a sense of spatial mobility suffering, they became upset, worried, helpless, and highly concerned over their own and others' safety in their immediate world. This led to the need to protect themselves in the on- and off-line world and a sense that they were 'imprisoned' in their lifeworld.

6.4.2 The internet enables visibility and invisibility

The internet offered and enabled the visibility and invisibility of disabilities, physical attributes and gender to the participants. This contributed to their wellbeing by allowing them to achieve projects, interact with admired celebrities, and form and maintain online friendships with those they felt may judge them negatively offline based on their disabilities, physical attributes and gender. This brought about a sense of intersubjective mobility. The participants could also make themselves invisible to avoid negative experiences which had brought about a sense of spatial and intersubjective dwelling suffering. For example, after John experienced being exiled and alienated in the online game Final Fantasy, he left this game and inhabited another MMO as a male character. He knew a male character would bring about invisibility for him, and thus less attention from other players, but it also made John feel isolated and lonely. At times the internet forced the participant to be visible or invisible. For example, by simply being a female character online the participant’s visibility increased to other online players. This brought about a sense of wellbeing: intersubjective mobility through the experience of being female, gaining additional powers, becoming more approachable to other females, and enhancing status through the increased visibility. For others, like John (who played a female character in Final Fantasy) and Andrea (who played a female character in GTA), this visibility brought unwanted attention and a sense of identity dwelling suffering as they were reduced to mere objects and ‘things’, simply because they were female. They experienced feelings of discomfort and unwanted interruptions to online activities that were fundamental to their sense of wellbeing.

6.4.3 The internet as liberating

The internet offered a liberating experience which increased the participants' sense of wellbeing in many lifeworld dimensions, notably, the sense of spatial dwelling-mobility: the sense that anything could be achieved, anything was possible, and the limitations and restrictions present in their offline lives, which contributed to their sense of suffering, could easily be overcome on the internet. It also brought about a sense of mood dwelling: peacefulness, and intersubjective dwelling: a sense of belonging and feeling needed by others, specifically in MMORPGs and MMOs. But the liberating aspect of the internet brought forth questions and challenges from the participants about their current lifeworld: why could they not experience such liberation offline too?

However, while liberation is offered to all who experience the internet, liberation may lead to others online becoming unwilling participants in others' adventurous horizons. Being an unwilling participant in another's online liberation and being oppressed was something experienced by some of the participants in this study and led them to feel angry, frustrated and helpless. For example, the liberation offered in GTA allowed players to target and violently attack Andrea's female character in this game and restrict her own liberation. Andrea felt that this only happened because she was a female within a male dominated game and therefore was not welcomed by male players. The liberation Andrea experienced while driving her car in GTA, when not being targeted, was important to her sense of wellbeing because she experienced a sense of suffering and restrictions in her offline life: coming to terms with the death of her grandfather and feeling restricted and frustrated at how other treated her as a female and not able to get a paid job.

6.4.4 The internet meets unmet needs

The internet meets unmet needs, many of which are often taken for granted by those without IDs: a valued role in a community, friendship, a relationship, getting married, living independently and having children. All participants desired a balance of spatial, temporal, intersubjective, mood, identity and embodied dwelling and mobility. These were often experienced on the internet (but not offline) and were sought to add balance and contribute to the participants' sense of wellbeing. The internet as the fulfiller of unmet needs also contributed to the participants' sense of spatial and identity wellbeing by allowing them a way to plan, prepare and practise for their future. In a sense, the internet experience kept their hopes and horizons alive because whilst they may have not been able to achieve this presently offline, for example, getting married and having children, they felt that their experience of this online would help them practise, learn and help to achieve this offline in the future.

6.4.5 The internet creates a decision maker and expert

The internet as a creator of a decision maker and expert contributed to participants' sense of wellbeing, specifically identity mobility: 'I can', by teaching, equipping and empowering them to make their own offline decisions. Some of these were decisions they were unsure and scared of making previously. Their internet experience led to them becoming more independent, they could plan their own projects, move towards or reach the role of 'expert', and influence others to fulfil their goals. The information

Michael and his cousin collected on the internet, about an item Michael wanted to buy, helped him to convince a family member to allow him to buy this item. The participants' new knowledge, and with this new or developing roles, were seen in themselves to also contribute to the participant's sense of wellbeing. For example, after looking up health conditions on the internet, specifically epilepsy, Steven felt he would no longer feel like a passive onlooker when someone he knew was having an epileptic seizure. The participants' knowledge of health, and their own and others' health conditions, meant that they could enhance, positively influence, advise and maintain their own and others' sense of wellbeing.

6.4.6 The internet as friend and foe

Internet as friend and foe, especially alongside the context of the participants' lived experiences of other phenomena which had shaped the way they connected with others online, what they expected from them, and who to view as a 'friend', was integral to their sense of wellbeing. Alex and John both concluded that whilst the internet increased their sense of wellbeing there were times they experienced something negative online: verbal abuse, threats, being criticised, or rejected, which they often blamed on themselves, specifically their disability and difficulties understanding others, rather than the perpetrator. Online verbal abuse or other online experiences that made them feel uncomfortable, 'un-nerved', upset, or worried, appeared to be accepted by Alex and John, more so than when they had experienced verbal abuse or an attempt to financially exploit them offline. Their offline negative experiences of friends and foes may have normalised abuse directed towards them online and their need for friendship, specifically John, meant that they were willing to be verbally abused, controlled, used, rejected, labelled and treated as a female and a sexual object to experience friendships and relationships with others online. The need to connect with another online to form a friendship or relationship contributed to both Alex and John’s sense of wellbeing, but they felt their needs and feelings were less important than being needed and valued by another, or the another’s own needs and feelings. These participants described not being resilient enough or that they had not been able to tell if someone was a friend or a foe online. After a negative online experience, they often then made friends with the online perpetrator, stating that it was not the online behaviour of the perpetrator, or their relationship between them, which had changed, but their own acceptance of the perpetrator’s behaviour and how they now viewed the perpetrator: as a “good fella” that did not “mean any harm”. The online experience for Alex was a chance to fight back and reconcile the anger he felt over the abuse he had received from two men, directed at his appearance, whilst walking down a street. When Alex was younger, the online abuse he experienced also made him angry, upset and worried. But now, he has built up a level of resilience and has strategies to employ when encountering online abuse and threats, or when other aspects of the internet experience make him angry and upset. John’s only strategy was to make himself invisible and remove himself from the online experience. However, the experience of being invisible online resulted in John feeling upset, lonely, worried and sad and it was a sense of suffering which lasted for a number of months.

The internet was often perceived as a foe, rather than a friend, by those who supported the participants, whilst the participants with IDs saw the internet as both friend and foe. The potential to meet online friends and girlfriends online was acknowledged and this contributed to both spatial, intersubjective, mood and identity wellbeing. One participant, John, went to meet his online best friend in person. This gave him a greater sense of closeness to her and enjoyment in communicating with her offline. It was unclear if his family were aware of this. John did speak about wanting to take a friend with him to meet his online friend to keep himself safe, but none of his offline friends would agree to go with him, so John went alone.

6.4.7 The internet connects to, and disconnects from the internet

The body connecting to, and disconnecting from, the internet contributed to both a sense of wellbeing and suffering. Participants' bodies were being prepared for connection and immersion through changing aspects of their immediate environment, ingesting stimulants, tending to parts of their body (by heating them and cleaning them), and imagining they were the online character in order to fully connect, or become immersed. This contributed to the participant's sense of wellbeing, specifically embodiment mobility, which other offline experiences could not contribute to on the same level. Participants experienced playing within online games at their 'optimum': when their body was no longer slow or disabled, and they felt an adrenalin rush as their heart beat faster whilst immersed.

Once disconnected from the internet, embodied suffering was experienced by some of the participants. Their offline body became lethargic and exhausted, and motivation was lost for any offline alternative. Their thoughts were dominated by activities they did on the internet and the fear of not being able to re-connect to their internet activities. This was either alleviated by re-connecting to the internet, listening to the online games' background music, or going to sleep until the chance to re-connect appeared again. Their sense of embodied wellbeing, with the internet experience entwined with their body, was viewed in a variety of ways by the participants and those supporting them. It was described as an 'addiction' to the internet or, through reflection by the participants, an act and consequence of relying on, or investing, so much of themselves into the internet as a way to contribute to their sense of wellbeing.

6.5 Participant and interview demographics

Seven participants were interviewed four times, and one participant decided to withdraw from the study after completing one interview. He did however agree to the data from his interview being analysed. Each interview lasted up to one hour and interviews took place over several weeks, but in some cases several months, in order to work around the participants' wishes, volunteering schedule, and personal commitments.

Six of the eight participants were observed to be of white ethnicity and two participants were from black and minority ethnic groups. Considering the Office of National Statistics (2011) data that states 86% of the population in Yorkshire and Humber region's ethnicity is white, this study had a good variation in participants' ethnicities. The exact details of individual's ethnicity were anonymised as this may have identified the participants and when the participants described their lived experiences of wellbeing and internet they did not relate these to their ethnicity, unlike gender. Tables 6.1 and 6.2 summarise the participant and interview demographics.

Table 6.1 Participant Demographics.

Participant pseudonym	Age (years)	Gender	City pseudonym	Living status	Disability and health status
Alex	19	Male	1	Living at home with parents and with 1 or more siblings Other adults living at the family home	ID Autism Speech and language difficulties Mental health condition
Andrea	22	Female	1	Living at home with parents and with 1 or more siblings	ID
Ella	38	Female	5	Living at home with parents Sibling have left family home	ID Down's syndrome
John	25	Male	1	Living at home with parents	ID Autism Mental health condition
Leona	19	Female	2	Living at home with parents Sibling have left family home	ID Speech and language difficulties
Michael	62	Male	3	Living at home as sole occupier	ID Visual and hearing impairments Speech and language difficulties
Steven	22	Male	1	Living at home with parents	ID Autism Speech and language difficulties
Yvonne	26	Female	4	Living at home with parents and with 1 or more siblings	ID Speech and language difficulties Down's syndrome Mental health condition

Table 6.2 Interview Demographics.

Participant pseudonym	Number of interviews completed	Average time of each interview (in minutes)	Time period for all interviews to take place (in weeks)	Interview/s where images of the internet were used
Alex	4	57	5	None used
Andrea	4	52	4	Interview 2 – Generic images used Interview3 – Personalised images used Interview 4 – Personalised images used
Ella	4	45	19	Interview 2 – Generic images used Interview 3 – Personalised images used
John	4	50	5.5	None used
Leona	4	39	5	Interview 1 – Generic images used Interview 2 – Generic images used Interview 3 – Personalised images used Interview 4 – Personalised images used
Michael	4	49	15	Interview 2 – Generic images used Interview 3 – Personalised images used
Steven	1	42	1	None used
Yvonne	4	42	19	Interview 2 – Generic images used Interview 3 – Personalised images used

Chapter 7

Findings: The Liberating Nature of the Internet

7.1 The internet as mirror

Constituent one: the internet as a mirror, which reflects the lifeworld, has been categorised into the following subthemes:

- Reflections increase awareness.
- Reflections of the self and identity.
- Reflections of female and male roles.
- Reflections that exaggerate able-bodiness and present the essence of the ‘thing’ of interest.

All subthemes contributed to the participants’ sense of wellbeing and suffering. After the related context to this constituent is outlined I will explore and describe, using examples of participants’ lived experiences, each subtheme.

7.1.1 Context to the liberating nature of the internet: spatial freedom of the participants

The context of the participants, that was not the lived experience of the phenomenon in question, was gathered and themed separately from the phenomenological analysis to increase the sense-making breadth of this study. In this chapter the participants’ context of spatial freedom was seen as fundamental to the constituents that encompass the liberating nature of the internet.

Many of the participants’ offline worlds were spatially limited by the restrictions imposed on them by their family members, or as a result of their negative offline experiences with others. Leona was only able to walk to the shops at the end of her street on her own, only travelling further with a family member or her carer. This was because Leona’s mother was worried that she may get lost in an unfamiliar place. Leona often used the word ‘we’ or ‘with my carer’ to describe going out somewhere on her ‘own’, thus going out on her ‘own’, even to the shops at the end of her road, may still mean going somewhere with the support of a carer. Whilst Leona stated she would like to travel on the bus to other cities on her own, this was something she was not allowed to do and which she accepted as ‘normal’. Leona did not particularly express that she found her spatial limitations uncomfortable. Ella found herself in a similar situation to Leona and, despite describing herself as an “independent traveller”, because of her experience with the organisation she attended she was not able to travel “too far” on her own, only travelling further with her mother or with the staff she volunteered with. Andrea had slightly more spatial freedom than Leona and Ella but was unable to go anywhere on her own without one or more of her family members knowing where she was going. They often contacted her on her mobile phone to check that she was where she had said she was (something that happened during an interview). Although Andrea wanted to, she was not allowed to visit or contact an ex-boyfriend (or his family or friends) due to her mother’s fear of Andrea getting hurt again by a relationship break up or being used by ‘lads’. Andrea attended the home matches of her favourite sports team but always planned her travel to these matches to coincide with a friend’s travel plans. She was unable to go for a drink after the match with her friends because 10 pm was deemed by Andrea’s family to be too late and dark for her to be out socialising.

All the participants encountered some limitations in their spatial freedom, imposed or influenced by others, but male participants appeared to have more spatial freedom than most of the female participants. Any spatial and project limitations male participants encountered was not attributed to their gender, unlike some of the female participants had identified. Andrea was one of the participants who noticed this and she described boys as being able to do anything they wanted, unlike her, as a female. Similarly, Yvonne’s idea to move out of the family home was restricted by her being regarded as a “little girl” by her father:

> Yvonne: “…me dad doesn’t want me to move, cause I’m still his little girl. [I: Right.] Type thing so. [I: And what do you think about it?] In my mind I will say dad I’m not your little girl, I’m a woman, I want to move out.”

John’s dream of going to work abroad to teach English as a foreign language and/or work with others with IDs was not supported by his job supervisor or his mother, who both felt that he would not be able to look after himself:

> John: “I’d been hoping to teach English as a foreign language but it’s like, I’ve got my job supervisor saying, ‘are you sure you’re going to be able to cope with the stress of that job?’ [pause] so I’m, I mean, fair, fair concern, I can understand where she is coming from, but it feels like I dunno that I’m just being [pause] held back at every opportunity. / … My mum also has similar concerns. As in but more.. like more outside the job like would I be able to look after myself? Feed, clothe myself? Make sure washing’s done? Stuff like that so would I be able to live independently?”

John’s mother also had concerns over his ability to look after himself if he were to move out and live independently locally but, similar to Yvonne, his family encouraged him to increase his offline spatiality beyond the internet world they had both created for themselves. Yvonne, and specifically Alex, had chosen to spatially limit their own offline worlds in response to the possibility of unwanted offline experiences with others:

> Alex: “The reason erm why I prod’ stick to the internet because all these people that are like on streets normally like do drugs or… [I: Yeah.] … like smoke or they tend to go mischievous and stuff like that and I don’t really want anything to do with that, I tend to stay inside be myself and just stay on the internet and talk people”.

Michael, the oldest participant, had experienced spatial and other limitations when he lived with his mother. After she died, Michael’s world became far less controlled and limited across many of the lifeworld dimensions, which Michael stated was because of the support he received from various professionals. Michael described independently travelling to and from many social groups he attended and other places and events, often to perform his volunteering roles. He also bought his own groceries at the shops. However, Michael’s finances were controlled by a member of his family to ensure he spent his money on bills and not ‘inappropriate’ items such as a record player.

7.1.2 Reflections increase awareness

Leona looks at the online news which increases her awareness but also makes her feel upset

On Facebook, Leona described reading both good and bad news and finding out about events that were happening, specifically those she was going to or wanted to go to. Being able to see future events on the internet, particularly on Facebook, made her feel happy:

> Leona: "…It [internet] just makes me happy. [I: …. Happy in what way?] Like when some, when events coming up? [Respondent laughs. I: When events are coming up?] Yeah. Always makes me happy, yeah, when you look on internet, and there's like an event coming up…. Cause I did, we go to this family fun day… for Down Syndrome… At ________ … park, and when that comes up, I always join it [respondent smiles]."

Leona does not have Down's syndrome (DS), but her friend, who she goes with to this event, does. Leona described how she could see online what was happening that day and who was performing, which meant they could both decide what to do when they attended this event. Leona also described a running event and finding other information about performers (where and when they would be performing). Most of the good news online that Leona referred to was based on sports or celebrity news:

> Leona: "… Where someone's like won an award… for something. Like pop stars…"

The positive news that Andrea read online also appeared to centre around celebrities and her favourite sports team, whereas the non-celebrity or nonsports news, which both Leona and Andrea spoke about, centred on less positive stories:

> Leona: "… sometimes er, people put like bad stuff on about news… You know when there's been bad news on news? Like that dog er, like that dog attack at, at er ______ [name of a park local to the respondent] park."

Online news stories that had drawn Leona's attention included news that related to her own life or interests: places, activities, people, and her general interest in animals. Alongside the news story of the dog attack, Leona described reading online about an accident that happened on a ride at a theme park (which Leona herself had visited) which led to a woman having her leg amputated, a child going missing from Leona's local area, and an international news story of a woman entering a tiger enclosure in an animal park abroad to retrieve her hat. Whilst the news story of the woman climbing into a tiger enclosure was viewed by Leona as being quite funny and entertaining, similar to a YouTube video Leona had watched of a lion climbing onto a safari vehicle carrying people abroad, the online news of the dog attack in a local park, that Leona knew and which she had visited, made her feel upset:

> Leona: "cause me friends got a dog…. It makes you upset, you know you see like other dogs attacking people."

Similarly, the accident at the theme park and the child going missing also made Leona feel upset:

> Leona: "made me feel a little bit upset cause I've been to ____ ____ …. And they're reopened ride again… It's mad."
>
> Leona: "Upset so, upset cause they might not find her."

Negative news that was “far away” from Leona did not result in her feeling upset or worried, unlike the dog attack, the accident, and the missing child, which were all things Leona could readily relate to from her own offline experiences of them.

Michael avoids looking into the internet mirror

Michael, the oldest participant, learnt how to use the internet at college as a mature student and his main internet activity was email, as part of his volunteering role. Although Michael does not have the internet at home and at times he thinks that he would like this, he also described that without the internet he felt he had more control over what he wanted to think about. Michael elaborated and explained his concerns by comparing the internet as being like the media he experienced when he was younger, which initiated an uncomfortable awareness of the world around him:

> Michael: “It [the internet] makes you think… about the world, what it’s like… Cause I used to, I used to do that… think of, a, too mu, too much of that… when I was a lad, younger… I often, I often think… what the world is…is… about… [pause]… and when I watched the news when I was younger… I realised then, what the world was about…. It wasn’t very good… there was wars, even now…”.

Michael is an avid watcher of the news programs on television, which was different from many of the other participants who found news in various forms online.

Andrea experiences reflections of the lifeworld that are chaotic, violent and out of control

Whilst on Facebook, Andrea described being able to see and read the everyday happenings of other people, as well as “listening” to their argumentative comments about immigrants fleeing war and moving across to countries in Europe, including the United Kingdom (UK). Andrea described that some people on Facebook were telling the immigrants to: “go back to your own country”, and these comments had led to a range of feelings and emotions for Andrea. At first, they made her feel mad, then sad at how others were talking about other human beings fleeing war. A sense of helplessness and a lack of control over the apparent chaotic situation of immigrants moving over to Europe countries then came over Andrea:

> Andrea: “…it’ll [Facebook notifications] just be tell you about… what each other’s doing or where they’ve been or if they’ve gone partying or whichever and [pause] sometimes that’s [pause] OK but you don’t really want to listen to people arguing especially about the immergrations coming over and everything and I’ve thought… It’s not exactly like we can do anything about it cause, Germany they’ve taken in loads of immergrations and they’ve had to close the gates cause they can’t let in anymore, but it’s not exactly like the immergrations are staying in one place they’re… going across the world to any other countries like Greece… and everything.”

But from seeing, and wanting others to see, the immigrants as human beings deserving of respect and empathy from others, Andrea also moved to feeling that it was the immigrants that were creating chaos across the world and that the immigrants may believe that a life in the UK would be ‘greener’ than in their own country. Andrea stated this was a misconception on their part and, once in the UK, the immigrants were a drain on the resources available:

> Andrea: “we don’t have the enough money… in well, what David Cameron says, in our budget for us to take care of them because we’ll have to give them housing, kids er schools and they can’t even speak English so we’re gunna have to help them do that as well while get them into er… English language school or something… And it’s not right. If we go over there, we have to speak their language but if they come over here they can’t speak ours…. It’s not right.”

In Andrea’s interviews, when talking about her general experience of the internet, the subject of wars, people fleeing war and being killed on en masse, the potential for World War III, acts of terrorism, women and children leaving the UK to fight for ISIS, riots, and those in authority (such as the police) being attacked, were repeatedly brought up by Andrea in relation to the phenomenon of wellbeing and internet. They were an obvious concern for her and she strived to understand why they were happening. Andrea felt that these events could lead to the potential for the human race to become extinct:

> Andrea: “…I just told him, are you really kidding they think that we’re gunna start a world war three, we’ve only, we’ve already had world war one and two and millions of people died from them so. What w.., what were they thinking, thinking that we would start world war three? Other countries w’ be part of other countries we’d get.. I don’t know if other countries’ will just stick with us or not… [I: Mmm.] … and… we just be firing on each other and there’s no point. [I: Mmm.] Cause [pause]… billions of people die and the human race will be extinct [pause]… and… [I: Mmm.] … they… I don’t like violence, there’s no point in doing something when it’s just going to wipe out the whole world. / It’s just getting chaotic [pause]. All the people from er [pause, respondent thinking] overseas,…”

Andrea also plays Grand Theft Auto (GTA) online and she described experiencing unwanted violence in this game by being targeted, bombed and shot by other players because she was a female player:

> Andrea: “I got killed a lot, just because I’m…a…girl… doesn’t… mean… they…. have … to… kill …. Me. / …they think ‘Ohhhh she’s a

> girl, lets go and kill her and bomb her orrr, do whatever to her… cause girls can't play GTA'"

Andrea was unable to do anything about this, including defending herself against unwanted attacks, in GTA. When asked if she would kill others in GTA if she could work out how to do this, Andrea replied:

> Andrea: "I would do yeah if I… knew how to do it but I'm not the really killing type [pause]… Even on a game like that".

Andrea initially thought that GTA would allow her the chance to experience what it was like to live in a: "character world". A world she thought may perhaps offer a better world for her to occupy, for a little while at least, than her current offline world, which brought her sadness through the loss of her grandad, the break up with her ex-boyfriend, and her frustration at not being able to get a paid job. But once in GTA, Andrea soon found that this "character world" did not offer something better than her offline world:

> Andrea: "[I: …So why play Grand Theft Auto where all, where people are shooting and bombing each other [respondent smiles] and police are chasing people?] At the start, I thought it be er… good game and I st, I know what it's like to live in er… character world. [I: Right.] But… it's just the same as here basically."

GTA did offer Andrea opportunities which increased her sense of wellbeing, such as driving. This activity took her mind off things that she did not want to think about, it brought her calmness, and offered her spatial and temporal freedoms not available to her offline. But Andrea also felt that GTA was an obvious choice of game for 'psychopaths' and 'terrorists' to play, who may practise violent acts within this game before acting these out in the 'real' world as well:

> Andrea: …if you like er… psychopath or terrorist… then you're obviously going to play this [GTA] and think 'aww I might as well do it in the real world as well' [respondent emphasises 'aww' and states it in a higher tone]. [I: Right… right.] And [pause]. [I: Is that, is that what you think… people might do?] [Pause, respondent thinking] Yeah well just have a look at what they did to… us in the London underground and in Paris."

In the internet mirror, the reflections of chaos, conflict and violence in the lifeworld created a sense of helplessness and a lack of control for Andrea. It also created her understanding of the 'whole' of some of the phenomena in her lifeworld, which made her feel angry and frustrated. The only option Andrea had was to not look at the reflections of lifeworld on Facebook and GTA:

> Andrea: "…there's nothing really I could do except ignore it."

However, ignoring such reflections sometimes did not help and they continued to contribute to Andrea's sense of suffering: her concern, worry and the negative emotions she felt.

Alex sees reflections of the lifeworld from watching YouTube videos and playing Call of Duty

Alex was a daily user of the site YouTube, watching over 60 new videos uploaded each week in order to keep himself up to date. As well as watching music videos, Alex also watched and learnt about: "human bodies", human behaviour and weird facts: "that we don't know about". This is what Alex described as "researching". On one YouTube channel that Alex watches, they try to make the "real life news" more interesting and positive, rather than it being: “this is wrong, this is wrong, this is wrong,…”. They also think of solutions, something Alex thinks is a good feature of this news, such as the use of sex dolls by paedophiles to prevent them from abusing children. Alex also likes to watch videos about: “little secrets”, short documentary-style videos about on- and off-line events that have happened, 9/11 for example, and events which could happen like a nuclear war or bombs that have not exploded. Alex explained that the presenters in the videos explore events or subject matter to reveal what was true or false, the ethics surrounding them, what was seen by everyone and what could be hidden (often by the government or a similar organisation). Alex described these videos as generating “good anxiety” in himself and encouraged him to question and find answers about the on- and off-line world around him:

> Alex: “[It is] pretty cool actually [I: Yeah?] Cause, cause the more you question something, the more you’re going to find out something… The more you going to find out better, the more you gunna find answers to it.”
>
> Alex: “false things going around, why is, why is there so many conspiracies… if people ain’t got nothing to hide,…”

Alex also stated that they enabled him to be better at spotting “false” information presented to him. Many of Alex’s online experiences were on YouTube or on the game Call of Duty (CoD) and often centred around and reflected conflict, threats, war, terrorism, attacks, untruths, conspiracies, and/or being spied on. All of which could occur in almost any place, at any time, and from anyone. Like Andrea, this had created a hyperawareness and the sense that the world around him was uncontrolled, chaotic, and threatening. Alex felt helpless and anxious at the thought of certain threats occurring to him and his family offline. These feelings appeared to be heightened by the fact that online, specifically in CoD, Alex had control over threats and attacks directed towards him as they occurred. He was able to solve, combat, or understand and accept conflict and threats (often in the form of online abuse) that was aimed at him and his family members. This is explored in the next chapter within constituent seven: Internet as friend and foe. Unlike Andrea in GTA, Alex had developed a 'mastery' of not only defending himself in CoD, but killing others with relative ease in order to attain a high level of status in the game and this brought respect from most players. But when Alex thought about being presented with a similar threat offline, which was a real concern for him, he worried that he would not be able to 'act' as he could in CoD to protect himself and others whom he cared about. The example Alex gave was the scenario of members of ISIS coming to his house:

> Alex: "[If they] lined everyone up, and started killing people one by one, I feel like I'm meant to just sit there with a popcorn and just start watching."

Alex is aware that others, who are not part of the online gaming community, may think that he just wants to kill people on- and off-line when he plays games like CoD. But in the game CoD, Alex describes being able to prepare himself for these types of offline threats, and "apocalyptic" worlds, that may arise in the future from the conflicts that were currently happening in the world. Alex explained that by learning how to defend and kill online, he would be far more ready and able to 'act' in an offline life and death situation (rather than be a passive participant):

> Alex: "what would happen if a zombie apocalypse actually happened and all these zombies just started running around?"

> Alex: “[Call of Duty]…helps you… because you know, in a game, you kind of realise… like if it did actually happen, you know what to do…. If it did actually happen.”

YouTube also reflects another threat to Alex: how people, companies, governments and the “FBI” can, and do, spy on others online, including himself. Alex pays particular attention to this and likes to watch and learn about this from YouTube videos. Alex does not want others: “invading” his privacy or “snooping” on him, so he takes a whole plethora of precautions to keep himself hidden and protected online. At home, Alex sets strong passwords on the internet, and away from home he does not connect to the internet using hotspots at places like his college, as he knows these are not secure. By viewing YouTube videos, Alex has also seen how others can set up fake accounts and pretend to be you: “troll accounts”, by stealing your online picture and using this against you. Alex guards against this by not putting up any images or videos of himself online and keeping information about himself online to a minimum. Any more than the minimum may result in Alex’s pictures or information being stolen, and this may result in both on- and off-line consequences:

> Alex: “… you still feel insecure about using the internet because you still gonna feel like, if I, if I was a picture… [I: Yeah.]…of something, then that picture’s gonna be spread around with everyone, everyone’s going to be able to see it, and that means you’re gonna get comments, stuff like that, people probably gunna take the mick and stuff like that… [I: Yeah.] … and people are going to find out, [respondent takes in a sharp intake of breath]… if it gets it into wrong hand, people can, can either, actually find out where you live, and maybe come onto you and do whatever and… / … I cannot be tracked on Facebook… / … It feels a little bit more safer”.

But no matter how un-trackable and invisible Alex makes himself, he still does not feel safe online because the internet is not “strong enough” at protecting those online. Alex has learnt to accept that he, as well as everyone else online, is neither safe or immune from being spied on by others, online verbal abuse and/or threats, or having something used against them:

> Alex: “People record you, people blackmail you, people try to do stuff like that but you, you just make sure you try to avoid it as much as possible.”

Leona, Andrea and Alex all described how their concrete experiences of the reflections in the internet mirror increased their awareness of their lifeworld, which at times contributed to their sense of wellbeing by allowing them to know what was happening and be informed, especially when they did not have the means to do this offline. But online reflections that showed chaotic, violent and threatening aspects of the world, helped them to form the ‘whole’ of ‘things’ in their lifeworld: dog, theme park ride, immigrants, World War III, and terrorist attack, as examples. Although Alex described a “good anxiety” as a result of his increased awareness from internet mirror, it also contributed to Alex, Leona, and Andrea’s sense of suffering, particularly mood, leading to them feel upset, mad, sad, anxious and concerned. It also created a sense of helplessness and that they had little control over their offline world. As the participants lacked spatial and other freedoms offline, which could also inform and increase their awareness of the lifeworld, they had to rely on the internet mirror to create the ‘whole’ of their lifeworld. For Andrea and Alex their reaction to the internet mirror’s reflections, which at times brought objects closer to them, brought about a hyperawareness of potential threats and influenced their perceptions of the world in which they lived in. Their sense of wellbeing/suffering also contributed to how they felt about aspects of their lifeworld and how they approached, or planned to approach, offline situations.

7.1.3 Reflections of the self and identity

Yvonne and Ella are aware of the potential the internet mirror has of reminding them, and increasing their awareness, of their own and others' perception of the condition DS. Both participants have DS and when asked whether or not they looked up IDs and/or DS on the internet (which was asked as a general prompt) it initiated a strong response from both of these participants (which was not seen in the other participants who had an ID but not DS). Both Ella and Yvonne did not look up IDs or DS on the internet, and being asked about this resulted in them becoming very uncomfortable. Ella became upset when answering this, and Yvonne replied "no" and steered the conversation away from discussions about DS:

> Yvonne: "…cause I have Down syndrome you see… [I: Yeah, yeah.]… and I don't want to look at it. [I: You don't want to look at it?] No [Pause]. [I: Am I allowed to ask why?] I, I don't know er… [Pause]… I don't know now… [Long pause. Respondent sighs but looks as if she is thinking]… I've forgot what I want to say now. [I: That's o.k…]"

Instead, Yvonne spoke about her preferred identity of being "creative". The topic of looking up ID and DS online was not further explored in subsequent interviews, due to the clear verbal and non-verbal indications from both Ella and Yvonne that this was not something they wanted to talk about.

Ella sees her reflection in the internet mirror as ‘supportive’, ‘needed’ and ‘valued’

Ella saw DS as a fundamental part of her identity stating: “I am Down syndrome” rather than ‘I have Down syndrome’. She described that being called ‘Down syndrome’, or talking about this condition, was upsetting for her:

> Ella: “I am Down syndrome, I don’t like people saying something about that.”

The mere thought of typing ‘Down syndrome’ into a search box on her iPad also upset her. Despite knowing that her friends used Facebook, some of whom also have DS, Ella was neither allowed, or wanted, to use Facebook herself. This was because her mother, and other members of her family, had told Ella about their own negative online experiences or suggested what would happen to Ella if she did use Facebook, specifically centred around how others online would react to her having DS, which would upset Ella:

> Ella: “No, me mam, me mam will not let me go onto it [social media] because, reason why…… I don’t want other people, erm sending email, sending erm threatening message about me. So me mam’s said that, that I’m not allowed to go on it, because I don’t want people say something about me, that I’ve got Down syndrome. [Interviewer: Right, o.k., so,… Would you, if, if your mum was o.k. would you use it, for something like Facebook?] No, it’d be too upsetting for me.”

The thought of what she may find, or what others would say, about her and her having DS on the internet prevented Ella from searching for information on DS, or using social media and YouTube. For Ella, YouTube was a place where people could potentially make “nasty comments” about her or video her without her permission. A member of Ella’s family has had negative online experiences on Facebook, which Ella is aware of and has been told about. However, Ella’s mother appears not to have had any negative online concrete experiences, or be a regular internet user herself. But Ella’s mother’s belief that others online would dislike and say negative things about Ella having DS is readily believed by Ella, and validates Ella’s belief that others do not like DS. Ella too dislikes having DS, so why would anyone online have a different perspective on this condition to Ella or her mother? The internet’s potential to reflect others’ negative opinions of her having DS still contributed to Ella’s sense of suffering, making her feel upset. As a result, she avoided looking at the reflections the internet mirror cast of DS, which for Ella was more than a condition or label. DS was bound up and interwoven with Ella’s feelings of being restricted and feeling ‘stuck’ in her offline life.

> Ella: “… it’s between like I’m stuck… with leaving ___ ___ [name of organisation 1]... / …doing more training and presentation… / …and getting a job, now this! Now being Down syndrome! It really is getting too much for me at moment, it’s getting too much for me.”

Ella does not know whether to continue volunteering, something she wishes to do, or move towards getting a paid job in order to fulfil her family’s wishes and address their concerns that the cost of Ella’s volunteering is too expensive. Ella herself is unsure if she has any control over this decision and reaches out to both the staff she volunteers with and her family (and in one interview to myself) to help her solve this.

Unlike the reflections of DS, a reflection of “people making love”, that was out of her control, was presented to Ella on her laptop as a consequence of a “virus”. Ella was unable to not view them, she did not want or like these pictures and it made her feel embarrassed as this was something, Ella explained, she would never do herself. Ella turned her laptop off when she saw the pictures and stopped using her laptop for a period of time until a member of the family removed the virus for her.

Ella did, however, frequently and intentionally search the internet at home to find photographs of herself participating in activities and volunteering alongside others, taken and posted online by the ID-related organisation with whom she participated and volunteered with. This is something Ella does easily by typing the name of the ID-related organisation into Google which results in photographs appearing that show Ella actively engaged in her participant and volunteer roles. When asked why she looked up these photographs online, Ella spoke about how she liked looking at them because they showed her being a 'participant', as well as a 'supporter' for another participant who has physical and intellectual disabilities and epilepsy. Ella "supports" her "friend" by caringly attending to his needs when he has a seizure, a role Ella sees as being very similar to the staff when they work with people with IDs:

> Ella: "Erm _____ [first name of a male carer] who supports ______ [name of participant/friend 1] erm, and I've been supporting him for, I've been doing it for over a year, been helping him. / And me, my job, as a, a, researcher… [I: Mm?] I al, I, I, when I see him having that, I get up and get, I get up and sit close to him. [I: Yeah.] And then I always stroke him on his arm, on his arm or on his knee…"

Ella described instinctively sensing and being the first to notice and attend to her friend's apparent distress by placing herself physically close to him in order to speak to him whilst caringly stroking his arm or knee. Although he cannot verbalise, Ella knows that he can hear, sense and feel her presence, because he smiles at her. Ella feels sorry for her friend whom she supports because he makes rocking movements, which she knows is how he expresses that he is finding the situation he finds himself in difficult. He also uses a wheelchair which restricts his movement and roots him to one space, which Ella highlights is another cause of his distress. Ella’s role as ‘supporter’ encompasses both feelings of being needed by another and feeling sorry for her ‘friend’. It marks her as different from the other participants, who also have an ID, as in this role it is her ‘job’ to support others, as the carers and staff also do. This elevates Ella from the one who needs support, to the ‘supporter’, and Ella can clearly see herself in these preferred roles by looking into the photographs reflected in the internet mirror. But Ella’s role of ‘supporter’ is precarious and threatened by both her family’s perception of her and how she now needs support from the staff to continue in her volunteering role. One of Ella’s family members said to her that she is actually: “doing baby work” in her volunteering role, and her family have told Ella that she should stop attending the ID-related organisation:

> Ella: “______ [a member of Ella’s family], wanted me to leave ____ ____ [name of organisation 1]. / It’s sometimes, it’s always him who wants me, because he think that I’m doing, doing… like being here, doing, he thinks that coming to work is… doing like baby work, and that’s, that’s how he thinks. [I: Yeah.] But it ain’t that. / I went ‘look, I wanna carry on coming here and you can’t stop me coming here because I do everything, like I do, I do a lot of training, I do a lot of presentations, I talk in front of a lot of people… [I: Yeah.] … and I’ve got convident and I need to carry on doing that, I can’t leave… [Interviewer took ‘convident’ to mean ‘confidence’]… [I: Yeah.] … ____ ___ [name of organisation 1]. They need me to be here, so I can get involved with the work what I do here”.

To maintain her role as ‘supporter’ and not fall into the role of the ‘supported’ one who is seen to perform “baby work”, Ella refrains from telling all of the staff about her family’s wishes for her to leave, even though she desperately wants and needs to tell them to gain their support. The situation upsets Ella. But her state of being upset may make the staff feel sorry for her and this may mean Ella moves from being the ‘supporter’ to the ‘supported one’. To get the ‘help and support’ she wants, Ella must first willingly enter the role of the ‘supported one’, the ‘pitied one’, for the ‘supporters’ to help her, and Ella is not willing to completely enter into this role. She describes feeling “stuck” and not being able to let her feelings out:

> Ella: “I have a conversation with him [a family member] about it and he said ‘don’t tell me about ____ ____ [name of organisation 1] because I’m not interested’. [I: Right… That’s such a shame.] But, them lot out there don’t know…[Pause]… plus me mam, and me dad thinks that as well. [I: Right, I see. What… so what are you going to do if erm…] I don’t know what to do. [I: You don’t know what to do.] I’m stuck. / It’s easier talking to you about it and then like, like when I get upset… I just want to let it out [Respondent opens her hands that are clasped to her chest and opens her arms and hands out, gesturing perhaps ‘let[ting] it out’ her feelings], but I can’t. I like to, I like to just keep it inside. [I: Right. So what, what stops you from letting it out to people?] Because I don’t want them to feel sorry for me [Interviewer took ‘them’ to mean the staff at organisation 1].”

Yvonne: “I have Down Syndrome you see… and I don’t want to look at it”

When asked if she looked up ID or DS, Yvonne simply stated: “I have Down syndrome you see… and I don’t want to look at it”. Yvonne then spoke about looking up another condition on the internet, autism, for her own research and project work. She then associated herself with other preferred identities, such as a “creative person” and one who writes. Yvonne, unlike Ella, had stopped looking at the photographs of herself that the ID-related organisation had posted online. Yvonne knew that her father enjoyed looking at these photographs, which depicted her working as a volunteer and interacting with others. When asked why she thought her father looked at the photographs of her online, Yvonne replied: "…I think, cause I'm, cause of my work I doing". But these photographs also showed Yvonne in a role linked to the ID-related organisation and thus connected her to an ID/DS-related identity, which Yvonne stated she did not want to look at online. Yvonne herself stated on a number of occasions about the identities she was proud of, identified with, and was working hard on creating and developing. For example, Yvonne stated: "I am a really creative person" and went onto describe that she achieved this by working on her "life" projects on her computer. These included collections of writings and images that represented her family, friends, ex-boyfriend, and the people from the organisations she volunteered for. Yvonne explained that this was because they are all a part of her life and:

> Yvonne: "it's really nice when I type it everything down on the PowerPoint project."

Unlike her history projects (which she works on individually and will show to others) and the photographs of her volunteering taken by the organisation and displayed on Facebook, Yvonne's "life project" work is different:

> Yvonne: "because it's private to me… I don't show no one in the world… / [but I've] always dreamed of having my own blog… [but]… cause I've been so busy I never get time to do it really…".

On her own online "diary blog", Yvonne plans to "show off" her history projects and film her everyday life, including herself volunteering and performing at the ID-related organisation for others to see, in particular, her childhood friends who have moved away. They are now “leading separate lives” from Yvonne and have careers in medicine, as an example, and are now engaged or married with children. The internet mirror, in the form of a blog reflecting Yvonne’s preferred identities, could potentially reflect Yvonne in a way she wants to be reflected to her childhood friends, who are unaware of what she is doing, and she could connect with them once again. But filming her life is something Yvonne cannot do currently because she doesn’t know how to do this. But if she could create her own virtual reflection, Yvonne can move away from the reflections that are currently seen in the internet mirror (the images posted online by the ID-related organisation) and re-present herself as “…a really creative person” and not one who simply has ID/DS.

By not looking up DS online, both Yvonne and Ella do not have to view DS, an identity given to them and one which they do not necessarily feel comfortable having or which represents them as they would like to be viewed by others. Although DS can remain hidden to them in the internet mirror, through the action of not looking into the mirror, this does not mean DS is ‘out of sight, out of mind’. Their thoughts of what could be in the internet mirror, which would bring an increased awareness of how others and themselves viewed their ID/DS-related identities, contributed to their sense of suffering. Instead, Ella and Yvonne viewed reflections of their preferred identities, the ‘supporter’ and one who is ‘creative’, which contributed to their sense of wellbeing.

John sees his reflection as helpful, strong, valued, needed and protective of others

John described himself as “vulnerable” and had resigned himself to this given label:

> John: “…I’m considered a vulnerable adult like, I’d rather taken the precautionary… [I: Mmmm.] … side of things… /
>
> John: [I: …It’s interesting how before you described yourself as vulnerable.] Yeah? [I: Yeah. Is that how you describe yourself?] Well that’s what I am medically… classed as I am, because of my automism… a vulnerable adult so,…”

But then later, reflecting on the label of ‘vulnerable’ and setting aside the medical and legal classifications of himself, John explained that he would not say he was vulnerable:

> John: “I have like, I do have things that I miss, but general I’d say I’m not vulnerable but… unfortunately, the law says I am and I can’t change that so [respondent looks unhappy]”.

Whilst John explained that what he has to face is nothing more than what other people face, these classifications and labels (as one who is vulnerable and one who faced “challenges” particularly around “social skills and understanding non-verbal communication”) appeared to overpower his own alternative perceptions of his identity.

John volunteers for an ID-related organisation and prides himself as one who helps others. However, this role often leads to him struggling to fulfil the duty of supporting others and this leads to what John describes as an “emotional type burnout”. John’s role of ‘helper’ (as well as other preferred identities) is also reflected in the internet mirror through the online game

Final Fantasy. In this game, John, in his role of either ‘tank’ or ‘healer’, does not have to wait long to be chosen by other players to play in a multi-player game. Tank and healer roles are in demand and are both valued and needed within this game and by this community. The physical appearance and attributes of the character John plays in his tank role are opposite to his offline identities of ‘vulnerable’, ‘dependent’ and a “burden” on others. The ‘tank’ reflects the identities John prefers: ‘helper’, ‘protector’, ‘strong’ and resilient:

> John: “As I’m a tank I can look like I’m the sort of person… that looks like… an actual wall… That looks like it could take an absolute pounding.”

John described also feeling more attuned to this online character and to the race he had chosen for his character, which he described as “big”, “tall”, “quite rotund”, tough, resilient, and like a “walking wall”:

> John: “… I felt like I was in a, a big strong person able to look out and protect others so I think from er, from a roleplay standpoint sort of thing it’s like you know I felt like I could be the, I could protect others I could you know… basically like a shield for them. / [and] who goes into the forefront of a fight… takes the hits from the enemies… [acting as] a protector of the weaker members [to keep them alive, / and are] built to withstand… [and]… take the brunt of the beatin[g]s”.

The players in Final Fantasy do not “have enough health” to be able to get through a full battle and therefore, they require healing from a ‘healer’:

> John: “[The] healer is responsible for keeping the rest of the group alive and themselves obviously”

The role of ‘healer’ was what John described as his “style”. He plays “powerful” healers, either a White Mage, who is a: “pure healing powerhouse", or a Scholar who: "put[s] up shields to mitigate damage". As a 'healer' John is useful and helpful to other players. He can offer a great deal to a group of players which means that he gets picked more often to join a group. He then gets to do the "job" they have picked for him to do. John described both the tank and the healer as being more "direct", more "powerful", a "bigger… asset to the group" and "very valued because they're the ones with the responsibility". Playing these characters is what John describes as: "definitely higher pressure", but John has always been the sort of person that likes to help others and, in the role of tank and healer, he feels that he is really able to do this. He can see himself in Final Fantasy reflected as a 'helper' in the internet mirror, as well as 'one who protects', 'shields' and is 'strong' and resilient, as oppose to 'vulnerable', burdensome and dependent. These latter identities are given to John offline by others, or by himself, and which often restricted him in his life, particularly in projects (this is explored in later constituents).

7.1.4 Reflections of female and male roles

Female and male participants described and viewed the roles of females, who they saw reflected in the internet mirror in GTA, Final Fantasy, CoD, Fable, and Mine Craft, in a number of ways (some more surprising than others). These reflections were used by participants to understand both themselves and others on- and off-line, in regards to gender and gender roles, and to create the 'whole' of female. The 'whole' of female was someone who would easily cheat on men, were fickle, untrustworthy, un-caring towards men, only interested in money, would prostitute themselves for money, would lie, could get things more easily than men, and whose mere presence online indicated that they were seeking the attention of males, who then legitimately targeted them sexually or violently within online spaces.

Andrea’s experience of females on- and off-line

Andrea has played both the off- and on-line versions of GTA. In the offline version of GTA Andrea chooses to play a male character, but in the online game she could not choose, and found herself playing a female character. Leona also played GTA, but whilst she would have preferred to play a female character, she described having to play a male character on GTA because:

> Leona: “there’s no girls on it. You can’t play a girl character on it [Respondent laughs].”

Even though Andrea dresses her character up to look like a “tomboy”, her character is still identified as a female in the game. Andrea would much prefer to play a male character in GTA as this would make it easier for her to drive and ‘hang around’ in GTA whenever she wanted, without getting targeted, bombed or shot at because she is a girl. Andrea explained that girls like her, who are interested in playing GTA, are in the minority. The boys on these games do not give girls a chance to play, which Andrea feels is “cruel”. Andrea described a typical girl offline who would not be interested in playing GTA, instead, preferring to:

> Andrea: “dress up nicely, fancy high heels, makeup, do all their hair and everything… That’s not me”.

Andrea does not understand why these girls bother to look this way, with their excessive make-up and specific style of dress, which is both humorous and disastrous to Andrea:

> Andrea: “[It’s] a disaster… It’s like they’re looking for attention… Cause they wear… so short dresses and they’ve got their boobs out and then they wear high heels, they can’t even walk in”.

Andrea describes how she is not like these ‘attention’ seeking females, but attributes some of her weaknesses to being female:

> Andrea: “…Unlike boys, they can stay on [GTA] twenty-four seven… I can’t stay on that long cause… sometimes I get bored of it so I go off and go and do something else in the house…”

John’s experience of female and male characters in Final Fantasy

John has played female characters in many online games, but in Final Fantasy the decision to play a female character came about when he received a reward from a “raid”, a robe, which looked “ridiculous” on his male character. So, John changed his character’s gender to female, in order for his robe to look more aesthetically pleasing. John described going back and forth from playing male to female characters and felt no difference playing either gender. But John did get treated differently by others in Final Fantasy as a female character, compared to when he played a male character. John explained that when he is playing a female character, other players think he is also a female in real life and will try and ask him out. Once, when this happened in Final Fantasy, it made John feel uncomfortable and unnerved and resulted in him blocking the male player. John explained that as a male character, even one which is the biggest sized character in the game, he tended not to draw much attention from other players (the visibility of female and the invisibility of male online characters is further discussed later in this chapter). Whilst John sees other female characters as just another player, he has also seen that female characters, played by females or by males who can give the impression they are female in real life, “will get sexually harassed”, even “abused”, by other players, who are predominantly male. They will also get given things from male players who are just “trying to get laid”. John described these types of male players as: “low down”, “insecure” and on “an ego trip” and stated that the way female characters in the online games get treated, especially by male players, is not very much different from the way women are treated in real life: “it’s like it just gets extended onto there [the online game]…”.

Alex’s experience of females and males in Call of Duty

Alex explained that the game CoD: “has always been known as a boy thing”, and as such, there was no customisation of the online characters like there is now. Whilst many still complain that the choice of customisation is not enough, Alex thinks that they need to remember that CoD is “a man’s game” and customisation is something that does not fit within a man’s game because this is a female, rather than a male, need. Alex stated that the majority of the players in CoD were male, validated by the fact he did not see many female players whilst in this game. There were, however, obvious signs which signified to Alex and other players if a player was female though, even if they were playing a male character. Some indicators included a female looking profile, or if their clan tag says ‘girl’. A player with the clan tag ‘girl’ means more than just telling other players you are female, it is also: “…kind of flirty, cheat-e-ish”, a “flirty technique” and “the most obvious way to flirt with guys”. It attracts and invites male players to look at their profiles and start messaging them. When the girls in CoD are ‘flirty’ and are acting in a “sluttified” way:

> Alex: “they put on a voice to say that they’re single, … they start obviously asking for… Facebook or stuff like this, so they can talk… and then they come out and they say ‘oh would you like to be my boyfriend?’ or whatever and [respondent starts chuckling]… then you start getting into this like… online relationship.”

This is something that has happened to Alex, but after they become his girlfriend they will betray him:

> Alex: “[They] move on and try get someone else, it’s all about like just… seeing how many boys you can get… that’s how they see it as.”

As female players are not so visible in CoD, the sighting of a female player is a rare and exciting occurrence for male players, who, when they see a female player shout “girl, girl”. Alex feels this behaviour, and the “weird” flirty interactions that happen between the ‘girls’ and the male players, should not be replicated online in CoD. It is something Alex ignores most of the time and it does not bother him as long as these ‘girls’ do not intervene in his game.

Alex’s experience of females in Mine Craft and Fable

Alex once went into the game Fable where he found himself in a room within the game, along with at least six other people, where there was a female character in her underwear walking around:

> Alex: “She got a bunch of people in this room, obviously cause she gunna have sex with the A.I.… and she was like ‘up for a threesome?’… I’m like ‘really?’ [respondent laughs loudly]… So I joined your lobby and the first thing you wanna do is have a threesome…”

Alex declined the offer and left the game. Alex described how common it was for females to engage others to watch, or get involved with, them in a sexual act. This was the easiest way for women, or indeed a man playing a female character, to get money, and for others to find: “a little bit of fun”. Alex plays a male character in the game Fable and felt that the ease in which female players could get money in the game was a bit biased against men. Alex’s experience of how the female character’s money-making antics, which were active rather than passive, did not align well with the “olden days” idea that the game Fable was built around:

> Alex: “[In the game Fable] the dad gets the money in… the mum uses the money for the kids… / [By saying] I’m a girl… people just start giving you money, free money. [I: Right] Cause you just use that at to your advantage… It’s like prostitution really.”

Alex described that in real life women are discriminated against because they are seen as “weaker” and this may mean they get paid less than men, even though they may work more. Alex wonders what it would be like to be female: “I think everyone has had that question before”. Given the opportunity, Alex would change his offline male body to a female body, as he can online through his characters, because he feels his personality is more akin to, what he considers, female personality traits. Alex also reflected that a visible female body could also be advantageous for him, including making it easier for him to get a job, something he currently cannot get:

> Alex: “[I: …Do you think it’d be easier in a female body or harder?] Yeah I think it’s more, I think it’s a lot more easier, it’s a lot more easier for you to get a job, obviously… / [I: … why, why do you think it’s a lot easier?] I think you can get away with lies a lot more. [I: Right ok, so you think as a… [respondent starts laughing]] I just think if you’re a girl, you can get things a lot, get away with things a lot more easier [respondent continues to laugh].”

But similar to Andrea, Alex also attributed, what he perceived as, weaknesses in himself to his own feminine traits, for example, feeling upset after an online relationship break up and taking CoD seriously:

> Alex: “Well I’ve always said that if I’d had, if I’d have just changed my body type I would be a girl. [I: Would ya?] Yeah. [I: If you could choose.] Any… sex? Yeah. / Cause I’ve always seen myself as a more… feminist, I mean… just being, well that’s not really like… that’s my personality [Interviewer took ‘feminist’ to mean ‘feminine’] [I: Yeah, yeah.] Cause obviously, I take things more seriously… [I: Yeah] … than guys normally would do.

Alex described that because he took his online relationships too seriously he found that, due to his sensitive nature, he got upset when they ended and gave an example: Alex was aged twelve when he started talking to a girl on Mine Craft, who then asked him if he would like to be her boyfriend. Alex said yes, but he knew it wouldn’t last because some girls cheat. Even though Alex was “loyal”, and not the type to flirt and cheat with other girls, after a few years she found someone from her real life and moved on from her online relationship with Alex. Alex assumed she thought: “screw it… dump him [Alex], get with him”. A couple of years later, Alex met another girl in the game Fable, who, after talking to her for about a month, he married and had a child with within the game (which is possible because the characters can have safe and unsafe sex with each other). Although Alex never knew her real name, only the name she gave herself in the game, he described this relationship as “cool”. Alex was loyal and stuck with his online wife and did not marry anyone else online, but after about a week of marriage, she divorced Alex and left him with their child. These events contributed at first to Alex’s sense of wellbeing, then suffering, particularly emotionally/mood and intersocially:

> Alex: “I took it kind of seriously… Cause obviously like, that’s what I do, take the game seriously, take my emotions in the game… When you see it happen you’ll learn your lesson, and you just learn to… talk to em more and try not to…”

Alex tried to message her, but she had blocked him. After the divorce, each time Alex went into the game he had to pay a fee that went directly to his online ex-wife. This is the way the game works and the females in the game take advantage of this:

> Alex: “[the] guy has to pay money towards the girl… So if you divorce em, it’s how they roll in the money.”

In order to make money in the game, female players will sleep around with thirty to forty male players: “getting money in each time,.. each day”. It is the easiest way to get money in the game and Alex felt that she had not wanted an online relationship with him, she just wanted his money. Others said to Alex that he had got “too deep” into his first marriage on Mine Craft, and because of this, he had taken this online relationship too seriously and suffered as a result of the online breakup. In Alex’s second and more “intimate” online relationship in Fable, his friends had told Alex not to “get too attached”, but this was difficult for Alex:

> Alex: “…obviously I take it more seriously than that… Obviously I, cause obviously my, obviously my dream is to… grow up, have kids, get married… Stuff like that, and buy a house…”

Playing these types of games made Alex think and question things more, especially relationships with females. In the games, when a ‘girl’ ‘dumps’ Alex, they do not tell him the reason why they have dumped him. This means he is unable to “improve on it”. Even when Alex asks the ‘girl’ directly why they have dumped him, he never gets an answer. Alex has decided that he may not get married online again, but for Alex an online relationship is still easier for him than an offline relationship for a number of reasons. Online, after a break-up, Alex can move on and he is not kept “attached”, which means the other person cannot use and hurt him. This happened to Alex offline when he was at college after going out with a girl for a month or two. She still had feelings for her ‘ex’ and Alex’s friends told him that she was trying to “hook” him. Alex was initially unaware or knew of this term and what it meant. They explained to him that being “hooked” was when the other person keeps you attached:

> Alex: “[when you are] attached… it’s like their little pet… Guinea pig… they just use that against you, to hurt your feelings even more.”.

Another reason why Alex feels an online relationship would be easier is the judgements girls make over Alex’s appearance:

> Alex: “if some girl just saw me, they’d think ‘oh I see he’s got acne, he’s got all of this’ I mean… I mean, ‘he’s got long hair’, you know what I mean? But when you’re online, you can just tell em about it, rather than them seeing you and looks isn’t really a factor…”

Alex stated that girls preferred: “big bulky guys because like… erm… girls like the protection”, to be their “saviour” or their rescuer. But even with a “six pack and abs”, most girls can and will dismiss these guys in an uncaring manner, thinking of them as being all the same. But for guys like Alex: “every girl’s different”.

There was a distinct perception of females and their roles, on- and off-line, by Andrea, John and Alex, which was that females online initiated attention from males in a less than positive manner, they would easily cheat on men, were fickle, untrustworthy, and un-caring towards men, were only interested in money, would prostitute themselves in the games for money, would lie, and could get things more easily than men. Their mere presence online indicated that they were seeking the attention of males, who then legitimately targeted them sexually or violently. Alex described the game Fable as being built around the ‘traditional’ idea of the male as the one who makes money, and the female as the one who received the money from her husband in order to look after the family unit. It appeared female characters in Fable were breaking the traditional role set within the game and finding other ways to earn their own money, rather than passively waiting for their husbands to give them this, as the game’s design/ers intended. It appeared that both Andrea and Alex’s perception of themselves as female, or having female traits, contributed to how they viewed themselves and their identities. In Andrea’s case, being female explained her lack of concentration over a long period of time and the lack of freedom she experienced on- (in GTA) and off-line as a female. Andrea viewed females offline as the cause of how she was viewed as a female, and the cruelty shown by boys in games like

GTA towards female players. Alex explained that being too sensitive and emotional in online games was due to his feminine traits.

7.1.5 Reflections that exaggerate able-bodiness and present the essence of the ‘thing’ of interest.

Although the internet mirror can be flat, presenting a relatively ‘true’ reflection, it can also distort: bringing reflections of the lifeworld closer, magnifying, and calling attention to conflict, violence, chaos, and the roles of females and males. The internet mirror can also reflect exaggerations of able and coordinated bodies (male African style dancers, a street dance group, and male bodies withstanding pain) and distil the ‘thing’ of interest, for example, a sea lion, to its essence, as experienced by the participant on YouTube. The reflections that were presented to Leona and Alex, through the YouTube videos they watched, contributed to both their sense of wellbeing and suffering. The sea lion show brought happiness to Leona when she was unable to go to her favourite theme park and zoo, but watching able and coordinated bodies brought about a realisation of the vulnerability and weakness of their bodies for both these participants. This meant they were not able to pursue projects, such as learning to street dance or joining the army.

Leona sees the reflection of the coordinated and able dancers on YouTube

When Leona visits her favourite theme park and zoo, about once a year, she always goes to watch at least three of the four male African style dance group's performances, which includes their amazing feat: "limbo[ing] under fire". Leona would like to go more often to the theme park, but when she is not able to, she watches the male African style dancers on YouTube nearly every day. Alongside these videos, Leona is also able to see: "loads of [the re-] views" they have got from other people, who congratulate and celebrate their performances. On YouTube, Leona can carefully watch the dancers limbo-ing astoundingly low under the pole, which has been set on fire. To Leona, the dancers and their feats are: "amazing". She wonders how they are able to do this and never gets bored of watching them dance or listening to the music they dance to. As Leona described their limbo-ing style of dance and their feats, she moved her own body to copy the rhythmic limbo style of the dancers. Leona explained that this type of dance, and the acrobatics they perform, is not something she could ever do herself. But Leona states: "I'd love to like limbo", and this is another reason Leona watches the dancers on YouTube. Leona has been able to copy one of the male African style dancer's moves, which she demonstrated in the interview: a whistle and a clap, but what Leona considers their more difficult dance moves and acrobatics, like standing on someone else's shoulders, she does not think she could do: "I don't think I could". Leona also likes to watch her favourite street dancing group on YouTube too. Like the male African style dancers, she would like to dance like them as well, but Leona explains that she cannot dance like them because they are "too good". The lack of confidence in her own bodily abilities to learn to street dance meant that Leona did not take up an opportunity on holiday to pursue something that she wanted to do:

> Leona: “I [respondent sighs briefly…], the, I’d love to dance but the, I mean, the dance group I like is like _______. But I couldn’t follow them. They’re too fast…. I’m off to see em soon, so I can try and copy… [I: So have you tried to copy _____?] Too, I think they’re too difficult to copy…. / I was gunna do this dance show cause they’re doing, cause they do _____ [name of a UK holiday resort] they do like this dance show afternoon, you can copy em but it’s like, it’s, it’s sixty-five pound. [I: Well, at… _____ [name of a UK holiday resort]?] Yeah. No to copy em… Sixty-five quid… You can do like a dance camp in the eve, morning, afternoon… and then you watch show in the evening. But I think it was too difficult, so we didn’t look at it.”

Alex sees reflections of the strong male body which is impervious to pain

Alex realised that he could not get the full experience of being female by playing a female character within online games, but, he has seen other ways, by watching YouTube videos, in which he could experience something only females can experience: the painful contractions during childbirth through a device strapped to his body. The pain of childbirth contractions is something others have told Alex is painful:

> Alex: “[It is the] most… pain… ever, that you can have. But I want to try it me… Cause I want to see if it as bad as they say it is”.

Research, that Alex has found on YouTube, shows men can handle more pain and for a longer length of time than women (who are more sensitive to pain), because of the testosterone in the male body. This is something Alex firmly believes and additional YouTube videos that Alex has watched, which show men doing painful feats, further validates this belief. The internet reflections show Alex the pain a male body can withstand and he described examples of this. The first was a man who stuck toothpicks through himself for a Guinness world record, a feat Alex describes as being “actually quite cool”, possible because the man does not feel pain:

> Alex: “[The man did it] for show, some people will see it as ent, en, enterchanging, funny… But if you can’t feel it, it don’t affect you don’t it?”

The further examples Alex gave was the YouTube videos he had watched that showed men, who practise martial arts, strengthening parts of their bodies to withstand pain. For example, strengthening their Adam’s apples so that they could withstand a 1000Ib force on this area of their body. This is something that Alex described as too much for an average man’s body to withstand. Another example Alex gave was a man, who also practised martial arts, in a YouTube video:

> Alex: “ …[who] ended up getting kicked in the nuts as hard as they can…. Which, for us average guys, it’s painful [respondent smiles]… and he was able to manage, and didn’t feel anything.”

Whilst Alex is happy to lay his online character’s body in danger in CoD and imagine the experience of pain and suffering when his online character gets shot or stabbed in a combat situation (to increase his sense of immersion in the game), Alex admits that he is scared of putting his own physical body into that position offline. Alex has thought about a career in the army, but the pain and suffering his physical body could potentially endure, or the upset his death may cause his parents, prevents him from pursuing this career choice. Alex described that his physical body was at best: “average”, and at worst: ‘sensitive’ like a female body. If Alex could withstand female childbirth contractions, through a device which simulates this, he may prove that his own body, although not as strong as the male bodies he has seen on YouTube, is still masculine and stronger, rather than feminine, because he can withstand more pain than females can.

The sea lion-ness of a sea lion: the exaggeration and distilled sea lion on YouTube viewed by Leona

Leona watches YouTube videos of sea lion shows, because like the male African style dancers, she only gets to see these a few times a year at her favourite theme park and zoo, or when she is on holiday. Leona likes the way the sea lions clap when they perform, how they wave to the audience on command, and kiss audience members who have volunteered themselves:

> Leona: "I, I wonder how they do it with flippers? [Respondent moves her hands and arms like a sea lion, whilst thinking about the question] I never thought they could do it… I like how they wave as well… They can wave, can't they? Have you seen them wave?"

But the internet mirror, like the offline sea lion shows, reflects a distilled and somewhat exaggerated and unnatural 'sea lion', a performing animal, one which Leona recognises as an animal which claps, waves, and kisses audience members on command and, as such, has become a large part of Leona's 'whole' of a sea lion. But a sea lion would not do 'perform' outside this context without human intervention. In fact, the sea lion (situated in a show) reflected in the internet mirror, is not only free from the unneeded and irrelevant stimuli, for example, the uncomfortable seating, proximity to other people, distracting noise and uncomfortable weather conditions, it is more sea lion than a sea lion Leona could see offline in its natural setting (which would not be performing).

7.1.5 Summary

Many of the participants spatial experiences offline was limited and controlled, often by those who supported them. However, the internet as mirror allowed these participants to experience spatial freedom online and increased their awareness of many aspects of their lifeworld and themselves. Whilst a sense of spatial mobility led to many of the participants feeling more in control, informed, happy and satisfied, at times, the online reflections they saw were magnified, distorted and/or exaggerated. For one participant this met her need to experience a sea lion (when this was not possible online), which was a distilled reflection of a sea lion or its essence. For others it also drew attention to ‘things’ which formed the participant’s whole of phenomena in their lifeworld. For some participants, this led to the perception of a dangerous, scary, uncontrollable, threatening, and conflict-driven offline world and contributed to their sense of suffering.

The internet mirror enabled participants to view and control their chosen identities, which opposed their given offline primary identities: disabled, dependent, burdensome and vulnerable, as examples. Performing their chosen identities online contributed to the participants’ sense of wellbeing, whereas offline identities contributed to a sense of suffering for many participants in the phenomenon: wellbeing and internet. As an example, for some participants offline, DS/ID identities brought fear around what others would think about, say or do to them online.

Both female and male participants viewed the reflections of female and male characters in the internet mirror whilst they played GTA, Final Fantasy, CoD, Fable, and Mine Craft. These participants also experienced playing a character that was the same or the opposite of their gender. These online reflections of males, but in particular females, were used by participants to understand and reflect on both themselves and others on- and off-line in regards to gender and gender roles and to create the ‘whole’ of female. The ‘whole’ of female for some participants was someone who would easily cheat on men, was fickle, untrustworthy, un-caring towards men, only interested in money, would prostitute themselves for money, would lie and could get things more easily than men. The mere presence of a female character online indicated that they were seeking the attention of males, who would then legitimately targeted them sexually or violently within online spaces, especially in online games that were deemed male spaces such as GTA and CoD.

The internet mirror reflected the male, able, coordinated, and pain resistant body to participants, which was displayed through YouTube videos and online games, was described as desirable by the participants. However, this led to participants feeling their own bodies were average, un-able and/or uncoordinated, or that they had ‘feminine traits’ which were unwanted/undesirable, such as the inability to concentrate and sensitivity.

7.2 The internet enables visibility and invisibility

Constituent two: the internet enables visibility and invisibility, is broken down into the following subthemes:

- Making one’s disability and physical appearance visible or invisible on the internet.
- Female characters are visible and male characters are invisible to other players within online games.
- Making the self visible to celebrities on social media.

All subthemes contributed to the participants’ sense of wellbeing and suffering which I will now explore and describe, as identified by the participants, and give examples.

7.2.1 Making one’s disability and physical appearance visible or invisible on the internet

Steven tries to remain invisible on Facebook

Steven ensures that he is ‘private’ and thus un-accessible online to those he has not met offline. But still, this does not prevent others, from his past whom he has met offline, from finding and contacting him online. For Steven, his forced visibility on Facebook means others he knows can find and communicate with him, which at times can be welcome, but at other times unwelcome. Some of Steven’s relatives, living where he was originally born, tried to get back into contact with him through Facebook. Because Steven did not want contact with them he blocked them. In contrast to this unwelcome contact, one of Steven’s old school friends unexpectedly contacted him through Facebook, which pleased him. As with his other Facebook friends, Steven occasionally enjoys talking with his old school friend through Facebook.

Alex makes himself invisible online

Although Alex makes himself highly visible in online games, personal information about himself is invisible online. Alex achieves this by not posting information about or photographs of himself (apart from the “basic”). This is because Alex fears others online would use this information against him and he wants to remain as safe as he can whilst on the internet:

> Alex: [I: …do you put on a lot of information on about yourself?] No not really, just basic. [I: Yeah.] Just basic information like… that I play X box, that’s all you need to know. [I: Yeah.] That’s what I put on my Facebook status, I play X box, and I go to sleep. Well play X box and YouTube and that’s it, go to sleep. [I: Yeah.] That’s all I put on my You, er my Facebook status. [I: Yeah, would you like to put on… more information? Would you ever put a real pho, a real picture of your face on?] Not really cause I know that people can steal it. [I: Right.] And people start can start trolling with those pictures…”

John makes himself invisible to avoid conflict on the internet

Since leaving the online game Final Fantasy, after he was rejected by this game’s community and his online friends and wife (‘the exile’ and ‘the snap’, which is described later in Chapter 8), and receiving criticism from others in online forums, John described that he had been doing better because he is now just removing himself from certain situations:

> John: “[I’m] pulling myself out… if things are going wrong … [and] … when issues crop up… where I can run I am.”

John continues to talk to his online friends in other areas of the internet who, whilst they “understand the battles” he goes through, have told John that there is no need for him to take his anger out on them. John has pulled out of quite a few situations online because someone has got annoyed with something he has said. By pulling out of these situations, John is literally making himself invisible and this feels safer for him than remaining visible. John gave an example of a time he decided to make himself invisible when he felt himself “getting wound up” and “annoyed” by something someone else was saying online. It was part of a joke with John and the other people present, but John could not work out why he had taken what this person had said in “the wrong way”, as what they said was not “nasty”. To ensure he did not “explode”, and become the annoyance of another, John followed his “exit strategy” and pulled out of the “server”, thereby making himself invisible.

John has noticed the pressure others online face to be visible to others, by seeking and getting “likes” and “followers” on Facebook and Twitter, and trying to be, what John describes as, “a social media mogul”. This is a pressure John also feels and explained that because people, who are trying to be “social media mogul[s]”, have their own beliefs and are vocal about these on the internet they create a belief of what should and should not be visible online. One of the things they are vocal about, and “broadcast” online, is an image of ‘perfection’:

> John: “…you know like everyone has their image of like what… what perfection should be and everything, you know stuff like that, and they… broadcast it and people you know like feel like they have to be that…”

Although John appreciates that people have the right to free speech, their beliefs and vocalisation of this online have, in John’s opinion, had too much of an influence on himself and others. It has caused his confidence to decrease because his visibility online is “constantly” of annoyance to others and he is attacked by others online:

> John: “I’m constantly… you know, people seem to be upset with me a lot because of like I’m… putting my foot in it…”.

On the day of an interview, someone online had called John an “irresponsible coward” and had criticised him for talking about his servers all the time. They said to John: “whenever there’s a problem you just run away”. John then “pulled out” of and made himself invisible from this server, but to him, ‘pulling out’ and making himself invisible, is far from irresponsible, cowardly or running away. It is John’s best way to try and avoid problems and to ensure that the internet remains the other ‘critical’ person’s: “happy place”:

> John: “I was trying to sort… make that your happy place again you know I’m like, I was trying er. Because if I’d just said oh I wouldn’t do it again I couldn’t guarantee that it wouldn’t happen again so it’s like well… something more definitive.”

John feels he should face up to it, but if he can get away from it and make himself invisible, he will, so that he can avoid problems and conflict. John does not trust that his own visible presence can consistently make another person’s internet place happy. When invisible online, John is no longer in: “a position where… [he could] upset them again”. But invisibility also means that John discounts his own feelings and needs: to be present online in order to be able to talk to others and be helpful and valued. To remain invisible, John played a male character in another MMO which meant that other people left him alone (as he was invisible as a male character). Although he no longer felt he was an annoyance to others online, he felt lonely and disconnected and experienced a sense of suffering when invisible online.

Alex’s appearance and speech and language difficulties are invisible on the internet

Alex enjoys using the internet, it makes him happy as he is able to meet and interact with new people, have a laugh, and talk about “random things”. Alex described having speech and language difficulties (SLD) and explained that he found it more comfortable, preferable, and felt less: “judged all the time”, when he was communicating (through text and verbal communication) to others online compared to those offline:

> Alex: “you’re not judging by their face, not judging how they look [respondent pauses and takes inhales breath and bangs hand down]… You know judging about how they talk… what they’re interested in…”.

For Alex, when he is online there is less of himself visible for others to judge him on, and whilst Alex states he needs help with his SLD offline, when he is talking to his friends online he feels that he does not have SLD. Alex has told his friends online that he has specific “difficulties”, including SLD:

> Alex: “[They say to me] ‘oh no you haven’t’ and stuff like that, cause, I could talk to them… more clearly… Cause obviously I mean it’s just… it’s not face to face, but when it comes to face to face it’s more difficult… That’s when I like slur my words and stuff like that.”

Alex spends most of his time in his bedroom on the internet and the only friends Alex stated he had offline were the other volunteers. Alex was relatively invisible offline, but online, he has many friends and is visible, especially in CoD. Although Alex's online visibility is through his online characters, he is still invisible because he withholds aspects about himself, apart from 'basic' information. Alex deliberately makes friends with girls because this is less "gay-ish" and they are easier to talk to and get on with than 'guys', who are more judgemental and less understanding about Alex's disabilities than girls:

> Alex: "Girls are more like… more heart-warming and like,… if you become friends with them you tell em what's actually wrong with you, they're not going to judge you… But with a guy, he might do… And obviously I mean they might tell everyone and stuff like that, so obviously I mean that's… I feel more comfortable talking to girls in a game…".

Alex's close female friends on the internet have asked him if: "there anything that's like… wrong with you?" out of "curiosity". Alex is not really afraid to tell them because: "everyone has their weak side, everyone has their problems" and when he did: "let it out" and told them about his disabilities they understood:

> Alex: [They said to me] "you don't sound like it… So I pretty much sound normal to them. / [they] didn't really abandon me, they just saw it as normal, and they just said to me obviously, they don't think there's anything wrong with me. Because I can speak comfortable online… than I can in person."

Alex has known his online friends for a year now, but they have not seen a picture of him yet, despite asking to see what he looks like. Alex has said "no" to their requests because:

> Alex: “I know opinions can change… So I’d rather not take that risk… [and] stay hidden”.

Alex has seen opinions change towards others online when they have revealed something about themselves many times before. He has also heard other people’s stories of this happening too. This makes Alex cautious about revealing certain aspects about himself to others online, especially around his physical appearance. Alex explained that online it was all about looks these days:

> Alex: “if you don’t look good, you’re not going to have any friends”.

But Alex is able to present his perception of a ‘good’ look, one which is visible to others online through his characters:

> Alex: “[Online characters] don’t have any spots that’s for sure… that’s when your looks come. Good enough for me. / [Online characters have] all smooth skin, baby face… which I guess it ruins people’s minds I think.”

Alex concluded that the physical appearance of online characters meant that the “expectations” of those who spend time online has increased. He also suggested this was not just about the appearance of virtual characters in games, but the appearance of people depicted in online pornography as well:

> Alex: “[If men watch online porn they think that] they’ve got to have a massive… dick… And they think all women, have to have smooth skin and all these make-up on… / [but these are all just] gimmicks… if a guy loves someone, for who they are, then it don’t matter if they wear make-up or not.”

John is rejected when he tells others online about his disabilities

Unlike Alex, who keeps much of his offline self invisible to others online, John often tells other people online about his autism and ID, in the attempt to be open and honest with them:

> John: “[Interviewer: … do you ever tell people about your autism or your learning disability, do you ever tell anybody?] I try to yeah cause I feel like… there’s, it should just be open you know so people know. [pause]. Erm, not everyone takes it very well.”

John does not see the point in lying to others online about himself and wants to be more open with everyone, particularly when he notices he is getting close to someone as a friend and there may be the potential for an online relationship. John tells them not only about his disabilities, but also what could happen as a result of his disabilities and how they should deal with him and his disabilities. However, this open and honest disclosure by John is often met with silence and rejection by the other he has become close to online. After telling one online friend, John stated that: “they didn’t say anything they just, cut me out [pause]”. Being cut out by others after he has disclosed, and thus made visible, his disabilities to another online has happened a lot to John.

7.2.2 Female characters are visible and male characters are invisible to other players within online games

Andrea’s experience as a female in Grand Theft Auto

In the online version of GTA, Andrea cannot choose the gender of her character and a female character is chosen for her. Even though Andrea dresses her character to look like a “tomboy”, her character is still identified as a female in the game. Andrea feels that other players know there is a female player behind the female character and this attracts both attention and the assumption that she should not be there:

> Andrea: “Character online, dressed as a girl, driving a car and they think ‘Ohhhh she’s a girl, let’s go and kill her and bomb her orrr, do whatever to her… cause girls can’t play GTA’ / …they just automatically come straight up behind either bump into me, do er, shot rifle so they kill me in my car and burn my car up… …or I try and run and they shoot me from my back… and they’ve done that quite a few times last time I played. [I: and how do you feel about being kind of…] Yeah, awful… Picked on because I’m a girl and I’m playing GTA five and cause [pause] mainly boys don’t think that girls can play this sort of game and I think it’s very cruel… They’re not given [pause] girls a chance to play,…”

Andrea can sometimes spend a long time without “anyone touching” her in GTA, but at other times her journeys and explorations in GTA are interrupted by other players. Andrea knows that she is perpetually targeted and killed in GTA simply because her character is female and these players think that girls cannot play games like GTA:

> Andrea: “last time I went on I got killed a lot, just because I’m…a…girl… doesn’t… mean… they…. have … to… kill …. me.”

Sometimes being targeted and killed in GTA makes Andrea feel so mad that she wants to throw her console at her television. Andrea would much prefer to play a more invisible male character in GTA because he is less likely to get targeted and this could potentially make it easier for Andrea to drive and “hang around” in this game whenever she wanted, without getting shot at or bombed. But as a female character, Andrea is left feeling annoyed, frustrated, helpless: “[they] keep… doing everything to me”, and wondering what the point of it all is. To prevent herself from throwing her console at her television when she is annoyed and has had enough of being bombed and killed by other players, Andrea often decides to come off GTA altogether and do something else, making herself, like John, disappear and become invisible in this game.

John’s experience of playing a female character in Final Fantasy

Whilst playing a female character in Final Fantasy, John was approached by a male character who did not know John was: “a male behind the screen”. The player then tried to “chat” John up. John did not know what the “guy” was doing at first or how to take this. John also found out that it was not just him that was being chatted up by the ‘guy’, he had chatted up all the female characters he had come across in the game and they had not been “comfortable with that”. John explained that being chatted up was a more common experience for other female characters, but a less common experience for him when he played female or male characters. John found the experience of being chatted up by the ‘guy’:

> John: "…unnerving / … Cause I didn't feel comfortable with it you know it's like, made me feel uncomfortable…"

John added the "guy" to his 'blacklist' and blocked him, but later, when playing a male character, he met the 'guy' again and ended up befriending him. This is something further explored in constituent seven: internet as friend and foe, in Chapter 8.

Alex's experience of females in Call of Duty

Alex stated that the game CoD: "has always been known as a boy thing" and, as such, there was no customisation of the online characters in older versions of CoD, unlike there is now. Alex concluded that the majority of the players in CoD are male because he did not see many female players in this game. Despite describing that customisation was a more female need in the male orientated game CoD, Alex made his character more or less visible, and identifiable, by making changes to (customising) his character's outfit, appearance and gender. If given an option in an online game, Alex will pick a female character because there are certain abilities that he gains if he chooses a female character, which are not available to him if he chooses a male character. These abilities include kinetic armour, which makes it more difficult for Alex to be killed, but this ability only available to a female character often brings online accusations from other players that he is cheating, a quality that was associated with females in constituent one: internet as mirror. Alex's female character in CoD is automatically visible, as female players are rare and instantly recognised by other male players. Alex has changed his female character's hair colour to a pink and chosen: "skin white, erm hat on… and erm like a reddish jacket on”, yellow combat trousers and purple “splatters” on the jacket’s shoulders to help “identify” him. As a female character, Alex is “brightly coloured” and describes himself in this game as not the sort of person to “go camouflage” or remain hidden from others. Remaining hidden in CoD is something Alex neither likes or understands. He chooses to rush in and attack within this game and make himself visible to others who may hide:

> Alex: “I just run in… run in like a headless chicken… That’s how, that’s how I’ve always played… Just be quick, that’s all it is”.

Alex described feeling more comfortable playing a female character and, despite having a female character, he still “gets hit on” in the game by women, who know that he really is a male. This is because his name indicates this, they can hear his voice, and his profile is not “girlish”. Alex does not receive “grief” in the game for being a girl, but he does get called “gay”, which does not bother Alex because he knows he is straight, and it is common for other players to give Alex racist “grief”:

> Alex: “[As his online name indicates he may be from an ethnic minority, other players say:] “‘you’re p bastard’ … and stuff like that [respondent whispers ‘p bastard’, he mouths ‘paki’ after pronouncing the ‘p’ in ‘p bastard’]… I’m like ‘you racist… person’”.

Alex’s choice to play a female character is because he knows what it is like to be a “guy” and play a male character, which: “gets boring after a while”, unlike being a “girl”, which is not as familiar to him. Alex’s choice to play female characters is reassured by listening to those on YouTube who state that it does not matter if a male chooses to play a female character, or if females want to play male characters.

John and Alex’s experiences of playing an online male character

As a male character in Final Fantasy, John explained that other people just think that there is a: “bloke at the other end [and] tend to leave me alone…”. This is something John was thankful for at times and formed part of what he described as his ‘exit strategy’. John, who had played both female and male characters, described that playing a male character meant that he was less visible and could blend into the background:

> John: “[I can be] quite reclusive and just avoid problems…”

This was welcomed by John following ‘the snap’, which is detailed in the next chapter.

If Alex has to pick a male character, he does not pick one whose body is either “big and bulky” or “skinny like a twig”. Alex prefers to pick one that has an average build because then:

> Alex: “people can’t say anything about you then… They can’t say you’re too skinny, they can’t say you’re too big…”

Both John and Alex appeared to be fully aware of the invisibility and the lack of attention a male character brought them compared to female characters, who are highly visible. With this knowledge they played different gendered characters depending on their needs at the time.

7.2.3 Making the self visible to celebrities on social media

Andrea and Leona make themselves visible online to celebrities by posting up images on social media

During the break at a concert, Andrea was able to take a photograph of one of her favourite boybands. The next day she posted the photograph onto Facebook and Twitter, with the name of the boyband attached to the post. This meant that Andrea's photograph would be visible on the boyband's page and, hopefully, to the boyband themselves. Andrea was delighted when she became visible to the boyband and they acknowledged her:

> Andrea: "It worked really well, cause they… they send me a message back saying it was really nice to meet you and the picture looks great [pause] and when I saw that, it just make me feel really good because I didn't think I'd hear anything from em back… … when I put the picture up on er… Twitter cause they like that and they like the one on Facebook as well."

When Leona went to visit an animal park with her family, the photographs of the animals they took were put on Facebook for others to see. For Leona this was:

> Leona: "so people can see, like what I'm doing, you know like at weekends or summut".

Leona also visited a theme park and zoo about once a year and on one of these occasions she met the male African style dance group, who she watches almost every day on YouTube, when she went backstage after one of their offline performances. Leona's brother took photographs of Leona with the dancers and put these onto Facebook. Leona described that one of her friends commented: "'that's a cute picture'".

As well as making herself visible on social media to her friends, who acknowledge Leona by liking or commenting on her photograph, Leona also uses Twitter to display photographs which she has found on the internet of, as well as photographs of herself with, the person she would like to become visible to, to try and initiate contact with them. Sometimes this tactic is successful and at other times unsuccessful. Leona gave a number of examples:

Leona found a picture of a rugby player, whom Leona and her mother both liked, and put this onto Twitter. It received both a like and a comment from the rugby player in the picture.

More recently Leona saw a picture of another rugby player on Facebook whom she also liked, which she copied and then posted onto Twitter. Again, Leona found that by posting this photograph up onto twitter it made her visible to the player in the photograph. The player kept commenting on Leona's photograph, saying that he liked the picture she had put up.

A few years ago, Leona and her friend went into a rugby shop in a town, where her friend took a photograph of Leona wearing a rugby shirt with her favourite player's name on. Together they posted this photograph onto Twitter and a few days later the rugby player, whose name was on the shirt, tweeted back saying to Leona: "'you look good in the rugby shirt'" and retweeted the photograph. Leona was "excited to know like that he'd commented back".

Leona was in a bar in town on a night out, when a rugby player walked in and started dancing with her after she had asked him to dance with her. Leona's mother took a photograph of them dancing and afterwards Leona and her mother posted the photograph they had taken onto Twitter. Leona described how the rugby player had put loads of comments about the photograph saying that: “’we could go on like Strictly’”, to which Leona replied back saying: “’I’d love to go on Strictly with you’”.

The last time Leona put a picture up of a rugby player, from her favourite team, she got 35 likes and 15 comments from others online, including a like from the rugby player in the picture. Although Leona has been successful at initiating contact with rugby players using this tactic, she has been less successful in initiating contact with others in the public eye, whom she also admires. For example, Leona posted a picture of one of her favourite pop stars onto social media, which she had chosen from the many pictures and photographs she had collected of him on her mobile phone, but Leona failed to make herself visible to him:

> Leona: “...I didn’t get a reply from him / [I felt a] bit upset… Cause I thought he’d reply to it, but he didn’t.”

7.2.4 Summary

The participants spoke about their experiences offline when they had been unfairly judged on their appearance and disabilities, including being verbally abused in public, which had sometimes prevented them from continuing to experience aspects of the offline world and pursue their chosen projects. Whilst some participants avoided contact with others on the internet, other participants described making aspects of themselves invisible, including their disabilities, SLD, and appearance, whilst they inhabited virtual worlds such as CoD, Final Fantasy and Fable. Choosing to be invisible online led to the participant feeling safer, specifically from others online who could, if the participants were to make themselves visible, misuse their information or images of themselves. Making aspects of themselves invisible online also reduced the chance for others online to make negative judgements about their disabilities or appearance, leading to possible verbal abuse, rejection and/or abandonment. Becoming or remaining invisible online was also used to avoid or end a conflict with other players or forum users.

Whilst some participants feared to make certain aspects of themselves visible online, some would choose to disclose their disabilities to those they had made friends with, or felt close to, online, particularly females with varying responses. After telling his online friends about his disabilities and difficulties, one participant described that his online friends had replied that they felt he was not disabled, because online this was not how he appeared to them, and offered their support and friendship to him after this disclosure. However, another participant described that when he disclosed his disabilities and autism (including how to handle him and his disabilities and autism), in an attempt to be genuine, honest and open about himself to those online to develop friendships and relationships, he would often be rejected or “cut out” by the other online.

Participants were aware of how visible and invisible the gender of their characters were online, with female characters being visible, and male characters being invisible. Being able to play a female character was utilised by some of the male participants to meet their needs for their character to look good in the specific clothes and the status that was generated from the female character’s abilities and visibility in CoD and Final Fantasy. Male participants also described that playing a female character would encourage other players, especially females, to engage with them in a friendly and supportive manner. For one participant, playing a female character also brought unwanted attention from a male player (in the form of being ‘chatted up’) that made him feel ‘uncomfortable’ and ‘unnerved’. When the male participants wanted to be left alone and not be targeted by other players in an online game they would play male characters, often with an average body size, as they knew this would insure their invisibility to others online.

One female participant also realised that playing a male character in GTA would have allowed her more freedom to explore GTA, as opposed to being disrupted by being targeted, shot and bombed by male players because she was a female character. Many participants viewed females as not belonging, or being particularly visible, in what they described as male-orientated games, such as CoD and GTA. As such, the violent and/or sexual targeting of females was accepted. Females were placed in subservient roles and were criticised if they veered from, what was viewed as, traditional and subservient roles set in the design of the game. For example, female characters were criticised when, rather than waiting for money from one online husband in Fable, they married and divorced multiple male players to generate additional money in this game.

Two participants, both female, made themselves visible to celebrities whom they admired by posting photographs they had taken of the celebrity (or themselves with, or something connected to, that celebrity) or photographs they had found online, onto Facebook and Twitter. They tagged the celebrity into this post to increase their visibility to the celebrity. When a participant did not become visible to one celebrity using this strategy, she remained invisible and unacknowledged, and this made her feel ‘upset’. However, when these participants became visible, and the celebrity liked and/or commented on their photograph, they felt happy and excited.

7.3 The internet as liberating

Constituent three: the internet is liberating, was broken into two subthemes:

- Liberation is experienced on the internet
- Liberation on the internet that interrupts or prevents others' liberation.

All subthemes contributed to the participants' sense of wellbeing and suffering, which I will now explore and describe as identified by the participants' experiences.

7.3.1 Liberation is experienced on the internet

Andrea's liberating experience on Grand Theft Auto

Andrea has played GTA offline on her own, and online with other players. Online she is able to play lots of games through GTA and finds competing against others in racing games or quests and trying to win money fun. Andrea has a few friends she talks to and plays with in GTA, two are what she describes as "real friends" (which she has met offline previously) and her other friends are those she has met only through playing GTA. Andrea enjoys interacting with all her online friends in this game and they often contact each other, to ask when the other will be on GTA to talk and/or play, by text, sending messages or requests online to each other. In GTA Andrea looks at other player's profiles to choose who to add as a friend and who not to add. Once a player is added as a friend, Andrea is then able to start talking or messaging them when she is present in the game. When Andrea's friends are absent in GTA, and she is alone, she likes to drive around in the game in her car which she has customised. Although Andrea would like to drive offline, this is not possible for her because she cannot afford to buy a car and she worries that she will not pass the necessary tests. But in GTA, Andrea has her own car and she describes driving in this game as “awesome”. She enjoys the fact that she can go really fast, be reckless and go anywhere she wants in this online world:

> Andrea: “…you could, go er… go round different towns in your car, cause there’s loads of roads going everywhere and nowhere. [I: Mmm.] … and… you can practically do anything, you could go in a helicopter… blow people up, kill em,… [I: Right.] … anything…”

Andrea drives without a map in GTA to see where the roads lead her, but after her car has been bombed by other players and she returns back into the game, she goes onto the map to find out where her car is. Sometimes Andrea keeps driving on the ring road or on the motorways until she reaches another city, or happens upon somewhere hard to find, like an airport. Whilst driving around different towns and cities, Andrea comes across buildings and lots of shops that sell clothes and guns. If Andrea has the money in GTA, she can go into these virtual shops, which display to her “hundreds of choices to make”, and buy what she likes without much thought. As a result she has amassed lots of different clothes, shoes, hats and glasses for her character to wear. However, for Andrea, these items do not count compared to the status of what a ‘real world’ designer item could generate. Whilst Andrea can enter the many different types of designer shops in her ‘real world’ home city, she knows that inside these offline shops are expensive items that she cannot afford, unlike what she finds in GTA. She would not dare to buy these expensive offline items for herself unless she had a job and was earning lots of money. If Andrea did have the ‘chance’ to buy a two or three hundred-pound bag offline, she imagines that she could show it off when she was out and about, and not continue to wonder how others can afford such expensive items. For Andrea, virtual material items in GTA do not appear ‘to count’, but driving does count and it also contributes to her sense of wellbeing:

> Andrea: [I: … So why do think you spend lots of time doing this [driving in GTA] then? [pause, respondent thinking] I don’t know, I just, I guess it just… keeps my…mind off of stuff that I’m either thinking of or don’t want to think of and [pause]… just try and focus on… either driving round the city or driving on the motorway… …and then going to a different city…”

Driving has the ability to calm Andrea when she feels upset, stressed, frustrated and angry from offline events, specifically not being able to find a paid job and the loss of her grandfather (which are later explored in Chapter 8), and it also allows her spatial and temporal freedom, which is lacking in her offline world.

Alex’s experience of liberation on the internet

In an online game, such as CoD, Alex explains that if you are killed you can easily: “come back alive… [and are] reborn” without suffering, being able to feel any pain or any ill or lasting effects on the body from this death. Online characters do not get a “single mark” on them:

> Alex: “You could walk around barefooted in… like a sandstorm and you’d be fine.”

If this was the same in “real life”, Alex reflected that this would be both “funny” and “interesting”. He could have as much fun as he wanted and do potentially fatal things like “jump off a cliff” because:

> Alex: “you’ll have no fear… You wouldn’t have to, you wouldn’t have to be fearful… It would be a lot more fun…”

Alex reflected that dying and suffering would be a real possibility if he were to join the army offline, something he has seen whilst watching the film ‘Saving Private Ryan’. Alex stated that he would not be able to “handle it” in the army and would not want to see his parents get upset if something were to happen to him. But knowing that he cannot permanently die offline and not being fearful, leads Alex to conclude that most people, including himself, would join the army offline for some fun:

> Alex: “if I knew that I couldn’t die in the army I’d be like ‘damn right, book me in there… straight away’ [respondent laughs]… No second thought to it.”

Similarly, if there were no laws offline (as there isn’t, as such, in the games) and you were reborn after dying, Alex feels that he, and everyone offline, could do whatever they wanted without being arrested or fined, for example, driving a car at 500mph (something “not possible in… real life”) and there would be no “need to take life so seriously”.

7.3.2 Liberation on the internet that interrupts or prevents others' liberation

Andrea's freedom on Grand Theft Auto is disrupted.

At times in GTA, Andrea doesn't notice the rifle aimed at her from the male player in a helicopter until she and her car blows up, which results in her character dying temporarily until the game 'reboots'. Players in GTA predictably come up behind Andrea's character, and her car, and bump into her to attract her attention before they then shoot and kill her with a rifle. Andrea has tried to run from them, but they just shoot her character in the back. Driving away from them doesn't work either, as they always find her and quickly kill her. Each time her character comes back to life and appears back in GTA after the game has 'rebooted', they come after Andrea again and again, to try and kill her as many times as they can. Within GTA, Andrea has never escaped from the players that seek her out in order to kill her, and her attempts to escape just add to their sport of killing. Andrea is not just looking for the players that kill her, but also for the police who pursue her in GTA too. Because of these experiences, Andrea is watchful when in GTA:

> Andrea: "I kind of have to er [pause] keep an eye on things, watch from side to side or [pause] well mainly that or in front".

Andrea can now sense what certain players may do, and what may happen next, as she has experienced their actions many times before. Andrea's uninterrupted presence and liberation in GTA is not just dependent on the time and day she goes on GTA, as there will be a different number of players on as well as Andrea's friends, but the presence and motivation of other players. Sometimes Andrea can spend a long time without “anyone touching” her in GTA, at other times her journeys and explorations in GTA are constantly interrupted by other players using Andrea’s female character to enact their own possibilities. These possibilities are often violent, which Andrea feels just shows how the male players feel about the presence of a female player, like Andrea, in a game like GTA. Sometimes being targeted and killed in GTA makes Andrea feel so mad that she wants to throw her console at her television. After having her own liberty interrupted in GTA, Andrea is left feeling helpless and wondering what the point of it all is as they “keep… doing everything to me”. Andrea just wants to be left alone in the game to talk to her friends and drive around. To stop feeling annoyed and prevent herself from throwing her console at her television, because she has become an unwilling participant in others’ online liberating experience, she often decides to come off GTA and do something else instead.

Andrea plays the target in Grand Theft Auto to engage another player

Andrea also described an experience in GTA where she invited a male player to catch her, laying down the challenge to him of finding her:

> Andrea: “I were talking to someone er [pause, respondent thinking]… he were trying to find me and I says… well, you’ll have to catch up to me and find me then, cause you won’t find me at all… and he actually did [respondent smiles].”

When caught, Andrea got out of her car and into his and he then drove them around the town and on the motorway. Andrea enjoys driving her friends around GTA, as well as being driven around by another, but this is also interrupted. At first, when the game (and being driven around by the other player) unexpectedly pauses, Andrea does not know what has happened. Andrea then realises that the pause may mean that the person may have gone off to do something else. She waits patiently until he returns and the driving experience starts up again.

Michael feels that the internet’s liberating quality is sometimes at the expense of children

Although Michael himself has not experienced much liberation online, or has been part of others’ liberating online experiences, he holds strong views around the freedom those who abuse children, by taking and sharing indecent photographs of them, have on the internet. Michael has heard about these types of people, who are in gangs on the internet, from listening to the news on television. For Michael, the internet’s purpose is to keep friends and family in contact with one another, but as the internet is there for anybody to use and offers so much freedom, this means that there are lots of men and women in gangs sharing photographs of children, using email and going online to look at children’s “privates”. Michael sees this as wrong and feels that these people should be banned from using the internet for life.

Michael knows that a child should be left alone to grow up, but despite this, the person taking the photographs does not think this is wrong, in fact, he gets a thrill at looking at things like children’s “privates” and this “gets him going”.

Michael has also heard on the news that children are also in danger from people they talk to on the internet, who pretend to be young like them:

> Michael: “I’ve heard it on the news… and it, the family are at home… [I: Mm]…their children, on the internet at ho, in their bedrooms, don’t know what the, the parents don’t know what, what they, who, who’s talking to. / Well… [pause]… the person whose on the… internet talking to em [I: Mmm] There, they type in ‘oh, I’m only a youngster, same age as you’ [I: Yeah] But when they actually meet em… They’re fully grown… That’s when it happens”

Michael himself would not fall prey to this tactic, as he is fully grown and he has more sense now that he is an adult rather than a child. The liberating nature of the internet, which is there for anyone to use, can also oppress others and this is one reason Michael does not use the internet more to experience his own possible online liberation.

7.3.3 Summary

The internet offered a liberating experience to many of the participants, all of which were experiencing a lack of offline liberation, restrictions, and barriers in their lives which prevented them from connecting with others and completing their chosen projects: following their own career goals, getting a paid job, owning a car, being able to drive, and living independently, as examples. Participants described the enjoyment and fun they had within the online games as they could “do anything”. They did not need “to take life so seriously” in these games, and they could be “reckless” and have no “fear” of the consequences which were present offline, such as pain and death.

Some of the online activities the participants engaged in were integral to their sense of wellbeing, and it appeared they would seek out a particular online liberation if this was not available to them offline. For example, when Andrea’s offline spatiality was limited and restricted, and passing a driving test and owning a car was not possible, she spent time driving on “roads going everywhere and nowhere” in GTA (seeing where these would lead her). This brought her a sense of calmness and a welcome diversion when she felt upset, stressed, frustrated and angry at events in the offline world. GTA also offered her endless choices of clothes, accessories, and guns for her character, which could be easily and instantly bought/acquired. These affordable virtual items were unlike the expensive designer items Andrea could not afford from her home city’s designer shops.

Whilst liberation is offered to all who experience the internet, one person’s online liberation, such as acts of violence, hateful interactions, rejection, and unwanted displays towards participants, often resulted in the interruption of their liberating internet experience. Making the participants unwilling targets in another’s adventurous horizons contributed to their sense of suffering: feelings of anger, frustration and helplessness.

7.4 Discussion

Selected participants’ concrete lived experiences of the phenomenon: wellbeing and internet within the constituents: internet as mirror, internet enables visibility and invisibility, and internet as liberating, in this chapter will be discussed alongside Galvin and Todres’ (2011, 2013) ‘Dwelling-mobility’ lattice and framework for delineating different kinds of suffering (which are depicted in Tables 1.1 and 1.2. on page 25 within this thesis).

7.4.1 The sense of identity dwelling-mobility through internet experiences

Identity dwelling is the ‘I am’:

> ‘in touch with one’s sense of personal identity… [An identity whereby one] feels connected to a sense of being which is given to us in its most fundamental sense’ (Galvin and Todres, 2013:91).

Whereas identity mobility is the ‘I can’:

> ‘An emphasis of personal identity is experienced, the person will experience themselves as being on the move… in ways that are valued or wanted’ (Galvin and Todres, 2013:90).

Identity mobility and dwelling was a common sense of wellbeing for the participants and integral with the internet experience. Offline, Ella’s given identity was bound up with DS, one who needs support and performs “baby work”, but online, Ella no longer sensed her identity was one that needed support. Viewing the images of herself online (which had been uploaded by the organisation she volunteered for) and performing her volunteering role (which the images depicted) contributed to Ella’s sense of identity dwelling-mobility. For Ella: ‘I am’ meant she was caring, and a ‘supporter’ of another with an ID. She was valued, needed, and did not need to be supported by the staff. ‘I can’ was Ella viewing the online photographs of herself being caring and supportive, and experiencing her preferred identities through this internet experience. For Yvonne, ‘I am’ meant she was ‘creative’, and ‘I can’ was experienced by researching history and creating personal projects of her own life story using the internet to find information or images. These activities did not encompass her identity as someone with DS, or a participant within an ID-related activity structured by the ID-related organisations. For John, ‘I am’ meant he was strong, helpful, protective, powerful, and resilient in his role as tank and healer in Final Fantasy. ‘I can’ was sensed by John through his online characters and the roles they performed. In this internet experience, John was no longer someone who was “vulnerable”, dependent or a “burden” on others.

Andrea and Leona’s sense of wellbeing, identity mobility in particular through GTA, Criminal Case and Junior Vets on Call, was integral to their internet experience. They were:

> ‘able to develop a tacit sense of optimism that dreams can realistically achieved on the basis of one’s hard work and personal capabilities.’ (Galvin and Todres, 2013:90).

Although many participants experienced a sense of identity dwelling-mobility entwined with their internet experiences, the offline world hampered their sense of identity dwelling-mobility: ‘layered continuity’, and they were prevented (when disconnected from the internet) from ‘just being’ (Galvin and Todres, 2013:92). At times it appeared the historical details and connections that made up their identity dwelling-mobility, someone with an ID and/or DS, vulnerable, dependent, etc… was too ingrained and dominant for them to completely shed, on- and off-line. But many participants rejected their ID, DS, ‘vulnerable’, ‘wrong’ or ‘female’ identities, which often meant:

> ‘I am an object or ‘a thing’…[sensing] the nauseous anxiety of being turned into something or someone else of ‘who one is’ being deformed’ (Galvin and Todres, 2013:109).

Galvin and Todres (2013) referred to this as ‘soul murder’ or ‘soul suicide’ (Shengold, 1998; Sinason, 2011), which was often sensed offline by the participants in this study, but also online by Andrea in GTA, and contributed to their sense of identity suffering.

Whilst many participants had a sense of identity wellbeing online, and simultaneously offline, sensing identity suffering, Michael was different. Michael had an ID, various impairments, difficulties, health conditions, and years of experience engaging with health and social care professionals in this identity. He was able to share with students and professionals and contribute to their learning by retelling his experiences of suffering and how he overcame his struggles. He not only accepted his ID identity he used ID identity to perform his roles as advisor and expert by experience, which in turn contributed to his sense of identity wellbeing, as well other lifeworld fractions such as intersubjectivity through his friendships with health professionals. For Michael, he was all of his ID and medical identities, but could he ever become more than an example of someone with an ID overcoming his ID when this appeared to be so integral to his sense of wellbeing through all dimensions? Michael longed for a romantic partner to care for and keep him company. He reflected that if he did have a partner, he would spend more time at home with her, rather than spending his time volunteering. But Michael had been unable to find a partner and unlike other aspects of his life, the health and social care professionals had not supported him in this area of his life.

Ella had a fiancé who she met, and only had contact with, when she volunteered. The staff appeared to support their relationship unlike her parents. Ella’s parents did not encourage the development of a sexual relationship or a marriage between them, the latter of which Ella was currently planning. Douglas et al. (2010) highlighted that those who support people with IDs often restrict their access to sexual health information and services due to their ‘protective attitudes’ towards those they see as vulnerable, to guard against abuse and in line with the view that they are ‘‘eternal children’ rather than sexual beings’ (:232-33). Those with IDs often have:

> ‘greater dependence than other young people on their parents into adulthood… [and have] limited opportunities for independent socialising, which may constrain their access to informal channels through which young people learn about sex and sexuality.’ (Douglas et al., 2010:233).

7.4.2 Internet reflections being more real than the real thing, and reducing a ‘thing’ to its essence

The constituent: internet as a mirror, could reflect ‘true’, distorted, magnified, exaggerated, and distilled reflections of the lifeworld to the participants. Leona’s internet experience of the sea lion shows in YouTube videos, which she would watch on a daily basis, fulfilled a number of unmet needs: to work with animals, to decide to volunteer at a sea lion show (discussed in constituent five: The internet creates a decision maker and expert), and because she could not visit her favourite theme park and zoo as much as she wanted (discussed in constituent four: The internet meets the participant’s unmet needs). Leona was particularly fascinated by watching her favourite animal, the sea lion, clapping, waving and doing other tricks that sea lions perform at such shows off- and on-line. Sea lions were often brought up by Leona in her interviews and I found that I was given ‘homework’ by Leona to watch specific sea lion shows on YouTube, which I completed before meeting her for the next interview. Because Leona was fascinated, I too became fascinated by the sea lion shows Leona was experiencing online, and I found myself viewing sea lion shows on YouTube more often than I thought I would. It was only after reading Turkle's (2011) account of taking her fourteen year old daughter to the Darwin exhibition at the American Museum of Natural History that Leona's performing sea lions on YouTube, and subsequently our mutual fascination with these, started to make more sense. Turkle (2011) described that at the exhibition entrance was two turtles from the Galapagos Islands, one resting motionless in its cage and the other hidden from view. In response to the turtles, Turkle's daughter:

> '…inspected the visible tortoise thoughtfully for a while and then said matter-of-factly, "They could have used a robot." I was taken aback and asked what she meant. She said she thought it was a shame to bring the turtle all this way from its island home in the Pacific, when it was just going to sit there in the museum, motionless, doing nothing. Rebecca was both concerned for the imprisoned turtle and unmoved by its authenticity… I began to talk with some of the other parents and children. My question— "Do you care that the turtle is alive?"—was a welcome diversion from the boredom of the wait. A ten-year-old girl told me that she would prefer a robot turtle because aliveness comes with aesthetic inconvenience: "Its water looks dirty. Gross." More usually, votes for the robots echoed my daughter's sentiment that in this setting, aliveness didn't seem worth the trouble. A twelve-year-old girl was adamant: "For what the turtles do, you didn't have to have the live ones." Her father looked at her, mystified: "But the point is that they are real. That's the whole point"' (Turkle, 2011:3-4).

Turkle (2011) then went on to describe the realism displayed by the animatronic creatures in parts of Disneyworld:

> 'When Animal Kingdom opened in Orlando, populated by 'real' – that is, biological – animals, its first visitors complained that they were not as 'realistic' as the animatronic creatures in other parts of Disneyworld. The robotic crocodiles slapped their tails, rolled their eyes – in sum, displayed archetypal 'crocodile' behaviour. The

> biological crocodiles, like the Galapagos turtle, pretty much kept to themselves' (:4).

Taking a phenomenological approach to Turkle's observations, I feel they directly link to Leona's wellbeing and internet experience of the sea lion shows and beyond into other participants' experiences of MMORPGs and MMOs, where the characters and environment did not come with 'aesthetic inconvenience[s]'. If Turkle's term 'real' is exchanged for the term 'essence', then YouTube could be offering a reflection of the 'essence' of a sea lion to Leona. An essence of sea lion that she recognises from her offline experience of sea lions at shows. Like the animatronic crocodile, an audience expects the sea lion to "displayed archetypal…['sea lion'] behaviour" (Turkle's 2011:4), but this depends on the subjective view of what the archetypal behaviour of a sea lion is. Leona did not describe experiencing a sea lion out of the context of a show on- or off-line. If a sea lion in its natural context was visible to Leona, perhaps sitting on a rock or beach motionless and still, and certainly not clapping or waving at a human audience, this would not be the 'essence' of sea lion for Leona. In this case the internet offers not only a 'real' experience of a sea lion, one she would not gain necessarily offline, but also a concentrated and distilled experience, the essence, of a sea lion for Leona.

7.4.3 The internet as a liberating experience which contributes to a sense of wellbeing across the lifeworld dimensions

Whilst limitations and restrictions were present in the participants’ offline lives, which were contributing to their sense of suffering, the internet was a liberating experience which contributed to their sense of wellbeing in many lifeworld dimensions. This was specifically spatial dwelling-mobility, the sense that anything could be achieved and anything was possible, and temporal mobility, which emphasises the ‘future orientation’ and future possibilities. These were sensed by Alex when he viewed spectacular natural events from across the world on YouTube (planning to visit them in person once he could afford to travel) and when he played CoD. His sense of purpose in CoD:

> ‘provide[d] a quality of flow and continuity to the ongoing progression of one’s life in time.’ (Galvin and Todres, 2013:83).

For Alex, this was a career as a professional gamer which was quite different from his offline context of being ‘stuck’ in a volunteering role and not being allowed to apply for paid work until the doctors had found out what was “wrong” with him. Offline there were no ‘meaningful invitations into the future’ (:83) for Alex, unlike what he was experiencing in CoD, encompassed by the world of professional gaming (Galvin and Todres, 2013). Alex was not alone in experiencing suffering in the temporal and project dimensions offline, Ella was experiencing a current predicament of wanting to stay in her volunteering role whilst her family wanted her to get a paid job. This, a sense of being ‘stuck’, contributed to Ella’s sense of temporal mobility suffering: ‘blocked future[s]’, and temporal dwelling suffering: ‘elusive present’ (Galvin and Todres, 2013:101-102). It was unsettling and upsetting for Ella as she strived for an elusive volunteering position. She was unable to relax and felt anxious about both the present and the future, a possible future without feeling needed and valued or having a project. The future for Ella also appeared overwhelming alongside having DS, her preoccupations around being bullied by some of her friends (which led to her hair loss), and the potential for being targeted by people who would say “nasty” things about her and DS if she went on YouTube or social media. Galvin and Todres (2013) describe that a person experiencing dwelling suffering in the temporal dimension: ‘may be constantly looking backwards to ‘ghosts and fears’ that possess the present’ (:102). Ella was indeed preoccupied with ‘ghosts and fears’ that possessed the present and these contributed to the ‘whole’ of the phenomenon: wellbeing and internet, as experienced by Ella. In Final Fantasy, friendship and meaningful relationships with another formed John’s sense of temporal-mobility: future orientation, but it also acted as John’s ‘ghosts and fears’ in the present after he experienced ‘the exile’ and ‘the snap’ (described in the next chapter). Like Ella, this contributed to John’s sense of temporal dwelling suffering and this led him to cast doubt on everything in his off- and on-line worlds.

7.4.4 Mobility suffering in the embodied lifeworld dimension

Galvin and Todres (2013) gave a number of examples of literal variations (muscle weakness and impaired speech or memory, as examples) which contributed to mobility suffering in the embodied dimension. These variations included the body's inability to move, a 'sense that 'nothing can go forward' (112), and an interference:

> 'with the power of the body to function smoothly in taken-for-granted-ways, to express itself, or to 'body forth' spontaneously or intentionally. In this form of suffering there is a preoccupation with the body, and the feeling of this can vary from panicked alarm to resigned despair' (Galvin and Todres, 2013:112).

From watching the YouTube videos of coordinated and masculine bodies, some of which were impervious to pain, Leona and Alex saw their own bodies as limited, uncoordinated, unable to withstand pain, and un-masculine, which contributed to their sense of mobility suffering in the embodied dimension. Whilst watching the dancers on- and off-line, and indeed thinking and talking about this in her interview, Leona moved her body rhythmically, clicking her fingers and whistling. However, she would not attempt anything more than this, such as standing on another's shoulders, or indeed, joining in on a street dancing workshop whilst on holiday, because she felt this would be too hard for her and her body would not 'function smoothly in taken-for-granted-ways, to express itself,' (112), unlike the dancers could (Galvin and Todres, 2013). For Alex, the softness and vulnerability of his own body, which was vulnerable to attack, pain and death, was quite unlike his experiences in his character's body in CoD and the male bodies he had viewed on YouTube. Alex compared and sensed that his own body was less than masculine, even likening it to being feminine, and was waiting for medical professionals to conclude what was "wrong" with his body so that he could then apply for jobs. Both Leona and Alex were sensing embodied dwelling suffering, as opposed to embodied dwelling, because they did not 'sense 'comfort' as a bodily experience [or felt a sense] of ‘being at home in one’s body’ (Galvin and Todres, 2013:94) outside an internet embodied experience (such as those playing a character in CoD or Final Fantasy). The phenomenon: wellbeing and internet brought a ‘preoccupation with the body’ to some of the participants and in Alex’s case a ‘resigned despair’ of his body in the offline world. Virtual embodied wellbeing and suffering is further explored in Chapter 9: The Immersive Internet and Virtual Embodiment.

7.4.5 Intersubjective dwelling-mobility by making the self visible to celebrities online

The sense of wellbeing: intersubjective mobility, is described by Galvin and Todres (2013) as a:

> ‘Mysterious interpersonal attraction…[which when] present, a person is tuned into the interpersonal possibilities that offer movement… Such desire or attraction, when experienced as well-being, constituents a kind of radiance and a ‘leaning towards’ (:85).

Intersubjective mobility was sensed by Andrea and Leona through their experiences on social media (Facebook and Twitter), specifically their attraction to ‘celebrities’: entertainers, presenters, pop bands, sports people and dancers. The internet facilitated their tactic of taking their own photographs, or finding online images, relevant to the chosen ‘celebrity’ and posting these onto social media, tagging the other: the ‘celebrity’, they were attracted to. When Andrea and Leona became visible to the ‘celebrity’, who at times engaged in conversation with them, this contributed to their sense of wellbeing: it made them feel happy, excited and acknowledged (visible). However, the ‘celebrity’ still appeared ‘undiscovered’, ‘partially hidden’, and having ‘the sheer energy of the ‘beyondness’…[and] otherness’ (Galvin and Todres, 2013:85). Andrea and Leona were not alone in their intersubjective mobility experiences of ‘celebrating the celebrities’ on social media: ‘fan bases’ were mass celebrations of the ‘celebrity’s ‘undiscovered-ness’, ‘otherness’ and ‘beyondness’. Andrea searched for, found, and asked to be friends with other Facebook users who were fans of the boybands she was also drawn to. She called these friends her “fan-based friends” and would talk to them about their mutually desired celebrities. Andrea’s active membership of the fan bases and her experiences of this contributed to her sense of intersubjective dwelling: ‘kinship and belonging’ (Galvin and Todres, 2013:86), which is further explored in the next chapter within the discussion.

This chapter focused upon the liberating nature of the internet, it’s ability to reflect the lifeworld and the self to the participants (which increases their awareness of the lifeworld and themselves), and offer, or force upon them, visibility, invisibility, freedom and oppression, which contributed to their sense of wellbeing and suffering. However, the internet is not only able to mirror aspects of the lifeworld, it can also simulate aspects of the lifeworld. The next chapter is focused on these online simulations and their contribution to meeting adults with IDs’ unmet needs and their sense of wellbeing or suffering.

Chapter 8

Findings: The Internet Simulates Aspects of the Lifeworld

8.1 The internet meets the participant’s unmet needs

Constituent four: The internet meets the participants’ unmet needs is divided into four subthemes:

- The internet meets the participants’ unmet needs for identity, intersubjectivity, spatiality and project.
- The internet meets the participants’ unmet needs for mood/emotional support.
- The internet meets the participants’ need for consistency, structure, and an escape from conflict and everyday busyness.
- The internet is not sought to meet a participant’s needs.

All subthemes contributed to the participants’ sense of wellbeing and suffering, which I will now explore and describe using examples of participants’ lived experiences.

8.1.1 The internet meets the participants' unmet needs for identity, intersubjectivity and project

Alex's need for getting married, having children and owning a house is (simulated and) met in the online games he plays

Alex explains that most people take their "real life… intuition in the game" and do whatever they want within games like GTA:

> Alex: "[In GTA people] get a prostitutes and… pole dancing…/ Strippers and stuff like that, you can go to the strip clubs and stuff like that… / …I mean there's no rules… Do whatever you want. Go out and go murder some people, get chased by coppers, murder them as well, get chased by FBI, murder them as well… Get chased by tanks, blow em up".

Alex described that most people online want to escape from their mundane realities of marriage, children and owning a house and experience things online, such as "prostitutes… pole dancing… [and] strippers", which may not be readily available to them offline. But what is available offline and mundane to most players (marriage, children and owning a house), are the very things Alex feels may not be possible or available to him offline, because there is too much control over his offline life. But within the online games which simulate most parts of the 'real' world, the unattainable and the attainable for each individual, Alex can experience marriage, having children, and owning a house. The online games also give Alex the opportunity to make choices and to learn from making these choices, bringing him the hope that he can put this learning into practice one day offline:

> Alex: “you can make more choices in a game and if you make the wrong choices, you learn from those wrong choice, wrong choices and you, obviously I mean, you learn and that… And obviously, I mean you put it in real practice.”

Alex can make more choices in the games and does not have to stick to one: “if you mess up, there’s no serious consequences”. The type of choices available to make in the online games can be different from real life, and are not choices Alex would necessarily like to make outside the game: “I mean I just can’t go around and start cutting up civil, civilians…”. Alex lacks money in the offline world and is prevented from applying for paid jobs presently. To do anything he wants offline requires money, therefore Alex is unable to do many of the things he would like to do, travelling as an example. In the games, however, Alex described that you can do whatever you want, and if money is needed you can get this in various ways:

> Alex: “…you can just murder some people and steal their money and… [respondent laughs]… or rob a bank and stuff like that, or do some jobs… [I: Yeah?] … and sell some drugs stuff and stuff like that.”

Offline, Alex’s ability to fulfil his needs are limited and restricted, whereas online, he has many opportunities to meet his unmet needs. He can try making different choices, make mistakes and learn from them, without incurring offline consequences.

Leona’s need for a career working with animals is (simulated and) met partially by the internet

Leona would “love” to work with animals, preferably sea lions, or as a zoo keeper who prepares food for the animals to eat (combining her love for cooking and her preferred job, working with animals). But Leona cannot find or apply for any jobs working with animals at a wildlife park, or with sea lions at her favourite theme park and zoo, because they are both too far away for her to get to. If there was a job at Leona's favourite theme park and zoo, she would like to: "apply… straight away" and move to a town close to the theme park and zoo where she would be working. But Leona doesn't think she will ever get a job working with her favourite animals:

> Leona: "Cause I don't think my mum would let me move to _____ [name of town 1]… But I'd love it to happen".

Although Leona likes volunteering, her current roles do not involve working with animals or in a restaurant, another career aspiration Leona has. Leona, who is unable to meet her need to work with animals offline, uses the internet to find videos and websites of her favourite animals by putting in the name of her favourite theme park and zoo, and/or words like "sea lion shows", into YouTube. Leona watches the videos she finds on YouTube by just clicking on them. Once they are playing she can watch the keepers, "see[ing how] they work…." with the sea lions and how the sea lions clap and interact with the audiences in the shows. When asked why she watched these videos on a daily basis, Leona replied: "Cause I'd like to work with them in a zoo".

Leona also watches animal-related television programmes on the CBBC website, often featuring vets treating animals, and sometimes plays animal-related games on the internet too, for example, Junior Vets on Call. In this game Leona plays a vet and is required to treat the animals in the vet's surgery. By helping the animals with their injuries and making them better, Leona: “earn[s] money from it” and moves up to the next level in the game.

Yvonne’s need for independence is partially met by the internet, which helps her to dream and plan

Yvonne would like to move out of her family home into her own house, but moving out is not currently available to Yvonne offline. Online, however, she “dreams” of this whilst on her computer:

> Yvonne: “I always, I dream always, I always dream or think of moving out, but it never happens [I: Oh so you, so you dream it… when you’re sleep?] No I dream it when I’m on the computer.”

However, Yvonne loves to look at two bedroomed houses that she finds for sale on the internet using Google. She has concluded that it would make it easier to attend her volunteering activities if she had her own house in a town close to the organisation she volunteers for, which reflects her online house search. Yvonne has created a list of things she requires from her own home, including two bedrooms (so that she could turn one into a study) and a big kitchen (as she loves to cook). Yvonne describes herself as having a: “really good sense of style” and has clear ideas about how she would decorate her own house and what colours to paint the walls. Yvonne would also be able to get a pet of her own choice. to keep her company, if she had her own home. One of the reasons Yvonne feels moving out may not happen for her is her father’s perception of her:

> Yvonne: “[it’s] cause I’m still his little girl… [but in my] mind I will say dad I’m not your little girl, I’m a woman, I want to move out… I’m going to move out when I’m thirty… For good.”

Moving out is something Yvonne has not yet directly discussed with her father, but when she turns thirty, a “perfect age” and the: “jackpot number” (as Yvonne describes) for her to move out, she will. Another volunteer with DS, who Yvonne knows, moved into a place of his own when he was thirty and he “loves” having his own place. Whilst waiting to turn thirty, Yvonne doesn’t mind looking at houses for sale online because then she can “know” what kind of place she will be looking for when she is ready to move. Whilst the internet is not completely fulfilling Yvonne’s need to move out into her own house, it allows her to prepare and plan for this and to ‘dream’ about moving out, which gives her the hope that this will actually happen.

Leona’s need for intersubjectivity is met by the internet

On Facebook, Leona can see what other people are doing, like her friends, and it sometimes tells her where they are:

> Leona: “…it [Facebook] can tell you where they are. So like their location… So I can know where my friends are, so I can go visit them”.

Without the internet, Leona would not be able to contact many of her friends to talk about what they have been doing over the weekend, because Leona does not have their phone numbers. Apart from one friend, who lives two streets away from her, Leona does not go to her other friend’s houses because: “they live quite far” and she does not know where they live, as she is only familiar with her own town’s centre. Her ability to travel on her own is also restricted by her family. Leona sometimes finds herself without friends to talk to, but by playing a pool game through Facebook on her iPad, when she is at home, she gets to play and talk to lots of different people. These are always people she has not met before because each time she plays: “they shuffle it around, so you don’t know who you’re getting.” The other player can talk to Leona and she can talk back to them:

> Leona: “[They say] ‘hello, what…’, like ‘what are you doing tonight?’ Or something…”.

Leona replies back, telling them what she is actually doing that night and they tell her what they are doing too. Leona talks to lots of people in this way and they have always been “nice” to her. They have never said anything that has made her feel uncomfortable:

> Leona: “No. I don’t get anything like that! [Respondent states ‘I don’t get anything like that’ with what sounds like disappointment and then laughs].”

Leona would still play games online even if she was not getting points, money, or other such rewards, because playing these games enables her to interact and talk with others when she cannot do this on Facebook or offline.

8.1.2 The internet meets the participants' unmet needs for mood/emotional support

Andrea cannot get a job and the frustration and stress she feels are calmed and distracted by her internet experience

Andrea has been looking for a job for a long time and is now “sick” of job hunting. She recently completed a job trial, followed by an interview, at a fast food restaurant, but then found out online that she had not got the job because the employer thought it would be too busy and hard for her. Andrea's support worker at the job centre told her that she had done really well and explained why she had not got the job. At first, this made Andrea feel better, but then Andrea just felt let down and upset because she thought she had been successful. Not being given a chance to learn on the job and show the employer that she could do this role made Andrea feel “awful” and “annoyed”, especially because everyone else in her family has a job. Andrea concluded that no matter how good she was at this job trial and interview, the employer had no intention of offering her a job and did not want her to succeed. Andrea stated that they just felt sorry for her. The pity they felt for her was the only the reason Andrea can think of as to why they allowed her to do the job trial and interview in the first place, and why the staff taught her how to make the drinks during the trial. The next day, Andrea told her support worker that not only did the clothing stores not want her, the fast food restaurants did not want her either and she would not pursue any more jobs at fast food restaurants because they were all part of the same chain and they would only let her down again. Andrea's support worker told her not to talk like this, but Andrea explained that if the support worker could see it through her eyes she would understand how helpless she felt. Not getting a paid job contributed to Andrea’s sense of suffering and she regularly felt “stressed” when she returned home having not secured a job. Listening to music on her television or on YouTube provides Andrea the emotional support she needs:

> Andrea: “…I just put er certain type of music on if it’s either er… boy band, girl band or er solo artist or a mixture or em and I just close my eyes and listen carefully to the music and the beat… [I: Mmm.] … of it. [I: Mmm.]… and sometimes it helps and sometimes it doesn’t. [I: Right, in what, what do you mean by that then?] Well it helps lots when I’m depressed but, when I get sad it either helps me or it doesn’t.”

Driving in GTA also offers Andrea emotional support, because it keeps her mind off the things that she does not want to think about and it helps her to let her anger out as well.

Alex takes out his anger and releases tension in the game Call of Duty

Like Andrea, Alex also listens to music on YouTube to try and “calm down” and alleviate his ongoing feelings of anger towards the two men that verbally abused him in the street and others like them:

> Alex: “sometimes that intention still keeps in me… / …always keeps in me… whenever you’re bad day you remember stuff, and it always comes back and then you tense your bones up again, so you never forget it.”

Sometimes this is unsuccessful and Alex’s anger has resulted in him doing: “a little bit of damage” at home. But Alex has also used this anger to his advantage in the game CoD, which has then provided a way for him to relieve the tension he feels:

> Alex: “Take my anger out on the game itself…/… cause I can use that to er kind of release tension. I would, I would rather kill people in the game, than go round and kill people in real life [respondent smiles].”.

But the game CoD can also be a source of annoyance and anger for Alex and he often ends up “banging on me Xbox” when it unexpectedly crashes. When Alex is losing in CoD he sometimes kills members of his own team (a “team kill”) and angrily quits the game (a “rage quit”). Alex then goes onto YouTube to listen to music for a few minutes to calm down.

Watching a YouTuber’s channel helps Alex to feel happy when he feels upset

There are a number of things that make Alex feel stressed and upset, including his social and “standard life stuff” and the commitment he feels he has to invest in the online games to retain his reputation and status:

> Alex: “I know people always say ‘don’t get stressed over a console, it’s just a game, blaa, blaa, blaa’, but… when you, when you’re repetition is… for gaming… It kind of ties you in.”.

Alex often turns to YouTube when he is feeling angry, annoyed, stressed and upset, and it is a place where he can listen to music, watch a range of videos and connect with other YouTubers. Alex described being a “patron” on a streaming service on YouTube, where he puts in one pound each month and in exchange he gets certain perks in return. For example, sometimes being able to get things (an autograph, poster or a selfie) from the person that he is a “patron” of. Alex does not mind paying to get these things because by getting something personal from them he feels “more connected with the person”. One YouTuber, who likes a game which is associated with specific blades, gets sent knives, swords, and other expensive items, such as iPhones, to his “PO” (Post Office) Box. It also allows people to send him letters to tell him how much he and his YouTube channel have positively contributed to their lives and sense of wellbeing. Like these people, Alex also watches this YouTuber’s channel when he feels upset because it makes him feel happier.

John’s online friends and wife provide emotional support and tell John he is a good person, rather than a “burden” on his family

John helps others both in his volunteering role and in the roles he plays in the online game Final Fantasy:

> John: “[I am] the sort of person who always likes helping other people… I’m always willing to take them on. / [In Final Fantasy] I’m usually the one that tries to support everyone and just, help everybody out for everything… / I was always [pause] if there’s someone that needed a hand I’d, I’d almost always be up for lending them a hand and just try to… support them… It want were I’d just give them free money game or whatever, I would try, if they needed, let’s say they were having trouble accessing something or if they needed, some, somebody to help them kill something I would usually be up for that and just be like ‘yeah sure, just drop me invite and I’ll come along and help ya’ so.”.

But as John is: “helpful to a fault” in his volunteering and Final Fantasy roles it can mean that he takes on too much and will then “burn out”. When he has taken on too much volunteering this manifests into a: “physical exhaustion type burnout” from the extra “physical responsibilities”. In Final Fantasy, John experiences an emotional type burnout from taking on others’ emotional problems on this game:

> John: “I am taking on people’s emotional problems I take on too much, that can make me feel really down.”

“Being there” for his friends when they have felt “extremely down” has resulted in John himself “feeling depressed”. But his online friends in Final Fantasy have noticed and: “caught wind” of John’s emotional “burn out” and have helped him:

> John: “…they refused to let me go through that alone, much as I try and… keep my problems inside, like I, I internalise, but at the same time try to help everyone else… [I: Yeah.]… So I just bottle it up. [I: Yeah.] They seem to have a way that they can just… Get in and still extract problems.”

As well as supporting others off- and on-line, John is also known for having strong viewpoints, for example, his strictness around punishments for offences. At school, John described that he was not happy when the teachers: “let things slide” because of his disability, and since school he has:

> John: “shift[ed] over to the other extreme like, really strict punishments for even the tiniest things, above and beyond the punishments that other people get”.

John reflected that if “normal” people forgot to do their homework they may receive a negative comment in their “planner”, but if he forget to do his homework the right punishment for him would be isolation from the rest of the school for the entire day. John used to get extremely angry, which would sometimes progress to self-harm, when he made a mistake: “I’m me own worst enemy”. John’s online friends worry about how hard he is on himself, but in Final Fantasy, John has got better at managing himself when he does make mistakes in this game, being able to “restrain” himself by using verbal strategies. When others make mistakes, John has supported them and said to them: "'don't worry it happens'… [and allowed them]… plenty of breathing room". This positive support when someone makes a mistake is something John has observed his online friends and wife in Final Fantasy also doing.

Describing his marriage in Final Fantasy, John stated there are different reasons why people get married online. The first is to get "item rewards" and the second, which is John's primary motive, to: "pull the bond, create that extra bond with" a good friend, which then enables you to do more together in the game. Once married, either person can go to the other when they are "out in the open [online] world", using teleportation. At first, John was saving getting married online until he had an online girlfriend, but he soon figured out that he had to loosen his expectations of who to marry in the game, and although he did not want to marry anyone, they did not necessarily need to be his girlfriend. John got married in Final Fantasy "fairly quickly" to a woman he had not known for long, who lives in a different part of the UK to John. John stated that she had her: "own mental health problems", but she also noticed when he was having problems and she would: "be there for" him. When one of them was feeling down, the other would try and: "coax it out of them", in order for them to open up to each because they both tended to: "try to bottle it up". The support and time they gave to each other in order to 'coax' and un-'bottle' the problems they were having was:

> John: "cause we are both sort of person we don't like being a burden on our mothers."

There have been times when she has needed support from John and he has said to her:

> John: “do I have to get on a plane and go over there to make sure you’re alright sort of thing…”.

John knew he would not have actually been able to do this and could only support her though the online game or via video calling. John described their similarities and how they supported each other through positive verbal statements to one another, something they did not often get offline:

> John: “I just want her to be happy just like she’s a lovely person like she’s… But like me she’s also very tough on herself so like… We’re having to constantly tell each other how good we are. Because neither of us can see it in ourselves.”

Andrea’s need for emotional support after the loss of her grandfather is met by the internet

Eight years have passed since Andrea’s grandfather died of cancer, but Andrea still cannot help but think of him. This makes her feel both emotional and upset at losing him, and she worries that she will lose the memories she has of him:

> Andrea: “sometimes even now I, think about him and I… try not to cry but sometimes I can’t help it cause I’ve got that emotion inside me and I just need to let it out. / …I just think since his passed away I’m going to… forget what he looks like or… forget how his voice sounds but, I’ve got a picture in… my bedroom when I was little with my dad, my nan and my granddad…”

Andrea described being close to her grandfather and, whilst he was ill, Andrea, along with her parents and younger brother, went to visit him at a hospital nearly every day until he became sicker. At that point, Andrea and her younger brother were left at home whilst her parents continued to visit him because: “they didn’t want us to see my granddad like that”. Despite receiving cancer treatment and plans made by the hospital to operate, Andrea's grandfather was too far into his illness for them to do anything to save him and Andrea stated that "they stopped trying". The death of Andrea's grandfather has had a lasting effect on her and her relationships with others:

> Andrea: "through… the rest of high school and the rest of my life it's been… very hard to… mainly let people in because sometimes I'd… either feel shy cause I didn't know em and then when I've got to know em I've [pause]… kind of put up a wall… So they could get any closer, so I'm just a bit wary of… what I'm doing, but I know I have got… family and friends round me"

Similar to when Andrea feels stressed about not being able to get a paid job, when she feels upset over the loss of her grandfather she closes her eyes and listens carefully to some of her favourite music on her television or on YouTube through her mobile phone, just: "hoping that it calms down". Andrea knows that her parents are aware that she misses her grandfather, but she finds it hard to talk to them about it because they do not fully understand how she feels. Instead, Andrea turns to one of her friends who has offered her support when things are going wrong or when she feels upset:

> Andrea: "we've become very good friends and he says that er… If there's anything wrong or, you're upset and you wanna talk anything, I'm always here for you and, that's really good to hear cause sometimes I can't talk to my… parents about it cause they think that [pause] they know that I miss but I don't think they're… understand properly what I'm going though sometimes it's hard to talk to them about it so I talk to my friend instead."

But Andrea's friend is also male, and both Andrea and her mother are very wary of the intentions of Andrea's male friends. Because of this, Andrea is restricted in her contact with male friends, including her friend who offers her the emotional support she needs. Additionally, Andrea does not like putting up statuses on Facebook about how she is feeling, because if she does others will read this and ask her: "'what's up?' or… 'what's wrong with you?'" When Andrea has shared her feelings around the loss of her grandfather on Facebook others have empathised by telling her that they know what she was going through and how she was feeling, because they too have experienced the death of a family member. Instead of feeling comforted by others on Facebook and their apparent similar experiences, Andrea does not think they know what she was going through at all because, unlike her, they were with their family member until the end, and she was not. Andrea also feels the emotional support they were offering was just because they felt sorry for her. Andrea will sometimes put up a status on Facebook saying that she is happy, good or great when she is actually feeling upset, sad, angry, frustrated or annoyed, so that no one on Facebook can ask her questions.

Yvonne comes to terms with the loss of her grandmother and her friend with the support of the internet

Yvonne described her grandmother as someone who looked after her, raising, protecting and doing things with Yvonne, whilst her mother was "busy" working full time. Yvonne remembers when she took on her second volunteering role because this was just after her grandfather and grandmother died. Yvonne explained how life changed for her when her grandmother died with dementia:

> Yvonne: "… I've been looking after myself. [I: Right.] Nursing myself, if I hurt myself. [I: Right [Pause].] Sometimes my nan, when I, when I hurt myself my nan used to… erm put a plaster on and stuff. [I: Yeah,

> yeah [pause].] When I was a kid. [I: Yeah.] But now, she’s not here no more, I have to do it myself.”

Yvonne loved her grandmother and described enjoying her hugs and touch. She was, and still remains, someone significant and important in Yvonne’s life:

> Yvonne: “ [she is my] rock, hero, my best friend, my rock and a second mum to me.”

After her grandmother died, her mother and brother made Yvonne feel angry and stressed out. She found it hard to cope and this resulted in Yvonne running away from home. Yvonne then created a new friendship to help meet her need for someone to protect and look after her, as her grandmother once did:

> Yvonne: “I couldn’t cope so made a new friend in, in, I made a new friend in, in an old lady… a neighbour round the corner… / [who was a] nice kind person.”

Yvonne used to go around to her new friend’s house to have a drink, to talk to her and help her. But Yvonne has not seen her since she and her family moved away: “I don’t what happened to her recently, I think she died”.

Yvonne has experienced periods of depression from when she was a teenager to the present, which she explained was often initiated by the death of a family member or the loss of someone significant to her. When it came to her sense of wellbeing and suffering, Yvonne described having: “two different sides.. [to her], one is happy and the other one’s sad...”. Yvonne explained that she was happy when she is with her friends, but sad when she is at home or when people leave her. However, throughout Yvonne’s life, her computer and the internet have had the ability to emotionally support her by transporting her into a “different world” when she has needed this:

> Yvonne: “I get emotionally attached to someone I really like… And they sometimes leave or die or something like that… So… every time I go on the computer I’m in a different world”.

Despite living with her family, spending time with another neighbour, volunteering, and having a close friend, Yvonne reflected that she did not have anyone she felt able or comfortable talking to about how she feels, specifically about the loss of significant others. Some people in Yvonne’s life are simply not physically or emotionally available for her to talk to, as they are “busy” with their own activities or looking after younger members of their own family. Although Yvonne considers the staff and her friends where she volunteers to be like a second family to her, she would not feel comfortable talking to them about feeling unhappy, or about drinking too much alcohol in order to cope with her unhappiness. When asked why she did not feel comfortable talking to the staff, Yvonne stated: “I don’t know how she might feel” and “it’s difficult”. Yvonne also felt that even if she could find someone to talk to, talking would not help her. Instead, Yvonne tries herself to remain “busy” to distract herself from feeling “depressed” and the thoughts she has:

> Yvonne: “We [Yvonne, her parents and a close friend] don’t talk, we don’t really talk about these kind of things… I just use, especially with my colouring, going to listen to music and stuff, I normally in my bedroom so… that’s what I do, I keep busy… Not to think about it all the time.”

Some people in Yvonne’s life, who may have recognised signs that she was feeling “depressed”, have told her to: “just keep busy”. But being “busy” doesn’t always work for Yvonne and she has needed to use psychological services in the past. However, this is not something Yvonne wants now. Instead, she has thought about getting her own dictaphone so that she can have it in her bedroom to talk to. Yvonne explained that a dictaphone had the advantage of not being able to talk back to her:

> Yvonne: “Unfortunately… I know people answer me back, so I like one of them [Yvonne points at the dictaphone on the table], to talk to myself”.

Between her second and third interview, Yvonne experienced the loss of two friends, one who had died and another, a staff member, who had left the organisation Yvonne volunteered for (which also meant that Yvonne’s friend could no longer provide respite for her). On the last day before the summer break, the friend/staff member told Yvonne that she was leaving the organisation. They both cried and Yvonne was left feeling upset. As Yvonne does not have someone she feels comfortable talking to, she turned to writing poetry and placing this into a box. This provided Yvonne with her “own therapy”:

> Yvonne: “…I went and hit rock bottom the other night. I decided on doing this erm, box with, writing poetry and put it in box type of thing.”

Yvonne used the internet to find poetry by typing words into Google like:

> Yvonne: “‘missing friend’ or ‘depart something’… ‘friend, broken friendship’…’friendship drifted apart’ type thing.”.

Yvonne’s internet searches, using these words, brought up lots of results, including poetry which she felt would help her to get the words out. Whilst she listened to music on YouTube, Yvonne wrote the poetry she found down onto paper and placed these into her “memory box”. Yvonne explained that this enabled her to say the words she wanted to say to the lost friend and helped her to: “get all the words out…”. Doing this activity was the reason why Yvonne had: “been staying up and going to bed late…”, but it made Yvonne feel a lot better. It helped her to cope by herself at a time in her life when she felt depressed and could not share how she felt with others:

> Yvonne: “I try to keep it me self really… Trying not to… [Pause]… cope with it so.”.

In later interviews, Yvonne reflected that the act of writing the poetry out, that she had found on the internet, and placing this into her memory box, along with listening to music on YouTube and doing her colouring in, had “saved” her. It had helped Yvonne to cope during her non-busy (the summer break: a time when she is likely to “lose it”), until her busyness could continue (her normal routine of volunteering and other activities) and she built up her confidence again. At the point Yvonne returned to her normal level of volunteering, she had stopped searching for and writing poetry to put in her memory box and drinking alcohol during the day because she did not have time to think about things or drink alcohol during the day.

John’s need for emotional support and friendship following ‘the exile’ and ‘the snap’ is met by the internet

Within Final Fantasy John continued to be a helpful person and, because of his helpfulness, “a decent human being”. John spoke of putting his own individual progression through Final Fantasy on hold in order to help his online wife get “levelled up”, so that she could do the “end game” content too, and being a “moderator”: one who: “keeps the peace” and “intervene[s],

[and] calm things down”. John also helped within practice groups in Final Fantasy and described being the sort of person who, if he notices something that has gone wrong, likes to provide solutions and ask others if they have tried or considered alternative actions. In Final Fantasy John had found good friends, who he met up with regularly, who really supported him and made life easier for him within the game. When things went wrong during practice, they were supportive and did not: “create a culture of blame”. They encouraged John to not to be so hard on himself and together they worked collectively and “constructively” to all be more successful in Final Fantasy:

> John: “[We found] solutions… [by] everyone just chipping in and just… being a team.”

In other practice games, where John is not able to meet up and play in a team with his “supportive” friends, he is matched with other unknown players. The interaction between these players can be, what John describes as; “very cut throat”. But John also suggests that this is something that can happen offline between people too. The players in this online practice game are not going to see each other again and this, John notices, brings out the worst in them. They can do what they want without incurring any repercussions. John sometimes makes a note of a character, if they are at their worst, and what server they are on. John has then contacted the leader of their group to tell them what the character has said. A couple of times this has led to the player getting into trouble and the leader deciding that they did not want that sort of person in their community.

When playing in the practice groups John stated that some players see him as “constructive” and one who “provide[s] suggestions to help them handle it”, whilst others will be “nasty” about it. John felt that this was because there is a: “group nature” to this game and players will gain a reputation from the interactions that have with others they come into contact with. John described that he generally has a good reputation and is seen as someone in the game who is not going to “jump down [someone’s]… throat” if something goes wrong. But if John sees someone, on- or off-line, who needs help, he: “will help them in a constructive manner…”, like his friends in Final Fantasy do.

John experienced being exiled from Final Fantasy: ‘the exile’

The abuse John received in Final Fantasy, specifically in practice group games, is often about him taking the “leading role” and being slow and deliberate whilst: “assess[ing] the group” to see what they can and cannot achieve. Someone who is new to a role, such as the healer, may result in John assessing and deciding that the group cannot attempt the “bigger stuff”, because John does not want this person to be thrown out of their depth. John replicates the role his mother takes with him, who has also decided that John will be out of his depth helping or teaching others abroad. However, there are some in the group who want to “get through it as fast as possible”, which goes against how John approaches the practice group games. John got into trouble with his community leader, about half a year ago, and was asked to leave the Final Fantasy community after someone took offense to him:

> John: [I was taking a] theatrical type of approach… [using words like]… scene 1, act 1, take 2… [after the] wipe… when everyone dies [in the game]”.

John explained that he took this approach to keep track of the practice, to take stock, figure out what went wrong, and to keep things “light hearted” to make the group feel that they could “carry on”. This was because John knew a wipe (when everyone is killed in a battle) can “demoralise a team” and signify failure. Someone “took offense” to John doing this and then started to spread rumours: “really bad stuff” was said to John’s community leader and the whole community was targeted. John never found out the content of what was said about him, but because of the bad reputation created by the offended player and the effect this was having on the online community in Final Fantasy, the community leader and John agreed that John would have to leave the community. John described that it was not something the community leader wanted to do as he knew John was “a decent guy”:

> John: “[but to] withhold the rep of the group, they had to actually let me go”.

The community leader told John that he was “a member of the community in everything but name”. If John ever needed help from the community he was free to ask for it and they would be happy to help. Although John is: “still allowed to talk to them”, his access to the community chat was “forcibly removed” and this has meant that John cannot talk to some of his “real-life” friends, who are part of the community, anymore. Whilst he is still able to talk them outside the community, John has to first ask if he can do so. John also explained that he does not have that community listed or associated with his character, which would show to everyone that he was part of a community, which is important to him. After being asked to leave the online community, ‘the exile’, the events leading up to this weighed heavy on John’s mind and made him “wary” and unsure of the permanence of, and his ability to maintain, friendships online:

> John: “I think it’s just… further driven down my self-esteem [pause] because it’s like that… I can’t seem to keep people… Like even when I try to keep people I’ll be able to seem to fail it’s just like well… what’s the point sort of thing,…”

John ‘snaps’ in Final Fantasy: ‘The snap’

Even after ‘the exile’ (which happened about six months ago), John had continued to inhabit Final Fantasy nearly every day, like he had been doing for the past two years until, out of the blue (in between John’s first and second interview), something triggered inside him. John and his counsellor think it was a result of his struggle to find paid work, which had also been: “knocking my confidence down” and adding to his already existing “self-esteem issues” and feelings of being “worthless”. It started in a two week period when John was not able to see his counsellor. He started to feel that he was “underserving” of the supportive online friends and wife he had on Final Fantasy and tried to get them to “forcibly remove him” as a friend and spouse, but they refused:

> John: “because they didn’t want to play a part in my [pause] erm, self-hatred prophecy”.

In response to their refusal to remove him, John “just snapped” which caused: “things to just spiral out of control”. John ended up “pushing” them all away in a “brutal” fashion by saying “rude” things to them, “spraying [bullets from his guns] every which way”, blocking them, and leaving the community they all belonged to (one he had joined after ‘the exile’). It happened very quickly, one-minute things were going well and then, within a matter of minutes, it had gone to something: “catastrophic”. John described how the guns took on a life of their own and he had: “just tore it all apart” to enact his decision to put up: “unbreakable walls”. The day after, someone suggested to John that he should apologise to his online friends and wife whom he had “pushed away”, but John refused at first to apologise:

> John: “now I apologised for the drama that I caused but …. I can’t apologise for pushing for pushing away because I felt like it was the right thing to do.”

However, after a week, John realised the full ramification of what he had done and the permanence of it:

> John: “the way I done it I just caused a whole heap of problems and I’ve upset them and I just [pause] but, I’ve only been able to apologise to one person so far, the others I hadn’t figured out how am going to apologise to them… / I started to realise what I had done and it was like… wanted to put things right but by that point it had pretty much gone too late so.”

John knew that his online friends and wife had not done anything wrong and had not deserved what he had done to them. He felt he had let go of:

> John: “strong friendship[s]… [in which] people understood me you know, stood by me you know was, always there for me”.

John “lashing out” was not something they were used to and did not expect from him. John was upset and stated that it was completely out of character for him:

> John: “I’m usually the one that tries to support everyone and just, help everybody out for everything… /…it just looked like it was just intentional, me intentionally me being selfish…”.

John subsequently decided that he wanted to apologise to his online friends and wife, but it was not what he had to say to them, in order to apologise, that proved difficult, but the method of communicating his apology to them within Final Fantasy. As John's online friends and wife had also blocked him, this prevented him from messaging an apology to them. The one friend John had been able to apologise to and explain that he "felt really bad" about what had happened was someone he had known in the game for a year and a half. Although he accepted John's apology, John stated that they no longer talked to each other much now and his recent messages to him had not initiated any response. John attributed his friend's unresponsiveness to his friend's girlfriend, specifically her attempt to protect her boyfriend from: "getting used and abused" as he is: "too nice for his own good". John understood why she was doing this stating: "[it's] because the way I acted was wrong…".

John's online wife also got very angry as a result of what happened when John snapped. While John spoke about having lost a lot of his online friends, it was the loss of his online wife, who had provided him with a great deal of emotional support and friendship, that he began to focus on. John explained that for a while he had been saying to his online wife that he was not: "deserving… of her friendship" and that he had doubts over their online marriage. She tried to reassure John by telling him it would be alright, but: "in the end it just wasn't". John described how exploding during 'the snap': "turning really nasty", and cutting his friends and wife off with "no sense of remorse", ended up proving his doubts to be true:

> John: “look, it’s just ended up proving my point, proving my doubts to be true. [I: And why’s that?] Because in the end you know what I mean, she couldn’t, she couldn’t cope…”.

As a result of the loss of contact with his online wife and not knowing if she had returned her wedding ring to the online chapel, which would signify they were now divorced, John felt he needed to change his Final Fantasy character’s hair, from the style that had matched his online wife’s hair, back to his “signature colours”. John reflected that if she had kept the ring then this could mean she was: “hoping that… things pull through in the end…”, but John was unable to message her to get clarity around this. Returning his character’s hair to his signature colour, which was more like him, signified a new start to John and provided closure, something he was also unable to achieve with the ‘catfish’. John’s encounter with the ‘catfish’ is described in constituent six: The internet as friend and foe.

After ‘the snap’ John still remained in Final Fantasy, but people were saying things about him: that he was an “egomaniac” and “narcissistic”, which John knew was not true. John could not put a name to what exactly happened during ‘the snap’, but he stated “I do feel remorse…”. John felt that his experience of ‘the exile’, six months previously, had played a part in his decision to “push away” his online friends and wife and helped ‘the snap’ to “snowball as it did”. He explained that during ‘the snap’ he had started to relive what happened during ‘the exile’:

> John: “…where someone had actually, started spreading rumours about me because they didn’t like the way I’d tried to keep a practice group in high spirits…”.

‘The snap’ was an online experience that was still contributing to John’s sense of suffering a number of weeks later in his final interview:

> John: “I wish there was a way to put things right… [to] just stop it playing through in my mind [respondent looks upset]… / [and] reliving that horror”.

John had decided to stop going into the game Final Fantasy, because of his experiences of ‘the exile’ and ‘the snap’, but by not going back into the game John felt a sense of suffering:

> John: “To be honest I’ve been feeling quite, bit lonely now because I feel like I’ve been…disconnected… / [and it has]… generally just be pretty [pause] quiet for me…”.

John tried to re-connect himself by playing other MMOs, but these had not been as “intense” or “active” as Final Fantasy, or had brought him the same level of enjoyment, in part because of his memories of ‘the exile’ and ‘the snap’:

> John: “Knowing that the damage that I’d caused just [pause, respondent sighs] making it harder for me to play.”

John found that in other MMO games he was not able to be “constantly talking to people”, like he could in Final Fantasy:

> John: “it tends just be, going about doing my thing, doing my business and just… / You still can talk to people and stuff on it like in, but yeah I don’t do that anywhere near as much now so.”

‘The exile’ and ‘the snap’ continued to weigh heavy on John’s mind and was, as John described in his final interview, stopping him from: “from getting back up.” John’s reputation, that was “already in tatters” from ‘the exile’, had been further damaged from ‘the snap’. With a damaged reputation and experiencing a lack of enjoyment in a new MMO, John now felt that he was “dropping out of gaming world completely”. At times John spoke about how he felt that he may return to Final Fantasy, logging in for “seasonal events” (if these were accessible to him) to see if they would rekindle his enjoyment for the game. At other times, John described that he felt unsafe in Final now, and may not ever re-enter or re-connect with the game. John is afraid that if he returned to Final Fantasy the online friends and wife he had would spread rumours about him being a: “drama queen that’s selfish”, not understanding him, and others would believe what they said:

> John: “[They] don’t understand the battles I’m going through it’s just like but [pause, clears throat] the problem is that… If they do start a witch hunt most people will end up believing them.”

In John’s final interview he described how he had made new contacts with others online in the forums associated with Final Fantasy. John had mentioned on a thread that he was thinking of moving servers because of the events surrounding ‘the snap’. One person on the forum had offered John a potential friendship if he did decide to move servers:

> John: “…there was one that said that you would offer me, if I moved over to their server then they would make sure that I got, they’d, they’d hang around with me, make sure I had a friend there…”

John described having received lots of support from the online forum members who told him: “just don’t do it, don’t talk to them”, after John had explained to them what had happened and how he wanted to make contact and apologise to his online friends and wife he had lost in Final Fantasy. John had even found someone he felt he may want to eventually marry online, after posting a marriage “offer” on a: “marriage partner hook-up thread”. This had been noticed and commented on by John’s new online friends on the forums. They had said to John: “are you sure you’re ready?” and suggested to him that he may be moving on a little too quickly from his first online wife. John knew they were concerned for him, but he also felt that they were “a bit patronising” towards him. John was aware that his first online marriage: “wasn’t good” and that he had had doubts about this relationship and, before that his relationship with the ‘catfish’: someone John felt had been using him and others in Final Fantasy. This time, however, John was determined to take things more slowly and get to know this new person better.

8.1.3 The internet meets the participants’ needs for consistency, structure and an escape from conflict and everyday busyness

Alex’s need to solve problems and conflict, achieve challenges, raise and maintain his status, and experience predictability, is met by the internet

Alex cannot always achieve or solve the problems that occur in his offline life or make changes:

> Alex: “you can’t do it in real life… You just have to go with the flow [pause]…. you can change bits by bits, but you can’t make a big giant leap.”

For example, Alex cannot pay for a holiday he would like because he does not have the money to pay for it. This is because he cannot apply for a paid job until the medical professionals have found out what is “wrong” with him. But in a game like Fable, Alex has money and he can do whatever he wants. He can buy a house straight away, own it, and rent it out to make more money. This, and other changes, are all simple for Alex to do in the games, but in real life Alex cannot do this because: “there’s loads of limitations in life”. Although Alex feels he often has to go with the ‘flow’, the direction of this flow is not the direction he wants to move in. Alex reflected that the online games’ simplicity has affected himself and others who play them, because they have come to think that ‘real life’ is simpler than it actually is. For Alex, ‘real life’ can sometimes be easier than what he experiences online, and at other times ‘real life’ is ‘trickier’ (like “tax stuff” and buying a house) and more unpredictable that what he experiences online. On CoD, Alex knows the game well and knows how to do things because he has spent a long time within this game. He knows instinctively where everyone will go and where they will be hiding. Sometimes the “odd person” will do something Alex has not predicted, but he is able to deal with that and get the “job” done by shooting them in the head. Alex described CoD as predictable and stated: “I don’t exactly need to work my brain”. CoD was different from life offline where:

> Alex: “anything can happen really… I mean… I could get the bus back home and I mean see a car crash… For example… Something that you don’t see every single day”.

Alex enjoys a balance of being both on- and off-line and does not mind volunteering, something he stated that he enjoyed. But Alex admitted that his online games were far easier and less challenging than volunteering and brought him far more status. Alex specifically used CoD as an example, and described this game as a place where he had built up a high status and reputation and was happy and proud that he is ranked in the top 800 (and in the top 700 in a difficult game mode). Compared to his lack of status and visibility offline, in CoD Alex is visible to others and has a high status:

> Alex: “[It is like my] own personal medal on a game, cause you can go in a game lobby, people look on leader boards,… And they’ll see me there, on lobby leader board on the highest bit… And people like ‘bloody hell look at his score’… Shows what I like to do. You kind of like shows off a little bit… But… I’m not really showing off because I’m just doing what I do best.”
>
> Alex: “…[other players] look at me and like… you know like… ‘effing hell, look at ____ _____ [respondent’s online name in the game]’ and stuff like that, it’s like… [respondent laughs]… I don’t mind if people say my name and say how good I am, and I go in game and get sixty plus kills and I’m like ‘yeah that’s nothing to me, cause its average for me’…”

The good reputation Alex has in CoD keeps him “positive”, including when others offline show off their financial status, something Alex does not have himself offline:

> Alex: “old people say ‘…I’ve got like a f, an ISA’… and I’m like ‘yeah whatever’,… I’ll whoop their butts whatever [respondent laughs]… nothing compared to me.”

Alex’s good reputation and becoming better at CoD is important to him and he stated that he: “cares about it too much”. This is because it opens up a career opportunity for him as a professional gamer, which is especially important to Alex if he was unable to get a paid job offline. At present Alex is prevented from applying for a job by the job centre until the medical professionals find out what is “wrong” with him. Alex explained that a professional gamer can earn millions of pounds for each championship they play in and that anybody, as long as they are good at the game, can do this.

Alex would like to work as part of a gaming team full time to continue to improve and become really good in order to do: “professional stuff”:

> Alex: “I just want to try it once… To see how far I can get… at least… and as I say then at least then if I lose, I can then at least improve on it.”.

Alex likes challenges online, but not “real life” challenges, or solving and dealing with challenges that involve conflict offline:

> Alex: “…in real life, you just end up fighting. [I: Right.] Because that’s what people are like [pause]… [respondent sigh and then smiles]… / [It is] a lot easier in the game to solve it… Cause you just go round shooting people… [respondent laughs]… in, in real life you can’t just go round shooting people…”

Alex prefers conflict online because it is easier to sort out than conflict offline. Offline conflict often results in others “causing fights” and this is something that Alex has experienced a lot. If someone starts saying that Alex is “crap” online, he would solve this by competing against them and defeating them to solve the conflict:

> Alex: “if I beat you, you’re gunna keep your mouth shut then aren’t ya? [I: Yeah… yeah.] Cause then you’re gunna realise aren’t ya?”

If Alex accidently kills a member of his own team in CoD he says sorry to them to ensure: “there ain’t no conflict”, but he has not found such easy solutions to the problems and challenges he faces offline:

> Alex: “There’s no solution… I mean there is a solution, but it’s just trying to figure it out…. Which is the most difficulty bit…”.

John’s need for structure is met by the internet

In his volunteering role, John: “raise[s] awareness”, helps others and, as he describes, going out and “getting [himself]… out there”. His volunteering role encompasses so many different things:

> John: “helping, set up events and projects, erm, going out and meeting people, things like that, there’s sooo [respondent emphasises ‘so’ by lengthening the word] much that goes on that you can’t really bolt it down.”

John described having a “certainty” about the days when he was on the internet, but offline in his varied volunteering role, every day was different: they lacked certainty and were difficult for John to “bolt down”. John also described his sleeping patterns often going “out of whack”, which meant the times he was going to sleep were constantly changing and he was not: “sleep[ing] at the right times”: sometimes sleeping during the day. John has wondered if it is a lack of structure offline, his own unresponsive “body clock”, or his internet use that has caused his sleeping patterns go out of ‘whack’. But after John “quit” Final Fantasy, a place he once frequently inhabited, he found that he still struggled at times to: “keep his sleeping pattern bolted down”. John concluded that his “out of whack” sleeping patterns may be due to him having little “structure” in his offline life compared to the structure he had in Final Fantasy. Volunteering was the only structure John could name offline, but he stated that this was not like having a: “job type structure”, unlike in Final Fantasy, which was the closest John felt that he had to a “job type structure”.

Yvonne’s need to avoid conflict, and escape busyness and structure, is met by the internet

After a “busy” day, Yvonne just wants to: “rewind, relax, not do anything [respondent smiles]… on the computer” as soon as she gets home on an evening, until she goes to bed at about 11.30pm. Yvonne’s evening routine is centred around her computer use, which starts when she arrives home:

> Yvonne: “first thing I do is get changed into my pyjamas, … and then switch my computer on… Put me head phones on, and then, then empty my purse… sort my money out into my money box… Tuck it under the bed afterwards and then, put my head phones on, put… go on Google, put YouTube on and that’s me for the day [Respondent smiles].”

During this time Yvonne does not: “want any disturbances”. One such “disturbance”, that makes Yvonne feel “stressed out”, is people texting her. To eliminate this “disturbance” Yvonne either puts her phone on silent, so she can still keep an eye on the time, or switches her mobile phone off and puts it into a drawer for the evening. This means she misses calls from certain friends, but more importantly for her, she is not interrupted whilst on her computer. Sometimes Yvonne will work on her projects, or do her colouring in while listening to music on YouTube and drinking alcohol, all of which Yvonne described as: “fantastic… it keeps me happy.” Drinking alcohol on an evening, rather than during the day (as Yvonne may do in the holidays), is viewed as better by Yvonne:

> Yvonne: “[Drinking alcohol during the day is a] bad thing in my mind”.

Being busy is something Yvonne shares with the rest of her family, but at times their busyness impacts on her life. This can result in Yvonne having her tea “a bit late” because her family are: “always busy all the time”. Yvonne describes having to do things, like leisure activities or visiting places with her family, that she herself would not choose to do. Yvonne knows that what her family do, often outside, they expect and encourage her to also do. They say to Yvonne:

> Yvonne: “’come and help me and do the garden’ [or] … ‘can you come with me to see grandma’”.

At times Yvonne will get told to do things by her family, like taking the dog for a walk or doing some gardening. They also say to Yvonne: “’get off the backside and do some exercise’”. These are often suggested alternatives to Yvonne spending time on her computer, which is her preferred and chosen activity. Yvonne gave the example of gardening as something her mother does and finds “therapeutic”, but was not what Yvonne liked or found “therapeutic” herself because she is: “more [of an] indoor person” and enjoys being on her computer, doing colouring in or project work. This is what Yvonne finds “therapeutic”. Yvonne replies to her mother’s requests with: “’mum I’m busy’”, but sometimes Yvonne feels obliged to venture away from her computer, colouring in, and project work on a weekend, to go walking first thing or to visit her grandmother. Yvonne also takes the dog for a walk and does other jobs around the house, unlike her brother who does not do anything apart from watch television in bed. This frustrates Yvonne because the time it takes her to do these jobs takes away the time she has for herself on her computer. This is when Yvonne describes herself as “losing it” (losing her temper). But Yvonne explained how she used her computer as an escape from the demands from her family and to stop her from “losing it”: When Yvonne is on her computer, with her headphone plugged in, she is: “in another world” and this enables her to “blank out” the calls from her family telling her that her dinner is ready. Answering this call is not something Yvonne likes to do because she has to: “pause everything… take my headphones off and stress out again”. Yvonne then gets into “bother” when she takes her dinner upstairs (in order to continue being on her computer) by her brother who says to Yvonne: “‘don’t you dare take our dinner upstairs’”. Her brother’s warning makes Yvonne angry and stressed out, and she reacts by storming off and “banging the door”. Yvonne will then go back upstairs to her room where she can calm down by going back onto her computer to listen to music on YouTube, something she finds relaxing. She will wait until later, when her brother has gone out, to go back downstairs to retrieve her dinner and bring this back upstairs to eat whilst on her computer.

The “big massive tempers” displayed by her brother when he was younger is something Yvonne found difficult to cope with. During these times going onto her computer and listening to music on YouTube, through her headphones, offered Yvonne, what she described as, a “safe thing” and it enabled her to “blank out” family conflict. Yvonne continued to use her computer as a “safe thing” because her family still argue a lot:

> Yvonne: “inside of the computer… in a different world… with er drink inside…/ [I am able to]… switch myself off, on the computer… and then in a, in, in another world… [and I] try and blank out anything else”.

Yvonne finds that this other world is different from her offline world, where she “works”. The other, digital, world is relaxing: “therapeutic”, and it makes her happy. It is a place where Yvonne is able to: “think about stuff… [pause]… do nothing back… type thing”. It is something she would like to do more of but is not able to because she is “so busy” and away from her computer throughout the week in her offline world. When she can, often at the weekend, Yvonne will take full advantage of the times she is able to go onto her computer and the internet, often staying up until 2 am on a Sunday morning and getting up later that morning to return back to her computer until 11.30pm that evening. Yvonne will go to bed at 11.30pm to ensure that she can get up the next day to volunteer.

Yvonne likes the combination of her off- and on-line worlds, but they are different from each other. Yvonne explained that her offline world encompassed her volunteering roles and her family, but in her online world it was just her: “Me [respondent smiles]… myself really”. In the online world, Yvonne has more control and is able to get to do what she wants, but Yvonne’s offline world is busy and this busyness prevents her from doing some of the activities that she really enjoys doing. Yvonne specifically spoke about not being able to go on her computer and the internet to, for example, look at two-bedroom properties because: “I’ve been too busy”.

The internet can also help Yvonne catch up on things that she has missed whilst being busy, such as watching iPlayer to catch up on the television programmes she has missed:

> Yvonne: “I do it [watch iPlayer] because my life has always been busy and I never get time. I do have a TV in my room but I never use it.”

Although the time Yvonne spends on her computer and the internet is something she would like to do more of (but is unable to), there is an acceptance by Yvonne of her ‘busy’ life because being busy is something that Yvonne feels is essential to her ability to maintain her own balance and control over her sense of wellbeing:

> Yvonne: “I like being busy otherwise I just can curl up for days… [and] so I won’t lose it, without losing the plot… [or] my mind”.

This is similar to how Michael described what would happen if he too was not busy volunteering:

> Michael: “… if I ain’t been doing this… being busy, the way I am, all I’d be doing is looking at… these walls… and when I was poorly, I had enough of that.”

When Yvonne ‘loses the plot’, often during holiday times when her ‘busy’ routine is interrupted and severely reduced, she drinks more alcohol at home. Drinking alcohol is something Yvonne finds difficult to do at home because both her parents and brother do not like her doing this. Yvonne buys and prepares her alcoholic drink away from home and then transports it into her bedroom in “a sneaky way” in order to be able to freely drink while she is on her computer. Whilst Yvonne’s parents respect her privacy and let her do what she wants, her brother does not, and he will regularly invade Yvonne’s privacy by entering her bedroom whenever he wishes to in order to check if Yvonne is drinking alcohol or not. This is easy for him as Yvonne’s bedroom does not currently have a door. Yvonne describes her brother as: “too sensitive… [and]… Over protective”. He worries about what alcohol could mean to Yvonne’s wellbeing, which is something she does not like about him. The invasion and “disturbance” of Yvonne’s privacy causes conflict between herself and her brother, and this leaves Yvonne feeling stressed and angry. But it is not something Yvonne is prepared to talk to her brother about because it would upset him and he will lose his temper, something she could not cope with in the past and what first initiated her using her computer as a “safe thing”.

Yvonne is forced to spend more time at home when there is a summer break from “working”/volunteering. Yvonne replaces the busyness of “working”/volunteering for busyness on her computer to ensure she does not: “lose the plot”. During this period Yvonne spends much of her time:

> Yvonne: “sleeping, waking up late, do nothing. [I: Do nothing?] Go on computer… Colour in, listen to music and that’s it really.”

Leona’s need for busyness and structure is met by the internet

Like Yvonne, Leona’s days are normally “busy” too. She is always doing something, for example, volunteering, going to college, or going out with her family for walks and visiting places. When something gets cancelled and Leona is left without anything to do, and is therefore not busy, Leona turns to the internet which “entertains” her and stops her from becoming bored. Sometimes Leona uses the internet when she is out and there is a break in her busyness, for example, if she has a break time while volunteering she will look at the internet on her mobile phone. On a weekend Leona will generally use the internet more, but her internet use also fits around Leona’s chosen activities and routine:

> Leona: “[I have a] strict routine at home… I watch me favourite programme on a morning and then I go on the internet after… I go on internet about half past ten”.

Leona uses the internet to look at television guides every evening to see what is on the next day and plan her routine.

8.1.4 The internet is not sought to meet a participant’s needs

Michael’s project, identity, spatiality and sociality needs are met by his volunteering and teaching roles and not the internet

Michael’s current volunteering roles involve him going out to certain places to teach health-related professionals and students to better understand people with IDs in order:

> Michael: “to make easy for the job what they do… to understanding p, people… what they doing… more.”

Michael does this by talking about his own life experiences:

> Michael: “what I’ve had to put up with… when I was a lad. / …the way I’ve had, the way I’ve suffered with, with it.”

One of Michael’s first experiences of teaching others was when he was invited to talk to a group of students who were: “studying, for people who got problems”. Michael found that he enjoyed talking about his experiences, including his problems, growing up and how this made him feel. He is “very proud” of being a ‘teacher’ and this has contributed to his own sense of wellbeing, specifically identity. Michael described that he was not the only benefactor of his teaching, the students themselves found it useful and they learnt a lot when he talked and they wrote down what he had said:

> Michael: "all I wanted to do… is let people know… learners know. If, what we doing. I've always been… interested telling people. To get up, to do… it can be, it, it can better, you can get yourself… sorted out…. The thing what, what, what necessary".

If the students do learn from Michael, he stated that he is able to say: "I've done my job". Not only is Michael doing a job that is meaningful to him, it is also meeting his need for project, spatiality and sociality, aspects he fears would not be met if he was not volunteering offline:

> Michael: "[if I wasn't volunteering] I wouldn't be, I don't think I'd know what I was doing. Be probably looking at, watching me television every day… Not even… going out anywhere."

For Michael, the people in his life are important to him, especially the health professionals, who he describes as having saved his life in various ways: by teaching him to "speak more clearly", helping him when he was poorly, supporting him to improve his health and independence after his mother died and to feel "wiser" about himself, and to achieve things in life that he felt was important. Michael described some of the nurses that he has met in his life as being his closest friends. Michael spoke about one nurse in particular, whom he has known for a long time:

> Michael: "[She, the nurse, is a] best friend for me… towards me. I think a lot of her… in a nice way."

Michael does not use email to keep in contact with his friends and family, but he does use email in one of his volunteering roles, to keep in contact with the health professionals he has spoken to as part of his volunteering role.

One of the nurses Michael volunteers with, will read his emails for him but sometimes Michael can work them out and read the emails he receives by himself. When Michael is involved in training or presenting he will tell the groups he works with:

> Michael: "'if you ever want to ask me any questions… if you want any advice… on, about the job. Let me know and I'll do me best to advise you'."

Despite offering his help and advice for a number of years to health professionals, no one has yet asked Michael for his advice by emailing him. Michael is often promised email contact by the health professionals he meets in person, but then does not receive any emails from them. Michael has found that email is neither a quick or reliable way to keep in contact with the health professionals he comes into contact, or a way for him to 'teach' and 'advise' others. In fact, online, Michael's role as 'advisor' and 'teacher' is ignored and, as such, the internet does not meet Michael's need for project, identity, spatiality or sociality. Other internet activities, such as online supermarket shopping, do not appeal to Michael either. Although he knows things are cheaper online, going shopping "the old-fashioned way" makes Michael happy and meets his needs:

> Michael: "It's exercise. It gets you out the house. Gets you, you get to meet other people. If were, it, all you seeing on the internet is… were, you seen the screen, you seen the, you seen the… stuff what, what you want to order. That's all you seen."

8.1.5 Summary

The internet simulations met many of the participants unmet needs across the lifeworld fractions: identity (not only viewing, controlling and choosing identities, as seen in constituent one, but playing out identities in online multi-player spaces), sociality/intersubjectivity, spatiality, project and mood. These needs included: having a paid job, pursuing a chosen career, living independently, connecting and communicating with others, having a relationship, getting married, and starting their own family. One participant described his needs (often being unavailable or unattainable offline for him and other participants) as being taken for granted by those without an ID, who sought out other online experiences, such as online strippers and prostitutes, to meet their needs. As a result of having needs met by internet simulations, some participants acknowledged that their approach and use of online games was more serious than other players. Some participants needs, if met by those they knew on- or off-line, could place the participant further into the role of the 'dependent', 'vulnerable', pitied, burdensome or "wrong" one, who needed support and often control and limitations. But when the internet simulations met the participants' needs this did not often strengthen the participants' unwanted identities and roles that related to being dependent, vulnerable, etc…

Most aspects of the lifeworld are simulated on the internet and available in many forms for the participants to experience and, as such, participants were also able to plan, prepare, learn about and practise for their various and individual futures (as they wished they would be) and any possible situation they may find themselves in offline, without incurring permanent consequences for making the wrong choice or decision. On the internet, they could “dream” of their futures by: looking at houses that one day they would live in, cook meals by following recipes they found online in preparation to feed themselves when they eventually lived independently, and view the animals on YouTube they wished to one day to work with. The internet simulations kept their hopes and horizons alive, often against the opposing, pessimistic and paternal views of those who supported them, and which restricted and limited them.

Many participants experienced a sense of suffering across the lifeworld dimensions because they were not able to secure a paid job and/or experienced verbal abuse in public, unfairness in the online games, relationship breakups, and the loss of family (often the death of) and friends (on- and off-line). The participants often felt they were a ‘burden’ on their families and pursued their need for an identity which was good and represented them as a “decent person”. They felt that this identity, pursued, for example, through the act of helping others, performing a job or role, or acquiring a high status in an online game, would be accepted and valued by those around them. However, striving for this need, on- and off-line, was often difficult and this led to some participants feeling angry, annoyed, upset, stressed, depressed, sad, feeling ‘burn[t] out’ and wanting to self-harm. The participants longed for emotional support, someone they could talk to who would understand them, rather than pity them. But the participants were aware that having an ID, and disclosing their sense of suffering to, and seeking out emotional support from, others offline would lead to further restrictions on them. Experiencing simulations of driving in GTA and battles in CoD, listening to music or watching specific YouTuber’s channels on

YouTube, receiving emotional support from online friends and wife, searching for poetry online (then writing it out and placing in a ‘memory’ box), and being present in ‘another world’ to escape their offline world, all met the participants needs for emotional support. It decreased their feelings of anger, it calmed them, acted as a distraction, and made them feel happier, while they retained a level of independence from those supporting them offline. Even though participants were experiencing considerable sadness, anxiety, and unhappiness, it was a common a theme that they did not want to talk to those supporting them offline. Not only did the participants fear they would be further restricted by doing this (including their independent or volunteering/professional status), they also felt the supporters did not, or would not, understand how they felt, thus the emotional support offered to the participant would be because the supporter ‘felt sorry’ for them. One participant went as far as putting up statuses on Facebook saying she was happy, good or great, when she actually felt upset, sad, angry, frustrated or annoyed, so that people she knew offline would not ask her questions on- and off-line.

Experiencing the simulations of the lifeworld online met many participants’ needs and contributed to their sense of wellbeing. But the more integral the online experiences were to the participants’ sense of wellbeing, and relied upon, the more time and effort was needed to be invested into these online games, to ensure their reputation, status and roles remained in place to meet their needs for identity, intersubjectivity, spatiality, project and mood. When such an investment had been made, especially over a long period of time, any interruption to, or end of, the internet simulation (which was meeting the participant’s needs) contributed to a sense of suffering: guilt, loneliness, isolation and a sense of unwanted quietness, sadness, and feeling disconnected.

Of course, the liberating nature of the internet and its easy access to simulations of most aspects of the lifeworld, that could be experienced without offline consequences, led some participants to compare their off- and on-line worlds. Most participants described the internet as a place where things were easier and simpler for them to achieve, solve problems or conflict, change things they would like to change (rather than going with the flow offline), acquire money, and deal with verbal abuse. Some participants, two having both ID and autism, described life on the internet as being more ‘predictable’, ‘structured’ and ‘certain’, than their lives offline, which encompassed busy volunteering roles and activities organised by others. The internet was also a place which offered a routine they could choose, where they could complete tasks or get a job done without needing to ‘work’ their ‘brain’, or somewhere they could enter to escape, relax, ‘unwind’, feel happy and concentrate on their own needs. The participants’ routines and roles on the internet had offered a consistency for them over many years; whereas the roles, activities, and the people they encountered offline were not constant, they were interrupted or resulted in unwanted endings, for example their volunteering roles.

The participants’ status and reputation could be developed and maintained on the internet, for example, by being in a good position on a leader board, the roles they played, and/or the skills they possessed in an online game. Offline, many participants felt they did not have things that could increase their status and value, such as money or a job. Only one participant’s volunteering role brought him a high status of advisor/educator of health and social care professionals and others with IDs. His offline roles met many of his needs (identity, project, intersubjectivity and spatiality) and he described certain internet activities, such as online shopping, as something he did not want to do because it did not meet his needs: the enjoyment he gained from getting out and walking to the shops and talking to people.

8.2 The internet creates a decision maker and expert

Constituent five: The internet creates a decision maker and expert is divided into the following subthemes:

- The internet creates an informed decision maker and expert who can influence others.
- The internet creates an expert in one’s own and others’ health.
- The internet creates independence and the ability to plan one’s own projects.

All subthemes contributed to the participants’ sense of wellbeing, which I will now explore and describe using examples of participants’ lived experiences.

8.2.1 The internet creates an informed decision maker and expert who can influence others

Leona watches others in YouTube videos and made a decision to volunteer in the future

There was a sea lion show at a theme park and zoo Leona had visited while on holiday abroad. In this show she saw one member of the audience, who volunteered by putting their hand up, get picked to have a hat put on their head and then be kissed by a sea lion. At the show, Leona was going to put her hand up to volunteer but she hesitated because she was scared to be kissed by the sea lion. When she did decide to put her hand up, it was too late as someone had already been picked. After returning from her holiday, Leona found videos on YouTube of this specific sea lion show she had been to. Leona watched and observed audience members at the sea lion show being kissed by the sea lion and by watching this online, it made Leona more determined and less scared at the thought of putting her hand up to be picked to be kissed by the sea lion. Leona stated that she planned on volunteering, by putting her hand up, when she returned to this theme park and zoo on holiday. Although Leona had come to the decision to volunteer by observing others in this situation online, she was unsure that she would get the opportunity to receive a kiss from the sea lion: “I don’t think I’ll get picked… Cause there’s loads of people”.

Leona decides that she would like to go to the gym to lose weight after seeing her character in Grand Theft Auto getting ‘fitter’ at the virtual gym

In GTA, Leona went to a gym at the beach, through her male character, to lift weights in order to get her character’s body “fit” and look the way she likes. By getting her character “fitter” he would not only look good, but he could also: “get people better… Like arrest em better.” Leona reflected that even if she was playing a female character, she would still go to the gym in GTA, not to get “fitter” but to lose weight. At a gym Leona knows you can lose weight and she has seen her character get “fitter” and develop his body into, what Leona perceives as, a more desirable shape. Going to the gym offline is not something Leona currently does, but it is something she would like to do herself: “find a gym and lose weight”.

The information Michael found on the internet made him an influential ‘expert’

The repercussions from a series of financial decisions Michael made after the death of his mother had a lasting outcome on his life, including the control he has over his finances:

> Michael: “Just after me mam left… er, died. She left me a lot of money to… to do, to get on with, in life…. I… [Respondent sighs]… went out… one day… had some money in my pocket, I wanted to buy things… I bought, I went a lot, I went out and bought a lot of things… [Pause]… and, because I, I had the money…. So, when me ____ [a member of Michael’s family] found out, … he told me really bad. He said ‘that money was for… for your, keeping, keeping comfort for the rest of your life’… At that time, I didn’t think… He was such annoyed about it.”

As a result of a member of Michael’s family finding out about his “spend, spend thing”, he decided that he wanted to see everything Michael spent, written down. Michael did this to make the family member happy and he soon got out of this “spend, spend thing”. He no longer went out and bought big presents, or other things like this, without first asking for the family member’s permission. Following the death of this family member several years ago, Michael continued to show his spending and ask permission to buy things that he wanted from another member of his family.

When Michael’s printer broke he told his cousin, who advises him on things he wants to buy, that he wanted to buy a printer. Michael explained that his cousin is always on the internet looking things up and had told Michael that things were cheaper to buy online than in the offline shops. Because Michael has not searched for anything ‘properly’ on the internet himself since he was at college, he asked his cousin to help him to look into printers on the internet. When Michael is at his cousin's house he will sit with him and watch him: "do[ing] it all" (looking up things on the internet). His cousin will highlight to Michael if something is 'a nice one', which Michael can see on the screen. Even when Michael knows what he wants, his cousin advises him what he should actually buy, for example, not just a 'basic printer', which Michael initially wanted, but an all-in-one scanner and printer. On the internet Michael and his cousin are able to see how much this will cost to buy, which is important to Michael, as he will not be able to buy it if he does not have the right money or is able to gain permission from the family member. After his cousin had found Michael a printer on the internet and Michael knew the price, he rang the member of his family, 'the permission granter'. She asked Michael predictable and anticipated questions on the matter of buying an item: what is wrong with the old one; do you need it; and, how much is it? Michael convinced her that the old printer was broken and that he did indeed need one. Michael was also able to tell her how much it would cost him. The information online that Michael's cousin had helped Michael to find, convinced her that it was a good idea for him to get one, and not just a printer, but an all-in-one printer and scanner.

8.2.2 The internet creates an an expert in one's own and others' health

Alex looks up information on the health risks of sitting for long periods of time and the anxiety he feels

Alex has gone to the jobcentre and told them clearly that he wants to work. He does not care what job he does as long as he is not sat at a computer all the time. Alex would prefer to do a job that is practical: “hands-on work”, like moving stuff around, because this type of work would enable him to move his legs, something he would rather do than just sitting. Sitting is something he currently spends a lot of time doing whilst on the internet. Alex knows the issues sitting down can cause to the body: blood clots, back strain from slouching and hunching of the back (which leads to damage to the spine), to name but a few, which he has learned about from watching YouTube videos. To guard against blood clots, Alex tries to move around between each game he plays in CoD, sometimes by going downstairs to find something to eat, to ensure he is moving at least a little bit. Alex described ‘slouching’ all the time when he is on computer games and how he had been watching a “chiropractor” every day on YouTube. This had made him think: “‘yeah, I probably need one of them’”. Alex is also interested and learns about other aspects of his health by watching YouTube videos, for example, nutrition and anxiety. Alex described himself as having anxiety and explained that he worried about his life and how everything was going. He would like a “decent” job, and the money that this would bring him, but he worries about not being able to achieve this, and what that may mean for the rest of his life. Alex also worries about the plans the government have to stop the money he currently receives. Sometimes the worry Alex feels stops him from getting to sleep and keeps him awake at night. Alex looked up ‘anxiety’ online by using Google, and by doing this found people’s “reviews”, their “points”, and:

> Alex: “stuff saying anxiety’s all about worry… about small things [I: Mmm.] Which I would say I do a lot”.

Online Alex finds that he is not alone when it comes to worrying and feeling anxious, he found that everyone worries: “it’s just how much you worry”. What Alex found online helped him a little bit, he became more of an ‘expert’ in his own health and knew that changes in his life may help but it could only help him so much, as the cause of his anxiety and worry were specifically around getting a decent job and the threat of the government stopping his benefits, both of which he felt was unchangeable:

> Alex: “…nothing’s really much has happened since them… But obviously once you see a change [respondent bangs his hand down on the table], that’s when you, that’s when it [the anxiety] kind of goes away. That’s why, the more change that happens, the more good change that happens, the better it is… But that’s how, that’s how it all go it kind of works.”

Alex explained that if he got a job and enough money to: “get out of here” he felt his anxiety would decrease because the more “good” things that happened to Alex, the less his anxiety would continue. From using the internet Alex was a more informed expert around his health, but he felt that he had little control over changing the offline context he found himself in, which was causing his own anxiety and contributing to his sense of suffering.

Leona looks up health information for herself and other members of her family

If Leona has a cold, or something else that interrupts her health and overall sense of wellbeing, she looks up: “how to cure it” by typing in the symptoms that she has and/or looking on the websites of her local health centre or hospital. When Leona was last unwell with a chest infection, she looked this up online and followed the advice she found, as she always does, and went to her doctors where she was given some medication to take which cured her. Similarly, if members of Leona’s family are “poorly” or have got “problems with them”, which she feels are not being well managed by the current medication they are taking, Leona uses the internet to find out about their condition, the recommended treatment, related advice, and “stronger medication” they may need to be taking. When Leona has found this information she shows it to the member of her family or sends them it online. In return they verbally say, or send an online message saying, thank you. Leona does this for both of her parents, and she once helped her mother by typing in “infections” and searching online for the relevant information. Leona explained that she did this because her mother could not be bothered to do this on her own iPad. Leona showed her mother what she had found online, and told her about the antibiotics she should take and the amount of time she should have off work. Leona’s mother said: “‘thank you’” and Leona was pleased when her mother had some time off work, something Leona had recommended for her. Looking up a condition or illness for others made Leona feel:

> Leona: “happy, excited… that I can look em up and like find like a cure for em… to make em better.”.

Leona felt she was finding a ‘cure’ for them and was part of making them ‘better’, identifying herself as a ‘healer’. However, looking up and identifying her own illnesses and the medication she needs to receive online is not something Leona tells her doctor about when she goes for an appointment. When Leona, and members of her family are well, and not ill, she does not look up anything health related online.

Steven searches for ‘autism’ and ‘epilepsy’ on the internet to become an ‘expert’ rather than a passive spectator

Steven has autism and an ID; to find out more and get an insight into autism he has typed ‘autism’ into Google to find out more about it and about others who also have these “conditions”. Steven not only found out about autism, including the fact that males get autism more than females, but also about others who have these “conditions”. Steven has also looked up ‘epilepsy’ online to gain more of an understanding about the condition because someone he knew had this, and this meant they may have a seizure. By learning about epilepsy. Steven explained that if his friend had a seizure he would no longer passively stand there while this happened. He could move towards someone who had an insight into this, understand what was happening and act as an ‘expert’ if needed.

8.2.3 The internet develops independence and the ability to plan one’s own projects

Leona finds recipes online and her iPad helps her to cook, preparing her to live independently

Leona plays cooking games on the CBBC website and looks at the recipes online from the chefs she watches on television:

> Leona: “I look at recipes on internet…. Like, _______ ones. I look at them ones. That inspired me to, er, cook something for it.”

Leona bakes at her grandfather's and sometimes at home with her father. Leona can cook meals, mostly Italian dishes which are her favourite, on her own at home for the members of her family, who appreciate this. They always award Leona ten out of ten for the meals she cooks for them and this is something she has been doing for a couple of years. Despite Leona's father not liking many of the types of meals Leona cooks, he often helps her to choose an online recipe that she likes and prepare to cook them by supporting her to write down the ingredients she needs. They then go together to the supermarket to purchase the ingredients. Although Leona finds it easy to read the recipes online, she prefers to use her iPad to help her cook her chosen recipe. She places her iPad on a stand and by clicking on the recipe, that is on the iPad's screen, it shows her, by talking to her, how to cook the meal in steps. Leona follows the steps and finds this easier than reading the recipe herself. Leona gave an example of the steps that her iPad tells her to do, without Leona having to press anything, which was to put the pasta into boiling water, then cut all the vegetables up and cook them in a frying pan. Cooking meals that turn out: "perfect [and], spot on" for her family, and also for her friends who she has invited over to cook for, makes Leona feel:

> Leona: "Happy. Like to work in me own restaurant or summut. [I: Would you?] Yeah, love to…. Work in an Italian…"

Leona recently saw a job for a "waitress" in an Italian restaurant, which: "was to do with cooking…", but she didn't know whether to apply for it or wait for another job to come up, such as a job working with animals which she would prefer. As well as teaching and preparing Leona for a possible future job, cooking meals also makes Leona feel happier and more independent:

Leona “[I feel] happy, that I can cook for me self.”

The skill of cooking a meal is something Leona feels that she will be able to do if she moved out and lived on her own.

Yvonne prepares for her own catering business by looking recipes up online, adapting them, and writing them down in a book

Yvonne, like Leona, also enjoys and is good at cooking. Cooking is a “passion” of Yvonne’s and she has always wanted to have her own catering business. Sometimes Yvonne will look up a recipe online by typing “anything” she can think of into Google to find recipes. As Yvonne is intolerant to certain types of food, she will look for recipes that are free from the foods that she is intolerant of. Once Yvonne finds these recipes online she will copy them by hand into her hand-made recipe book. The recipes that Yvonne finds which do include ingredients’ that she is intolerant to are changed and replaced during the process of copying them into her recipe book. Yvonne’s recipe book is not yet finished, and she explained this may take a while to finish, but the act of searching for and copying recipes into her recipe book is something Yvonne loves to do. This is not only because she loves cooking, but the recipes she collects will be the “main foods” she will offer to her customers when she opens her own catering business.

8.2.4 Summary

The internet as the creator of a decision maker and expert contributed to the participants’ sense of wellbeing, specifically identity mobility: ‘I can’, by allowing them to view themselves in situations and giving them the resources to plan, practise and learn. This equipped and empowered the participants to make their own offline decisions, which included deciding to volunteer to be kissed by a sea lion at a theme park and zoo and to go to the gym to lose weight, if the chance presented itself offline. Two participants were finding and collecting recipes online to practise cooking, in part for themselves and their family, but also in preparation to live independently, to get a job in a restaurant, or to start their own catering business.

One participant, with the help of his cousin, was not only able to find out information about a printer and scanner on the internet, it enabled him to decide that he would like to buy this and the persuade the family member to let him buy this. He was able to influence the family member because, as a result of viewing the printer/scanner online, he knew the price, where it could be purchased from and how he would use the item. From the information gathered he had also thought about the benefits the family member would gain from him having a printer/scanner, which added to his success at gaining their permission.

The experience of the internet led some participants to become an informed decision maker and ‘expert’ on their own and others’ physical and mental health and conditions, including infections, nutrition, autism, epilepsy and anxiety. The internet offered the participants information in various forms which included: text information on websites including their local health services, forum discussions, and YouTube videos. From looking at or viewing these, the participants no longer felt that they were the only ones experiencing anxiety, or autism, or the effects of inactivity. They were coming to their own decisions about their own health and conditions and in some cases, acting on the advice and information they had found online when this was possible, for example, going to the doctor when they had a chest infection. One participant offered advice from the information she found online to family members who were not well, guessing what medication they required, and recommending treatments and that they should have time off work. One participant found online information on epilepsy so that he could understand the condition further, because his friend had this condition. This helped the participant feel that he was moving towards being an ‘expert’ because it prepared to act if his friend was experiencing a seizure, rather than being a passive onlooker.

With the help of the internet, becoming an informed decision maker and expert, who could also help/support others, was embraced by the participants and it contributed to their sense of wellbeing. This was not only in a practical sense, such as enabling them to make the decision to go to the doctor or realising what anxiety was and how to manage this, but also a position that contributed to their identity and mood wellbeing. For example, the process of searching for and learning about cooking or a family member’s illness online was described as ‘exciting’ and it made them feel ‘happy’ because they were working towards their own chosen projects and independence.

8.3 The internet as friend and foe

Constituent six: The internet as friend and foe, has been divided into the following subthemes:

- The internet as a perceived threat by those who support the participants.
- Negative on- and off-line experiences.
- The potential to meet those online in person.

All subthemes contributed to the participants' sense of wellbeing and suffering, which I will now explore and describe using examples of participants' lived experiences.

8.3.1 The internet as a perceived foe by those who support the participants

Michael and Ella's family members advise them not to use the internet

Michael had always lived with his mother up until her death a number of years ago. Because Michael was brought up to respect his mother's wishes and it was her house they lived in together, it meant there was a lot of things Michael was not allowed to do. One of the things she would not allow in her house was the internet. After Michael's mother died, a member of Michael's family decided that it may be a good idea for Michael to have the internet at home. But after: “looking into it”, Michael was told that the internet wasn’t for him:

> Michael: [He said] no… leave it alone… [but] it’s up to you… to use it, if you want to use it, it’s up to you. I won’t stop you… [but] I’m advising you not to do it…”

When Michael asked the family member again why the internet was not for him, he was then told him that it was too complicated for him, and not worth the cost (Michael was on a strict budget) or the risk, because people could break into Michael’s account and find all his details. Getting “hacked into” was something one of Michael’s family members had experienced himself on his own laptop and he was concerned that Michael would not know what to do if this did happen to him. Michael followed his family member’s advice, as he did on many other things, and decided not to get the internet at home.

Initially explored in constituent one: The internet as mirror, as a consequence of being advised or warned by her mother that people would say nasty things about her, and her identity as someone with DS, on social media and YouTube, Ella, like Michael, did not use parts of the internet:

> Ella: “[Interviewer: …are you on any social media? You, you know like Facebook or…] I’m not allowed to go on that. [I: How come?] Because me mam won’t let me go on it, because the, the other people will send an awful message onto it about me. [I: Right, oh so was you on it?] No, me mam, me mam will not let me go onto it because, reason why…… I don’t want other people, erm sending email, sending erm threatening message about me. So me mam’s said that, that I’m not allowed to go on it, because I don’t want people say something about me, that I’ve got Down syndrome.”
>
> Ella: “I do get YouTube on me iPad, but I’m not allowed to go on it. [I: Oh right so… how come? Who says you’re not allowed to go on it?] Me mam. Because I don’t want other people write about, about me.”

Andrea’s mother threatens to disconnect Andrea from the internet after a friend wrote something ‘rude’ on her Facebook profile

For Andrea’s mother, the internet does not pose as much as risk to Andrea as ‘lads’ offline do, but there was an instance where Andrea’s connection to the internet was threatened by something that happened, which was out of Andrea’s control:

> Andrea: [Interviewer: …So what does your family think of you using the internet?] [Pause, respondent thinking] They thought ok but at one point my mum didn’t like this much and she says if… because I had a friend in college that he, I used to borrow his iPad and then forgot to log off, so he used to put… something… rude or nasty on… / But not kind of nasty just like er… I liking bums or something like that or something stupid and when I got home and I saw it and I thought… ‘I’m gunna kill him’, and I tried to er… delete it but the only way I could do that when I first got the hang of it was to… do it on my laptop cause it wouldn’t do it on my phone… / And then, cause I’ve got so many friends and family on Facebook, they told my mum and then mum told me and I thought ‘oh my god’ … and she, and she just sss.., and I just says ‘I’m sorry mum.. I forgot to log off his iPad and everything’ and she just says ‘you need to be more careful, if not then I ‘m.. going to let you er [pause]… disconnect or dis-account it’. [Interviewer: Right, and how did that make you feel?] [pause, respondent thinking] Horrible.

Andrea described keeping herself safe on the internet by not accepting friend requests on Facebook from people who she did not know, because they may be after something or they could be a “weirdo”. But Andrea was happy to send friend requests to those she did not know on Facebook to find “fan-based friends”, those who shared her interest in particular bands, musicians or sports teams. These friends were seen as safe and so was their friends as well.

8.3.2 Negative on- and off-line experiences

Alex's negative on- and off-line experiences

For Alex the internet is more fun and less threatening than the people he has experienced in his offline world, specifically those who:

> Alex: "normally do drugs or… like smoke or they tend to go mischievous and stuff like that and I don't really want anything to do with that, I tend to stay inside be myself and just stay on the internet and talk people."

Alex described an incident when he was verbally abused by two men he did not know whilst he was walking through a town and the effect this had on him:

> Alex: "I remember ages ago, when I was at college erm, walking through town [pause]. [I: Yeah?] And erm, just walking through town nothing else and then there's were these two guys, just walk past me… and they said 'ohh ermm… [pause]… don't look right' or something like that or some sort of offensive word… to me. They looked at me first and then said… some sort of offensive word… And I didn't realise until after a few second, or maybe a thingy later and then, all the tenses like built up in me, I felt like went go up to them and punching em… Because it just, you don't expect it… [I: No.] … and you really, it is stupid how people can just go up to random people and just have… thingy, and I hate people that do that because not only are they affecting people, but some of them might have a bad day… and if they said that, they might kill their selves… And they won't get the blame then. [I: Yeah.] Because… they really don't care…. Apparently they don't care about people… And it makes me phys, physically angry because they don't care about anybody… and so yeah it does, I mean people in real life when they do say stuff like that it makes me angry. [I: Mmm.] But… er… I mean that's why I listen to music and try calm down and stuff like that. [I: Yeah [pause].] But sometimes that intention still keeps in me… [I: Yeah.] It always keeps in me cause you always… like you, when you, whenever you're bad day you always remember stuff, and it always comes back and then you tense your bones up again, so you never forget it."

Alex described taking the anger he felt from receiving the verbal abuse offline into the game CoD and positively using his anger to defeat people, especially those who verbally abused him within this game. Alex first encountered online verbal abuse when he was aged twelve, playing online games. He did not expect it, especially from: “men who you respect”. When someone verbally abused Alex online he would have a “benny” at them, get upset and feel worried. Alex then learnt the “history” behind “trolling” by watching a video on YouTube, which he gave as a general example of something he had learnt about from watching YouTube in response to the prompting question from myself: “So what else have you learnt [online] then?”:

> Alex: “Err, like stuff about human bodies, stuff about erm people, what people find weird and stuff like that, weird facts about people. [… tell me an example…] Erm that peop, obviously people like to hurt each other and stuff like that, even though it’s bit… wrong, and stuff like that… People that erm… [pause] [I: Oh I’ve not heard about… What, what do you mean?] Erm… obviously like you got internet trolls stuff like that, you got people that, because they… are unhappy themselves… The only way to release that stress that is by hurting other people to make sure they feel bigger… which doesn’t really… help others. [I: Yeah. Have you, have you ever been trolled?] Yeah I have been trolled a lot of times, I get a lot time every single day. [Respondent laughs] [I: Do you?] But, because I know the history behind it, it doesn’t bother me as much. [I: Did it, did it bother you before you knew this?] It did yeah, but, I kind of… was able to handle it because people were just saying to me ‘ah you’re crap, your la la’ … but then I’d, I don’t say anything… I just let my actions on games and stuff like that, take over and beat them on a game…”

The “trolls” did not like being beaten by Alex though and often reverted from saying that Alex was not very good at the game to suggesting that he was cheating, saying to Alex: “‘Ah you’re a bitch, you’re a cheater…’” . Alex knows that they are just others’ opinions of him, and offsets these negative opinions with the knowledge that he knows others have good opinions of him too and that he is good enough at CoD to defeat these “internet trolls”. Alex gave examples of the online abuse and threats he has received:

> Alex: “[The internet trolls have said] ‘oh I you… I’m gunna rape like your mum’… ‘I’m going to rape your grandma’,…”

It was common for the ‘internet trolls’ to aim their online abuse and threats at the female members of his family, but Alex thinks that what people say online is different to what they might actually do offline. Alex explained that they say these things without thinking, often to get a reaction and because they know they are safe:

> Alex: “the only reason why they are saying it is because they know that they’re safe… [pause]… So, that, if they did it, they wouldn’t do it in real life… as much as they do”

Alex meets the online verbal threats to rape female members of his family with indifference, in the attempt to make the threat “backfire” onto them:

> Alex: “I’ve always said to em like if they’re gunna do it… do it… It’s not going to bother me, well it is going to bother me if you’re going to do it in person.”

Even though his grandmother is alive and well, in response to an online threat to rape his grandmother, Alex says: “‘well my grandma’s dead so if you wanna rape a… a dead body’”, so that their threat: “backfires”.

Although being trolled online has contributed to Alex’s sense of suffering when he was younger, after ten years of experiencing this, he has now got used to it. Alex approaches online interactions with others depending on how the other person online treats him. If they are nice and respectful towards

Alex, he will be nice and respectful back, but if they start “slandering” and saying he is “crap”, Alex will do the same back.

Alex viewed online abuse as something that automatically occurred in his online experiences and something quite normal. Alex felt that any impact on the victim, was the fault or weakness of the victim rather than the fault of the perpetrator. Alex concluded that the negative things people said to other people, who were new to the internet, would not fail to contribute to their sense of suffering, as it had done to his own, because they were not used to it. Alex is now “not bothered” when he is ‘trolled’, he both accepts and expects it, and even lends himself as a “scapegoat” to protect other less resilient players in online games:

> Alex: “really it’s just a waste of their time having a go at me and if they’re not wasting, if then wast, wasting their time on me, then that means they’re not having a go at other people.”

The only thing that Alex feels he is losing in these exchanges is his time, but as Alex has plenty of time, he feels nothing is being wasted:

> Alex: “because it really don’t waste my time… because I’ve got plenty of free time…”.

At times Alex lets, and likes it when, another player is more “awful” to him, than he is to them, and then they end up losing:

> Alex: “I’ll let them be more, I like them when they more awful to me but then they end up losing [Respondent smiles]… Cause it’s like, I’m not really a bully… I’m not really a bully anyways, it’s like, I like the fact that they bullied me but it backfired onto them [Respondent laughs].”

In CoD Alex has people who follow him because they think he is good, and when people look at Alex's, and his online friend's, scores on the leaderboard:

> Alex: "[They] back out of lobby, cause they don't want nothing do with us, cause we're that, cause we're that high in the leaderboard they don't want nothing do with us… They'll just back out, or sometimes, or sometimes we'll do good in the game and then we end up getting cursed out…".

Being "cursed out" (receiving verbal abuse from other players) on a game in CoD validates how good Alex and his friends are at CoD, but there have been times when "getting cursed out" has turned into more:

> Alex: "I think that was like three or four days ago… And erm… If like 'ah you, you're crap' and he put a smiley face at the end and he said to me 'you're crap' and then erm he invited me to his lobby and then all his friends started ganging up on me, but then…they looked at my lobby leaderboard and realised I was top one thousand in the world…and it was like oh they regretted what they said because I was that good…at the game… and then afterwards the guy actually started to become liking me and stuff like that. [I: Right.] So now it went from him hating me… to me, obviously him liking me… in the end, but I didn't have to say anything it was my, it was just my gaming performance that changed his point of view…"

Alex concluded that whilst the internet contributed positively to his life, and to his sense of wellbeing, there would still be times when it would not. Alex's acceptance and awareness of how the internet contributed to both his sense of wellbeing and suffering was key to how he was able to continue to maintain his sense of wellbeing despite receiving daily online threats and abuse in CoD:

> Alex: "you are gonna get a bad time, you gonna get the worst times and stuff like that, but…like if you know and you're aware of it… It's not really that bad of an issue and you don't really af, it doesn't affect you, it don't really, did at first."

John’s negative on- and off-line experiences

Although John tries to help others off- and on-line, he stated that he does not give money to people who are homeless, and described the time a ‘homeless woman’ approached him: “out of the blue”, to get him to give her money:

> John: … a homeless woman like she got up f… [inaudible], she gave a flower, she gave a hug and that and I got flustered by it cause it’s like what going on? /… [This] Came completely out the blue [pause] erm so it’s like, and then she saying like.. Oh, alright I only got twenty quid notes which in hindsight was a stupid thing to say [respondent smiles], but because I was flustered and like, not thinking straight… In the end my mate that I was with at time was able to just get out of that but like she said, ‘oh I’ll give you change’ and that, it’s like and he was saying after like, we were joking right, you really expected a homeless person to give you change from a twenty-pound note? I’m thinking… Yep I’ve learnt my lesson there [respondent laughs].”

John described receiving a bit of “playful… stick” from his friend for it but was able to laugh off the incident:

> John: “cause I’ve known him a long time to t… I know I can just take it in, in good stead.”

John posted onto Facebook what had happened with the “homeless woman” and one of his friends told John that he would now get a lecture from his mother. John’s mother: “saw it on [his]…face” before he had told her directly what had happened. John decided to tell her because he thought: “well if I made a mistake I’m like no I might as well admit it”. John’s mother did not give him a lecture but she was a “bit concerned”, saying to him: “’oh just be careful like you know’”. John described that he felt it was his fault that he was thrown off guard by someone asking for money from him, but he had now learnt his lesson. Those around John continued to highlight his vulnerability by saying that if he was with someone who was not vulnerable it would not have happened. The perception that John is not able to look after himself has prevented him from doing some of the things he would really like to do, for example, working abroad helping others with IDs or teaching English as a foreign language. John sought out various opportunities to help and teach others online, but the root to John's need to help others was that it was "right" and it made him: "a decent human being":

> John: "Well I mean to me that's just, part and parcel of what, that's just, I just see it as stuff that I have to do because you know I have to help people like its only right to help people, so I don't see it as anything special I just see it as, me just me being a decent human being sort of thing so."

John's need to help others in order to be a 'decent human', as previously described earlier in this chapter, has resulted in John acquiring preferred identities and achieving projects, but also taking on too much and becoming "burn[t] out". His pursuit of being a helpful and decent human, which contributed to both his sense of wellbeing and suffering (particularly identity and intersubjectivity) has also been taken advantage of, or attacked, by others which, again, contributed to his sense of suffering. At times John has felt that he has had to remove himself from areas of the internet because his help, or even his visibility, has contributed to others' suffering, by making them unhappy. But once he has removed himself, he has felt lonely and disconnected. In his later interviews, John described that he definitely felt more appreciated offline than within the game Final Fantasy, even if he was being helpful towards others or performing perfectly in the role of tank or healer. Like Alex, John not only expected he would receive "grief" (online abuse and name-calling from other players), but that he should: “take that abuse and just still soldier on with it”.

John’s experience of being “catfished” in Final Fantasy

Prior to marrying his first wife in Final Fantasy, John met someone else he was going to marry in this game and whom he felt he would have arranged to meet offline as well. However, John had noticed that this person, in the form of a female character, was quite controlling over him. John made excuses for her behaviour, for example, not allowing him to talk to other female characters, getting “snarky” if he did, whilst she was allowed to speak to other male characters:

> John: “…she was quite, well I thought no maybe she’s just, like perhaps she’s just a bit of a jealous type you know, or maybe like there’s.., like she’s scared of losing me sort of thing you know I thought, maybe it’s that [pause]…”

John continued to go and help her in the game, but John noticed that if he needed help from her she was less enthusiastic:

> John: “it was generally like, mmm sorry I’m busy, so it w.., it was a very much a one-way thing so like… I was pretty much all give, give, give because that’s how I like to give you know… and be there for people…I didn’t really get much back from her if anything so.”

It was John’s online friends that first noticed and believed that this person was: “catfishing” John, because they had “picked up on the behaviours [that were]… not right”. They had observed the way she was acting with others in the game which had made them think that she was trying to: “take [John]… and someone else out for a ride at the same time”. This was something John explained had not crossed his mind during their online relationship and could not see or pick up on himself. John then realised that the ‘catfish’ was not interested in marrying him:

> John: “[They were] just using us… I guess like for like their own personal gain.”

The ‘catfish’ started to try and distance herself from John and the relationship between them fell apart. John has not heard from the ‘catfish’ since she moved onto a different game. He was a bit upset at first when she disappeared and it also meant that John was not able to say what he wanted to say to her. John’s online friends in Final Fantasy helped him to move on by talking to him. John had thoughts about what he would do if the ‘catfish’ returned:

> John: “Obviously if they come back I’ll probably signed up talking to them again… / I’ll be like if you’re trying to like…actually you disappeared you said you wanted to be alone in this game and stuff like that and it’s like I just gave it space, I ended up finding some else and I’m sorry I’m already taken now sort of thing so.”.

John’s experience of being chatted up and befriending another player in Final Fantasy

Whilst playing a female character in Final Fantasy, John was approached by a male character who did not know John was: “a male behind the screen”. The male player, the “guy”, then tried to chat John up. At first John did not know what the ‘guy’ was doing or how to take this. John found out that it was not just him that had been chatted up by the ‘guy’, he had chatted up all the female characters he had come across in Final Fantasy and they had not been: “comfortable with that”. John explained that being chatted up was more common for other female characters and less common for him and he found the experience of being chatted up by the “guy”:

> John: “unnerving /… Cause I didn’t feel comfortable with it you know it’s like, made me feel uncomfortable…”

John added the ‘guy’ to his “blacklist” and blocked him. John then ended up moving servers, but later when he moved back to his original server (not realising that his ‘blacklist’ containing the players he had blocked had been cleared) he ended up being put back with the ‘guy’ in a practice group. John was now playing a male character and he then got to know the ‘guy’ who had initially: “un-nerved” him and made him feel: “uncomfortable”:

> John: “I got to know him and I saw that actually was a he a, he was a quirky fellow but you know like he was generally quite an upbeat fellow you know… / …when things went wrong you know he just have a laugh right, be upbeat and you know try and get everyone you know, to just carry on and you know like… So it turns out that he was actually a lot nice, he was a much nicer fellow than I’d given him credit for at first you know I’d. I realised it’s like I’d ended up befriending him it’s like got… It’s like you know it’s like,… I’m going to say this now, I’m going to say this now mate I’ve, from what you I thought it but, you’ve just proven me wrong you know he was like, ‘cool’ you know it’s like, he, he appreciated you know I think as well that I’d taken the time to get to know him better through that, it’s like realising ah he’s actually a really good fellow you know like, he’ll help you out and such you know.”

John found that the ‘guy’s sexual advances towards him were just the ‘guy’s “persona”. The ‘guy’ was “crazy” and did not “mean any harm by it”. John not only got to know the ‘guy’, he ‘befriending’ him, and started to understand the ‘guy’s “banter” and “jokes”. They still have jokes about when they first met, which is funnier now that John’s character is a male “hulking walking wall”. But despite playing a big, well-built, male character and telling the ‘guy’ he was in fact a male:

> John: [the ‘guy’] still says I’m a,… he still sees me as a female, but I don’t…”.

This continues in their online friendship and the ‘guy’: “didn’t seem to stop” saying and seeing John as a female, despite John saying he wasn’t.

8.3.3 The potential to meet those online in person

Alex has thought about meeting online friends and girlfriends offline

Alex explained that when he was younger he was not as careful as he is now on the internet. He is highly aware of internet dangers and goes to great lengths to protect himself, for example, not disclosing too much about himself online and not connecting to hot spots. Alex can tell if a girl online is a girl by listening to her voice, and this was a strategy he used in the online game Fable to tell if a female player was female, before he accepted her as his online girlfriend. Alex added that if he had seen her online as well, then he may have arranged to meet her offline, because she didn’t live too far away from him. Alex reasoned that it would be stupid, and few people would go to the effort of getting and paying for a voice changer to change their voice, to sound like a female. Alex had seen YouTube videos of people using voice changers, which was quite funny because their voices will be really high pitched, like a “helium voice”.

In CoD Alex has made and maintained many friendships and he has also thought about meeting these friends offline too, possible because they all arrange to meet each other offline, at a theme park for example. The only thing that puts Alex off going to meet them offline is that they are older than him. Alex has not met anyone offline that he has made friends with online, but he does not rule this out in the future.

John meets his best online friend in person

John was the only participant that gave an example of going to meet someone offline, that he had only met online. John took the view that he did not judge where a "good friend" came from, because being a "good friend" was all that mattered to him. John knows that meeting and making friends online can often lead to meeting them offline too, and this is something many of his online friends often do. John got to meet one of his best friends (who he met initially online) in person after about eight years of knowing her online. The length of time he had known her online was important because of:

> John: "safeguarding reasons… / … I'm considered a vulnerable adult like, I'd rather taken the precautionary… side of things".

John's parents knew about this online friend and how long he had known her, but it was unclear if they knew John had travelled to another city to meet her in person. John admitted that he had not followed the standard internet safety advice, specifically by not taking someone with him when he travelled to meet her for the day. John could not find a friend who was: "comfortable" going with him to meet his online friend in person. So, he took the decision to go and meet her alone, because he felt he had a good idea of what his online friend was like and trusted her, after spending eight years in contact with her (which included talking to them frequently on video chat). When he met her in person, John found that he was able to talk to her a lot and they got on very well. For John, hanging out, sitting, talking and laughing in person with her, beyond the “computer screen”, felt “different”. It was more interesting and preferable to communicating with her online. John has plans to see her again, as they have not met offline for a few years. He continues to talk to her online and they continue to get along. If there is anything the other needs they are there for each other.

8.3.4 Summary

The internet was often perceived as a foe, rather than a friend, by the family members of the participants with IDs. Those who supported two of the participants (the oldest participants) advised or told these participants they should not use the internet, or aspects of the internet because the financial cost was too high, it was too complicated for them to use, there was a risk of getting their computer hacked (and others could acquire their personal details as a consequence), others would send them nasty messages (centred on their DS), or film and then display them on YouTube without their consent. Despite describing putting into action some positive internet safety strategies, another participant was warned by her mother (after the participant forgot to log out of Facebook and her friend wrote something rude on her profile page) that she would not be able to continue accessing the internet if she was not more careful online.

However, many of the participants saw the internet as both friend and foe, and more complex than simply just a risk to themselves or a ‘foe’, as their family members often did. Alex and John gave concrete experiences of the internet contributing significantly to their sense of wellbeing even though they also experienced verbal abuse, threats, criticism, and/or rejection from others online. When reflecting upon these negative online experiences, which at times angered, upset and frustrated them, and made them feel uncomfortable, unnerved, sad, lonely and disconnected, these participants attributed them as being a natural part of the ‘whole’ internet experience. Not only did they view online abuse, threats, criticism and rejection as ‘normal’, they often blame themselves and other victims for this happening, specifically their lack of resilience, weakness, and inability to tell if someone was a friend or foe, rather than the perpetrator’s behaviour.

The offline context derived from the lived experiences of the participants was important to many of the constituents that made up the structure of the phenomenon: wellbeing and internet. Within this constituent, participants intersubjective offline experiences had shaped the way they viewed and interacted with friends and foes online. Alex described two men who had verbal abused him about his appearance and the ongoing feelings of anger and the tension he felt within his ‘bones’ as a result. Alex described how he withdrew from offline activities, choosing to spend his time on the internet instead, where it felt safer. He listened to music online to calm the anger he felt, but he was also able to take his anger into the game CoD and defeat those online who, like the two men who did “not care”, verbally abused him and other, less resilient, players. John described the time when someone had attempted to financially exploit him offline, which his friends and mother had attributed to him being ‘vulnerable’, naïve and not being careful enough, rather than as a result of the perpetrator’s behaviour. After Alex was verbally abused and threatened online in CoD by another player and his friends, and John was made to feel uncomfortable and unnerved from being ‘chatted up’ by a male player on Final Fantasy, both participants then described how they made friends with the online perpetrators. This was either after the perpetrator had recognised the participant’s high status in an online game and expressed liking them, or the participant had accepted the perpetrator’s behaviour because they were actually a “good fella” that did not “mean any harm”.

The online abuse John received and the experience of being rejected contributed to his sense of suffering over a number of months; it affected his self-confidence and made him feel upset, worried, sad and lonely. Johns’ only strategy was to make himself invisible by removing himself from the online space. However Alex, unlike John and Andrea in GTA (discussed in the previous chapter), had transitioned from getting upset and feeling worried by these encounters to accepting these, remaining visible, and even offering himself up as a target to the trolls in order to protect less experienced and less resilient players. Alex described that he had slowly built up his resilience over many years by learning about and understanding why trolls abuse others online (by viewing YouTube videos on why people troll). He had developed strategies to employ when he encountered online abuse and threats daily in CoD, which included threatening to rape his mother and grandmother, or when aspects of the internet experience made him angry and upset. Not only did the online verbal abuse and threats not appear to contribute to Alex’s sense of suffering, from his point of view, it would often serve to validate to Alex how good he was at the game. In a similar theme, John’s need to help others on- and off-line, in order to be a ‘decent human being’, which he also described as an aspect of friendship, was described by John in his experiences in Final Fantasy. Even when John helped and gave himself to the ‘catfish’ without receiving much in return, and experiencing her controlling and ‘snarky’ behaviour towards him, her behaviour was viewed as not only acceptable, but a sign of friendship, that he meant something to her and she did not want to lose him. It was John’s friends that suggested to him that the ‘catfish’ was actually ‘using’ him, and the eventual breakup of their friendship/relationship left John feeling upset.

Andrea was another participant who made friends online with those she had not met offline. Whilst she described keeping herself safe on the internet by not accepting friend requests from those she did not know on Facebook (because they may be ‘after something’ or they could be a “weirdo”), Andrea was happy to send friend requests to those she did not know on Facebook, but who shared her interest in certain bands, musicians or sports teams. Andrea described these as her “fan-based friends” because they had a shared interest and they were viewed as safe.

The potential to meet online friends and girlfriends offline was described by two participants and concretely experienced by one participant. He described that as none of his offline friends were ‘comfortable’ going with him to meet this person, something he knew would be safer, he decided to go meet her alone. It was unclear if he told anyone he was meeting this person, but when he did meet her it was a positive experience and it contributed to his sense of wellbeing, specifically intersubjectivity and mood.

It gave him a greater sense of closeness to her and he enjoyed the chance to communicate with her offline.

8.4 Discussion

Selected participants' concrete lived experiences of the phenomenon: wellbeing and internet within the constituents in this chapter: the internet meets the participant's unmet needs, the internet creates a decision maker and expert, and the internet as friend and foe, will be discussed alongside Galvin and Todres' (2011, 2013) wellbeing 'dwelling-mobility' lattice and framework for delineating different kinds of suffering (Tables 1.1 and 1.2., which can be found on page 25 within this thesis).

8.4.1 Identity dwelling-mobility and project sensed through experiencing online simulations of the lifeworld fractions

Identity dwelling (the 'I am') and mobility (the 'I can') was initially explored in the previous chapter, but within this chapter, specifically within the constituent: the internet meets the participant's unmet needs, identity dwelling-mobility was again sensed by the participants. But this was within an online space in which their identities were simulated and played out by the participants, among simulations of others and objects often in order to achieve a project and intersubjective dwelling-mobility. John and Leona described examples of internet experiences that simulated the lifeworld which contributed to their sense of identity dwelling-mobility. For John: 'I am' meant he was strong, helpful, protective, powerful, and resilient, in his online role as tank and healer in Final Fantasy, and ‘I can’ was through John performing his identities online to achieve project. In Final Fantasy John was no longer someone who was “vulnerable”, dependent or a “burden” on others.

Leona’s sense of wellbeing, identity mobility in particular, was integral to her internet experience in Criminal Case, GTA, and Junior Vets on Call. Leona, and John, were both:

> ‘able to develop a tacit sense of optimism that dreams can be realistically achieved on the basis of one’s hard work and personal capabilities.’ (Galvin and Todres, 2013:90).

Unable to pursue projects or identities she wanted to in her offline world, Leona performed roles such as a detective/police officer in Criminal Case and GTA, and a vet in Junior Vets on Call. She successfully analysed evidence, caught the criminal and cured the animals in exchange for points or money, which made her happy.

8.4.2 Internet addiction or the experience of wellbeing and online simulated of the lifeworld?

The realisation that the experience of the online simulations was integral to their sense of wellbeing (further brought to the attention of some participants and their supporters when they were disconnected from the internet, which is described in the next chapter), led to some participants, and those who supported them, describing the phenomenon: wellbeing and internet, as an ‘addiction’. It is important at this point to state that I use the term ‘simulated’, as coined by Turkle (1995), Poster (1999) and Schwartz (1996), with caution. This is due to the arguments, put forward by Boellstorf (2008), that the use of ‘simulation’ and ‘virtual’ could be seen to mean almost real. ‘Almost real’ is not agreed upon to fully describe all experiences on the internet and I do not believe ‘simulated’ fully describes some of the participants’ wellbeing and internet experiences, for example, Alex’s immersive experiences in CoD, which is described in the Chapter 9: The Immersive Internet and Virtual Embodiment. Alongside the problems with the term ‘simulation’, internet ‘addiction’ is also debated. ‘Addiction’ as a term conjures up many negative connotations and internet terminology is laden with ‘addiction’ connotations, for example: ‘use’ and ‘users’. Alex used interesting ‘addiction’ related discourse to describe his wellbeing and internet experiences. For example, rather than ‘drinking’ a cup of coffee to enhance his playing abilities, Alex ‘took’ a cup of coffee, as you would take a medication or a drug. ‘Addiction’ is widely used to describe ‘excessive’ or ‘problematic’ online gaming use, but Griffiths (2014) suggests that this may not be the most appropriate term to use. Alex and John spent a lot of time on the internet, especially in CoD and Final Fantasy, respectively. Like John, Alex found that his online experiences contributed significantly to his sense of wellbeing: identity (building a reputation, gaining status and purpose), sociality (friendships, relationships and a good social life), project (purpose and achieving high scores), spatiality (freedom to move and inhabit spaces) and embodiment (by experiencing an able, strong and ‘optimised’ body through an online character’s body, as discussed in the next chapter). Alex described that offline experiences did not contribute much to his sense of wellbeing, in fact it often interrupting his sense of wellbeing and contributing to his sense of suffering across all the lifeworld dimensions. It is interesting to note that in internet-related literature, ‘excessive online gaming’ is seen to lead or cause the gamer to experience loneliness and introversion (Caplan et al., 2009), social inhibition (Porter et al., 2010), low self-esteem (Ko et al., 2005), state and trait anxiety (Mehroof and Griffiths, 2010), increased stress, absence of real-life relationships, and lower psychological wellbeing (Griffiths et al., 2012), because for many of the participants in this study these variations of suffering were exactly the reasons why they had turned to the internet in the first place. The internet experience alleviated/eliminated their stress and frustration (Andrea and Alex), loneliness and isolation (John), introversion (Alex), need for relationships in response to the absence of offline relationships (Alex and John), and low psychological wellbeing (Andrea, Yvonne and John). In regard to internet ‘addiction’, or excessive use of the internet, adults with IDs unique lifeworld context in this study throws doubt onto whether they were really ‘addicted’ to the internet, or if their apparent ‘addiction’ to the internet just highlights the lack of opportunities in their offline lives. Alex described how he was on the internet “24/7”, but that if he was given a choice (and had the money) he would rather go travelling and experience new places offline. Alex and John’s ‘addiction’ (as they and those who supported them labelled it) was to experience everyday lifeworld experiences simulated online. We all seek to experience the lifeworld and be a ‘well being’, so why is it that online simulations, which can contribute to a sense of wellbeing, are labelled ‘addictive’ and seen as less valuable than offline experiences?

8.4.3 Mood mobility-dwelling: loss, bereavement and busyness

Galvin and Todres (2013) described mood mobility as:

> ‘Excitement or desire… [to the] sense of excitement when one is about to leave for a much longed-for holiday… a feeling of possibility; a feeling that the world is inviting one into horizons that connect with the desires of one’s heart.’ (:87-88).

Although not as visible through the text/data in the transcripts, the memory of Alex excitedly describing an evening clan battle in CoD: how and what would happen, his role and others’ roles in this, the need to be ready at a specific time simultaneously with the rest of his clan, across a continent, in order to go into the clan battles and ‘smash it’, was vivid, memorable and infectious. It appeared that Alex did not get a sense of mood mobility offline, but the anticipation and experiences of CoD clan battles contributed significantly to his sense of wellbeing before, during, and after the clan battle, and ‘energised’ Alex. It provided him, along with other aspects of CoD, with motivation, a heritage with the game (and with all the CoD versions that had been released), and connected him with his own ‘meaningful life desires’ (Galvin and Todres, 2013:88): a professional gamer and a fearless soldier. But CoD did not provide Alex with a sense of mood dwelling:

> ‘peacefulness’ [which has] the qualities of stillness, settledness or reconciliation… one of peace and welcome ‘pause;’ (Galvin and Todres, 2013:88).

But both Alex and Andrea experienced a sense of mood dwelling when they listened to music on YouTube. Additionally, Andrea experienced a sense of mood dwelling in GTA when she was driving and Yvonne, when she searched for poetry on the internet (and writing this down), while listening to music from YouTube. Yvonne specifically described using her computer as a welcome ‘pause’ from the busyness of her offline lifeworld. Mood dwelling requires:

> ‘some effort and commitment… [and] the process of settling or ‘coming to accept’ things may be challenging, and that the direction of acceptance may be a journey that includes sadness, patience, and concern’ (Galvin and Todres, 2013:88).

It was noted that a number of the participants, Yvonne, Andrea, Ella and John, were coming to terms with multiple losses in their lives. These included the death of family members and friends, the loss of friends as they transitioned in their own lives or careers, and the anticipated loss of volunteering or other roles. In Yvonne’s case, she learnt about the loss of her friend (also a staff member and her respite carer) in the last week of her volunteering role before the holiday period started (when volunteering ceases for a period of time). As such, she did not have support from the staff at this organisation for a substantial period of time whilst she experienced this loss and she did not want to talk to her family or friends about how she felt. For Ella, the loss of her volunteering role would have resulted in multiple losses, including her preferred identity as a valued ‘supporter’ of others with ID, achieving meaningful projects, and her connection with the staff, her friends and fiancé. Although loss is a universal experience and is the way bereavement is understood (Penson, 1992; Oswin, 1991), there is a body of developing literature which highlights that people with an ID:

> ‘may be confronted with a wide range of losses: some will be common while many will not be so common and pertinent only to this population’ (Read, 2010:156).

In Yvonne’s case, she regarded the staff member as a friend, a common theme among people with IDs, but perhaps a less common theme among those without an ID at a similar age. Thus, when the staff member left the organisation, there may have been little understanding by the staff of the significant impact this would have had on Yvonne, who had already experienced multiple losses of significant people in her life, including her grandmother. The loss of significant people in her life had contributed to Yvonne’s sense of suffering: poor mental health. Because Yvonne was reluctance to talk to those around her she coped by escaping into the internet and drinking alcohol.

Andrea, like Yvonne, had also experienced the death of a much-loved grandparent many years previously, and both described feeling quite upset about these losses, missing their loved one dearly, not appearing to find resolution or reconciliation after many years. Andrea was able to keep her grandfather’s memory alive in her own mind, by keeping photographs of him in her room. She continued to struggle with the feelings of guilt at not being there at the end for her grandfather (a decision made by her parents) and this was perhaps preventing her from moving through the stages of grief, as suggested by Kübler-Ross (1969). Andrea’s parents believed it was best that Andrea did not see her grandfather when he was very ill and near to his death, but to Andrea, this decision made her feel that she was not being treated like the other adult members of the family, who continued to visit her grandfather. Andrea refused to talk to others about this loss because she felt that they could not understand without pitying her. This was a similar situation Ella found herself in when faced with the threat of having her volunteering position being taken away from her by her family.

Whilst Andrea and Ella experienced a sense of ‘peacefulness’ by driving in GTA or by viewing images of themselves online in their volunteering role, which acted as a distraction or escape, it was Yvonne who experienced a sense of ‘coming to accept’ the loss of her friend through the act of finding poetry online, writing these poems down onto paper and placing them into a ‘memory’ box. Yvonne described this as a way to say the words she wanted to say to her lost friend, something she could not do in person as her only connection with her friend was through the organisation she volunteered for. This prepared Yvonne to return to her volunteering role at the ID-related organisation and face the loss of her friend. Yvonne explained that she realised that on returning she would find it strange and uncomfortable seeing another staff member replace the role of her friend, but she had also come to understand that with time she would accept this. She acknowledged her feelings of sadness, but was pleased that it was also the start of a new year of volunteering, with new possibilities and adventures ahead for her. In this wellbeing and internet experience, Yvonne experienced a sense of mood-dwelling: ‘mirror-like multidimensional fullness’ (Galvin and Todres, 2013:89).

As well as loss, another theme that arose from this study was the busyness of participants’ lives. Participants often sought busyness out and stressed to me (sometimes repeatedly) in their interviews how busy they were. But the participants’ very busy lives (often coordinated by family and professionals) allowed no time for mood-dwelling. It appeared the ID-related organisations, services, and professionals, placed an importance on busyness/existential mobility for their service users, but there was an absence of support, even discouragement, when it came to existential dwelling. Not being busy, or a participant sensing, or in danger of sensing, existential dwelling, was seen as the individual not participating or being included in ‘something’ (anything, as being busy was more important than what the participants were actually doing), often alongside others with IDs. Alex and John spoke of their busyness online and actively avoided taking on extra volunteering activities provided by the ID-related organisation they attended. The staff’s encouragement for them to volunteer more was to ensure they were ‘busy’ in meaningful activities offline and not isolated from others, but the staff did not take into account, or acknowledge, how busy these participants were online. One participant described how he intended to avoid certain staff members who he knew were going to ask him to do extra volunteering tasks, which he did not want to do. John, who was managing busyness both off- and on-line, described how he experienced ‘burn-outs’ when he took on too many volunteering activities (also observed by the gatekeeper supporting him). But because he wanted to help others, including myself as a researcher, and be a ‘decent person’, he felt as though he had no choice but to take on these extra volunteering activities, even though this was contributing to his sense of mood, identity and temporal suffering, rather than a sense of wellbeing, which was surely the aim of the ID-related organisation and the staff in the first place.

When Yvonne disclosed to others who supported her about the bereavement she felt in her life due to losing loved ones and friends over the years, she was simply told to “keep busy”. Although Yvonne was indeed keeping herself busy, it was not particularly contributing to her sense of wellbeing, as she was sensing suffering: she felt sad and depressed. Indeed, the busyness or existential mobility that Yvonne was encouraged to pursue, rather than spending time dwelling to come to terms with the loss of her grandmother, was another factor which contributed to her inability to move through the grief stages (Kübler-Ross, 1969).

Overall, mood dwelling was a wellbeing experience some participants appeared uncomfortable or fearful of experiencing. Michael and Yvonne had experienced mood dwelling suffering, an:

> ‘unsettled restlessness [and] agitation… disturbance, [and] a sense that something is wrong’ (Galvin and Todres, 2013:107).

They stated that if they were not to be busy in their volunteering roles and were in a position where they could choose their own projects or dwell, they may ‘lose the plot’, or not know what they were doing. As such they went to great lengths to keep themselves busy and their life structured, with the help of those who supported them and, in Yvonne’s case, the use of the internet, so they did not have a chance to experience a sense of mood suffering. But the avoidance of any dwelling meant that many participants did not experience a sense of mood dwelling wellbeing.

8.4.4 Spatial and intersubjective dwelling-mobility and suffering

An important context to the phenomenon wellbeing and internet was spatial mobility suffering, sensed by many participants in their experiences offline as a consequence of the restrictions and limitations placed on them by family members and society (participants’ spatial context was outlined in Chapter 7). As suggested by Galvin and Todres (2013), wellbeing and suffering can occur at the same time without cancelling each other out and indeed, whilst spatial suffering was occurring offline for some participants, online they were experiencing a sense of spatial mobility: ‘adventurous horizons’ and spatial dwelling: ‘at-homeness’ (Galvin and Todres, 2013:81-82). This was experienced primarily through the participants’ experience of the simulations in MMORPGs and MMOs, such as Final Fantasy, GTA and CoD, which offered them both liberation (in order to meet their needs), ‘a place of promise’, and a sense of ‘at-homeness’ (Galvin and Todres, 2013:81-82). Andrea experienced a sense of spatial mobility through the experience of driving in GTA because the online environment offered her the movement and freedom that she desired and needed, but which she could not easily achieve offline. Andrea greatly valued driving on endless roads and motorways through towns and cities in GTA and this can be linked to, and merged with, Galvin and Todres’ (2013) description for spatial mobility:

> ‘[GTA] invited [Andrea] to explore new places and things: [for her] there is a ‘sense of adventure’ provided by the spatial possibilities [within GTA]’ (:81).

John, like Andrea, could not explore new and unfamiliar places or engage in projects that he wished to offline, such as going abroad to teach or support others with IDs. But within Final Fantasy John’s ‘sense of adventure’ and need for spatiality was not only met, it exceeded what was possible for many humans to experience offline (when Western cultural views and logic are applied). For example, John’s use of magic to instantly bring others back to life from the dead, and Alex’s experience of feeling fearless when faced with death in CoD, as death was not a permanent state and suffering was not sensed in his physical body.

Whilst experiencing spatial mobility within GTA and Final Fantasy, Andrea and John also experienced spatial dwelling: a sense of at-homeness in spaces that offered them settling experiences. The sense of wellbeing: calmness and peace, Andrea experienced whilst driving in her own customised car in GTA took her mind off the unsettling feelings of frustration and anger, and distracted her when she felt upset. John would often meet his online friends in Final Fantasy, sometimes in the form of feasts after raids, which gave John the chance to just be with his friends (his comrades) and enjoy their company while they sat around a virtual fire eating virtual food (food that other online friends, as characters, had prepared for them). Together they reminisced and rejoicing over previous battles fought and won, and successful raids. These online experiences contributed to John's sense of spatial dwelling-mobility: 'abiding expanse' (Galvin and Todres, 2013:82). But this sense, for both John and Andrea, could be interrupted at any time by others within these games. When this happened it contributed to both participants' sense of spatial suffering. For Andrea, a sense of spatial mobility suffering was linked to the times when she was repeatedly targeted, shot at and bombed by male players in GTA. There was no safe place in GTA for her to hide or escape to and this led to Andrea's sense of imprisonment, both at the time of the experience and afterwards. John experienced spatial dwelling suffering after 'the exile' and 'the snap' in Final Fantasy and he no longer felt safe in this game. It had become 'un-homelike' for John (Galvin and Todres, 2013:100). He not only sensed his spatial exile, but he also intensely longed for :

> 'familiar sights, sounds and rhythms, and [had] a deep pang for home [home being Final Fantasy]' (Galvin and Todres, 2013:100).

John listened to the Final Fantasy soundtrack to bring back, or contribute to, his sense of home (Final Fantasy) and wellbeing, but this also brought back his sense of exile too, which subsequently contributed further to his sense of spatial suffering.

8.4.5 Intersubjective dwelling-mobility and suffering: friends, foes and loneliness

The constituent: the internet as friend and foe, is one that will interest many people with IDs and those who support them. It contributes to the literature on how the ID-population can enjoy the internet safely and independently but it does not offer solutions of restricting or controlling the internet, or segregation, as some would advocate. Instead, it offers further understanding derived from participants with ID's lived experiences, free from other voices, which is lacking in this area. The internet as friend and foe overlaps with the constituent: the internet meets participant's unmet needs, and the participants' offline context, which demonstrated that the phenomenon: wellbeing and internet, does not happen in an online vacuum away from the offline world.

A sense of 'kinship and belonging': intersubjective dwelling (Galvin and Todres, 2013:86) was sensed by Alex and John when they experienced the simulations of the lifeworld they encountered in CoD and Final Fantasy. Both these participants spoke about themselves, the game, and others within the game, like they were their 'kindred spirit[s]', compatible to their own personalities, their life narratives, and their interests (Galvin and Todres, 2013:86). Kinship and belonging, which was experienced through the online game, was not fully experienced offline for Alex or John. John described how he personally faced “challenges” and “battles” offline due to his disabilities and described how he fought to overcome these with limited results. However, within Final Fantasy he also faced challenges and battles, which he described as triumphing over and which provided him with triumphant narratives and ‘cultural homecomings and shelter’ (Galvin and Todres, 2013:86). Companionship, which was both ‘at home’ and ‘in adventure’ (Galvin and Todres, 2013:87) within the intersubjective dimension of wellbeing was joyfully experienced by John in Final Fantasy as others in the game accompanied him on new quests and he developed and maintained friendships and relationships. John’s friends and wife in Final Fantasy were both familiar and strange, familiar as friends he had also experienced offline, but unfamiliar because of their unwavering and non-judgemental support and care for him. However, this became too much, or too unfamiliar for John and he started to feel he was undeserving of their friendship, support and care, and he “snapped”. It was after ‘the snap’ that John sensed intersubjective dwelling-mobility suffering and it became clear for both himself, and for me as an interviewer (observing and listening to him), that his experiences in Final Fantasy had been fundamentally integral to his intersubjective wellbeing: dwelling-mobility. The intersubjective suffering sensed by John after the ‘snap’ was intense and long-lasting. He felt loneliness, disconnected, persecuted, alienation and isolation. John found no on- or off-line substitute for Final Fantasy and the ‘calling’ (which John described as him thinking about the game and what he would do once he started to inhabit Final Fantasy once more) was still evident. John fought the need to re-connect to Final Fantasy, the calling. If he did answer this call John felt he would be giving in to his ‘addiction’ to this game.

As already discussed, the experience of loss in the participants’ lives was common and often contributed to a sense of loneliness. This was slightly surprising as the study design aimed to recruit participants who already had established support networks. When first meeting many of the participants informally, often where they volunteered, it appeared as if they had good networks consisting of: friends, family members, staff, health and social care and counselling professionals, and other volunteers. Despite this initial appearance and my own assumptions, many of the participants described that they did not feel able to talk to anyone, and share their real feeling, in their social or support networks. Some of the participants expressed that they were pleased they had participated in this study because it had given them the chance to talk to someone honestly and openly. There was one common reason why the participants did not want to talk to others in their lives and this was the fear that they would be pitied, “felt sorry for”, or viewed as a “burden”. Once in the position of the pitied, vulnerable, burdensome and dependent one, those who supported them would react by further limiting their on- and off- line activities and opportunities in order to protect them and minimise further risk and suffering (perceived and actual). The participants already felt restricted, controlled and limited in their offline worlds and rather than talk to others offline about how they genuinely felt, they accepted that they needed to ‘bottle up’ their feelings and keep these hidden from those supporting them, primarily to keep their independence, value and status. However, many participants found other ways to let their emotions out, often through their wellbeing and internet experiences.

Participants not being able to talk to those supporting them meant that assumptions were often made, which were quite untrue. One participant’s practice of finding images of celebrities online, that looked like the staff where she volunteered, appeared humorous to the staff, but they did not realise that the participant did this because she did not have access to any real images of the staff (which she would have preferred) to place in her project work, which was important and meaningful to her and contributed to her sense of wellbeing.

When sensing intersubjective suffering online, John would make himself invisible, but when experiencing online abuse in CoD, Alex did not always disappear, he was visible, ‘letting his actions speak’ rather than letting his anger take him over in this game. He was not only defeating those who verbally abused him online, but those who had verbally abused him offline, and he was able to release and re-direct his anger, change the situation and gain status from his efforts. Despite experiencing online verbal abuse and threats, Alex continued to enjoy the vibrant social life he had built up on the internet and actively avoided going outside and socialising offline, fearing further negative intersubjective experiences. Johansson (2008) and Bremer et al. (2009) gave an example of wellbeing found by the survivors of a cardiac arrest which resonates with the online life Alex rearranged away from his offline world:

> ‘[The survivors of cardiac arrest] went on living with an existential sense of insecurity, but… they could also rearrange their everyday lives to form some peace. Sometimes they even found a better quality of life than before the illness entered. By actively confronting these threats against well-being and existence, feelings of confidence and joy of life were strengthened’ (Galvin and Todres, 2013:41).

One of the interviewees from the study stated:

> "If we compare what I have now, then I have, then… now it's completely different, you could say I am living another life. Now I am living at my own pace, you know, and I am doing whatever I want during the day… It's much more fun to live nowadays than [laughter] before,…" (Galvin and Todres, 2013:41-42).

Alex had rearranged his life onto the internet and he described experiencing a better life online than he ever could offline. However, unlike Alex, the survivors of cardiac arrest eventually returned to: 'everyday activities… [which] was found to give existence stability and clarity' (Galvin and Todres, 2013:41). Alex described not wanting to return to offline activities. His volunteering was an effort by himself, and those supporting him, to return to a life offline, which they hoped would give him 'stability and clarity'.

Despite moving away from the offline world, the online world meant Alex still faced daily online abuse and threats, something he did not like about his life offline. But Alex had developed a resilience online, which he had built up over a number of years), and he had become so used to online verbal abuse and threats that it had become normal and was now accepted. As an example, Alex described how he was ganged up on in CoD and threatened by one player (and this player's friends) but, once they realised Alex's high ranking in the game, they were nice to him and he then regarded them as friends. John also experienced feeling uncomfortable and 'unnerved' by being 'chatted up' by a male player in Final Fantasy, who he ended up blocking. However, sometime later, he met this player again whilst playing a male character and found that the player who chatted him up was a 'decent' person and then proceeded to 'befriended' him. The player continued to regard John as female, and it appeared the behaviour that once unnerved and made John feel uncomfortable had not stopped, John had just accepted this as part of their online friendship. Both John and Alex stated that they did not have many friends offline, and that they had both experienced intersubjective suffering offline. It could be suggested that those with IDs offline experiences of intersubjectivity, specifically friendship, are incredibly important to their enjoyment and safety online. If the participants had experienced positive friendship offline this may have led to them not accepting online abuse and other unfriendly behaviours that made them feel uncomfortable from those they viewed as online friends. The idea that adults with IDs are unable to deal with negative online experiences was noted by Holmes and O'Loughlin's (2014) study, but in Molin et al. (2015) study, set in Sweden, one parent described her daughter with an ID assertively dealing with a negative online experience by a friend:

> '"[A Facebook friend] started to be very, insulting about sex and that kind of things. But then she deleted him right away and sad [sic] that she was not interested in him as a friend"' (:29).

Could this woman with ID have positively experienced friendship offline and known that 'insults' were not something that is part of a friendship? However, as Alex's wellbeing was integral to his internet experiences what option did he really have to accept or reject others' abusive and threatening behaviour, as alternative opportunities offline were clearing lacking. Alex and John may have accepted negative online experiences in exchange for positive online wellbeing and internet experiences, including friendship and belonging.

Alex and John described it as normal to meet those they met online, offline in person. Unlike Alex, John had met a friend whom he had known for over eight years online. He had communicated with her in a number of ways, including video chat, and felt he knew her very well. John was aware of how to keep himself safe when meeting people he had met online in person, and had asked his friends if one of them would be able to go with him to meet his online friend in person. No friend felt comfortable accompanying John, so he took the decision to travel alone to a different city, a number of miles away from where he lived, to meet his online friend. It is unknown if anyone knew that John had done this, but he described the experience of finally meeting his online friend as one with happiness, and that he would do this again in the future.

This chapter explored the wellbeing and internet experiences, specifically online simulations of the lifeworld. No matter whether or not online simulations or the vitural are ‘real’, ‘real enough’, or surpass the ‘real’, the findings of this chapter suggest that online simulations can contribute significantly to adults with IDs sense of wellbeing (and suffering), and thus, from the view point of the participants, online simulations are a valid and real alternative to the ‘real world’. In the next chapter the phenomenon: wellbeing and internet is taken one step further into immersion online and virtual embodiment, which continues many of the threads started in this and the previous chapter.

Chapter 9

Findings: The Immersive Internet and Virtual Embodiment

9.1 The body connects to, and disconnects from, the internet

Constituent seven: The body connects to, and disconnects from, the internet is broken into the following subthemes:

- The internet can easily embed itself into a participant’s life and contribute to their sense of wellbeing and suffering.
- The monitoring and display of bodily rhythms on the internet.
- Preparing and maintaining the immersion of the physical body within an online game.
- The internet is hard to disconnect from and contributes to a sense of suffering.

All subthemes contributed to the participants’ sense of wellbeing and suffering, which I will now explore and describe using examples of participants’ lived experiences.

9.1.1 The internet can easily embed itself into a participant’s life and contribute to their sense of wellbeing and suffering

Michael fears the internet could contribute to a sense of suffering

Michael, who used the internet less than any other participant, explained that if he wanted anything or needed to find something out from the internet he would ask a family member or a member of staff where he volunteered to do this for or with him. Michael was undecided about whether he wanted to use the internet more than he currently did or to get an internet connection at his home. Michael felt that being on the internet more would change him quite a lot and reflected on what might happen if he did have an internet connection at home. One prevailing thought was that he may be on it all the time and go “crazy on it”, like other people do. The last time Michael went ‘crazy’ and lost control was when he spent some of his inheritance money on, what was deemed by his family, inappropriate things and activities. Subsequently, Michael was told off by a family member and put under strict financial control to prevent this from happening again.

Michael has noticed the changes the internet has brought to the world around him, stating: “Today is all about computers and mobile phones…” and explaining that people are on the internet all the time to find out about things and to get answers. Michael believes that this has meant big changes to the way people learn. At school, Michael explained that he used his: “mind and brain”, as well as pens and paper, to learn how to write, spell and do mathematics. Replacing the ‘mind and brain’ with internet use could potentially contribute to someone’s sense of suffering:

> Michael: “back then, the answers people got were from their mind and brain, and this was interesting to find out / [and it]…keeps your mind healthy… Keep it, keep it working… If they don’t keep it working the, the, your mind, your, your brain will fall asleep… It won’t wake up…. And when you get your… it’s not… healthy enough to get the right the answer.”

By only using the internet for work-related activities, for example email, Michael concluded that he used his brain more and it was healthier because it was unaided by the internet. He also did not run the risk of becoming reliant on it, which meant his brain or mind would not “fall asleep”.

The internet makes Leona happy: “It just makes me happy”

Without the internet Leona described that she could not do or look at anything, for example news stories and events that were happening. When asked directly if the internet contributed to her wellbeing, Leona described that it did, not because it did not make her sad, only having the ability to “just” make her happy:

> Leona: “[Interviewer: So do you think the internet…] Yeah. [Interviewer: … affects your…] No. [Interviewer: … wellbeing?] No…. No [Respondent laughs, interviewer laughs too]… It just makes me happy. [I: …. Happy in what way?] Like when some, when events coming up? [Respondent laughs. I: When events are coming up?] Yeah. Always makes me happy, yeah, when you look on internet, and there’s like an event coming up….”

Alex had grown attached to the internet

Alex has always played games on a console, even when he was: “little” and has been playing CoD since 2008. This has meant that Alex has had plenty of practise and this was a factor he highlighted as the reason for him doing “really well” in CoD. Alex spent most of his time on the internet: “I never come off the internet”, and had a daily online routine which started with watching YouTube, followed by playing online for about three hours before going downstairs to ‘grab’ something to eat. Alex would then return to his bedroom to play for another three hours. Alex explained that everyone in his house uses the internet and it is something that: “we don’t really think about”. Alex described that he was on the internet “24/7” and rarely spent time downstairs. The only reason he would go downstairs was to get food and occasionally watch television. This pattern had been observed by Alex's mother and she had labelled him as being 'addicted' to the internet. Alex himself reflected that for others the internet was not normal and that they may want to get: "fresh air" instead. But he also described that the internet had become a part of his life and has been with him whilst he was growing up. As such, an attachment had been formed between them:

> Alex: "I rely on it too much… / I can't live without internet [respondent smiles] [I: Oh can you not?]… No…. I've grown too attached to it. / it's kind of not really a second thought…/… because it's just so normal to me…/ [without it,]… it feels like the end of the world because it feels like I'm in nineteen fifties".

9.1.2 The monitoring and display of bodily rhythms on the internet

John's fitness band displays and monitors his body's rhythms

John wears a fitness band which works through his mobile phone and home computer. One of the reasons John bought the fitness band was so that he could use it to monitor his heart rate and to:

> John: "…stream [my heart rate] so people could see as I was playing… my games, they could see what my heart rate was."

John has seen people doing this online and the ability to stream a player's heart rate, John feels, is very useful, especially in horror games because:

> John: "you see when someone's getting scared senseless [respondent smiles], you know like their heart rate it does tend to, does tend to fluctuate quite a bit."

There are different ways to display a player’s heart rate online, live or after it has been edited. Recording the heart rate and then editing it means that you can: “make it look as good as possible and then upload it [onto YouTube]”. However, John prefers to stream his heart rate live, just like a live: “Big Brother” show where:

> John: “they’ll say like this is Davina you’re live on channel four please don’t, like that, where it is literally live right there… /….what you see is… is what’s just happened you know it’s like it’s not pre-recorded or anything like… So it feels more genuine… you can’t really airbrush it while live you know?”

Displaying his heart rate while playing means that John: “adds another dimension to” his gaming: he can show others online how the game is contributing to aspects of his own body and his sense of wellbeing/suffering contemporaneously. John had described that he wanted to be open and honest with people online and this included disclosing his disabilities to those he got close to and which he felt may lead to a romantic relationship. It is unsurprising that John preferred the idea of live streaming his heart rate (an inner bodily rhythm) for others to see, as this displayed openness and offered something “genuine” about himself. John was symbolically giving his heart at that moment to others online who choose to view. However, like many other things that he wanted to do, John had not been able to do this recently because he had been busy volunteering, but planned to do this when things had: “calmed down again”.

John’s wearable band also helped him to keep track of his sleep by automatically detecting and noticing when he is asleep: “tracing him”. The band kept and presented a bar chart online that showed John when he was awake, in light sleep, or in restful sleep. John viewed the bar chart (on his mobile phone or through his Microsoft account) to see how his sleeping patterns had been, finding this helpful when his sleeping patterns did: “go out of whack” and he had been feeling tired. John explained that this information on its own seemed: “quite empty”, but when he put it against the “bigger picture” he could figure out if something was going on that day which may have been contributing to his own sense of suffering, specifically feeling stressed, and deduce what was changing his sleep patterns. With his wearable band, John could monitor and attend to his own body’s need to sleep by understanding, addressing and decreasing the antecedents to the stress that he felt.

9.1.3 Preparing and maintaining the immersion of the physical body within an online game

Alex prepares his body and environment for immersion in Call of Duty

In his bedroom, Alex will close his door, so that he cannot hear anything outside his room, and turn the lights off. His window has both a curtain and a blind, layered one over the another, both of which Alex closes to eliminate any sunlight from entering his bedroom, something he does not like whilst he is gaming. Alex uses a bright artificial light to have control over the lighting in his room. When this light is off, his bedroom is: “pitch black” with the only light coming from his monitor and mobile phone. This, Alex explained, helps him get into the “zone” while in CoD. Alex cannot talk and concentrate at the same time in CoD, because talking takes him: “out of the zone”. The music that Alex listens to on YouTube, through his headset, also helps him to keep in the ‘zone’ whilst he is playing. Alex wears two sets of headphones: a pair of small bud type headphones and larger ones that fit over the top of these. Alex explained that others think this is “crazy”, but it is what they do in: “professional studios” and it allows him to listen to “everything”: the music and the sounds of the game (in his earbud headphones) or talk to someone, whilst also blocking out unwanted external sounds with his larger headphones. Wearing two sets of headphones means Alex is: “properly tuned out” which helps: “boost” him up in the game.

Alex finds it “weird” how his own body works and how it sometimes does not work when it comes to playing CoD. CoD is a fast shooting game which requires Alex to be able to react very quickly and be what he describes as: “maxed”. However, sometimes Alex’s fingers, specifically the joints in his fingers, will not be: “up to it” and are: “slow”. To loosen his finger joints up before a game, Alex puts his hands and fingers into hot water and:

> Alex: “[I will] wiggle them round [in the water]… Just so it loosens the joints up a bit”.

This loosening effect can last from a few hours up to a few days. Alex will also wash his hands regularly, not just because they can be slow and this will warm them up, but because they get: “greased up”. This is a regular occurrence for Alex and something that initiates hand washing about every twenty minutes or after each individual five to fifteen-minute game in CoD. Alex has been to see the doctor about his “greased up” hands but the cause was put down to a warm environment. Alex found this: “weird” as he has his bedroom window open which makes his room cold. His: “hand can be a little bit fussy” around different temperatures, but a cooler temperature is what

Alex prefers when he is gaming because this helps him to play at his "optimum". When Alex is at his "optimum" in the game, he is: "smashing it" and "getting the highest scores all the time", which has a positive effect on his rankings on the leaderboard, and therefore his status, in CoD:

> Alex: "for me I have to be optimum, I can't be not optimum."

Alex also used to: "take" energy drinks because they also enabled him to be good and "smash" the online games he played. Although drinking energy drinks increased his gaming ability and contributed to his sense of wellbeing during play, Alex would not be able to sleep until 5 or 6 am after drinking them because his heart would be beating fast and hard (more so than what he felt from just playing the online game). However, after watching a YouTube video which warned that energy drinks could kill, Alex decided to stop drinking them and now drinks flavoured water instead. Unlike drinking a relatively small amount of energy drink, Alex has to drink a litre of flavoured water in order: "to get a buzz out of it". Alex had also found, what he described as, more "natural" ways to get his heart beating faster and to get him ready for the online game CoD: drinking strong coffee with sugar.

> Alex: "[I will] take a cup of coffee [which will]… protect me / [give me] a kick / coffee [or] sugar rush".

Drinking coffee and sugar enabled Alex to get: "all the job done" by making him faster and helping him "mentally" within the game, which was specifically important when Alex wanted to do well in a particular game. Alex described that his body was highly influenced by eating or drinking sugar and after eating/drinking a teaspoon of sugar Alex stated: "that's it, boom…/ [I get a] sugar rush". During the day Alex will drink 3 to 4 cups of strong coffee, with each cup containing 2 to 3 spoonful’s of coffee, plus sugar. The sense of wellbeing Alex feels from drinking the sweet coffee lasts about 2 hours, sometimes even up to 5 hours if Alex is not distracted while playing CoD. When the effects have subsided Alex may then get a further cup of coffee depending on how much he wants to continue to play the game, but after one cup and playing CoD Alex often feels “drained out”. At this point he will go onto YouTube and then fall asleep. Without prompting, Alex described knowing what drinking too much coffee could do to his wellbeing, which included: “mentally… messing yourself up”, adding this was not something he had experienced personally.

Sometimes Alex wanted to play CoD but his: “eyes are not really up to it”, he would be “eye tired”:

> Alex: “[My eyes] just don’t wanna work…[and] I’ll be slow in my head”.

When this happens Alex cannot move his hands or see quick enough to react when he sees the enemy in CoD: “everything feels like a blur” and Alex has to watch YouTube instead. Unlike his fingers, hands and mental focus, which can be enhanced by either immersing them in hot water or drinking coffee and/or sugar, Alex cannot prepare or enhance his eyes when they are tired:

> Alex: “they [my eyes] just sometimes work and sometimes don’t… I can’t really choose what, how to train them.”

As well as the preparation of Alex’s immediate environment and his physical body, he also takes a “seriousness” towards CoD, playing: “a little trick” in order to connect his physical body to the online character’s body to experience and increase the immersion and the “rush” he feels:

> Alex: “…what I tend to do is like I take it seriously. [I: Yeah.] Like as I say like, if I die, I die in real life…. Not actually mean it, but obviously it’s just to get that rush going... [I: Right.] … It’s like a little trick in my head. [I: Yeah, yeah.] But it works. / …I, I, I, I take, I take it like I’m in, I’m actually there… Just because obviously it kind of helps with the rush.”

Alex’s “trick” was to think or imagine that while his online character was getting shot, he was also getting shot offline, and, when his character died in the game, Alex also died in real life. This ‘trick’ deliberately allowed Alex to connect his body to the online character’s body and feel like he was: “actually there” in the character’s body and in the CoD environment. Alex stated that the “trick” was purely to sense an immersion in the game in order to feel a ‘rush’. Once immersed Alex described himself as being “hyped”, a state which made him faster in the game, raised his heart rate, and made him want to move both his physical/offline body and his online character’s body around a lot more:

> Alex: “I’m hyped on here like, I mean, real life… I’m also putting that in the game as well… and because obviously I’m hyped, my fingers are moving a lot more, my eyes are moving a lot more, my, my brain’s reacting a lot more faster.”
>
> Alex: “[I] always like get like adrenaline pumping… through me… Because I take it so seriously… / Just my heart beat faster [pause]”.

After the game is over, Alex’s heart rate slows down but he is then often ready for the next game. Not even being on a “rollercoaster” gives Alex the “high” he gets when he is immersed and “hyped” while playing in CoD. After the “rush” has been felt and this sense has left his body, the feelings Alex has towards his online character (having now been injured and/or died) is often one of embarrassment, frustration and/or anger (which often leads him to quit the game). Sometimes the injury or death of his character can also mean Alex loses all his possessions and abilities.

The various strategies Alex uses to immerse himself in CoD, so that he feels like he is actually there, allows him to get “sucked” into the game and lose sense of time. Alex can feel that 2 hours have passed when he has actually been online playing a game for 6 hours non-stop. Endless game modes and getting “sucked” into the games means that Alex experiences a sense of wellbeing (an immersion and a ‘rush’, and the rewards gained from playing well) as well as a sense of suffering when his sleep is affected and delayed. Other bodily needs, such as going to the toilet and eating, are seen as unwelcome interruptions of Alex’s online gaming experience. The nature of CoD means that if Alex is in the game he is either in a state of readiness or has to be present ready to manoeuvre his online character’s body, which means he cannot attend to his own physical bodily needs easily. They become quick and annoying jobs in-between games. If an offline task or bodily need is not quick, Alex has to “back out” of the lobby to enable him to complete it, something he does not like to do.

John’s immersion in Final Fantasy and feeling an adrenalin rush

John, like Alex, also spoke about experiencing an adrenalin rush and how playing the online game Final Fantasy initiated changes to his heart rate and sense of wellbeing. John moved from playing the role of “tank” to the role of “healer” in this game because he was more involved and got: “a much stronger adrenalin rush”:

> John: “a tank buster stop my heart for a second, but with the healers like, my heart stops a lot more because it is so much more involved.”
>
> John: “in person I felt like, like fearing my heart stops… /… it just stopped for a few seconds and then it would mm… then it would start going again so, and then started up again.”

For John, the healer role was more: “proactive”, trickier to play and less “structured” than the more “reactive” tanks and “structured” damage dealers, who ‘just’ dealt with the situation as it occurred. Tanks have to ‘just’ deal with things that come “out of nowhere”, whereas healers have:

> John: “…also got healing people to deal with and… you got making sure that everything’s on you / So, there’s a lot, and like you can’t judge it if a crates going to come out from nowhere, do a lot more damage [I: Yeah.] So “[as a healer] you have to be… always ready to see that occurring and deal with it”.

Healers require: “lightning fast reactions” and John explained that it is not a role that can just be learnt because it also depends on what other players are going to do and their skill level. There is also an unexpectedness brought about by having to be “on the ball” and “ready” to deal with things that come out, or happen, from nowhere. Audible and visual warnings in Final Fantasy sound out in John’s “surround sound” headphones and he is able to listen: “from the primal sense”, which direction danger is coming from to then react and decide what to do:

> John: “[I have to be] more alert and aware… and deal with things on a, on a knife edge so to speak…”

John described being ready and dealing with the unexpected with lightning fast reactions as “exhilarating”, and how he was left feeling exhausted: “from the come down” afterwards, when his adrenalin had burnt out:

> John: “cause always like when you’re in, actually in the content, you’re adrenalin, your adrenalin kicked in with me and that’s driving me forward… [I: Yeah.] … eventually that’ll burn out and that’s when I start t’ feel exhausted”.

When exhaustion is felt by John during a game, often when he has been playing for too long, he will take a break to “recompose” himself, but he knows that this is usually a: “good time to go to bed”. John reflected that other people do not understand and think that gamers, including himself, are ‘just’ playing games and underestimate:

> John: “just how exhausting it can be especially for someone like me that really drives off adren… Really goes off adrenalin…”

Although playing in Final Fantasy is tiring for John, being alert and the sense, he is: “on a knife edge” is where he: “finally get[s] the biggest adrenalin rush”.

9.1.4 The internet is hard to disconnect from and contributes to a sense of suffering

Alex experiences dis-connection from the internet

There have been times when Alex has been without the internet at home: when the internet connection isn’t working or the household gets “cut off” for up to 3 days when his mother is unable to pay the combined television and internet bill. When this happens, the family have to find something else to do until Alex's mother eventually finds a way to get the money to pay because:

> Alex: "she's got kids, and obviously she's needs TV for kids… To watch TV at least… Erm… I, obviously she does her stuff… like, Facebook,.."

Alex's initial response when the internet becomes unavailable is to ask his mother why it is not on. She will often reply that she does not know, so Alex will try and sort out the disruption to his internet connection by: "pratting around with the router". If this doesn't work, Alex may then walk around the house and complain further to his mother about not having an internet connection and asking her to get it back on. When the internet is not available, Alex states: "[It's] just like the walls has dropped on my head". Alex gets very "bored" and "very sleepy" and without the internet and he will indeed go to sleep, a "sad sleep" Alex described, rather than finding something else to do offline:

> Alex: "[It's] …not easy-ish it's just like… I don't know it's kind of like more of a sad sleep [respondent chuckles… I: A sad sleep?] Yeah because… like… there's no internet, I don't know what to do, there's nothing else to do. [I: Right.] So what am I meant to do? Go outside? Do what, do what like when I go outside?... I mean there's not real anything to do, so I just go to sleep."

Alex spends about 4 hours asleep, which is just about the right amount of time for Alex's mother to get bored herself and get the internet connection back up. Because Alex has encountered times when he has not had the internet and has experienced a sense of suffering from being disconnected from it, he now has his own internet connected mobile phone. This ensured Alex's constant connection to the internet:

> Alex: “I’ve always got the internet on me… It’s always the backup plan.”

Like his mother, Alex believes that he is “addicted” to the internet, because he is “always on it”. But when asked what he would like to do instead of going on the internet, Alex spoke of his offline plans and the barriers he faced to achieve his plans:

> Alex: “I would get out of here… and go adventurous…/ Go travelling… [pause]… Go somewhere cold… I’ve always wanted to go to Iceland… Cause of the Northern lights… and…maybe Canada… / … all of that visiting and stuff like that… But obviously it’s money int it?”

John experiences disconnection from the internet

Whilst Alex had experienced periods of disconnection from the internet at home, John described longer periods of disconnection from the internet as a consequence of ‘the exile’ and ‘the snap’ within Final Fantasy. He described in detail the ways he was, and was not, coping with his experience of being disconnected from Final Fantasy. One of the ways he had been coping was by listening to the music from Final Fantasy (which he had listened to when he was within the game) nearly every day:

> John: “It just helps bring back those memories from the game, you know like the good ones mostly.”

There was nothing else that brought back the memories of the good times in Final Fantasy (like the battles John had fought in) so vividly. Although they were mostly good memories, listening to the music also brought back bad memories too, which resulted in John feeling guilty and “playing” things over in his mind. John’s counsellor suggested that John’s disconnection to Final Fantasy was perhaps a good thing as now he could concentrate on getting a paid job. But moving on from Final Fantasy had not been easy for John and he had also realised, since leaving the game, that he had been “addicted” to this game:

> John: [I: …and how have you found moving on? [from Final Fantasy]] It hasn’t been easy but I think it’s been, I think now, since I’ve cut clean from the game you know it’s kind of helped to an extent. It’s like am no longer being driven by addiction, you know it’s kind of like am just like, I’ve been able to take a step back.”

The disconnection, or withdrawal, from Final Fantasy had contributed to John’s sense of suffering:

> John: “To be honest I’ve been feeling quite, bit lonely now because I feel like I’ve been…disconnected [and it has]… generally just be pretty [pause] quiet for me…”

John’s sense of suffering, which was visible to see in his expressions and behaviour in his interviews as he described his experiences, highlighted to both of us just how much his experiences in Final Fantasy had contributed to his sense of wellbeing.

John was now reflecting the contribution of playing Final Fantasy to his sense of wellbeing as an “addiction”. This addiction to Final Fantasy, John felt, had been masking the fact that he had not been enjoying his experience in this game, made worse by having to pay a monthly fee to play the game because he wanted to get his money’s worth. John explained that he needed to spend a lot of time having to: “grind away at it” and: “keep playing and playing and playing” in order to keep up with the other players. This meant that his play was not “casual friendly” as he felt it was supposed to be in a game like this. After a period of disconnection from Final Fantasy, John felt he was: “no longer being driven by addiction”, which was defined by John as always thinking about and wanting to get on the game. Once disconnected John had to “resist the urge” to go back onto Final Fantasy though:

> John: “…there’s been times when I’ve been wanting to go back on but it’s like I’m having to just… you know resist the urge otherwise I might fall back into how I was before. / It’s not that I don’t want to go back, it’s just I don’t want to get addicted again.”

Alex’s investment in and commitment to Call of Duty

Similar to John having to: “grind away at” Final Fantasy in order to keep up with the other players, Alex also had to invest time and effort in CoD to maintain his high status, which included showing his commitment in CoD through ‘clan battles’. Alex belonged to and fought with a clan made up of about 400 players and he explained that anyone can join as long as you are from Europe and you have been judged by the clan leader as being good at the game:

> Alex: “you have to have be good…. or else you’re not in it”.

Only the clan leader can choose who can be in the clan but Alex feels that not everyone who the leader accepts into the clan is a good player. But these players compensate by being “willing” to be in the game when the scores come on from 6 pm to 10 pm, which is when all players in the clan: “start smashing it… [by being] … quick and super hyped up”, ready to compete and create strategies against the other clans. Someone who does not regularly fight for the clan, within this set time period, is “kicked off” the clan.

Although his status in CoD and being part of a clan contributed to Alex’s sense of wellbeing and increased his resilience towards the attacks from ‘internet trolls’, when he was unable to do well in, or he was treated unfairly, in CoD, for example being killed by a member of his own team, this “wound [him] up” and annoyed him. When this happened to Alex several times a day it resulted in his score being reset, which meant Alex was forced to “work again” to regain his status, which contributed to his sense of wellbeing.

9.1.5 Summary

The potential for, or the experience of, the internet embedding itself in the participant’s life was highlighted by several participants at three levels: avoiding connection; internet connection taken for granted, and; awareness of a connection which contributes to a sense of wellbeing, interrupted by disconnection that contributed to a sense of suffering.

- Avoiding connection: Michael (the oldest participant) was aware of the potential for the internet to embed itself into his life, which could contribute to suffering: the mind falling asleep or losing control. He took steps to avoid aspects of the internet embedding itself. Ella was similar to Michael and avoided parts of the internet so that it would not interrupt her sense of wellbeing: by videoing her without her permission or sending her “nasty” messages centred around her having Down Syndrome.

- Internet connection is taken for granted: When asked if the internet affected her wellbeing in any way, Leona (one of the youngest participants) stated that it did not, it “just” made her “happy” despite giving concrete examples of wellbeing and internet experiences.
- Awareness of a connection which contributes to a sense of wellbeing, interrupted by disconnection that contributes to a sense of suffering: Participants, such as John and Alex, were highly aware of their lived experience of the phenomenon wellbeing and internet and gave rich descriptions of their online connection and disconnection. They recognised that they had formed an attachment, and invested a great deal of time and themselves, to the internet and how these experiences were entwined with their sense of wellbeing and suffering, labelling it as an ‘addiction’.

There were two themes which described the relationships between John and Alex’s internet and wellbeing experience and their bodies: monitoring and displaying bodily rhythms, including for others to view online, and preparing the body for connection and experiencing the sense of immersion in the online experience.

John used his fitness band to keep track of his sleeping patterns, as his sleeping would often ‘go out of whack’ and he would feel tired. By viewing the information generated by his fitness band that had ‘traced’ John, he was able to monitor and attend to his own body’s need to sleep (an established sleep pattern) by understanding and trying to address/decrease the antecedents to the stress he feels (which disturb his sleep patterns). John also described that he could use his band to stream his heart rate live (rather than edited and streamed later) while he played an online game. It not only showed others online how the game was contributing to his own bodily rhythms but provided John with the chance to be open and genuine with others online.

To prepare his body for connection and immersion in CoD, Alex changed aspects of his immediate environment (his bedroom): blocking out unwanted or unneeded outside stimuli, ingesting stimulants and tending to parts of his body (his hands, by heating and/or cleaning them) so that his physical body would perform at its ‘optimum’. Once on CoD, Alex would imagine he was the online character in order to fully connect, or become immersed, in the online experience, which contributed to his sense of wellbeing (particularly embodiment). Both John and Alex experienced an adrenalin ‘rush’ and increases in their heart rates (at times feeling as if their heart was going to stop), while they were immersed in an online game, often a battle they were fighting in. Whilst playing at his “optimum” and experiencing this immersion, Alex felt his physical body was at one with the online body. He was energised by this embodied experience, he felt ‘hyped’, and that his brain was reacting faster than it could or would offline. John described the immersive experience as ‘exhilarating’ and where he would get the ‘biggest adrenalin rush’ because he needed to be ready for anything, an awareness John likened to being ‘on a knife-edge’.

Once disconnected from the internet, embodied suffering was experienced by both John and Alex: their offline bodies became lethargic and exhausted, motivation was lost for any offline alternative, thoughts centred around their activities on the internet, and there was a fear of not being able to re-connect to the internet or the online community. These participants' sense of suffering was alleviated by listening to the online games' music, finding another alternative online replacement (if available), or, going to sleep until the chance to re-connect appeared again.

9.2 Discussion

9.2.1 Wellbeing and the internet: avoided, taken for granted and awareness

The findings in this and previous chapters indicated that the internet was either recognised by adults with IDs as something that could become embedded in their life and contribute to a sense of suffering (even take over the person's behaviour or mind) and was therefore avoided, or was already embedded seamlessly in their life, unnoticed and taken for granted, or so integral to their sense of wellbeing and suffering that they noticed and were aware of their connection and disconnection to the internet. All the participants fell within one of these three groups:

Avoiding wellbeing and internet

Ella described wellbeing as being about 'healthy eating' and 'healthy living', and as her internet experience did not encompass healthy eating and healthy living, the phenomenon: internet and wellbeing, was not recognised explicitly by Ella. Both Ella and Michael could easily explain the advantages of the internet and its potential contribution to their own or others’ sense of wellbeing, specifically intersubjective, even though they had not concretely experienced this online for themselves. They were also both suspicious of, angry at, and at times scared of certain aspects of the internet, specifically social media and YouTube, and the online users that inhabited these spaces. They protected their own sense of wellbeing by avoiding these aspects of the internet (those they had not concretely experienced) so that: ‘their brain did not fall asleep’, they would not go ‘crazy’ on it, form a reliance or attachment to it, become a victim of online verbal abuse, or unwanted filming and display. It was clear that Ella and Michael had experienced some aspects of the internet offline, from listening to televised news and those who supported them. From this they had formed much of their ‘whole’ of the phenomenon: internet and wellbeing, which they avoided because for them the internet was integral to a sense of suffering. This, and the sense of suffering experienced by Alex and John when they were disconnected from the internet, raises the idea that you do not have to be ‘online’ to experience the phenomenon: wellbeing and internet. Simplified definitions of the internet, such as a connected networks of computers, no longer encompasses what an internet experience has become.

Taking for granted wellbeing and internet

All participants gave concrete lived descriptions of the phenomenon: wellbeing and internet, as they talked about their everyday experiences of being on the internet. However, when asked directly if the internet effected, in anyway, their wellbeing, Andrea, Steven, Leona and Yvonne all answered ‘no’. As an example, despite giving examples of looking up health information online which resulted in her deciding to go see her GP or giving advice to members of her family, Leona described how she did not think the internet contributed to her sense of wellbeing, as it only made her happy and not sad. Whilst the term ‘wellbeing’ was unsurprisingly a difficult term to comprehend (for both myself and some of the participants), it was puzzling that even when an example of the phenomenon: wellbeing and internet, that the participant had given to me was relayed back to the participant, their reply or response was often still ‘no’, an indifferent shrug, or, in Leona’s case, a statement that the internet just made her happy and not sad. These participants were all aged between 19 and 26, many of whom spoke about how they had learnt how to use the internet from a very early age and had continued to do so throughout their lives. Unlike the older participants (Michael and Ella), it appeared that the internet for these participants was seamless in their lifeworld and generally went unnoticed, along with their sense of wellbeing, also highlighted by Galvin and Todres (2013) in Chapter 1, as something that was taken for granted and went unnoticed until it was disrupted (Galvin and Todres, 2013).

When Andrea experienced being targeted and shot at by male players in GTA, the phenomenon wellbeing and internet was disrupted. She compared the world within GTA with her off-line world and did not see much difference. She described them both as being “horrible” to live in, marked with conflict, violence and restrictions, and places where she was often a helpless participant. The literature on virtual worlds, for example, by Campbell (2004), often emphases a permeability, blend or blur between the virtual and the actual. As noted in Chapter 7 experiences on- and offline came together to create the participants' 'whole' of phenomena, but specifically Boellstorff (2008) suggested that aspects in virtual worlds, such as sociality:

> '[reference] the actual world but is not simply derivative of it. Events and identities in such worlds may reference ideas from the actual world (from landscape to gender) and may index actual-world issues (from economics to political campaigns), but this referencing and indexing takes place with the virtual world' (:63).

Although Andrea had started to reflect an awareness of the phenomenon wellbeing and internet, it was Alex and John, both of whom described themselves as having an ID and autism, who were highly aware of the phenomenon, not only experienced by themselves but also by others. They no longer took the internet for granted, for them remaining connected or living unconnected to the internet had become an important concern for them.

Awareness of wellbeing and internet

Alex and John appeared to spend more time online than the other participants. They were navigating themselves through complex virtual spaces and communities and experiencing and learning much about themselves and others. They were uncomfortably aware that they had invested so much of themselves online that their sense of wellbeing had become integral to their internet experience, often using the term 'addicted' to describe this state. Both Alex and John's offline context was lacking meaningful and equitable friendships, activities, roles and status (which reflected their preferred identities beyond their disabilities), and this made the internet, particularly MMORPGs, desirable for both participants.

Alongside the fact that Alex and John took advantage of the internet's ability to hide aspects of themselves (their offline disabilities, appearance and vulnerable status) to make connections with others online, I was reminded of Turkle's (2011) comment:

> 'technology is seductive when what it offers meets our human vulnerabilities… We are lonely but fearful of intimacy. Digital connections and the sociable robot may offer the illusion of companionship without the demands of friendship' (:1).

Wellbeing and internet was certainly not taken for granted by John and Alex and it was not necessarily out of fear of intimacy that they sought wellbeing and internet experiences, but because experiences of intimacy were not often available to them offline. The internet was not only desirable and seductive for the participants, but necessary to their sense of wellbeing. When the internet connection was disrupted this led to a sense of suffering: agitation, sadness, loneliness and isolation. Having experienced this, and the sense of wellbeing when connected to the internet, they were not only aware of the phenomenon, but also preoccupied with keeping a connection to the internet, or to specific places on the internet, to maintain their sense of wellbeing.

9.2.2 Temporal and embodied wellbeing and suffering, immersion and virtual embodiment

Embodiment is a lifeworld fraction or dimension, bringing together "body, mind and experience" (Strathern and Stewart, 2011:388), which is always present in experience. The discussions in Chapters 7 and 8 highlighted embodiment, for example Leona and Alex's comparisons with the internet mirror’s reflections of bodies (performing - the male African style dancers, the street dance group, and men withstanding pain) and their own offline bodies. Leona and Alex found it difficult to, or felt they could not, replicate the strong male human bodies they saw reflected, which performed feats, were celebrated and at times exaggerated. The experience highlighted their own perceived and actual bodily limitations which prevented them from pursuing projects offline: a dance workshop or joining the army. It led to the participants viewing and describing their own bodies as unable, uncoordinated, weak, ‘average’, unable to withstand pain and suffering, feminine and lacking embodied vitality (wellbeing). It is in the last constituent: the body connects to, and disconnects from, the internet, that two participants, Alex and John, sensed embodied mobility-dwelling in their immersive internet experiences and these may also have been examples of virtual embodiment.

As discussed in Chapter 1, it has been argued that the virtual, and people’s online presence in the virtual, should not be considered meaningful, or that an embodied environment or experience is something which could surpass the ‘real’ (Boellstorff, 2008, Turkle, 2011; Zhao, 2007; Sperber and Wilson,1982; Graham, 1999). Starting with Merleau-Ponty’s (1995) idea that a living body provides an anchorage or a home in the lifeworld, Boellstorff’s (2008) idea that avatars also provide an anchorage in a virtual environment/space/world is quite logical. Through an avatar ‘residents experience[d] virtual selfhood’ (Boellstorff, 2008:129), which Taylor (2006) suggested was central to online immersion. No matter what form an avatar takes:

> ‘a fundamental way in which it constitutes a kind of embodiment is as an anchor for subjectivity….[and whether or not one is using a first- or third-person perspective] the avatar is the locus of perception and sociality’ (Boellstorff, 2011:507).

Alex and John, through their avatar-body in CoD and Final Fantasy, experienced a connection and immersion, and a disconnection, of their physical bodies to the internet which contributed to their sense of wellbeing and suffering, specifically embodied. In CoD, Alex no longer found his body (which was under investigation by doctors to see what was “wrong” with it) disabling and the barriers present in his offline world no longer held him back. His physical body was performing to its “optimum” and working with the online character’s body to achieve his project. Alex was sensing, what Galvin and Todres (2013) describe as, embodied mobility:

> ‘a kind of wellbeing because it essentially provides life-forward and life-positive qualities of ‘being an actor’ or ‘agent’ in the world; of extending one’s power freely, a ‘life force’ in the world through bodily sensation and capacity…’ (:93).

This links with Strathern and Stewarts’ (2011) work on embodiment and personhood which brings together body and:

> patterns of behaviour inscribed on the body or enacted by people that find their expressions in bodily form… [Embodiment] thus bridges over from the body as a source of perception into the realms of agency, practice,… the exercise of skills, performance, and in the case of rituals performativity” (:389).

As highlighted by Ashworth (2015), the lifeworld fractions do not stand alone from one another, but overlap, and in the case of Alex and John, temporality overlapped embodiment in their experiences of CoD and Final Fantasy.

Temporal dwelling can be summarised as a deep connection, ‘absorbing challenges’ whilst being ‘‘in the zone’’ (Galvin and Todres, 2013:84). ‘In the zone’ were words used by both Alex and John when describing their immersive online experiences and temporal dwelling was specifically sensed during intense battles. Continuing to describe temporal dwelling, Galvin and Todres (2013) state that it:

> ‘emphasises ‘present centeredness’’. When a person is absorbed in the present moment, they are tuned into a kind of temporal focus that offers ‘at oneness’, an intimacy, a sense of belonging or a deep connection with what is happening in the moment in ways that are valued or wanted’ (84).

In CoD and Final Fantasy both Alex and John experienced a sense of temporal dwelling-mobility, a:

> ‘Renewal…[a] freshness, aliveness and uniqueness of the present moment that has never before quite happened like this’ (Galvin and Todres, 2013:84).

In fact, Alex and John’s immersive experiences were *so* fresh, alive, and unique to them, specifically Alex’s, that a sense of wellbeing derived from any offline alternative was not seen as anywhere near as inviting as the immersive online experience. This was in part because their online immersive experience had become integral with their sense of wellbeing.

Immersion is often linked to a wellbeing experience, but often as part of an offline experience. Within the wellbeing-related discussion in Chapter 1, Vernon (2008) highlighted Popper’s (2002) description of ‘autark’, translated as:

> ‘sufficient in oneself, and carrying the implication of being fully absorbed and acting instinctively’ (Vernon, 2008:36).

Vernon (2008) went onto describe ‘autark’ as an ‘intense mental condition’ through which one can forget or lose oneself, such as in intellectual and artistic work:

> ‘the state of being in flow…being immersed in an activity that challenges you but does not confound you [in which] people in flow lose all sense of the passage of time and know they are alive’ (:34).

Vernon’s (2008) description of ‘autark’ can be linked to immersion, both combine temporal dwelling and mobility, the losing all sense of the passage of time and experiencing a unique aliveness in the present moment. Alex described that he preferred his immersive experiences in CoD (in which he could lose both himself and his disabilities in) to offline experiences which were more unpredictable and often ‘confound[ed]’, confused and challenged him. Within Galvin and Todres’ (2013) theory of existential wellbeing is the idea of embodied dwelling (comfort), the sense that one’s body is comfortable, feeling:

> ‘warm, full, relaxed, still, satiated, rooted… a welcome sense of ‘being at home’ in one’s body, simply feeling the support and nourishment of the reliable rhythms of one’s natural bodily functions,…’ (:94).

The immersive wellbeing and internet experience was contributing to both John and Alex’s sense of embodied wellbeing. Alex’s awareness of this had led him to purposefully use a strategy (pretending that he was “actually” in the virtual environment and body) to further connect his physical body with the virtual body in order to increase this immersion. Alex’s additional strategies, some of which were ritualistic, to achieve immersion included tending to his immediate environment (often by blocking out offline distractions), warming his finger joints in water, and ingesting stimulants. This immersion contributed to a sense of embodied wellbeing (a ‘rush’, a sense of flow and comfort) and suffering (when the character was hurt). John also described a sense of immersion in Final Fantasy and experienced embodied mobility in Final Fantasy which he sensed as a “rush”. The ‘rush’ that Alex and John described could indicate that they were sensing embodied dwelling-mobility (grounded vibrancy): the hum of ‘grounded vibrancy… unifying vitality with comfort’, in an embodied sense (Galvin and Todres, 2013:95).

Embodiment in virtual worlds, or virtual places, has been a longstanding concern for many researchers (Argyle and Shields, 1996; Balsamo, 1996; Doyle, 2009: Gee, 2008; Heim, 1995; Hillis, 1999; Ihde, 2002; Ito, 1997; McRae, 1997; Mitchell and Thurtle, 2004; Nakamura, 2007; Reid, 1996; Stone, 1991; Sundén, 2003; Taylor, 2002; Van Gelder, 1991; White, 2006; Yee and Bailenson, 2007; Boellstorff, 2011). Boellstorff (2011) stated: ‘[H]istoricizing and analytically unpacking the Western cultural logics’ (:505) that shape our view of virtual worlds is important to understanding virtual embodiment, for example the very idea of virtual embodiment: ‘challenge[s] a longstanding presumption of cognition as disembodied’ (Boellstorff, 2008:134). A descriptive-empirical phenomenological study on wellbeing and internet, free from pre-assumptions and pre-knowledge, appeared to show that the immersive online experience was integral to Alex and John’s embodied wellbeing and, as they connected their minds and bodies with the virtual body and environment, they experienced both embodied ‘performance’ and ‘(proprioceptive) sensation’, which Egoyan (2007) suggested is what defines virtual embodiment. What also appears important to the argument for virtual embodiment is Alex's sense of embodied suffering when his physical body was disconnected, involuntarily, from the internet. Straight after disconnection, Alex felt tired, bored, agitated, and then he entered a "sad sleep" until he could re-connect again to the internet and continue to sense embodied dwelling-mobility online (when his body was 'optimum' and 'hyped'). Linking this to Galvin and Todres' (2013) theory of existential wellbeing, specifically embodied, offline Alex was:

> '…Without this possibility [embodied dwelling-mobility, and thus] one [Alex] may feel depleted and lacking in bodily energy and functional capacity (:93).

9.2.3 Displaying an online embodied experience to others online to show openness and genuineness

Another area for discussion is John's wish to display his embodied experience of playing Final Fantasy to others online, specifically his heart rate, using his wearable fitness band (which monitored his bodily rhythms). There is a lack of literature into this practice, but this process could be partly described as biofeedback, defined by Champion and Dekker's (2011) as:

> '…represent[ing] a real-time two-way feedback loop between the machine and the user: the user reacts to an action initiated by the system, and the system can then react based on the participants' physical/emotional reaction (and so forth).' (:380)

One of the earliest examples of a bio-adaptive interface centred on a player's heart rate was Tetris 64. In this game, the player would place a sensor into their ear to monitor their heart rate and in response, the game would speed up or slow down depending on how fast or slow the player's heart rate was. But John wanted to take his physiological signal (his heart rate) whilst playing a game, the biofeedback or the embodied wellbeing and internet experience, and stream this onto YouTube for others to see. This practice is common on YouTube and the heart rate is often presented along with a view of the player and what they can see in the game. John described that to display his heart rate online projected an openness and genuineness to others online, which would not only enhance his gaming experience but also enable him to reach out to others, inviting them to share his wellbeing and internet experience. John emphasises two ways of streaming his heart rate online: editing it before uploading it, or streaming it live; the latter appeared more appealing to John as openness and genuineness was important to him. He longed for friendship and relationships with others online that accepted him for who he was and to achieve this he opened himself up and disclosed aspects of himself, including his disabilities. Displaying his heart rate was one of many ways John opened up to others online in order to develop connections and friendships.

This chapter: The Immersive Internet and Virtual Embodiment, which described one constituent of the phenomenon wellbeing and internet: the body connects to, and disconnects from, the internet, gives a glimspe into how wellbeing and internet is avoided or taken for granted, seamlessly embedding itself into the participant’s life. A few participants were highly aware and reflective of their experiences of the internet and it’s profound contribution to their sense of wellbeing and suffering, often using the term ‘addicted’ to describe their attachment to the wellbeing and internet experience. The liberating aspect of the internet and it’s simulations of the lifeworld provided the foundation for these participants to experience immersion and virtual embodiment, and sense embodied wellbeing. Again the participants’ context, specifically a lack of opportunities in the offline world, were important to this constituent.

The next chapter: Conclusions and Recommendations, summarises the phenomenon: wellbeing and internet, and brings together and reflects upon the themes, narratives and findings in this thesis in order to reach conclusions, make recommendations, and highlight further research opportunities in this area, which has lacked the input of those with IDs’ lived experiences.

Chapter 10

Conclusions and Recommendations

In this chapter the constituents of the phenomenon: wellbeing and internet, set across the findings of Chapters 7, 8 and 9, will be summarised. Significant themes and narratives within the thesis will then be reflected upon and discussed alongside this study's design, findings, overall aims, and aspects of the research process. Together, with the consideration of those with IDs' place and treatment in society and research and their relationships with others, conclusions about adults with IDs' experiences of wellbeing and internet will be reached. Recommendations to reduce the barriers and restrictions found in an adult with IDs' life and support their safe, enjoyable and independent use of the internet (which can contribute to their sense of wellbeing) will be presented. Finally, the strengths and limitations of this study and suggestions for further research will be identified and discussed.

10.1 Conclusions

10.1.1 The phenomenon: wellbeing and internet

The internet is a mirror, and when adults with IDs viewed the reflections of the lifeworld in the internet mirror it increased their awareness of the lifeworld, themselves and others. Their spatial limitations offline meant that the online reflections, which could be 'true', distorted, magnified, exaggerated and distilled, contributed significantly to their ‘whole’ of phenomena and was integral to both their sense of wellbeing and suffering. The internet mirror meant adults with IDs could choose, view and play out their preferred identities, which contributed to their sense of wellbeing, as opposed to their given offline ID-related identities which were unwanted and, at times, contributed to their sense of suffering.

The internet enabled and enacted visibility and invisibility, including adults with IDs’ visibility to celebrities on social media. It was clear that female characters in online games were highly visible, negatively judged, and often violently or sexually targeted by other players. Male characters were often invisible to other players and attracted less attention. Male adults with IDs in this study often chose to play both male and female characters depending on how visible they wanted to be in the game. Playing a male character often brought about more liberation in the game than a female character, especially if the game design had gender roles that were inequitable. Male adults also withheld or disclosed their disabilities and appearance to others online, depending on their need to be visible (and genuine) to, or invisible (and safe) from, others online. The internet offered adults with IDs liberation, a place where they could do anything, as opposed to their offline world which was marked by restrictions and limitations. However, others’ online liberation could interrupt adults with ID’s liberating experiences and make them unwilling participants/targets in another’s online adventurous horizons. One female participant was not able to play a male character in GTA and was forced to be visible as a female character in GTA. This meant that other players legitimately targeted her character and killed her, repeatedly, interrupting her online driving experience, which contributed to her sense of wellbeing.

The internet had the ability to simulate all aspects of the lifeworld and, by experiencing these online simulations, adults with IDs' needs were met across all lifeworld dimensions. Identity, intersubjectivity, spatiality, project, emotional support, consistency, structure, predictability, and an escape from their everyday busyness (which left little time to dwell) was highlighted by the participants as needs that were being met by experiencing online simulations. It was clear that many adults with IDs did not have the opportunities to have these needs met offline, and this had contributed to their sense of suffering. On the internet, adults with IDs were able to dream of their own futures, and they could practise and prepare for these futures: living independently and looking after themselves, starting a chosen career, and having a relationship and a family, without incurring lasting consequences which were present in their offline world. The wellbeing and internet experiences led to adults with IDs becoming highly skilled in specific online spaces, especially within games, as well as informed, influential, active and independent decision-makers and experts, including in their own and others' health.

Those that supported adults with IDs often viewed the internet as a threat and an experience that may expose adults with IDs to the negative side of the internet, especially to those who would target adults with IDs because of their ID, Down's syndrome (DS) or 'vulnerable' status. The discouragement of and the restrictions from using parts of the internet made one female with IDs and DS scared to use social media and YouTube, fearing she would be targeted by others because of her DS. Despite the lack of offline opportunities which would contribute to their sense of wellbeing and while their internet experiences significantly contributed to their sense of wellbeing, two adults with IDs and autism were labelled as being ‘addicted’ to the internet by themselves and those who supported them. Many adults with IDs were discouraged from spending time on the internet from professionals and those who supported them.

Many adults with IDs were aware that online they would encounter both friends and foes, which meant they would also receive online abuse, threats and rejection, which for some adults with IDs was viewed as normal and acceptable. It became clear in this study that adults with IDs had somewhat limited offline intersubjective experiences, which were not always positive. Many adults with IDs had experienced bullying, verbal abuse and attempts to financially exploit them in public places. It became clear that those who supported these individuals had often attributed these negative experiences to adults with IDs’ vulnerability or naivety, rather than the perpetrator’s behaviour. Offline intersubjective negative experiences, the lack of positive friendships and relationships, and the victim blaming views from those who supported them, meant that adults with IDs’ often accepted verbal abuse, threats, rejection, and behaviour that made them feel uncomfortable and controlled, from others online, often in exchange for a friendship or relationship. The acceptance of unwanted behaviour from others online was also so that adults with IDs could continue to access online experiences which contributed to their sense of wellbeing. One adult with an ID had developed strategies to combat the online verbal abuse, and the threats he received online daily, and built a high level of resilience to enable him to continue to access and enjoy his internet experiences. Despite being aware of internet safety advice, adults with IDs still sent out friend requests and talked on social media to those they did not know. One adult with an ID met someone in person they had only known online. These were described as positive experiences and did not generate any negative consequences.

The phenomenon: wellbeing and internet, was seen, specifically by those who were older, as an experience that could easily embed itself in their lives and have the real possibility to contribute to a sense of suffering. Aspects of the internet were therefore avoided. For many of the younger adults with IDs, who had grown up with the internet, wellbeing and internet experiences were so embedded and seamless in their lives that it was taken for granted and went unnoticed. Other adults with IDs, who also had autism, were highly aware of their internet experiences, especially within games, because they were integral to their sense of wellbeing. When they had experienced a disconnection from the internet this had contributed to a sense of suffering: for example, feeling lonely and sad.

There was a variation of wellbeing and internet experiences, which could be viewed as a continuum - at one end: a temporary relief from boredom and somewhere to find information, and at the other, immersion (a type of embodied wellbeing) and virtual embodiment. Immersion and virtual embodiment were experiences in which an adult with an ID could shed their disabilities and experience a virtual body which had abilities and attributes beyond that of most physical bodies. One adult with IDs and autism followed a specific ritual to prepare his offline body and environment for connection to the internet and immersion. He changed aspects of his immediate environment (his bedroom): by blocking out unwanted or unneeded outside stimuli; and his body: by ingesting stimulants, tending to his hands by heating and/or cleaning them, and imagining he was actually there in the virtual environment and body. Two adults with IDs and autism had experienced the full continuum of wellbeing and internet experience.

10.1.2 Adults with intellectual disabilities, wellbeing and the internet

Two of the aims of this research study were to explore adults with IDs' concrete lived experiences of wellbeing and internet, and to conduct a research study in a way that respected and valued the involvement and contribution of adults with IDs in the research process. Viewing this group as 'experts' in their own lives, allowed this study to address the concerns of those with IDs and enable this group to contribute to research which would help inform and shape ID-related internet and wellbeing guidance, advice and policy. These aims, and the research process centred on adults with IDs' lived experiences, appeared simple and trouble-free to conduct, but the places within research and society that those with IDs find themselves requires careful consideration by any ID-related research study to ensure past patterns of segregation, control, restrictions and unethical treatment are not subtly repeated. Any research that considers the health or wellbeing of those with IDs, especially when approached from a discipline such as health, needs to carefully reflect and choose a clear rationale to what IDs, health and wellbeing are. This is because those with IDs still often fall outside what society and medicine view as healthy (able-bodied), ideal and 'normal'. An

ID (which is not curable but still often viewed as an illness) is problematic for health and medical disciplines because it opposes the aims of medicine, which wants to:

> ‘cure or rehabilitate people [that have become]… disabled following an individual tragedy…, returning them to the normal condition of able-bodied or as close as it is possible’ (Lovell, 2010:85).

It is argued by other disciplines that an ID is neither a condition or disability, but simply a construct of society which has been: ‘a source of speculation, fear, and scientific enquiry for hundreds of years’ (Clarke, 1986:9; Edgerton, 1969; Gustin, 1963; Kurtz, 1981; Dexter,1958). Not only has the term ID ‘served as a way of segregating this group from society’ (Clarke, 1986:9), it has also led to the stigmatisation, exclusion, exploitation, abuse, and, in some cases, the death of those with IDs (Mencap, 1999; Gravell, 2012; Price-Jones and Barrowcliff, 2010; Gates et al., 2007; Atherton, 2007; Lucardie and Sobsey, 2005). ID as a term and label can be so powerful and dominating that it becomes that individual or group’s primary social identity (Beart et al., 2005; Burns, 2000). In my findings there was a great deal of evidence for these primary ID identities: Ella as one ‘doing baby work’, Ella and Yvonne having Down’s syndrome (DS) (Ella: “I am Down syndrome”), John as ‘vulnerable’ and a ‘burden’ on his mother, Alex as someone who had something ‘wrong’ with him, and Andrea who felt she was an object of pity. These identities, which were overriding and dominating, were unwanted by the participants and did not correspond with how they viewed themselves, or how they wanted others to view them. Chadwick et al. (2013) described an ID as being ‘historically and culturally bound’ (:230) and the terms that some of the participants used to describe themselves had negative historical links. For example, John’s use of the term ‘burden’, when describing himself and his emotional dependence on his mother, was also a term used during World War II as a way of legitimising a well-planned, systematic and rationalised euthanasia program by the Nazis on those they viewed and labelled as ‘burdens on society’, including those with IDs (Atherton, 2007).

‘Eugenic overtones’ are still present today, in medicine and general society, which question ‘the value’ of those with IDs, for example, tests that allow for the identification of genetic abnormalities and the option to prevent someone with an ID being born (Watson, 2008:33). There is a lack of progress for the rights of those with IDs and unfortunately for many:

> ‘the violation of their human rights is seen as a normal part of their everyday lives (HMSO, 2008:16).

I would suggest that the progression of human rights for those with IDs would be helped by a move away from ID-related medical parameters to avoid the medicalisation of IDs. The continued stigmatisation, exclusion, exploitation and abuse of those with IDs is also partly due to a lack of consideration for, and an absence of, the unmanipulated and untethered voices of those with IDs, which would help this group to freely choose and positively influence their own identities and place in society. Even in the liberating online world, Seale (2007) found that ID-related organisations and family members of those with IDs were at times manipulated and dominating the voices of those with IDs, in the form of home pages published on the internet, to further their own aims and objectives. As highlighted by Oliver (2009), any support provided to people with disabilities should develop:

> ‘independence, choices, rights and entitlements, proactiv[ity], user led support, security [and] creative solutions [rather than] disabling services [which develop]… dependency, fixed options, discretionary services, [and offer] reactive, service led support, anxiety [and] partial solutions’ (:127).

The lives of adults with IDs, including their access (or no access) to the internet, was hinged on the complex interdependent relationships between those who supported them, and the differing views they had of each other and phenomena, such as the internet. Löfgren-Mårtenson (2008) noted that supporter’s views were often: ‘predominant and controlling’ over adults with IDs’ internet experience (:136). In my study both Michael and Ella’s wellbeing and internet experiences were also being restricted by controlling family members, and at times professionals, who generated a fear in the participants towards others online. This appeared to ensure the individual with an ID complied with the supporter’s wish for them not to access parts of the internet. The ‘predominant and controlling’ nature of the supporters was also evident in other areas too, for example, many adults with IDs in my study were being encouraged, coordinated and/or manipulated into offline identities, roles, and busyness (an overall aim of most ID-related professionals and organisations), which was putting undue pressure on adults with IDs and, in some cases, making them feel mentally unwell. Yvonne was encouraged to keep busy when she felt sad over the loss of a friend. But she was not given the chance to dwell and come to terms with the loss, or indeed other previous losses, which then led to her feeling depressed and using unhealthy coping strategies. John felt he needed to help others to be a ‘decent’ and good person, but described experiencing ‘burnout[s]’ when he took on too much volunteering. Although knowing John struggled when he took on too much, he was still offered more volunteering opportunities by the organisation, which he felt he needed to accept to remain a ‘decent’ person. My assumption was that participants, because they were not recruited through health-related organisations, would perhaps be experiencing a sense of wellbeing/suffering nearer to what the general population was experiencing, rather than those with IDs who were engaged with health services. Although evidence cited in Chapter 1 suggested that mental health conditions are higher in those with IDs compared to the general population (Baxter et al., 2006; Deb et al., 2001), it was surprising that 5 of the 8 participants described (without being asked directly about their mental health status), having experienced, and/or were currently experiencing low self-esteem, anxiety, depression, and other mental health conditions. Adults with IDs in my study also described physical conditions (which had scared or worried them) that had been discounted by medical professionals, often being attributed to the participant’s ID. Many participants in my study were turning to the internet to help relieve them of depressive symptoms, gain emotional support, and learn more about their condition, anxiety, or the mental and physical symptoms they felt. In Shpigelman and Gill’s (2014) study, a participant was quoted as saying Facebook was:

> “a good place to be when you’re bored and lonely cause you get to talk to people… [and] sometimes it’s a way to get emotions out” (:1608-1609).

Many adults with IDs in my study also described using the internet to get their emotions out: Yvonne (when experiencing loss), Andrea (when experiencing sadness and frustration), and Alex (when experiencing anger and frustration). It was unsurprising that the fluid nature, and the independence and support offering, internet had caused such a high level of anxiety from those who supported the adults with IDs. The internet was sometimes unfamiliar to the supporters, but it could also threaten their role as supporter as well as the control they had over those with IDs. Adults with IDs' internet use was simply not often in the 'interest' of those who supported them.

In my study, many staff members, who were used to knowing almost everything about the participants, were surprised when I refused to tell them what the participant had said in their interviews, as these were confidential. This led to the full realisation of how open the lives of the participants were to those who supported them, and with this, controlled. Most participants accepted or acknowledged this as part of their volunteering role and overall lives as someone with an ID. One participant had harnessed the 'interest' health and social care professionals and students had in his life (as one with an ID), into a role and identity from which he derived meaning, status and friendships. However, he appeared unable to break free from the medical parameters he found himself in to generate any support to pursue other aspects of his life he needed, for example, finding someone to have a sexual relationship with. As also noted by Löfgren-Mårtenson (2008), my own findings showed that if an adult with an ID was accessing the internet (especially if the online experience was integral to their sense of wellbeing) and their offline context was, as the participants described it, limited and restricted by those who supported them and society, they were less likely to disclose any information about their online activities to those who supported them, including negative online experiences. This was because such disclosures would lead to a further increase in the limitations and restrictions over them, including their internet access. Löfgren-Mårtenson (2008) was one of the few researchers, from the studies included in the literature review, who had critically thought about some of the fundamental concepts relevant to the topic, specifically ‘intellectual disability’, ‘safety’, ‘independence’ and ‘risk’, asking: ‘which risks [presented by the internet] are worth our concern’ (:136) and who should judge this? Löfgren-Mårtenson (2008) cited Breck (2002) who concluded that risk was:

> ‘always the result of a social process and… [h]ow people view risk is determined in a large part by their social position’ (Löfgren-Mårtenson, 2008:136).

In regards to internet use and risk, one participant in Löfgren-Mårtenson’s (2008) study stated that: “the biggest risk is that nothing will ever happen to me!” (:132). My findings appeared to concur with this participants’ statement but adds context that helps to understand this view further. Offline, adults with IDs in my study experienced limitations and restrictions that reduced the opportunities for them to experience a sense of wellbeing across most lifeworld dimensions, specifically identity, spatial and intersubjective, even when it appeared they were socially included and active in volunteering roles. Indeed, offline, nothing much was happening for adults with IDs and they lacked a variation of offline experiences compared to their non-ID peers. But on the internet something was happening, and their online experiences were helping to increase their awareness and make up the ‘whole’ of phenomena. This was helping them make sense of their lifeworld. At times what they viewed and read on the internet was helpful and informed them, but at other times, the magnified, distorted, distilled and exaggerated reflected aspects of the lifeworld online led to a sense of suffering amongst the adults with IDs in this study.

In Chapter 1, those with IDs were cited as a group who experienced a digital divide, but from the findings from my study, the younger participants, who had grown up with the internet and did not know a life without it, were not experiencing a digital divide. They were very able to use the internet and were navigating their online presence in quite complex virtual worlds and communities. However, the two older participants (aged 62 and 38) faced more restrictions in their internet access from those who supported them and used the internet less than their younger peers with IDs.

Due to the apparent inaccessible design of the internet for those with IDs, highlighted in the literature review, and the feeling that this population would be safer segregated from mainstream internet activities, the case for creating specialised ID websites appeared in many of the studies that were reviewed in Chapter 2. My conclusions around specialised ID websites are similar to those of Löfgren-Mårtenson (2008) and Molin et al. (2015); they are not what most people with IDs want, because they want to use the internet like everyone else and connect with those online who do not have an ID (often because they want to share the same interests with them rather than a disability). From the literature review, most adults with IDs in the studies were highly motivated to use the internet. They engaged with and enjoyed online activities, especially those that offered the opportunity to make connections with others online. In fact, Löfgren-Mårtenson (2008), McClimens and Gordon (2008, 2009), Shpigelman and Gill (2014), and

Holmes and O’Loughlin (2014) attributed adults with IDs’ motivation to learn and use the internet with their ‘longing’ to make contact with others. The internet also offers a multitude of ways to communicate and connect with others and in my findings many adults with IDs had mastered complex parts of the internet. Not only had they formed connections with others, they had become active, valued and respected members of mainstream online communities, but this was often disregarded by those supporting them. This was also noted in the literature review, for example, when McClimens and Gordon (2009) described online friends, specifically the number of online friends, as not being: ‘an indicator of anything more relevant and certainly nothing real’ (:27). In many of the studies there was evidence that the participants with IDs did find the internet, including their online friendships and relationships, very relevant, ‘real’, and important. These differing views highlight the ongoing debate on whether the ‘virtual’ can ever be considered ‘real’, and if people’s online presence could be considered meaningful (for example, friendship) and surpass the ‘real’ (Turkle, 2011; Boellstorff, 2008, Graham, 1999). As noted in Chapters 1 and 2, adults with IDs have limited opportunities to meet new people and to develop and maintain friendships, and this can lead to loneliness (Mason et al., 2013; DoH, 2001b). Friendship itself, has been seen to have a positive impact on an individual’s wellbeing and can be a preventative factor for mental and physical health problems (Duck, 1991, Chappell, 1994, Uchino, 2004, Brackenridge and McKenzie, 2005, Lunsky, 2008). My study highlights that virtual friendship is ‘real’ enough to contribute to adults with IDs’ sense of wellbeing, and when it ceases or becomes unfriendly, it can contribute to a sense of suffering.

Returning to the question posed in the first chapter about whether the internet or the ‘online’ world is any more ‘dangerous’ or ‘risky’ for adults with IDs than their current offline world, the answer is yes and no. Earlier in this thesis the high rates of offline hate- and mate- crime towards people with IDs was highlighted (Davies, 2013a; Beadle-Brown, et al., 2014) and in my findings, negative experiences, such as verbal abuse, had happened to adults with IDs both and on- and off-line. Some participants in my study spent more of their waking time online than they did offline, thus most of their negative and positive experiences happened online as a result. But these participants had experienced verbal abuse and an attempt to exploit them offline. One participant described that he was more able to combat the online verbal abuse, and develop resilience to this, than verbal abuse offline, as he had acquired an understanding over why someone would verbally abuse him online. However, because some of the adults with IDs in my study lacked experiences offline across all lifeworld dimensions, they had developed limited ‘wholes’ of phenomena, such as ‘friend’, which meant they viewed ‘friend’ off- and on-line differently from, perhaps, someone with a wider social network of friends would. Löfgren-Mårtenson (2008) and Holmes and O’Loughlin (2014) highlighted that an adult with IDs’ lack of friends and inclusion in the offline world coupled with their longing to create connections with others online (as this was a place that was possibly less restrictive) sometimes led to their participants with IDs making themselves vulnerable to obtain a ‘friend’. In my study adults with IDs were also seeking friendship online due to a lack of friendships offline and they were more accepting of the behaviour of others online, which had made them feel angry, upset, unnerved and uncomfortable, in exchange for friendship.

Sometimes the adults with IDs in my study blamed themselves (specifically their disabilities or feminine traits) when they received verbal abuse, threats, were rejected, or were not being able to tell if someone was a friend or foe. In Molin et al. (2015), Holmes and O'Loughlin's (2014), and McClimens and Gordon's (2008, 2009) studies, those who supported the adults with IDs, and sometimes the researchers themselves, cited the reason for a negative online experience, such as sexual exploitation, on the perceived characteristics of a person with an ID: their apparent naivety, gullibility, vulnerability, sensitivity, how they presented themselves online, and their difficulties in understanding the motives of a non-ID online user. In my findings, this also happened to John when someone attempted to financially exploit him offline. His friends and mother reacted by suggesting that he would be in trouble, or that he needed to be more careful in the future. Together, the victim blaming attitude towards adults with IDs, their reluctance to share negative online experiences with those supporting them (fearing further restrictions), their lack of offline intersubjective experiences, and their longing for friendship (accepting online abuse and threats in exchange for friendship), then this could leave adults with IDs vulnerable to online exploitation and abuse. Importantly, however, in my study adults with IDs described many examples of positive, supportive and understanding friendships and relationships with others online, and, in some cases, their only chance to sense belonging and kinship. These participants described that connecting with others online was easier and felt safer than offline connections because the invisibility the internet offered them allowed them to remain free from the judgements others made about them, based on their IDs, difficulties, and appearances. However, the more time spent on the internet experiencing the online simulations of the lifeworld, the more difficult, complex, uncontrollable and unpredictable the lifeworld and others offline appeared to adults with IDs. Turkle noted that:

> ‘[d]igital connections … may offer the illusion of companionship without the demands of friendship’ (2011:1).
>
> ‘Human relationships are rich and they're messy and they're demanding. And we clean them up with technology. Texting, email, posting, all of these things let us present the self as we want to be. We get to edit, and that means we get to delete, and that means we get to retouch, the face, the voice, the flesh, the body -- not too little, not too much, just right.’ (2017:1).

Through experiencing the online simulations of the lifeworld, it was not just friendship that could be found on the internet, but anything an adult with an ID would like to experience or needs. Over a decade ago the internet was viewed optimistically as something that would bring about a revolution in the way we worked, irreversibly changing our culture, creating active digital citizens, and acting as a safe place to explore our identities, which Miller (2011, citing Riva and Galimberti, 2001) stated would be ‘free from the prejudices of offline society’ (:1). In my study, adults with IDs often viewed the internet as a safer place (compared to offline spaces) and freer from offline prejudices and unwanted ID identities. For some adults with IDs, it was the only place that removed any of the barriers presented in their offline world which disabled them. On the internet they could explore their preferred or new identities and gain experiences of the lifeworld which contributed to their sense of wellbeing, but it was still not a place where everyone could feel safe and free from the prejudices of offline society, particularly females and those with disabilities they did not want to, or could not, hide.

10.1.3 Unethical treatment of those with intellectual disabilities in contemporary internet-related research studies

A meta-study approach to reviewing literature aimed to create: ‘meanings that extend well beyond those presented in the available body of knowledge’ (Paterson et al., 2001:4) and one of the unexpected themes that came from the literature review in this thesis was the unethical practice some of the researchers had shown towards their participants with IDs. Adults with IDs’ experiences of taking part in research, including experiencing unethical practice by researchers, was also noted in the studies undertaken by Crook et al. (2015) and McDonald (2012). For example, one research study revealed a participant’s real name in a publication without her consent. Some of the studies, included in this thesis’ literature review, revealed that at times the treatment of participants with IDs ranged from paternalistic and controlling, to a complete disregard for the participants’ rights and welfare. These included:

- Using chaperones for all the participants with IDs (not taking into account their existing level of internet competency) even after they had received internet training to ensure their safety online and that they did not post anything inappropriate online (McClimens and Gordon, 2008).
- Choosing online activities unsuited to the participants’ needs and/or skill level, for example, blogging when participants with IDs found it hard to write (McClimens and Gordon, 2008), giving verbal instructions over the internet (VoIP) when participants had hearing

impairments (Brewer et al., 2010, Taber-Doughty et al., 2010) and a lengthy online text-based survey (Shpigelman and Gill, 2014).

- Attributing the lack of success of an internet activity in a study on the participants with IDs rather than on the unsuitably chosen online activity, such as blogging (McClimens and Gordon, 2008).
- Designing a study that allowed the participants with IDs to engage with and learn how to use an aspect of the internet, but then not taking into account that the internet would not be available to them after the study finished and not arranging or sign-posting further opportunities for them to access the internet (Moisey and van der Keere, 2007; McClimens and Gordon, 2008, 2009; Edler and Rath, 2014). Access to the internet could be viewed as an incentive for the participants with IDs to have taken part in these studies.
- Placing more importance on the data gathered from those without an ID, than the data from those with an ID (Holmes and O'Loughlin, 2014; Hegerty and Aspinall, 2006; Brewer et al., 2010; Taber-Doughty et al., 2010).
- Not taking into consideration the participants with IDs' understanding around 'friend' on the internet and therefore not supporting the safe use of the internet. McClimens and Gordon (2008, 2009) observed the participants excitement at receiving their first online connection with an unknown other: a fake friend request on MySpace, without appearing to explain what a fake friend request was to the participants.
- Not obtaining the consent of participants with IDs who were taking part in their studies. For example, when photographing Information

and Communication Technology (ICT) related equipment in the homes of those with IDs (Hegarty and Aspinall (2006), or to install a web camera and microphone (VoIP) in the homes of the participants with IDs, and monitoring and communicating with them during the day and night (Brewer, et al., 2010; Taber-Doughty et al., 2010). This included instructing them not to do certain things, such as eating at night, which the participants with IDs verbalised they did not like.

In the Brewer, et al. (2010) and Taber-Doughty et al. (2010) studies it was quite clear that some of the participants were uncomfortable with the equipment used in the study and were not consenting to being monitored and communicated with through the VoIP installed in their homes.

Only 4 of the 14 studies in the literature review reported gaining ethical approval to conduct their research studies. However, there were some good examples of ethical consideration for participants with IDs. For example, Hall, et al. (2011) ensured there was a continuation of resources and support to allow the participants with IDs to continue accessing the internet, and Moisey and van der Keere (2007) designed their internet training sessions to suit the individual needs of the participants with IDs in their study.

10.2 Reflections and discussion on the study design and research process

It was important for me to choose an approach and methods that would suit the aims of this topic, respect and value those with IDs, and which would help me to stay close to, and re-present, the data given by the participants with IDs. This was re-presented into the constituents of the phenomenon with as little interpretation as possible. Interpretation and related theory was reserved for the discussions that followed the constituents. I adopted an open phenomenological attitude and bridled my own pre-assumptions around IDs, internet and wellbeing which allowed the phenomenon: wellbeing and internet, to reveal itself in a way not captured by previous internet-ID-related studies.

Descriptive-empirical phenomenology is not often an approach used with participants with IDs and the methods were adapted to suit this population. As a result, there were some interesting outcomes from using this approach. By not excluding those with Speech and Language Difficulties (SLD) from participating in the study, this led to more participants having SLD than was initially anticipated. From listening to their comments out of the interviews and observing another research study taking place, the keenness of those with IDs and SLD may have been due to their exclusion from taking part in many research studies (because it was deemed they were not able to communicate fluently enough for the study) or because their communicated responses to the researcher’s questions were not acknowledged or recorded because the researchers did not understand the participant’s speech and language style. The choice to conduct multiple interviews worked well and allowed me to gather rich data on the phenomenon in question for a number of reasons:

- It helped the participants who struggled to concentrate for a full hour because it allowed them to be able to engage for shorter time periods and have breaks when they wanted during the interviews.
- It helped to build rapport between myself and the participants, which led to some of the participants to feel that they could be more honest and open in their interviews (especially when they realised their data was indeed being kept confidential and not being given to those supporting them).
- The chance to gather a variation of complex temporal narratives and experiences of wellbeing (and suffering) and internet experiences which had happened over the period of time the interviews took place, a strength of multiple interviews also highlighted by Flowers (2008). This would not have been captured from one single interview.
- It gave myself and the participants time to reflect on the concrete experiences of wellbeing and internet discussed in the interviews and allowed me to prepare questions, prepare prompts and images for the next interview to clarify the lived experiences they had discussed.
- It enabled the participants to give me ‘homework’ to allow myself to experience their internet experiences, and for the participants to take the lead in their interviews.
- It gave me a chance to listen to the audio recordings of the interviews in order to tune into the participant’s speech and language patterns, especially if they had SLD.

The semi-structured/open and flexible interview format elicited some surprising encounters with the participants. Some participants thrived on the freedom that this type of interview offered and they slowly took the lead in the interviews. This included asking me to look at specific things on the internet so that we could talk about this in the next interview (as I would then have a basic experience and understanding of it). In the case of one participant, Leona, as well as watching the videos of sea lion shows that she had recommended, I also printed out screenshots of these YouTube videos and brought these to the next interview. This created amazement and excitement from Leona who wanted to know exactly what I had watched and what I thought about them. After a brief mutual exchange of thoughts over these videos, the participant was seen to take the lead in the interview, talking about her own online experiences and how these made her feel. In many respects, my own inexperience of the participants’ online activities, such as Junior Vets on Call, Criminal Case, Candy Crush, Final Fantasy, GTA, and CoD, appeared to encourage the participants to take an ‘expert’ role in the interview and describe and reflect upon their lived wellbeing and internet experiences in more detail. Leona would verbally scold me for not knowing certain things about the internet at times but would, like many participants, patiently explain to me what they were based on their own experiences, which was invaluable to this study.

Although most participants thrived with the semi-structured/open interviews, a few participants struggled. It took a while for some participants to get used to a semi-structured format and, rather than taking the lead, would ask for formal questions from myself. In these cases, even prompts about what they had already been talking about in their interview, had to be asked in a more formal way. One participant found that he disliked the intrusive nature of being asked questions in his first interview and withdrew from the study.

The use of the images of internet activities was useful for some participants, including those who struggled slightly with the interview structure and remembering activities they had done on the internet. The images were not used in any of the participants’ first interview so that they had the chance to talk about internet and wellbeing on their own terms and lead the interview. But when it was clear they were struggling, images were introduced into the interview as prompts, which often initiated the participants to voice their opinion on aspects of the internet they did not like, particularly online gambling. Rather than direct them to talk about a specific wellbeing and internet experience, the images appeared to lead them onto other relevant experiences not featured in the images.

One of the aims of the study was to offer, if needed, support to safely and independently access the internet to both the participants and those supporting them. However, support was not required or needed by the participants or those supporting them when it came to internet experiences. Instead, support was required around mental and physical health matters, in the form of signposting and helping the participant talk to a chosen staff member.

10.3 Recommendations

From findings and conclusions of this study, a number of recommendations can be made in regards to enabling adults with IDs to enjoy safe and independent use of the internet as well as increasing their agency, independency and opportunities for on- and off- line experiences.

10.3.1 Supporting adults with intellectual disabilities' safe, enjoyable and independent internet use

From the findings and the discussion in the conclusion, supporters of adults with IDs need to acknowledge the importance internet experiences are to many adults with IDs, and that these often become integral to their sense of wellbeing. Rather than labelling, what is judged as, excessive internet use as an addiction, the views and context of the individual needs to be taken into consideration for a number of reasons. Opportunities for experiencing aspects of the lifeworld and a sense of liberation (both of which are offered on the internet) may not be available to the individual offline and the internet experience may be the only opportunity they have to meet this need. In the findings, the lack of understanding, acknowledgement and/or discouragement of the adults with IDs' wellbeing and internet experiences by those who supported them led to a feeling of resentment by adults with IDs. Adults with IDs not only valued their online experiences and longed for them, they were often the only aspect of themselves and their lives that was not open to those who supported them. Adults with IDs often withheld information about what they did online, including negative experiences, to protect both their privacy, independence, and access to the internet. The support of adults with IDs to use the internet both safely and independently requires those supporters to be able to listen to an adult with IDs' wellbeing and internet experiences, with understanding, openness, and without judgement or resorting to control, restrictions and punishment when an adult with an ID encounters something negative online. The unpunished on- or off-line perpetrator, who remained safe from consequences or punishment, made many adults with IDs angry, left them feeling helpless and sometimes the one who was at fault. Further disclosures of online experiences may not be forthcoming if control, restriction and punishment are the consequences for an adult with an ID disclosing online experiences. This approach may require supporters to examine their relationship with the adult with an ID and ask themselves, how much control and restriction they exert in the adult with an ID's everyday life, and if there is any way they could be less restricting. By equipping adults with IDs with internet safety knowledge and positive support, which could include listening, discussing negative experiences, and building resilience, internet savviness can be developed, and safe and independent internet use can be realised.

10.3.2 Avoid segregating adults with intellectual disabilities on- and off-line

Adults with IDs wanted to use, and were using, mainstream internet activities in their everyday lives, rather than seeking out specialised ID websites. Specialist ID websites are yet another way to segregate those with IDs from society and further increase the digital divide this population often faces. It has to be acknowledged that many parts of the internet are not designed for access by those with an ID and the input of those with IDs would be invaluable in increasing the accessibility of the internet for all users. However, many adults with IDs in this study were not only navigating themselves around complex virtual worlds and communities, and extracting useful and relevant information, but were mastering online games, and performing high value roles in these games, which brought them preferred and relatable identities, status, respect, meaning and friendship. In a world that is becoming increasingly dominated by technology, the internet will continue to be part of our lives in the UK and will blur the boundaries between what is deemed ‘real’ and the ‘virtual’. ID-specialised websites, which may appear to increase access to those with IDs in the short term, may only hamper adults with IDs’ digital inclusion and independence in the long run, because they are not learning how to navigate themselves around mainstream online activities and relate to others online who do not have an ID. These skills will be essential for this population in the future if they are to lead independent and meaningful lives.

10.3.3 Better ethical treatment and representation of adults with intellectual disabilities’ lived experiences in research

The apparent lack of ethical consideration and respect towards those with IDs in some of the studies included in the literature review leads to the obvious recommendation that both researchers and organisations need to consider the ethical implications of a research study on participants with IDs. Potential participants with ID’s capacity should be assumed (in accordance with the Mental Capacity Act) and consent should be obtained by those with ID first, not from those who support them or the organisation in which they belong to, before they are included in a study.

This study highlighted that adults with IDs can give rich and reflective descriptions of their experiences if the right approach is used and the study design takes into account the differing needs of this population. They are indeed ‘experts’ on their own lives, and research that is around the lives of those with IDs needs to include, if not focus on, the voices of those with IDs. Including and re-presenting adults with IDs in research will increase the control they have over their own lives and influence research, policy and guidance that impacts on their lives.

10.3.4. More opportunities are needed for adults with intellectual disabilities to experience all aspects of the lifeworld

Many offline experiences, which those without an ID often take for granted, are out of reach for many of those with IDs. Many adults with IDs long for friendship, independence, meaningful projects, to feel valued and needed by others, and that they belong. The internet can simulate most aspects of the lifeworld and, despite the lack of offline opportunities, adults with IDs are finding the experiences they long for online and these are contributing to their sense of wellbeing and suffering. Whilst I feel adults with IDs should be encouraged to take up the opportunities presented by the internet, this study also raised the concern that many are turning to the internet to meet basic human needs due to a lack of, or undesirable, opportunities offline. A recommendation would be that adults with IDs should have opportunities to experience all dimensions of the lifeworld offline, and choose, if they wish, to take up further online opportunities for further experiences. However, internet simulations can contribute to an individual’s sense of wellbeing, and therefore could become more integral to everyone’s sense of wellbeing, not just adults with IDs. Perhaps we should not be afraid to admit that simulations online can feel ‘real’ enough to contribute to our sense of wellbeing and explore the phenomenon of wellbeing and internet in order to reap the benefits.

10.3.5 Support is needed for the mental health of adults with intellectual disabilities

It emerged in this study that five adults with IDs often experienced a sense of suffering from offline events. Many spoke about not having anyone they wanted to talk to about how they felt, even when it appeared they had a good network of support and were engaged in volunteering activities. Adults with IDs did not often want to share how they felt, which included feeling helplessness, anxiety, frustration, anger, sadness, depression, loneliness, and ‘stuck’ in one’s life, to name a few. A common reason for not wanting to share exactly how they felt with those who supported them, especially when it was not a positive feeling, was the fear of consequences, punishment, being pitied or placed further into the role of dependent, vulnerable or burdensome one. The relationship between adults with IDs and those who support them needs to be open, non-judgemental and aware that an adult with an ID is often striving for their own non-ID identities and roles and these can be threatened when they place themselves into the role of one who needs support. A recommendation would be to raise awareness of mental health in adults with IDs and offer independent and confidential support, which would not threaten their volunteering/working role and relationships with staff members. Those who support adults with IDs should be aware of the signs that an individual is struggling with their mental health, try to listen to how they feel, and not simply encourage further busyness. Wellbeing is a combination of mobility and dwelling, and whilst ID services are often focused on coordinating mobility (keeping an adult with an ID busy), they neglect or discourage an adult with an ID to dwell, which would contribute to a sense of wellbeing. This could be in the form of mindfulness or meditation.

10.3.6 Internet training

Many adults with IDs who were active on the internet appeared to know the basics of internet safety, for example, not giving out passwords to others. Some adults with IDs internet safety knowledge went beyond what most internet users know and practice. What many adults with IDs found difficult was subtle internet safety recommendations, for example, what are on- and off-line friendships, and, is someone who they say they are if you can see a photograph of that person? It is recommended that internet education covers more subtle internet safety topics, and should include concrete steps for an adult with an ID to follow when they experience something negative online. The steps should not result in restrictions or punishments, but empower adults with IDs to take action and not accept others' abusive, exploitative or manipulating behaviour towards them. We need to be mindful that many online spaces have their own etiquette and ‘norms’, which may be different from the offline spaces adults with IDs are used to. It became apparent that some of the participants in my study had both knowledge and experience of many online spaces (including the etiquette and ‘norms’), effectively navigating themselves within these spaces, connecting with others, and dealing with negative online experiences. Adults with IDs with this level of knowledge and experience would be well equipped to deliver internet safety training to other individuals and groups with IDs who have fewer online experiences.

10.4 Suggestions for further research

From this specific study there are a number of suggestions for further research that stand out:

- Using a descriptive-empirical phenomenological approach; one of the strengths of this study was that it focused on the experiences of those with IDs in an area dominated by the views and opinions of those without an ID. This methodological approach would benefit many other ID-related topics which are also overshadowed by non-ID voices.
- This study did not include participants with IDs who had an absence of social networks and volunteering opportunities. Research into this population could provide more insights into adults with IDs’ everyday lived experiences of wellbeing and internet.

- Research into adults with IDs' experience of friendships and their social networks and how this contributes to their sense of wellbeing and suffering, which may help to further understand their approach to friendship online as well as online mate-crime.
- Adults with IDs' identities (on- and off-line) were a strong feature in this study, notably those with Down's syndrome (DS) strongly rejected and did not like their DS identity. This could be further explored to understand how those with an ID and DS view themselves and how this may contribute to their sense of wellbeing and suffering.
- Many adults with IDs were experiencing poor mental health and using the internet to meet their emotional needs and support them. Further research exploring the variation of emotional support the internet offers adults with IDs would further illuminate the phenomenon wellbeing and internet and highlight ways in which this population's mental wellbeing could be supported online.
- Although there are good examples of adults with IDs inclusion in research, this needs to be continued so that they can continue to meaningfully influence decisions and policies that impact their lives. Research with or led by adults with IDs may need to be creatively adapted, re-thought, or approached differently in order to fully include those with IDs. For example, many adults with IDs in my study were comfortably inhabiting MMOs and MMORPGs and this offers future opportunities for research studies that take place within MMOs and MMORPGs to engage with adults with IDs in their online worlds. These online worlds are often less disabling for adults with IDs than traditional offline places used in ID-related research.

10.5 Strengths and limitations of this study

One of the requirements of Giorgi’s (2009) descriptive-empirical phenomenological methods is to gather a variation of experiences. Not only was there a variation in experiences, there was also a variation the participants’ ages (which ranged from 19 to 62), their gender (which was evenly split: 4 males and 4 females) and conditions, disabilities and difficulties (2 had DS, 2 had autism, and 5 had SLD). This gave some insights into age, gender and disability status in relation to the phenomenon: wellbeing and internet as experienced by those with IDs. Very few studies have focused only on participants with IDs and, by using a descriptive approach, new aspects to this topic were highlighted. Gender was new and surprisingly integral to the phenomenon wellbeing and internet, as was four participants’ experiences in MMORPGs and MMOs.

However, the participants were not a complete representation of a population with IDs. The participants all appeared to have a mild ID and all but one (who lived in his own house), currently lived with their family rather than in residential care or supported living. All participants were actively volunteering in one or more roles at the time of the study and they all had a social network on- and/or off-line. It was clear that the offline networks were not often as supportive or enabling for the participant as what might have at first appeared. Most participants experienced restrictions from these networks, in one way or another, and expressed disagreement or dissatisfaction with them. The restrictive nature of their offline support networks was often a factor for some of the participants’ extensive use of the internet.

As previously noted, descriptive-empirical phenomenology is not often used to approach research studies involving adults with IDs, but Finlay (2011) proposed that the use of Giorgi's (2009) descriptive-empirical phenomenological methods, if applied well, can create:

> 'powerful, rigorous and applicable findings, particularly well-suited to current demands for evidence-based practice' (:105).

But descriptive-empirical phenomenology still receives some criticism, such as being too rigid, structured and detached (Finlay, 2011; Giorgi, 2009). Similar to Reflective Lifeworld Research (RLR), descriptive-empirical phenomenology could also be criticised for not being:

> 'ambitious in terms of establishing essentialist or general understandings which, they would say, is the point of phenomenology' (Dahlberg et al., 2008:135).

Descriptive-empirical phenomenological approaches protect against:

> 'claiming too much certainty when offered general accounts of essential structures of experience' (Dahlberg et al., 2008:135).

It guards against the pre-understandings and pre-knowledge of the researcher, and misinterpretation of the participants' experience, often trying to make 'definite what is indefinite' (Finlay, 2011:136). A lifeworld approach can indeed present 'paradoxes and integrate polarities demonstrating holism' (Finlay, 2011:136; Dahlberg et al., 2008). The call for 'definite' is perhaps from positivist methods, because, if done well, descriptive-empirical phenomenology offers a way to present something that is as close as possible to re-presenting the participants' experience, while also capturing all the complexities, ambiguities and contradictions any experience brings (Finlay, 2009b). I feel wellbeing and internet is a good example of a complex phenomenon, which I feel the findings represented, without taking or adding to the participants' lived experiences, in all its complexity and ambiguity, as far as the phenomenon allowed itself to be shown in this study.

Considering the lack of concrete experiences by adults with IDs in the area of internet and wellbeing, this study automatically met a demand for research which originated from the concerns of adults with IDs and those who supported them. The findings not only re-presented the voice of adults with IDs but, from this voice, they also brought together an essential structure of the phenomenon: wellbeing and internet, which brings new understandings that are not currently considered in ID-related literature or have only been hypothesised and theorised.

List of References

Agyrou, V. (2013) *The gift of European thought and the cost of living.* New York: Berghahn Books.

Akram, A. H., Thomson, M. J. S. (2008) Morton Characterization and evaluation of UK websites on attention deficit hyperactivity disorder. *Archives of Disease in Childhood*, 93 (2008):695-700.

Allgar, V., Mir, G., Evans, J., Marshall, J., Cottrell, D., Heywood, P., Emerson, E. (2008) Estimated prevalence of people with learning disabilities: template for general practice. *The British Journal of General Practice*, 58(551):423-428.

Aman, M. G., Handen, B. (2006). Reactions to “Ethical challenges and complexities of including people with intellectual disability as participants in research” by Dr. Teresa Iacono. *Journal of Intellectual & Developmental Disability*, 31:180–182.

American Association on Intellectual and Developmental Disabilities (2013) *Definition of Intellectual Disability*. [online] *American Association on Intellectual and Developmental Disabilities*. Available online: http://aaidd.org/intellectual-disability/definition 2013 (accessed 06.08.2017).

American Psychiatric Association (2013) *Diagnostic and statistical manual of mental disorders: DSM-5. 5th Edition*. Washington, DC: American Psychiatric Publishing.

Andrzejewska, H. (2012) *Optimizing Your Campaigns: Best Days to Send Emails* [online] Get Response. Available: https://blog.getresponse.com/optimizing-your-campaigns-best-days-to-send-emails.html (accessed 24.09.2017).

Antaki, C., Billig, M., Edwards, D., Potter, J. (2002) Discourse analysis means doing analysis: A critique of six analytical shortcomings [online] *DAOL Discourse Analysis Online*. Available: https://extra.shu.ac.uk/daol/articles/open/2002/002/antaki2002002-paper.html (accessed 06.01.2018).

Araten-Bergman, T., Avieli, H., Mushkin, P., Band-Winterstein, T. (2015) How aging individuals with schizophrenia experience the self-etiology of their illness: a reflective lifeworld research approach. *Aging & Mental Health*, 20(11):1147-1156.

Argyle, K., Shields, R. (1996) Is there a Body on the Net? In Sheilds, R. (ed) *Cultures of Internet: Virtual Spaces, Real Histories, Living Bodies*. London: Sage. Pp:58-69.

Ashworth, P. D. (1996) Presuppose nothing! The suspension of assumptions in phenomenological psychological methodology. *Journal of Phenomenological Psychology*, 27:1-25.

Ashworth, P. (2003) The phenomenology of the lifeworld and social psychology. *Social Psychological Review*, 5 (1):18-34.

Ashworth, P. D. (2006) Introduction to the place of phenomenological thinking in the history of psychology. In Ashworth, P., Chung, M. C. (eds) *Phenomenology and Psychological Science: Historical and Theoretical Perspectives*. New York, US: Springer.

Ashworth, P. D. (2015) The Lifeworld – enriching qualitative evidence. *Qualitative Research in Psychology*, 13(1):20-32.

Atherton, H. (2013) Dangers of ambivalence: lessons learned from the Nazi era. *Learning Disability Practice*, 16(1):16-20.

Atherton, H. (2007) A history of learning disabilities. In Gates, B (ed) *Learning Disabilities. Towards Inclusion*. Philadelphia, USA: Elsevier Limited, 43-66.

Atkinson, D. (1993) Life history work with a group of people with learning disabilities. *Groupwork*, 6 (3):199-210.

Auger, P., Gallaugher, J.,M. (1997) Factors affecting the adoption of an internet-based sales presence for small businesses. *The Information Society*, 13(1), 55-74.

Avni, B. (2014) 'Who do you trust to run the internet?' *Newsweek Global*, 162(13):1-5.

Balsamo, A. (1996) *Technologies of the Gendered Body: Rading Cyborg Women*. Durham, NC: Duke University Press.

Bannon, S., McGlynn, T., Quayle, E. (2015) The positive role of Internet use for young people with additional support needs: identity and connectedness. *Computers in Human Behaviour*, 53:504–14.

Barak, A., Boniel-Nissim, M., Suler, J. (2008) Fostering empowerment in online support groups. *Computers in Human Behaviour*, 24(5):1867-1883.

Barnes, C. (1992) *Disabling Imagery and the Media: An Explorartion of the Principles for Media Representation of Disabled People*. Keele, UK: Keele University Press.

Barnes, C. (1996) Theories of disability and the origins of the oppression of disabled people in Western society. In Barton , L. (ed) *Disability and Society: Emerging Issues and Insights*. London: Longman.

Bartle, R. A., (2004) *Designing Virtual Worlds.* Indianapolis, US: New Riders.

Bartle, R. A. (2014) Design Principles: Use and Misuse. In Quandt, T., Kröger, S (eds) *Multiplayer. The Social Aspects of Digital Gaming*. 10-22. Oxen, UK: Routledge.

Baxter, H., Lowe, K., Houston, H., Jones, G., Felce, D., Kerr, M. (2006) Previously unidentified morbidity in patients with intellectual disability. *British Journal of General Practice,* 56:93–8.

Bijou, S. W. (1992) Concepts of mental retardation. *Psychological Record*, 42:305-322.

Beadle-Brown, J., Richardson, L., Guest, C., Malovic, A., Bradshaw, J., Himmerich, J. (2014). *Living in Fear: Better Outcomes for people with learning disabilities and autism. Main research report.* Canterbury, UK: Tizard Centre, University of Kent.

Beart, S., Hardy, G., Buchan, L. (2005) How people with intellectual disabilities view their social identity: a review of the literature. *Journal of Applied Research in Intellectual Disabilities*, 18:47-56.

Bengtsson, J. (1991) *Den fenomenologiska rörelsen I Sverige. Mottagande och inflytande 1900-1968 (The phenomenological movement in Sweden 1900-1968).* Göteborg: Daidalos.

Bengtsson, J. (1998) *Fenomenologiska utflykter (Phenomenological excursions)*. Göteborg: Daidalos.

Bernstam, E. V., Shelton, D. M., Walji, M., Meric-Bernstam, F. (2005) Instruments to assess the quality of health information on the World Wide Web: What can our patients actually use. *Internal Journal of Medical Informatics*, 74(1):13-19.

Bernstein, R., J. (1988) *Beyond Objectivism and Relativism: Science, Hermeneutics and Practice.* Philadelphia, PA: University of Pennsylvania Press.

Bettany-Saltikov, J. (2012) *How to do a systematic literature review in nursing*. Berkshire, UK: Open University Press.

Blaxter, M. (1996) Criteria For The Evaluation Of Qualitative Research Papers. *Medical Sociology News*, 22 (1).

Blaxter, M. (2003) Criteria For The Evaluation Of Qualitative Research Papers. *Medical Sociology Online*, 7 (1):4-7.

Boellstorff, T. (2008) *Coming of age in Second Life. An Anthropologist Explore the Virtually Human.* New Jersey, US: Princeton University Press.

Boellstorff, T. (2011) Virtuality. Placing the Virtual Body: Avatar, Chora, Cypherg, in Mascia-Lees, F. E. (ed) *A Companion to the Anthropology of the Body and Embodiment*. First Edition. UK: Blackwell Publishing Ltd.

Bourke, B. (2014) Positionality: Reflecting on the Research Process. *The Qualitative Report*, 19:1-9.

Bowker, N., Tuffin, K. (2002) Disability discourse for online identities. *Disability & Society*, 17(3):327-344.

Boyatzis, R. E. (1998) *Transforming qualitative information: Thematic analysis and code development.* Thousand Oaks, CA, US: Sage.

Brackenridge, R., McKenzie, K. (2005) The friendships of people with a learning disability. *Learning Disability Practice*, 8(5):12-16.

Bradburn, N. (1969). *The structure of psychological well-being*. Chicago: Aldine.

Braddock, D., Rizzolo, M.,C., Thompson, M., Bell, R. (2004) Emerging technologies and cognitive disability. *Journal of Special Education Technology*, 19 (4):49-56.

Bradley, B. (2015) *Well-Being*. Cambridge, UK: Polity Press.

Braud, W. G., Anderson, R. (eds) (1998) *Transpersonal Research Methods for the Social Sciences: Honoring Human Experience.* Thousand Oaks, CA: Sage.

Braun, V., Clarke, V. (2006) Using thematic analysis in psychology, *Qualitative Research in Psychology*, 3(2):77-101.

Braun, V., Clarke, V. (2013) *Sucessful Qualitative Research*. London, UK: Sage Publications Ltd.

Bredberg, E. (1999) Writing disability history: problems, perspectives and sources. *Disability and Society*, 14(2):189-201.

Breck , T. (2002) *Riskkommunikation. Dialog om det osäkra (Risk Communication. A Dialogue about the Uncertain* (not available in English): Stockholm: Natur och kultur.

Bremer, A., Dahlberg, K., Sandman, L. (2009) To survive out-of hospital cardiac arrest: A search for meaning and coherence. *Qualitative Health Research*, 19:323-338.

Brentano, F. (1874) *Psychology from an Empirical Standpoint* (Rancurello, A. C., Terrell, D. B., McAlister, L, trans). UK: Routledge.

Brewer, J. L., Taber-Doughty, T., Kubik, S. (2010) Safety assessment of a home-based telecare system for adults with developmental disabilities in Indiana: a multi-stakeholder perspective. *Journal of Telemedicine and Telecare,* 16(5):265-269.

British Broadcasting Corporation (BBC) News (2008) Parents Fight for Right to Life [online] *BBC*. Available*:* http://news.bbc.co.uk/1/hi/wales/7483099.stm (accessed: 10.1.2013).

British Broadcasting Corporation (BBC) News (2009) When Life and Death Involves the Law. [online] *BBC*. Available: http://tinyurl.com/bbcnews2013 (accessed: 10.1.2013).

British Dyslexia Association (n.d.) Dyslexia and specific learning difficulties in adults [online] *British Dyslexia Association*. Available: http://www.bdadyslexia.org.uk/dyslexic/dyslexia-and-specific-learning-difficulties-in-adults (accessed 06.08.2017).

British Institute for Learning Disabilities (BILD) (2017) Information about learning disabilities [online] *BILD*. Available: http://www.bild.org.uk/resources/faqs/#What-is-the-difference-between-the-terms-learning-disabilities-learning-difficulties-and-intellectual-disabilities (accessed 09.09.2017).

Brock, J.,K., Yu, Z. (2005) Organizational use of the internet: Scale development and validation. *Internet Research*, 15(1):67-87.

Brown, H., Thompson, D.(1997) The ethics of research with men who have learning disabilities and abusive sexual behaviour: A minefield in a vacuum. *Disability & Society*, 12(5):695–707.

Bruce, N., Pope, D., Stanistreet, D. (2008) *Quantitative methods for health research: A practical interactive guide to epidemology and statistics.* London: Wiley.

Burleigh, M. (1994). *Death and deliverance: ‘Euthanasia’ in Germany c. 1900 - 1945*. Cambridge: Cambridge University Press.

Burns, J. (2000) Gender identity and women with learning difficulties: the third sex. *Clinical Psychology Forum*, 137:137-139.

Bussing, R., Zima, B. T., Mason, D. M., Meyer, J. M., White, K., Garvan, C. W. (2012) ADHD knowledge, perceptions, and information sources: Perspectives from a community sample of adolescents and their parents. *Journal of Adolescent Health*, 51 (2012):593-600.

Campbell, J. E. (2004) *Getting It On Line: CyberSpace, Gay Male Sexuality, and Embodied Identity*. New York: Harrington Park Press.

Caplan, S. E., Williams, D., Yee, N. (2009) Problematic Internet use and psycological well-being among MMO players. *Computers in Human Behavior*, 25(6):1312-1319.

Caplone, G., Goyal, P., Ares, W., Lannigan, E. (2006) Neurobehavioral disorders in children, adolescents, and young adults with Down syndrome. *American Journal of Medical Genetics. Part C, Seminars in Medical Genetics, 142C*:158- 172.

Carey, A. C., Friedman, M. G., Bryen, D. N., Taylor, S. J. (2005) Use of electronic technologies by people with intellectual disabilities. *Mental Retardation,* 43(5):322-333.

Caton, S., Chapman, M. (2016). The use of social media and people with intellectual disability: A systematic review and thematic analysis. *Journal of Intellectual & Developmental Disability*, 41, 125–139.

Chadwick, D. D., Fullwood, C., Wesson, C.J. (2013a) Intellectual Disability, Identity, and the Internet. In R. Luppicini (ed) *Handbook of research on technoself: Identity in a technological society*. US: Information Science Reference (an imprint of IGI Global), 229-254.

Chadwick, D. D., Quinn, S., Fullwood, C. (2016) Perceptions of the risks and benefits of Internet access and use by people with intellectual disabilities. *British Journal of Learning Disabilities*, 45(1):21-31.

Chadwick D. D., Wesson C. (2016). Digital inclusion & disability. In Attrill A., Fullwood C. (eds) *Applied Cyberpsychology: applications of cyberpsychological theory and research*. Chennai: Palgrave Macmillan, 1-24.

Chadwick D., Wesson C., Fullwood C. (2013b) Internet access by people with intellectual disabilities: inequalities and opportunities. *Future Internet*, 5(3): 376–97.

Changsu, K., Galliers, R. D. (2000) Towards a diffusion model for internet systems. *Internet Networking Application and Policy*, 14 (2):155-166.

Chappell, A. L. (1994) A question of friendship: community care and the relationships of people with learning difficulties. *Disability & Society*, 9(4):419-434.

Cheatham, L., P. (2012) Effects of Internet use on well-being among adults with physical disabilities: A review. *Disability and Rehabilitation: Assistive Technology*, 7 (3):181-188.

Chowdhury, J., Drummond, J., Fleming, D., Neufeld, S. (2002) Content analysis of online autism specific websites. *Journal on Developmental Disabilities*, 9(2):157-165.

Clarke, D. (1986) *Mentally handicapped people living and learning*. London: Bailliè Tindall.

Cohen, S., Wills, T. A. (1985) Stress, social support and the buffering hypothesis. *Psychological Bulletin*, 98(2):310-357.

Cole, J. I., Suman, M., Schramm, P., Zhou, L., Tang, A. S. (2012) *World Internet Project international report (5th ed.)*, World Internet Project, Los Angeles, CA (2012).

Comer, D. (2000) *The Internet Book: Everything You Need to Know about Computer Networking and how the Internet Works*. US: Prentice Hall.

Comte, A. (1979) *Om positivismen (On positivism).* Götenborg: Korpen.

Cox, B. G., Koelzer, W. (2003) *Internet marketing*. Edgewood Cliffs, NJ, US: Prentice-Hall.

Cromby, J., Standen, P. J., Brown, D. J. (1996) The potentials of virtual environments in the education and training of people with learning disabilities. *Journal of Intellectual Disability Research*, 40 (6):489-501.

Crook, B., Tomlins, R., Bancroft, A., Ogi, L. (2015) 'So often they do not get recruited': exploring service user and staff perspectives on participation in learning disability research and the barriers that inhibit it. *British Journal of Learning Disabilities*, 44:130-137.

Cummings, J. N., Sproul, L., Kiesler, S. B. (2002) Beyound hearing: Where the real-world and online support meet. *Group Dynamics*, 6 (1):78-88.

Dahlberg, K., Dahlberg, H., Nyström, M. (2008) *Reflective Lifeworld Research*. *Second edition*. Lund: Studentlitteratur.

Davies, J. (2013a) Four things you probably didn't know about disability hate crime [online] *Mencap*. Available: https://www.mencap.org.uk/blog/four-things-you-probably-didnt-know-about-disability-hate-crime (accessed 19.12.2016).

Davies, J. (2013b) Staying safe online [online] *Foundation for people with learning disabilities*. Available: http://www.learningdisabilities.org.uk/our-news/blog/13-02-25-stayingsafeonline/ (accessed 01.10.2013).

Deb. S., Thomas. M., Bright. C. (2001) Mental disorder in adults with intellectual disability. 1: Prevalence of functional psychiatric illness among a community based population aged between 16 and 64 years. *Journal of Intellectual Disability Research*, 45(6):495–505.

December, J. (1996) Units of Analysis for Internet Communication. *Journal of Computer-Mediated Communication*, 1(4).

Department of Health (DoH) (2001a) *Valuing people: a new strategy for learning disability for the 21st century*. London: DoH.

Department of Health (DoH) (2001b) *Nothing about us without us*. London: DoH.

Department of Health (DoH) (2009) *Valuing people now: a new three year strategy for people with learning disability*. London: DoH.

Department of Health (DoH) (2012) *Transforming care: A national response to Winterbourne View Hospital. Department of Health Review: Final Report*. London: DoH.

Di Pietro, N.C., Whiteley, L., Illes, J. (2012) Treatments and services for neurodevelopmental disorders on advocacy websites: Information or evaluation? *Neuroethics*, 5(2):197-209.

Devine, D. (2017) The bullying of people with autism and learning disabilities [online] *Learning Disability Today*. Available: https://www.learningdisabilitytoday.co.uk/the-bullying-of-people-with-autism-and-learning-disabilities (accessed 25.01.2018).

Dickerson, K., Chan, S., Chalmersx, T.C., Sacks, H., Smith, J. (1987) Publication bias and clinical trials. *Controlled Clinical Trials*, 8(4): 343-353.

Diener, E. (1984). Subjective well-being. *Psychological Bulletin*, 95, 542–575.

Diener, E. (2009) Subjective well-being. In Diener, E. (Ed.) *The science of well-being*. New York: Spring. 11-58.

dimensions (2017) Hate Crime towards people with learning disabilities and autism [online] *dimensions*. Available: https://www.dimensions-uk.org/position-statement/hate-crime-learning-disability-autism/ (accessed 28.09.2017).

Doan, K., Bloomfield, A. (2014) 'The effects of browse time on the Internet on students' essay scores', Techtrends: Linking. *Research & Practice To Improve Learning*, 58(6):63-72.

Dobransky, K., Hargittai, E. (2006) The disability divide in internet access and use. *Information Communication and Society*, 9(3):313-334.

Dodge, R., Daly, A. P., Huyton, J., Sanders, L. D. (2012) The challenge of defining wellbeing. *International Journal of Wellbeing*, 2 (3):222-235.

Doka, K. J., (2002) *Disenfranchised Grief: New Diections, Challenges and Strategies for Practice*. Illinois, US: Research.

Douglas, M., Wood, R., Sim, J. (2010) Sexuality. In Talbot, P., Astbury, G., Mason, T. (eds) *Key Concepts in Learning Disabilities*. London: Sage Publications Ltd. 232-238.

Doyle, D. (2009) The Body of the Avatar: Rethinking the Mind-Body Relationship in Virtual Worlds. *Journal of Gaming and Virtual Worlds*, 1(2):131-141.

Drake, R. F. (1996) A critique of the role of the traditional charities, in Barton, L. (ed) *Disability and Society: Emerging Issues and Insights*. London: Longman.

Duck, S. (1991) *Understanding relationships*. New York, US: Guilford Press.

Dunckley, V. L. (2016) Autism and Screen Time: Special Brains, Special Risks [online] Psychology Today. Available: https://www.psychologytoday.com/blog/mental-wealth/201612/autism-and-screen-time-special-brains-special-risks (accessed 26.01.2018).

Dutton, W., Helsper, E., J. (2007) *The internet in Britain*. Oxford, UK: Oxford Internet Institute, University of Oxford.

Eastgate, G., Van Driel, M. L., Lennox, N. G., Scheermeyer, E. (2011) Women with Intellectual Disabilities – a study of sexuality, sexual abuse and protection skills. *Australian Family Physician*, 40(4):226-230.

Edgerton, R. (1975) Issues relating to the quality of life among mentally retarded persons. In Begab, M., Richerdson, S. (eds) *The mentally retarded and society: a social science perspective*. University Park Press, Baltimore: Pp: 127-140.

Edler, C., Rath, M. (2014) People with Learning Disabilities Using the iPad as a Communication Tool - Conditions and Impact with Regard to e-inclusion. In K. Miesenberger, D. Fels, D. Archambault, P. Penaz, W. Zaglar (eds) *Computers helping people with special needs. 14th international conference, ICCHP 2014*. Paris, France: ICCHP. 169-176.

Egoyan, M. (2007) Virtual Embodiment [online] Embodied Research Group. Available: http://embodiedresearch.blogspot.com/2007/12/virtual-embodiment.html (accessed 06.08.2018).

Equality and Human Rights Commission (2016) England's most disadvantaged groups: people with learning disabilities. An Is England Fairer? Review spotlight report (3 of 4) [online] *Equality and Human Rights Commission*. Available: http://www.equalityhumanrights.com/IsEnglandFairer (accessed 29.09.2017).

Elliott, R., Fischer, C.T., Rennie, D. L. (1999) Evolving guidelines for publication of qualitative research studies in psychology and related fields, *British Journal of Clinical Psychology*, 38:215-229.

Elliston, F. (1977) Husserl's phenomenology of empathy. In Elliston, F., McCormick, P. (eds): *Husserl. Expositions and appraisals.* London: University of Notre Dame Press, 213-231.

Emerson, E. (1985) Evaluating the impact of deinstitutionalization on the lives of mentally retarded people. *American Journal of Mental Deficiency*, 90 (3), 277.

Emerson, E., Baines, S., (2010), *Health Inequalities & People with Learning Disabilities in the UK*. London: Improving Health and Lives: Learning Disability Observatory supported by the Department of Health.

Emerson, E., Hatton, C. (2010) Socio-economic position, poverty and family research. In L. M. Glidden and M. M. Seltzer (eds) *On families: International review of research on mental retardation*. New York, US: Academic Press.

Emerson, E., Hatton, C., Felce, D., Murphy, G. (2001) *Learning disabilities: the fundamental facts*. London: The Foundation for People with Learning Disabilities.

Emerson, E., Mallam, S., Davies, I. and Spencer, K., (2005) *Adults with learning difficulties in England 2003/4.* London: Office of National Statistics and NHS Health and Social Care Information Centre.

Emerson, E., McVilly, K. (2004) Friendship Activities of Adults with Intellectual Disabilities in Supported Accommodation in Northern England. *Journal of Applied Research into Intellectual Disabilities*, 17(3):191-197.

England, K. V. L. (1994) Getting Personal: Reflexivity, Positionality, and Feminist Research. *The Professional Geographer*, 46(1):80-89.

Eysenbach, G., Powell, J., Kuss, O., Sa, E. R. (2002) Empirical studies assessing the quality of health information for consumers on the World Wide Web: A systematic review. *The Journal of the American Medical Association*, 287(20):2691-2700.

Feng J., Lazar J., Kumin L., Ozok A. (2008). Computer usage by young individuals with down syndrome: an exploratory study. *In Proceedings of Assets '08 Proceedings of the 10th International ACM SIGACCESS Conference on Computers and Accessibility*. New York, US: ACM. 35–42.

Finlay, L. (2008) Introducing Phenomenological Research [online] *SCRIBD*. Available: http://www.apac.org.uk/alms/sessions/4/IntroductionToPhenomenology2008.pdf (accessed 05.08.2015).

Finaly, L. (2009a) Debating Phenomenological Research. Methods. *Phenomenology & Practice*, 3:6-25.

Finlay, L. (2009b) Exploring lived experience: principles and practice of phenomenological research. *International Journal of Therapy and Rehabilitation*, 16(9):474-481.

Finlay, L. (2011) *Phenomenology for Therapist. Researching the Lived World*. UK: Wiley-Blackwell.

Finlay, L., Evans, K. (2009a) *Relational centred qualitative research for psychotherapists and counsellors: exploring meanings and experience*. Chichester, UK, Wiley–Blackwell.

Finlay, L., Evans, K. (2009b) Examples of relational research in action [online] *lindafinlay.co.uk.* Available: http://lindafinlay.co.uk/wp-content/uploads/2014/05/Examples-of-relational-research-in-action.pdf (acessed 29.09.2017).

Flowers, P. (2008) Temporal tales: The use of multiple interviews with the same participant. *Qualitative Methods in Psychology*, 5:24-27.

Forgeard, M. J. C., Jayawickreme, E., Kern, M., Seligman, M. E. P. (2011). Doing the right thing: Measuring wellbeing for public policy. *International Journal of Wellbeing*, 1(1):79–106.

Fox, S., Duggan, M. (2013) Health online 2013. [online] *Pew Research Centre Internet & Technology.* Available: http://www.pewinternet.org/2013/01/15/health-online-2013/ (accessed 05.05.2017).

Fox, S., (2011) *Americans living with a disability and their technology profile. Washington*, DC, US: Pew Research Centre's Internet & American Life Project.

Friedlander, H. (1995) *The origins of Nazi genocide: From euthanasia to the final solution*. Chapel Hill: University of North Carolina Press.

Fullwood, C., Wooton, N. (2009) Comforting communication in an online epilepsy forum. *Journal of Cybertherapy and Rehabilitation*, 2 (2), 159-164.

Gable, S. L., Haidt, J. (2005). What (and why) is positive psychology? *Review of General Psychology*, 9, 103–110.

Gadamer, H. G. (1995/1960) *Truth and method. Second revised edition* (Weinsheimer, J., Marshall, D., Trans). New York: The Continuum Publishing Company.

Gadamer, H. G. (1996/1975) *Truth and Method*. (2nd edn). London: Sheed and Ward.

Gagnon, J. H., Simon, W. (1973) *Sexual conduct. the social sources of human sexuality.* Chicago, US: Aldine Publishers Company.

Galvin, K., Todres, L. (2013) *Caring and Well-being*. *A lifeworld approach*. UK: Routledge.

Galvin, K., Todres, L. (2015) Dignity as honour-wound: an experiential and relational view. *Journal of Evaluation in Clinical Practice*, 21:410-418.

Galvin, K., Todres, L., Richardson, M. (2005). The intimate mediator: A carer's experience of Alzheimer's. *Scandinavian Journal of Caring Sciences*, 19:2-11.

Galvin, K. T, Todres, L. (2011) Kinds of well-being: A conceptual framework that provides direction for caring. *International Journal of Qualitative Studies in Health and Well-being*, 6:1-13.

Gallagher, H. G. (1990). *By trust betrayed: Patients, physicians, and the license to kill in the Third Reich*. New York: Henry Holt.

Garcia, F. A. Teruel, A. G., Calduch, P. B., Frias, R. R., Blasco, L. C. (2005) A comparative study of six European databases of medically oriented web resources. *Journal of the Medical Library Association*, 93 (4): 467-479.

Gates, B., Reading Speaking Up Group., People First Bradford Group. (2007) The nature of learning disabilities. In Gates, B. (ed) *Learning Disabilities Towards Inclusion.* Philadelphia, US: Churchill Livingstone Elsevier. 3-20.

Gazaway, R. (1969) *The Longest Mile.* Doubleday, Garden City, New York.

Gee, J. P. (2008) Video Games and Embodiment. *Games and Culture*, 3(3/4):253-263

Giorgi, A. (1985) *Phenomenological and Psychological Research*. Pittsburgh, PA, US: Duquesne University Press.

Giorgi, A. (1989) One type of analysis of descriptive data: Procedures involved in following a scientific phenomenological method. *Methods*, 1(2):39-61.

Giorgi A (1997) The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. *Journal of Phenomenological Psychology*, 28(2):235–60.

Giorgi, A. (2008a) Difficulties encountered in the application of the phenomenological method in the social sciences. *Indo-Pacific Journal of Phenomenology*, 8:1-9.

Giorgi, A. (2008b) Concerning a serious misunderstanding of the essence of the phenomenological method in psychology. *Journal of Phenomenological Psychology*, 33-58.

Giorgi, A. (2009) *The Descriptive Phenomenological Method in Psychology. A modified Husserlian Approach*. Pittsburgh, Pennsylvania, US: Duquesne University Press.

Goggin, G., Newell, C. (2003) *Digital disability: The social construction of disability in new media*. Lanham, MD, US: Rowman & Littlefield.

Gordon, C. F., Juang, L., Syed, M. (2007) Internet Use and Well-Being Among College Students: Beyond Frequency of Use. *Journal of College Student Development*, 48(6):674-688.

Graham, G. (1999) *The Internet. A philosophical inquiry.* London: Routledge.

Gramsci, A. (1971) *Selections from the Prison Notebooks*. London: Lawrence and Wishart.

Gravell, C. (2012) *Loneliness + Cruelty. People with learning disabilities and their experience of harassment, abuse, and related crime in the community*. London: Lemos and Crane.

Grbich, C. (1999) *Qualitative Research in Health. An Introduction*. London: Sage Publications Ltd.

Griffiths, M. D., (2014) An Overview of Online Gaming Addiction. In Quandt, T., Kröger, S. (eds) *Multiplayer. The Social Aspects of Digital Gaming*. New York, NY, US: Routledge. 195-201.

Griffiths, M. D., Kuss, D. J., King, D. L., (2012) Video game addiction: Past, present and future. *Current Psychiatry Reviews*, 8(4):308-318.

Gross, E., F. (2004) Adolescent internet use: what we expect, what teens report. *Applied Developmental Psychology*, 58 633-649.

Guerin, E. (2012) Disentangling Vitality, Well-being, and Qulaity of Life: A Cenceptual Examination Emphasizing Their Similarities and Differences With Special Application in the Physical ctivity Domain. *Journal of Physical Activity and Health*, 9:896-908.

Gustin, S. (2014) The Internet Is About to Take Its Next Gaint Evolutionary Leap. [online] *Time*. Available: http://time.com/25931/us-internet-oversight-plan/ (accessed 30.01.2017).

Gutiérrez, P., Zaragoza, A. M., (2011) People with Intellectual Disability and ICTs. *Comunicar*, 36(18):173-180.

Giubilini. A., Minerva. F. (2012a) After-birth abortion: why should the baby live? [online] *Journal of Medical Ethics. Online First*. Available: http://jme.bmj.com/content/early/2012/03/01/medethics-2011-100411 (accessed 30.01.2017).

Giubilini. A., Minerva, F. (2012b) An open letter from guibilini and minerva. [online] *British Medical Journal Group Blogs. Brassington, I.* Available: http://blogs.bmj.com/medical-ethics/2012/03/02/an-open-letter-from-giubilini-and-minerva/ (accessed 30.01.2017).

Guo, B., Bricout, J. C., Huang, J. (2005) A common open space or a digital divide? A social model perspective on the online disability community in China. *Disability and Society*, 20(1):49-66.

Gustafsson, B. E., Quensel, C. E., Lanke, L. S., Lundqvist, C., Grahnen, H., Bonow, B. E., Krasse, B. (1954) The Vipeholme dental caries study – the effect of different levels of carbohydrate intake on caries activity in 436 individuals observed for five years. *Acta Odontologica Scandinavica*, 11(3-4):232-264.

Hafner, K. (2004) For Some, the Blogging Never Stops. [online] *New York Times*. Available: http://www.nytimes.com/learning/teachers/featured_articles/20040527thursday.html (accessed 30.01.2017).

Hall, V., Conboy-Hill, S., Taylor, D. (2011) Using virtual reality to provide health care information to people with intellectual disababilities: acceptability, usability, and potential utility. *Journal of Medical Internet Research*, 13(4):e91.

Halling, S. (2007) *Intimacy, Transcendence, and Psychology: Closeness and Openness in Everyday Life*. New York, US: Palgrave MacMillan.

Harris, J.,C. (2006) *Intellectual disability: Understanding its development, causes, classification, evaluation, and treatment*. New York, US: Oxford University Press.

Harrysson, A., Svensk, A., Johansson, G. I. (2004) How people with developmental disabilities navigate the Internet. *British Journal of Special Education,* 31: 138–142.

Heidegger, M. (1962/1927) *Being and Time*. Blackwell, Oxford.

Heidegger, M. (1966/1959) *Gelassenheit [Discourse on Thinking]* (Anderson, J. M., Freund, E. H. Trans) New York, NY, US: Harper & Row.

Heidegger M. (1975/1988) *The Basic Problems of Phenomenology* (Hofstadter, A. trans). Bloomington, IN, US: Indiana University Press.

Heidegger, M. (1976) *'Brief über den 'Humanism'.'* Wegmarken. GA 9 Ed. Friedrich-Wilhelm von Hermann. Frankfurt a.M.: Klostermann.

Heidegger, M. (1998/1927) *Being and Time* (Macquarrie, J., Robinson, R., trans.). Oxford, UK: Blackwells.

Heim, M. (1995) The Design of Virtual Reality. In Featherstone, M., Burrows, R. (eds) *Cyberspace/Cyberbodies/Cyberpunk:Cultures of Technological Embodiment.* London: Sage.

Hegarty, J. R., Aspinall, A. (2006) The use of personal computers with adults who have developmental disability: Outcomes of an organisational-wide initiative. *The British Journal of Developmental Disabilities*, 52 (103):137-154.

Henwood, K. L., Pidgeon, N. E. (1992) Qualitative research and psychological theorising. *British Journal of Psychology*, 83(1):97-112.

Hilbert, M. (2015) Digital Divides(s). *The International Encyclopedia of Digital Communication and Society*, 1–7.

Hillis, K. (1999) *Digital Sensations: Space, Identity, and Embodiment in Virtual Reality*. Minneapolis: University of Minnesota Press.

Her Magesty's Stationary Office (HMSO) (2008) A Life Like Any Other? Human Rights of Adults with Learning Disabilities. London: HMSO.

Her Magesty's Stationary Office (HMSO) (2014) *Care Act*. London: HMSO.

Holland, K. (2011) *Factsheet: Learning Disabilities*. British Institute of Learning Disabilities: Birmingham, UK.

Hollins, S., Attard, M., van Frauhofer, N., McGuigan, S.,M. & Sedgwick, P. (1998) Mortality in people with learning disability: risks causes, and death certificate findings in London. *Developmental Medicine and Child Neurology*., 39:50-56.

Holm, P., Holst, J., Black Olsen, S., Perti, B. (1997) Efter normaliseringen (After the normalization). In Tøssebro (ed) *Den Vœnsklige Integreringen (The Risky Integration)*. Oslo: Universitetens Forlag.

Holmes, K.M., O'Loughlin, N. (2014) The experiences of people with learning disabilities on social netowrking sites. *British Journal of Learning Disabilities*, 42 (1), 3-7.

Hoppestad B. S. (2013) Current perspective regarding adults with intellectual and developmental disabilities accessing computer technology. *Disability and Rehabilitation: Assistive Technology*, 8 (3):190.

Horsley, T., Dingwall, O., Sampson, M. (2011) Checking reference lists to find additional studies for systematic reviews. *Cochrane Database of Systematic Reviews*, Issue 8. Art. No.: MR000026.

Huber, M., Knottnerus, J.A., Green, L., Van der Horst, H., Jadad, A. R., Kromhout, D., Leonard, B., Lorig, K., Loureiro, M. I., Van der Meer, J. W. M., Schnabel, P., Smith, R., Van Weel, C., Smid, H. (2011) How should we define health? *British Medical Journal*, 343:d4163.

Husserl, E. (1964/1928) *The phenomenology of internal time consciousness* (Churchill, J. S. Trans) London: Indiana University Press.

Husserl, E. (1970/1900) *Logical investigations: Vol. 1. Prolegomena to pure logic.* (Finlay, J, Trans). London: Routledge & Kegan Paul.

Husserl, E. (1970/1936) *The crisis of European sciences and transcendental phenomenology* (Carr, D. trans). Evanston, IL: North Western University Press.

Husserl, E (1973/1950) *Cartesian meditations: an introduction to phenomenology*. Martinus Nijhoff: The Hague.

Husserl, E. (1973/1939) *Experience and Judgement* (Churchill, J. S., Amerikis, K., Trans). Evanston, IL, US: South Western University Press.

Hurssel, E. (1977/1929) *Cartesian meditations* (Cairns, Trans). The Hague: Mertinus Nijhoff.

Husserl, E. (1982). *Ideas pertaining to a pure phenomenology and to a phenomenological philosophy: first book, general introduction to a pure phenomenology.* (F. Kersten, Trans.). Boston: Kluwer Academic Publishers.

Husserl, E. (1991/1893–1917) *On the phenomenology of the consciousness of internal time.* Kluwer: Dordrecht.

Hurssel, E. (1992 / 1929). *Cartesianska meditationer En inledning till fenomenologin (Cartesian meditations)* (Birbaum, D., Wallenstein, Trans). Göteborg: Daidalos.

Husserl, E. (1998 / 1913) *Ideas pertaining to a pure phenomenology and to a phenomenological philosophy. First book* (F. Kersten, Trans.) London: Kluwer Academic Publication.

Iacono T., Murray V. (2003) Issues of informed consent in conducting medical research involving people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 16: 41–51.

Ihde, D. (2002) *Bodies in Technology. Minneapolis*: University of Minnesota Press.

Ito, M. (1997) Virtually Embodied: The Reality of Fantasy in a Multi-User Dungeon. In Porter, D. (ed) *Internet Culture*. New York: Routeledge. Pp:87-109.

Jadad, A.R. O’Grady, L. (2008) How should health be defined. *British Medical Journal*, 337;a2900.

Jahoda, A., Wilson, A., Stalker, K., Cairney, A. (2010) Living with Stigma and Self-Perceptions of People with Mild Intellectual Disabilities. *Journal of Social Issues*, 66(3):521-534.

James, W. (1988). *Writings 1902–1910.* New York: Library of America.

Jepson, M. (2015) Applying the Mental Capacity Act to research with people with learning disabilities. *British Journal of Learning Disabilities*, 43:128-134.

Johansson, K., Ekebergh, M., Dahlberg, K. (2008) A lifeworld phenomenological study of the experience of falling ill with diabetes. *International Journal of Nursing Studies*, 46:197-203.

John, L., Wright, R. (2006) Quality of Life and Sujective well-being: historical, conceptual and methodological clarification. *Social Work Mental Health*, 4 (2):47-65.

Jordan, J. S. (2009) Intentionality and Perception, In Bruce Goldstein, B. (ed) Encyclopedia of Perception. Thousand Oaks, CA, US: Sage Publications.

Kahneman, D., Diener, E., Schwarz, N. (1999). *Well-being: Foundations of hedonic psychology*. New York: Russell Sage Foundation Press.

Kaye, H.S., (2000) *Computer and internet use among poeple with disabilities. Disability Statistics report. 13*. Washington, DC, US: Department of Education, National Institute on Disability and Rehabilitation Research.

Kennedy, H. (2009) Going the extra mile: Emotion and commercial imperatives in new media work. *Convergence*, 15(2):177-196.

Kennedy, H., Evans, S., Thomas, S. (2010) Can the Web be made accessible for people with intellectual disabilities? *The Information Society*, 27(1):29-39.

Kerbage, H., Richa, S. (2011). Abord de la vie affective et sexuelle des déficients intellectuels [An approach to the sexual and emotional life of people with intellectual disability]. *Neuropsychiatrie de l'Enfance et de l'Adolescence*, 59:478–483.

Khoo, K., Bolt, P., Babi, F. E., Jury, S., Goldman, R. D. (2008) Health information seeking by parents in the Internet age. *Journal of Paediatrics and Child Health*, 44(7–8):419-423

King, B. H., Toth, K. E., Hodapp, R. M., Dykens, E. M. (2009) Intellectual Disability. In Sadock, B., Sadock, V. A., Ruiz, P. (eds) *Kaplan & Sadock's comprehensive textbook of psychiatry (9th ed., Vol. II, pp. 3444–3474)*. Lippincott Williams & Wilkins: Philadephia, 3444-3474.

Kirkevold, M., Bergland, A. (2007) The quality of qualitative data: Issues to consider when interviewing participants who have difficulties providing detailed accounts of their experiences. *International Journal of Qualitative Studies on Health and Well-being*, 5(2):68-75.

Ko, C. H., Yen, J. Y., Chen, C. C., Chen, S. H., Yen, C.F. (2005) Gender differences and related factors affecting online gamoing addiction among Taiwanese adolescents. *Journal of Nervous and Mental Disease*, 193(4):273-277.

Kockelmans, J. (1994). *Edmund Husserl's phenomenology*. West Lafayette, IN, US: Purdue University Press.

Krasse, B. (2001) The Vipeholm Dental Caries Study: Recollections and Reflections 50 Years Later. *Journal of Dental Research*, 90(9) 1785-1788.

Krugman, S., Ward, R., Giles, J. P. (1962) The natural history of infectious hepatitis. *American Journal of Medicine,* 32(5):717-728.

Kurtz, R. (1981) The sociological approach to mental retardation. In Brechin, A., Liddiard, P., Swain, J. (eds) *Handicap in a social world*. Suffolk: Hodder & Stoughton.

Kvale, S. (1996) *Interviews.* Thousand Oaks, CA: Sage.

Kübler-Ross, E. (1969) *On Death and Dying*. New York, US: Macmillan.

Laing, R. D. (1967) The Politics of experience and The Bird of Paradise. London, UK: Penguin books.

Leiberman, M. A., Golant, M., Giese-Davis, J., Winzlenberg, A., Benjamin, H., Humphreys, K. (2003) Electronic support groups for breast carcinoma. *Cancer*, 97 920-925.

Leiner, B. M., Cerf, V. G., Clark, D. D., Kahn, R. E., Kleinrock, L., Lynch, D. C., Postel, J., Roberts, L. G., Wolff, S.,S. (1997) The past and future history of the internet. *Communications of the ACM*, 40(2):102-108.

Lenhart, A., Horrigan, J., Allen, K., Boyce, A., Madden, M., O'Grady, E. (2003) *The ever shifting Internet population: A new look at the disability divide.* US, The Pew Internet and American Life Project.

Lennox N., Taylor M., Rey-Conde T., Bain C., Purdie D.M. et al. (2005) Beating the barriers: recruitment of people with intellectual disability to participate in research. *Journal of Intellectual Disability Research*, 49:296–305.

Lincolnshire Police (n.d.) Mate Crime. Good Practice Guidance [online] Available:

https://www.lincoln.gov.uk/EasySiteWeb/GatewayLink.aspx?alId=10881 (accessed 01.07.2018).

Livingston S., Haddon L. (2009). *EU Kids Online Final report.* London, LSE: EU Kids Online (EC Safer Internet Plus Programme Deliverable D6.5).

Löfgren-Mårtenson, L. (2008) Love in Cyberspace: Swedish Young People with Intellectual Disabilities and the Internet. *Scandinavian Journal of Disability Research*, 10(2):125-138.

Lovell, A. (2010) Disability Studies, in Talbot, P., Astbury, G., Mason, T. (eds) *Key Concepts in Learning Disabilities*. Sage Publications Ltd. 84-89.

Lucardie, R. Sobsey, D. (2005) Homicides of people with developmental disabilities: An analysis of news stories. *Developmental Disabilities Bulletin*, 33(1):71-98.

Lunsky, Y. (2008) The impact of stress and social support on the mental health of individuals with intellectual disabilities. *Salud Publica De Mexico*, 2:151-215.

Lyubomirsky, S., Lepper, H. S. (1999). A measure of subjective happiness: Preliminary reliability and construct validation. *Social Indicators Research*, 46:137–155.

Mansell, J. (2010) *Raising our sights: services for adults with profound intellectual and multiple disabilities*. Kent, UK: Tizard Centre, University of Kent.

Mason, P., Timms, K., Hayburn, T., Watters, C. (2013) How Do People Described as having a Learning Disability Make Sense of Friendship? *Journal of Applied Reseach in Intellectual Disabilities*, 26:108-118.

McClimens, A., Gordon, F. (2008) Presentation of Self in E-veryday Life: How People Labelled with Intellectual Disability Manage Identity as They Engage the Blogosphere, *Sociological Research Online*, 13(4):1

McClimens, A., Gordon, F. (2009) People with intellectual disabilities as bloggers: What's social capital got to do with it anyway? *Journal of Intellectual Disabilities*, 13 (1), 19-30.

McDonald, K. E. (2012) Adults with Intellectual Disabilities Address Respect in Research. *American Journal on Intellectual and Developmental Disabilities*, 117(4):263-274.

McKenna, K. Y. A., Bargh, J. A. (2000) Plan 9 from cyberspace: the implications of the internet for personality and social psychology. *Personality and Social Psychology Review*, 4:57-75.

McKenna, K. Y. A., Green, A. S., Gleason, M. E. J. (2002) Relationship formation on the internet: what's the big attraction? *Journal of Social Issues*, 58:9-32.

McRae, S. (1997) Flesh Made Word: Sex, Text, and the Virtual Body. In Porter, D. (ed) Internet Culture. New York: Routledge. Pp:73-86.

Mehroof, M., Griffiths, M. D. (2010) Online gaming addiction: The role of sensation seeking, self control, neuroticism, aggression, state anxiety, and trait anxiety. *Cyberpsychology and Behavior*, 13(3):313-316.

Meissner, R. (2010) *Lives Remembered: Life Stories of Victims of National Socialism* (Higgs, S. trans) Vienna: National Fund of the Republic of Austria for Victims of National Socialism.

Mencap (1999) *Living in Fear*. London: Mencap.

Merleau-Ponty, M. (1968/1960) *The visible and the invisible* (Lingis, A, Trans). Evanston, IL: Northwestern University Press.

Merleau-Ponty, M. (1987/1960) *Signs* (McCleary, R. trans) Evanston, IL: Northwestern University Press.

Merleau-Ponty, M. (1995 / 1945) *Phenomenology of perception* (Smith, C, Trans). London: Routledge.

Merleau-Ponty, M. (1962/1945) *Phenomenology of perception*. London: Routledge and Kegan Paul.

Merleau-Ponty, M. (1991/1964) *Consciousness and the acquisition of language* (Silverman, H. Trans). Evanston, IL: Northwestern University Press.

Merleau-Ponty, M. (1964a/1946) The Primacy of perception and its philosophical consequences. In Edie, J (Trans) *The Primacy of perception*. Evanston, IL, US: North Wester University Press.

Michaels, S. (1981) ‘Sharing time:’ Children’s Narrative Styles and Differential Access to Literacy. *Language and Society*, 10:423-442.

Michaels, S. (1985) Hearing the Connections in Children’s Oral and Written Discourse. *Journal of Education*, 167:36-56.

Michaelson, J., Abdallah, S., Steuer, N., Thompson, S., Marks, N. (2009). *National accounts of well-being: Bringing real wealth onto the balance sheet.* London: New Economics Foundation.

Miller, H. (1995) The Presentation of Self in Electronic Life: Goffman on the Internet. [online] *Hugh Miller.* Paper presented at Embodied Knowledge and Virtual Space Conference Goldsmiths' College, University of London, June 1995. Available: http://www.dourish.com/classes/ics234cw04/miller2.pdf (accessed: 29.09.2017).

Miller, V. (2011) *Understandning Digital Culture*. London, UK: Sage Publications Ltd.

Mitchell, R., Thurtle, P. (2004) *Data Made Flesh: Embodying Information*. New York: Routledge.

Mitscherlich, A., Mielke, F. (1962) *The death doctors*. London: Elek Books.

Moisey, S., van der, K. (2007) Inclusion and the Internet: Teaching adults with developmental disabilities to use information and communication technology. *Developmental Disabilities Bulletin*, 35(1-2):72-102.

Molin, M., Sorbring, E., Löfgren-Mårtenson, L. (2015) Teacher's and parent's views on the internet and social media usage by pupils with intellectual disabilities. *Journal of Intellectual Disabilities*, 19(1):22-33.

Moon, R. J., Curtis, E. M., Davies, J. H., Cooper, C., Harvey, N. C. (2017) Seasonal variation in Internet searches for vitamin D, *Archives Of Osteoporosis*, 12(1):28.

Moran, D. (2012) *Husserl's Crisis of European Sciences and Transcendental Phenomenology*. Cambridge University Press: Cambridge.

Moreno, M. A., Kolb, J. (2012) Social networking sites and adolescent health. *Pediatric Clinical North America*, 59(3):601-612.

Morisse, F., Vandemaele, E., Claes, C., Claes, L. & Vandevelde, S. (2013) Quality of Life in Persons with Intellectual Disabilities and Mental Health Problems: An Explorative Study. *The Scientific World Journal*, 2013:1-8.

Nakamura, L. (2007) *Digitizing Race: Visual Cultures of the Internet*. Minneapolis: University of Minnesota Press.

Näslund R., Gardelli A. (2013) ‘I know, I can, I will try’: youths and adults with intellectual disabilities in Sweden using information and communication technology in their everyday life. *Disability and Society*, 28(1):28–40.

Natanson, M. (1973) *Edmund Husserl. Philosopher of infinite tasks*. Evanston, IL: Northwestern University Press.

National Health Service (2015) Down's syndrome - Characteristics. [online]. *NHS.* Available online: http://www.nhs.uk/Conditions/Downs-syndrome/Pages/Symptoms.aspx (accessed 06.07.2015 2015).

National Health Service (2017) Wellbeing self-assessement: How happy are you? [online] *NHS Choices*. Available: https://www.nhs.uk/Tools/Documents/Wellbeing%20self-assessment.htm (accessed 28.09.2017).

National Health Sevice Egland (NHS England) (2017) NHS Five Year Forward View [online] NHS England. Available: https://www.england.nhs.uk/five-year-forward-view/next-steps-on-the-nhs-five-year-forward-view/the-nhs-in-2017/ (accessed 15.05.2018).

National Institute for Health and Care Excellence (2015) The guidelines manual: appendices B-I. [online] *National Institute for Health and Care Excellence.* Available online: http://publications.nice.org.uk/the-guidelines-manual-appendices-bi-pmg6b/appendix-h-methodology-checklist-qualitative-studies (accessed 06.07.2015).

National Institute for Health and Care Excellence (2012) Methods for the development of NICE public health guidance (third edition). Appendix G Quality appraisal checklist - quantitative studies reporting correlations and associations [online] *National Institute for Health and Care Excellence*. Available online: http://www.nice.org.uk/article/pmg4/chapter/appendix-g-quality-appraisal-checklist-quantitative-studies-reporting-correlations-and-associations (accessed 06.07.2015).

National Telecommunications, Information Administration and Economic, Statistical Administration. (2013). Exploring the Digital Nation: America’s Emerging Online Experience. [online] *U.S. Department of Commerce*. Available: https://www.ntia.doc.gov/files/ntia/publications/exploring_the_digital_nation_-_americas_emerging_online_experience.pdf (Accessed 28.09.2017).

Neugebauer, W., Stacher, G. (1999) Nazi child ‘euthanasia’ in Vienna and the scientific exploitation of its victims before and after 1945. *Digestive Diseases,* 17(5-6):279-285.

Nicholson L., Colyer M., Cooper S. A. (2013) Recruitment to intellectual disability research: a qualitative study. *Journal of Intellectual Disability Research*, 57:647–56.

Obst, P., Stafurik, J. (2010) Online we are all able bodied: online psychological sense of community and social support through membership of disability-specific websites promotes well-being for people living with a physical disability. *Journal of Community and Applied Social Psychology*, 20 525-531.

Office for National Statistics (2011) Ethnicity and Nationality in England and Wales: 2011 [online] Office for National Statistics. Available: https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/ethnicity/articles/ethnicityandnationalidentityinenglandandwales/2012-12-11#ethnicity-across-the-english-regions-and-wales (accessed on 01.07.2018)

Office for National Statistics. (2013). Internet Access – Households and Individuals, 2012, part 2. [online] *Office for National Statistics*. Available: https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/bulletins/internetaccesshouseholdsandindividuals/2017 (accessed 28.09.2017).

Office of the High Commissioner for Human Rights (1989) *UN Convention on the Rights of the Child.* Switzerland: Office of the United Nations High Commissioner for Human Rights.

Oliver, M. (1990) *The Politics of Disablement.* Basingstoke: Macmillan.

Oliver, M. (2009) *Understanding Disability. From Theory to Practice. Second Edition.* Hampshire, UK: Palgrave Macmillan.

Oswin, M. (1991) *Am I allowed to Cry?* London: Souvenir.

Oxford University Press (2017) English Oxford Living Dictionaries: digital native [online] *Oxford University Press*. Available: https://en.oxforddictionaries.com/definition/digital_native (acessed 29.09.2017).

Palmer, R. E. (1969) *Hermeneutics. Interpretation theory in Schleiermacher, Dilthey, Heidegger and Gadamer.* Evanston, IL: North Western University Press.

Palmer S. B., Wehmeyer M. L., Davies D. K., Stock S. E. (2012) Family members' reports of the technology use of family members with intellectual and developmental disabilities. *Journal of Intellectual Disability Research*, 56(4):402–14.

Paterson, B., Thorne, S., Canam, C., Jillings, C. (2001) *Meta-study of qualitative health research.* London: Sage.

Payne (2006) Christmas with Foster Parents for Charlotte [online] *The Telegraph.* Available: http://www.telegraph.co.uk/news/uknews/1537483/Christmas-with-foster-parents-for-Charlotte.html (accessed 30.01.2017).

Penson, S. (1992) *Bereavement: A Guide for Nurses.* London: Chapman and Hall.

Perls, F. (1969) *Gestalt therapy verbatim*. Moab, UT, US: Real People Press.

Pluye, P., Robert, E., Cargo, M., Barlett, G., O'Cathain, A., Griffiths, A., Boardman, F., Gagnon, M., P., Rousseau, M. C. (2011) Mixed Method Appraisal Tool (MMAT) - Version 2011. [online] *WebCite.* Available: http://www.webcitation.org/5tTRTc9yJ (accessed 06.07.2015).

Pollard, E., Lee, P. (2003). Child well-being: a systematic review of the literature. *Social Indicators Research*, 61(1):9–78.

Porter, G., Starcevic, V., Berle, D., Fenech, P. (2010) Recognizing problem video game use. *The Australian and New Zealand Journal of Psychiatry*, 44(2):120-128.

Poster, M. (1999) Theorizing Virtual Reality: Baudrillard and Derrida. In Marie-Laure, R. (ed) *Cyberspace Textuality: Computer Technology and Literacy Theory*, 42-60. Bloomington: Indiana University Press.

Power, D, Teigland, R. (2013) Postcards from the Metaverse: An Introduction to the Immersive Internet. In Teigland, R., Power, D (eds) *The Immersive Internet: Reflections on the Entangling of the Virtual with Society, Politics and the Economy*. Palgrave Macmillan, UK, London.

Price, L., Walker, L. (2015) *Chronic Illness, Vulnerability and Social Work. Autoimmunity and the contemporary disease experience*. Oxon, UK: Routledge.

Price-Jones, D. W., Barrowcliff, A. L. (2010) Intelligence. In Talbot, P., Astbury, G., Mason, T. (eds) *Key Concepts in Learning Disabilities*. London: Sage. 132-138.

Proctor, R. N. (1992) Nazi doctors, racial medicine, and human experimentation. In Annas, G. J., Grodin, M. A. (eds) *The Nazi Doctors and the Nuremberg Code*. New York: Oxford University Press. 17–31.

Proctor, R. (1998) *Racial hygiene: Medicine under the Nazis*. Cambridge, MA, US: Harvard Press.

Public Health Resource Unit, (2006) *Critical Appraisal Skills Programme (CASP) making sense of evidence. 10 questions to help you make sense of qualitative research.* England, Public Health Resource Unit.

Pullin, G. (1964) *Design meets disability*. US: MIT Press.

Puri, B. K., Lekh, S. K., Langa, A., Zaman, R., Singh, I. (1995) Mortality in a hospitalized mentally hanicapped population: a 10 year study. *Journal of Intellectual Disability Research*, 39:527-531.

Rakusen, I. (2012) ‘Mate Crime’: Fake friend abuse that can end in murder [online] *BBC News*. Accessible: http://www.bbc.co.uk/news/uk-19009826 (accessed 21.11.2016).

Read, S. (2010) Loss. In Talbot, P., Astbury, G., Mason, T. (eds) *Key Concepts in Learning Disabilities*. 155-160 London: Sage.

Read, S. Bowler, C. (2007) ‘Life story work and bereavement: shared reflections on its usefulness’, *Learning Disability Practice*, 10(4):10-15.

Reichow, B., Gelbar, N. W., Mouradjian, K., Shecyk, A., Smith, I. C. (2014) Characteristics of international websites with information on developing disabilities. *Research in Developmental Disabilities*, 35(10):2293-98.

Reichow, B., Halpern, J. I., Steinhoff, T. B., Letsinger, N., Naples, A., Volkmar, F. R., (2012) Characteristics and quality of autism websites. *Journal of Autism and Developmental Disorders*, 42:1263-1274.

Reichow, B., A. Shefcyk, A., Bruder, M. B. (2013) Quality comparison of websites related to developmental disabilities. *Research in Developmental Disabilities*, 34:3077-3083.

Reid, E. M. (1996) Text-based Virtual Realities: Identity and the Cyborg Body. In Ludlow, P. (ed) *High Noon on the Electronic Frontier: Conceptual Issues in Cyberspace*. Cambridge, MA: MIT Press. Pp:327-345.

Rejeski, J. W., Mihalko, S. L. (2001) Physical Activity and Quality of Life in Older Adults. *The Journals of Gerontology*, Series A, 56(2):23-35.

Rheingold, H. (1993) *The virtual community: Homesteading on the electronic frontier.* Reading, MA: Addison-Wesley.

Riessman, C. K. (1991) When gender is not enough: women interviewing women. In Lorber, J., Farrell, S. A. (Eds) *The social construction of gender*. London: Sage in association with Sociologists for Women in Society. 217-236.

Ritzer, G. (2011) *The McDonaldization of Society 6*. Thousand Oaks, California, US: Pine Forge Press.

Riva, G., Galimberti, C. (2001) The Mind in the Web: Psychology in the Internet Age. *Cyberpsychology & Behavior*, 4(1)1-5.

Robertson, J., Emerson, E., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., Linehan, C. (2001) Social networks of people with mental retardation in residential settings. *Mental Retardation*, 39:201-214.

Rogers, C. (1961). *On becoming a person*. Boston: Houghton Mifflin.

Romano, M., Truzoli, R., Osborne, L. A., Reed, P. (2014) The relationship between autism quotient, anxiety, and internet addiction. *Research into Autism Spectrum Disorders*, 8(11):1521-1526.

Ruston, D. and Akinrodoye, L., (2002) *Social Capital Question Bank June 2002.* London: Social Analysis and Reporting Division, National Statistics.

Ryan, J., Thomas, F. (1987) *The politics of mental handicap*. London: Free Association Books.

Ryff, C. D. (1989a) Happiness is everything, or is it? Explorations on the meaning of psychological wellbeing. *Journal of Personality and Social Psychology*, 57:1069–1081.

Ryff, C. D. (1989b). Beyond Ponce de Leon and life satisfaction: New directions in quest of successful ageing. *International Journal of Behavioral Development*, 12:35–55.

Ryff, C., Keyes, C. (1995). The structure of psychological well-being revisited. *Journal of Personality and Social Psychology*, 69(4):719–727.

Salvador-Carulla, L., Bertelli, M. (2008) ‘Mental Retardation’ or ‘Intellectual Disability’: Time for a Conceptual Change, *Psychopathology*, 41(1):10-16.

Salvador-Carulla, L., Reed, G. M., Vaez-Azizi, L., M., Cooper, S., Leal, R. M., Bertelli, M., Adnams, C., Cooray, S., Deb, S., Dirani, L. A., Girimaji, S. C., Katz, G., Kwok, H., Luckasson, R., Simeonsson, R., Walsh, C., Munir, K., Saxena, S. (2011) Intellectual development disorders: towards a new name, definition and framework for “mental retardation/intellectual disability” in ICD-11, *World Psychiatry*, 10(3):175-180.

Samiee, S. (1998) The internet and international marketing: is there a fit? *Journal of Interactive Marketing*, 12 (4):5-21.

Sarda, E. Bégue, L., Bry, C., Gentile, D. (2016) Internet gaming disorder and wellbeing: A scale validation. *Cyberpsychology, Behaviour and Social Networking*, 19(11):674-679.

Sartre, J. P. (1956/1943) *Being and nothingness*. New York: Philosophical Library.

Schalock, R. (2011) The evolving understanding of the construct of intellectual disability. *Journal of Intellectual & Developmental Disability*, 36 (4):227-237.

Schutz, A., Luckman, T. (1973, 1975) *The structures of the life-world. Two vols*. Evanston, IL: Northwestern University Press.

Schwartz, A. (2013) The selling of attention deficit disorder. [online] *The New York Times*. Available: http://www.nytimes.com/2013/12/15/health/the-selling-of-attention-deficit-disorder.html?pagewanted=all (accessed 30.01.2017).

Schwartz, H. (1996) *The Culture of the Copy: Striking Likenesses, Unreasonable Facsimiles*. New York, US: Zone Books.

Scullard, P., Peacock, C., Davies, P. (2010) Googling children's health: Reliability of medical advice on the internet. *Archives of Disease in Childhood*, 95:580-582.

Seale, J. K. (2007) Strategies for supporting the online publishing activities of adults with learning difficulties. *Disability and Society*, 22(2):173-186.

Seale, J. (2014) The role of supporters in facilitating use of technologies by adolescents and adults with learning disabilities: a place for positive risk taking? *European Journal of Special Needs Education*, 29(2):220–36.

Sedghi, A. (2014) Campaign urges change in how learning disability is portrayed on TV and radio [online] *The Guardian*. Available: https://www.theguardian.com/media/2014/jul/25/campaign-learning-disability-portrayed-tv-radio (accessed 25.01.2018).

Seedhouse, D. (1995) 'Well-being': health promotion's red herring. *Health Promotion International*, 10(1):61.

Shapira, N., Barak, A. & Gal, I. (2007) Promoting older adults' well-being through internet training and use. *Aging Mental Health*, 11:477-484.

Shaw, L. H., Gant, I. M. (2002) In defense of the internet: the relationship between internet communication and depression, lonliness, self-esteem, and perceived social support. *Cyberpsychology & Behavior*, 5:157-171.

Sheehy, K., Nind, M. (2005) Emotional well-being for all: mental health and people with profound and multiple learning disabilities. *British Journal of Learning Disabilities*, 33(1):34-38.

Sheets-Johnson, M. (1999) *The primacy of movement*. Amsterdam/Philadelphia: John Benjamins.

Shengold, L. (1998) *Soul murder: The Effects of Childhood Abuse and Deprevation*. London, UK: Karnac Books.

Shpigelman, C., Gill, C.,J. (2014) How to adults with intellectual disabilities use Facebook? *Disability and Society*, 29 (10), 1601-1616.

Sigerson, L., Li, A. Y. L., Cheung, M. W. L., Luk, J. M. Cheng, C. (2017) Psychometraic properties of the Chinese Internet Gaming Disorder Scale. *Addictive Behaviours*, 74:20-26.

Silberg, W. M., Lundberg, G. D., Musacchio, R. A. (1997) Assessing, controlling, and assuring the quality of medical information on the Internet: Caveant lector et viewor-Let the reader and viewer beware. *Journal of the American Medical Associtation,* 277(15):1244-1245.

Sinason, V. (2011) *Trauma, Dissasociation and Multiplicity: Working on Identity and Selves.* London: UK: Routledge.

Slater, R. (2011) the disabled woman abandoned to be murdered for fun by a gang of savages who she thought were her friends [online] *MailOnline*. Available: http://www.dailymail.co.uk/femail/article-2020648/Gemma-Hayter-Disabled-woman-abandoned-murdered-fun.html (accessed 19.12.2016).

Smith, S. J., Lloyd, R. J. (2006) Promoting vitality in health and physical education. *Qualitative Health Research*, 16(2):245-267.

Smaling, A. (1995) Open-mindedness, open-heartedness and dialogical openness: The dialetics of openings and closures, in Maso, I., Atkinson, P. A., Delamont, S., Verhoeven, J. C. (eds) *Openness in research: The tension between self and others.* Assen, The Netherlands: van Gorcum. 7-19.

Soh, C., Mah, Q. Y., Klein, K. J., Gan, F.J., Chew, D., Reid, E. (1997) The use of the internet for business: the experience of early adopters in Singapore. *Internet Research: Electronic Networking Applications and Policy*, 7(3):217-28.

Sohlberg, M., Ehlhardt, L., Fickas, S., Todis, B. (2002). CORE: Comprehensive overview of requisite email skills. Conputer Science Technical Report 02-01 October 2002. [online] *Department of Computer and Information Science University of Oregan*. Available: http://www.think-and-link.org/researchers/CORETech.pdf (accessed 28.09.2017).

Spencer, L., Ritchie, J., Lewis, J. and Dillon, L., (2003) *Quality in Qualitative Evaluation: A framework for assessing research evidence. A Quality Framework.* London, Government Chief Social Researcher's Office.

Stevens, E., Hebblewhite, G. (2014) Empowering Adults under the Mental Capacity Act. *Learning Disability Practice*, 17(8):16-20.

Stendal K. (2012) How do people with disability use and experience virtual worlds and ICT: a Literature Review. *Journal of Virtual Worlds Research*, 5(1):1–17.

Stendal K., Balandin S. & Molka-Danielson J. (2011) Virtual worlds: a new opportunity for people with lifelong disability. *Journal of Intellectual and Developmental Disability*, 36(1):80–3.

Stephenson, J., Carter, M., Kemp, C. (2012) Quality of the information on educational and therapy interventions provided on the web sites of national autism associations. *Research in Autism Spectrum Disorders*, 6(1):11-18.

Stiglitz, J., Sen, A., Fitoussi, J. P. (2009). Report by the commission on the measurement of economic performance and social progress [online] *The Commission on the Measurement of Economic Performance and Social Progress.* Available: https://www.economie.gouv.fr/files/finances/presse/dossiers_de_presse/090914mesure_perf_eco_progres_social/synthese_ang.pdf (accessed: 30.01.2017).

Stone, A. R. (1991) Will the Real Body Please Stand Up? In Benedikt, M. (ed) *Cyberspace: First Steps*. MIT Press. Pp:81-118

Strathern, A. J., Stewart, P. J. (2011) Embodiment and Personhood, in Mascia-Lees, F. E. (ed) *A Companion to the Anthropology of the Body and Embodiment*. First Edition. UK: Blackwell Publishing Ltd.

Sundén, J. (2003) *Material Virtualities: Approaching Online Textual Embodiment*. New York: Peter Lang.

Svenaeus, F. (2000) *The Hermeneutics of Medicine and the Phenomenology of Health*. Dordrecht, The Netherlands: Kluwer Academic Publishers.

Svensson, O., Hallberg, L. R. M. (2011) Hunting for health, well-being, and quality of life. *International Journal of Qualitative Studies on Health and Well-being*, 6(2):1-5.

Swain, J., Finkelstein, V., French, S., Oliver, M. (1993) *Disabling Barriers, Enabling Environments*. London: Sage.

Swain, J., Heyman, B., Gilman, M. (1998) Public research, private concerns: ethical issues in the use of open-ended interviews with people who have learning difficulties. *Disability and Society*, 13(1):21-36.

Taber-Doughty, T., Shurr, J., Brewer, J. & Kubik, S. (2010) Standard care and telecare services: comparing the effectiveness of two service systems with consumers with intellectual disabilities. *Journal of Intellectual Disability Research*, 54(9):843-859.

Taylor, T. L. (2002) Living Digitally: Embodiemnt in Virtual Worlds. In Schroeder, R. (ed) *The Social Life of Avatars: Presence and Interaction in Shared Virtual Environments*. London: Springer-Verlag. Pp: 40-62.

Thomas, J., (2009) *Working paper: Current measures and the challenges of measuring children's wellbeing*. Newport: Office for National Statistics.

Thompson, J. R., Bradley, V. J., Buntinx, W. H. E., Schalock, R. L., Shogren, K. A., Snell, M. E., Wehmeyer, M. L., Borthwick-Duffy, S., Coulter, D. L., Craig, E. P. M., Gomez, S. C., Lachapelle, Y., Luckasson, R. A., Reeve, A., Spreat, S., Tassé, M. J., Verdugo, M. A., Yeager, M. H. (2007) Conceptualizing Supports and the support needs of people with intellectual disability (2007*) Intellectual and Developmental Disabilities*, 47(2):135-146.

Todres, L. (2005). Clarifying the life-world: descriptive phenomenology. In Holloway, I. (ed) *Qualitative research in health care*. New York: Open University Press.

Todres, L., Galvin, K.. (2005a) Pursuing Both Breadth and Depth in Qualitative: Research: Illustrated by a Study of the Experience of Intimate Caring for a Loved One with Alzheimer’s Disease. *International Journal of Qualitative Methods*, 4(2):20-31.

Todres, L., Galvin, K. (2005b). Caring for a partner with Alzheimer’s: Intimacy, loss and the life that is possible. *International Journal of Qualititative Studies on Health and Well-being*, 1(1):50-61.

Todres, L., Galvin, K. (2010) “Dwelling-mobility”: An existential theory of well-being. *International Journal of Qualitative Studies on Health and Well-being*, 5 (5444):1-6

Toombs, K. (1993) *The meaning of illness – a phenomenological account of the different perspectives of physician and patient. Philosophy and Medicine, nr 42*. Boston: Kluwer Academic Publishers.

Tsitsika, A., Critselis, E., Kormas, G., Filippopoulou, A., Tounissidou, D., Freskou, A., Spiliopoulou, T., Louizou, A., Konstantoulaki, E., Kafetzis, D. (2009) Internet use and misuse: a multivariate regressin analysis of the predictive factors of internet use among Greek adolescents. *European Journal of Pediatrics*, 168(6):655-665.

Turkle, S. (1996) Parallel lives: Working on identity in virtual spaces. In D. Grodin (ed) *Constructing the self in a mediated world. inquiries in social construction*. Thousand Oaks, CA, US: Sage Publications. 156-175.

Turkle, S. (1995) *Life on screen: Identity in the age of the internet*. New York, US: Touchstone.

Turkle, S. (2009) *Simulation and Its Discontents*. US: Massachusettes Institute of Technology.

Turkle, S. (2011) *Alone Together. Why we expect more from technology and less from each other*. Basic Books: New York.

Turkle, S. (2017) Sherry Turkle Quotes [online] *Goodreads*. Available: https://www.goodreads.com/quotes/710710-human-relationships-are-rich-and-they-re-messy-and-they-re-demanding (accessed: 29.09.2017).

Tuffrey-Wijne I., Bernal J., Hollins S. (2008) Doing research on people with learning disabilities, cancer and dying: ethics, possibilities and pitfalls. *British Journal of Learning Disabilities*, 36:185–90.

Turkle, S. (1995) *Life on screen: Identity in the age of the internet*. New York, US: Touchstone.

Uchino, B. N. (2004) *Social support and physical health: Understanding the health consequences of relationships.* New Haven: Yale University Press.

Vagle, M. D. (2014) *Crafting Phenomenological Research.* Walnut Creek, US: Left Coast Press inc.

Van Gelder, L. (1991) The Strange Case of the Electronic Lover. In Dunlop, C., Kling, R. (eds) *Computerization and Controversy: Value Conflicts and Social Choices*. Boston: Academic Press. Pp:364-375.

Vanderheiden, G., Cress, C. (1992) Application of artificial intelligence to the needs of persons with cognitive impairments: The companion aid. In Murphy, H. J. (ed) *Proceedings of the 7th International Conference on*

Technology and Persons with Disabilities. California State University Centre on Disabilities. Northridge CA, US: Calafornia State University Centre on Disabilities.

Vernon, M. (2008) *Wellbeing, the art of living*. Stocksfield: Acumen.

Vingilis, E., Sarkella, J. (1997) Determinants and Indicators of Health and Well-being: Tools for Educating Society. *Social Indicators Research*, 40(1-2):159-178.

Wallace, P. (1999) *The psychology of the internet*. Cambridge University Press: New York, U.S.

Warwickshire Safeguarding Adults Partnership (2010) Serious Case Review. The Murder of Gemma Hayter. 9th August 2010. Public Summary [online] *Warwickshire Government*. Available: www.warwickshire.gov.uk/seriouscasereview (accessed 19.12.2016).

Waterman, A. S. (1993). Two conceptions of happiness: Contrasts of personal expressiveness (eudaimonia) and hedonic enjoyment. *Journal of Personality and Social Psychology*, 64(4):678–691.

Watson, D. (2008) Causes and manifestations of learning disabilities. In Gates, B. (ed) Learning Disabilities Towards Inclusion. Philadelphia, US: Churchill Livingstone Elsevier. 21-42.

Wehmeyer, M. L., Smith, S. J., Palmer, S. B., Davies, D. K. (2004) The effect of student-directed transition planning with a computer-based reading support program on the self determination of students with disabilities. *Journal of Special Education Technology*, 19(4):7-22.

Welton, D. (1998) *Body and flesh: a philosophical reader*. Oxford, UK: Basil Blackwell.

Wenestam, C. G., Dahlberg, K. (1990) *Interaction between people and society as seeing and not-seeing*. Paper presented at International Human Science Research Conference, Quebec, Canada.

Wertz, F. J. (2011) A Phenomenological Psychological Approach to Trauma and Resilience. In Wertz, F., J., Charmaz, K., McMullen, L. M., Josselson, R., Anderson, R., McSpadden, E. (eds) *Five Ways of doing Qualitative Analysis*. New York, US: The Guilford Press. 124-164.

Wertz F (2005) Phenomenological research methods for counseling psychology. *Journal of Counseling Psychology*, 52(2):167–77.

Whitaker, S., (2013) *Intellectual Disability. An Inability to Cope with an Intellectually Demanding World*. UK: Palgrave Macmillan.

White, M. (2006) *The Body and the Screen: Theories of Internet Spectatorship.* Cambridge, MA: Mit Press.

Wilkinson, V. J., Theodore, K., Raczka, R. (2014) 'As Normal as Possible': Sexual Idendity Development in People with Intellectual Disabilities Transitioning to Adulthood. *Sexuality and Disability*, 33(1):93-105.

Williams, P. (2008) Transition and people with learning disabilities. Reflections on the quality of content that emerges from the process of involving service users in information provision. *Aslib Proceedings*, 60(5):474-492.

Willig, C. (2008) *Introducing Qualitative Research in Psychology. Adventures in Theory and Method*. Berkshire, UK: Open University Press.

Willis, P. (2008). Getting a Feel for the Work: Mythopoetic Pedagogy for Adult Educators Through Phenomenological Evocation. In Leonard, T., Willis, P. (eds) *Pedagogies of the Imagination: Mythopoetic Curriculum in Educational Practice.* Netherlands: Springer.

World Health Organisation (WHO) (1946) *Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference*. New York, US: World Health Organisation.

World Health Organisation (WHO) (1984) *Health Promotion: A Discussion Document on the Concept and Principles.* WHO Regional Office for Europe, Copenhagen. New York, US: World Health Organisation.

World Health Organisation (WHO) (2015a) Disabilities [online] *World Health Organisation*. Available: http://www.who.int/topics/disabilities/en/ (accessed 11.11.2015).

World Health Organisation (WHO) (2015b) The Health Internet. [online] *World Health Organisation*. Available online: http://www.who.int/ehealth/programmes/governance/en/ (accessed 01.07.2015).

World Health Organisation (WHO) (2017a) Definition: intellectual Disability [online] *World Health Organisation*. Available: http://www.euro.who.int/en/health-topics/noncommunicable-diseases/mental-health/news/news/2010/15/childrens-right-to-family-life/definition-intellectual-disability (accessed 08.04.2017).

Yee, N. Bailenson, J. (2007) The Proteus Effect: The Effect of Transformed Self-Representation on Behavior. *Human Communication Research*, 33:271-290.

Young, K (2008). Toward a model for the study of children’s informal internet use. *Computers in Human Behavior*, 24:173-184

Zahavi, D. (2005) *Subjectivity and selfhood: investigating the first-person perspective*. Cambridge, MA: MIT Press.

Zaheer, S., Manrakhan, S. (2001) Concentration and dispersion in global industries: remote electronic access and location of economic activities. *Journal of International Business Studies*, 32(4):667-686.

Zhang, J. T., Yao, Y. W., Li, C. S. R., Zang, Y. F., Shen., Z. J., Liu, L, Fang, X. Y. (2016) Altered resting-state functional connectivity of the insula in young adults with internet gaming disorder. *Addiction Biology*, 21(3):743-751.

Zigler, E. (1967). Familial mental retardation: A continuing dilemma. *Science*, 155:292–8.

Zigler, E., Balla, D. Hodapp, R. (1984). On the definition and classifications of mental retardation. *American Journal of Mental Deficiency*, 89:215–30.

Appendices. Appendix A: Literature Review

A.1 Keyword search.

Keyword search:

autis* OR “cognitive delay*” OR “cognitive disabilit*” OR “developmental delay*” OR “developmental disabilit*” OR “developmental disorder*” OR “Down syndrome” OR “Down’s syndrome” OR “intellectual development disorder*” OR “intellectual* disabilit*” OR “learning difficult*” OR “learning disabilit*” OR “learning disorder*” OR “learning impairment*” OR “mental* deficienc*” OR “mental* handicap*” OR “mental* impair*” OR “mental* retard*” OR “mental* disab*” OR “mental* subnormal*” OR “profound and multiple disabilit*” OR “Severe* disab*”

AND

avatar* OR blog* OR chatroom* OR “computer?mediated” OR cyber* OR digital* OR “e-communication” OR email* OR “e-mail” OR facebook OR “Information and communication technolog*” OR ICT OR Internet OR “media sharing” OR “mobile device*” OR “mobile internet” OR “mobile phone” OR online OR “second life” OR “smart phone” OR “social media” OR troll* OR twitter OR virtual* OR webcam* OR “world wide web*”

AND

abuse OR anxi* OR aspiration* OR depress* OR dignity OR eudaimonia OR flourish* OR friend* OR goal* OR happiness OR happy OR health* OR identit* OR illness OR independen* OR “interpersonal relation*” OR isolat*

OR lifestyle* OR lonel* OR mood* OR participat* OR “personal development” OR psych* OR rights OR relationship* OR satisfaction OR “self?actuali*” OR “self?determination” OR “self?esteem” OR “social inclusion” OR “social exclusion” OR thriv* OR unhappiness OR unhappy OR wellbeing OR “well-being” OR wellness OR value*

A.2 Rationale for each exclusion criteria

Literature was excluded using the following exclusion criteria:

1. The population sample does not have an intellectual disability (ID) as defined by the DoH (2001).

The key terms used for ‘intellectual disability’ (ID) represented alternative terms used across the world and terms which may have overshadowed the description of the population as having an ID, such as autism or Down’s Syndrome (DS). Where alternative terms, such as autism, were used in the literature, the study was examined in full to ensure the population had an ID. People with intellectual disabilities (IDs) can have autism, but some individuals who have autism may not have an ID. This population is often described as ‘high functioning’ because their IQ (intelligence quotient) is average or above that of the general population. In this case they would not be included in the literature review as an ID population. Where specified in the literature, the IQ of the population was taken into consideration to help decide if the population had IDs. Populations with an IQ of 70 or below were considered to have IDs. If a population was self-selecting and it was clear that the population sought was one with an ID, this was included. ‘Learning difficulty' was another term used to describe an ID, but it can also refer to conditions such as dyslexia, which does not impair an individual's IQ and does not fall within the Department of Health's (DoH, 2011) stated definition for an ID, and therefore these populations were excluded.

2. The population sample was under 18, thus not defined as an adult under United Kingdom (UK) law (Office of the High Commissioner for Human Right, 1989).

Adults with IDs were chosen as the focus of this literature review, rather than those aged under 18, or a mixed population of adults and children. There are many differences between adults and children with and without IDs and there are types of online activities those aged under 18 may not able to participate in legally, such as certain online social networking sites, dating agencies, games and gambling.

3. The internet was used only as a data collection tool for the researcher/s, without the input, engagement or participation of adults with IDs.

4. Literature that used any of the keywords for the term 'internet', but did not fulfil the definition used in this review: communication exchange and/or information retrieval and/or dissemination across a global network of computers or mobile devices.

For example, many studies had created 'virtual' spaces that were not connected to the internet, these were excluded as they were not considered within the definition of the internet.

5. Research that does not state any effects on the health, wellbeing or Quality of Life (QoL) of adults with IDs, using the holistic definitions for these concepts.

6. Literature that was not primary research, including literature reviews.

7. Literature where an English translation could not be found.

A limiter for ‘only English text-based literature’ was not used when searches were made on the databases as this may have incurred a language bias. Dickerson et al. (1987) noted that positive results were more likely to be published in English and Bruce et, al., (2008) noted that databases tended to publish or include articles from certain countries, such as the United States of America (USA) (Bettany-Saltikov, 2012). If a non-English text-based study was found, further searches using online search engines were used to find any published translated copies.

8. The literature was a shortened or incomplete version of a full and complete published research study.

All excluded literature was coded with each of the above numbers to indicate the reason for exclusion (Figure 2.1 Search Process and Results, page 49).

A.3 Influences and Interpretations by the Researchers over Adults with Intellectual Disabilities’ Online Experiences and Wellbeing

A.3.1 The researchers’ control over the experience

Within many of the included studies it was clear to see the influence and control the researchers had over the adults with IDs’ online experiences, especially if the researchers had provided the online opportunity for the participants as part of their study. In some cases the internet was not available to some of the participants with IDs outside the research study and it could be suggested that some of the researchers, for example Moisey and van der Keere (2007), may have taken advantage of adults with IDs’ lack of access to the internet and their strong motivation to experience the internet to aid their recruitment and maintain participation. The participants’ opportunity to access the internet and engage with others within these studies often stopped when the research study finished and the researchers did not appear to offer or signpost the participants to any further opportunities to access the internet (McClimens and Gordon, 2008, 2009, Moisey and van der Keere, 2007). As a consequence, the participants in these studies did not tend to continue to access the internet, even though it was documented that they expressed the wish to do so:

> “Today is the last day of the blogging project. I feel a little upset today, I do not have a computer so I may not be able to do anymore blogging which makes me sad” (McClimens and Gordon, 2009:22).

In Hall et al. (2011) study they located the online experience at a setting which was already used by and familiar to the participants with IDs. The setting already had computers connected to the internet and an existing support network for the participants, which allowed for their continued use of the internet and support. In comparison, McClimens and Gordon (2008; 2009) and Moisey and van der Keere (2007) brought participants into an unfamiliar setting, in one case a University (an influential setting for the participants in this study), and offered both on- and off-line experiences and status that they would not normally have access to. Hall, et al.'s (2011) rationale for a research setting already used by those with IDs was clear, they wanted to ensure their online Virtual Environment (VE) could continue to be accessed in the community by health and care professionals and adults with IDs. It also provided a familiar and less influential environment for the participants in this study which lessened the influence on their online experience and presentation. This was something Seale (2007) also highlighted in the study as being problematic. Unlike the studies conducted by Edler and Rath (2014), McClimens and Gordon (2008, 2009) and Moisey and van der Keere (2007), Hall et al. (2011) used a familiar and already existing environment which provided ICT to adults with IDs to ensure ongoing supported internet access long after the study had finished.

A.3.2 Researcher/s' reasons, approaches and viewpoints

The researcher/s' rationale for the studies and their approaches and viewpoints, including how they viewed adults with IDs and their place in society, were highlighted by the meta-study as being highly influential in the approaches taken, the findings, discussions and conclusions. The lack of critique for terms such as 'intellectual disability', 'internet', 'friend', 'independence' and 'risk' by some of the researcher/s also became an important element within the literature review.

The 14 research studies took a variety of approaches to the research: interactionist and symbolic interactionist perspectives, multiple-case study design, participant observation, interviews, and the use of frameworks based on the Social Capital Bank (Ruston and Akinrodoye, 2002) and Gagon and Simon's (1973) classical sexual script. Aside from whether a methodology or an approach was stated or not, there were other clues which suggested that some of the studies had appeared to take either a social or a medical model approach towards the adults with IDs in their study. The studies by Edler and Rath (2014), Hall et al. (2011), Löfgren-Mårtenson, (2008) and Moisey and van der Keere, 2007) viewed the environment and societal views towards the adults with IDs as disabling and something which had created barriers for this population, for example parts of the internet's inaccessible design, which hampered their ability to access and use the internet. In response to this, the researchers proposed or implemented alternative formats, approaches and adaptations in their studies such as the audio and visual presentation of information online within a VE and understandable structures and language to meet the needs of participants with IDs. Some studies, specifically by McClimens and Gordon (2008, 2009) and Holmes and O’Loughlin (2014), took a more medical approach and, at times, a paternal role towards the adults with IDs. They tended to focus on the characteristics of the participants with IDs to explain their unsuccessful attempts at the online activities they had set for them in the study or their negative online experiences. For example, in McClimens and Gordon (2008, 2008) study the participants’ ID was cited as the reason why they were not being able to construct a text-based blog which contained the right amount of self-presentation that would initiate contact from other online users. In the study by Holmes and O’Loughlin (2014) the restricting of an adult with an ID’s finances, after another online user had financially exploited them, was legitimized because of the participant’s ID, which made them more suseptable to being exploited, rather than attributing the exploitation with the online user who exploited her.

In the studies by Edler and Rath (2014), Hall et al. (2011), McClimens and Gordon (2008, 2009), and Moisey and van der Keere (2007), support was provided to all participants with IDs no matter what their prior internet experience had been or what ICT skills they already possessed. This placed the participant within a care/support receiving role from the very beginning of the study. It was not just information on the level of ICT skills the participants with IDs had already that was absent from many of the studies but also the context of the participant’s background and prior experiences. These would have helped to explain many of the observations the researchers’ made in their studies. For example, the participant with an ID who wanted his avatar to be pushed around in a virtual hospital bed in Hall et al. (2011) study and the apparent uncooperative behaviour of the supporters towards the adults with IDs using iPads in Edler and Rath's (2014) study. Relevant context within both of these studies may have further illuminated what appeared to be submissive behaviour within a medical environment (which may have been due to a previous experience in a similar environment), or the relationships between the participants with IDs and those supporting them.

In the study by McClimens and Gordon (2009), even after the participants with IDs had received internet safety training, 'chaperones' were assigned to support all of the participants to ensure the participants' safety and that their online behaviour was not offensive whilst they blogged:

> 'The Internet safety of the participants was of prime consideration for the conduct of the project and a training session on this issue was conducted for all participants. In this session we discussed the need to use pseudonyms, to withhold any private information and not to use any offensive language… With these cautions and under the direct supervision of the student chaperones, we felt that concerns for safety were being addressed' (:22).

The combination of being monitored and the use of blogging as an online activity placed these participants in a relatively passive off- and on-line user role in this study. Blogging, a presentation of their 'self' online, was possibly inhibited by being monitored by the chaperones because they may not have been able to post certain information about themselves, information the researchers and chaperones deemed 'private', to initiate contact with others online who would read their blog.

In Holmes and O'Loughlin's (2014) study the online experiences of three women with IDs were reported in third person vignettes. It was not clear exactly how the data was gathered and no quotes from the participants themselves were included in the paper. The professional and clinical roles of the researchers (who worked within a community learning disability team) and those they gathered data from, their responsibilities, the approach taken towards these clients and the research process was not accounted for within this study. The lack of reflexivity led to an unreflective, and at times, detached, paternalistic and clinical account/view of the participant's online experiences and their offline lives. Understandably, Holmes and O'Loughlin (2014) may have been too focused on the negative on- and off-line experiences of the adults with IDs in their study due to their professional roles, organisation, professional and legal demands and expectations, and the clinical relationship they had with the three women with IDs to interpret many positive on- and off-line experiences. What may have appeared to be a positive on- and/or off-line experience for the clients with IDs was viewed as a negative experience for the participant by the professional/researcher. An online experience which was viewed as negative by the professional/researcher often resulted in control being taken away from the client/participant following the disclosure of the online experience (which was not the fault of the individual with an ID). Whilst two of the three 'clients' with IDs in this study appeared quite passive to the health and social care professionals supporting them, one client clearly had a quite different view of what was risky in her life and what was not, compared to the professionals' views. The professionals took away the client's/participant's control and placed restrictions on both her finances and internet access. This may have been viewed as punishment by this client/participant and could lead to a reluctance in the future to disclose both positive and negative on- and off-line experiences because of the fear of subsequent consequences imposed by those supporting her. This was something that was also highlighted by the participants in Löfgren-Mårtenson’s (2008) study.

Although in many cases the study designs meant that participants were not considered in the validation of the findings, the only study that reported feeding back the data, findings or conclusions to the participants with IDs, to ensure that they were a fair and accurate account, was Hall, et al. (2011). Hegerty and Aspinall (2006) fed their findings back to the senior managers of the organisation (who ran the day services where the research study took place) to check for inaccuracies rather than to the staff and service users they had interviewed and observed. This was unsurprising given that the reasons behind the research study were initiated by a request from this organisation perhaps with the intention to gain a sympathetic external report on their current ICT usage to secure additional funding. Hegarty and Aspinall (2006) and Williams (2008) both had personal connections to the organisation and/or website their research focused on, but Williams (2008) clearly acknowledged his position and the relationship he had with the organisations who had authored the websites. Williams (2008) then took a balanced and critical approach towards his analysis in order to help adults with IDs and those supporting them to improve their website content. Ann Aspinall was previously the ICT service development manager for the organisation being studied by herself and Hegarty (2006). These researchers reported only on the barriers effecting the staff, such as the staff’s lack of time and un-met training needs which they suggested could be solved with additional funding. They did not look at, or comment, on the wider barriers that may have been influencing adults with IDs’ ICT access and use in this organisation, such as the physical access of ICT equipment by the service users with IDs, the abling or disabling design of the internet they were using, the skills the service users themselves had as opposed to the staff's, and further environmental and societal barriers to ICT access and use, such as staff's perceived risk of the service users accessing the internet.

The clear underlying rationale for the studies conducted by Brewer et al. (2010) and Taber-Doughty et al. (2010) had also influenced their research studies. Both studies appeared to focus on the same telecare system that incorporated VoIP and had an underlying aim to offer a significant cost-effective solution to the increasing number of adults with IDs who needed support as well as a decrease in the availability of support staff for this population. They believed their telecare system would provide safe, secure and private care and support to the service users while also increasing their independence. Both Brewer, et al. (2010) and Taber-Doughty, et al. (2010) constructed an altogether positive and convincing argument for the use of the telecare system which continued into their overall positive conclusions around the system. This was despite service users with IDs and the staff who supported them expressing concern over their own privacy, specifically because they were being monitored online by cameras, and the decrease in opportunities for the service users to interact with the staff face-to-face. In response to the telecare system in Brewer, et al. (2010) study participants with IDs stated:

> "they [the people monitoring her via the web-camera] follow me, I don't like people watching me (:267).
>
> "they won't let me eat at night" (:268).

Taber-Doughty, et al. (2010) only interviewed onsite support staff on their perceptions of the telecare system and did not ask the service users with IDs for their views on how the telecare system may or may not have increased their independence. The data collected was measured quantitatively based on the observations of the participants with IDs.

Interestingly only 4 of the 14 studies reported gaining ethical approval to conduct their research. These were Hall, et al. (2011), Brewer, et al. (2010), and McClimens and Gordon (2008, 2009). It was surprising, given the personal nature of the study, that Löfgren-Mårtenson's (2008) study did not receive any ethical approval. Ethics was, however, acknowledged by Löfgren-Mårtenson (2008) and a statement was offered in the paper to suggest that ethical consideration had been taken and adhered to. Compared to other studies, which had gained formal ethical approval, Löfgren-Mårtenson (2008) maintained a relatively good standard of ethics during her study based on the description of her approach, methods and research process. Not only did many studies not report that they had received ethical approval, at times they may have crossed into what could be described as an unethical approach and, at times, disrespect towards the participants with IDs and sometimes those who supported them (McClimens and Gordon, 2008, 2009; Hegarty and Aspinall, 2006; Moisey and van der Keere, 2007; Shpigelman and Gill, 2014). For example, Hegarty and Aspinall (2006) obtained consent to observe and interview staff and service users from the management of the organisation but not from the staff or service users themselves. They also took photographs of ICT equipment inside service users' homes without any mention of consent being obtained from these service users. The disappointment of the participants with IDs, and perhaps also the researchers McClimens and Gordon (2009), at not having been successful at initiating engagement with unknown others online or making an online friend through their blogging activities may have been the reason behind the decision to encourage the participants to sign up to Myspace. Once signed up to Myspace the participants then received a fake friend request:

> '…when our participants logged on after their initial sign up to Myspace they were uniformly delighted to discover that they had a new 'friend' called Tom. Unfortunately Tom is nobody's friend because Tom is not real' (McClimens and Gordon, 2009:27).

It is assumed that the fake friend request was an automatic friend request generated by Myspace. The researchers, who acknowledged in their paper that adults with IDs longed for friendship off- and on-line, did not state what they did in response to the participants receiving a fake friend request or if the participants were told that this was a fake friend request and what this meant. As highlighted by Holmes and O'Loughlin (2014), adults with IDs struggle with the meaning of the online term 'friend', which the researchers stated was different from the offline meanings of 'friend' for their participants. A fake friend request for McClimens and Gordon's (2009) participants, without explanation, may have added to the misunderstanding of the concept 'friend' and/or it may have encouraged them to accept friend requests online from people they do not know.

Williams (2008) searched for, and Seale (2007) revisited, the contents of web pages created by adults with IDs/DS and those who supported them in order to analyse these. Williams (2008) already knew some of the context and the rationales behind the development of the web pages he was analyzing, as previously noted, and focused on the headings and content of these pages. Whilst this remote research strategy appeared appropriate for William’s (2008) evaluative research aims, Seale (2007) was unable to fully ascertain the motives or the level at which ‘others’ without an ID supported or published on behalf of the adult with DS in her research study. This detached and remote approach sometimes led to Seale (2007) speculating and over-interpreting her findings, leading to a perspective that may not have been a true reflection of these adults with DS’ online experience.

Some studies acknowledged that adults with IDs were the experts or authorities in their own lives and consulted and valued their experiences and accounts of using the internet. They fed back their findings to the participants with IDs where appropriate and ensured that their rights were upheld during the study (Shpigelman and Gill, 2014; Hall et al, 2011; Löfgren-Mårtenson, 2008). Other studies claimed the same approach or ethos but then did not report on examples of how they created a participatory or ‘user expert’ approach (Edler and Rath, 2014), or disregarded the input of those with IDs in favour of those without IDs supporting them (Hegarty and Aspinall, 2006; Moisey and van der Keere, 2007). This was clearly seen in Hegarty and Aspinall’s (2006) study when they sought out staff members’ views, rather than the adults with IDs, to steer the design of the software and applications in order to develop personal independence and quality of life for the service users. Hall, et al. (2011) demonstrated the most participation by including adults with IDs in their steering group and the delivery of the study. Hall et al. (2011) collaborated with a charity who already provided a community service and support to adults with IDs living in the community. The charity had a fully equipped ICT suite with an internet connection which already allowed the participants with IDs to access the internet. The researchers placed an importance on working alongside people with IDs and their supporters to ensure that their rights were recognized in the research process and their experiences were accurately represented. However, no researchers reported any involvement by adults with IDs in the design or dissemination of the study.

A.3.3 Defining the terms ‘intellectual disability’ and ‘adult’

Only 2 of the 14 studies included an internationally recognised definition for an ID. The AAIDD’s (2013) definition for the terms ‘developmental disability’ and ‘intellectual disability’ were used to describe the participants’ ID status in the studies by Brewer et al. (2010) and Shpigelman and Gill (2014). Many of the remaining studies, which originated from the UK, US, Sweden, Germany, and Canada, used a selection of terms to describe participants’ IDs which included ‘learning disability’, ‘learning difficulty’ and ‘severe multiple disabilities’. However, these terms often have different definitions and meanings throughout the world and they do not always mean the same as ‘intellectual disability’ as defined by the DoH (2001) and the AAIDD (2013). Seale’s (2007) participants were described as having both DS and learning difficulties and although an ID was not specified or defined this study was included as one of the characteristics of adults with DS is the presence of an ID (National Health Service, 2015). Reflecting on ‘the changed construct of disability', Molin et al. (2015) used a description by Schalock (2011) as a rationale for their use of the term 'intellectual disability':

> '[intellectual disability] aligns better with current professional practices that focus on functional behaviours and contextual factors, [and] provides a logical basis for individualized supports provision' (Molin et al., 2015:23; citing Schalock, 2011:228).

Holmes and O'Loughlin (2014) also critiqued the term 'learning disability' citing Beart, et al. (2005) and Burns (2000) in order to describe ID as a culturally defined, powerful and overriding label, based on what is deemed to be 'normal' learning abilities and how 'others' respond to them. They also highlighted the effect that the term 'learning disability' has on the person with an ID's identity. The lack of a clear definition for an ID, or the inclusion of additional descriptions that lacked clarity, may have led to some participants not having an ID, especially where self-selection had been adopted at the sampling stage, in some of the studies (Löfgren-Mårtenson, 2008; Shpigelman and Gill, 2014). Self-selection was not problematic for either of these studies but the descriptions for an ID to help potential participants self select was. Shpigelman and Gill (2014) described an ID in their participant information as 'disabilities that make learning hard or slower' (:1606). This may have resulted in some participants with a learning difficulty, such as dyslexia, completing the online questionnaire. Both an ID and a learning difficulty make learning hard or slower, but a learning difficulty does not impair intelligence or align with other factors included in the definitions of an ID by DoH (2001) and AAIDD (2013). All studies that did not have a clear definition for ID and/or a reported sampling strategy could be questioned around whether or not their participants had an ID or not (Edler and Rath, 2014; Hegarty and Aspinall. 2006; Holmes and O’Loughlin, 2014; Löfgren-Mårtenson, 2008; McClimens and Gordon, 2008, 2009, Moisey and van der Keere, 2007; Molin et al., 2015; Shpigelman and Gill, 2014; Taber-Doughty et al., 2010; Seale, 2007). Although definitions for an ID vary, are often debated and generally originate from westernized countries, it would have been useful if the studies included, described and/or critiqued ID definitions, descriptions or benchmark and given further information on the inclusion criteria for their participants.

There were other definitions used in the studies that were also not universally accepted or recognized in the study’s country of origin. For example, Seale’s (2007) definition for ‘adult’, which she defined as someone aged 13 or over, is different from the accepted age of an adult as being someone aged 18 or over in the UK (Office of the High Commissioner for Human Right, 1989). This research study was included because the active home pages that were first accessed in 2001, which were revisited for Seale’s 2007 study, meant that any participants that were aged 13 in 2001 would now be aged 19 and therefore could be included within this literature review in accordance to the set inclusion criteria for ‘adult’: someone aged 18 or over. Interestingly, Löfgren-Mårtenson (2008) used the term ‘young people’ to describe her participants with IDs who were all aged between 18 and 31. It is unclear if Löfgren-Mårtenson (2008) used an age inclusion within her sampling strategy or why she would describe all the study’s population as young when some were aged in their late 20s and early 30s. It is hoped that this was not an example of the infantilization of adults with IDs but more an oversight in the study design, recruitment, or the translation of the paper into English.

A.4 Others' influence and control over adults with intellectual disabilities' online experience and the effect this has on their health, wellbeing and quality of life.

A.4.1 Views and attitudes of adults with intellectual disabilities and 'others'

A common theme throughout many of the studies was the inclusion of 'others' without an ID's views, specifically teachers, staff, family members, specialists, health and care professionals and researchers. 'Others' had an array of attitudes towards the internet and perceptions of the benefits and risks of the internet for adults with IDs. The synthesis of these studies using meta-study methods also made it clear that 'others' had an influence over the adult with an ID's online experience and their wellbeing.

Many of the adults with IDs in the studies perceived the internet as positive, offering them an opportunity for adventure, connecting with others, and the possibility of finding friendship and a relationship (Edler and Rath, 2014; Holmes and O'Loughlin, 2014; Löfgren-Mårtenson, 2008; Shpigelman and Gill, 2014). There was a range of views and attitudes held by others without an ID which ranged from positive, ambivalent, or the most common, negative. 'Others' negative views around the internet centered on its potential to be risky and dangerous, or that it had no value to an adult with ID's life or wellbeing (Löfgren-Mårtenson, 2008; Molin, et al., 2015; Moisey and van der Keere, 2007). 'Others' negative views and attitudes were often bound up in the responsibility they felt they had towards adults with IDs they support or cared for. Those without an ID who held positive views acknowledged similar risks posed by the internet, but they balanced these risks with the benefits and opportunities they believed the internet may offer adults with IDs (Molin et al., 2015).

The weight or importance given to the data from those with and without IDs in the studies varied. The ‘multi-faceted picture’ of adults with IDs’ internet experiences created by Löfgren-Mårtenson (2008) appeared to include both the views of staff members and ITC experts without taking away the importance of the lived experiences of those with IDs. This approach, viewing the topic from those with an IDs’ perspective, led to rich data and new findings around adults with IDs’ on- and off-line behaviour and how this was often influenced by others in their lives, something lacking in many of the studies in this literature review.

Positive views held by some of the researchers, teachers and staff members without an ID often included the notion that the internet could help adults with IDs learn about health information (so that they could make informed decisions), improve their literacy and ICT skills, make an important contribution to their own development, and/or interact with others (Hall et al., 2011; Löfgren-Mårtenson, 2008; McClimens and Gordon, 2009; Moisey and van der Keere, 2007). Many of the optimistic ‘others’ felt that online communication, participation, socialisation and interaction could help support those with an ID to lead a ‘normal’ life (Löfgren-Mårtenson, 2008; Molin et al., 2015). Löfgren-Mårtenson (2008) noted that these positive views often came from younger members of staff who, like the young people with IDs they supported, had grown up part as part of the Swedish ‘Net generation’. These staff members were frequent internet users themselves and appeared to focus on the social and educational benefits the internet could offer the young adults with IDs they supported. Molin et al. (2015) identified that many parents of the adults with IDs living in Sweden were generally positive towards the internet and encouraged their children to take advantage of the opportunities it presented to them, specifically creating and maintaining social bonds with others in order to:

> ‘gain more knowledge of a specific disability and maybe find other peer group mates /…/ [to] find out that he is not alone” (Molin et al., 2015:30).

Whilst some parents expressed concerns over the internet, they also acknowledged their society was moving more towards a ‘24/7 digital society’ (:28) and that the benefits and opportunities offered by the internet far outweighed the disadvantages (Molin, et al., 2015). Their worry was that if their children did not learn the ICT skills needed to use the internet this could result in a reduced or limted participation in society for them in the future. Some of the parents also reported they were not worried about their children accessing the internet and did not want to know exactly what they were doing or who they were contacting on the internet. This was because their children already discussed and shared their online experiences with them. As a result the parents did not think their children would be accessing ‘suspicious’ online content that would lead them into ‘trouble’. Molin et al. (2015) compared the parents’ attitude with the earlier study by Löfgren-Mårtenson (2008) and noted a general change from negative to positive attitudes concerning those with IDs using the internet. In Löfgren-Mårtenson’s (2008) study it was reported that staff members held very negative views towards the internet, describing it as ‘unsuitable’ and ‘addictive’ for young adults with IDs (:136). Other concerns by those without IDs were that the young adults with IDs:

> ‘could come in contact with pornography or meet strangers who delude them financially or abuse them sexually’ (Löfgren-Mårtenson, 2008:136).

Molin, et al. (2015) suggested that the more relaxed and trusting attitude demonstrated by the parents in their study, seven years after Löfgren-Mårtenson’s (2008) study, may have been because the internet had become more integrated and accepted into Swedish society. Molin et al. (2015) may be correct in this assumption but Löfgren-Mårtenson (2008) also found that the young adults with IDs often reassured those who support them, including their parents, that they understood the risks of the internet but at times did not disclose their negative online experiences to others. This was to ensure their internet access was not restricted or denied by those supporting them as a result of their disclosures.

Molin et al. (2015) found that parents valued offline face-to-face interaction for their children. One parent in Molin et al. (2015) study suggested that they would prefer their son to be part of, experience and learn about things in the ‘real’ world, rather than through the internet (Molin et al, 2015). The teachers, however, viewed the internet more sympathetically and as a viable and alternative way for the students to connect with others, especially when another offline face-to-face communication was not available. Resistance to online communication and activities from those without IDs supporting those with IDs was also noted in Brewer et al. (2010) and Taber-Doughty et al. (2010) studies. In Edler and Rath’s (2014) study the resistance towards the iPads shown by the staff supporting those with IDs led to them exhibiting uncooperative behaviour and increasingly retracting the support they offered to those with IDs during the study. Edler and Rath (2014) concluded that this was because:

> “they realized that the use of these devices did not make their work easier” (:180).

In Löfgren-Mårtenson’s (2008) study the media was noted as a source that may have been influencing the staff members’ views on the internet, especially towards the risk it posed, creating pre-conceptions around people with IDs’ internet use. Holmes and O’Loughlin (2014) and McClimens and Gordon (2008) also highlighted how influential media reporting was on how the internet is viewed in the UK and how it focuses on the vulnerabilities of children and young people on the internet, specifically acts of identity theft and financial scams on this population. As little research existed on the potential risks of the internet for adults with IDs the media appeared to be the only accessible source of information for those without IDs in these studies.

A.4.2 Consequences of the views and attitudes of ‘others' on the adults with intellectual disabilities’ wellbeing

When it came to adults with IDs’ internet use, ‘others’ without an ID, who were supporting and caring for the adult with an ID, often became negative, controlling and dominating (Löfgren-Mårtenson, 2008; Molin et al., 2015). For example, a teacher in Löfgren-Mårtenson’s (2008) study who viewed the internet in a positive light described how some of the staff projected their feelings of responsibility into protective and controlling views, attitudes and actions. This took the form of fixing their ‘Netiquette rules’ onto the young people with IDs, controlling the time the individual with an ID spent on the internet, or banning and controlling access to sites they viewed as unsuitable, pornographic and/or violent (Löfgren-Mårtenson, 2008). In response to the young adults with IDs’ attempts to find and arrange offline dates with romantic partners they had found on the internet (whom they had not previously met offline), staff arranged alternative offline social events to provide the young adults with IDs a chance to “meet people in a proper way” (Löfgren-Mårtenson, 2008:134). Löfgren-Mårtenson (2008) turned to Holm et al. (1997) to understand and describe these controlled and segregated events for adults with IDs which were organized by ‘others’ rather than the adults with IDs. They were described by Löfgren-Mårtenson (2008) as ‘created communities’ and a way for ‘others’ to control adults with IDs. Control over internet use was also seen in Moisey and van der Keere’s (2007) study when the participants with IDs could not find another ‘computer coach’ or had to wait for their ‘agency’ to make the decision as to whether their ICT training could continue after the research study had finished. Moisey and van der Keere (2007) realised that the reason why these participants did not continue to access the internet was not because they did not want to, but because they lacked the support of ‘others’ to help them to do this due to ‘others’ attitudes and beliefs around adults with IDs and their internet access. But the control that those without an ID had over participants with IDs was aided by Moisey and van der Keere’s (2007) study design. They did not foresee adults with IDs’, who enjoyed accessing the internet during the study, struggle to continue their online activities without the support of ‘others’.

Teachers’ views in Molin et al. (2015) study had also influenced the internet use of adults with IDs. One parent had described how the views of teachers, who had “talked about how many people get hurt and become sad” (:28) on the internet, had stopped their child with an ID using online social media. The parent stated:

> “he [their child] thinks that… everyone only everyone hurt each other on Facebook – it’s either Black or White, he thinks” (:28).

The views expressed by those without an ID had also made adults with IDs loath to try new things on the internet and feel it necessary to protect themselves from the internet risks as reported by those without IDs (Molin et al., 2015).

A.4.3 Suggested solutions and recommendations

The support that adults with IDs received offline is generally based on care coupled with:

> ‘strong feelings of responsibility… a feeling that is often manifested through different forms of control’ (Löfgren-Mårtenson, 2008:126).

Whether or not they liked it, some of the parents in Molin et al. (2015) study realised that they needed to encourage their children with IDs to access the internet whilst also encouraging face-to-face interactions. This was so that a balance could be achieved and to ensure their children made the most of all opportunities available to them. Holmes and O'Loughlin (2014) also suggested a need to offer a balance between offering adults with IDs:

> 'the same rights and freedom as everyone else, whilst ensuring that we can empower them to deal with any difficulties they experience online' (:7).

In other studies, even when it was evident that control by 'others' may not be the most successful way to encourage independent and safe internet access for adults with IDs, Seale (2007) still suggested adults with IDs should be supported by volunteers to:

> 'ensure that there was some element of 'supervision' whilst they were creating their home pages' (:18).

Shpigelman and Gill (2014) suggested specialist websites for adults with IDs, such as a simplified version of Facebook intended for users with visual impairments. McClimens and Gordon (2009), who had taken the step to use blogging as its online activity, also considered using a specialist ID site in the future. However, Moisey and van der Keere (2007) expressed that 'congregating or segregating' (:97), on- or off-line, should not be employed for adults with ID. Holmes and O'Loughlin (2014) and Löfgren-Mårtenson (2008) found that adults with IDs had a strong preference towards non-specialist ID websites where they could connect and communicate with others that did not have an ID. Seale (2007) put forward another, what she described as a more optimist, approach where support would be offered to adults with IDs without 'under-estimating their ability to cope with the risks of internet use' (:22). This more trusting and less controlling approach was also shown by Shpigelman and Gill (2014) who suggested adding a function or a link on Facebook that would allow the user with an ID to access online help from an advisor who would be available in a chat window ready to offer support if they required this. Shpigelman and Gill (2014) argued that this online support would:

> ‘increase safe and effective participation of people with intellectual disabilities in social media’ (:1611).

McClimens and Gordon (2008, 2009), Holmes and O’Loughlin (2014) and Moisey and van der Keere (2007) all provided internet safety training for adults with IDs but did not indicate if these were helpful during or after the research studies. It appeared in Molin et al. (2015) Swedish study that all adults with IDs had received internet training and advice from both their parents and their school, but there was a debate between parents and teachers over who should actually be responsible for providing this. This was the only study which reported an assertive and effective response by an adult with an ID towards a negative online experience, which they had disclosed to their parent. Löfgren-Mårtenson (2008) highlighted that adults with IDs did not always disclose a negative online experience to ‘others’ as they feared this would lead to their internet access becoming restricted or even denied. This was evident in Holmes and O’Loughlin’s (2014) study where a woman with an ID had financial and internet restrictions placed on her following a disclosure of a negative online experience. The relationship between adults with IDs and ‘others’ appears fundamental to safe and positive internet access, as seen in Molin et al. (2015) study and elaborated by Löfgren-Mårtenson’s (2008) discussion over concepts such as ‘risk’ and the different perceptions held by adults with IDs and those without IDs.

In Holmes and O'Loughlin (2014) study internet training was offered after the researchers had discovered the participants with IDs' negative online experiences. It was unclear if they had received any internet safety advice before the study was conducted. In comparison, the adults with IDs in Molin et al. (2015) study appeared to have had regular discussions with both parents and teachers around internet safety and had received training and information at school on:

> 'how to behave and write on the internet – and what possible consequences might result' (:28).

The debate between teachers and parents in Molin et al. (2015) study was not about whether or not the young people with ID would receive internet training, but who should be delivering this. McClimens and Gordon (2008, 2009) and Moisey and van der Keere (2007) also provided internet safety training but did so prior to or during the research study. All of the training sessions were only briefly reported on in these studies but they appeared to focus on what was and was not safe for the participants to reveal about themselves online.

To combat the inaccessible design of the internet, Shpigelman and Gill (2014) suggested the use of voice-controlled programs, such as speech-to-text applications, audio/video to read the text on the screen, and an increase of graphics and easy-read information to overcome difficulties in reading and writing on the internet. Seale (2007) also recommended finding technological solutions which would allow adults with IDs to be able to publish online independently or with very little support. Shpigelman and Gill (2014) and

Löfgren-Mårtenson (2008) suggested that the longterm solution should be developments in the design of the internet to make it accessible for all. Williams (2008) also added that this could be achieved by involving adults with IDs in the future development of the internet.

A.4.4 Support versus control in the adult with intellectual disabilities' online experience

At times adults with IDs required support from others without an ID to access and use the internet. Seale (2007) suggested that this interdependence should be a fluid notion, resulting in periods when more support was required and on other occasions, less support. This, Seale (2007) suggested, would result in the independent and autonomous use of the internet by those with IDs. Shpigelman and Gill (2014) found that adults with IDs who did require a level of support to access the internet, specifically how to use Facebook and to chat with their friends, tended to look for and contact people they already knew to ask for help. A 'one-size fits all' support by was provided to many of the participants with IDs within the studies regardless of their current ICT skill level or experience and what support they actually required for the online activity (Edler and Rath, 2014; Hall et al., 2011; McClimens and Gordon, 2008, 2009). In McClimens and Gordon's (2008, 2009) study some of the participants stated that they possessed some ICT skills already and specified what they needed support with:

> "I do know a little about computers and can use the mouse by myself, but need help with spelling and finding my way around the screen" (McClimens and Gordon, 2008:8).

McClimens and Gordon (2008) noted that two of the participants: ‘composed and typed their blogs independently’ (:8) and the unedited extracts from these specific blogs showed a high level of literacy. This appeared to indicate that these participants did not need too much support. The decision to introduce ‘chaperones’ for all participants in this study was not based solely on supporting the participant to access the internet and the chosen online activity blogging, their role was to also monitor the participants’ online engagement and ensure what they wrote online was appropriate (McClimens and Gordon, 2088, 2009). Once a participant had posted a blog online in this study it was read by the participants, chaperones and researchers, described as being done in ‘a spirit of mutual congratulation’ (2009:25). With the strict rules in place and the use of chaperones for all participants, even those who could compose and type their own blogs, this may have been congratulatory as well as protective and controlling.

The ‘facilitators’ in Hall, et al. (2011) study also provided support to all participants which sometimes resulted in over-support and control of the adults with IDs’ internet experience. Hall et al. (2011) observed that they often intervened: ‘when participants could have done things for themselves’ (:e91). Hall et al. (2011) had instructed the facilitators to use a participant-directed, informal, lighthearted and playful approach towards supporting and helping the participants engage in a spontaneous and emotional way with the Virtual Environment (VE) but they reported that this less directive approach by the facilitators meant that: ‘the balance of the exposure was lost, and the person did not spend time in every area’ (Hall et al., 2011:e91). In response to this, the facilitators started to use a more directive approach to ensure the participants spent time experiencing all the areas available in the VE. At times this resulted in the facilitators: ‘taking over the controls or telling the participant where to visit’ and this resulted in lost opportunities for playful engagement, an over-reliance on the facilitator, and some participants losing interest in the activity (Hall et al., 2011:e91). Adults with IDs’ passiveness, over-reliance on those supporting them and lack of control was also noted by McClimens and Gordon (2008), Moisey and van der Keere (2007) and Hegerty and Aspinall (2006). The staff in Hegarty and Aspinall’s (2006) study reported the arrival of the internet in their services and their observations that no service users accessed the internet by themselves, only with staff support. In one case one resident with an ID is described as being:

> ‘…helped by the staff there, especially C. his key worker who looks up stuff on the internet for him.’ (:141).

Reliance on support from those without an ID was also seen in McClimens and Gordon (2008):

> ‘Another of the group 'C', who was unable to type asked her supporter to comment. The supporter remarked:
>
> ‘C did want to write things but I don't type fast enough for her. And she didn't want it to be boring so I said I'd change it. She wants to do more on the computer but she doesn't feel there's much time for her to do it." (:7)’

The home pages of adults with DS often indicated they also had a high level of ICT competence as they had descriptions of the adult with DS’s word processing and emailing skills, and that they played playing computer games and browsed the internet. But there were also indications that they had also received support too:

> “My mom helped me to set up some pictures that help me find my favourite websites” (Seale, 2007:9).

Overall the adults with DS’s ICT competence and the level of support they received in Seale’s (2007) study was often unclear due to the remote methods employed. Seale (2007) did find evidence of an organization and others without IDs using the adults with DS’ home pages to forward their own causes and to create an identity for the adult with DS. For many of the adults with DS support to publish their home pages was generally provided by family members and friends. Seale (2007) noticed that at times there was a lack of first-person narrative on the home pages and an absence of any personal experiences or expressions of feelings by the adults with DS. Seale (2007) drew upon a theory by Miller (1995) and proposed that this high level of support may be an effort by the supporters without DS to ensure that a ‘safe image’ of the adult with DS was presented to the online world to protect them against prejudice from other online users. But this conflict of interest over how the adult with DS is presented online may have the potential to place adults with IDs into passive recipients of:

> “technological expertise and protective guardianship as opposed to active advocators for the opposition of oppression” (Seale, 2007:22).

Appendix B
Supporting Documentation for the Research Study

B.1 Interview schedule

Notes.

It is anticipated that the interview will take on an open-ended participant-led format, encouraging the participant to talk about their own personal online experiences and the effect these may have had on their wellbeing. The first question will be asked to all participants and further questions will depend on how willing the participant is to lead the interview.

This format may be difficult at first for some participants. Some participants may need prompting to talk about the research area rather than unrelated matters. Open-ended questions have been created to help prompt the participant.

Interview schedule

I would like to ask you about yourself, the internet and how the internet may have changed things about your life, your health or how you feel.

I will be recording us talking on this (show the audio recorder) recorder. This is so I can remember what we have said and I can write this down later.

I have to remind you, that if you say something which makes me think that you or someone else might be in danger, I may have to tell someone about this, who will be able to help. If this does happen, we will stop the interview and talk about this.

If there are anything you don’t want to talk that is OK.

If I ask you any questions that you don’t want to answer that is OK too.

Do you have any questions for me?

Are you happy to start?

1. Is there anything you would like to tell me about what happens when you use the internet?

Prompts to include:

Why do you use…. (the example they have given)?

What happened when…. (an example they have given)?

Can you tell me more about…. (an example they have given)?

How did you feel when….. was happening?

What did you do after…. happened?

If further questions are required these will be as follows:

2. Can you tell me what a normal day is like for you?

(this is for context and any voluntary information about internet use)

3. When did you first start using the internet?

4. Why did you start using the internet?

5. Can you tell me what the internet is like for you?

6. What do you do on the internet?

7. Has anything happened to you whilst you have been using the internet that you would like to tell me about?

8. Has the internet changed anything for you?

Followed by these two prompting questions if required:

Has using the internet (if they have given an example use this) made anything better for you?

Has using the internet (if they have given an example use this) made anything worse for you?

9. How do you feel when you are using the internet? (if they have given an example of an online activity refer to this)

10. How do you feel after using the internet? (if they have given an example of an online activity refer to this)

11. What do other people think of you using the internet?

12. Is there anything you thought I would ask you today?

13. Is there anything you would like to ask me?

Prompts to include:

Why do you use…. (the example they have given)?

What happened when…. (an example they have given)?

Can you tell me more about…. (an example they have given)?

How did you feel when….. was happening?

What did you do after…. happened?

Thank you for letting me interview you.

I have enjoyed or learn a lot from listening to what you have to say (do not say ‘enjoyed’ if the participant has recalled a negative online experience though).

Are you still OK to let me write about what you have told me?

Would you like to talk to me again?

If yes arrangements could be made at this point or the participant could go away and think about this.

Rationale behind specific questions and adaptations

This was not used for two participants, because they had already started to talk about the internet and wellbeing before the interview started. I took this to indicate that they knew were they wanted to start, which in one case was when he first learnt how to use a computer and the internet.

Further questions, depending on the response to the opening question/statement and were the participant was leading the interview were:

‘What is a normal day for you?’

This was asked in order to gather context about the participant. When it was clear that the participants spent a large proportion of their time on the internet, the following question was also asked:

‘What is a normal day for you on the internet?’

Next was a question that not only would provide more context, but could also provide a chance for the participant to recall a further wellbeing ad internet experience in regards to their inter-relations with others and to reflect upon this:

‘What do other people think of you using the internet?’

In many cases the participant started to answer this question without being asked directly, and prompts to initiate more detail were used. Next came questions that linked wellbeing to internet use. This was often asked in the third or fourth interview as the participants were naturally giving examples of wellbeing and internet experiences, without the interviewer influencing their understanding of wellbeing. The question about wellbeing and internet experiences were staged to allow for different levels of understanding around the term ‘wellbeing’, but did not assume the participant did not have an understanding of ‘wellbeing’ or indeed myself having a fixed notion of what ‘wellbeing’ may mean:

‘Do you know what wellbeing means?’

If the participant had their own idea of what ‘wellbeing’, then the following was asked:

‘Can you tell me what wellbeing means to you?’

The following was then asked:

‘Do you think the internet changes anything about your wellbeing?’ (Prompt: Can you give me an example?)

If the participant did not know what wellbeing meant, I explained loosely that wellbeing could be: ‘…anything to do with your health, your life, or how you feel.', making sure that they could decide what wellbeing actually meant. Sometimes I used the words 'happy', 'challenges' and 'satisfaction', often as a result of what the participant had already said in their interviews. Sometimes I repeated an example that the participant had already given me in a previous interview, that was a wellbeing and internet experience. As an interview was nearing the end the following questions were posed:

'Is there anything you thought I would ask you?'

'Is there anything you would like to ask me?'

B.2 Participant information

Participant information sheet for

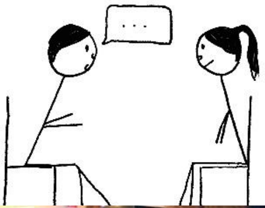
The internet and well-being research project.

You are being invited to take part in a research project called:

The internet and well-being research project.

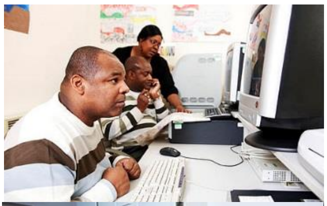
What is the internet and well-being research project about?

Hello, my name is Gillian Hebblewhite. I am studying for a PhD in health studies at the University of Hull.
I am doing a research project about people with learning disabilities, the internet and well-being.



By talking to people with learning disabilities I want to find out:

1. What people with learning disabilities views are on the internet, what they like to do on the internet, things that have happened when using the internet and why they use the internet.



2. If people with learning disabilities think using the internet has changed anything about their life, their health or how they feel (this is sometimes called well-being).

3. How other people might think of people with learning disabilities using the internet.

Why is this research project being done?

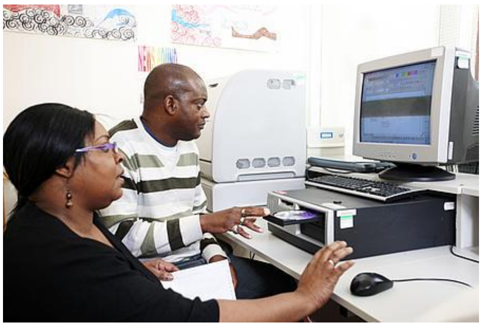
I think that research about people with learning disabilities should include the views of people with learning disabilities and what they have to say.

This is because people with learning disabilities are ‘experts’ in their own lives. They have something important to say about the internet and their well-being.

I think that by doing this research project we will learn how to help more people with learning disabilities to enjoy using the internet safely.

Who are you looking for to take part in this research project?

To take part in this research project, I am looking for people who are:



Aged 18 years old or older,
and
Have used the internet for 2 months (or longer) in the past 2 years,
and
Have a learning disability.

A learning disability means that you may have difficulty with everyday activities like household tasks or managing your money.

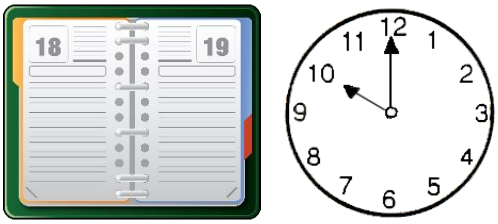
You may also need more time or support to:

- Learn new skills
- Understand new or complex information
- Socialise with other people

A learning disability is not a learning difficulty like dyslexia. Someone with a learning disability can have a learning difficulty too.

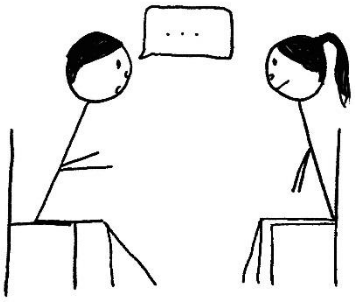
What will I have to do if I agree to take part?

If you agree to take part in this research project I will contact you using email or by telephone to ask you:



What date and time you would like to meet with me to talk to me?

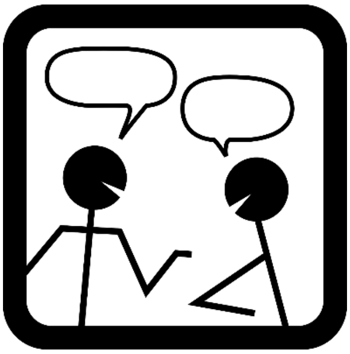
Where you would like to be interviewed?



When we first meet we will talk about the research project and what will happen if you consent (this means agree) to taking part.

If you consent (agree) to take part you will sign a consent form.

If you cannot sign your name you can still consent by saying you agree to take part. I will write down your name and what you have said to show you have consented (agreed).



I will ask you to talk about yourself, the internet and how it may have changed your life, your health or how you feel. I will listen to what you have to say and ask questions. This is called an interview.

Here are some of the questions you will be asked:

Can you tell me what you do on the internet?

When did you start using the internet?

Has the internet changed anything for you?
Has it made anything better?
Has it made anything worse?

You do not have to answer all the questions I ask you or talk about things you don't want to.

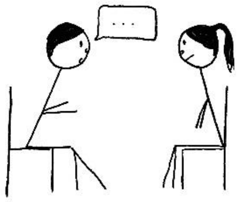
You might like to ask me questions too.

I am interested in anything you want to tell me about the internet and if it has changed anything for you.

Each interview will last up to 1 hour and you will be offered breaks in the interview.

After your first interview, I may ask if I can interview you again. If you agree, we will talk about the different ways we can do this. You may be asked to be interviewed up to 4 times. You may choose you only want to be interviewed 1 or 2 times and this is OK.

You can choose to:



Meet me in person to talk again, or

Talk to me using email, or

Talk to me using Skype, or

Talk to me using the telephone.

You might choose to use a few of these depending on how you feel.

Where will I be interviewed?

We can choose somewhere you know. This could be a service you use or a place you go to meet a group you belong to.

or I can find somewhere for us to meet. This could be a learning disability charity or at a University close to where you live.

X We will not meet at your home.

The place where you will be interviewed will be comfortable and safe for you. It will be a place where other people cannot hear what you are saying.

To help you remember, I will email or ring you 2 days before to check that you can still meet with me. I will remind you what day, time and where we are meeting.

Will I be recorded?

Yes ✓ the interview will be recorded with an audio recorder.

If you talk to me using email these will be saved too.

All of these will be kept very safe and secure on a computer that has a password. Only I use this computer and it is in a room that is locked.

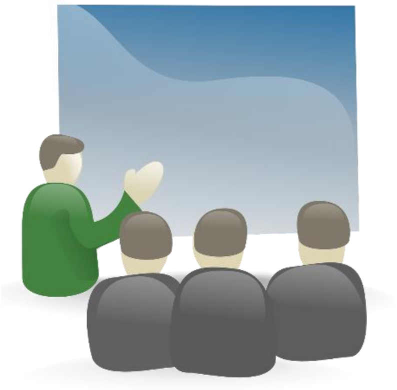
Who will be able to listen to what I have said?

My supervisors (they are like my teachers) may want to listen to what you have said too. They are called Nick and Kate and they both work at the University of Hull. This is because they need to check I have written down what you have said correctly. They will not know who you are and they will not tell anyone the names of people or places you have said.

After your interview, I will listen to and write down what you have said. This is when I make sure that no one knows it was you that was interviewed. I do this by
No X Not writing down your real name.
No X Not writing down the names of other people or places you have talked about.
No X Not writing anything down which may identify you to other people.

What will you do with what I have said or written?

I will write about what you and other people have told me about the internet, themselves and their well-being.
I might use something you have said to me or written down to help other people understand what you and other people think about the internet and your well-being. I will not use your real name or names of people or names of places you have said, so no one will know it is you that said this.



I may talk about this to groups of people.

It may be published in a Journal (this is like a magazine or book) for people who are interested in the internet, well-being and your experiences and views.

What if I tell you something that suggests that I or someone else might be in danger?

If you tell me something that makes me think that you or someone else might be in danger, I may have to tell someone who may be able to help.

If this happens, we will stop the interview and talk about it. I may have to tell someone you know, someone from a safeguarding team or the police.

Can I bring someone with me to the interview?

Yes ✓ you can choose to bring someone with you to support you when you talk to me. This might be a friend, a family member or someone who supports you.

It is OK if you do not want to bring someone with you as well.

What are the good things (the advantages) that may happen if I take part?

- You may really enjoy talking about yourself, the internet and your well-being.
- You may have questions about the internet that you would like to ask me. I will try and answer your questions honestly and give you information if you need it.
- Other people are interested in what you have to say about the internet and yourself. They can learn from what you tell me. This could help other people in the future to enjoy and use the internet safely.

What are the bad things (the disadvantages and risks) that may happen if I take part?

I am interested in both good things and bad things about the internet.

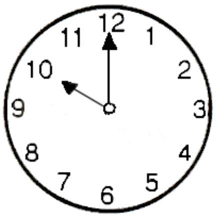
You may not have enjoyed using the internet. Something may have happened when you were using the internet that made you feel uncomfortable or upset.

It is OK to talk about this BUT… No one will make you talk about anything that you don't want to.

You decide what questions you want to answer and what you don't want to answer.

If you become upset when you are talking to me, we will stop the interview and have a break.

You can decide if you want to continue with the interview after the break or if you would like to stop.



We can arrange another interview on another day or you might decide that you would like to leave the research project.

You can decide to leave the research project at any time. This is Ok. You do not need to say why you want to leave.
I will ask you if it is still OK to write about what you have told me.
You can say yes ✓ or no X

Do I have to take part?

This is up to you!

It is up to you to decide whether or not to take part in this research project.

Talking to other people you know can help you think about and make this decision.

If I decide to take part can I change my mind?

Yes ✓ You might decide to take part and then change your mind.
This is OK.
You can stop taking part at any time.
You do not have to say why you want to stop taking part.

What should I do if I would like to take part in the research project?

If you decide you would like to take part in the research project or if you have any questions, email me, Gillian Hebblewhite, using this email address:

g.h.hebblewhite@2014.hull.ac.uk

B.3 Consent form

Consent Form

If you agree, put a tick ✓ in the box ☐, like this ☑

I have read and understood the participant information sheet. ☐

I understand that I can leave the research project and stop taking part whenever I choose to. ☐

I understand that what I say will be recorded and if I send emails these will be saved too. They will be encrypted (this means ☐

the words are jumbled and can only be read when a password is used) and stored securely

I understand that my real name and the names of any people and places I have talked about will not be used. ☐

I agree (say yes) to Gillian Hebblewhite using parts of what I have said in her essay, in presentations and in journals. ☐

I understand that I will not be paid to take part in this research project. I will receive drinks during the interview and I will get back the money I paid to travel to get to the interview ☐

If I talk about myself or others being in danger I will be supported to tell someone who can help about this.

Depending on what it is, Gillian may have to tell someone who can help, even if you do not agree to it. This is to make sure that yourself and others are safe and not in danger. ☐

I would like to take part in the research project ☐

Please write your name here…………………………………………………………………….

Please sign your name here…………………………………………………………………………………

What date is it today?...

If you cannot write your name or sign your name you can give verbal and non-verbal consent. This means you agree to consent by saying or doing something. What you say or do will be written down by Gillian Hebblewhite. This will be read back to you to make sure you agree.
How and what was said to agree to taking part in this research project?
……………………………………………………………………………
……………………………………………………………………………
……………………………………………………………………………
……………………………………………………………………………
……………………………………………………………………………
……………………………………………………………………………
……………………………………………………………………………
……………………………………………………………………………
………

The student researcher's name is Gillian Hebblewhite

Researcher's signature
……………………………………………………………………

What date is it today?
……………………………………………………………………

You will be given a copy of this consent form to keep.

You can change your mind at any time and stop taking part. This is OK. You do not have to say why you want to stop.

B.4 Publicity poster

The Internet and well-being research project

Do you use the internet? Do you have a learning disability?

Are you aged 18 or older?

If you answered yes to all of the 3 questions and would like to talk about:

Yourself and the internet, and

How using the internet may have changed anything about your life, your health or how you feel (sometimes called your well-being).

Please email Gillian Hebblewhite asking for more information using this email address:

g.h.hebblewhite@2014.hull.ac.uk

University of Hull
Faculty of Health and Social Care

I will then send you some information about how you can take part in this research project.

B.5 Consent and making a choice information sheet

What is Consent?

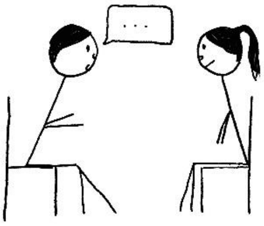
Consent is about being asked if you agree to something.

If you are asked to consent to something you have a choice. You can say
yes ✓ or no x

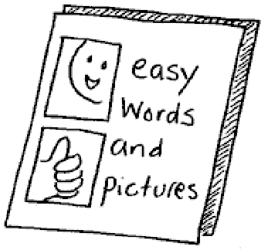
Making a choice

Making a choice can be difficult. Take some time to think about the choice you will be making.

There are things that can help you to make a choice such as having:



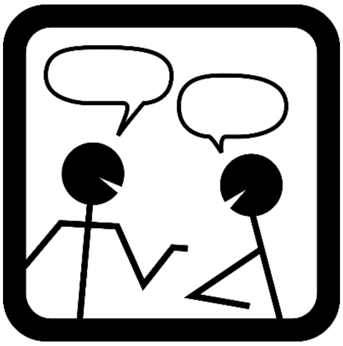
- someone to explain things about the choice in a way you can understand.



- All the information about the choice written down in a way you can understand. This may include photos, pictures, symbols or a recording of someone reading the information.

- It is good to ask questions if you don't understand something.

- You can find out more about the choice you have to make by asking other people, using the internet or your library.



When we first meet, we will talk about the research project and what will happen if you say yes to taking part. This is to make sure you understand what will happen if you consent (agree) to take part.

You can ask me questions about the research project and taking part.

I hope this information has helped you understand what capacity is and helped you make a choice to take part in this research study.

Appendix C
Analysis

C.1 A snap shot of how a section of data from Alex’s transcript was analysed using descriptive-empirical phenomenological methods.

Table C.1 An example of the transformation of meaning units into Phenomenological Psychologically Sensitive Expressions.

Development of Meaning Units (:149-152)			
Original data (pages 188-191 from transcript)	**Development of meaning units**		
R: [Pause] Any questions that you would have asked me? I: Yeah [respondent chuckles] … R: You could have asked about anything. I: [Pause] Could have asked about anything? [Pause, respondent didn’t appear to be listening]. No I find it interesting about. R: Women and males? [Pause, respondent exhales and chuckles]. I: Well yeah I suppose so, both online and offline. R: Cause it’s like, I guess it’s like for you, you… it’s the ex, not really the expectations, it’s like, the, what would it be like if I was a guy? … For me it’s what would it be like if I was a girl? I: Yeah… yeah. R: I think everyone has had that question before. /	For a girl, they would wonder what it would be like if they were a guy, and for L2 he wonders what it would be like to be a girl; “I think everyone has had that question before.”.	L2 wonders what it would be like to be of the opposite gender; “I think everyone has had that question before.”.	
I: And you can get that experience, can’t you, online? R: Not exactly, you can’t get the full experience. I: No, would you want the full experience? R: See stuff… [respondent laughs]… the thing is right yeah is that, people will say to me like childbirth is the most…pain…	You cannot get the full experience of being the opposite gender online. People say that childbirth is the; “most… pain… ever, that you can have. But I	Although people have told L2 that childbirth, something only females experience, is the most painful experience to have, L2 wants	

ever, that you can ever have. But I want to try it me. I: Do you? [interviewer chuckles]. R: I do want to try it. Cause I want to see if it's actually as bad as that they say it is. /	want to try it me… Cause I want to see if it as bad as they say it is".	to experience the this type of pain, one that females experience. If he were to experience this pain he would know if it is as painful as females state.	
I: Would you ever go on an online game, where you can, where you can either be male or female… R: Yeah. I: … and be female and have a baby? R: [Pause] I wouldn't have a baby… no [respondent emphasises 'baby' is a negative, slightly disgusted way]. I: You wouldn't have a baby? R: No. /	Online as a female character L2 would not consider having a baby.	Although L2 goes online and could be male or female, as a female he would not want a baby.	
Because I know that erm, I know that in… in real life… there's these things that you can actually get attached to your body and they make like constraction like er, like er giving birth [Interviewer took 'constraction' to mean 'contraction']… I wanna try that me [respondent smiles]. I: Do you? Interviewer smiles]. R: Yeah [respondent smiles and interviewer chuckles]… I actually wanna try it. I: It's very painful. R: I know, but, at least I can say, you women go through a lot then can't I?... Rather than saying 'ah it's a breeze whatever' [respondent and interviewer laugh, perhaps at different things at this point]… /	In real life L2 knows you can get things attached to your body that give you contractions, the ones you get when you are giving birth. This is something L2 wants to try and then he can say, if it is painful; "you women go through a lot then can't I?... Rather than saying 'ah it's a breeze whatever'".	Alex does not always believe that the pain experienced by females giving birth is 'a lot', it may be a 'breeze'. But by experiencing this type of pain himself, through an attachment on his body, L2 would know if it indeed was painful or just a 'breeze'.	
I was watching video about obviously way, like women and men, pain and stuff like that… It was saying like… like there was this research, but it wasn't a very big research, so people hadn't not really classing it as, er research because of, those figures were like twelve people.	L2 was watching a video about pain and women and men. The research was saying that guys can handle pain for longer, whereas women		

But obviously you mean, you need different various people… And it was saying like, I mean people was all saying, guy, more it was aiming it towards guys stuff like that and they were saying… guys can handle pain longer, but women are more sensitive to pain…. Which I guess is kind of true. I: Mmm. R: I mean and when erm, and they were also asked erm… to motion if you feel pain… and the women feel a lot more easier than guys do, guys don't exactly feel that…. Than women do… Cause obviously we've got testosterone in us, which obviously helps you against pain and stuff like that… Which obviously I mean I guess it's true. I: Mmm. R: I mean… so, I do think that males can handle pain… longer than women, I can't say longer, I can, I can, ok I can, think of… more pain,… more pain than more pain, if that makes sense… Women can… protense it quicker than… they sense pain quicker, which I guess is a good thing [Interviewer thought that the respondent may have combined the words/ phrases; 'process it' and 'sensed' into his word 'protense'].. Once you've, once you find it, that's it, you're straight out there…Simple as that. /	are more sensitive to pain, influenced by men have testosterone in their bodies which helps again pain. L2 guesses this is true as he does think males can handle pain more than women, but women detect pain quicker, which is a good thing. Once you sense the pain; "your straight out of there".		
… R: That's what I mean and there's actually some people where they don't feel pain… I think that's actually quite cool actually. I: Oooo. R: I know, I know it's dangerous… You can just stick a needle straight through you, it's like ding. Cause erm there's actually erm, Guinness world record and the guy stuck errrm, do you know the erm… tooth picks? [Respondent states 'ding'	Some people don't feel pain, which is; "actually quite cool". "You can just stick a needle straight through you". For the Guinness world record, a guy stuck tooth picks though himself. The reason for this could be;	L2 has seen on YouTube a man who does not feel pain and who stuck tooth picks through himself for a Guinness world record, a feat L2 describes as "actually quite cool" and something he	

in a high pitched ringing tone. Pause]. I: No. R: Those little f, er. I: Oh yeah the little cocktail sticks… R: Yeah.. It's like, there was a longer one and he stuck it straight through and I guess. I: Like a skewer? R: Yeah… [respondent and interviewer laugh]. I: Why would you want to do that? [respondent and interviewer laugh]. R: For show? I: Yeah… [pause]. R: You know what I mean, some people will see it as for show, some people will see it as ent, en, enterchanging, funny… But if you can't feel it, it don't affect you don't it? /	"for show, some people will see it as ent, en, enterchanging, funny… But if you can't feel it, it don't affect you don't it?".	did; "for show, some people will see it as ent, en, enterchanging, funny… But if you can't feel it, it don't affect you don't it?".	
… R: … yeah, I was watching a video and it was on summut like erm, like karate and stuff like that, and they've put together their, like their, you know the apple? [respondent point to his own throat, specifically his Adams apple]… They had to like strengthen like the apple up so they can actually handle there and also down there as well… So erm, then when they got this erm, this I think MMA or whoever it is that's kind of like can deliver a thousand pound of force, but I think that's a bit… [Interviewer took MMA to stand for mixed martial arts]… too high for a guy to, really? I: Mmm. R: But, cause, I mean it's a little bit weird on how that works… Cause everyone seems to be getting rich on that thingy and basic, and everyone keeps reaching about a thousand. I: On the MMA? R: No not on, like cause… before they test it against the guy… They put like sensors on his legs… And they kick like a bag… or whatever and they	L2 was watching a video on something like karate where they were strengthening their adams apple so they could handle the force the thousand pounds on their Adam's apple area. This is too high for a general guy to really be able to with stand. L2 feels it is weird how it works because the sensor that is strapped to the guy's legs, always reads a thousand pounds dead on, it is rounded up and not precise; "Everything is rounded off". In the end; "he	On YouTube L2 has also seen men strengthening their Adam's apples to they could withstand a 1000lb force on this area as part of their karate, something that is too much for an average man to withstand. As well as another man who; "…ended up getting kicked in the nuts as hard as they can…. Which, for us average guys, it's painful [respondent smiles]… and he was able to manage, and didn't feel anything."	On YouTube L2 has seen men strengthening parts of their body to withstand large forces in these areas as part of a performance. They are not average men, as an average man could not withstand the pain they do and not feel anything.

send, and they tell it, and they managed to get two people, from two different things like, one from erm… kick boxing and one from… MA… To be able to kick a thousand pounds of force, but it's so precise and I think it's yeah, it's not that… It's not like that, it's not gonna be like a thousand pounds dead on… It's got to be a bit lower than that at least… and there's no such thing as exact, it's just rounded… Everything's just rounded… [respondent takes in a long breath]… So erm, he ended up getting kicked in the nuts as hard as they can…. Which, for us average guys, it's painful [respondent smiles]. I: Ah yeah… [respondent and interviewer chuckle]… I've, I've heard. R: Yeah, it's very painful and erm [Respondent chuckles] … and erm, and he was able to manage, and didn't feel anything. /	ended up getting kicked in the nuts as hard as they can…. Which, for us average guys, it's painful [respondent smiles]… and he was able to manage, and didn't feel anything."		

Table C.2 An example of the transformation of Phenomenological Psychologically Sensitive Expressions into essential structures of the phenomenon: wellbeing and internet.

Essential structure 14: Online the ability to withstand pain is displayed and exaggerated online (:22 of L2's (Pseudonym Alex) essential structures of experience). But L2 realises that he cannot get the full experience of being female by playing an online female character, but he has seen other ways on YouTube were he could experience something only females experience, the painful contractions females feel during childbirth. This is something others have said is the: "most… pain… ever, that you can have. But I want to try it me… Cause I want to see if it as bad as they say it is". L2 has also seen on YouTube, and believes, that men can handle more pain for a longer length of time than women, because of testosterone in the male body, whereas women are more sensitive to pain. YouTube appears to demonstrate this to L2 by showing men doing painful feats. L2 has seen on YouTube a man who does not feel pain and who stuck tooth picks through himself for a Guinness

world record, a feat L2 describes as being “actually quite cool”. It is something he did:

“for show, some people will see it as ent, en, enterchanging, funny… But if you can’t feel it, it don’t affect you don’t it?”.

On YouTube L2 has also seen men, who practise karate, strengthening their Adam’s apples to they could withstand a 1000lb force on this area, something that is too much for an average man to withstand. Another man L2 watched on YouTube:

“…ended up getting kicked in the nuts as hard as they can…. Which, for us average guys, it’s painful [respondent smiles]… and he was able to manage, and didn’t feel anything.”

Table C.3 Section from findings connecting Alex’s experience to Leona’s experience.

Section from theme 1: Internet is a mirror, further developing the….
Whilst Alex is happy to lay his online character’s body in danger in CoD, and pretending to experience the pain and suffering when his online character gets shot or stabbed in a combat situation, to increase his sense of immersion in the game, Alex admits that he is scared of putting his own physical body into a position that could incur pain and suffering. Alex has thought about a career in the army, but the pain and suffering his body could potentially endure or the upset his death may cause his parents, prevents him from pursuing this career choice. Alex describes his body at best; “average”, and at worst; ‘sensitive’ like a female body. If Alex could withstand female childbirth contractions, through the device which simulates this, he may prove that his body, although not as strong as the male bodies he has seen on YouTube, but is still masculine rather than feminine, because he can withstand more pain than females could… Leona and Alex compared the reflections they saw of bodies performing to their own bodies, and this led them to perceive their own bodies as unable, uncoordinated, weak, ‘average’, unable to withstand pain and suffering, and feminine. Leona and Alex found it difficult to, or feel they could, replicate the strong male human bodies they saw reflected in the internet mirror, which were often celebrated and exaggerated. It highlighted their own perceived bodily limitations and prevented them from pursuing projects offline; a dance workshop or joining the army. The internet mirror can distil a ‘thing’ of interest, a sea lion, to its essence for the one who sees the reflection to experience the sea lion. The internet mirror reflects different constituents of sea lion, but for Leona only a sea lion that can clap, wave and kiss audience members is truly a sea lion.

C.2 A snap shot of how a section of data from Andrea’s transcript was analysed using thematic analysis

Table C.4 An example of a coded transcript for the thematic analysis stage.

I: Am I allowed to ask what’s happened to your grandad? /	
R: I had him for… fourteen years and then he started getting ill with er stomach cancer and they couldn’t do anything about it cause they tried to operate on him but whenever they did, something went wrong before they did the operation so, and I think he were getting too late so they stopped trying and… think he had some radiotherapy or whichever cause he came out of hospital one day, and he’ll fine one day and then he went back in and then… just passed away because,.. / me, my mum, dad, _______ [name of younger brother] and my nan went in the car to the __________ [name of hospital taken out] hospital to see him… nearly… every day or like once a day and then when he was getting bad er, my mum and dad left me and ______ [name of younger brother] home cause they didn’t want us to see my grandad like that / and, when they told him that he had passed away… I just burst into tears, cause er me and my grandad were very close…	A1’s grandad started to get ill when she was about fourteen with stomach cancer. Despite planning to operate on him and having radiotherapy, he was too far into the illness and they couldn’t do anything to save him. They stopped trying. One day he came out of hospital and then he went back in and then he died. During her grandad’s illness A1, her parents, younger brother and grandma visited him in hospital nearly every day, but when when he became more ill, A1 was left at home with her younger brother, whilst her parents visited, because they didn’t want them to see their grandad like that.
I: Mmm.	
R: … and… sometimes even now I, think about him and I… try not to cry but sometimes I can’t help it cause I’ve got that emotion inside me and I just need to let it out.	
I: Yeah, oh that’s quite naturally, that’s completely natural, sorry to hear about your grandad.	
R: That’s Ok. It’s [pause] eight years I think now, wait a minute [pause, respondent is quietly counting to herself]… yeah eight years. /	When A1 heard that her grandad had died, she burst into tears because they were very close. Eight years has passed since his death and A1 cannot help but still think about him. She tries not to cry, but sometimes she cannot help it because of the emotion she feels inside and that she needs to let out.
I: Eight years.	
R: Mmm.	

I: Yeah, yeah.	
R: I just think since his passed away I'm going to… forget what he looks like or… forget how his voice sounds but, I've got a picture in… my bedroom when I was little with my dad, my nan and my grandad because my mum was still in hospital at that point cause she had something wrong for, so my dad had to call my nan and grandad to step in and… I think I had just woken up as well from sleeping, so I wasn't in a very good mood [respondent chuckles] and er, I've just got that on the wall er, where my TV is, just above it, with that picture and I've got er [pause] another picture like, er you know like, four pictures in one frame?	
I: Yeah.	
R: I got that and I've got er, four pictures of my grandad in that as well, one with I think _____ [a British Prime Minister], when he met him, and er… three other pictures in there as well. /	A1 keeps a number photographs in frames of her grandad in her room, which partially eleviate her fears that she will forget what her grandad looks like or how his voice sounds. They remind her of times that she spent with her grandad and grandma when she was younger.

Text that was participant context was coded green in the transcript and then analysed using Thematic Analysis (TA). This text was then coded as 'The Death of A1's Grandfather' and was then placed under the subtheme of 'Experiences of Loss and Being Let Down'.

Appendix D
Findings

D.1 The Participants' individual summarised context: the 'sense-making breadth'

D.1.1 Alex

Alex is aged 19 and has an ID, autism, Speech and Language Difficulties (SLD) and experiences anxiety. He lives with his mother and approximately five other children and adults and volunteers at an ID-related organisation at least once a week. The daily living allowance that Alex receives helps his mother and auntie financially and gets spent mainly on food for everyone in the house, the cost of the internet, and support for Alex himself. But this leaves Alex with very little money to spend on the things he would like to, like going on a holiday, travelling to another country or buying a computer. Alex currently accesses the internet via his console and mobile phone.

Alex would like a paid job, perhaps in a warehouse, but the jobcentre has "stuck" him on volunteering and will not let him apply for work until the doctors find out what is "wrong" with him. This frustrates Alex:

> Alex: "…well you can't work just yet cause we need to find out what's wrong with you../… Cause we don't just wanna… put you in a workplace, when we don't actually know the issues [']… which I think is too stupid… cause why not just try me out first for like a week or so, obviously then…/… see what happens."

Alex's mother has concerns about Alex's ability to look after himself if he was to live independently:

> Alex: “my mum was like ‘bluming hell, how will he cope’ and all this kind of stuff. I don’t know how to cook [pause]… [I: Right] I don’t know how to cook at all… they’ll say put longest in first and gradually get the shorter bits last. [I: Yeah] Which still doesn’t make sense to me.”

Alex has experienced verbal abuse from people he did not know whilst walking through his home town. He described people on the streets, near to where he lives, as getting up to “mischief”. Alex does not have many friends offline, only fellow volunteers, and spends the majority of his time in his bedroom on the internet watching YouTube videos and playing online games, especially CoD.

> Alex: “that’s all I ever do / [it is] just kind of the same… everyday”.

Alex explained that he had a good and varied social life online and there was nothing “wrong” with him when he was on the internet. He also felt safer and more in control over certain situations online. Alex was able to learn about the things that interested him, including the news, by watching YouTube (something he did for about six hours a day). Watching YouTube also increased his emotional wellbeing. Alex experienced being part of a community when he was online, he had friends and achieved and gained status in CoD, a game he played in the afternoons and evenings until he went to bed. Alex has played other online games such as Fable, Grand Theft Auto (GTA) and Mine Craft. In some of these games Alex was able to own his own house, make money, get married and have children. These were things that he enjoyed and, upon reflection, he explained that these were things he could not do currently offline. Alex invested a lot into his online relationships and took them “seriously”. He was hurt when these relationships ended. Alex described growing up with the internet and has spent a lot of time online. As such, Alex is very aware of the negative things that can happen online, for example trolling, online verbal abuse and being spied on, and he takes precautions to keep himself as safe as he can. When he was first ‘trolled’ (verbally abused and threatened) by others online it made him upset and uncomfortable. After he watched a YouTube video on ‘trolls’ and the reasons behind their behaviour he started to understand this more and he then often accepted that these things would happen to him online.

Alex has what he calls a “bucket list” (many ideas about what he would like to do in the future), but this requires money that Alex does not have. He described feeling “stuck” while waiting to be allowed to apply for a paid job. He knew a paid job would earn him the money to be able to build his own computer (which would help him become a professional gamer), or travel to places to see the natural events that he only got to see on YouTube.

D.1.2 Andrea

Andrea is aged 22 and has an ID. She lives with her parents and younger sibling and volunteers at least once a week for an ID-related organisation. Andrea likes to support her favourite rugby team and loves to attend the concerts of boybands and musicians. Andrea follows the boybands and musicians on YouTube and likes to post up the photographs that she takes at the concerts she attends. On Facebook she also searches for ‘fan based friends’ who share her interest in specific boybands, musicians and her favourite rugby team. By requesting to be friends with those who share her interests Andrea has accumulated many friends on Facebook who she regularly chats to. Andrea only makes or accepts friend requests from fan based friends (and their friends). When she receives friend requests from those who are not interested in boybands or her favourite rugby team she wonders if they have made a mistake. Sometimes she looks at their profiles and will generally not respond to these friend requests in case they turn out to be “fake”, a “weirdo”, or want something from her. Andrea is comforted by knowing that if someone, who she did not know, messaged her she can block them or report them to Facebook. They would the get “told off” for harassing her.

Andrea described that at times she felt stressed, upset and frustrated at not being able to secure a paid job and upset when she missed her grandfather who died several years ago. Andrea had been searching for a long time for a paid job and finds it frustrating that she cannot work like the rest of her family do. Andrea gets upset when she does well at job trials and interviews but is then rejected for the job because they have judged she cannot cope with certain aspects of the role. Often Andrea feels the companies just let her try out for the job because they feel sorry for her, not because they are interested in hiring her.

Around eight years ago Andrea’s grandfather, whoi she was very close to, died of cancer. She cannot help still feeling upset at losing him:

> Andrea: “sometimes even now I, think about him and I… try not to cry but sometimes I can’t help it cause I’ve got that emotion inside me and I just need to let it out. / …I just think since his passed away I’m going to… forget what he looks like or… forget how his voice sounds but, I’ve got a picture in… my bedroom when I was little with my dad, my nan and my grandad…“

Andrea described that his death had a long-lasting effect on her relationships with others:

> Andrea: “through… the rest of high school and the rest of my life it’s been… very hard to… mainly let people in because sometimes I’d… either feel shy cause I didn’t know em and then when I’ve got to know em I’ve [pause]… kind of put up a wall… So they could get any closer, so I’m just a bit wary of… what I’m doing, but I know I have got… family and friends round me.”

Andrea knows that her mother is very worried about her and “boys” because she is her only daughter and “doesn’t want anything to go bad” for her. Last year Andrea split up from her boyfriend because he did not want her in his “lifestyle” anymore and she acted like someone younger than who she was. The break up and reasons upset Andrea a great deal. The combination of Andrea’s mother trying to protect her from being hurt again in relationships and Andrea wanting to see her ex-boyfriend has led to conflict between Andrea and her mother. Andrea’s mother accused her of lying about what happened in the relationship and if she had been seeing him again.

Andrea does not have much freedom offline and her whereabouts are closely monitored by her family members. On the days Andrea is due to go watch her favourite sports team she has to wait for her friend to tell her when he is going into town so that she can then get a bus to meet him. The game finishes at about ten o’clock and afterwards Andrea walks with her friends to the bus stop to get a bus home. It is too late and dark for Andrea to have drinks after the game with some of her friends, something she would like to do. But with summer coming and lighter evenings she is excited at the prospect of having a drink after the game with her friends rather than catching their buses straight home.

Andrea uses social media, Facebook and Twitter, to connect with friends and family. She described also seeing and reading people arguing on Facebook and the news stories about immigrants fleeing from war, terrorism, conflict, violence, and the prospect of a world war III, something Andrea feared would increase the chaos in the world. Andrea sensed the offline world was out of control and was highly concerned about future wars and how these may lead to the extinction of the human race. Andrea also sees conflict occurring at the rugby matches she attends and towards herself within the game GTA. Andrea still plays GTA because she loves to drive around the game and explore, compete in games, and talk to her friends, but she also has to endure being targeted, shot at, and bombed by male players because she is a female player and character. This interrupts her game and makes her feel angry and frustrated.

Andrea has clear plans for her future, which she felt she could start working towards once she was able to get a paid job. Andrea would like to learn how to drive, buy a car, and get her own house or flat to then be able to live on her own. All of these things would increase her freedom and independence and she would feel that she was able to “fend for” herself. These are hard for Andrea to afford at the moment because she is on benefits and paying board at home. Andrea also sees her own ID as something that may make passing her driving test more difficult:

> Andrea: “…Cause, with me as I am, I need to really practise on stuff a lot so it gets through my brain. [I: Ah right.] Cause if I only do it once then, I’m just thinking that I might fail it. [I: Right.] So if I try and get the, some of the answers through my brain and then actually go for the test, I might be able to pass it.”

But Andrea is determined to practise her driving theory every day so that she can answer some of the questions in the test in order to pass.

D.1.3 Ella

Ella is aged 38 and has ID and Down's Syndrome (DS). She lives with her parents and has volunteered at an ID-related organisation since it first started for several years. Ella described volunteering as something which had changed her life because this was how she had met friends and her fiancé. Volunteering had also increased her confidence and enabled her to be what Ella described as an "independent traveller". But Ella cannot travel "too far" on her own, only travelling further with her mother or the staff she volunteers with. There are many parts of her life, on- and off-line, that is restricted by her family. For example, whilst Ella's mother does not mind her looking at recipes or the organisation she volunteers with on the internet, she does not want or allow Ella to go onto Facebook or YouTube in case Ella gets laughed at, or people say nasty things about her:

> Ella: "I'm not allowed to go on it, because I don't want people say something about me, that I've got Down syndrome."

Despite watching her brother in law freely access eBay, Amazon and Argos online, Ella does not go onto these herself because, like Facebook and YouTube, her mother does not allow her to. Ella referred to her "habit" as the reason for the restriction:

> Ella: "I keep buying all sorts and I, I've got an habit for, I've been, I've got an habit for… go onto it, and buying something what, what's nice to put in my bedroom. / I've got, I've got an habit for going to hole in wall and draw money out."

Once, whilst stopping over at a friend's house, Ella drew some money out from a cash machine using her own bank card. This was because her mother had not given her enough money. Since then, Ella is not allowed to go to a: "hole in the wall" to draw her own money out. Ella explained that if she did this again her mother would find out and she would get into trouble. Ella's mother is the 'main' one who looks after Ella's money and gives Ella some "spending money" which Ella keeps in her purse to buy things like her lunch when she is volunteering. The "spending money" Ella has is what she describes as her own money: "I have money what's in my purse, that's mine". But the money Ella has in her bank account is restricted by her mother.

Currently Ella feels "stuck" having to decide whether to leave her volunteering role or stay. Ella's mother, sister and brother in law want Ella to leave the organisation she volunteers for because her direct payments are being cut and volunteering is expensive to pay for. They would like Ella to get a job that pays instead. While some of Ella's family members describe/view her volunteering work as "baby work", Ella loves her volunteering role and it is important to her. She confronts members of her family who want her to leave her volunteering role and do not see it as important, stating to them:

> Ella: "I wanna carry on coming here and you can't stop me coming here because I do everything, like I do, I do a lot of training, I do a lot of presentations, I talk in front of a lot of people… and I've got convident and I need to carry on doing that, I can't leave…"

Compared to her family, the staff that Ella volunteers with speak to and treat her in an "adult way". They do not tell her what to do and this is something else Ella likes about her volunteering role. Ella spends much of her time on the internet searching for the organisation she volunteers for and looking at the photographs of herself as a participant in the activities she attends and supporting others within these activities.

Like many of the other participants, Ella has experienced loss in the past and she was facing the loss of people and meaningful and valued roles she has in her life. Ella also spoke of experiencing being bullied and how this reminded her of the death of her loved ones:

> Ella: ‘she [Ella’s auntie] died with cancer, and even me grandad, he’s passed away, my uncles’ passed away… everybody’s passed away on me, and, and she [the individual bullying Ella] keeps saying that, that she said she, I can hear her saying ‘you will be down there’… and that’s what she said.”

Ella explained that she got upset quite a lot due to the death of so many family members and the threat to her volunteering role:

> Ella: ‘The way the feelings I, I have got about like being scared or trapped or something, and I’m just stuck in er, in a dark place, I can feel it, I can, I can go back in me memory, and I do have a picture of it in me head and I can’t let it out… It’s, it’s stuck in here, but, I just want to tell”.

Ella felt that she has “lost that feeling” inside, and when she got upset and has these feelings she just wanted to let it out but preferred:‘to just keep it inside’. Ella wanted to talk about this and she found it easier to do this within an interview as she felt she could get upset and let it all out. Ella would like to be able to open up to the staff she volunteers with and show them the feelings that she has (about the loss of important people in her life, her volunteering role, and the bullying), but Ella feels that she cannot do this because she does not want them to feel sorry for her. When Ella was asked about her future she described being “stuck”; “stuck” between staying or leaving the organisation, having feelings “stuck” inside her, and being “stuck” with the identity of Down’s Syndrome (DS):

> Ella: “it’s between like I’m stuck… with leaving ___ ____ [name of organisation 1] and getting a job, now this! Now being Down syndrome! It really is getting too much for me at the moment, it’s getting too much for me.”

D.1.4 John

John is aged 25 and has an ID and autism. He currently lives with his parents and volunteers at an ID-related organisation at least once a week. There is a certain amount of “pressure” John feels in his volunteering role but he still likes volunteering and stated: “you know I’m out either giving my time and I’m just helping people…”. John would like and has been “persevering with” trying to find paid work but has not yet been successful. John would ideally like to go abroad and teach English as a foreign language and support people with IDs, something he feels he would be good at:

> John: “[It’s] something I would be really able to do because I understand the battles that they go through”

But John’s job supervisor and mother have concerns about his ideal job. The job supervisor said to John: “are you sure you’re going to be able to cope with the stress of that job?” and his mother had concerns about his ability to look after himself, specifically whether he would be able to live independently, feed and clothe himself and do his own washing. In response to their concerns John stated:

> John: “[I’m] just being [pause] held back at every opportunity… [,as an] adult[,] no one can… can stop me from trying…”

The job abroad would also give John the opportunity to leave home and the UK where he currently lives. He would then be able to live independently and not be: “smothered” by his parents:

> John: “If I’m not.. that far away, it’d be all too easy for them to come up and just check and make sure I’m alright and end up without [pause] without meaning any harm they just end up essentially smothering me just because they are that protective and concerned, whereas I feel like I would need that long distance just to essentially… [pause]… essentially swing the axe of finality in just make it clear, make it so they can’t help me.”

John does not confide in his parents because he does not want to be seen as: “too dependent”. He often ends up hiding things from them and when he is anxious or worried he will: “bottl[e] it up”.

John uses the internet for a variety of purposes; social media, chat forums, looking at online maps to find places he needs to get to, and keeping track of the buses he needs to catch (using an app on his mobile phone). John also plays on- and off-line games and highlighted that he found the stories within these games important to him and thus avoided games like CoD because they have no: “real reason behind it… as I say feels like mindless shoot em up”. When there is a well designed story and a good rationale in the on- and off-line game, John cited Halo as a good example, he can connect and feel for the characters and it is like he is: “exploring another world you know, you know like you’re in somewhere new.” At the end of the offline game Halo John got “really emotional” and started crying because the Artificial Intelligence (AI), who had been guiding and helping him throughout the game and he had connected with “emotionally”, had used the last of her energy and:

> John: “…essentially die[d…It was] heart rendering… it’s like a pet that you knows is about to get the… you know get put to sleep, it’s like, those like those last few minutes, it’s like you know… you know it’s going to happen but it doesn’t make it any less… emotional… / … , as I said I was crying because it was like, it was such er, an emotional end it’s like well… you know [pause]… having, having to say farewell to em.”

The sadness John felt stayed with him long after the game had ended: “it’s still hitting me hard…”. After finishing Halo John decided to try Final Fantasy, an “MMO” (Massively Multi-Player Game), because his offline friends had played MMOs too. John did not have many offline friends though, but in MMOs like Final Fantasy he found he could meet a lot of people and experience “intense” and “dramatic” stories. Stories and experiences which did not exist in his offline world. The friends John made in Final Fantasy would worry about him, talk to him, look out for him and always make sure he was alright. John found that most people were alright in MMOs and he liked the interaction within these online communities, especially meeting with a group of players regularly to practise. John had multiple characters within Final Fantasy and, as well as making online friends, he also married another character. John’s relationship with online games, particularly within Final Fantasy, the related communities, his friends and wife changed during the four interviews that took place over a five and a half week period. They included an incident where John “snapped” on Final Fantasy, which he felt was caused by events offline, specifically not being able to get a paid job and having low self-esteem, which made John feel he was not “deserving” of the friendships he had in Final Fantasy. After the ‘snap’ John cut off his online friends and wife and quit Final Fantasy. Although John did not go into Final Fantasy anymore he reminisced about the good times he had there each day while listening to the Final Fantasy soundtrack he has on his computer. John regretted what he did and wondered how he could send a message to his friends and wife in Final Fantasy who had blocked him and were ignoring any messages he could send to them.

Wellbeing for John was about how happy people were and their work-life balance. John described his own sense of wellbeing as still: “need[ing] work” and he was currently receiving counselling:

> John: “[I have] problems with like self-esteem and self-worth and stuff like that. I still have problems managing my frustration…. [I don’t find counselling easy, and sometimes when it feels it’s helping] it just seems to all just all come back. Come crashing back down… / …it’s really difficult… [because] I think it’s, it’s just so ingrain, the way these, these ways are just so ingrained into me like it just feels like I just can’t… get them out.”

D.1.5 Leona

Leona is aged 19 and has an ID and SLD. She lives at home with her parents and describes herself as: “always busy”. She volunteers three days a week at a sports and leisure centre and at an ID-related organisation, and attends college two days a week to study Maths and English. Leona is currently looking for a paid job either working with animals or in a restaurant and used the internet to help look for jobs. Leona has not had a job before and is nervous at the prospect of getting her first paid job. However, if Leona got a paid job, other than buying theatre tickets, she was not sure what she would spend her earnings on.

Leona uses email, Facebook and Twitter to talk and send messages to her family members and friends who she has met previously offline. Leona posts statuses up if she is going somewhere nice, like a concert, and photographs she has taken. For example, Leona posted a photograph of the family pet after they had been to the vets. Leona does not have her friends' phone numbers or knows where many of them live but Facebook allows Leona to be able to contact them and arrange to meet up with them in the town where she lives. By only letting her friends see her profile Leona does not worry about her online safety. When she has received friend requests from people she does not know she ignores and deletes them.

Leona enjoys playing games on Facebook with people she has not met previously offline, especially when she wants to talk to someone, as well as the online games and quizzes on the CBBC website. Leona also loves to watch YouTube videos of music videos, animal shows and other performances she has seen at the theme parks and zoos she has visited. As she can only visit her favourite theme park and zoo once a year Leona looks at the theme park and zoo's online reviews and details on the internet. This includes the entry cost, the rides, cost for over-night accommodation and videos of performances and shows. Leona continues to search online for information on theme parks and zoos regularly, as well as holiday deals, specifically when using Facebook, because: “that's what I do”. When she has found a “deal” Leona tells her parents but often by the time she has told them: “time ha[s] run out” on the ‘deal’ and so they are unable to book it.

Leona used the internet when she was at school and spoke about a website where she learnt math skills and how she was currently able to look at her college timetables and get help her with her exam preparation. Leona easily used the internet to learn about things and find information:

> Leona: “[To learn about something]…I just type it into internet… Like, what I want to learn… And it finds it.”

Leona also searched the internet to help her family when they were “poorly” or had a health problem by searching for the symptom on the internet. When her family were looking to move house Leona searched for a house in the area they want to move to on the internet.

Leona supports her local rugby team and attends their home games. As long as they are not “too far” away Leona also attends some of their away games with her carer or a friend. Leona would like to attend more of her favourite rugby team’s away games, those that are “too far” away, but she is not allowed to. Leona is only allowed to walk to the shops at the end of her street and get the bus into the town centre near where she lives on her own. She is not allowed to get the bus anywhere else on her own despite knowing quite a lot about buses that could take her to different towns and cities because her mother does not want her to travel too far because she worries about Leona getting lost in unfamiliar places, which has happened before:

> Leona: “last time out on me own with my carer and we both got lost”.

On the internet Leona buys games, music for her iPad and items from Argos and eBay:

> Leona: “[I type into]… like a category and it brings them all up……what you want…/ cause you can look at stuff what you want to buy… [Interviewer: But you can do that at a shop] Yeah but you can, better online cause you can get it posted out straight away…

> [Interviewer: Right] …off online and, in a shop you might have to wait like a couple of weeks for it."

eBay gives Leona the freedom to look at and to buy items for herself and presents for her friends. Leona and her mother agree on the maximum limit they will bid on an item because Leona uses her mother's eBay and PayPal accounts as she does not have her own. Leona would like to sell things on eBay like her mother does, but not having her own eBay and PayPal accounts prevents her from doing this.

In the future Leona would like to get a paid job and, although she knows her mother would worry about her, wants to move into her own house, close to her parents, either on her own or with a friend and get a pet dog. Moving out is something Leona has talked to her parents about and they have said: "it would be good to do". Getting a paid job and moving out are things Leona feels she could achieve in the future because she is on a new course at her college:

Leona: "[The new course] helps you get a job. So that'll help me."

D.1.6 Michael

Michael is aged 62 and has an ID, hearing difficulties, SLD and epilepsy. All of the disabilities and difficulties Michaels has was acquired when he was young and contracted a serious infection. Michael lives on his own in a house that he used to share with his now-deceased mother and volunteers with a health organisation and a higher education institute. Michael also attends social groups set up for people with IDs. Michale explained that life was not easy for him growing up because of his hearing and SLD:

> Michael: “everywhere, every time I spoke out, tried to speak, it was chuttering… / I had to put up with… kids, er, taking the micky out of me…. There was a wire, going into my ear…. And… [pause]… the, the kids thought it was a radio, kept saying… ‘What’s on radio one? What’s on radio two?’… I say ‘it’s not a radio’, I got ups, I was that frustrated with it,… I was upset about it. It wasn’t my fault I had, I was, I had ______ [an infection]… It was, ______ [infection] come to me…. I was healthy, growing up lad.”

Michael fondly remembers his brother taking him to a “hearing speech clinic” when he was young every Saturday morning:

> Michael: “[he] didn’t grumble or anything like that… Because he, he cared about me, the way I was… And I cared about him.”

At the clinic Michael learnt how to speak more clearly but despite making much progress with his speech, when he returned to school the children started taking the “micky” out of him again. Michael described himself as “normal” when he was born and before the infection “struck” him. Whilst he concluded that he was still “normal” the infection took away what Michael felt was a ‘normal’ future:

> Michael: “I had all my life to look forward to, as a normal child… Like everybody else.”

Michael holds feelings of gratitude towards the doctors at the hospital who treated him when he had the infection. At the time the doctors did not know much about the type of infection Michael had and were still learning about:

> Michael: “I could have died with, if it got… [pause]… so I’m grate, I was grateful at the time, it left me… with problems that I had… Otherwise, I wouldn’t be here today.”

Michael had always lived with his mother up to her death approximately fifteen years ago. As it was his mother's house there was a lot of things Michael was not allowed to do, one of which was getting an internet connection at home. After Michael's mother died his brother decided that it may be a good idea for Michael to have the internet at home. But after: "looking into it" on Michael's behalf, Michael's brother told him that the internet wasn't for him:

> Michael: "[My brother said] no… leave it alone… [but] it's up to you… to use it, if you want to use it, it's up to you. I won't stop you… [but] I'm advising you not to do it…".

When Michael asked his brother exactly why the internet was not for him his brother told him that it would be too complicated, not worth the cost for the amount of time Michael would use it, and that there was a risk people could break into Michael's account and find out all his details. Michael followed his brother's advice, as he did on many other things, and decided not to get the internet at home. Around the same time Michael made a series of financial decisions with the money he had inherited after the death of his mother which was to have a lasting effect on Michael's life, including the control he had over his finances:

> Michael: "Just after me mam left… er, died. She left me a lot of money to… to do, to get on with, in life…. I… [Respondent sighs]… went out… one day… had some money in my pocket, I wanted to buy things… I bought, I went a lot, I went out and bought a lot of things… [Pause]… and, because I, I had the money…. So, when me brother found out, … he told me really bad. He said 'that money was for… for your, keeping, keeping comfort for the rest of your life'… At that time, I didn't think… He was such annoyed about it."

As a result of his brother finding out about his "spend, spend thing" Michael was told he had to write down everything he spent his money on to show to his brother, which Michael did to make his brother happy. Michael described that he soon got out of this “spend, spend thing” and he no longer went out out and bought big presents without first asking for his brother’s permission. Following the death of his brother several years ago Michael continued to show a record of his spending and asked permission to buy bigger things that he wanted from another member of his family.

Michael described his life as being happier and more interesting now because he was doing things during the day and on a number of evenings throughout the week. Michael compared his current “busy” life with the time when he was “poorly” and not “busy”:

> Michael: “I wouldn’t have it any other, other way… cause I am… [pause]… I’m, if I ain’t been doing this… being busy, the way I am, all I’d be doing is looking at… these walls… and when I was poorly, I had enough of that.”

In the period of Michael’s life when he was “poorly” a nurse supported him to start to do things that he wanted to do, for example, going to college to learn how to read and write. It was at college Michael learnt how to email and search for things, suggested by Michael’s teachers, on the internet. After college Michael could not continue to use the internet as he did not have an internet connection at home. Michael sometimes revisits the idea of getting the internet at home but when asked what he would search for if he had the internet at home Michael replied:

> Michael: “But I’ve never actually searched for anything… [I: Have you not? Would you like to?]… I’d like to yeah [..I: What would you search for if you, if you could?]… [Pause] Mmmm… [Pause. Respondent smacks his lips together whilst thinking]… Don’t know… [I: You don’t know?]… No. I’ve never been toproach… be er, that sort of question before…”

Michael currently volunteers as an ‘advisor’ and someone who ‘teaches from experience’ for a health organisation and a higher education institute. These roles are something Michael feels proud of and enjoys doing. He also feels these are very important for the health professionals who work with people with IDs:

> Michael: “to make easy for the job what they do… to understanding p, people… what they doing…more…. [I tell them about] what I’ve had to put up with… when I was a lad. / …the way I’ve had, the way I’ve suffered with, with it.”

Michael’s role also fulfils and goes beyond one of his childhood aspirations:

> Michael: “when I was a lad I always wanted to be a nurse [Respondent smiles]… Cause it was fascinating for me… but now… I am… best is, I’m better… I’m a nurse’s advisor… So I’m not a nurse but, I’m second one up, better than that… I can. Nurses can come ask me for advice… And I enjoy it [Respondent laughs].”

For Michael, the people in his life are important to him, especially health professionals which have improved his life in a variety ways for much of his life. They taught him to “speak more clearly”, helped him when he was poorly, supported him to improve aspects of his health and sense of wellbeing, to feel “wiser” about himself, and to achieve things in life that he felt was important. Michael remembered what a nurse said to him several years ago:

> Michael: “…[she said] you need us, but not now, we need you… [pause]… to help, to help yourself have a life… To take us with you, were ever you go… in life”.

Michael described some of the nurses he had met in his life as being his closest friends, describing one particular nurse who he had known for a long time as being a: “best friend for me… towards me. I think a lot of her… in a nice way.” Michael’s volunteering roles rely on the telling of his own life story to health-related professionals and students - the lack of enjoyment he had when he was growing up because of his “complaint”, his suffering and his personal triumphs over his disabilities and medical conditions to get where he is today. Rather than comparing himself to others who have had what Michael describes as a “normal” life, he takes comfort in knowing that there are always others who are worse off than himself, like others who have more severe disabilities. Michael does not let his disabilities stop him in life and he described getting on the best he could, often more so than those without disabilities. The health professionals had not only saved Michael’s life they had raised his status from ‘one who is advised’ and ‘taught’ to one who ‘advises’, ‘teaches’, and who is listened to and inspires professionals and students. Michael also explained that he was also a role model to others with IDs and this helped them to “get on in life”:

> Michael: “[people with IDs may think] ‘do you know, he just helped me about doing something I can do in my life. I, he’s done it, well, why can’t I do it?’.

As well as feeling needed, having friends and company, volunteering also brings about a busyness in Michael’s life. This reduces the risk of the possibility of Michael returning to his old life, one he did not get much enjoyment from and experienced suffering, ill health and bullying. Michael’s old life also encompassed an old self, one who had a “spend, spend thing”, which his family member still reminds him of by controlling his finances and putting Michael firmly in the role of ‘one who is advised’. There were also examples Michael gave when he also had to ask permission do do in his volunteering role that others in the office did not have to do, for example using the internet. Getting the internet at home was something Michael mentioned to someone in the office when he first started volunteering and they told him he should not bother getting the internet at home because he could access the internet on the computer in the office when he volunteered, but Michael explained that doing this was not that easy:

> Michael: “I’d like to do that [search for things on the internet]… I’ve got to ask permission if I can do it though… [I: Right, is that the same for everybody…]… I don’t know.”

Michael got a further opportunity to use the internet when he received an iPad as part of a health-related research study, something he was allowed to keep. Someone rang Michael up to ask him if he wanted to go on a website and do something else on the iPad given to him but Michael did not have the internet at home and he could not access the specific website where he volunteered. The service involved in the research study told Michael they would arrange for him to go to a café with internet access to meet someone who would show him how to use the website and other things on the iPad. Michael waited for them to ring him, as promised, but no one rang him to arrange this:

> Michael: “I said ‘when, when am I having this person down… to talk about it?’ He says ‘we’ll get contact with him’, but he hasn’t bothered. / ‘If they can’t be bothered with it, then I can’t be bothered’”.

Looking towards the future Michael stated that he was not going to: “sit back and say ‘that’s it, close the door and lock the door, not, not go out at all’”. Even though he explained that he was in his sixties: “there’s a lot of doors… to open, in my future”. For Michael the future looks “lovely” and will bring him further enjoyment as long as he can get the right people in it. Having the right people in his life makes Michael’s “life go round” and without these people there would be no point: “I’d lock the door and not come out”. While Michael is happy “in every way” with, what he described as, his “working wellbeing” he would like a girlfriend. He once had a girlfriend when he was very young and reflected that if he did had a girlfriend he would have some company on a night and would be able to sit and talk to someone. He could also look after someone and make sure they were alright. This is something Michael did for his mother and missed being able to do for another person. Michael added that if he had a girlfriend or was married he would go out less to the social groups he currently attended as he would have the company of his girlfriend/wife instead.

D.1.7 Steven

Steven is 22 and has an ID, autism and SLD. He lives at home with his family and volunteers at least once a week for an ID-related organisation. Steven had more friends online than he had offline and described himself as a “private person”. Online his “points of view” and “private things”, such as his photos, can only be seen by his friends and family and not by “lots of people” he did not know. Being private and un-accessible to others on- and off-line meant that Steven could “stay safe”. He would not make friends with anyone online that he had not met offline because they may be pretending to be someone they were not. Steven independently accessed the internet to view his emails, keep in contact with friends and family on Facebook and Twitter, and to find out what was happening next in his favourite television soap. Steven only received emails, often job-related ones, but did not send any emails. Steven took a passive role in keeping in contact with those he knew by viewing what they were up to, rarely putting up his own statuses or comments.

Steven described the internet as being important for work purposes, not only for himself but others too. He described how he liked to look up places that he knew or had heard of, like restaurants, and using Google maps in conjunction with online bus timetables to plan a possible journey to that place or to find out more. Steven held a general apathy towards the internet, it did take centre stage in his everyday activities or take up much of his time. Despite Steven describing how he found the internet easy to use, he spoke about an older relative in his family who found the internet difficult to use and, as a result, asked members of Steven's family for help but not Steven himself: "he just asks other members, not me".

I, as the interviewer, was neither Steven's friend or family and at times during the interview Steven's status of "private person" was tested unintentionally and occasionally he refused to answer initial questions or prompts about certain things that he felt were private to him. These included what types of social media he used or what football team's scores he looked at online. Outside the interview he later freely talkied about these with myself. In his everyday life Steven was not really used to being asked questions and he was observed taking a passive role in groups. He admitted that whilst he knew that he would be asked questions in the interview about the internet and himself, being interviewed felt "funny" and as such Steven left the study after one interview.

D.1.8 Yvonne

Yvonne is aged 26 and has DS, an ID and SLD. She lives with her parents and her brother and currently volunteers four days a week in two roles: one with an ID-related organisation and another at a café. Yvonne plays sport each week and goes walking twice a week, and has Thursdays off:

> Yvonne: “Thursday’s my day off, but I’m with my neighbour…spend[ing] time together]”.

Yvonne’s busy week starts early, often requiring her to get up around 6am to account for her travel on buses, taxis and trains to get to the different towns and cities to volunteer or do certain activities. Yvonne has no time to get breakfast at home, but before getting off the train:

> Yvonee: “[I] get some cash, get and then show them me ticket, grab some breakfast on the route…”

On one evening Yvonne generally only get home at about 8.30pm and stated that this makes her feel tired. When the weekend arrives Yvonne’s busyness decreases: “I don’t do nothing, but I go walking in morning”, which is often followed by going on her computer. The busy life that Yvonne leads indicates to her that she has her own life:

Yvonne: “got me own life, I’ve got a life [Respondent smiles broadly and laughs]”.

Yvonne does not currently have a paid job and uses her direct payments to pay for both of her volunteering roles. When her parents go travelling in a few years’ time Yvonne would feels that she will need to get a paid part-time job on an evening and a car. She added that she would have to learn about banking and finances so that she can:

> Yvonne: “Keep on look after the money [including her own direct payments] and look after the house [and continue to volunteer]”.

One of the reasons why Yvonne took on her second volunteering role was because her grandmother died. She was someone who looked after Yvonne whilst her mother was “busy” working full time; raising and protecting her and they often did things together.

Yvonne loved going on respite with a staff member at one of the organisations she volunteered for. While on respite Yvonne is away from her home, a place she refers to as: “the madhouse”, and this was important for Yvonne: “it means I’ve got time to myself”. Yvonne regards herself and those at the ID-related organisation as being like a big family and a second family for her. She often preferred her ID-related organisation family to her own family because they did not tell her that she could not do things, make her do jobs she did not want to do or answer her back. One example of the difference between her family and volunteering family Yvonne gave was their reactions to her intolerance to specific foods. Some members of Yvonne’s family do not believe she has any food intolerance:

> Yvonne: “sometimes my brother doesn’t believe in me so [Respondent shrugs her shoulders. Pause].”

But the staff where Yvonne volunteers also have food allergies and intolerance, and some are also vegan. Yvonne’s food intolerance is accepted where she volunteers and she also feels she has “their support” and understanding around her food choices.

Yvonne learnt how to use the internet when she was at school and, because she had her own computer in her bedroom, continued to use the internet after she left. Yvonne uses the internet for a range of reasons; to conduct research for her own personal projects, to listen to music and watch videos, including those about celebrity relationships, to watch “catch up TV”, to search for online recipes, poetry, maps to help her mother with directions, and the weather (to plan what to wear). On the internet Yvonne can watch and listen to anything she wants to: “I can pick”. Some of the online activities Yvonne used to do, such as Facebook, hae now been abandoned because she received too many messages from people she did not know, misunderstandings occurred when she posted things about events and Yvonne became too “busy” with her own life. Yvonne described the internet as her “safe thing”, something which had helped her escape and block out conflict with her family at home. Online Yvonne felt safe and described not having had any bad experiences on the internet. Yvonne is not allowed to play online games but would like to play Candy Crush. She would also like to go on eBay and create her own blog. At present Yvonne does not do any online activities where she makes contact with other online users. Offline she does not like talking to other people about her private life (including the staff she volunteers with) and she does not like others invading her personal space to touch or hug her. The process of talking into a dictaphone and recording herself talking appealed to Yvonne and she related this to a character on a television program who also used a dictaphone:

> Yvonne: “[she] just tells the world, the world who, how she feels and stuff… [I: Yeah.]… And that’s who I am as well [Respondent smiles and chuckles].”

For Yvonne the act of talking to a dictaphone would be like: “getting it off your chest” and would be “like therapy really”. Yvonne explained that at times she would like to talk to someone about how she feels. She had thought about using a phone-in doctor on the radio, which would feel different from talking to someone she knows.