Examining the stigma-resistance process in adult self-advocates with intellectual disabilities

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DClinPsy thesis (Volume 1)

2021

University College London

UCL Doctorate in Clinical Psychology

Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

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Overview

The present thesis investigates the stigma-resistance process in individuals with intellectual disabilities, who experience widespread stigmatisation and, consequently, are at risk of facing numerous harmful outcomes. Although intellectual disability stigma has been targeted through a (limited) number of multilevel interventions (i.e., structural, interpersonal, familial, and intrapersonal), it is yet unknown, directly from their perspective, how individuals with intellectual disabilities resist stigma. Additionally, to date no studies have explored perceived barriers to and facilitators of stigma resistance. Therefore, exploring these factors seems crucial for advancing our understanding of how the well-being of this stigmatised population may be enhanced.

Part One comprises an introductory chapter exploring (1) the concepts of stigma and stigma resistance in the existing literature; and (2) the negative impacts of stigma on people with intellectual disabilities. These explorations, alongside methodological considerations and other gaps in the evidence, represent the motivations behind the empirical study.

Part Two involves a qualitative investigation of the stigma-resistance process, and its barriers and facilitators, directly from the standpoint of adult self-advocates with intellectual disabilities in England. Results indicated that participants resist stigma in many ways, both individually (e.g., asserting themselves) and collectively (e.g., working with others to drive change). Challenges to and enablers of stigma resistance were attributed to factors both *within* and *without* the person. Implications of the study, together with limitations and suggestions for future research, are discussed.

Part Three presents a critical appraisal of the overall research process, including key learnings and take-home messages for fellow researchers conducting studies with stigmatised groups.

Impact Statement

The first part of this thesis has highlighted the adverse impacts of continued stigmatisation on the lives of individuals with intellectual disabilities, further justifying the urgent need for more work around increasing their capacity to tackle stigma and its negative consequences. The second part showcases the strengths of people with intellectual disabilities in resisting stigma in multiple ways, both individually and collectively. Finally, the third section discusses the researcher's 'learnings from experience' that other investigators may benefit from when conducting similar studies. Consequently, impacts resulting from the project apply to two key areas: research and clinical.

Research Impact

This was the first attempt to systematically investigate the stigma-resistance process, and its corresponding facilitators and barriers, directly from the perspective of people with intellectual disabilities. Therefore, the present study could be considered as a model of research to be replicated and expanded on to advance existing knowledge. These efforts could be implemented on a global scale too; namely, in parts of the world where such research may be limited or lacking.

Furthermore, this project demonstrated the value of consulting with different parties on different aspects of the research process (e.g., study design, development of the interview schedule). More specifically, this process involved close collaboration with (1) colleagues working in the field of stigma within the UCL for Stigma Research Unit (UCLUS); and (2) members of the National Mencap Research Advisory Group of self-advocates with intellectual disabilities in London. It is hoped that the strategy of collaboration may be used (but also extended to include co-research with individuals with intellectual disabilities) by other researchers.

Also, to maximise the impact of the research findings, the following plans have been made: first, the results will be discussed at a monthly UCLUS seminar, as well as at national conferences; secondly, the research will be published in an academic journal; and thirdly, an Easyread summary of the findings will be shared with all participants and their self-advocacy organisations.

Clinical Impact

It is hoped that the study insights may inform existing and ongoing intrapersonal-level interventions aimed at challenging intellectual disability stigma. One such intervention is the "STORM" (STanding up fOR Myself) programme, managed by Dr Scior's team at UCL. Therefore, the current findings could provide the basis for a range of examples, which group members in the STORM study may draw from, in further thinking about approaches they could use to support their efforts in resisting stigma.

Additionally, the results may be incorporated in both direct (e.g., group/individual sessions) and indirect work (e.g., consultation, teaching, training) within the NHS, to continue to strengthen the ability of people with intellectual disabilities to counteract stigmatisation.

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Acknowledgements

The first people to whom I am *wholeheartedly* grateful are all the self-advocates involved in the research study. Thank you for sharing your experiences with me, spontaneously and from the heart. Your awe-inspiring courage and determination in fighting intellectual disability stigma has filled me with hope, as well as with a strengthened sense of determination to continue fighting for the things that are important to me too. I also want to acknowledge the extremely valuable contribution of the group facilitators, not only for identifying suitable participants in the midst of a pandemic but also for offering them, when needed, the necessary support to engage in online research.

I am also hugely indebted to Katrina Scior and Lisa Richardson for their sustained support and encouragement, as well as for *generously* sharing their expertise with me at all times. Your investment in the project has helped me produce this worthwhile result, and this would not have been possible without your supervision.

Finally, I would like to thank my friends and family for believing in me and always being *interested*, *receptive* and *ready to think with me*.

Part 1: Literature Review

Stigma and stigma resistance in people with intellectual disabilities: A conceptual introduction

Introduction

This thesis aimed to increase our understanding of how individuals with intellectual disabilities resist stigma. Stigmatisation of people with intellectual disabilities is widespread, with individuals facing high levels of prejudice and discrimination (e.g., Ali et al., 2012; Scior, 2011; Scior et al., 2020). This gives rise to multiple adverse outcomes; for example, not only can stigma restrict the fundamental freedoms and rights of people with intellectual disabilities and stop them from accessing valuable opportunities (Scior & Werner, 2016), but it also correlates negatively with quality of life and positively with psychological distress (Ali et al., 2015; Hatton et al., 2014). Moreover, stigma can lead to reduced self-esteem and a higher risk of developing poor psychological health for individuals with intellectual disabilities (Emerson, 2010; Paterson et al., 2012; Szivos, 1990; Szivos-Bach, 1993).

Despite efforts to address intellectual disability stigma through interventions at multiple levels, including structural, interpersonal, familial and intrapersonal (Werner & Scior, 2016), evidence is still limited regarding how individuals with intellectual disabilities manage and, potentially, resist stigma. In addition, it is not known, from the perspective of people with intellectual disabilities, what barriers and facilitators may support or, conversely, hinder their efforts towards stigma resistance.

This project sought to close the aforementioned gaps in the evidence by conducting semi-structured interviews with individuals with intellectual disabilities who attend self-advocacy groups. Specifically, the aim was to investigate how self-advocates with intellectual disabilities respond in different situations to resist stigma, and what they believe helps them to stand up for themselves or prevents them from doing so. Self-advocates were the focus of the project because one would expect them to have grappled with issues around stigma resistance in the course of engaging with self-advocacy, and therefore being in a position to offer richer data than cohorts who may not have done so.

It is hoped that this project will yield new insights into how to promote well-being for individuals with intellectual disabilities. This includes supporting their efforts to not be restricted from the damaging effects of stigma. Moreover, this research is important because as clinicians and researchers, we should not just advocate for people with intellectual disabilities, but also promote their voices as the people best positioned to lead the anti-stigma agenda on the basis of their lived experience (Scior & Werner, 2016); and indeed, it is arguably our moral duty to do so.

The present conceptual introduction sets out the context of the thesis first, by presenting the concepts of intellectual disability, stigma and intellectual disability stigma. Secondly, it provides information regarding different forms of intellectual disability stigma and the effect of stigmatisation on the social identity of people with intellectual disabilities. Thirdly, this section examines the main theoretical and methodological underpinnings motivating the empirical study. This is achieved by reappraising and synthesising relevant stigma and stigma-resistance literature. Finally, this chapter provides the rationale for the empirical study and outlines its aims.

Background

What is an intellectual disability?

Intellectual disability is the most prevalent neurodevelopmental condition, affecting 1.04% to 1.55% of the global population (Maulik et al., 2011; McKenzie et al., 2016). The World Health Organisation (n.d.) has defined intellectual disability as involving a significant impairment in how one understands, learns and applies new information. This in turn affects one's social functioning (i.e., one's ability to operate independently). Additionally, an intellectual disability is classed as being one that manifests before adulthood, and that has a lifelong impact on the cognitive and/or intellectual development of affected individuals. However, that said, the World Health Organisation has also stated that a person's degree of disability is dependent upon the extent to which society enables (or hinders) people with intellectual disabilities to fully participate in everyday life. This is in line with the social model of disability (Oliver, 1996), which proposes that disabilities are socially constructed phenomena. As such, the notion of 'disability' may represent a society's failure to adjust to the needs of individuals who, compared to what is considered 'typical', may have additional physical, sensory or cognitive needs.

What is stigma?

Early sociological work described stigma as a process according to which a person's or group's normal identity is "spoiled" by others' negative reactions, on the basis of the person/group possessing "an attribute that is deeply discrediting" (Goffman, 1963, p. 3). This involves the target individual (or group) being marginalised due to their different values or personal characteristics, such as mental health problems, intellectual/physical ability or ethnicity. However, Goffman's (1963) conceptualisation of stigma has been criticised for centring attention on the social interplay between the target and the dominant person/group, and therefore neglecting to consider significant political or structural forces inherent in the process of stigmatisation (Weiss et al., 2006).

Another important definition of stigma, which takes into account such forces, involves discrimination arising from stereotypes and prejudice against the stigmatised person or group, typically in a power situation that allows or even facilitates such processes (Link & Phelan, 2001). Crucially, these processes are thought to be maintained through social and political structures that are biased and partial, leading to an adverse cycle of discrimination and loss of power for those affected by them (Rapley, 2004).

Intellectual disability stigma

Despite the intellectual disability field still lacking a clear conceptualisation of stigma, social science researchers have long been interested in understanding the concept of intellectual disability stigma and its impacts (e.g., Ditchman et al., 2013; Scior & Lynggaard, 2006). Moreover, the existing (albeit limited) literature suggests that being labelled as an individual with an intellectual disability confers a highly stigmatised status (e.g., Beart et al., 2005; Cunningham et al., 2000). This status is linked to negative stereotypes commonly endorsed by the public about people with intellectual disabilities (e.g., that they are impaired or childlike, see especially Gilmore et al., 2003), leading to prejudice and discriminatory treatment towards them, e.g., others may exclude them from activities, stare at them, etc (Scior, 2011; Mencap, 2015). Such acts often result in harmful consequences for people with intellectual disabilities (Ditchman et al., 2016; Scior, 2016). These include frequent exposure to bullying; poor psychological health; social rejection; and difficulties accessing heath care, education, employment, housing and leisure opportunities, to name but a few of the damaging effects (e.g., Ditchman et al., 2016; Emerson, 2010; Mencap, 2007; While & Clark, 2010).

The stigmatisation of people with intellectual disabilities

Although stigmatisation of individuals with intellectual disabilities appears to have abated over time in highly developed countries, such as in the United Kingdom (UK) (Scior, 2016; Mencap, 2015), negative attitudes continue to exist around the world (Scior et al., 2020). For example, recent data collected from a global web survey indicated that the general public might not wish to interact with individuals with intellectual disabilities, an attitude which denies people’s rights and sees their social inclusion as unattainable (Scior et al., 2020). Therefore, it is essential that we continue to advance our understanding of what contributes to and maintains the stigmatisation of individuals with intellectual disabilities. This will help minimise continuing prejudice towards them and their social exclusion, as it means that more targeted interventions can be developed.

From an evolutionary point of view, disability may be stigmatised on the basis of affected individuals being perceived as unable to contribute effectively to ensure their group's survival (Neuberg et al., 2000). Hence, it is possible that individuals with intellectual disabilities are believed to be unable to contribute to the functioning of society (e.g., working towards group goals, contributing resources, etc.) as successfully as their non-disabled peers. Additionally, a factor in maintaining the stigmatisation of individuals with intellectual disabilities may be their low status in the social hierarchy (Scior, 2016). That is to say, people with intellectual disabilities are highly disadvantaged by not having the capacity and/or opportunity to exercise direct control over things that matter to them, such as their rights or assets. At the same time, important opportunities and decisions are often determined *for* them (Scior, 2016).

These processes further perpetuate discrimination and status loss for this population. This conforms to the notion that the stigmatised identity of people with intellectual disabilities is a social problem, resulting from oppressive interactions taking place between society and individuals with disabilities, while also highlighting another important issue. That is, if the social construction of intellectual disability is to be deconstructed, one may discover that the stigmatised status of people described as intellectually disabled may merely be "*the product of* technological professional practices and knowledges" (Rapley, 2004, p. 8). Such a critique derives from an in-depth examination of interactions between people in positions of power (e.g., psychologists, carers, researchers) and those described as intellectually disabled. Notably, the said analysis showed that despite the "asymmetric power" between all parties involved in the aforementioned interactions taking place in supported housing settings, people described as intellectually disabled (and subsequently treated as "supposedly interactionally incompetent") were able to successfully interact with their non-disabled counterparts, as well as master and/or deal effectively with what was expected of them

(Rapley, 2004, p. 8). This *subtle* resistance of people with an intellectual impairment to their stigmatisation and infantilisation, as proposed by Rapley (2004), has important implications for current research practices and the outcomes they create.

Forms of intellectual disability stigma

Although research on the topic of intellectual disability stigma is generally lacking, there is literature that provides some insight into its multiple origins (Ali et al., 2012). First, there is institutional/structural stigma. This may manifest, for instance, in the stigmatisation that people with intellectual disabilities face within healthcare (Mencap, 2007; While & Clark, 2010). A recent example of this inequality was the case of people with intellectual disabilities not being prioritised for Covid vaccinations, despite their highly vulnerable clinical status (Scown, 2020). Another example of structural stigma is evident in the absence, or shortage, of reasonable adjustments (such as Easyread materials or a range of communication aids) in healthcare services for people with intellectual disabilities (Dagnan et al., 2015; Tuffrey-Wijne et al., 2014).

Secondly, there is public stigma. This includes the public's prejudice against people with intellectual disabilities, leading to discriminatory behaviours towards them (e.g., violence, avoidance) (Ditchman et al., 2016). Another example of public stigma is evident in the many derogatory stereotypes about people with intellectual disabilities found in mass media, where individuals are portrayed as needy or problematic (Renwick, 2016). These negative stereotypes, which often obscure the complexity or positive attributes of people with intellectual disabilities, fuel more prejudice against them and perpetuate their stigmatised identities (Renwick, 2016).

Thirdly, public stigma can result in self-stigma (or internalised stigma). This is a process where a member of the stigmatised group comes to recognise and endorse the undesirable attitudes others hold towards them, in addition to accepting these as valid and applicable to themselves (Corrigan & Watson, 2002). However, internalised stigma has not been investigated extensively in people with intellectual disabilities, as it is a difficult concept to measure (Roth et al., 2016). Importantly, studies examining self-stigma have been conducted with small participant samples, which limits the generalisability of the findings (Sheehan & Ali, 2016). Therefore, the (long-term) impacts of self-stigma on the well-being of people with intellectual disabilities, together with strategies to manage these effects, remain unknown.

Moreover, people do not exist in isolation, and need to be understood within their contexts (e.g., their families). In the case of people with intellectual disabilities, it has increasingly been found that their family members may also be subject to stigmatising attitudes and behaviours by others (Ali et al., 2012; Mitter et al., 2019). This fourth type of stigma, which can cause family members to both develop and maintain a negative view of themselves, and even to conceal their relative's disability from others, is known as courtesy stigma (Goffman, 1963). When those affiliated with a person with intellectual disabilities (e.g., family members) internalise courtesy stigma, what follows is the development of affiliate stigma, which, in turn, affects the target person's affiliates on three levels: cognitive, emotional, and behavioural (Mitter et al., 2019). This has been found to cause considerable stress and poor mental health for the person's affiliates (Baxter et al., 2000). It often also compromises the level of care that affiliates may offer their relative with intellectual disabilities (Mak & Cheung, 2008). Thus, in sum, not only does stigma have multiple origins, but it also negatively affects people with intellectual disabilities and their affiliates in many ways.

The effects of stigmatisation on the identity of people with intellectual disabilities

Although stigma appears to be harmful for the lives of individuals with intellectual disabilities, it is not clear whether everyone with this type of disability is negatively affected.

A systematic review has explored this issue in the context of how the social identity of people with intellectual disabilities may be formed (Logeswaran et al., 2019). More specifically, this research investigated: (1) whether individuals with intellectual disabilities understand that they have a 'disability'; (2) the reactions of people with intellectual disabilities to the 'intellectually disabled' label *given* to them and (3) whether people with intellectual disabilities are conscious of their label having a devalued status in society.

The authors concluded that some people with intellectual disabilities may not endorse their 'intellectually disabled' label, as they may struggle to make sense of the concept and its consequences. As a result, they may have a limited awareness of their stigmatised position in society, a finding that is in keeping with previous work (e.g., Beart et al., 2005). Moreover, many individuals with intellectual disabilities, regardless of how conscious of their intellectual disability identity they are, do not view it as an important aspect of who they are (e.g., Davidson et al., 2014). Yet, the review also showed that there is evidence across many studies that some people with intellectual disabilities are aware of their disability and its negative status (for similar findings, see especially Kenyon et al., 2013). Accordingly, it is not uncommon for individuals with intellectual disabilities to routinely associate their ascribed label with inability (e.g., McEvoy & Keenan, 2014), a sense of emptiness, powerlessness, anger and frustration (e.g., Jahoda & Markova, 2004), as well as with the expectation of receiving poor treatment from others (e.g., Ali et al., 2016). For these reasons, and in order to cope with stigma and its associated emotions (e.g., shame, embarrassment), some people with intellectual disabilities may separate themselves from their ascribed label by constructing new identities for themselves (Jahoda et al., 2010). They may also attempt to appear in a better light; for example, by behaving in socially acceptable ways (Monteleone & Forrester-Jones, 2016). Additionally, others may reject the label of 'disability' completely

(Finlay & Lyons, 2005) and/or separate themselves from peers with intellectual disabilities, even at the risk of their own social exclusion (Ali et al., 2012).

Although the above findings have provided important insights into how individuals with intellectual disabilities may cope with the label of disability, the research studies reviewed by Logeswaran et al. (2019) have several limitations, chief among them the use of small samples and opportunity sampling. Not only does this make their results less generalisable, but it also affects the robustness of the overall conclusions drawn. Therefore, there is a need for more research aimed at: (1) building a better understanding of the impact of stigmatisation on the (social) identity of people with intellectual disabilities; (2) learning more about the ways in which individuals with intellectual disabilities try to cope with and/or resist stigma; and (3) developing, implementing and evaluating anti-stigma interventions to promote the well-being of individuals with intellectual disabilities (Werner & Scior, 2016).

Stigma resistance

Given that this project intended to investigate how people with intellectual disabilities resist stigma, understanding how this process has already been described in the mental health literature is an important next step. First of all, Thoits (2011) notes that stigma resistance involves "opposition to a harmful force or influence" (p.11). This strategy is different to stigma *management*, typically employed by people who have endorsed and accepted as valid the societal, stigmatising stereotypes and prejudice they face (Yasuike, 2019). While stigma management involves tactics such as concealing or understating one's stigmatised identity to avoid the harmful effects of stigmatisation (Elliott & Doane, 2015; Yasuike, 2019), stigma resistance centres on action one can take to safeguard the self against devaluation, and to fight negative public attitudes (Thoits, 2011). In other words, stigma resistance entails a process whereby stigmatised individuals are active, empowered and resilient agents aiming to create positive change for themselves and others (Buseh & Stevens, 2007).

Stigma resistance can commonly manifest in two ways (Thoits, 2011). The first, stigma deflection, is mainly cognitive in nature and involves stopping the process of self-stigmatisation by resisting identification with the negative stereotype(s). For example, a person may think "*that's not me*" when confronted with stigmatising stereotype(s) (Thoits, 2011). In addition, a person's deflecting strategy may involve reframing their problems as more socially acceptable (Thoits, 2011). For example, a person may talk about experiencing anxiety as opposed to being mentally ill. Although stigma deflection manoeuvres help to maintain the affected individual's self-esteem, this way of stigma resistance has been criticised for not targeting the harmful impact of stigmatisation inherent in social structures (Manago et al., 2017). The second form of stigma resistance is more behavioural in nature and involves challenging stigma interpersonally and structurally. This includes the stigmatised individual confronting stigmatisers and their negative views, becoming a self-advocate and educating the public, and attempting to change the social structures where power is exercised (Buseh & Stevens, 2007; Thoits, 2011). Stigma challenging promotes and enhances the affected individual's self-esteem, optimism and sense of empowerment (Fenn & Scior, 2019). Thoits (2011) proposed that "labelled" individuals, who have to take care of their "spoiled identity" (Goffman, 1963), may use either type of stigma resistance depending on their circumstances. That said, Thoits' (2011) model does not offer a detailed account of the factors that promote stigma resistance, despite the vital role of stigma resistance in enhancing a sense of agency for stigmatised individuals.

Firmin et al. (2017) qualitatively explored Thoits' (2011) model by interviewing 24 adults with self-reported severe and enduring mental health difficulties about their experiences with stigma and stigma resistance. The sample consisted mainly of White men, who were active stigma resisters. Participants were invited to discuss a range of topics and invited to share their thoughts and experiences about stigma and stigma resistance. Results revealed that participants resisted stigma in three ways: at the personal level (e.g., questioning stigmatising cognitions, proving people wrong through focusing on their recovery, learning about stigma); at the peer level (e.g., utilising one's own experiences to assist peers in resisting stigma); and at the public level (e.g., being an advocate, educating the public, campaigning). Firmin et al. (2017) noted that their participants used multiple strategies at the personal level. These include people actively learning about their recovery process and working towards building more meaningful social identities. This therefore contrasts with Thoits' (2011) theoretical work, which discussed stigma deflection as the only resistance strategy at the personal level. In addition, the participants recruited in Firmin et al.'s (2017) research reported that deflecting stigma was a passive approach, which did not feel like resisting at all. Instead, they viewed stigma resistance as an active, continuous process. That said, it is worthy of note that Firmin et al.'s (2017) conceptual model is based on the distinct experiences of stigma resistance of a relatively small participant sample. Therefore, findings may not generalise to individuals who are not active stigma resisters.

Tackling intellectual disability stigma through stigma change interventions

Given that stigma has multiple origins, negatively affecting the lives of individuals with intellectual disabilities in many ways (Ali et al., 2012; Marriott et al., 2020), Werner and Scior (2016) proposed a multilevel model for understanding and challenging it. This model, inspired by previous literature (see especially Cook et al., 2014), serves as a framework that captures the (limited) attempts to combat intellectual disability stigma structurally, interpersonally, intrapersonally and within families.

Structural-level interventions that challenge intellectual disability stigma have focused on introducing legislation (such as the Equality Act 2010) to ensure that the rights of people with intellectual disabilities are legally upheld (Werner & Scior, 2016). However, the impact of such interventions has proven hard to evaluate (Cooper, 2019). Next, there are interventions at the interpersonal level. These constitute the majority of approaches used thus far, and centre on changing stigmatising attitudes and behaviours among those who stigmatise, through education and contact (Werner & Scior, 2016). While the former strategy aims to alter negative stereotypes through educating laypeople and key stakeholders (e.g., teachers, health and social care providers) on intellectual disability stigma, the latter method focuses on shifting their stigmatising attitudes and behaviours through increasing their interpersonal contact with individuals with intellectual disabilities. Although some of these interventions have proven to be promising (e.g., Freudenthal et al., 2010), educational approaches have mostly been criticised for being ineffective in bringing about longer-term behavioural changes (Corrigan et al., 2012). Equally, contact-based approaches alone are believed to be not as successful as when combined with education (Werner & Scior, 2016).

Most familial-level interventions have focused on parents supporting their relative with intellectual disability with the stigma of receiving a diagnosis (Werner & Scior, 2016). However, such efforts may sometimes be hampered by negative reactions (e.g., shame) commonly arising within families due to experienced courtesy stigma (e.g., Manago et al., 2017). Having said that, there is a strong precedent for parents of people with intellectual disabilities being advocates for stigma change action (Werner & Scior, 2016). To give an example, it was due to a parent's campaigning that the government recently decided to put in place mandatory intellectual disability training for health care professionals (Mencap, 2019).

Interventions tackling intellectual disability stigma at the intrapersonal level are limited (Werner & Scior, 2016). For example, although cognitive behavioural therapy is used with stigmatised populations to modify unhelpful beliefs associated with self-stigmatisation (Butler et al., 2006), these interventions are not common with individuals with intellectual disabilities (Werner & Scior, 2016). This could be on account of cognitive, communicative and adaptive functioning being compromised in people with intellectual disabilities. This means individuals might struggle to successfully deflect stigma and/or directly challenge stigmatisers (Cooper, 2019). Crucially, given the existence of institutional and structural stigma, it is also possible that research in this area has been greatly neglected (Werner & Scior, 2016).

Having said that, a small body of evidence exists in favour of the effectiveness of intrapersonal-level interventions, designed to maximise stigma management and stigma resistance in individuals with intellectual disabilities (Werner & Scior, 2016). More specifically, Szivos and Griffiths (1990) developed psychological group interventions to help individuals with intellectual disabilities to manage internalised stigma and build positive social identities. Also, Scior and Lynggaard (2006) used narrative therapy in individuals with intellectual disabilities to facilitate deconstruction of self-stigmatising narratives. However, the potential impact of these interventions on self-stigma has not been formally assessed (Werner & Scior, 2016).

Two further intervention studies have been conducted (Cooper, 2019; Fenn, 2018). These were part of a larger feasibility and pilot project, testing an intervention aimed to improve the stigma management and stigma resistance strategies of individuals with intellectual disabilities at the intrapersonal level. These studies have been the first to directly manipulate stigma resistance through the delivery of five manualised sessions to people with intellectual disabilities. The participants recruited were aged 16 years and above, and attended either a self-advocacy group, a day service group, or a college group. Both studies were conducted against the backdrop of growing evidence in the mental health literature which positively associates stigma resistance with clinical recovery (e.g., Griffiths et al., 2015). Although both studies (i.e., Cooper, 2019; Fenn, 2018) are limited by their small sample sizes and the absence of a validated measure of internalised stigma, results showed: (1) small increases in participants' sense of power and self-esteem; and (2) small decreases in experienced discrimination and psychological distress. Importantly, the results were interpreted in light of the stigma-resistance framework by Firmin et al. (2017). Both studies found that participants resisted stigma in the following ways: at the personal level (e.g., empowering themselves through acknowledging discriminatory acts); at the peer level (e.g., supporting each other through sharing personal experiences of oppression and maltreatment); and at the public level (e.g., advocating for themselves and others, educating the public about intellectual disability stigma).

All things considered, despite existing benefits of stigma change interventions for individuals with intellectual disabilities (most notably, reduced discrimination), the current evidence on intellectual disability stigma reduction through the implementation of these interventions is not robust enough (e.g., interventions are limited and/or have not been formally evaluated) (Werner & Scior, 2016). As a result, the process of stigma resistance in this population remains unclear. This further emphasises the need to better understand this process, alongside determining what enables and hinders it.

Individuals with intellectual disabilities tackling stigmatisation through advocacy

While research on intellectual disability stigma change interventions is limited, there is growing evidence suggesting that individuals with intellectual disabilities may tackle stigma, at the intrapersonal level, by being members of a self-advocacy group (SAG) (e.g., Clarke et al., 2015). These groups have functioned as an important avenue for people with intellectual disabilities to break down entrenched stigmas by standing up for themselves, speaking out and acting in line with their rights (e.g., Dybwad & Bersani, 1996 as cited in Fenn & Scior, 2019; Goodley, 2000). In addition, self-advocates with intellectual disabilities may resist stigma by working together to change policies and how services operate, thereby influencing the social structures where power imbalances exist (Aspis, 2002).

Similarly, and despite some limitations (e.g., problems with interpretations of studies, increased chance of individual bias in reviewing the literature, quality rating of selected studies varying from high to low, small samples), a systematic review concluded that SAG membership empowers individuals with intellectual disabilities to demand their rights by speaking out (Fenn & Scior, 2019). For example, Gilmartin and Slevin (2010), who interviewed 13 self-advocates in Ireland about the benefits of belonging to a SAG, showed that people were able to initiate change by finding out from each other about their rights. As an illustration, participants discussed that it was within their rights to complain to their local authority about inadequate lighting on the streets, which they eventually did by writing a letter. Equally, another study, conducted with inpatient men with intellectual disabilities, concluded that people's SAG membership enabled them to effect change at a service level (e.g., improving the complaint handling procedure in the low-secure NHS service) (Miller, 2015). Other findings highlighted in the review, which may be associated with stigma resistance, include self-advocates with intellectual disabilities: (1) feeling confident to speak out, effect change and develop positive self-identities (Anderson & Bigby, 2017); (2) being able to change their negative self-perceptions (Beart et al., 2004; Mineur et al., 2017) and (3) resisting oppression through self-advocacy and developing leadership skills (e.g., speaking in public) (Caldwell, 2010).

Although the aforementioned body of research suggests the value of SAG membership for individuals with intellectual disabilities in tackling stigma, none of these empirical studies directly investigated stigma resistance in the way previous similar research has (i.e., Firmin et al., 2017). Instead, the studies mainly explored the effect that SAG membership has on people with intellectual disabilities, including their social identities. Moreover, their findings contrast with the mixed results of an Israeli stigma study of self-advocates with intellectual disabilities, which employed a partial participatory research method (Roth et al., 2016). More specifically, despite this research showing that being a member of a SAG allowed some to stand up for themselves, this was not the case for most participants who chose to ignore stigmatisers or keep away from them altogether. Importantly, those who opted for ignoring stigma also reported that they did so at an emotional cost (e.g., they felt bad, their fear of others' negative reactions was reinforced). Additionally, their attempts to ignore stigmatised treatment, often encouraged by their affiliates, were not always successful.

The findings discussed above highlight a limited but emerging evidence base in the field (e.g., Fenn & Scior, 2019) and have important implications for the way we start to conceptualise stigma resistance in individuals with intellectual disabilities. However, these results mostly indicate the actions that people engage in to resist stigma, leaving a gap in knowledge in relation to the barriers and facilitators promoting stigma resistance.

Literature Review

In order to further justify the need to examine the process of stigma resistance in individuals with intellectual disabilities, it is crucial that the impact of stigma (and self-stigma) on the lives of this population is well understood (Abraham et al., 2002). This is important since stigmatising treatment towards individuals with intellectual disabilities persists on a global scale, maintaining poor outcomes for affected individuals (Ditchman et al., 2016; Scior et al., 2020). In addition, a better understanding of how stigma affects this highly stigmatised population will help inform the intervention design of effective clinical and psychosocial efforts. Again, this is essential if we want to put an end to the perpetuation of social inequalities and restriction of rights of individuals with intellectual disabilities, thereby promoting their inclusion, well-being and quality of life (Scior & Werner, 2016). Yet, although stigma affects individuals with intellectual disabilities on multiple levels (e.g., safety, economic security, education, employment, mortality, health services) (Emerson et al., 2012), and research on this topic is growing (Ditchman et al., 2016), the present overview of the literature will focus only on the psychological effect of stigma on people with intellectual disabilities.

Stigma and self-esteem

Studies that have examined the association between stigma and self-esteem in individuals with intellectual disabilities found that greater awareness of stigma was linked to reduced self-esteem (e.g., Abraham et al., 2002; Paterson et al., 2012; Szivos, 1990; Szivos-Bach, 1993). More specifically, Abraham et al. (2002) conducted cross-sectional research, recruiting 50 men and women with mild and moderate intellectual difficulties who attended two days centres in the UK. This study used Szivos-Bach's (1993) scales of stigma and self-esteem, which address questions about whether people with intellectual disabilities think they can influence others, achieve social competencies (e.g., good behaviour), and are treated by others like a child to name but a few. Results indicated an association between high levels of stigma and low self-esteem, which is consistent with previous similar findings (Holmes, 1994 as cited in Abraham et al., 2002). However, although the measures used in the study had previously been reported to have good reliability (i.e., alpha 0.81 and alpha 0.90, accordingly) (Szivos-Bach, 1993), Abraham et al. (2002) found the stigma scale to have poor retest reliability for three of its 10 items. This thus limits the robustness of the findings.

The negative association between stigma and self-esteem was replicated by another cross-sectional study in the UK (Paterson et al., 2012). This study recruited 43 men and women with intellectual disabilities from one day centre. Measures used included the Stigma Perception Questionnaire (Szivos, 1991), an adapted social comparison scale to explore participants' evaluations of themselves following comparisons with others (Dagnan & Sandhu, 1999), and an adapted Rosenberg self-esteem scale. Participants reported lower self-esteem when stigma was higher, but this seemed to be mediated by the nature of the social comparisons made. For example, the more unfavourably participants saw themselves in relation to others, the lower their self-esteem was reported to be. Although this is in keeping with previous research (Finley & Lyons, 2000), the validity of these conclusions may be affected by methodological issues noted in the study (e.g., the adapted self-esteem scale also containing items relating to social comparison). A further study limitation, which is commonly observed in this type of research (e.g., Petrovski & Gleeson, 1997), includes participants being recruited from one place or type of setting only (i.e., day centre). This restricts the generalisability of findings to other settings (e.g., college).

Two other studies in the UK, using qualitative and cross-sectional designs, also concluded that increased levels of stigma were related to lower self-esteem in their small student samples (i.e., 50 participants) (Szivos, 1990; Szivos-Bach, 1993). This mainly manifested in participants' responses regarding their life aspirations. For example, when students were asked if they had a desire to do a number of things in the future (e.g., get married, drive a car), those who had scored higher on stigma also felt the least confident to fulfil their life goals. Having said that, no similar association was found by other researchers studying a similar student sample (e.g., Cooney et al., 2006). That is, Cooney et al. (2006) reported that their young participants with intellectual disabilities, recruited from both mainstream and segregated schools, were optimistic about their life aspirations despite having previously received stigmatised treatment. Moreover, it is noteworthy that in the Szivos study (1990) participants with work experience also reported higher life aspirations, although this did not appear to increase their self-esteem. However, this study may be limited by its measures, which combined items relating to self-esteem and stigma, thus rendering their content and criterion validity questionable (Field & Hole, 2002).

The findings by Szivos-Bach (1993) and Szivos (1990) contrast with the results of a cross-sectional study conducted in Australia with 31 male and female adult workers with a mild intellectual disability (Petrovski & Gleeson, 1997). Results of this study indicated a trend according to which only women scored lower in self-esteem and higher on perception of stigma, suggesting that men and women may be affected by stigma differently. However, the research is limited by its small sample size and participants being recruited from only one work agency. Thus, results cannot generalise to individuals in other work settings.

Despite some limitations (e.g., small samples), all studies suggest that stigma has a profound effect on the self-esteem of individuals with intellectual disabilities. Importantly, while the nature of this research means that we cannot draw conclusions regarding causality and its direction, the observed relationships imply that stigma resistance may require participants to have higher self-esteem.

Stigma and coping strategies

A small body of research indicates that individuals with intellectual disabilities may have access to a limited repertoire of coping strategies when managing public and self-stigma (e.g., Chen & Shu, 2012; Cunningham & Glenn, 2004; Jahoda & Markova, 2004). For example, Chen and Shu (2012) conducted research with 14 Taiwanese young people with mild to moderate intellectual disabilities. A grounded theory approach, used to qualitatively explore the subjective experiences of its participants, highlighted that the participants recruited managed stigma in three ways: first, by concealing information about their 'disabled identities' from others (i.e., hiding their 'handicapped identity card' issued by the government as a marker of intellectual disability); secondly, by isolating themselves and/or refraining from forming relationships with their non-disabled peers, lest they be discovered to have a disability; and thirdly, by intentionally and unrealistically promoting their self-image (e.g., saying that they are good at doing things, when in fact they are not) to manage the public's stigmatising views of them.

This study suggests that individuals with intellectual disabilities have a restricted gamut of strategies to manage stigma, which is consistent with findings from studies with people with mental health difficulties (e.g., Link et al., 1991). However, caution needs to be exercised when attempting to draw firm conclusions as participants were all from eastern Taiwan, and it is likely that important differences exist between this part of the country and western Taiwan (and indeed, between East Asian cultures and other cultures). Additionally, the sample was only made up of students with mild and moderate intellectual disabilities, thus making it unclear whether results generalise to cohorts who are more severely disabled.

Similar to Chen and Shu (2012), other studies in the UK showed a relation between stigma and coping strategies (Cunningham & Glenn, 2004; Jahoda & Markova, 2004). For example, research by Jahoda and Markova (2004) investigated how individuals with intellectual disabilities manage stigma when transitioning from institutions/family homes to live more independently in the community. The researchers used content analysis to examine the subjective experiences of their 28 participants with mild intellectual disabilities. Participants, who were all conscious of the disadvantageous impact of having a stigmatised identity, frequently handled stigma by separating themselves from their intellectually disabled peers. In addition, those from institutional settings tended to conceal any past connection to such environments in an attempt to present themselves with a new social identity. Such a manoeuvre is not surprising given the social consequences of the stigmatised status of individuals with disabilities but also the stigma related to institutionalisation (e.g., Craig et al., 2002). These findings thus add to existing literature describing the repertoire of coping strategies commonly employed by people with intellectual disabilities when managing stigma.

A further mixed-methods study used photographs, tests and interviews with 77 young adults with Down syndrome to explore 1) the experiences of stigma and intellectual disability; and 2) coping strategies used for stigma management (Cunningham & Glenn, 2004). This was the first study to investigate these phenomena in a representative, diverse sample of participants (e.g., people with a wide range of communication skills). The study is also different in that participants' parents were interviewed to ascertain their views on their children's disability, which increased the richness of the data and findings. Results revealed that people who had awareness of their stigmatised status were likely to minimise their (perceived) limitations to keep up their self-respect. This adds further support to the similar nature of coping strategies observed in existing research (e.g., Chen & Shu, 2012).

Thus, the studies reviewed all highlight the negative impact of stigma on individuals with intellectual disabilities and their coping strategies, and suggest that many people with intellectual disabilities manage stigma primarily by trying to distance themselves from their stigmatised identity.

Stigma and social comparisons

Although measuring self- and other-evaluation is complex in people with intellectual disabilities (Cunningham & Glenn, 2004), a small number of studies have explored the relationship between stigma and how this group of individuals view themselves in relation to others (e.g., Cooney et al., 2006; Finlay & Lyons, 2000; Paterson et al., 2012). Most of this body of research indicates that individuals with intellectual disabilities tend to see themselves more favourably than their peers with intellectual disabilities. These 'downward' comparisons, made towards their intellectually disabled peers, imply a protective tactic employed to maintain and/or improve subjective well-being (Crocker & Major, 1989).

More specifically, in their study of 33 adults with mild and moderate intellectual disabilities, Finlay and Lyons (2000) found that there was a tendency for participants to see themselves more positively compared with others with intellectual disabilities. However, when others did not have an intellectual disability, participants only made ‘lateral’ comparisons (i.e., they viewed themselves as the same as others). Although this research did not directly investigate participants’ experiences of stigma, its findings are echoed by results from a cross-sectional study of 60 young people with mild to moderate intellectual disabilities who had experienced stigmatised treatment from others (Cooney et al., 2006). Participants in the latter study, recruited from mainstream and segregated schools, were found to also compare themselves more favourably with peers with intellectual disabilities; however, they avoided making such comparisons with typically developing peers. This again suggests a strategy adopted by individuals with intellectual disabilities to cope with self-stigma by reducing (perceived) threat to their already devalued status, thereby maintaining psychic equilibrium (Allan & Gilbert, 1995). Yet, the findings of the latter study require further exploration on the basis of one of the scales used having low reliability (Cooney et al., 2006). Nonetheless, the association between perceptions of stigmatisation and negative social comparisons was replicated by another cross-sectional study in the UK (Paterson at al., 2012). This study found that its 43 intellectually disabled participants presented themselves as more capable compared to peers with intellectual disabilities.

In contrast to the aforementioned findings and their implications, Szivos-Bach (1993) reported mixed results in their research exploring the relationship between stigma and social comparisons. Although this research comprised a small sample of students with intellectual disabilities, results indicated that higher perceived stigma in participants was associated with more negative self-evaluations compared to others (e.g., friends, non-handicapped others, siblings). These findings are also in keeping with past intellectual disability research showing a relationship between participants’ higher perceptions of stigma and their negative self-evaluations (Dagnan & Waring, 2004). Nevertheless, Szivos-Bach (1993) further noted a tendency in participants to view themselves more favourably compared to their opposite-sex siblings only. This lends support to the hypothesis that individuals with intellectual disabilities, who are conscious of their stigmatised position in society, need to make ‘downward’ social comparisons in any given situation to maintain and/or improve their self-esteem (Crabtree & Rutland, 2001; Dagnan & Sandhu, 1999).

Therefore, despite some limitations (e.g., small samples, measurement issues) and conflicting conclusions between studies, the research reviewed here helps to elucidate the influence of stigma on the nature of self-evaluative beliefs and comparisons made by individuals with intellectual disabilities towards others; most notably, highlighting the protective function of people’s negative comparisons (i.e., to improve their subjective well-being and sense of self).

Stigma and psychological health

A small body of research indicates a negative association between stigma and psychological health in individuals with intellectual disabilities (e.g., Ali et al., 2015; Emerson, 2010; Gilmore & Cuskelly, 2014). For instance, data analysis from a UK survey of people with intellectual disabilities explored the association between individuals’ experiences of disability (disablism) and their overall well-being (Emerson, 2010). Despite the study’s cross-sectional design and its use of self-reported measures (which increase the risk of biases affecting the results), this was the first systematic investigation into such an under-researched problem (i.e., impact of disablism on health status). The results indicated a positive relationship between incidents of bullying, exposure to disablism and indicators of poor psychological well-being, including poor self-reported heath, lack of confidence, sadness, helplessness, and feeling left out.

However, this was not the case for all people involved in the study. In fact, those who had access to social support and adequate material resources experienced fewer and less severe mental health symptoms. It is therefore likely that, through this type of support, people are able to develop resilience, which may lead to improved confidence and mood. Access to positive social interactions with others may also provide a buffer against the harmful effect of stigmatisation and self-stigmatisation, through increasing affected individuals' overall cognitive representations of self. This means that people might view themselves more positively, therefore having a reduced need to make negative comparisons with others to maintain their subjective well-being. This idea also fits with the concept of self- complexity, which proposes that complex cognitive representations of self can safeguard against the adverse psychological impacts of stressful situations, including negative emotions and self-appraisal (Linville, 1987).

The negative association between stigma and psychological health was replicated by another UK study, of adults with mild and moderate intellectual disabilities from 12 sites (Ali et al., 2015). Measures used to collect data included 1) a self-reported stigma tool (Ali et al., 2008); and 2) the Clinical Outcomes in Routine Evaluation measure, adapted for individuals with intellectual disabilities (CORE-LD, Brooks et al., 2013). Both measures have good psychometric properties and are validated for intellectual disability research (Ali et al., 2015). Results indicated that increased self-reported stigma was correlated with increased psychological distress; the latter also being a predictor of frequent visits to mental health professionals (Mills et al., 2012). Despite the cross-sectional design of the research, which restricts inferences about causality and its direction, this is the first study to have obtained a large (i.e., 229 participants) and representative, community-based sample of participants with intellectual disabilities nationally.

Consistent with Ali et al.'s (2015) findings are the results from another cross-sectional study in the UK (Dagnan & Waring, 2004). This research involved 39 adults with intellectual disabilities completing self-report measures on stigma, social comparisons and self-evaluative beliefs. Results indicated that participants' negative self-evaluations were positively related to their feeling different in the context of having internalised stigma. This was in turn thought to increase their susceptibility to experiencing psychological distress. Nonetheless, given that psychological distress was not directly measured, no further information about the association between stigma and psychological health was gained from this research.

However, the negative association between stigma and psychological well-being was also proposed in a review on loneliness in people with intellectual disabilities (Gilmore & Cuskelly, 2014). This review suggested that public stigma reduces the number of opportunities that individuals with intellectual disabilities have for connecting with others, socially and emotionally. This, in turn, could increase their vulnerability to loneliness, leading to poor psychological health. Although this suggestion seems plausible, especially in light of all other findings reviewed so far, it is based on the authors' interpretation of the reviewed literature rather than on primary research findings. Therefore, one needs to be tentative in reaching conclusions about the role of social and emotional connections. Yet, taken together, these studies highlight that stigma has a negative effect on the psychological well-being of individuals with intellectual disabilities.

Summary

In conclusion, the overview of the literature presented here suggests that stigma and self-stigma are associated with multiple harmful psychological outcomes (e.g., poor psychological health, negative self-evaluations, low self- esteem) for individuals with intellectual disabilities. These, in turn, affect people's quality of life (e.g., increased vulnerability to loneliness, social exclusion). These conclusions highlight an urgent need to find effective means of supporting affected individuals' capacity to resist stigma and reduce their exposure to such negative impacts.

Methodological Considerations and Conclusions

Having synthesised and critically analysed the relevant stigma and stigma-resistance literature, several methodological flaws have been highlighted in the existing evidence. These limit the validity and generalisability of their findings and include: small samples (e.g., Gilmartin & Slevin, 2010; Szivos, 1990); recruitment of participants from only one setting (e.g., Paterson et al., 2012); measures not being reliable/sensitive enough (e.g., Cooney et al. 2006); lack of a control group (e.g., Fenn & Scior, 2019); stigma not being directly explored (e.g., Finlay & Lyons, 2000); employment of convenience sampling (e.g., Petrovski & Gleeson, 1997); as well as limited involvement of individuals with intellectual disabilities in different stages of the research cycle (e.g., Cooper, 2019; Fenn, 2018; Roth et al., 2016); and the coding frame not being assessed for validity or reliability (e.g., Jahoda & Markova, 2004). Moreover, all studies lacked respondent validation checks.

Further, apart from the two intervention studies that sought to enhance stigma resistance (Cooper, 2019; Fenn, 2018), no empirical studies have directly explored this concept in people with intellectual disabilities in the qualitative manner employed in stigma-resistance research in other fields (i.e., Firmin et al., 2017). Additionally, no studies have investigated barriers to and facilitators of stigma resistance directly from the perspective of intellectually disabled individuals. It is against this backdrop that the current study set forth to investigate stigma resistance in this population. This was achieved through conducting semi-structured interviews with self-advocates with intellectual disabilities, recruited from SAGs from five different geographical locations across England (e.g., Southern England, the Midlands).

The decision to focus on self-advocates with intellectual disabilities was deliberate. For example, existing literature highlights that discussing the topic of stigma with individuals with intellectual disabilities who have not raised the issue before, or who are not used to tackling distressing issues, can be emotionally disturbing for them (Kenyon et al., 2013; Roth et al., 2016). Therefore, self-advocates with intellectual disabilities, who may have discussed the topic of stigma with peers from their SAG and already have support systems in place (e.g., peer support from other group members), may be deemed to be at lower risk of becoming distressed by talking about the topic. Also, according to Liberation Psychology (Martín-Baró, 1994), self-advocates with intellectual disabilities are more likely to provide comprehensive data than peers who may not have acknowledged some of the inequalities and stigma they face.

Finally, the study was guided by models of stigma resistance proposed by Firmin et al. (2017) and Thoits (2011). This includes the interview schedule being initially inspired by Firmin et al.'s (2017) interview tool and subsequently developed by (1) reviewing the intellectual disability stigma and stigma-resistance literature; and (2) consulting with the National Mencap Research Advisory Group of self-advocates with intellectual disabilities.

Aims of the Thesis

The overall aim of this exploratory study was to explore the stigma-resistance process in individuals with intellectual disabilities. This was achieved by addressing the following questions:

1. How do self-advocates with intellectual disabilities resist stigma?
2. From the perspective of these self-advocates, what are some of the barriers to and facilitators of stigma resistance?

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Part 2: Empirical Paper

Examining the stigma-resistance process in adult self-advocates with intellectual disabilities

Abstract

Aims: As people with intellectual disabilities continue to face high levels of discrimination, investigating how they may resist stigmatisation is important. Therefore, the present research aimed to (1) qualitatively explore experiences of stigma resistance in self-advocates with intellectual disabilities; and (2) investigate barriers to and facilitators of stigma resistance directly from the self-advocates' perspective.

Method: Sixteen adults with intellectual disabilities, recruited from self-advocacy organisations across England, participated in virtual, semi-structured interviews. Thematic analysis was used to analyse the data.

Results: Four themes were identified in the context of participants' actions in resisting stigma; (i) asserting oneself, (ii) speaking out, (iii) using lived experience to drive change, and (iv) strengthening positive identities. Perceived barriers and facilitators were linked to personal and environmental/contextual factors.

Conclusions: This study addresses a gap in the literature on intellectual disability stigma by advancing our knowledge of how individuals with intellectual disabilities resist stigma. Although the research highlights the importance of individual and collective resistance, it also reminds us that work must still be done to tackle stigma within the institutional and social structures where power imbalances prevail.

Introduction

Intellectual disability is a common neurodevelopmental condition, with estimated worldwide prevalence ranging from 1.04% to 1.55% (Maulik et al., 2011; McKenzie et al., 2016). This disability has been defined as a significant impairment in both intellectual and adaptive functioning, widely affecting people's life and emerging during childhood (American Psychiatric Association, 2013). However, the World Health Organisation (n.d.) has highlighted that a person's degree of disability may also depend on how enabling or disabling their environment is, in terms of catering to the individual's additional needs. Not only does this argument contradict the medical model of disability, which claims that one's disability is a biological problem, but it also reflects our society's failure to accommodate all of its citizens (Oliver, 1996).

Being labelled as an intellectually disabled person has been found to confer a stigmatised status (Beart et al., 2005; Scior & Werner, 2016). Stigmatisation is a process by which specific groups of people are marginalised for possessing what is perceived by others as a "spoiled" identity on the basis of their non-normative personal attributes, such as race, cognitive or physical ability, or mental health status (Goffman, 1963). Importantly, the "labelling" of and discrimination towards a stigmatised group or person, deriving from stigmatising institutional/societal structures (e.g., policies that restrict one's opportunities in life) and the public's negative stereotypes and prejudices against the "labelled" party, cause loss of status and power for affected individuals (Link & Phelan, 2001; Pescosolido & Martin, 2015). This may result, for example, in individuals with intellectual disabilities being seen and treated as unable to exercise (full) control over their lives, leading to important decisions being made *for* them (Scior, 2016).

Additionally, individuals with intellectual disabilities may experience multiple other harmful consequences due to their stigmatised position in society (Scior & Werner, 2016).

These include social exclusion and economic disadvantage (Bigby & Frawley, 2010), barriers to accessing healthcare (e.g., Mencap, 2007; Scown, 2020; While & Clark, 2010), fewer employment opportunities (Li, 2004), reduced self-esteem and poor psychological health (Emerson, 2010; Szivos, 1990; Szivos-Bach, 1993), increased vulnerability to loneliness (Gilmore & Cuskelly, 2014), restriction of their fundamental freedoms and rights such as being denied the right to live independently (Scior et al., 2020), and becoming the target of hate crimes on account of their disabilities (Ditchman et al., 2016). Yet, despite these significant negative outcomes, research in the area of intellectual disability stigma has been limited (Ali et al., 2012).

Nevertheless, efforts to reduce intellectual disability stigma are now emerging at multiple levels (Werner & Scior, 2016). First, structural-level stigma change interventions, which aim to combat stigmatisation ingrained in social structures, may include the establishment of specific laws and policies. Secondly, there are interpersonal-level interventions, which focus on challenging public stigma through educating others, and through increasing their contact with intellectually disabled individuals (Freudenthal et al., 2010). Thirdly, there are familial-level interventions, which typically centre on offering information and support to families during the time of their affiliate's diagnosis. Finally, there are intrapersonal-level interventions, which endeavour to help affected individuals to manage or challenge the harmful impact of stigmatisation and reduce the risk of self-stigma (i.e., the process of internalising public stigma after is has been accepted as applicable to oneself; see e.g., Sheehan & Ali, 2016), for example via the use of psychological group work or narrative therapy (Scior & Lynggaard, 2006; Szivos & Griffiths, 1990).

Yet, the ultimate effectiveness of many of these multilevel interventions remains unclear, due to interventions lacking formal evaluation (Werner & Scior, 2016). At the intrapersonal level, there is a need to advance our understanding of how those affected respond to stigmatising encounters. One process worthy of investigation is stigma resistance, which, rather than relying solely on others to challenge stigma, may offer a means to counteract the harmful consequences of stigmatisation by placing individuals with intellectual disabilities at the centre of efforts to tackle stigma. This objective is also endorsed in a governmental report urging the NHS to improve its outcomes for this highly stigmatised population (Department of Health and Social Care, 2019).

Considering that the present research aims to investigate stigma resistance in individuals with intellectual disabilities, it is crucial to review how the process has already been explored in the wider literature. Stigma *resistance*, defined in the mental health literature as “opposition to the invasion of devaluation and discrimination” (Thoits, 2011, p. 23), differs from stigma *management*, which in the intellectual disability field is linked with i) a person hiding information about their disability (Jahoda & Markova, 2004); ii) promoting an unrealistic self-image to counteract harmful prejudices (Chen & Shu, 2012); and iii) individuals with intellectual disabilities distancing themselves from intellectually disabled peers to avoid being associated with them (Crabtree et al., 2016).

Moreover, stigma resistance may manifest in two ways (Thoits, 2011). The first involves deflecting stigmatisation cognitively (e.g., by thinking *“that’s not me*”), leading to a non-identification with the negative stereotype(s) (Thoits, 2011). Although this type of stigma resistance maintains one’s self-regard, it does not challenge deep-rooted stigma in social structures (Manago et al., 2017). The second form of stigma resistance, however, which involves challenging stigma interpersonally and structurally (e.g., through confronting stigmatisers, education, advocacy, campaigning), has been found not only to combat stigma in societal structures (Buseh & Stevens, 2007), but also to enhance a person’s self-esteem and sense of empowerment (Fenn & Scior, 2019). Stigmatised individuals may use either or both types of stigma resistance, although it is unclear what conditions promote stigma resistance in the first place (Thoits, 2011).

Further understanding of the stigma-resistance process comes from the only qualitative study thus far (Firmin et al., 2017), which researched and conceptualised stigma resistance directly from the perspective of those affected (in this instance adults with severe mental health problems, most of whom were White men). The researchers found that their participants (all active stigma resisters, which is in fact one of the study's main limitations, affecting generalisability) resisted stigma in three ways: at the personal level (e.g., questioning stigmatising thoughts, learning about their recovery and creating meaningful identities, proving people wrong); at the peer level (e.g., utilising personal experiences to help others stand up for themselves); and at the public level (e.g., educating the public, advocating for others, campaigning).

Crucially, in light of these findings, more recent research by Fenn (2018) and Cooper (2019), which involved the delivery of a psychosocial intervention designed to maximise the resilience for stigma resistance in adults with intellectual disabilities, suggested that their results could be mapped onto Firmin et al.' (2017) framework. This may imply the validity (and generalisability) of Firmin et al.' (2017) findings, although caution should be exercised when interpreting the results of Fenn's (2018) and Cooper's (2019) studies, due to limitations including small samples and the absence of a validated measure of self-stigma. That said, some of the findings of the two studies (e.g., participants advocating for self and others, educating others, sharing experiences of maltreatment with peers) are in line with the collective action that people with intellectual disabilities, who are also members of a self-advocacy group (SAG), take to tackle stigma (e.g., Anderson & Bigby, 2016; Clarke et al., 2015). Self-advocacy groups have as their core aim to empower people (through advocacy and activism) to speak up, demand their rights and challenge (and potentially change) stigmatising attitudes and structures in society (Beart et al., 2004; Fenn & Scior, 2019).

Taken together, the aforementioned body of research shows that it *is* possible to enhance the ability of people with intellectual disabilities for stigma resistance through psychosocial interventions or SAG membership. However, no empirical studies have yet explored stigma-resistance processes directly from the standpoint of individuals with intellectual disabilities in the qualitative manner utilised in previous research (i.e., Firmin et al., 2017). Not only is this important for producing new insights into how to promote well-being for individuals with intellectual disabilities, but it is also the moral duty of all those in a position of power (including researchers) to facilitate people's voices to be heard, in particular because, owing to their lived experience, intellectually disabled individuals are best positioned to be in charge of the anti-stigma agenda (Scior & Werner, 2016). Additionally, barriers to and facilitators of stigma resistance as perceived by individuals with intellectual disabilities have never been researched; therefore, this is yet another step that needs to be taken to support the efforts of this population to overcome the harmful impacts of stigmatisation. It is against this backdrop that the current research aimed to examine the objectives of (i) how self-advocates with intellectual disabilities resist stigma; and (ii) from their standpoint, what helps or hinders their efforts in doing so. Achieving these goals will help address gaps in the literature.

The decision to focus on self-advocates with intellectual disabilities was intentional. First, since "resistance is an agentic response" to discrimination (Thoits, 2011, p. 11), it is only individuals who have accepted stigmatisation as a problem applicable to themselves that would be motivated to engage in resisting it. Therefore, self-advocates were deemed the most suitable sub-group for study. Secondly, because some people have limited awareness of their stigmatised status, while yet others wish to distance themselves from the 'intellectual disability' label due to its negative connotations (see especially Logeswaran et al., 2019), raising the issue of stigma with self-advocates, who are likely already aware of discrimination experienced by individuals with intellectual disabilities, was regarded as the most ethical decision. Furthermore, the chosen sample was expected to have more support systems in place (e.g., through peers or facilitators of their SAGs), which is vital when discussing a potentially emotionally upsetting topic (Kenyon et al., 2013).

Method

Participants and recruitment

In total, 16 self-advocates, recruited between April 2020 and September 2020, participated in the research. All were aged 18 and above, used specialist services for individuals with intellectual disabilities, and were involved in a SAG across England (e.g., Greater London, Southern England, the Midlands, the Northeast and the Northwest). In order to take part in the study, self-advocates had to be able to give informed consent and engage in an interview conducted in English. Exclusion criteria were (i) current mental health difficulties, and (ii) being deemed by intermediaries (i.e., facilitators of SAG) to be at risk of finding participation too distressing. For the purpose of protecting participants' anonymity, demographic information is presented in Table 1 in broad terms.

Table 1

Demographic Data of Participants (P)

Characteristics	N	P
Total participants	16	
Gender		
Male	7	P2; P5-P6; P12-P15
Female	9	P1; P3-P4; P7-P11; P16
Age		
19-50	9	P1-P2; P4-P10
50-70	7	P3; P11-P16
Ethnicity		
White British	13	P1-P3; P5-P7; P9; P11-P16
Non-white British	3	P4; P8; P10
Geographical location		
London	1	P13
Other parts of England	15	P1-P12; P14-P16
Employment status		
In paid employment	14	P1-P5; P7-P8; P10-P16

Procedure

In order to explore the experiences of stigma resistance in the study participants with intellectual disabilities, individual semi-structured interviews were carried out. This method was chosen as it allows both focus and flexibility (unlike either fully structured or fully unstructured interviews) for in-depth sensitive information to be gathered (Bernard et al., 2016). This type of interview also gives the researcher the freedom to ask additional questions to elucidate possible interviewee responses that may have been unclear (Lyons, 2015).

The design of the interview tool was informed by the overview of the literature (see Paper 1), with an initial draft being developed through discussions with the research supervisors. The draft was finalised following a consultation with a research advisory group, composed of self-advocates with intellectual disabilities, at the Mencap Head Office in London. The final version of the interview schedule (see Appendix A) included questions about instances when the participant had stood up for themselves, and what had helped them with the process; or, conversely, what might have acted as barrier to them standing up for themselves. Moreover, advice on the design of the study was sought from colleagues within the UCL for Stigma Research Unit.

Importantly, based on the self-advocates' feedback and experience during the consultation, where some struggled to understand abstract questions, pictures of people engaged in a diverse range of activities standing up/speaking up for themselves were used during the interviews as communication aid (see Appendix B). The images were taken from Photosymbols (a picture library used for the production of Easyread information) and were selected to represent different ways of people with intellectual disabilities resisting stigma derived from previous research (Cooper, 2019; Fenn, 2018). Both the interview schedule and pictorial aids were piloted through an interview with a self-advocate. Based on their feedback, slight adaptations were made to the order of questions and the timing when pictures were presented during the interview.

In line with the purposeful and convenience sampling approach adopted in this study (Coolican, 2005), self-advocacy organisations across England were randomly chosen from a list published online (see Appendix C) and sent information about the study by email (see Appendix D). Once self-advocacy organisations had expressed interest, suitable participants were identified in discussion with group facilitators, who in turn discussed the study with potential participants. In addition, one participant made contact through online advertising on Facebook (see Appendix E for research study flyer). Following identification of potential suitable participants, an introductory meeting was arranged for the researcher to take them through the information sheet (see Appendix F), assess their capacity to consent and give them the opportunity to ask questions. A subsequent meeting followed for informed consent to be provided (see Appendix G) and the interview to be conducted. Participants were invited to have someone present at the interview to support them, if they wished (e.g., group facilitator, family member, friend).

Owning to the Covid-19 pandemic, interviews were conducted virtually. Interview questions were rephrased, when deemed necessary, to ensure that they were accessible to the participants. At the end of each interview, the researcher offered participants the chance to ask questions or add any comments. Additionally, the researcher reviewed carefully with participants how they felt about having taken part in the study, ensuring that they had space to talk about any difficult aspects that may have arisen from the interview. None of the self-advocates recruited became distressed throughout or after the interview and, overall, they all reported that they had enjoyed talking about their achievements in relation to how they stood up for themselves. All of the self-advocates were given a £10 Amazon voucher as an acknowledgement of their time and effort in participating in the study.

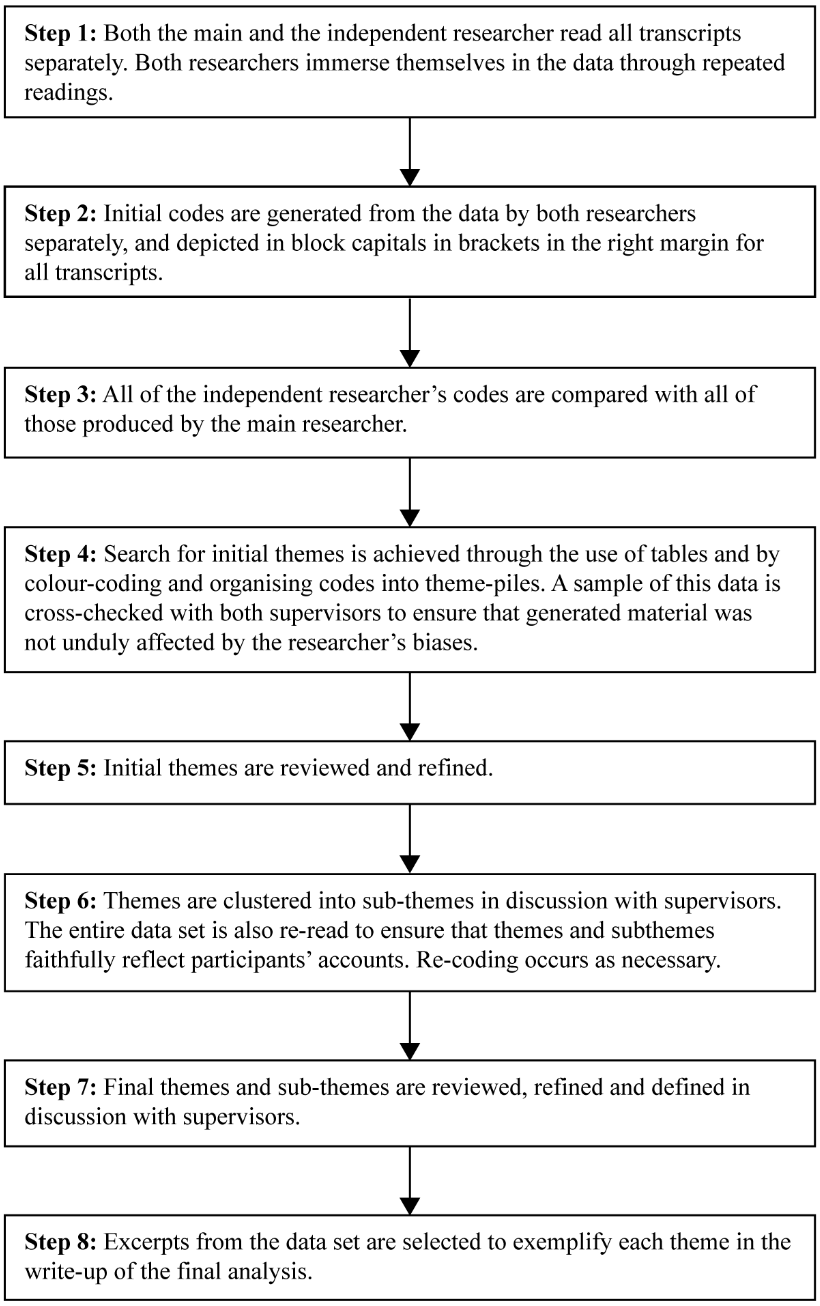
Analysis

Interviews were digitally recorded, and audio-recordings were swiftly transferred to the UCL N: drive via a password-protected memory stick. The interview recordings were transcribed verbatim using Trint (an Artificial Intelligence transcription software) and de-identified. The transcripts were analysed using thematic analysis since this method enables researchers to systematically identify, synthesise and interpret patterns of meaning (or themes) across the entirety of collected qualitative data (Braun & Clarke, 2006). Thematic analysis was preferred over other analytical approaches due to its flexible theoretical methodology and rigour (Howitt, 2019). Additionally, this method has the descriptive and interpretative capacity to capture the meaning of specific phenomena being investigated, particularly from the viewpoint of those encountering them (Braun & Clarke, 2006).

The thematic analysis process involved multiple readings of the transcripts by the main researcher, to ensure familiarisation with the data, as well as by an independent researcher (see Figure 1 and Quality Appraisal section below for more detail). Codes (i.e., a word or short expression that captures the essence of language-based data) were subsequently generated in line with recommendations for beginning qualitative researchers (Saldaña, 2016) (see Appendix H for a sample of a coded transcript). Code types included descriptive coding (i.e., using a noun to summarise a comment), in vivo coding (i.e., coding word for word), process coding (i.e., employing "-ing" words to indicate action in the material), and holistic coding (i.e., chunking data at a macro level). These were subsequently colour coded as they generated initial themes based on relatedness of meaning and prevalence (see Appendix I for thematic tables depicting this process). Codes and themes were constantly reviewed and refined to produce well-defined sub-themes and higher-order themes (see Appendices J-L for samples of these stages of analysis). The last phase of the analysis involved producing the report with chosen excerpts from the data set to represent each theme/sub-theme. Figure 1 illustrates the analytic process.

Figure 1

Diagrammatic Illustration of the Analytic Process



Step 1: Both the main and the independent researcher read all transcripts separately. Both researchers immerse themselves in the data through repeated readings.

Step 2: Initial codes are generated from the data by both researchers separately, and depicted in block capitals in brackets in the right margin for all transcripts.

Step 3: All of the independent researcher's codes are compared with all of those produced by the main researcher.

Step 4: Search for initial themes is achieved through the use of tables and by colour-coding and organising codes into theme-piles. A sample of this data is cross-checked with both supervisors to ensure that generated material was not unduly affected by the researcher's biases.

Step 5: Initial themes are reviewed and refined.

Step 6: Themes are clustered into sub-themes in discussion with supervisors. The entire data set is also re-read to ensure that themes and subthemes faithfully reflect participants' accounts. Re-coding occurs as necessary.

Step 7: Final themes and sub-themes are reviewed, refined and defined in discussion with supervisors.

Step 8: Excerpts from the data set are selected to exemplify each theme in the write-up of the final analysis.

Since the study was exploratory in nature, the method used to identify themes was an inductive one (Braun & Clarke, 2006), although the influence of theory in the design and delivery of the project cannot be denied. Moreover, the study themes were conceptualised at a semantic level (Boyatzis, 1998). This meant that the researcher interpreted the data based on what was described by participants, instead of looking for underlying meaning, an approach that also fits with the realist epistemological stance taken by the researcher (Harper, 2012).

Quality appraisal

When conducting qualitative investigations, it is useful that guidelines are adhered to in order to ensure good research practice (Elliott et al., 1999). Therefore, credibility checks were put in place (Barker & Pistrang, 2005). In line with this strategy, the trustworthiness of the study's findings was established through analyst triangulation (Patton, 2015 as cited in Candela, 2019). First, this meant that, to allow for a consensus approach, an independent researcher coded all interview transcripts separately, and their codes were compared with those produced by the main researcher. Secondly, a sample of initial codes and themes were discussed with both supervisors to establish that the generated material accurately mirrored the data and was not excessively biased by the researcher's perceptions. An extra safeguard against the researcher 'contaminating' the research process with his/her own experiences included the 'bracketing' of his/her assumptions (Fischer, 2009) (see Paper 3 for a detailed discussion on this matter). Thirdly, all themes and sub-themes were reviewed, refined and defined, again, in discussion with supervisors.

Ethical issues

Formal ethical approval for the research was granted by the UCL Research Ethics Committee (Reference Number: 17981/001; see Appendix M).

Results

Self-advocates with intellectual disabilities gave many examples of how they resist stigma, while also speaking about what facilitates or hinders their efforts in doing so. The analysis generated eight themes and 24 sub-themes, which were grouped under three superordinate domains to directly address the research questions (see Table 2). The domains, themes and sub-themes are presented below, together with verbatim interview excerpts to illustrate the narrative embedded in the data, thereby facilitating participants' voices. While curly brackets { } refer to clarifications made by the author, ellipses (…) are used where parts of transcripts have been excluded. Also, excerpts are accompanied by a capital P and a number (e.g., P4) to denote which participants said what.

Table 2

Summary of Domains, Themes and Sub-themes and their Frequency [a]

Domain	Theme	Sub-theme	Frequency
Participants' Actions in Resisting Stigma	**Asserting oneself**	Confronting/Reporting mistreatment	14
		Stating one's needs/rights	8
		Proving people wrong	6
	Speaking out	Public speaking	10
		Protesting/Campaigning	8
	Using lived experience to drive change	Educating others	11
		Supporting peers	12
		Working with others to effect change	13
	Strengthening positive identities	Taking on responsibilities	10
		Fulfilling aspirations	11
		"Putting my head up high"	8

Perceived barriers to stigma resistance	**Personal challenges**	Not understanding	8
		Not knowing how/what	11
		Internal struggles	13
		Fear of others' responses	7
	External invalidation	Negative attitudes and actions	12
		Absence of support	10
		Inaccessibility	9
Perceived facilitators of stigma resistance	**Personal growth**	Self-confidence	13
		Learning from experience	13
		Knowledge about human rights	9
		Acting in line with one's values	13
	External validation	Support from others	16
		Accessibility	11

[a] Reflects the number of participants who reported each theme and sub-theme.

Domain 1: Participants' Actions in Resisting Stigma

This domain summarises different ways in which self-advocates with intellectual disabilities described engaging in acts of stigma resistance.

Theme 1.1: Asserting oneself

Confronting mistreatment and *"putting people in their place"* (P1) was emphasised by the majority of participants as a vital step in defending oneself against the negative effects of stigmatised treatment. As one participant explained:

> *"There was a time when some boys were saying something to me, and I turned around and said grow up and act your shoe size"* (P3).

Another self-advocate stated:

> *"I had an episode with the hospital because when I went in for a procedure, they just left me there. And instead of talking to me, they were both talking over me. And I said to them, 'I am a person'. I said, 'I am the patient. You could speak to me'. But instead of speaking to me, they were speaking over me. And I don't think that's right at all"* (P16).

Self-advocates were also clear about the usefulness of <u>reporting mistreatment</u> and enlisting others' support. One participant, who experienced hospital staff as *"treating me like dirt",* stated:

> *"I used to stand up for myself when staff put me down. I used to go and tell an advocate about it*" (P14).

Similarly, a participant reported being mistreated by a support worker, adding:

> *"I didn't like it, I complained"* (P10).

Many self-advocates described the significance of <u>stating one's needs/rights</u> as part of resisting stigma. For example, one participant, referring to needing to ask for help at college, said:

> *"No, I won't do it unless someone helps me"* (P9).

Another interviewee stated:

> *"I am trying to find out about that* {benefits} *at the moment. Because me and my wife got married, we don't get carer's allowance at all"* (P15).

Six participants talked about stigma resistance within the context of <u>proving people wrong.</u> For instance, this was highlighted by the following self-advocate:

> *"My mum said I'd never hold down a full-time job, but I proved my mum wrong"* (P3).

In like manner, another participant shared:

> *"I have proved to people that I can do it. I went to the charity and spoke to somebody and said that 'I would love to do a nightclub for people with learning disabilities'. They said 'ok, find the resource, find the club, everything and we will support you'. And that's what I did"* (P15).

Theme 1.2: Speaking out

Most self-advocates emphasised public speaking as another way of tackling stigma. As an illustration, one participant reported that *"we speak out together for national forums and stuff like that"* (P4), while another added:

> *"I went to a conference and did a presentation in front of a 100 people. I'd never done that before"* (P16).

Protesting also featured in some self-advocates' accounts of stigma resistance. This is evidenced through the following declaration:

> *"We went down to London and we had two coaches and I can remember one of the coaches broke down (laughs). It wasn't the one that I was on"* (P7).

At the same time, several participants reported campaigning as a collective way of fighting stigma, e.g., through Mencap's *"Treat Me Well campaign"* (P13), as a group of people who *"are all on the same wavelength"* (P15).

Theme 1.3: Using lived experience to drive change

Educating others was described by most self-advocates as an important means of creating change. P6, for example, noted:

> "*We've talked to school groups about hate crime"*.

Equally, P13 stated:

> *"Mm-hm, we travel around the country. Speak to NHS staff".*

Further, the majority of interviewees expressed the value of supporting peers to stand up for themselves. As P5 explained:

> *"I listen to the person. And I try and get the right help for the person as well."*

Similarly, P15 shared:

> *"Because they* {other people with learning disabilities} *can learn not to… Me and my wife, we've had cold-calls. We have been called saying 'you owe this money, you owe that money'. 'No, we don't!' That's why we give people an understanding not to fall into the trap of the cold-caller."*

Nearly all self-advocates stressed the importance of working with others to effect change. To illustrate, a participant shared that the group she mentors and runs:

> *"Is a very highly mixed range of ages and of genders. We talk about things…we feedback to the board so the board can take that on and try and improve things in the outside world for them"* (P1).

In like manner, P15 stated:

> *"We speak up to the MPs... Last Wednesday, we spoke to the council about coronavirus. About how many people with learning disabilities have been affected by the coronavirus".*

Theme 1.4: Strengthening positive identities

Over half of the participants prided themselves on taking on responsibilities. For example, P10 emphatically stated:

> *"I've got three jobs and I go to college,* {which is} *something good that I can achieve".*

P14 shared likewise:

> *"I've got lots of things going on. I do advocacy work, I do research, like we are doing today and sometime, when we'll get back from this virus, I'm going to see if I can do the CTRs. It's a programme for people who are in hospital. Like myself, I have experience of hospitals".*

Most self-advocates further stressed the value of resisting stigma through fulfilling aspirations. P6, for example, shared that travelling independently was a significant objective for him:

> *"I did last Friday, when I went to my mum's new place".*

Similarly, P13, stated:

> *"I am a co-author of a book* {for people with learning disabilities}".

"Putting my head up high", and sometimes also saying *"I feel normal"* (P14), was also a crucial aspect of resisting stigma for most participants. For example, P6 stressed *"I don't believe them, no"* to draw attention to how he rejects bad things others say about him. P4 even felt confident enough to state:

> "*I don't actually tell people I have a learning difficulty…Because I have a problem with labels".*

In like manner, another self-advocate shared how she had responded to name-calling:

> *"I thought to myself 'That's not me. I am a human being, like everybody else is'"* (P6).

Domain 2: Perceived Barriers to Stigma Resistance

This domain outlines hurdles that self-advocates had faced, or were currently experiencing, when trying to resist stigma in different contexts. As the following themes and sub-themes demonstrate, these obstacles involved challenges encountered both *within* and *without* the person.

Theme 2.1: Personal challenges

Half of the interviewees gave prominence to not understanding as a common barrier to resisting stigma. P2, for instance, described with puzzled looks not quite understanding what his rights were:

> *"Well, I wouldn't know because I would just put in Google and see what happens".*

Similarly, P11 emphasised that "*reading all the questions on the form* {has been difficult}" while P13 spoke about finding it hard "*if they* {others} *are speaking too fast".*

Moreover, not knowing how to challenge stigma was another difficulty highlighted by some self-advocates. This was embedded in the following description:

> *"Probably because I didn't know how to do it"* (P2).

In a similar way, P13 put emphasis on individuals with intellectual disabilities being unaware of how to report mistreatment, e.g., *"I didn't know how to contact the Chief Executive".*

Equally, others discussed not knowing what to do as an important obstacle to resisting stigma. For example, while a few participants stated that some "{people with learning disabilities} *don't know what to say"* (P10), others were clear that "*um, finding my voice* {was hard} *because I didn't know what to do about it"* (P5).

Internal struggles included experiencing shyness or embarrassment, feeling mistrustful of others or emotionally overwhelmed, as well as not believing in oneself. For example, one participant described:

> *"But actually, having said that about wanting to be an advocate for disabled people's rights, I don't actually get very loud. Because I find it embarrassing…I'm, I'm actually a bit shy"* (P4).

In addition, P5 shared that not "*having the confidence to do it*" had got in the way of questioning things, while others reported finding it "*very hard to trust people"* (P16). Similar internal struggles were also communicated by P14:

> "*If it's something that is personal, it is difficult* {to talk about it}".

Moreover, P8, discussed in a saddened tone her efforts of *"trying to not say the wrong thing"* while P2 stated that "*sometimes they* {people with learning disabilities} *bottle it up*". These words resonate with those of P5 who cited "*getting down on yourself"* as an additional barrier.

Finally, fear of others' responses was noted in several self-advocates' descriptions of obstacles. One participant made the following poignant statement in the context of finding it hard to speak out:

> *"Partner doesn't believe this. But I do have the thing that I worry I'll get laughed at"* (P4).

Similarly, P12 emphasised:

> *"Sometimes, they* {people with learning disabilities} *might be frightened to stand up for themselves".*

Theme 2.2: External invalidation

The majority of the interviewees shared the opinion that others' negative attitudes and actions were detrimental to their efforts to resist stigmatisation. One self-advocate poignantly recalled that people used to:

> *"'Put me down'",* adding that they were telling her things *"like, 'you cannot do it' and I said 'ok'. I didn't believe in myself"* (P9).

Similarly, another participant stated:

> *"People don't think we can do anything, but we are good at something, we are. But people assume that we can't do anything"* (P7).

In addition, P14 spoke angrily about what had stopped him in the past from standing up for himself:

> *"If the support staff talked down to me. If they didn't talk to me as an adult".*

Absence of support was highlighted as a further hurdle that can render people helpless when attempting to resist stigma in different contexts (e.g., in meetings, at home). P9, for example, described the following difficulty when discussing her experiences with others:

> *"I won't be open up if I don't have support and commitment from people around me"*.

Equally, others experienced the lack of support as follows:

> *"I got family members, real family members, my sister who thinks I am not capable enough. I am. I can live by myself. It don't make sense, I want to live by myself"* (P6).

Finally, external invalidation was reported to be closely tied to inaccessibility (e.g., lack of Easyread documents, not having access to transport). In line with this barrier, P15 made the following sentiment:

> *"I got accused of something and I got arrested for no reason…And the police officer said 'oh, this is your book about your rights' and the book was so dark and wordy, I couldn't understand it. I said, 'this is no good for me'. He said 'why not? This is about your rights'. I said, 'I can't understand it, I can't read or write'. He said, 'that's not my problem'. I said, 'do you have it in Easyread?' He said 'oh, no'"*.

Domain 3: Perceived Facilitators of Stigma Resistance

This domain illustrates common enablers that had allowed participants to resist stigma, discussed by them as deriving from *within* and *without* the person.

Theme 3.1: Personal growth

Nearly every participant identified that going to, and/or working for, a SAG increased their self-confidence in challenging stigmatisation. P9, for example, explained that being part of a SAG had helped her to:

> *"Gain confidence. I am not alone, there are loads of people with my disability or similar…* {which enables} *fighting for your rights"*.

Equally, P7, described how her SAG membership had been a catalyst for finding her voice to speak up:

> "*I think when I first used to go, I was really shy, I wouldn't even talk or nothing but I'm the opposite now, they can't shut me up".*

Another participant emphasised the importance of her family in developing self-confidence:

> *"I suppose, I say I'm nervous and I'm shy, but…I've got an internal self-confidence. That I wouldn't have had if it wasn't for my family"* (P4).

The majority of the interviewees further shared how learning from experience had played a pivotal role in stigma resistance. P5, for instance, strongly voiced how his past experiences had helped him to support himself:

> *"Knowing my past experiences, because I experienced a lot in my life, and I can learn from my life experiences to know what to do".*

Similarly, P14, who stressed that "{people} *can't tell me what to do",* described that he had *"learnt over the years to get a second opinion"* in order to challenge others' negative attitudes.

For several self-advocates, having knowledge about human rights was essentially tied to the *"fight for people to have a voice"* (P16). The quote below, by the same participant, demonstrates this awareness:

> *"They* {people with learning disabilities} *are just as much entitled to go into work as other people are".*

That said, P12 emphatically clarified that individuals with intellectual disabilities will know about their rights only "*if they have read it".*

Finally, acting in line with one's values to challenge stigma was a sentiment shared by the majority of participants. P12, for example, clearly valued empowering others to stand up for themselves, as illustrated by his following assertion:

> "*I say to them, 'stick up for yourself if someone upsets you. That's what I do'. A lot of people take the mickey out of people".*

In similar fashion, P4 underlined that her desire to resist stigma came from:

> *"Kind of a little thing inside me that says you've got to do this, not just for yourself but for others".*

Theme 3.2: External validation

All participants stressed the importance of having <u>support from others</u> to challenge stigma (including self-stigma). To illustrate, one participant shared how her mother supports her before an interview:

> *"She sits with me and says and explains anything that I'm trying to explain but can't, because I do sometimes don't make any sense when I talk"* (P1).

Moreover, while P4 stated *"They* {SAG peers}, *and this is a big thing to say, but they basically saved my life*", P10 brought to the fore that *"my support worker helped me to fill the form in"* in order to report mistreatment.

Likewise, P15 proudly described how a pub owner once supported him and his wife to stand up for themselves by confronting the father of someone who had harassed them:

> *"And the landlord of the pub came and said, 'Excuse me, this couple is having a drink, they have done nothing, and your son went and asked them a rude question'".*

Lastly, most of the interviewees discussed <u>accessibility</u> (e.g., to resources, places where you can learn things) as a key facilitator of counteracting intellectual disability stigma. P5, for instance, summarised that "*you can, like, learn about your rights at college as well"*, while P12 spoke about having been given a card to hold *"up when you speak* {in meetings}*"*. Similarly, one participant talked about the importance of "*an advocacy service* {being available} *in the hospital"* (P14), while another emphasised the significance of gaining access to *"Easyread"* information (P11).

Discussion

This research aimed to explore stigma resistance in self-advocates with intellectual disabilities, a phenomenon that until now has not been studied directly from the perspective of this population. Investigating the stigma-resistance process in self-advocates entailed looking into what resistance actions they engage in, as well as what enables or hinders their efforts in doing so. The results indicate that self-advocates with intellectual disabilities resist stigmatisation in multiple ways. These include the two strategies of counteracting stigma (i.e., deflecting and challenging) previously proposed by Thoits (2011).

Additionally, the present findings suggest that barriers to stigma resistance, based on people's experiences, involve factors *within* but also *without* the person (i.e., resulting from their environment). Similarly, perceived facilitators of efforts to challenge stigma also fall under the aforementioned two categories (i.e., individual and environmental). Some of these considerations, such as people feeling empowered to speak up when they are supported, have been reported in previous literature (Cooper, 2019; Fenn, 2018; Fenn & Scior, 2019; Firmin et al., 2017; Thoits, 2011). Thus, not only do these results address a gap in the evidence base regarding the stigma resistance strategies of individuals with intellectual disabilities, but they also have implications for (i) how the factors and conditions that promote or hamper stigma resistance for this stigmatised group are better understood (Beart et al., 2005); and (ii) future steps that may be taken to support people's attempts to not be limited by the damaging effects of stigmatisation.

Summary of main findings

Evidence from the study suggests that one of the main ways in which participants engaged in stigma resistance was through asserting themselves. This involved confronting and reporting mistreatment, proving people wrong, and stating one's needs/rights. While the first two strategies echo Thoits' (2011) direct and indirect ways of challenging stigma, the third has not been previously identified in the literature. It is possible, though, that one may feel able to state what one needs or what one's rights are, when one feels empowered to do so. This idea would fit with participants' comments about their support networks having given them the confidence to stand up for themselves, which is in line with previous discussions on stigmatised individuals resisting stigma on a personal level through feeling empowered (Firmin et al., 2017). It is also worthy of note that there was a sense of gratification in participants' descriptions of proving others wrong. This is consistent with Thoits' (2011) work, which suggests that when one refutes people's stereotyped expectations, one's self-respect increases.

Previous research has shown that stigmatised individuals may resist stigma by protesting and campaigning as part of a group, as well as through speaking out individually (Cooper, 2019; Fenn, 2018; Firmin et al., 2017; Thoits, 2011). These collective and individual forms of stigma resistance were also evident in the present study. Such actions may be taken to reflect participants' motivations and shared goals to demand their rights, as well as to challenge and, ultimately, change stigmatising societal beliefs and structures, an idea also suggested in Thoits' (2011) theoretical work.

In addition, the present findings have highlighted that the participants recruited use their own experiences to drive change, a finding also reported with other stigmatised population such as individuals with mental health problems (Corrigan & Watson, 2002). This occurs through educating others, supporting peers, and working with other people to bring about change. Educating others to question negative stereotypes and challenge deep-rooted prejudices has been suggested in the current mental health and intellectual disability literature too (Cooper, 2019; Fenn, 2018; Firmin et al., 2017; Thoits, 2011). Additionally, while peer support as a stigma-resistance strategy was first indicated by Firmin et al. (2017), working with others to combat stigma fits with the idea of self-advocacy allowing for change through collective action (Brandon, 2005). All things considered, these results could be taken to suggest that self-advocacy groups are places where people with intellectual disabilities can build meaning through engaging in activities geared to reduce stigma (Clarke et al., 2015).

The fact that the current research featured participants resisting stigma through strengthening their positive identities is encouraging. Namely, the self-advocates in the present research highlighted the following elements of stigma resistance; (i) taking on responsibilities and fulfilling aspirations—akin to Thoits' (2011) and Firmin et al.'s (2017) suggestions that stigmatised individuals who hold various role-identities are better at resisting stigma than those who do not have such roles, possibly due to feeling more confident in themselves—; and (ii) not believing negative stereotypes and/or mentally challenging them, a finding also consistent with Thoits' (2011) and Firmin et al.'s (2017) deflecting strategies.

Participants' accounts illustrated that obstacles to stigma resistance involved challenges encountered both *within* and *without* the self. In terms of personal barriers, participants reported difficulties with not understanding (e.g., what their rights are or reading questions on a form) or not knowing how to counteract stigma. These results are consistent with existing literature highlighting these and other similar difficulties (e.g., individuals with intellectual disabilities having access to a reduced gamut of coping strategies) (e.g., Chen & Shu, 2012; Cunningham & Glenn, 2004; Ditchman et al., 2016; Jahoda & Markova, 2004). Additionally, participants reported obstacles concerning internal struggles or fear of others' responses. These findings are in keeping with previous studies indicating the harmful effect of stigma on self-esteem, and self/other-evaluation in individuals with intellectual disabilities (e.g., Abraham et al., 2002; Cooney et al., 2006; Dagnan & Waring, 2004; Emerson, 2010; Finlay & Lyons, 2000; Paterson et al., 2012; Szivos, 1990; Szivos-Bach, 1993). Also, these personal barriers may be linked to previous findings that experiencing stigma positively correlates with psychological distress (Ali et al., 2015). In terms of environmental obstacles, participants cited others' negative attitudes and actions, the absence of support, and inaccessibility (e.g., to Easyread materials, computers) as main contributors. These suggestions are also supported by previous literature (e.g., Dagnan et al., 2015; Ditchman et al., 2016; Tuffrey-Wijne et al., 2014).

Perceived facilitators too were attributed both to personal and environmental factors. For example, on an individual level, participants described an ongoing process of personal growth that entailed learning from one's experience, gaining knowledge about one's rights, having self-confidence, and acting in accordance with one's values. While it may be possible to map the first two components of stigma resistance onto Firmin et al.'s (2017) framework, the latter two factors might be understood in the context of people's SAG membership empowering them to take valued actions (e.g., encouraging others to speak up) (Fenn & Scior, 2019). Nevertheless, it is also likely that these components are interdependent. That is, learning from one's experience or finding out about one's rights may in turn lead to one becoming more confident, which may then result in one feeling more able to act in agreement with one's values. Thus, a virtuous, facilitatory cycle of resistance strategies may be operating.

Finally, in terms of environmental facilitators of stigma resistance, support from others (e.g., parents, partners, support workers, friends, advocacy group, healthcare professionals) and accessibility (e.g., to helpful resources) were identified. This finding may be taken to suggest the importance of enabling environments in fully facilitating the ability of individuals with intellectual disabilities to engage in anti-stigma action (Scior & Werner, 2016; WHO, n.d.).

Implications

Not only do these results confirm many stigma-resistance components identified in the existing literature (Cooper, 2019; Fenn, 2018; Firmin et al., 2017; Thoits, 2011), but they also build on it. For example, they enhance our knowledge of the range of resistance strategies individuals with intellectual disabilities may adopt, including some that have not previously been identified (e.g., stating one's needs/rights, acting in line with one's values). Additionally, the data show that most strategies employed by participants, or at least those recounted in the interviews, were behavioural in nature, rather than involving, for example, cognitive strategies such as positive self-talk. Therefore, emphasis should be placed on incorporating these new findings in the design of stigma change interventions to promote well-being for individuals with intellectual disabilities.

The data also emphasise the value of qualitative research in privileging the voices of stigmatised populations, including the current participant group (Jackson & Mazzei, 2009). Increasing these efforts through further similar studies will be particularly helpful in amplifying the multiple perspectives of individuals with intellectual disabilities, a means of honouring them as those best placed to lead the anti-stigma agenda. Crucially, these efforts might include co-research with intellectually disabled individuals, a process characterised by the *active* collaboration between members of the public/patients and researchers/academics, leading to contribution of joint input to different stages of the research process (Di Lorito et al., 2018).

Furthermore, the results provide added insight into the pivotal role of supportive networks and enabling contexts in augmenting the resilience of people with intellectual disabilities for stigma resistance. This is crucial to keep in mind since lack of support and the presence of disabling environments, mainly due to structural and public stigma, continue to remain an issue for individuals with intellectual disabilities (Scior et al., 2020; Scior & Werner, 2016).

While some previous literature has discussed the impact of stigma on people with intellectual disabilities by highlighting what they *cannot* do well, and thereby (inadvertently) privileging a narrative of *dis*-ability (e.g., Chen & Shu, 2012), the current results demonstrate that individuals with intellectual disabilities are often resilient and have many strengths. The researcher (and author) of this study was able to witness this by closely following participants' narratives. On this basis, the present study could act as a model for future research conducted to both challenge and redress society's 'thin descriptions' (White, 1997 as cited in Payne, 2006) of intellectual disability.

Limitations

The current findings need to be considered in the context of their limitations. The self-advocates in the study, most of whom were employed in self-advocacy work (14 out of 16 participants), are not a representative sub-group. In fact, only 6.6% of all intellectually disabled adults were found to be working in England between 2010 and 2011 (Emerson et al., 2012). Equally, most self-advocates were White (13 out of 16) while all participants could be described as active stigma resisters by virtue of being members of self-advocacy organisations, which typically engage people in activism and advocacy (Goodley, 2000). These sample characteristics, also noted as limitations in Firmin et al.' (2017) research, impact the transferability of current findings to other contexts/situations. Therefore, the narratives of the present sample may not represent the lived experiences of peers who: (1) are not White; (2) are not already actively involved in self-advocacy; (3) have mental health difficulties (since suffering from such problems was an exclusion criterion); or (4) present with moderate or more severe intellectual disabilities, although it is also possible that this latter cohort may resist negative attitudes and behaviours by engaging in challenging behaviour (Lloyd & Kennedy, 2014).

Furthermore, the reliability of the data may be impacted by the content of some themes/sub-themes (e.g., speaking out, educating others), which was inevitably pre-determined by the researcher's selection of pictures shown to participants. These images, representing similar stigma-resistance activity from research previously conducted by the same research team at UCL, may have acted as a detriment to the generation of other stigma-resistance actions. Equally, although the study makes assumptions of meta-cognitive understanding in participants (e.g., that one is aware of what stigma is and how it impacts on oneself, in addition to one being conscious of how one can tackle stigmatisation), it is also possible that some participants responded to the picture prompts to note the activities that: (1) they were either involved in doing as self-advocates/paid workers and/or (2) made them feel good, but not necessarily as a way of resisting stigma. This hypothesis is based on the self-advocates' consultation feedback on the interview schedule, which showed that for some people the notion of stigma/stigma resistance was too abstract to comprehend.

Having said that, investigating stigma resistance directly from the perspective of self-advocates was a strength of this research, in terms of starting to conceptualise resistance strategies in individuals with intellectual disabilities. To my knowledge, in the last fifteen years that stigma resistance has been researched, this is only the second study (after Firmin et al. 2017) to qualitatively examine the concept, directly from the standpoint of those affected by stigma. An additional strength of the research was its diverse, sufficiently large sample, recruited online (due to the pandemic) from different locations across England.

Future research

Some directions for prospective studies are indicated by the present research. First, given the absence of a theoretical model of resistance to intellectual disability stigma, it may be useful for future investigations to attempt to build such a model located in the perspective of intellectually disabled individuals. Conceptualising stigma resistance in this way could enhance our understanding of mechanisms involved in the process. Secondly, although this research explored the experiences of stigma resistance of both male and female participants, the analysis was not conducted in a manner that may reveal any similarities or differences based on gender. Therefore, it might be helpful for this aspect to be further investigated since this could have implications for the way we start to better promote each gender's capacity to resist stigma. This suggestion is made in line with previous findings, which indicated a trend according to which women with intellectual disabilities appeared to be affected by stigma to a greater degree than their male counterparts (i.e., they reported lower self-esteem than men, see especially Petrovski & Gleeson, 1997).

Thirdly, examining the views of individuals' affiliates' (e.g., SAG facilitators, family members, partners, friends) in a future study may be fruitful. Not only would this strategy enable further data triangulation, thus enhancing the credibility of the present results, but it could also yield richer, multi-perspective interpretations. Finally, although the chosen qualitative method (i.e., thematic analysis) addressed the exploratory research questions well, this approach is constrained by decontextualising individual responses (Harper, 2012). Therefore, alternative research methodologies (e.g., case study or narrative approaches) may be more useful for future studies that seek to investigate the complex phenomenon of stigma resistance within its context and as an individual 'journey' (Baxter & Jack, 2008; Harper, 2012).

Conclusions

In closing, this study offers an original contribution to the stigma-resistance literature by addressing a gap in the evidence base concerning stigma resistance in people with intellectual disabilities. While its results illustrate the many strengths of this population in counteracting stigma, it remains important that societal and institutional discrimination continue to be combated, alongside building up individual and collective resistance.

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Part 3: Critical Appraisal

Introduction

This final part of the thesis aims to engage in critical reflection regarding the overall research process. More specifically, this paper comprises (i) an overview of the main dilemmas and challenges I encountered and dealt with while conducting the empirical study; (ii) key learning points and take-home messages that fellow researchers might find helpful when doing similar research; and (iii) reflections on the personal/professional effect of the research process. The issues discussed in this section are drawn from my research journal (see Appendix N for samples of notes kept) and outlined here in chronological order.

The Research Cycle

Pre-research stage

My first dilemma centred around what topic to choose for my doctoral thesis. That said, I knew immediately that I wanted to investigate stigma resistance in individuals with intellectual disabilities when this topic came up during a supervisor research fair on the course (an event where potential supervisors speak to the whole cohort about possible projects). Four key factors motivated my decision to focus on this area of research. First, my previous four years of experience of working in clinical services within the NHS had exposed me to some of the inequalities and stigmatised treatment that people with intellectual disabilities commonly face, making me aware of how this stigmatisation may negatively affect their quality of life. To give an example, most healthcare services for people with intellectual disabilities lack reasonable adjustments, such as offering patients extra sessions or Easyread materials, to help improve patient care (Dagnan et al., 2015; Tuffrey-Wijne et al., 2014).

Secondly, by conducting a project that centred on the resilience of individuals with intellectual disabilities (i.e., how they resist stigma) I would be able to use my professional status and position as a trainee clinical psychologist at UCL to help challenge some of the negative stereotypes and deep-rooted prejudices against this group of individuals that are pervasive in society (Ali et al., 2012). These include the commonly-held belief that individuals with intellectual disabilities *cannot* attain their life goals compared to their non-disabled counterparts (Ditchman et al., 2016).

Thirdly, this project, was grounded partly in ideas and principles from liberation psychology (especially, uncovering social injustice, and encouraging people's self-determination; see e.g., Prilleltensky, 2003), which reflect both my personal and professional values. I have always been passionate about supporting and advocating for vulnerable individuals while attempting to facilitate public sensitivity to social issues. To give an example, in my role as an assistant psychologist for an intellectual disability NHS service, I supported a small group of patients to present the results of a co-produced project at a conference. This piece of work, centred on Top Tips for healthcare professionals, had been undertaken as part of improving the Trust's intellectual disability services and patient experience. Finally, both my primary and secondary supervisors are extremely experienced in, as well as committed to, conducting research on stigma around intellectual disabilities; therefore, I knew that I was in 'good hands' in terms of having access to high-quality guidance, support and supervision throughout my research journey.

The take-home message for future researchers is to try to establish a research topic that is well-supervised, but also close to one's heart. This will ensure one's sustained focus and motivation during some of the inevitably trying phases of the research process.

Research planning stage

My primary supervisor initially presented me with the choice of several intellectual disability stigma-resistance projects. While one of them was a mixed methods study, the other two were either quantitative or qualitative in nature. At the time, I felt slightly apprehensive about which of these projects to choose. This was based on a number of reasons. First, one project was attached to a larger project, which meant that some stages of the research process had already been completed (e.g., ethical approval had already been obtained). This made the project a tempting choice, especially given my status as a trainee facing multiple demands and deadlines as part of course requirements. Secondly, although I was more drawn towards the qualitative project (which is ultimately the one I ended up conducting), I had no prior experience of carrying out qualitative research, which was anxiety-provoking. However, I knew that I needed to take on a qualitative project if I was to *truly* facilitate the voices of individuals with intellectual disabilities to be heard, as opposed to speaking *for* them, which is a common occurrence in the intellectual disability clinical and research fields (Scior & Werner, 2016).

Besides, and contrary to quantitative research that is preoccupied mainly with statistics identifying trends, qualitative research is designed to encompass the human experience by privileging participants' voices and multiple perspectives (Jackson & Mazzei, 2009). Equally, I recognised that conducting this study would allow me to develop qualitative research skills of a high standard. Therefore, my take-home message for fellow researchers is to acknowledge one's own anxieties, motivations and assumptions when planning one's research; but also, to take into account one's own professional development as research can be an opportunity to grow one's skill set, as well as achieving growth on a personal level.

Another issue I became aware of, while discussing the nature of my project with other trainees, was related to their reporting of mixed views on the qualitative design of my research. While some people supported this type of methodology on the basis of its flexibility and creativity, others criticised it for not being rigorous enough, compared to quantitative research. In addition, some trainees minimised what I now appreciate is the inherently complex nature of qualitative studies, by suggesting that this type of research is 'easier' to conduct than quantitative research. Having now completed my empirical study, I can firmly state that: (i) qualitative investigations can be very rigorous, given that there are guidelines to ensure good and ethical practice with this type of research (Barker & Pistrang, 2005; Elliot et al., 1999); (ii) conducting qualitative research is a laborious undertaking and definitely *not* an 'easier' option; and (iii) following closely people's narratives in qualitative studies can be transformative for the researcher in a way that, in my experience, is not possible with quantitative research. This personal/professional aspect will be addressed fully in the final part of this paper.

In addition to choosing a project, a further inevitable challenge that I (and other trainees on the course) encountered during the research planning phase was caused by the coronavirus outbreak. Understandably, the pandemic gave rise to extreme anxiety and uncertainty in all of us regarding the viability of our research projects. I can vividly recall being overwhelmingly preoccupied with a whole spectrum of catastrophic thoughts, ranging from whether I would need to suspend data collection, to whether I would be forced to re-design my project, to the worst possibility, that of ultimately failing the course! However, by making the most of my regular supervision meetings to ensure discussion and containment of these issues, I was able to regain my thinking capacity and consider acceptable alternatives for the different stages of the research process. These included using video-meetings (e.g., Zoom) both for the recruitment and data collection phases, which, in my case, proved to be a blessing in disguise since it allowed me to recruit and interview participants from five different locations across England. This is a more positive outcome than the one expected as part of the original plan, which involved conducting face-to-face interviews with participants mainly from the Greater London area. Thus, on the basis of my experience of dealing with such a significant and entirely unforeseen crisis, I highly recommend that fellow researchers always make use of supervision to manage crises—whether small or large— effectively and ethically.

Recruitment stage

During this phase, I encountered the difficult task of having to ensure that informed consent was obtained in the most ethical manner. This issue was considered in the context of having to recruit participants online while keeping in mind that the target participant group, people with intellectual disabilities, often present with additional needs (e.g., communication difficulties). After careful discussion with my supervisory team, a strategy was agreed upon that entailed me providing several opportunities for potential suitable participants to learn about the study, a procedure that is in accordance with guidelines promoting ethical research practice (Thompson & Chambers, 2012). The opportunities in question consisted of (i) emailing self-advocacy group facilitators an information letter and accessible information sheet to share and discuss with potential participants; (ii) offering an introductory meeting to potential participants (and group facilitators, if this was deemed helpful by participants) to discuss the study and answer any questions; and (iii) arranging a subsequent meeting with the participant alone (or together with someone from their network to support them, if this was desired by participants) to obtain consent and conduct the interview.

Through this process, I learnt that offering multiple meetings to participants is an especially important means of building a mutually beneficial research relationship with them. Not only did this help the self-advocates to feel comfortable during the interview, thereby making it easier for them to talk openly about their experiences, but it also ensured that problems with acquiescence (such as a wish to please) were prevented or kept to a minimum. Acquiescence is an issue that often results from poor research relationships, rather than it being an innate behaviour of people with intellectual disabilities (Finlay, & Lyons, 2002). Therefore, my take-home message for future researchers is to carefully consider and address ongoing ethical issues when recruiting participants (for example factors affecting consent), as well as ensuring that the needs of your research sample are respected.

Another issue that arose for me during the recruitment stage was related to finding myself in the position of having to say *no* to a potential participant who had made contact via one of the self-advocacy group facilitators. What emerged during the introductory meeting with this individual was that they did not have an intellectual disability; instead, they had a different condition/diagnosis. When this issue revealed itself to me during the screening activity with them, I felt extremely uncomfortable with having to adhere to the study's inclusion and exclusion criteria and, thus, sensitively say *no*; after all, this was a research project on inclusion and the person was very keen to take part. Fortunately, noticing my personal discomfort in my countertransference helped me to handle the situation in the best possible way. This involved, first, me being radically genuine (Linehan, 1993) with the person about my concerns (i.e., openly explaining to them that I was uncertain how to proceed since they did not have an intellectual disability) and, secondly, me letting them know that I would need to speak to my supervisor about it. As a result, the person was very understanding. My main learning point from this experience was that being a gatekeeper to a research study comes with a tremendous amount of responsibility. Therefore, it is important that researchers acknowledge early on the power imbalances inherent in this role to ensure that the research has the best ethical result. Additionally, the use of supervision to discuss and work through such issues is, again, of paramount importance.

Data collection stage

During this phase of the research process, my supervisors and I discussed the importance of disclosing my perspective, as part of ensuring good practice in qualitative research (Elliot et al., 1999). This was done on the basis of the study being informed by a critical realist position (Harper, 2012). This stance was taken because it was accepted as unavoidable that my own experiences and perspectives, including those of which I may not be fully conscious, would inevitably affect the collection and analysis of the data. In other words, it was assumed that the collected data may not mirror participants' reality since they would have been subjectively filtered and constructed through my own personal lenses. More specifically, the assumptions I was likely to be holding were thought to be linked to: (i) my previous and current professional roles (i.e., as an assistant psychologist or trainee clinical psychologist working with individuals with intellectual disabilities, many of whom face stigma in their everyday lives); and (ii) my knowledge of the stigma and stigma-resistance literature. Therefore, 'bracketing' of my assumptions and perspectives was addressed in an interview with the primary supervisor at the start of the data collection phase (Fischer, 2009) (see Appendix O for a brief sample of this).

This strategy aimed to promote rigour in the research by ensuring that I was aware of, and able to critically evaluate, my position in relation to the study and its sample (Tufford & Newman, 2012). To give an example, during the bracketing interview we tried to explore some of my motivations behind wanting to do this research project. This included looking for any unacknowledged (limiting) beliefs I might have held about some of the capabilities of individuals with intellectual disabilities. This was done with the full recognition that negative attitudes towards this highly stigmatised population are not uncommon amid mainstream health professionals, which implies that nobody is immune to them, and thus we must all be actively vigilant against them (Pelleboer-Gunnink et al., 2017).

Additionally, we contemplated the potential impact on my perspective towards the poignant reality that most (if not all) intellectual disability teaching on doctoral training programmes is premised on a narrative of *dis*-ability, as opposed to a strengths-based narrative. This again demonstrates the implicitness and pervasiveness of society's negative construals of intellectual disability (Scior & Werner, 2016). Importantly, in addition to the aforementioned strategies, I attempted to safeguard against 'contaminating' the research with my own perspectives by (i) conducting the interviews in a non-leading way; (ii) collaborating with supervisors and an independent researcher as part of cross-checking the data and reviewing and defining the themes and sub-themes; and (iii) being committed to cultivating an atmosphere of personal reflexivity about all parts of the research process, in regular, transparent conversations with both supervisors and other members of the UCL for Stigma Research Unit (UCLUS). All things considered, my take-home message for fellow researchers is to always explore, openly and reflexively, one's own position in bracketing interviews early on in the research process. Also, it is vital that extra measures are put in place to ensure that the research does not become tainted by one's own perspectives and experiences. These safeguards will ensure that the aforementioned ethical dilemmas are negotiated effectively.

Another issue that I was faced with during the data collection phase was related to my increased anxiety about whether participants would be able to join our Zoom meetings for the interviews to take place. Having reflected on the matter, I realised that my thinking processes at the time had been influenced by two factors. First, while doing a literature search as part of Paper 1 of this thesis, I had come across literature that concerned the use of the internet by individuals with intellectual disabilities. Given that my study involved conducting virtual interviews, I decided to delve deeper into this subject area. As a result, I discovered that there are multiple obstacles that often hinder internet access for individuals with intellectual disabilities; for example, barriers associated with people's cognitive impairments (Chadwick et al., 2013). Consequently, I became concerned that these obstacles could potentially affect participants' ability to take part in the online research. Secondly, upon further reflection, I learnt that this worry had been exacerbated by the anxiety already caused by the pandemic.

In addition, due to the fact that at that point I had no prior experience of conducting online interviews, it is not surprising that I was beset with apprehensions and self-doubt about how virtual interviewing would in fact turn out. Following this experience, I have concluded that it is important to always remember that although some individuals with intellectual disabilities may struggle with different aspects of online research (e.g., joining virtual calls on their own), with the right support, the challenges in question can be overcome. This was in fact something that became evident throughout the interview process, where some people were able to participate fully when supported by family members, group facilitators and/or support workers. A further learning point concerns the need for one to constantly evaluate and reflect on their own internal processes (e.g., thoughts, emotions) when conducting research. This strategy is of prime importance as it is likely to help eliminate and/or overcome added barriers to good research practice, such as the researcher becoming (and remaining) overwhelmed by anxiety or self-doubt.

A final challenge I encountered during the data collection stage related to my wish to conduct effective interviews. To illustrate, one of the things I found particularly testing centred around having to hold a balance between my ‘neutral’ role as a researcher, versus the need to be empathic enough to enable participants to safely discuss their (difficult) experiences and worldviews. Although the literature emphasises the importance of researchers of being good and empathic listeners when aiming to conduct an interview skilfully (Wilkinson et al., 2004), striking this balance was in my experience not an easy undertaking. I have reflected that this was due to a number of reasons. First, my clinical training and experiences inevitably meant that I was more vulnerable to wanting to validate the participants’ difficult experiences. Although this was useful at times, in terms of communicating acceptance and understanding to participants which allowed them to open up

(Fruzzetti & Ruork, 2018), I found it cognitively and emotionally demanding to have to constantly be aware of my research role and context throughout the interview.

Secondly, I discovered that virtual interviewing presents additional difficulties in terms of maintaining professional, effective interview techniques. For example, not only was it occasionally hard to maintain eye contact with participants, but the reduced access to their body language (which would otherwise be available in a face-to-face interview) meant that I had limited means by which to gauge participants' levels of engagement and (dis)comfort, which prevented me from being able to adapt my interviewing strategy as flexibly as would be possible in a face-to-face setting. Having said that, participant feedback on the interview process was overall positive, which demonstrates that a facilitative atmosphere of safe exploration of experiences must have been established. Thus, on the basis of these reflections, my take-home message for fellow researchers, especially those who are also clinicians, is to try and keep in mind that research is not therapy; nonetheless, one can still draw on therapeutic skills and knowledge to establish and maintain an effective and empathic interview environment.

Analysis and writing up stage

During this phase, and in order to implement ethical research practices, I was committed to ensuring that my analytic evaluations of the data were grounded in the self-advocates' descriptions of stigma resistance (Thompson & Chambers, 2012). This was achieved by the continual process of reviewing and refining themes in collaboration with both of my supervisors (Braun & Clarke, 2006). However, one issue that emerged was related to the time when I was choosing participant excerpts from the data set to illustrate each theme and sub-theme. During this process, I initially noticed that I was using extracts from some participants more than others. However, this awareness subsequently motivated me to want to understand this behaviour.

After careful reflection, I reached the following conclusions. First, I wondered whether my behaviour was a parallel process of what is happening in our societies. That is, some people's voices are privileged more than others' and, as a result, some voices *do* get lost. This has implications for when one conducts research and/or works with participant groups like the current one (i.e., people with intellectual disabilities), whose members may lack good verbal communication skills and thus struggle to fully express themselves. Secondly, and perhaps due to having come to identify with the participants after the close contact I had had with them, I considered whether my initial urge to choose specific quotations was *my* way of wanting to strengthen their own fight against intellectual disability stigma. Additionally, I contemplated whether I was initially driven to be selective with quotes by an ambition to produce an 'impressive' thesis. Taking everything into account, however, I made a conscious effort to include extracts from each participant as often and as equally as possible. On that basis, the main learning point from this research phase pertains to the need for one to always conduct one's analysis as reflexively and ethically as possible, and to strive to ensure that, as far as is possible, every participant's voice is heard.

Furthermore, during this part of the research process I became increasingly aware of another issue. This was connected with a dilemma about whether to involve participants in member checking or not. This means of ensuring trustworthiness in qualitative studies usually involves the researcher confirming (or disconfirming) with the participants that his/her interpretations of views expressed in the data analysis resonate with them (Candela, 2019). Although member checking seems to have become an essential part of adding credibility and validity to qualitative research in recent years, it remains unknown how participants actually experience such a request for confirmation or disconfirmation of the interpretation of the data (Candela, 2019).

Additionally, Buchbinder (2011) has cautioned against this practice, arguing that during member checks it is possible that participants may choose to *not* disagree with the researcher due to inherent power dynamics in the relationship. If this indeed is the case, the function of member checking loses its value. Crucially, Hallett (2013 as cited in Candela, 2019) has warned that this practice could be injurious to participants who have been marginalised, as it can inadvertently put them in a position where they experience little control. For these reasons, and after careful consideration in supervision, I decided not to complete member checks with my sample. Nonetheless, in keeping with my goal of conducting responsible qualitative research with individuals with intellectual disabilities, it was agreed that the findings of the study would be shared with all participants in an accessible report (see Appendix P for this report). The main learning points arising from this complex matter include (i) the importance for researchers of not doing things tokenistically when carrying out research (i.e., engaging in specific practices for the sake of crossing off items on a to-do list), and (ii) the need to always safeguard the welfare of participants.

Personal and Professional Impact of the Research Process

I believe that the current project has been transformational for me in various ways. On a personal level, I have found it deeply moving to hear about the considerable achievements of the self-advocates with intellectual disabilities who I interviewed. In fact, there were many times during the interview process when I thought “Gosh, what this person is doing is incredible!”. Moreover, not only was it inspiring to follow closely people’s actions in resisting stigmatisation and in changing things for the better for themselves and others, but it was also humbling. Consequently, I have been left with a strengthened sense of determination to continue fighting for the things that are important to me too. One area of my life to which I have applied my strengthened resolve is the writing-up of this thesis. To explain more, every time I came across a barrier (e.g., losing motivation or doubting myself), I brought to mind my participants' unwavering commitment to their goals, and their determination to put in the effort necessary to achieve them. This memory has been immensely useful in keeping me going, and I will treasure it always.

On a professional level, the current research has been enriching in the following ways. First, I feel more committed to continuing to expose social injustice because I am now convinced that unless this is also supported by people in positions of power (such as NHS clinical commissioners, healthcare professionals), oppression will not end. Secondly, having witnessed my participants' resilience, through listening to their empowering narratives of stigma resistance, I am now determined on adopting a strengths-based approach when offering psychological assessment and treatment in clinical practice. Such an approach honours and builds on people's strengths, promoting self-determination and hope for the future (Anderson & Heyne, 2013). Thirdly, having completed a literature review on the psychological effect of stigmatisation on intellectually disabled people has increased my knowledge of what areas I would need to pay more attention to, when designing effective anti-stigma interventions to promote well-being (Werner & Scior, 2016).

Fourthly, hearing about the collaborative efforts of self-advocates in working with each other (as well as with their networks) to challenge stigma, I have come to appreciate the meaning of the old saying that 'one swallow does not make a summer'. This means that as I am transitioning into a newly qualified clinical psychologist post soon, I will need to carefully consider how to best work with others to create positive change both for clients and their affiliates (e.g., family members, partners, friends). Fifthly, using pictures to enable participants to articulate their thoughts and feelings, has strengthened my conviction regarding the importance of utilising reasonable adjustments to increase the quality and quantity of information provided by intellectually disabled individuals. This is a strategy that

I will continue to adopt, as well as promote, as part of my clinical practice too. Finally, I have learnt to be open to the transformative impact of research, which one may not experience if one is deficit-focused when conducting one's research. In other words, this study has made me reflect that if I had set out to understand what self-advocates *cannot* do, then this would be the data that this project would have elicited. However, since making, what I now appreciate to be, the critical decision to focus on people's strengths (i.e., their resistance to intellectual disability stigma), I have discovered an entirely different narrative.

Conclusions

To sum up, this project entailed numerous challenges and dilemmas throughout the research process. However, it was an extremely worthwhile study, given the necessity of advancing our understanding of how to promote well-being for individuals with intellectual disabilities facing increased levels of stigma. Importantly, this research study has demonstrated the need for those in positions of power (including researchers) to continue to amplify the voices of people with intellectual disabilities. Not only is this vital as such individuals are the people best placed to lead the anti-stigma agenda, but it also is the ethical and respectful thing to do, a means of honouring the strength and determination of people who face stigma and its negative consequences throughout their lives.

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Appendices

Appendix A: Interview schedule

RESEARCH DEPARTMENT OF CLINICAL, EDUCATIONAL AND HEALTH PSYCHOLOGY

Semi-Structured Interview Guide for Perceptions on Stigma Resistance

Tell me a bit about your group (say name of group)

- How long coming?
- How found out?
- Why joined?
- Why do you like being part of the group?

Do you think having a learning disability (LD) changes the way people think about or behave towards you?

- Have people treated you nicely because you have an LD?
- Has anyone been nasty to you because you have an LD?
- Have you ever been (or felt) excluded from things because you have an LD? (Weren't able to be part of something/to join in something?)
- How did that make you feel?

I am now interested in times when PWLD Stand Up for Themselves. (When they don't put up with people being nasty; When they don't put up with being left out).

There are different things people can do to stand up for themselves. I have got some pictures where people do all sorts of things to stand up for themselves.

Introduce pictures via screen share on Zoom (e.g., let's see what these pictures are).
Have you done anything like this to stand up for yourself?
What about this/that? How do you feel about this/that?

Prompts: What happened? What gave you the confidence to do that? What/who helped you to do that? **What was easy/difficult about it?** What about people you know? Have they done anything like that? Is this something you would like to do? **What would be easy/difficult about it?** What would you do if that happened to you?

What has stopped you from Standing Up/Speaking Up for Yourself in the past?
What could have helped you? (skills, friends, supporters, things you know, carers, group, experience)

Have you ever Stood Up/Spoken Up for other PWLD?

- (if yes) What gave you the confidence to do that? (something about you, things you know, friends, supporters, carers, group, experience)
- (if no) What stopped you from doing that?

What advice can you give to other people with an LD about how to Stand Up/Speak UP for Themselves? (things people can do themselves, or what other help they could get)

- Have you shared any of this with others?
- (If yes), what did you do? What was that like for you? How did they respond?
- (If no), what's stopped you from sharing any of this with others? what could you have done?

Is there anything else about Standing Up for Yourself you would like to talk about?

How did you feel today talking about those things? Was anything difficult or upsetting from the things we talked about?
(If so, talk about it with them there and/or identify further support, e.g., where can they go)

Appendix B: Pictures used as communication tool during interviews

Picture 1: Questioning or not believing bad things others say about you

Picture 2: Proving people wrong through achieving things

Picture 3: Finding out about your rights

Picture 4: Supporting other people with learning disabilities to have their say

Picture 5: Helping other people with learning disabilities by sharing your own experiences

Picture 6: Working with your peers to speak out and change things

Picture 7: Talking openly about people with learning disabilities being treated differently

Picture 8: Educating others about learning disabilities

Picture 9: Demanding your rights

Appendix C: List of self-advocacy organisations in England

List of English self-advocacy organisations, as of December 2018

Prepared by Barod Community Interest Company and Jan Walmsley Associates

Held by Learning Disability England

This list was compiled in November/December 2018 by Barod Community Interest Company and Jan Walmsley Associates as part of a RTR funded research project.

The list was compiled by:

- Searching the internet
- Checking social media
- Asking our reference group to check the list and suggest additional organisations

Organisations are included on the list if, in our best judgement, they are:

- A self advocacy organisation (ie an organisation set up by and for people with learning disabilities for the purpose of self advocacy) or
- An organisation that supports/hosts a semi-independent self advocacy group run by people

Inclusion on the list does not mean we endorse them.

We have not included anything that, in our best judgement, is:

- a time-limited project
- an opportunity for self-advocacy that is set up and/or run by a service provider or statutory agency, unless there is a clear statement on their website that the group is controlled by people with learning disabilities

We had to make decisions about which organisations met our criteria. We did not always agree among ourselves. We have left a lot of good organisations and projects off the list because they did not fit the definitions we have used.

We have not gained consent from organisations to be on this list. This means that under GDPR we can only provide a non-personal work email address. Where this is not available, we have included a link to the organisation’s website or social media account.

Contact details were correct on 20th December 2018.

Name	Contact
ACE Anglia	info@aceanglia.com
Advocacy Focus (ask for SAIL, Self Advocacy in Lancashire)	admin@advocacyfocus.org.uk
Advocacy for All (formerly People 1st Norwich)	info@advocacyforall.org.uk
Advocacy in Greenwich (People's Parliament and other self advocacy networks)	mps@advocacyingreenwich.org.uk
Aspergers Voice	aspergersvoice@gmail.com
Better Days	betterdaysolol@hotmail.com
Better Things	wearebetterthings@gmail.com
Bournemouth People First	speakingup@bournemouthpeoplefirst.co.uk
Bradford People First	office@bradfordpeoplefirst.org.uk
Brighton & Hove Speak Out	info@bhspeakout.org.uk
Bromley Sparks	sparks@advocacyforall.org.uk
Brothers of Charity	info@brothersofcharity.org.uk
Bury People First	admin@burypeoplefirst.co.uk
Calderdale Self Advocacy Network	enquiries@cloverleaf-advocacy.co.uk
Camden People First	info@camdenpeoplefirst.co.uk
Canterbury Day Opportunity Services Self Advocacy	https://www.freewebs.com/candos/

Central England People First	cepfnorthants@gmail.com
CHANGE	info@changepeople.org
Changing Our Lives	ask@changingourlives.org
CLASP Wokingham	admin@claspwokingham.org.uk
Cloverleaf Advocacy	enquiries@cloverleaf-advocacy.co.uk
Comet Group Malvern	info@cometgroup.org.uk
Croydon People First	info@croydonpeoplefirst.org.uk
Darlington Association on Disability	mail@darlingtondisability.org
Darlington People's Parliament	parliament@darlingtondisability.org
Devon Link Up	referralsdlup@gmail.com
Devon People First	devonpeoplefirst.121@gmail.com
Doncaster Advocacy	doncaster@voiceability.org
Dudley Voices for Choice	ask@dudleyvoicesforchoice.org.uk
Ealing Power Group	https://www.facebook.com/pg/ealing.power.group/about/?ref=page_internal
East Lancashire People First	No current contact details
Elfrida Society	elfrida@elfrida.com
Equal People Network	mail@yvc.org.uk
Erya (grew from Cornwall People First)	info@erya.co.uk
Future Visions Self Advocacy Group	projectofficer@ourfuturevisions.org
Gateshead People	gatesheadpeople@gmail.com
Gateway Into the Community	gatewayintothecommunity@btconnect.com

Grapevine Self Advocacy Project	admin@grapevinecoventryandwarwickshire.co.uk
Hackney People First	peoplefirsthackney@btconnect.com
Hackney Self Advocacy Support Group	pohwer@pohwer.net
Halton Speak Out	http://www.haltonspeakout.co.uk/contact-us/
Herts People First	admin@hertspeoplefirst.org
Inclusion Barnet (Ask for People's Choice)	info@inclusionbarnet.org.uk
It's My Life	info@webcas.org.uk
Just Advocacy Hampshire	info@hampshireadvocacy.org.uk
Knowsley Disability Concern, The BIG Group	https://www.kdc.org.uk/being-involved-group/
Leeds People First	manager@leep1.co.uk
Lewisham Speaking Up	info@lsup.org.uk
Louder Voice (Twitter/media group)	https://twitter.com/voice_louder?lang=en-gb
Manchester People First	mcrpeoplefirst@googlemail.com
Mid Sussex Speak Up	midsussexspeakup@googlemail.com
My Life My Choice	https://www.mylifemychoice.org.uk/pages/3-contact-us
New Ideas Advocacy	info@newideasadvocacy.org.uk
Newham People First	newhampeoplefirst@lycos.com
North Kent Independent Advocacy Scheme	http://nkias.co.uk/dpg/
North Somerset People First	enquiries.nspf@yahoo.co.uk
North Yorkshire Advocacy	admin@nyadvocacy.org

Northamptonshire People First	cepfnorthants@gmail.com
One Voice Advocacy Service	mail@1voice.org.uk
Opening Doors (formerly People 1st Norwich)	admin@openingdoors.org.uk
Our Vision Our Future	ourvision_ourfuture@yahoo.co.uk
Our Way	ourwayselfadvocacy@gmail.com
People Come First	https://www.hellohorsham.co.uk/event/People-Come-First
People First Cumbria	admin@peoplefirstcumbria.co.uk
People First Dorset	office@peoplefirstdorset.org.uk
People First Keighley & Craven	admin@peoplefirstkc.com
People First Limited	info@peoplefirstltd.com
People First Merseyside	info@peoplefirst.uk.com
People First Tameside	speakup@pftameside.org
Plymouth People First	admin@plymouthhighburytrust.org.uk
Poole Forum (Also known as People First Forum)	office@pooleforum.co.uk
Reach (at Asist)	enquiries@asist.co.uk
REACT (Catholic Caring Services)	info@caritascare.org.uk
Safety Net - People First	safetynetpeoplefirst14@gmail.com
SEAP (Ask about Bracknell Forest Inclusion Group, Be Heard and It's My Life)	info@seap.org.uk

SelfAdvocacyInAction	selfad93@yahoo.co.uk
Sheffield Voices	info@disabilitysheffield.org.uk
Skills for People	information@skillsforpeople.org.uk
Solihull Action Through Advocacy	office@solihulladvocacy.org.uk
Speak Up	team@speakup.org.uk
Speak Up Sutton	speakupsutton@voiceability.org
Speakeasy Advocacy	hello@speakeasyadvocacy.org.uk
Speakeasy NOW	mail@speakeasynow.org.uk
Speakout Hounslow	info@speakoutinhounslow.org
Speak Out Brighton and Hove	info@bhspeakout.org.uk
Splinter Group North	info@wafflingon.uk
Stockport Speaking Out Group	info@stockportadvocacy.co.uk
Suffolk People First	info@aceanglia.com
Sunderland People First	http://sunderlandpeoplefirst.com/contact-us/
Surrey Self Advocacy Network	info@kag.org.uk
SUSO Parachute	admin@maccsuso.org.uk
Swan Advocacy	reception@swanadvocacy.org.uk
Taking Part Shropshire	takingpart@takingpart.co.uk
Talkback	talkback@talkback-uk.com
Together All Are Able	toaaa@outlook.com
United Voices	enquiries@united-voices.co.uk
Warrington Speak Up	info@warringtonspeakup.org
West Berkshire Advocacy	info@webcas.org.uk
West Norfolk Self advocacy	http://westnorfolkselfadvocacy.blogspot.com/
Wigan and Leigh People First	info@wlpf.org.uk

Wiltshire People First	enquiries@wiltshirepeople1st.org.uk
Worthing SpeakAbout	https://worthingspeakabout.wordpress.com/contact-us/
York People First	yorkpeoplefirst@talktalkbusiness.net
Your Voice Counts	https://www.yvc.org.uk/contact

Appendix D: Letter to group facilitators/self-advocacy organisations

Dear____________ <*name of facilitator*>,

Re: '*Exploring the experiences of self-advocates with learning disabilities in challenging or resisting stigma'* – a research study

We are researchers from UCL Unit of Stigma Research and writing to ask for your help. However, given the current context we understand that this might be a difficult ask for you and although we would not want to add to your burden, we would be extremely grateful if you would consider supporting us in the following way.

About the research

We are keen to invite members of your local advocacy group to consider taking part in this research. The main aim of the study is to investigate how self-advocates with learning disabilities respond in different situations when they feel they are treated unfairly by others, and what they may do when trying to stand up for themselves. We hope to add to existing research evidence on different ways in which people with learning disabilities resist stigma, including actions that some individuals and groups engage with, and others can perhaps learn from. Ultimately, we hope this will help advance our understanding of how to promote well-being and support people with learning disabilities in not being limited or held back by others' negative attitudes and actions. In addition, we anticipate that participants may find it helpful to tell the researcher about times when they have attempted or succeeded in standing time up for themselves.

How people can participate

In light of current social distancing measures due to the coronavirus pandemic, at present we are unable to meet participants in person. Until such time that we can meet research participants in person, we will talk to (potential) participants via on-line platforms (e.g., Zoom, Skype, Microsoft Teams). Taking part in the project will involve an initial video or phone call with the main researcher (Nikos Sarras) to allow those who may be interested in taking part to hear more about the study, have their questions answered, and get to know Nikos a bit. Next, a video call will be arranged to obtain consent and to carry out an interview about experiences of standing up for themselves. Participants will be given the choice on each occasion to invite someone to join them for all or part of the meeting to offer support. They will be offered a £10 retail voucher to thank them for their time and effort in taking part in the research.

The help we need from you

We are writing to ask for your support in identifying individuals who may be interested in taking part. To be suitable to take part, they will need to:

- Be aged 18 and above and able to engage in an interview conducted in English;

- Have a learning disability (they will use specialist services for people with learning disabilities);
- Be involved in a self-advocacy group;
- Be able to give informed consent to participating in the study;

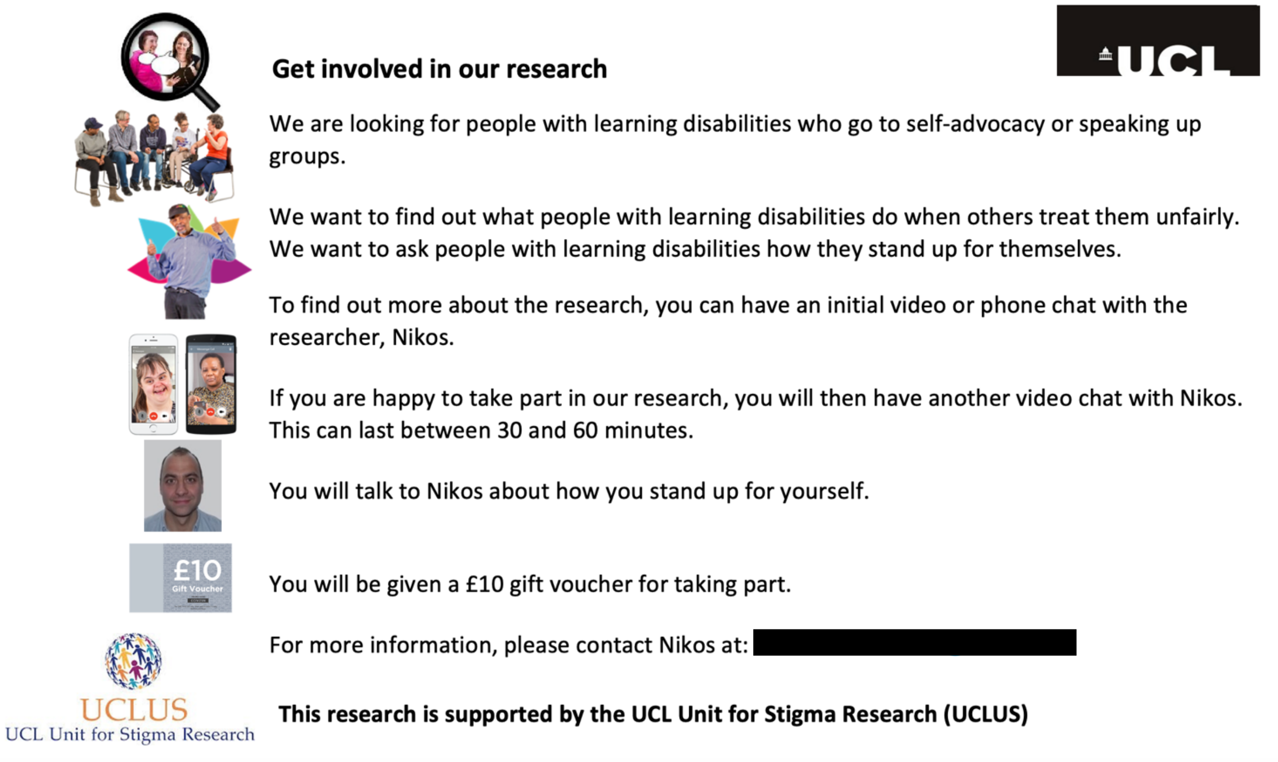
If any of the members of your local self-advocacy group might be interested, we would be extremely grateful if you could tell them about the study and share the EasyRead information sheet with them. Please contact us by email or ask the person to contact us if they may be interested in taking part:[redacted]
Also, please feel free to get in touch if you have any further questions.
This study has been given ethical clearance by the UCL Research Ethics Committee under reference *17981/001*. It is being conducted by Nikolaos Sarras as part of a Professional Doctorate in Clinical Psychology at UCL. The study is supervised by Katrina Scior and Lisa Richardson.

Please find enclosed a flyer and information sheet for potential participants, to share with those who may be interested.

Yours sincerely,

Nikolaos (Nikos) Sarras, Lisa Richardson and Katrina Scior

Appendix E: Research study recruitment flyer



Get involved in our research

We are looking for people with learning disabilities who go to self-advocacy or speaking up groups.

We want to find out what people with learning disabilities do when others treat them unfairly. We want to ask people with learning disabilities how they stand up for themselves.

To find out more about the research, you can have an initial video or phone chat with the researcher, Nikos.

If you are happy to take part in our research, you will then have another video chat with Nikos. This can last between 30 and 60 minutes.

You will talk to Nikos about how you stand up for yourself.

You will be given a £10 gift voucher for taking part.

For more information, please contact Nikos at: [redacted]

This research is supported by the UCL Unit for Stigma Research (UCLUS)

Appendix F: Participant information sheet

Information about this research

You can ask someone you know to help you read this letter .

Research means finding out about things.

My name is Nikos Sarras and I am doing this research.

I am from University College London.

You can contact me:

Nikos Sarras

Project Lead

[redacted]

Why I am doing this research

Some people with learning disabilities feel bad because of how others think of them or behave towards them.

I want to find out what people with learning disabilities do when others treat them unfairly.

I want to find out what gives them the confidence to stand up for themselves.

I also want to find out what makes it difficult to stand up for themselves.

We are asking you to take part

This is because you go to a self-advocacy or speaking up group for people with learning disabilities.

This letter will give you information about the research and what we will ask you to do if you want to take part.

You can talk about it with other people like your family and friends if you want.

What will happen if you would like take part

We will have an initial meeting by video or phone. You can ask me any questions about the research.

If you are happy to take part in the research, we will arrange a second video meeting.

I will then ask you questions about how you stand up for yourself.

Our meetings will be between 30 and 60 minutes long.

What we talk about will be recorded to help us with the research.

Choosing to take part in research

You can choose if you want to take part in the research.

It’s up to you.

You can say **no**.

If you say **yes** to the research, I will ask you to sign a consent form.

This consent form says that you agree to part in the research.

Changing your decision

You can stop taking part in the research at any time.
You don't have to tell us why.
If you choose to stop, I will not use anything that you will have told me.

What we do with your information

Your answers to questions the researcher asks will be confidential.

That means we don't show or tell your answers to anyone who is not working in the research team.

If you tell us something that makes us worry about you or someone else's safety, we may need to tell someone. This is to keep you and others safe.

My supervisor and I will listen to the recording.

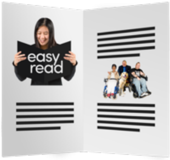
After our meeting I will type what we have said word for word. This is called a transcript. Once I have typed up our conversation, I will destroy the recording.

Where I keep your answers

I will keep your answers in a locked place on a computer.

The computer will use passwords to keep your answers safe. Your name will not be stored with your answers.

If you wish to know, I will let you know what the research found when it is finished. I will not use your name in my report.



If you wish to have a copy, I can send you an easy read report.

Good things about taking part

You might enjoy talking about your achievements or your group.

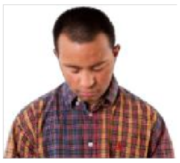
You will be given a £10 Amazon voucher for your time answering questions and to say thank you for taking part.

If you like, the researcher can contact you again to discuss the findings of the research.

What we find out might help you and other people with learning disabilities.

In past research many people have found it helpful to talk about their experiences to someone.

Things that might be difficult



Some questions might be difficult or make you feel sad.

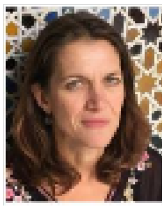
I will make sure that we have time at the end to talk about anything difficult or sad.

You can stop the meeting at any time.

How to make a complaint

If there is a problem, you can speak to me first and I will try and help.

If you are still unhappy, you can talk to my research supervisor, Dr Katrina Scior. Here are her contact details:

	Dr Katrina Scior Research Supervisor
[redacted]	

We will tell you when we think the problem has been fixed.

DATA PROTECTION POLICY UCL

** The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk

This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice:

For participants in health and care research studies, click here: https://www.ucl.ac.uk/legal-services/privacy/ucl-general-privacy-noticeparticipants-and-researchers-health-and-care-research-studies

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the 'local' and 'general' privacy notices.

The lawful basis that will be used to process your personal data are: 'Public task' for personal data and 'for research purposes' for special category data.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

If I have questions or concerns about data protection, and other UCL Privacy Notices, who can I ask?

You can read about it on –: https://www.ucl.ac.uk/legal-services/privacy/participants-health-and-care-research-privacy-notice and https://www.ucl.ac.uk/legal-services/privacy and get the details of your rights at: https://ico.org.uk/for-organisations/data-protection-reform/overview-ofthe-gdpr/individuals-rights/

Ask the UCL Data Protection Officer: **Alexandra Potts**

CONTACT DETAILS: data-protection@ucl.ac.uk

Please ask me any questions about DATA Protection, and other UCL Privacy Notices, and I will try to help you.

Appendix G: Participant consent form

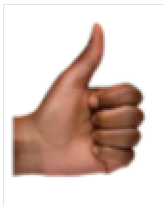
Interview Consent Form

Please tick the box if your answer is ‘Yes’.

1. Have you read the information letter or has it been read to you? ☐

2. Do you understand what happens if you take part? ☐

3. Do you understand the good things about taking part? ☐



4. Do you understand what might be difficult about taking part? ☐

5. Have you asked all the questions you want?

6. Were your questions answered in a way you understand? ☐

7. Do you understand that it is OK to stop at any time? ☐

8. Do you understand the interview will be recorded? ☐

☐

9. Do you understand what will happen to the recordings after the interview?

10. Do you understand that what you say will be kept safe?

☐

11. Have you had time to think about if you want to take part?

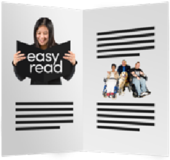
☐

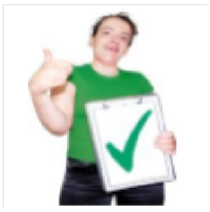
12. Are you happy for the researcher to contact you to discuss the findings of the research?

☐

13. Would you like to have an easy read report with the findings of the study?

☐





14. Are you happy to take part in an interview?

☐

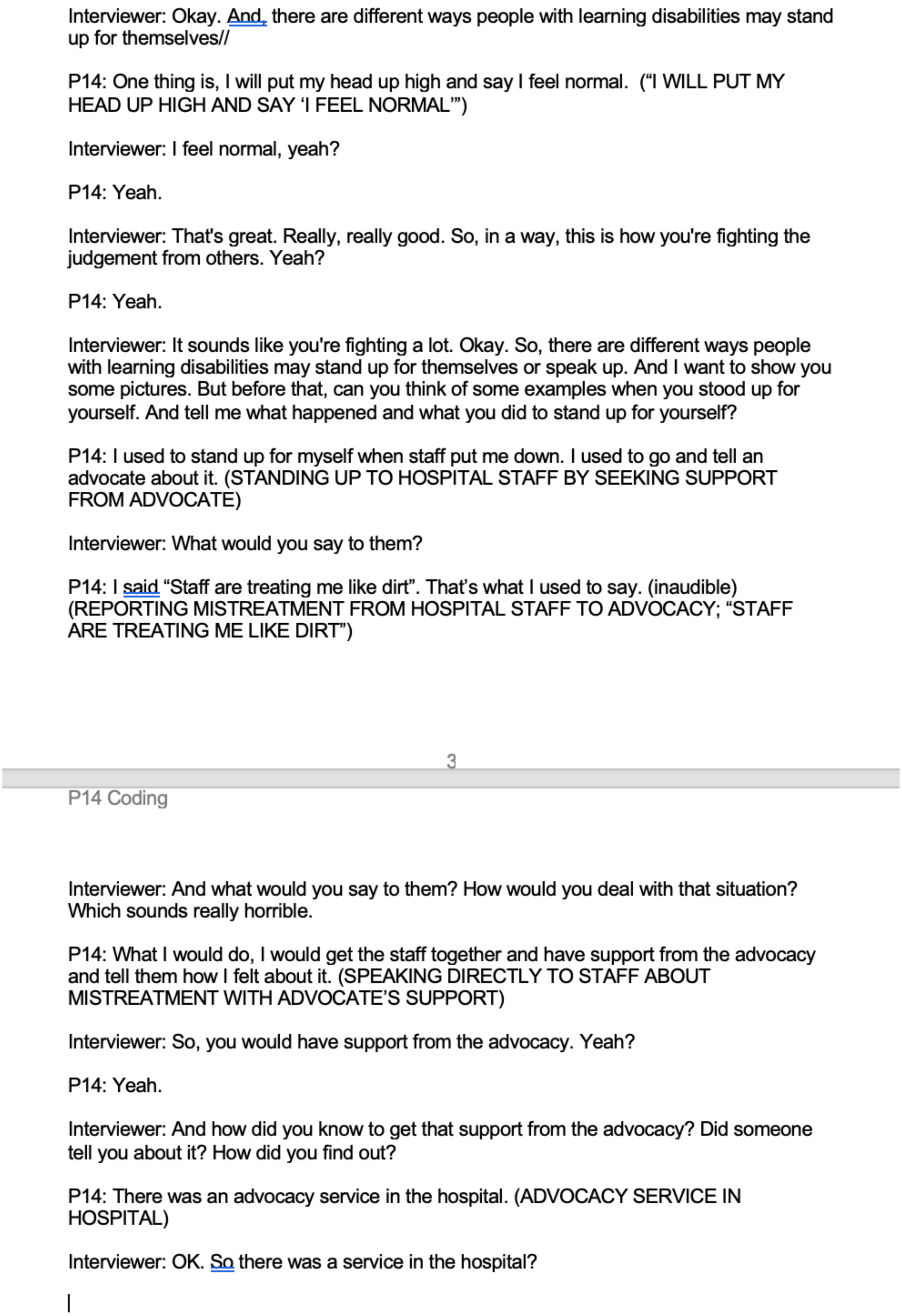
If you want to take part, please sign below:

Name: ____

Signature: ____ Date: ____

If you don’t want to take part, you don’t have to sign.

Appendix H: Example of a coded interview transcript. N.B. Initial codes are depicted in block capitals in brackets in the right margin for all transcripts



Interviewer: Okay. And, there are different ways people with learning disabilities may stand up for themselves//

P14: One thing is, I will put my head up high and say I feel normal. (“I WILL PUT MY HEAD UP HIGH AND SAY ‘I FEEL NORMAL’”)

Interviewer: I feel normal, yeah?

P14: Yeah.

Interviewer: That's great. Really, really good. So, in a way, this is how you're fighting the judgement from others. Yeah?

P14: Yeah.

Interviewer: It sounds like you're fighting a lot. Okay. So, there are different ways people with learning disabilities may stand up for themselves or speak up. And I want to show you some pictures. But before that, can you think of some examples when you stood up for yourself. And tell me what happened and what you did to stand up for yourself?

P14: I used to stand up for myself when staff put me down. I used to go and tell an advocate about it. (STANDING UP TO HOSPITAL STAFF BY SEEKING SUPPORT FROM ADVOCATE)

Interviewer: What would you say to them?

P14: I said “Staff are treating me like dirt”. That’s what I used to say. (inaudible) (REPORTING MISTREATMENT FROM HOSPITAL STAFF TO ADVOCACY; “STAFF ARE TREATING ME LIKE DIRT”)

3

P14 Coding

Interviewer: And what would you say to them? How would you deal with that situation? Which sounds really horrible.

P14: What I would do, I would get the staff together and have support from the advocacy and tell them how I felt about it. (SPEAKING DIRECTLY TO STAFF ABOUT MISTREATMENT WITH ADVOCATE’S SUPPORT)

Interviewer: So, you would have support from the advocacy. Yeah?

P14: Yeah.

Interviewer: And how did you know to get that support from the advocacy? Did someone tell you about it? How did you find out?

P14: There was an advocacy service in the hospital. (ADVOCACY SERVICE IN HOSPITAL)

Interviewer: OK. So there was a service in the hospital?

Appendix I: Thematic tables depicting the search for initial themes across all coded and collated data, forming part of Step 4 of the thematic analysis

Achieving things/having responsibilities
Working with others to change things
Asserting myself
Proving people wrong
Not believing what others say about me/believing in myself
Speaking out
Educating others
Supporting others
Sharing own experiences with peers
Protesting/Campaigning

WHAT PARTICIPANTS DID TO RESIST STIGMA

PARTICIPANT 1	**PARTICIPANT 2**	**PARTICIPANT 3**	**PARTICIPANT 4**
• DISCUSSING ISSUES WITH PEERS AND FEEDING BACK TO PEOPLE THAT CAN HELP E.G., BOARD MEMBERS (II • ASSERTING MYSELF (E.G., INFORMING THE EMPLOYER THAT I HAVE A DISABILITY AND ASKING FOR REASONABLE ADJUSTMENTS PUTTING PEOPLE IN THEIR PLACE; CONFRONTING PEOPLE'S MISTREATRMENT AND ASKING THEM TO STOP IT) • PROVING PEOPLE WRONG • HAVING MULTIPLE JOBS (II • RUNNING A SELF-ADVOCACY GROUP • PROTESTING • EDUCATING PROFESSIONALS (II	• BELIEVING IN MYSELF • TRYING TO ACHIEVE THINGS • DISCUSSING THINGS AT PEOPLE'S PARLIAMENT	• JOINED SELF-ADVOCACY GROUP • SHARING ONE'S OWN EXPERIENCES WITH GROUP OTHER MEMBERS • VERBALLY CONFRONTING ABUSIVE BEHAVIOUR FROM OTHERS (II • ACHIEVING THINGS • HAVING A JOB AND PROVING PEOPLE WRONG • SPEAKING OUT • SPEAKING OUT ABOUT PEOPLE WITH LEARNING DISABILITIES BEING TREATED DIFFERENTLY • EDUCATING OTHERS	• NOT BELIEVING HAVING A LEARNING DISABILITY • WANTING TO PROVE PEOPLE WRONG • SPEAKING OUT AT NATIONAL FORUMS • DOING A COMPETITIVE SPORT • BELIEVING THAT HAVING A LEARNING DISABILITY DOESN'T DEFINE WHO YOU ARE • SPEAKING OUT FOR A FRIEND WHO RECEIVED MISTREATMENT
PARTICIPANT 5	**PARTICIPANT 6**	**PARTICIPANT 7**	**PARTICIPANT 8**
• QUESTIONING MISTRETAMENT • LISTENING AND HELPING OTHERS WITH LEARNING DISABILITY • SPEAKING AT MEETINGS AND CONFERENCES • EDUCATING HEALTH CARE PROFESSIONALS • SHARING EXPIERENCES WITH OTHERS	• WANTING TO LIVE INDEPENDENTLY • TRAVELLING INDEPENDENTLY • REFUSED SUPPORTED LIVING • SPEAKING OUT AT CONFERENCES/IN FRONT OF LARGE GROUPS OF PEOPLE • WANTING TO CONVINCE FAMILY THAT I CAN LIVE INDEPENDENTLY • NOT BELIEVING WHAT OTHERS SAY ABOUT ME • BEING A TRUSTEE OF THE SELF-ADVOCACY GROUP • GOING TO PEOPLE'S PARLIAMENT	• BEING A TREASURER FOR SELF-ADVOCACY GROUP; HAVING RESPONSIBILITY • MONITORING HOSPITALS' DISABILITY SUPPORT • HAVING MULTIPLE RESPONSIBILIES/JOBS • DOING THINGS FOR THE CC • WALKING AWAY • CHOOSING TO NOT RESPOND TO MISTREATMENT • EDUCATING HOSPITAL STAFF	• BEING EDUCATED ON RELATIONSHIP AND HEALTH ISSUES AS PART OF GROUP WORKSHOPS • IGNORING BULLYING/TRYING TO BLOCK IT OUT (II • WALKING AWAY • EXPLAINING MY POSITION TO HOUSING OFFICER; ASSERTING MYSELF • SPEAKING MY MIND • REPRESENTING GREAT BRITAIN IN SPECIAL OLYMPICS

	• EDUCATING PROFESSIONALS (E.G., POLICE) • SPEAKING OUT IN SCHOOLS ABOUT HATE CRIME • WRITTING WITH OTHERS TO MPs • TALKING TO LOCAL COUNCIL	• REPORTING MISTREATMENT • ASSERTING ONESELF (E.G., SAYING TO PEOPLE THAT I DON'T LIKE WHAT THEY SAID/THAT IT'S NOT NICE) • NOT PAYING ATTENTION TO BULLIES • PUBLIC SPEAKING • SHARING EXPERIECES WITH PEERS • SPEAKING OUT AT MEETINGS • REPRESENTING OTHERS IN MEETINGS • PROTESTING	• HAVING A PART TIME JOB • TRYING DIFFERENT SPORTS • PROVIDING EMOTIONAL SUPPORT FOR OTHERS • WORKING WITH OTHERS/DOING WORKSHOPS • SPOKE OUT AT COLLEGE • WORKING WITH LOCAL MPs
PARTICAPANT 9 • SHARING EXPERIENCES WITH PEERS (II) • DISCUSSING WITH PEERS WHAT NEEDS CHANGING • BEING GOOD AT ART • DEMANDING HELP AT COLLEGE (E.G., "No, I won't do it unless someone helps me".) (II • DEMANDING HELP AT SCHOOL • NOT BELIEVING WHAT OTHERS SAY • WENT TO COLLEGE • SUPPORTING OTHERS WITH LEARNING DISABILITY BY BEING AVAILABLE IN CASE THEY NEED HELP • WORKING WITH OTHERS TO CHANGE THINGS • SPOKE OUT TO CLASSMATES	**PARTICIPANT 10** • REPORTED MISTREATMENT RECEIVED FROM PREVIOUS SUPPORT WORKER • IGNORING STIGMA • WALKING AWAY FROM STIGMATISED BEHAVIOUR • MENTALLY REJECTING STIGMATISING TREATMENT FROM OTHERS • HAVING MULTIPLE JOBS AND GOING TO COLLEGE • HOSTING A TALENT SHOW • SHARING ONE'S OWN EXPERIENCES WITH PEOPLE ONE CAN TRUST • EDUCATING OTHERS	**PARTICIPANT 11** • STANDING UP TO BULLIES/ ASSERTING SELF (II • HAVING A JOB • SUPPORTING OTHERS • TAKING PART IN A CAMPAIGN • TRAINED HEALTH PROFESSIONALS ABOUT DISABILITIES • JOINING A PROTEST	**PARTICIPANT 12** • NOT BEING AFRAID TO SHOW STRENGTH • WARNING OTHERS • HELPING OTHERS STICK UP FOR THEMSELVES • HELPING OTHERS (III • SHARING OWN EXPERIENCES WITH PEERS TO HELP THEM OUT • WORKING WITH OTHERS TO CHANGE THINGS • TEACHING OTHERS RESILLIENCE TO BULLYING
PARTICIPANT 13 • BEING A HEALTH SPOKESPERSON • SPEAK TO NHS WORKERS • CAMPAINGING; TREAT ME WELL CAMPAIGN • SPEAK UP FOR MY RIGHTS • IGNORED BULLYING • STANDING FIRM AGAINST MISTREATMENT FROM STAFF MEMBER • NOT BELIEVING WHAT OTHERS SAY ABOUT ME • TELLING OTHERS 'THAT'S NOT ME' • IN FULL TIME EMPLOYMENT; PROVING PEOPLE WRONG BY WORKING • SPEAKING AT CONFERENCES • SPOKE TO OTHERS ABOUT THE MISTREATMENT TO	**PARTICIPANT 14** • DOING ADVOCACY WORK • BEING A TRUSTEE FOR THE GROUP • CAMPAINING AGAINST HATE CRIME • I WILL PUT MY HEAD UP HIGH AND SAY 'I FEEL NORMAL'" • STANDING UP TO HOSPITAL STAFF BY SEEKING SUPPORT FROM ADVOCATE • CHALLENGING WHAT OTHERS SAY ABOUT ME • HELPING OTHERS • HELPING OTHERS BY SHARING OWN EXPERIENCES • WORKING WITH OTHERS TO CHANGE THINGS • TALKED IN FRONT OF A GROUP ABOUT MY PROBLEMS • SPOKE OUT TO HOSPITAL STAFF ABOUT HOW TO TREAT INDIVIDUALS WITH LEARNING DISABILITIES	**PARTICIPANT 15** • TRUSTEE AT CHARITY • CAMPAIGNING (IIII • SET UP A NIGHTCLUB FOR PEOPLE WITH LEARNING DISABILITIES • PHYSICALLY STOOD UP • PHYSICALLY STOOD UP AND SAID 'HOW RUDE YOU ARE • WALKING AWAY • RANG THE POLICE • PROVING PEOPLE WRONG/THAT I CAN DO THINGS (III • CHALLENEGED PEOPLE'S NEGATIVE COMMENTS IN MY HEAD • ACHIEVING THINGS • ACTIVELY FINDING OUT ABOUT RIGHTS • SHARING KOWLEDGE WITH PEERS AROUND SAFETY • SHARING OWN EXPERIENCES WITH	**PARTICIPANT 16** • LINK WORKER- EMPLOYED WITH THE CHARITY • SPEAKING UP FOR PEOPLE WITH LEARNING DISABILITIES • WRITE TO MPS • HELPING OTHERS WITH LEARNING DISABILITIES • PROVING TO PEOPLE THAT I CAN DO THINGS • SPEAKING OUT AT CONEFERENCE • EDUCATING TRAINEE NURSES • STANDING UP TO MISTREATMENT BY HOSPITAL STAFF BY SAYING "I AM A PERSON" • MAKING A COMPLAINT

INDIVIDUALS WITH LEARNING DISABILITIES • HELPING OTHERS WITH PRACTICAL STUFF • HELPING OTHERS STAND UP FOR THEMSELVES • ON A COMMITTEE WITH THE NHS TO HELP MAKE A CHANGE • BEING THE CO-AUTHOR OF A BOOK TO EDUCATE OTHERS ABOUT LEARNING DISABILITIES • EDUCATING NURSES		OTHERS TO INCREASE THEIR CONFIDENCE • EDUCATING PROFESSIONALS • PROTESTING	• SHARING OWN EXPERIENCES IN ORDER TO HELP OTHERS • INVITED MPS TO SIT IN ONE OF OUR MEETINGS

Support from others
Accessible information & **Practical things/Practical support**
Support from peers
Asking for support
Professionals wanting to learn
Knowing about human rights
Learning from experience/others
Confidence in self
Personal values

PERCEIVED FACILITATORS

PARTICIPANT 1	**PARTICIPANT 2**	**PARTICIPANT 3**	**PARTICIPANT 4**
• RECEIVING SUPPORT FROM MUM (IIIII • LIVING CLOSE TO A SELF-ADVOCACY GROUP • DEVELOPING A THICK SKIN • WILLINGNESS TO UNDERSTAND SITUATIONS BETTER • MAKING INFORMATION ACCESSIBLE (II • NOT CARING ABOUT WHAT OTHERS THINK • STARTING THE CONVERSATION FIRST • SUPPORT FROM CHARITIES • RECOGNISING MISTREATMENT • BEING A SELF-ADVOCATE HAS HELPED ME GROW EMOTIONALLY • STRONGER AS A GROUP	• SELF-ADVOCATES HELPING EACH OTHER • SELF-ADVOCATES ENCOURAGING CONFIDENCE IN ONE ANOTHER • PSYCHOLOGIST SUGGESTING SELF-ADVOCACY GROUP • RECEIVING SUPPORT FROM MY MOTHER • LEARNING FROM OTHERS • HAVING CONFIDENCE	• BEING TAUGHT BY PARENTS HOW TO STAND UP FOR MYSELF (II • RECEIVING SUPPORT FROM PARTNER (II • FATHER SUPPORTING EMPLOYMENT • RECEIVING SUPPORT FROM SUPPORT WORKER • LISTENING TO PEOPLE’S EXPERIENCES (II • HAVING ACCESS TO TRANSPORT	• RECEIVING SUPPORT FROM PARTNER (III • RECEIVING SUPPORT FROM SELF-ADVOCACY GROUP • RECEIVING SUPPORT FROM FAMILY (IIII • FAMILY BELIEVING IN ME • BEING A VOICE FOR OTHERS • HAVING THE SUPPORT OF FAMILY HAVE GIVEN ME INTERNAL SELF-CONFIDENCE • KNOWING WHAT MY RIGHTS ARE • SEEING OTHERS AS ROLE MODELS E.G., COUSIN • BEING TAUGHT THINGS ABOUT OUR RIGHTS BY SELF-ADVOCACY GROUP • RECEIVING SUPPORT FROM FRIENDS • INNER VOICE TELLS ME I’VE GOT TO DO THIS • WANTING TO PROTECT OTHERS, E.G., FRIEND • THINKING THAT YOU HAVE TO STAND UP FOR YOURSELF, BUT ALSO FOR OTHERS
PARTICIPANT 5	**PARTICIPANT 6**	**PARTICIPANT 7**	**PARTICIPANT 8**
• RECEIVED SUPPORT FROM FAMILY • KNOWING ONE’S RIGHTS • HAVING SUPPORT FROM SUPPORT WORKER • HAVING LEARNT FROM ONE’S PAST EXPERIENCES • RECEIVING SUPPORT FROM FRIENDS AND PARTNER • STRONGER AS A GROUP	• RECEIVING SUPPORT WITH HOUSING FROM SELF-ADVOCACY GROUP • RECEIVING EMOTIONAL SUPPORT FROM GROUP • BELIEVES THAT HE IS CAPABLE OF LIVING INDEPENDENTLY • LEARNT TO STICK UP FOR MYSELF THROUGH WORK IN SELF-ADVOCACY GROUP, E.G., DOING WORKSHOPS • LEARNING SKILLS FROM SELF-ADVOCACY GROUP	• RECEIVING HELP FROM SELF-ADVOCACY GROUP • HELPING EACH OTHER IN SELF-ADVOCACY GROUP • HAVING ACCESS TO COMPUTERS AND INTERNET TO FIND INFORMATION • KNOWING PEOPLE HELPS TO FEEL COMFORTABLE AROUND THEM • PREPARING THINGS TO SAY IN	• MEMBERS SUPPORTING EACH OTHER IN GROUP • RECEIVING SUPPORT FROM GROUP FACILITATOR AND FRIENDS • HAVING A SUPPORTIVE FAMILY • KNOWING WHERE TO GO TO FIND OUT ABOUT ONE’S RIGHTS, E.G., DAD WHO IS A SOLICITOR, OR TO GROUP FACILITATOR

	• RECEIVING SUPPORT FROM COLLEGE AND ADVOCATES (II • HAVING CONFIDENCE IN ONE'S SELF • SEEKING SUPPORT FROM OTHER MEMBERS • NOT HOLDING SELF BACK FROM SPEAKING UP	ADVANCE OF A MEETING • WANTING TO MAKE A CHANGE • PREPARING WHAT YOU ARE GOING TO SAY IN ADVANCE • STRONGER AS A GROUP	• HAVING PREVIOUS EXPERIENCE OF SOMETHING • RECEIVING SUPPORT FROM FRIENDS AND PARENTS • PREPERING FOR A MEETING • EXPANDING KNOWLEDGE, E.G., DOING RESEARCH ON THE COMPUTER • RECEIVING SUPPORT FROM COLLEGE • ASKING FOR SUPPORT
PARTICIPANT 9 • HAVING SUPPORT FROM FAMILY AND FRIENDS • BEING TREATED EQUALLY • RECEIVING HELP WITH PRACTICAL ISSUES, E.G., WALKING • MUM ADVISING ME TO ASK FOR HELP IF I CAN'T DO SOMETHING • ATTENDING THE GROUP HAS INCREASED MY CONFIDENCE/BELIEF IN MYSELF • STRONGER AS A GROUP • ASKING FOR EXTRA TIME TO DO COLLEGE WORK • RECEIVED SUPPORT FROM COLLEGE TUTOR • FAMILY ENCOURAGING ME TO STAND UP FOR MYSELF • GIVING PEOPLE TIME TO TALK • BEING INVITED TO SHARE MY STORY AND BEING IN A QUITE ROOMS HELPS • RECEIVING ENCOURAGMENT FROM OTHERS TO SPEAK OUT	**PARTICIPANT 10** • MEMBERS OF GROUP SUPPORTING EACH OTHER • GETTING HELP WITH REPORTING MISTREATMENT • HAVING BELIEF IN MYSELF • DOING THINGS THAT I CAN ACHIEVE • HAVING SUPPORT FROM SUPPORT WORKER • HAVING SUPPORT IN MAKING A COMPLAINT • TRUSTING OTHERS • KNOWING THE PEOPLE WHO ASK YOU TO DO SOMETHING, E.G., GIVE AN INTERVIEW/SPEAK OUT • BEING AWARE OF ONE'S OWN RIGHTS	**PARTICIPANT 11** • GOING TO SELF-ADVOCACY GROUP INCREASES CONFIDENCE • EASY READ HELPS UNDERSTANDING • HAVING THE SUPPORT OF STAFF TO ACHIEVE THINGS (II • BEING ABLE TO ACCESS TRANSPORT • ASKING SOMEONE FOR HELP (E.G., HELP WITH THE READING) • STAFF PREPARING THINGS IN ADVANCE FOR PERSON • STAFF WRITING THINGS IN EASY READ BEFORE DELIVERY OF TRAINING TO PROFESSIONALS • HAVING THE SUPPORT OF STAFF AND HUSBAND WHEN JOINING A PROTEST, E.G., TAKING PERSON TO ON BUSES	**PARTICIPANT 12** • LEARNING FROM OTHERS HOW TO STAND UP FOR HIMSELF • PEOPLE MAY NEED HELP TO ACHIEVE THINGS (E.G. FROM STAFF) • READING THE HUMAN RIGHTS ACT • HAVING THE ABILITY TO STAND UP FOR MYSELF; BEING CONFIDENT • HAVING A CARD UP WHEN YOU SPEAK • PEOPLE SPEAKING ONE AT A TIME
PARTICIPANT 13 • SUPPORT FROM PARENTS TO JOIN SELF-ADVOCACY GROUP • MEMBERS HELPING EACH OTHER • HAD SUPPORT FROM FRIENDS AND NHS • KNOWS ABOUT THE HUMAN RIGHTS ACT • BEING GIVEN HELP WITH UNDERSTANDING THE SUBJECT OF A DISCUSSION • WORKING WITH PEERS IN SELF-ADVOCACY GROUP	**PARTICIPANT 14** • MEMEBRS SHARING OWN EXPERIENCES WITH EACH OTHER • WANTING TO FIGHT BACK THE SOCIETY • OWN EXPERIENCE LED HIM TO WANT TO HELP OTHERS • FEELING ACCEPTED BY STAFF • HAVING SUPPORT FROM NEIGHBOURS • SPEAKING DIRECTLY TO STAFF ABOUT MISTREATMENT WITH ADVOCATE'S SUPPORT • ADVOCACY SERVICE IN HOSPITAL	**PARTICIPANT 15** • SUPPORT FROM PUB STAFF • SUPPORT FROM CHARITY • FINDING THE RESOURCES • SUPPORT FROM WIFE AND COORDINATOR • SUPPORT FROM SELF-ADVOCACY STAFF • ASKING FOR SUPPORT • ENCOURAGEMENT FROM WIFE • ASKING FOR HELP	**PARTICIPANT 16** • SUPPORT FROM CHARITY (II • PERSERVERANCE • SUPPORT FROM ADVOCATE (II • PRACTICAL SUPPORT FROM STAFF • PRACTICED PRESENTATION WITH STAFF BEFOREHAND • WANTING TO CHANGE THINGS FOR OTHERS • **BEING GIVEN THE OPPORTUNITY (II** • BEING RECOGNISED AS A PERSON

• HEALTH PROFESSIONALS HAVING THE WANT TO LEARN	• SUPPORT FROM ADVOCACY • EXPRESSING HOW YOU FEEL HELPS • LEARNING RESILIENCE OVER THE YEARS • MOTHER ENCOURAGED ME NOT TO BELIEVE WHAT OTHERS SAY • HAD SUPPORT FROM HOSPITAL STAFF TO DO A COURSE • KNOWING ABOUT HUMAN RIGHTS ACT • WAS READ HIS RIGHTS BY THE HOSPITAL • EASY READ • PEOPLE NOT JUDGING ME • **BEING GIVEN THE OPPORTUNITY** • HAVING THE SUPPORT FROM THE PEOPLE LISTENING	• CHARITY BUILT CONFIDENCE • RECEIVED SUPPORT WITH BENEFITS • STRONGER AS A GROUP • PROFESSIONALS WANTING TO LEARN • PRACTICAL SUPPORT FROM STAFF • KNOWING HOW TO USE THE INTERNET	• FEELING ACCEPTED BY OTHERS • PASSION TO HELP OTHERS

Lack of support from others
Lack of access to practical things
Difficult feelings
Not knowing how to do it/lack of confidence
Lack of understanding from others
Being discouraged/put down by others
Lack of understanding/knowledge

PERCEIVED BARRIERS

PARTICIPANT 1	**PARTICIPANT 2**	**PARTICIPANT 3**	**PARTICIPANT 4**
• LACK OF SUPPORT FROM EMPLOYER (II • GETTING THE NASTINESS FROM EMPLOYEES • BEING FRIGHTENED OF MY BOSS (II • DENYING EMOTIONS IN FRONT OF OTHERS TO NOT LOOK WEAK • MISREADING SITUATIONS • LACK OF ACCESS TO INFORMATION ON RIGHTS • PEOPLE’S PERCEPTIONS ABOUT DISABLED PEOPLE AREN’T LENIENT • FEAR OF NOT BEING ACCEPTED	• DOESN’T UNDERSTAND WHAT IS MEANT BY ONE’S RIGHTS • NOT KNOWING HOW TO STAND UP FOR PEOPLE WITH INTELLECTUAL DISABILITY • BOTTLING UP” FEELINGS • NOT HAVING A COMPUTER TO ACCESS INFORMATION	• HOSPITAL STAFF NOT UNDERSTANDING YOU • LACK OF UNDERSTANDING IN THE PUBLIC ABOUT LEARNING DISABILITY • HAVING BRAIN DAMAGE • NOT KNOWING WHAT TO SAY • BEING AFRAID OF ABUSE • HAVING MENTAL HEALTH DIFFICULTIES • LACK OF SUPPORT FROM OTHERS • MOTHER NOT ENCOURAGING EMPLOYMENT DUE TO FEAR THAT I WILL BE TAKEN ADVANTAGE OF • BEING PUT DOWN BY PEOPLE • PEOPLE JUDGING YOU • NOT UNDERSTANDING PEOPLE’S NEEDS • DIFFICULT TO EXPRESS FEELINGS • BEING NERVOUS SPEAKING IN FRONT OF PEOPLE • COVID-19 PREVENTING PROTESTS (II	• BEING DISCOURAGED BY OTHERS E.G., HEALTH PROFESSIONALS, SOCIETY • NOT FEELING EMOTIONALLY STRONG TO DO THINGS ON MY OWN • TRAVELLING ON PUBLIC TRANSPORT DUE TO PHYSICAL DISABILITY • LACK OF CONFIDENCE • FEAR OF BEING LAUGHTED AT • FEAR OF PREJUDGEMENT • LACKING THE CONFIDENCE TO SPEAK OUT/EDUCATE OTHERS • NOT BEING GIVEN THE OPPORTUNITY TO EDUCATE OTHERS
PARTICIPANT 5	**PARTICIPANT 6**	**PARTICIPANT 7**	**PARTICIPANT 8**
• BEING BULLIED • NOT KNOWING WHAT TO SAY (II • LACK OF CONFIDENCE • GETTING DOWN ON YOURSELF • NOT KNOWING HOW TO SPEAK OUT • NOT HAVING ACCESS TO TRANSPORT • PEOPLE NOT UNDERSTANDING WHAT YOU ARE SAYING • NOT KNOWING WHAT TO SAY • NOT GETTING THE RIGHT HELP TO DO IT	• BEING BULLIED • FAMILY DOESN’T BELIEVE THAT FAMILY MEMBER WITH LEARNING DISABILITY CAN LIVE INDEPENDENTLY • PEOPLE WITH LEARNING DISABILITIES MAY NOT KNOW WHAT TO DO WHEN OTHERS SAY BAD THINGS TO/ABOUT THEM • NOT GETTING A CHANCE TO TALK WHEN WORKING WITH OTHERS • BEING DISMISSED • FEAR OF BEING BULLIED • FEAR OF BEING JUDGED	• BEING BULLIED • NOT BEING TREATED EQUALLY • PEOPLE NOT TAKING TURNS TO SPEAK IN MEETINGS • NOT KNOWING OTHER PEOPLE IN A PROTEST	• NOT KNOWING CORRECT PROTOCOLS • PEOPLE MAY FIND IT HARD TO UNDERSTAND WHAT HUMAN RIGHTS ARE • WORRYING ABOUT JUDGEMENT FROM OTHERS (II • TRANSPORT PROBLEMS • BEING SHY AND NERVOUS WHEN MEETING NEW PEOPLE • PEOPLE NOT UNDERSTANDING DISABILITY • NOT BEING GIVEN THE OPPORTUNITY

			TO SPEAK IN MEETINGS • BEING ANXIOUS ABOUT SAYING THE WRONG THING
PARTICIPANT 9 • NOT BELIEVING IN MYSELF • DISABLED PEOPLE’S NEEDS NOT BEING UNDERSTOOD BY OTHERS • NOT ASKING FOR HELP • PEOPLE ARGUING OR NOT LISTENING • NOT HAVING THE SUPPORT AND COMMITMENT FROM PEOPLE AROUND ME MAKES IT DIFFICULT TO SHARE MY OWN EXPERIENCES • PEOPLE BEING UNWILLING TO LISTEN • PEOPLE NOT CO-OPERATING WITH YOU • PEOPLE NOT TAKING YOU SERIOUSLY	**PARTICIPANT 10** • DIFFICULTY WRITING COMPLAINT ON MY OWN • PEOPLE WITH LEARNING DISABILITY MAY NOT KNOW HOW TO RESPOND TO MISTREARTMENT/WHAT TO SAY • PEOPLE NOT HAVING SUPPORT AROUND THEM TO ACHIEVE THINGS • PEOPLE MAY NOT UNDERSTAND WHAT THEIR RIGHTS ARE • BEING SHY TO ASK FOR SUPPORT	**PARTICIPANT 11** • YOUTH LACK UNDERSTANDING OF DISABILITY • PRACTICAL ISSUES, E.G., IF BUSES DON’T HAVE RAMPS • READING QUESTIONS ON FORM • SHARING PRIVATE INFORMATION WITH OTHERS • PRACTICAL ISSUES, E.G., LIFT NOT WORKING (AS PERSON IS WHEELCHAIR BOUND) • JARGON WORDS	**PARTICIPANT 12** • QUESTIONING WHAT OTHERS SAY ABOUT YOU MIGHT BE DIFFICULT • PEOPLE MAY NOT UNDERSTAND WHAT OTHERS SAY TO THEM (II • PEOPLE WITH LEARNING DISABILITIES WOULD NOT KNOW WHAT THEIR RIGHTS ARE IF THEY HAVEN’T BEEN TOLD ABOUT IT OR READ IT • PEOPLE MAY FIND IT DIFFICULT TO SPEAK UP FOR THEMSELVES • PEOPLE TALKING OVER EACH OTHER • PEOPLE MIGHT BE FRIGHTENED TO STAND UP FOR THEMSELVES
PARTICIPANT 13 • NOT KNOWING HOW TO REPORT MISTREATMENT • NOT HAVING EASY READ • FAST SPEAKING IS DIFFICULT TO UNDERSTAND	**PARTICIPANT 14** • BEING AN INTROVERT; NOT SPEAKING OUT • BEING SHY • NOT REPORTING MISTREATMENT OUT OF FEAR THAT HE WOULD GET IN TROUBLE • NOT HAVING SOMEONE “OFFICIAL” TO SPEAK TO • NOT KNOWING ABOUT HUMAN RIGHTS • BEING NERVOUS AT MEETINGS • DIFFICULT TO EXPRESS YOURSELF • PERSONAL EXPERIENCES ARE DIFFICULT TO DISCUSS	**PARTICIPANT 15** • BEEN MENTALLY AND PHYSICALLY BULLIED • QUESTIONING MY OWN ABILITIES • INTERNAL BATTLE • BEING TOLD YOU WON’T ACHIEVE THINGS (II • JARGON • NOT EASY READ (II • LACK OF SUPPORT WITH USING THE INTERNET • PEOPLE WITH LEARNING DISABILIES HAVE COMMUNICATION PROBLEMS • LACK OF SUPPORT IN A LEGAL SITUATION	**PARTICIPANT 16** • BEING JUDGED BECAUSE OF DISABILITY (II • FELT LABELLED AND JUDGED FOR BEING IN A MENTAL HEALTH HOPSITAL • FEAR THAT I WILL DO SOMETHING WRONG • LACK OF SELF BELIEF • BEING PUT DOWN • FEELING INTIMIDATED BY BEING ASKED MANY QUESTIONS • PEOPLE NOT APPRECIATING MY HELP • FINDING IT HARD TO TRUST PEOPLE

	• NOT EXPRESSING DIFFICULT FEELINGS • ARGUING WITH OTHERS • PEOPLE JUDGING ME • NOT BEING TREATED AS AN ADULT • BEING TOLD NOT TO STAND UP FOR YOURSELF AND OTHERS BY STAFF • NOT WANTING TO GET IN TROUBLE	• SHARING INFORMATION WITH STRANGERS IS NOT EASY • CONFIDENCIALITY IS BREACHED • NOT BEING TREATED EQUALLY • LARGE CROWDS CAN STOP PEOPLE FROM JOINING A PROTEST	• PEOPLE DISAGREEING • PEOPLE SPEAKING OVER EACH OTHER

Appendix J: Samples of thematic tables illustrating the review and refinement of initial themes, forming part of Step 5 of the thematic analysis

PARTICIPANTS' ACTIONS IN RESISTING STIGMA

CONFRONTING/REPORTING MISTREATMENT	BELIEVING IN MYSELF/NOT BELIEVING WHAT OTHERS SAY	STATING ONE'S NEEDS/RIGHTS	WALKING AWAY FROM/IGNORING MISTREATMENT	PROVING PEOPLE WRONG
CONFRONTING PEOPLE'S MISTREATRMENT AND ASKING THEM TO STOP IT) VERBALLY CONFRONTING ABUSIVE BEHAVIOUR FROM OTHERS (II QUESTIONING MISTRETAMENT MONITORING HOSPITALS' DISABILITY SUPPORT; REPORTING MISTREATMENT; SAYING TO PEOPLE THAT I DON'T LIKE WHAT THEY SAID/THAT IT'S NOT NICE REPORTED MISTREATMENT RECEIVED FROM PREVIOUS SUPPORT WORKER STANDING UP TO BULLIES/ ASSERTING SELF (II) NOT BEING AFRAID TO SHOW STRENGTH; WARNING OTHERS STANDING FIRM AGAINST MISTREATMENT FROM STAFF MEMBER STANDING UP TO HOSPITAL STAFF BY SEEKING SUPPORT FROM ADVOCATE; CHALLENGING WHAT OTHERS SAY ABOUT ME PHYSICALLY STOOD UP PHYSICALLY STOOD UP AND SAID 'HOW RUDE YOU ARE; RANG THE POLICE STANDING UP TO MISTREATMENT BY HOSPITAL STAFF BY SAYING "I AM A PERSON"; MAKING A COMPLAINT	BELIEVING IN MYSELF NOT BELIEVING HAVING A LEARNING DISABILITY BELIEVING THAT HAVING A LEARNING DISABILITY DOESN'T DEFINE WHO YOU ARE NOT BELIEVING WHAT OTHERS SAY ABOUT ME NOT BELIEVING WHAT OTHERS SAY MENTALLY REJECTING STIGMATISING TREATMENT FROM OTHERS I WILL PUT MY HEAD UP HIGH AND SAY 'I FEEL NORMAL'" CHALLENEGED PEOPLE'S NEGATIVE COMMENTS IN MY HEAD NOT BELIEVING WHAT OTHERS SAY ABOUT ME; TELLING OTHERS 'THAT'S NOT ME'	WANTING TO LIVE INDEPENDENTLY; TRAVELLING INDEPENDENTLY; REFUSED SUPPORTED LIVING; WANTING TO CONVINCE FAMILY THAT I CAN LIVE INDEPENDENTLY INFORMING THE EMPLOYER THAT I HAVE A DISABILITY AND ASKING FOR REASONABLE ADJUSTMENTS PUTTING PEOPLE IN THEIR PLACE SPEAKING MY MIND; EXPLAINING MY POSITION TO HOUSING OFFICER DEMANDING HELP AT COLLEGE (E.G., "No, I won't do it unless someone helps me".) (II); DEMANDING HELP AT SCHOOL SPEAK UP FOR MY RIGHTS ACTIVELY FINDING OUT ABOUT RIGHTS	WALKING AWAY; CHOOSING TO NOT RESPOND TO MISTREATMENT CHOOSING TO NOT RESPOND TO MISTREATMENT NOT PAYING ATTENTION TO BULLIES IGNORING BULLYING/TRYING TO BLOCK IT OUT (II WALKING AWAY IGNORING STIGMA; WALKING AWAY FROM STIGMATISED BEHAVIOUR IGNORED BULLYING WALKING AWAY	PROVING PEOPLE WRONG HAVING A JOB AND PROVING PEOPLE WRONG WANTING TO PROVE PEOPLE WRONG PROVING PEOPLE WRONG BY WORKING PROVING PEOPLE WRONG/THAT I CAN DO THINGS (III) PROVING TO PEOPLE THAT I CAN DO THINGS

PERCEIVED BARRIERS

IN RELATION TO OTHERS	IN RELATION TO SELF
BEING FRIGHTENED OF MY BOSS (II); FEAR OF NOT BEING ACCEPTED BEING AFRAID OF ABUSE FEAR OF BEING LAUGHTED AT; FEAR OF PREJUDGEMENT FEAR OF BEING BULLIED; FEAR OF BEING JUDGED WORRYING ABOUT JUDGEMENT FROM OTHERS (II PEOPLE MIGHT BE FRIGHTENED TO STAND UP FOR THEMSELVES NOT REPORTING MISTREATMENT OUT OF FEAR THAT HE WOULD GET IN TROUBLE; NOT WANTING TO GET IN TROUBLE FELT LABELLED AND JUDGED FOR BEING IN A MENTAL HEALTH HOPSITAL; FEELING INTIMIDATED BY BEING ASKED MANY QUESTIONS	DENYING EMOTIONS IN FRONT OF OTHERS TO NOT LOOK WEAK BOTTLING UP” FEELINGS DIFFICULT TO EXPRESS FEELINGS BEING NERVOUS SPEAKING IN FRONT OF PEOPLE NOT FEELING EMOTIONALLY STRONG TO DO THINGS ON MY OWN GETTING DOWN ON YOURSELF BEING SHY AND NERVOUS WHEN MEETING NEW PEOPLE; BEING ANXIOUS ABOUT SAYING THE WRONG THING NOT HAVING THE SUPPORT AND COMMITMENT FROM PEOPLE AROUND ME MAKES IT DIFFICULT TO SHARE MY OWN EXPERIENCES BEING SHY TO ASK FOR SUPPORT BEING AN INTROVERT; NOT SPEAKING OUT; BEING SHY; BEING NERVOUS AT MEETINGS; PERSONAL EXPERIENCES ARE DIFFICULT TO DISCUSS; NOT EXPRESSING DIFFICULT FEELINGS; NOT EXPRESSING DIFFICULT FEELINGS FINDING IT HARD TO TRUST PEOPLE; FEAR THAT I WILL DO SOMETHING WRONG

PERCEIVED FACILITATORS

CONFIDENCE IN SELF	LEARNING FROM EXPERIENCE/OTHERS	KNOWLEDGE ABOUT HUMAN RIGHTS	MOTIVATION/PASSION/PERSONAL VALUES?
NOT CARING ABOUT WHAT OTHERS THINK; STARTING THE CONVERSATION FIRST HAVING CONFIDENCE BEING A VOICE FOR OTHERS BELIEVES THAT HE IS CAPABLE OF LIVING INDEPENDENTLY; HAVING CONFIDENCE IN ONE'S SELF; NOT HOLDING SELF BACK FROM SPEAKING UP ATTENDING THE GROUP HAS INCREASED MY CONFIDENCE/BELIEF IN MYSELF HAVING BELIEF IN MYSELF; TRUSTING OTHERS GOING TO SELF-ADVOCACY GROUP INCREASES CONFIDENCE HAVING THE ABILITY TO STAND UP FOR MYSELF; BEING CONFIDENT OWN EXPERIENCE LED HIM TO WANT TO HELP OTHERS; EXPRESSING HOW YOU FEEL HELPS CHARITY BUILT CONFIDENCE	DEVELOPING A THICK SKIN; RECOGNISING MISTREATMENT; BEING A SELF-ADVOCATE HAS HELPED ME GROW EMOTIONALLY LEARNING FROM OTHERS BEING TAUGHT BY PARENTS HOW TO STAND UP FOR MYSELF (II); LISTENING TO PEOPLE'S EXPERIENCES (II SEEING OTHERS AS ROLE MODELS E.G., COUSIN; BEING TAUGHT THINGS ABOUT OUR RIGHTS BY SELF-ADVOCACY GROUP; HAVING LEARNT FROM ONE'S PAST EXPERIENCES LEARNT TO STICK UP FOR MYSELF THROUGH WORK IN SELF-ADVOCACY GROUP, E.G., DOING WORKSHOPS; LEARNING SKILLS FROM SELF-ADVOCACY GROUP HAVING PREVIOUS EXPERIENCE OF SOMETHING LEARNING FROM OTHERS HOW TO STAND UP FOR HIMSELF WORKING WITH PEERS IN SELF-ADVOCACY GROUP MEMEBRS SHARING OWN EXPERIENCES WITH EACH OTHER; LEARNING RESILIENCE OVER THE YEARS	KNOWING WHAT MY RIGHTS ARE KNOWING ONE'S RIGHTS BEING AWARE OF ONE'S OWN RIGHTS READING THE HUMAN RIGHTS ACT KNOWS ABOUT THE HUMAN RIGHTS ACT KNOWING ABOUT HUMAN RIGHTS ACT	WILLINGNESS TO UNDERSTAND SITUATIONS BETTER INNER VOICE TELLS ME I'VE GOT TO DO THIS; WANTING TO PROTECT OTHERS, E.G., FRIEND WANTING TO MAKE A CHANGE EXPANDING KNOWLEDGE, E.G., DOING RESEARCH ON THE COMPUTER DOING THINGS THAT I CAN ACHIEVE WANTING TO FIGHT BACK THE SOCIETY; WANTING TO CHANGE THINGS FOR OTHERS; PASSION TO HELP OTHERS

Appendix K: Samples of thematic tables illustrating themes being clustered into sub-themes, forming part of Step 6 of the thematic analysis

PARTICIPANTS’ ACTIONS IN RESISTING STIGMA

ASSERTING ONESELF			
CONFRONTING/REPORTING MISTREATMENT	STATING ONE’S NEEDS/RIGHTS	WALKING AWAY FROM/IGNORING MISTREATMENT	PROVING PEOPLE WRONG
CONFRONTING PEOPLE’S MISTREATRMENT AND ASKING THEM TO STOP IT)	WANTING TO LIVE INDEPENDENTLY; TRAVELLING INDEPENDENTLY; REFUSED SUPPORTED LIVING; WANTING TO CONVINCE FAMILY THAT I CAN LIVE INDEPENDENTLY	WALKING AWAY; CHOOSING TO NOT RESPOND TO MISTREATMENT	PROVING PEOPLE WRONG HAVING A JOB AND PROVING PEOPLE WRONG
VERBALLY CONFRONTING ABUSIVE BEHAVIOUR FROM OTHERS (II		CHOOSING TO NOT RESPOND TO MISTREATMENT	WANTING TO PROVE PEOPLE WRONG
QUESTIONING MISTRETAMENT	INFORMING THE EMPLOYER THAT I HAVE A DISABILITY AND ASKING FOR REASONABLE ADJUSTMENTS PUTTING PEOPLE IN THEIR PLACE	NOT PAYING ATTENTION TO BULLIES	PROVING PEOPLE WRONG BY WORKING
MONITORING HOSPITALS’ DISABILITY SUPPORT; REPORTING MISTREATMENT; SAYING TO PEOPLE THAT I DON’T LIKE WHAT THEY SAID/THAT IT’S NOT NICE		IGNORING BULLYING/TRYING TO BLOCK IT OUT (II	PROVING PEOPLE WRONG/THAT I CAN DO THINGS (III)
	SPEAKING MY MIND; EXPLAINING MY POSITION TO HOUSING OFFICER	WALKING AWAY	
REPORTED MISTREATMENT RECEIVED FROM PREVIOUS SUPPORT WORKER		IGNORING STIGMA; WALKING AWAY FROM STIGMATISED BEHAVIOUR	PROVING TO PEOPLE THAT I CAN DO THINGS
STANDING UP TO BULLIES/ ASSERTING SELF (II)	DEMANDING HELP AT COLLEGE (E.G., “No, I won’t do it unless someone helps me”.) (II); DEMANDING HELP AT SCHOOL	IGNORED BULLYING	
NOT BEING AFRAID TO SHOW STRENGTH; WARNING OTHERS	SPEAK UP FOR MY RIGHTS	WALKING AWAY	
STANDING FIRM AGAINST MISTREATMENT FROM STAFF MEMBER	ACTIVELY FINDING OUT ABOUT RIGHTS		
STANDING UP TO HOSPITAL STAFF BY SEEKING SUPPORT FROM ADVOCATE; CHALLENGING WHAT OTHERS SAY ABOUT ME			
PHYSICALLY STOOD UP PHYSICALLY STOOD UP AND SAID ‘HOW RUDE YOU ARE; RANG THE POLICE			
STANDING UP TO MISTREATMENT BY HOSPITAL STAFF BY SAYING “I AM A PERSON”; MAKING A COMPLAINT			

PERCEIVED BARRIERS

PERSONAL CHALLENGES				
NOT UNDERSTANDING	NOT KNOWING HOW	INTERNAL STRUGGLES	EMOTIONS IN RELATION TO OTHERS	EMOTIONS IN RELATION TO SELF
MISREADING SITUATIONS DOESN'T UNDERSTAND WHAT IS MEANT BY ONE'S RIGHTS NOT UNDERSTANDING PEOPLE'S NEEDS PEOPLE MAY FIND IT HARD TO UNDERSTAND WHAT HUMAN RIGHTS ARE PEOPLE MAY NOT UNDERSTAND WHAT THEIR RIGHTS ARE READING QUESTIONS ON FORM PEOPLE MAY NOT UNDERSTAND WHAT OTHERS SAY TO THEM (II FAST SPEAKING IS DIFFICULT TO UNDERSTAND PEOPLE WITH LEARNING DISABILIES HAVE COMMUNICATION PROBLEMS	NOT KNOWING HOW TO STAND UP FOR PEOPLE WITH INTELLECTUAL DISABILITY NOT KNOWING WHAT TO SAY NOT KNOWING WHAT TO SAY (III); NOT KNOWING HOW TO SPEAK OUT PEOPLE WITH LEARNING DISABILITIES MAY NOT KNOW WHAT TO DO WHEN OTHERS SAY BAD THINGS TO/ABOUT THEM PEOPLE WITH LEARNING DISABILITY MAY NOT KNOW HOW TO RESPOND TO MISTREARTMENT/WHAT TO SAY; DIFFICULTY WRITING COMPLAINT ON MY OWN PEOPLE WITH LEARNING DISABILITIES WOULD NOT KNOW WHAT THEIR RIGHTS ARE IF THEY HAVEN'T BEEN TOLD ABOUT IT OR READ IT NOT KNOWING HOW TO REPORT MISTREATMENT NOT KNOWING ABOUT HUMAN RIGHTS SHARING INFORMATION WITH STRANGERS IS NOT EASY	LACK OF CONFIDENCE; LACKING THE CONFIDENCE TO SPEAK OUT/EDUCATE OTHERS HAVING MENTAL HEALTH DIFFICULTIES LACK OF CONFIDENCE NOT KNOWING OTHER PEOPLE IN A PROTEST NOT BELIEVING IN MYSELF; NOT ASKING FOR HELP PEOPLE MAY FIND IT DIFFICULT TO SPEAK UP FOR THEMSELVES DIFFICULT TO EXPRESS YOURSELF QUESTIONING MY OWN ABILITIES; INTERNAL BATTLE; LARGE CROWDS CAN STOP PEOPLE FROM JOINING A PROTEST LACK OF SELF BELIEF	BEING FRIGHTENED OF MY BOSS (II); FEAR OF NOT BEING ACCEPTED BEING AFRAID OF ABUSE FEAR OF BEING LAUGHED AT; FEAR OF PREJUDGEMENT FEAR OF BEING BULLIED; FEAR OF BEING JUDGED WORRYING ABOUT JUDGEMENT FROM OTHERS (II PEOPLE MIGHT BE FRIGHTENED TO STAND UP FOR THEMSELVES NOT REPORTING MISTREATMENT OUT OF FEAR THAT HE WOULD GET IN TROUBLE; NOT WANTING TO GET IN TROUBLE FELT LABELLED AND JUDGED FOR BEING IN A MENTAL HEALTH HOPSITAL; FEELING INTIMIDATED BY BEING ASKED MANY QUESTIONS	DENYING EMOTIONS IN FRONT OF OTHERS TO NOT LOOK WEAK BOTTLING UP" FEELINGS DIFFICULT TO EXPRESS FEELINGS BEING NERVOUS SPEAKING IN FRONT OF PEOPLE NOT FEELING EMOTIONALLY STRONG TO DO THINGS ON MY OWN GETTING DOWN ON YOURSELF BEING SHY AND NERVOUS WHEN MEETING NEW PEOPLE; BEING ANXIOUS ABOUT SAYING THE WRONG THING NOT HAVING THE SUPPORT AND COMMITMENT FROM PEOPLE AROUND ME MAKES IT DIFFICULT TO SHARE MY OWN EXPERIENCES BEING SHY TO ASK FOR SUPPORT BEING AN INTROVERT; NOT SPEAKING OUT; BEING SHY; BEING NERVOUS AT MEETINGS; PERSONAL EXPERIENCES ARE DIFFICULT TO DISCUSS; NOT EXPRESSING DIFFICULT FEELINGS; NOT EXPRESSING DIFFICULT FEELINGS FINDING IT HARD TO TRUST PEOPLE; FEAR THAT I WILL DO SOMETHING WRONG

PERCEIVED FACILITATORS

PERSONAL GROWTH			
SELF-CONFIDENCE	LEARNING FROM EXPERIENCE	KNOWLEDGE ABOUT HUMAN RIGHTS	VALUED ACTIONS
NOT CARING ABOUT WHAT OTHERS THINK; STARTING THE CONVERSATION FIRST HAVING CONFIDENCE BEING A VOICE FOR OTHERS BELIEVES THAT HE IS CAPABLE OF LIVING INDEPENDENTLY; HAVING CONFIDENCE IN ONE'S SELF; NOT HOLDING SELF BACK FROM SPEAKING UP ATTENDING THE GROUP HAS INCREASED MY CONFIDENCE/BELIEF IN MYSELF HAVING BELIEF IN MYSELF; TRUSTING OTHERS GOING TO SELF-ADVOCACY GROUP INCREASES CONFIDENCE HAVING THE ABILITY TO STAND UP FOR MYSELF; BEING CONFIDENT OWN EXPERIENCE LED HIM TO WANT TO HELP OTHERS; EXPRESSING HOW YOU FEEL HELPS CHARITY BUILT CONFIDENCE	DEVELOPING A THICK SKIN; RECOGNISING MISTREATMENT; BEING A SELF-ADVOCATE HAS HELPED ME GROW EMOTIONALLY LEARNING FROM OTHERS BEING TAUGHT BY PARENTS HOW TO STAND UP FOR MYSELF (II); LISTENING TO PEOPLE'S EXPERIENCES (II SEEING OTHERS AS ROLE MODELS E.G., COUSIN; BEING TAUGHT THINGS ABOUT OUR RIGHTS BY SELF-ADVOCACY GROUP; HAVING LEARNT FROM ONE'S PAST EXPERIENCES LEARNT TO STICK UP FOR MYSELF THROUGH WORK IN SELF-ADVOCACY GROUP, E.G., DOING WORKSHOPS; LEARNING SKILLS FROM SELF-ADVOCACY GROUP HAVING PREVIOUS EXPERIENCE OF SOMETHING LEARNING FROM OTHERS HOW TO STAND UP FOR HIMSELF WORKING WITH PEERS IN SELF-ADVOCACY GROUP MEMEBRS SHARING OWN EXPERIENCES WITH EACH OTHER; LEARNING RESILIENCE OVER THE YEARS	KNOWING WHAT MY RIGHTS ARE KNOWING ONE'S RIGHTS BEING AWARE OF ONE'S OWN RIGHTS READING THE HUMAN RIGHTS ACT KNOWS ABOUT THE HUMAN RIGHTS ACT KNOWING ABOUT HUMAN RIGHTS ACT	WILLINGNESS TO UNDERSTAND SITUATIONS BETTER INNER VOICE TELLS ME I'VE GOT TO DO THIS; WANTING TO PROTECT OTHERS, E.G., FRIEND SEEKING SUPPORT FROM OTHER MEMBERS WANTING TO MAKE A CHANGE EXPANDING KNOWLEDGE, E.G., DOING RESEARCH ON THE COMPUTER; KNOWING WHERE TO GO TO FIND OUT ABOUT ONE'S RIGHTS, E.G., DAD WHO IS A SOLICITOR, OR TO GROUP FACILITATOR; ASKING FOR SUPPORT ASKING FOR EXTRA TIME TO DO COLLEGE WORK DOING THINGS THAT I CAN ACHIEVE ASKING SOMEONE FOR HELP (E.G., HELP WITH THE READING) WANTING TO FIGHT BACK THE SOCIETY; ASKING FOR SUPPORT; ASKING FOR HELP WANTING TO CHANGE THINGS FOR OTHERS; PASSION TO HELP OTHERS

Miscellaneous	
PROFESSIONALS WANTING TO LEARN	PROBLEMS WHEN WORKING WITH OTHERS
HEALTH PROFESSIONALS HAVING THE WANT TO LEARN PROFESSIONALS WANTING TO LEARN	**PEOPLE TALKING OVER EACH OTHER** **PEOPLE ARGUING OR NOT LISTENING** **ARGUING WITH OTHERS** **PEOPLE NOT APPRECIATING MY HELP**

Appendix L: Samples of thematic tables illustrating the final themes and sub-themes, forming part of Step 7 of the thematic analysis

PARTICIPANTS' ACTIONS IN RESISTING STIGMA

ASSERTING ONESELF		
CONFRONTING/REPORTING MISTREATMENT (14 participants)	STATING ONE'S NEEDS/RIGHTS (8 participants)	PROVING PEOPLE WRONG (6 participants)
CONFRONTING PEOPLE'S MISTREATRMENT AND ASKING THEM TO STOP IT (P1); PUTTING PEOPLE IN THEIR PLACE (P1) VERBALLY CONFRONTING ABUSIVE BEHAVIOUR FROM OTHERS (P3) CONFRONTING MISTREATMENT ON BEHALF OF A FRIEND (P4) QUESTIONING MISTRETAMENT (P5) MONITORING HOSPITALS' DISABILITY SUPPORT (P7); REPORTING MISTREATMENT (P7) DEFENDING MY POSITION TO HOUSING OFFICER FOLLOWING COMPLAINT MADE TO THEM (P8); ASK PEOPLE TO STOP BULLYING (P8) CONFRONTING MISTREATMENT BY SAYING "I HAVEN'T BEEN IN TROUBLE OR ANYTHING (P9) REPORTED MISTREATMENT RECEIVED FROM PREVIOUS SUPPORT WORKER (P10) SAID TO BULLIES TO GO AWAY (P11): SPEAKING UP TO BULLIES/GIVING THEM AN EVIL LOOK (P11) NOT BEING AFRAID TO SHOW STRENGTH (P12); WARNING OTHERS (P12) STANDING FIRM AGAINST MISTREATMENT FROM STAFF MEMBER (P13) STANDING UP TO HOSPITAL STAFF BY SEEKING SUPPORT FROM ADVOCATE (P14); REPORTING MISTREATMENT FROM HOSPITAL STAFF TO ADVOCACY (P14); "STAFF ARE TREATING ME LIKE DIRT" (P14) PHYSICALLY STOOD UP TO CONFRONT BULLIES (P15); PHYSICALLY STOOD UP AND SAID 'HOW RUDE YOU ARE' (P15); RANG THE POLICE (P15) STANDING UP TO MISTREATMENT BY HOSPITAL STAFF BY SAYING "I AM A PERSON"; MAKING A COMPLAINT AGAINST A DOCTOR (P16)	WANTING TO LIVE INDEPENDENTLY (P6); REFUSED SUPPORTED LIVING (P6); WANTING TO CONVINCE FAMILY THAT I CAN LIVE INDEPENDENTLY (P6) INFORMING THE EMPLOYER THAT I HAVE A DISABILITY AND ASKING FOR REASONABLE ADJUSTMENTS (P1); HAVE ALWAYS WANTED TO HAVE INDEPENDENCE (P1) SAYING TO PEOPLE THAT I DON'T LIKE WHAT THEY SAID/THAT IT'S NOT NICE (P7) BE UPFRONT WITH YOURSELF (P8); SPEAKING MY OWN MIND (P8) DEMANDING HELP AT COLLEGE (P9); DEMANDING HELP WITH COLLEGE WORK (P9) STATING TO OTHERS THAT ONE KNOWS WHAT TO DO IN ONE'S LIFE (P14) TRYING TO FIND OUT WHY I AM NOT GETTING CARER'S ALLOWANCE (P15); ASKING FOR EASYREAD INFORMATION LEAFLET (P15); ASKING FOR SUPPORT THROUGH SOMEONE FROM AN ORGANISATION (P15) "PEOPLE RECOGNISING ME AS A PERSON AND NOT PUTTING ME DOWN" (P16); TELLING PEOPLE HOW I FEEL AND FOR THEM TO ACCEPT ME AS A PERSON (P16)	PROVING PEOPLE WRONG (P1); "IT'S LIKE PROVING MY WORTH AS A HUMAN BEING THAT I CAN FUNTION, EVEN THOUGH I HAVE GOT THIS" (P1) HAVING A JOB AND PROVING PEOPLE WRONG (P3) WANTING TO PROVE PEOPLE WRONG ALL THE TIME (P4) "THEY CAN'T SAY I CAN'T DO THINGS" (P14) PROVING PEOPLE THAT I CAN DO THINGS (P15); PROVING TO PEOPLE THAT I CAN DO THINGS (P15) PROVING TO PEOPLE THAT I CAN DO THINGS (P16)

PERCEIVED BARRIERS

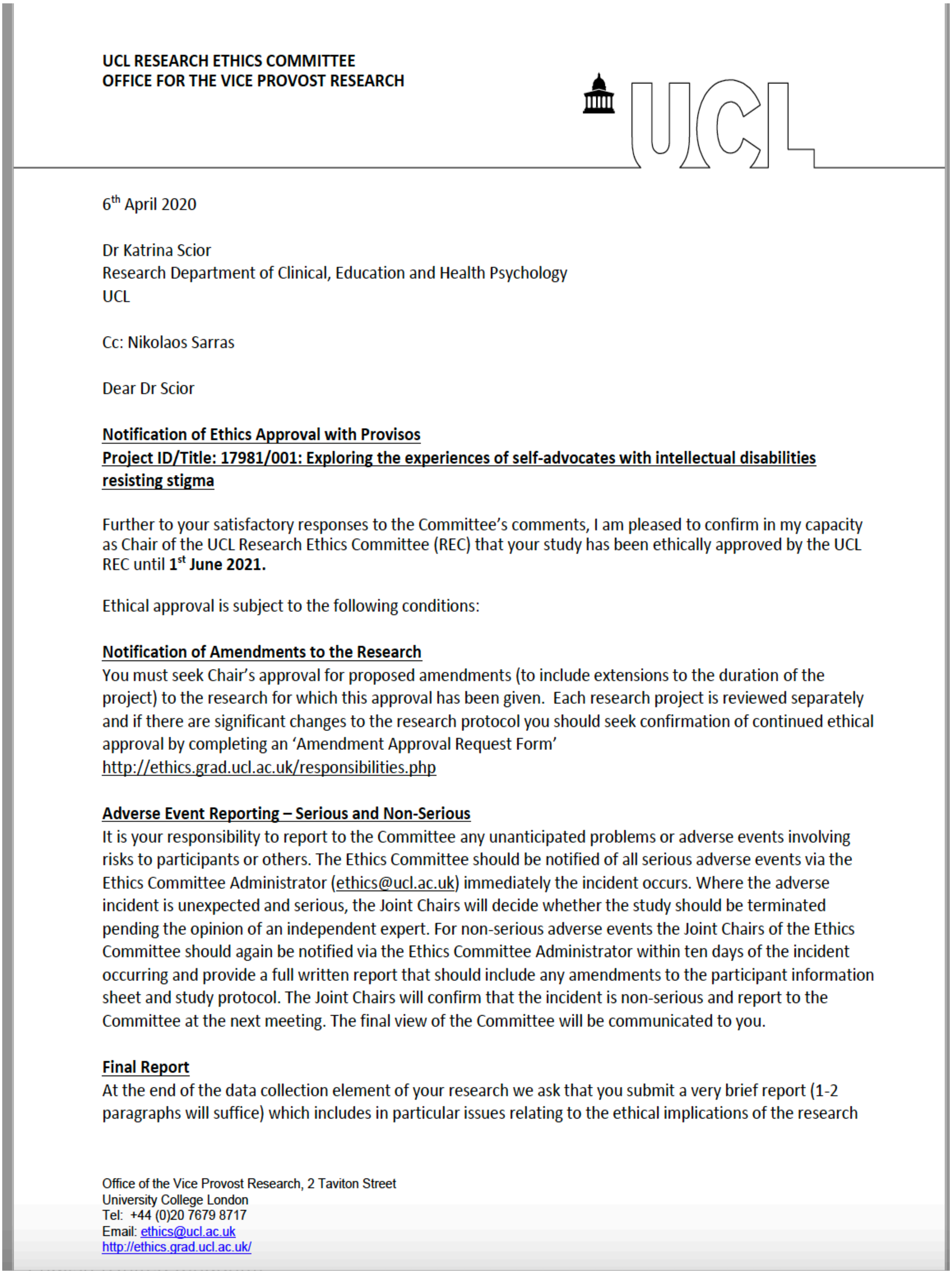
PERSONAL CHALLENGES			
NOT UNDERSTANDING (8 participants)	NOT KNOWING HOW/WHAT (11 participants)	INTERNAL STRUGGLES (13 participants)	FEAR OF OTHERS' RESPONSES (7 participants)
MISREADING SITUATIONS (P1) DOESN'T UNDERSTAND WHAT IS MEANT BY ONE'S RIGHTS (P2) PEOPLE WITH LEARNING DISABILITIES MAY FIND IT DIFFICULT TO UNDERSTAND WHAT HUMAN RIGHTS ARE (P8) PEOPLE WITH LEARNING DISABILITIES MAY NOT UNDERSTAND WHAT THEIR RIGHTS ARE (P10) NOT UNDERSTANDING ALL QUESTIONS ON A FORM (P11) PEOPLE MAY NOT UNDERSTAND WHAT OTHERS SAY TO THEM (P12) NOT UNDERSTANDING FAST SPEAKING (P13) PEOPLE WITH LEARNING DISABILIES FACE COMMUNICATION BARRIERS (P15)	NOT KNOWING HOW TO STAND UP FOR PEOPLE WITH INTELLECTUAL DISABILITY (P2) NOT KNOWING WHAT TO SAY (P3) NOT KNOWING WHAT TO SAY (P5); NOT KNOWING HOW TO DO IT (I.E., SPEAK OUT) (P5) PEOPLE WITH LEARNING DISABILITIES MAY NOT KNOW WHAT TO DO WHEN OTHERS SAY BAD THINGS TO/ABOUT THEM (P6) NOT KNOWING WHAT TO DO (P8) NOT ASKING FOR HELP (P9) PEOPLE WITH LEARNING DISABILITY MAY NOT KNOW HOW TO RESPOND TO MISTREARTMENT/WHAT TO SAY (P10); DIFFICULTY WRITING COMPLAINT ON MY OWN (P10) PEOPLE MAY NEED HELP TO ACHIEVE THINGS (P12) NOT KNOWING HOW TO CONTACT PERSON TO REPORT MISTREATMENT (P13) SOME PEOPLE WITH LEARNING DISABILITIES DON'T KNOW ABOUT HUMAN RIGHTS (P14) PEOPLE WITH LEARNING DISABILITIES MAY NOT KNOW WHAT TO SAY (P15)	DENYING EMOTIONS IN FRONT OF OTHERS TO NOT LOOK WEAK (P1) "BOTTLING UP" FEELINGS (P2) DIFFICULT TO EXPRESS FEELINGS (P3); BEING NERVOUS SPEAKING IN FRONT OF PEOPLE (P3); HAVING MENTAL HEALTH DIFFICULTIES (P3) LACKING THE CONFIDENCE TO SPEAK OUT/EDUCATE OTHERS (P4); FIND IT EMBARRASSING TO GET LOUD (P4); NOT FEELING EMOTIONALLY STRONG TO DO THINGS ON MY OWN (P4) LACK OF CONFIDENCE (P5); GETTING DOWN ON YOURSELF (P5) BEING ALL BY YOURSELF/NOT KNOWING ANYBODY (P7); USED TO BE SHY (P7) BEING SHY AND NERVOUS WHEN MEETING NEW PEOPLE (P8); BEING ANXIOUS ABOUT SAYING THE WRONG THING (P8) NOT BELIEVING IN MYSELF (P9) BEING SHY TO ASK FOR SUPPORT (P10) PEOPLE MAY FIND IT DIFFICULT TO SPEAK UP FOR THEMSELVES (P12) USED TO BE UNABLE TO EXPRESS MYSELF PROPERLY (P14); PERSONAL EXPERIENCES ARE DIFFICULT TO DICUSS (P14); BEING AN INTROVERT STOPPED ME FROM SPEAKING OUT (P14); PEOPLE WITH LEARNING DISABILITIES MAY SOMETIMES BE SHY (P14); CLAMMING UP AT MEETINGS (P14); NOT TALKING MUCH ABOUT THINGS I FIND DIFFICULT (P14) QUESTIONING MY OWN ABILITIES (P15); MY MIND TELLING ME THAT IT WILL BE HARD (P15); SHARING INFORMATION WITH STRANGERS IS NOT EASY (P15) LACK OF SELF BELIEF (P16); I WOULD GET UPSET IF THEY (PEOPLE) DON'T APPRECIATE MY HELP (P16); FINDING IT HARD TO TRUST PEOPLE (P16); FELT LABELLED AND JUDGED FOR BEING IN A MENTAL HEALTH HOPSITAL (P16); FEAR THAT I WILL DO SOMETHING WRONG (P16); FEELING INTIMIDATED BY "THEM ALL SITTING THERE THROWING QUESTIONS AT ME" (P16)	BEING FRIGHTENED OF MY BOSS (P1); FEAR OF NOT BEING ACCEPTED (P1) BEING AFRAID OF ABUSE (P3) FEAR OF BEING LAUGHTED AT (P4); FEAR OF PREJUDGEMENT (P4) FEAR OF BEING BULLIED (P6); FEAR OF BEING JUDGED (P6) WORRYING ABOUT JUDGEMENT FROM OTHERS (P8) PEOPLE MIGHT BE FRIGHTENED TO STAND UP FOR THEMSELVES (P12) NOT REPORTING MISTREATMENT OUT OF FEAR THAT HE WOULD GET IN TROUBLE (P14)

PERCEIVED FACILITATORS

EXTERNAL VALIDATION	
SUPPORT FROM OTHERS (16 participants)	ACCESSIBILITY (11 participants)
RECEIVING SUPPORT FROM MUM (P1); SUPPORT FROM CHARITIES (P1); STRONGER AS A GROUP (P1) SELF-ADVOCATES HELPING EACH OTHER (P2); SELF-ADVOCATES ENCOURAGING CONFIDENCE IN ONE ANOTHER (P2); PSYCHOLOGIST SUGGESTING SELF-ADVOCACY GROUP (P2); RECEIVING SUPPORT FROM MY MOTHER (P2) RECEIVING SUPPORT FROM PARTNER (P3); FATHER SUPPORTING EMPLOYMENT (P3); RECEIVING SUPPORT FROM SUPPORT WORKER (P3) RECEIVING SUPPORT FROM PARTNER (P4); RECEIVING SUPPORT FROM SELF-ADVOCACY GROUP (P4); RECEIVING SUPPORT FROM FAMILY (P4); FAMILY BELIEVING IN ME (P4); RECEIVING SUPPORT FROM FRIENDS (P4) RECEIVED SUPPORT FROM FAMILY (P5); HAVING SUPPORT FROM SUPPORT WORKER (P5); RECEIVING SUPPORT FROM FRIENDS AND PARTNER (P5); STRONGER AS A GROUP (P5) RECEIVING SUPPORT WITH HOUSING FROM SELF-ADVOCACY GROUP (P6); RECEIVING EMOTIONAL SUPPORT FROM GROUP (P6); RECEIVING SUPPORT FROM COLLEGE AND ADVOCATES (P6) RECEIVING HELP FROM SELF-ADVOCACY GROUP (P7); HELPING EACH OTHER IN SELF-ADVOCACY GROUP (P7); NOT BEING ON YOUR OWN (P7) RECEIVING SUPPORT FROM GROUP FACILITATOR AND FRIENDS (P8); HAVING SUPPORT FROM SELF-ADVOCACY GROUP (P8); RECEIVING SUPPORT FROM FRIENDS AND PARENTS (P8) HAVING SUPPORT FROM FAMILY AND FRIENDS (P9); FRIENDS AND FAMILY TREATING ME EQUALLY (P9); RECEIVING HELP WITH PRACTICAL ISSUES, E.G., WALKING (P9); MUM ADVISING ME TO ASK FOR HELP IF I CAN'T DO SOMETHING (P9); RECEIVED SUPPORT FROM COLLEGE TUTOR (P9); FAMILY ENCOURAGING ME TO STAND UP FOR MYSELF (P9); RECEIVING ENCOURAGMENT FROM OTHERS (P9) GETTING HELP WITH REPORTING MISTREATMENT (P10); HAVING SUPPORT FROM SUPPORT WORKER (P10); HAVING SUPPORT IN MAKING A COMPLAINT (P10) HAVING THE SUPPORT OF STAFF IN ORDER TO ACHIEVE THINGS (P11); HAVING THE SUPPORT OF STAFF TO JOIN A CAMPAING (P11); HAVING THE SUPPORT OF STAFF AND HUSBAND WHEN JOINING A PROTEST, E.G., TAKING PERSON TO ON BUSES (P11) SUPPORT WORKER MIGHT SUPPORT ME (P12) SUPPORT FROM PARENTS TO JOIN SELF-ADVOCACY GROUP (P12); HAD SUPPORT FROM FRIENDS AND NHS TO SPEAK UP IN CONFERENCES (P13) HAVING SUPPORT FROM NEIGHBOURS (P14); SPEAKING DIRECTLY TO STAFF ABOUT MISTREATMENT WITH ADVOCATE'S SUPPORT (P14); SUPPORT FROM ADVOCACY (P14); MOTHER ENCOURAGED ME NOT TO BELIEVE WHAT OTHERS SAY (P14); HAD SUPPORT FROM HOSPITAL STAFF TO DO A COURSE (P14); WAS READ HIS RIGHTS BY THE HOSPITAL; HAVING THE SUPPORT FROM THE PEOPLE LISTENING (P14); PEOPLE LISTENING TO ME (P14) SUPPORT FROM PUB STAFF TO STAND UP TO BULLIES (P15); SUPPORT FROM CHARITY (P15); SUPPORT FROM WIFE AND COORDINATOR (P15); SUPPORT FROM SELF-ADVOCACY STAFF (P15); ENCOURAGEMENT FROM WIFE (P15); RECEIVED SUPPORT WITH BENEFITS (P15)	MAKING INFORMATION ACCESSIBLE (P1); LIVING CLOSE TO A SELF-ADVOCACY GROUP (P1) HOLDING A CARD UP TO SPEAK OUT (P3); HAVING FREE ACCESS TO TRANSPORT (P3) GOING TO COLLEGE OR ONLINE TO LEARN ABOUT YOUR RIGHTS (P5) HAVING ACCESS TO COMPUTERS AND INTERNET TO FIND INFORMATION (P7); PREPARING THINGS TO SAY IN ADVANCE OF A MEETING (P7); PREPARING WHAT YOU ARE GOING TO SAY IN ADVANCE (P7) QUIET ROOM (P9) EASY READ (P11); BEING ABLE TO GO ON BUSES (P11); BEING ABLE TO GET ON TRAINS (P11); STAFF WRITING THINGS DOWN FOR PERSON (P11); STAFF WRITING THINGS IN EASY READ BEFORE DELIVERY OF TRAINING TO PROFESSIONALS (P11) HAVING A CARD UP WHEN YOU SPEAK (P12); PEOPLE SPEAKING ONE AT A TIME (P12) BEING GIVEN HELP WITH UNDERSTANDING THE SUBJECT OF A DISCUSSION (P13) ADVOCACY SERVICE IN HOSPITAL(P14); SPEAKING TO SOMEBODY WHO IS OFFICIAL (P14); WAS READ HIS RIGHTS BY THE HOSPITAL (P14); BEING GIVEN THE OPPORTUNITY (P14) PRACTICAL SUPPORT FROM STAFF, E.G., PREPARING THE SPEECH, HELP WITH BANNERS (P15) STAFF DOING PRESENTATION IN DIFFERENT WRITING (P16); BEING GIVEN THE OPPORTUNITY (P16)

SUPPORT FROM CHARITY (P16); SUPPORT FROM ADVOCACY (P16); PRACTICED PRESENTATION WITH STAFF BEFOREHAND (P16); SUPPORT FROM ADVOCATE (P16)	

Appendix M: Letter of approval from UCL Research Ethics Committee



UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

6th April 2020

Dr Katrina Scior
Research Department of Clinical, Education and Health Psychology
UCL

Cc: Nikolaos Sarras

Dear Dr Scior

Notification of Ethics Approval with Provisos
Project ID/Title: 17981/001: Exploring the experiences of self-advocates with intellectual disabilities resisting stigma

Further to your satisfactory responses to the Committee's comments, I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **1st June 2021.**

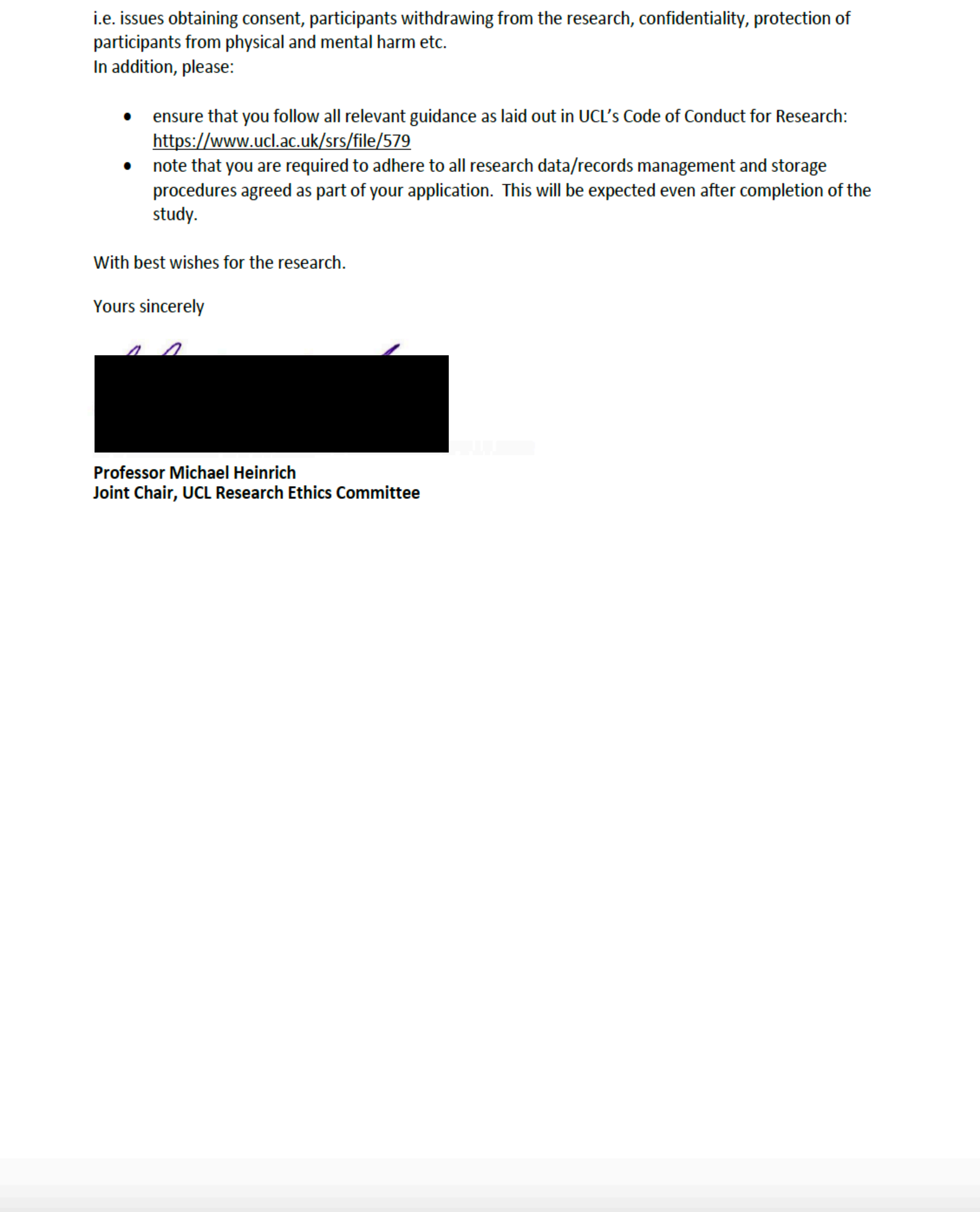
Ethical approval is subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'
http://ethics.grad.ucl.ac.uk/responsibilities.php

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research

Office of the Vice Provost Research, 2 Taviton Street
University College London
Tel: +44 (0)20 7679 8717
Email: ethics@ucl.ac.uk
http://ethics.grad.ucl.ac.uk/



i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.
In addition, please:

- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: https://www.ucl.ac.uk/srs/file/579
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

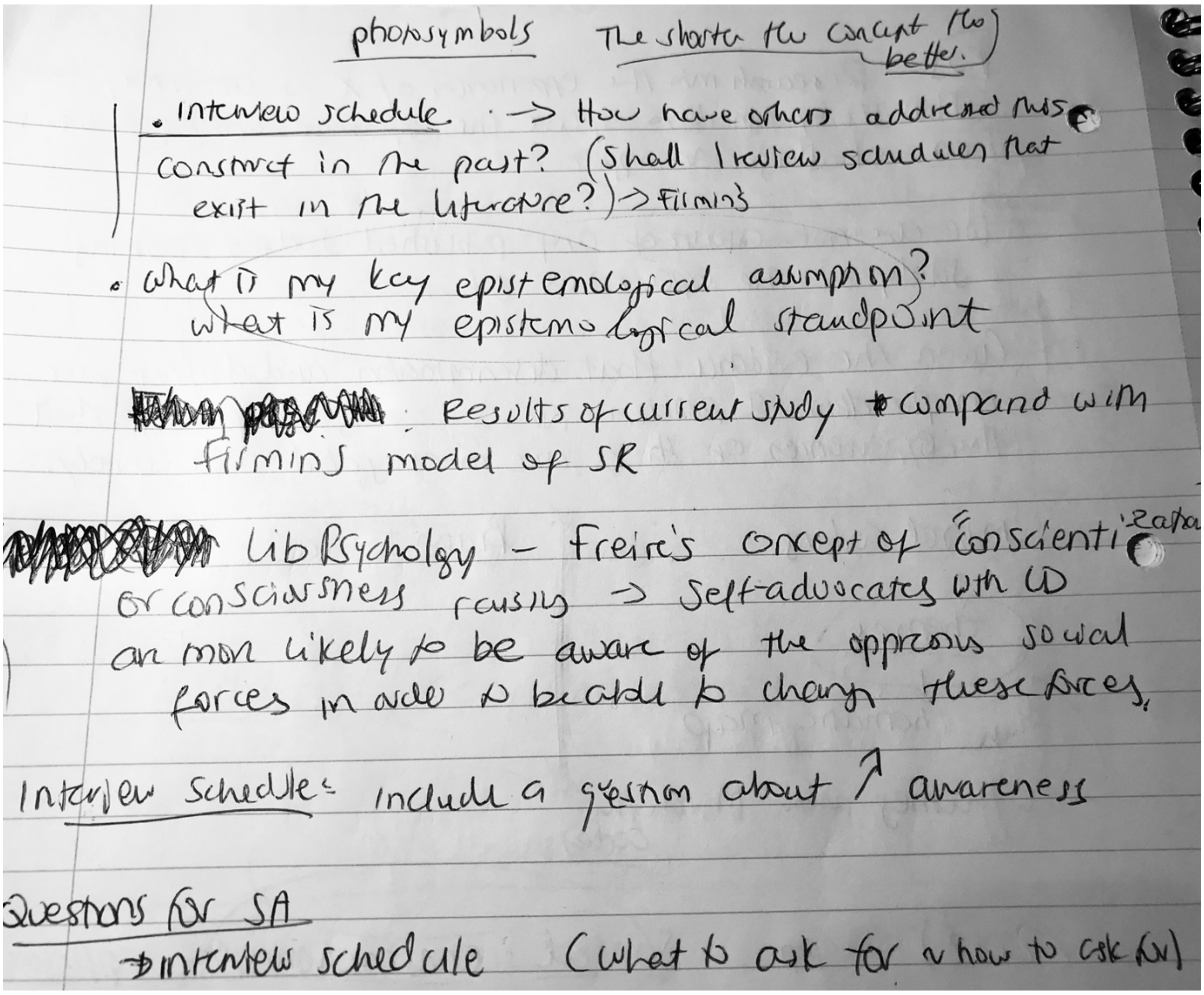
With best wishes for the research.

Yours sincerely

[redacted]

Professor Michael Heinrich
Joint Chair, UCL Research Ethics Committee

Appendix N: Brief samples of notes kept as part of the research journal



photosymbols The shorter the concept (the better.)

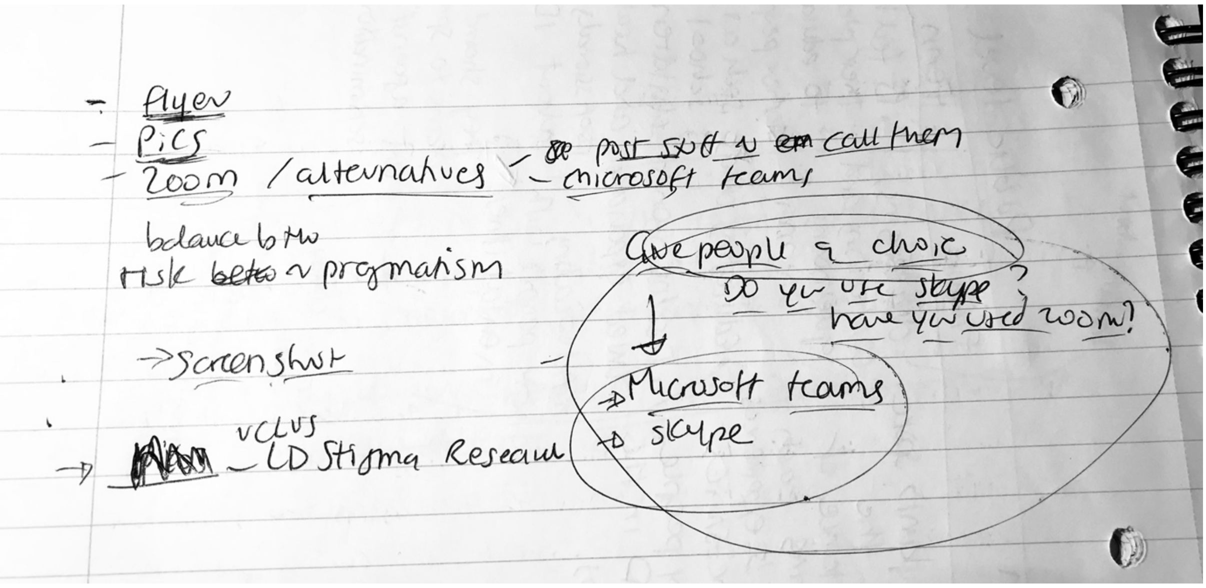
- interview schedule → How have others addressed this construct in the past? (Shall I review schedules that exist in the literature?) → Firmin's
- What is my key epistemological assumption? what is my epistemological standpoint

[redacted] : Results of current study * compared with Firmin's model of SR

[redacted] Lib Psychology – Freire's concept of conscientization or consciousness raising → Self-advocates with LD are more likely to be aware of the oppressive social forces in order to be able to change these forces.

Interview schedule: include a question about ↗ awareness

Questions for SA
→ interview schedule (what to ask for & how to ask for)



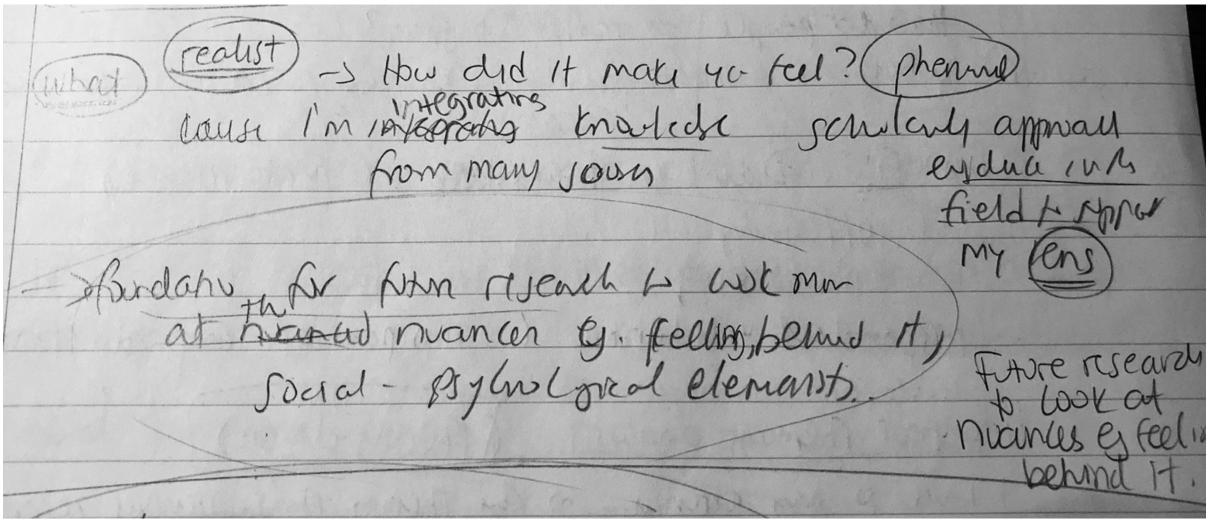
- flyer
- Pics
- Zoom / alternatives – ~~8e~~ post stuff & ~~em~~ call them
  – microsoft teams

balance btw
risk ~~betw~~ & pragmatism

Give people a choice
Do you use skype?
have you used zoom?
↓
→ Microsoft teams
→ skype

→ screenshot

→ [redacted] – VCLUS
LD Stigma Research



what realist -> How did it make yo feel? phenom

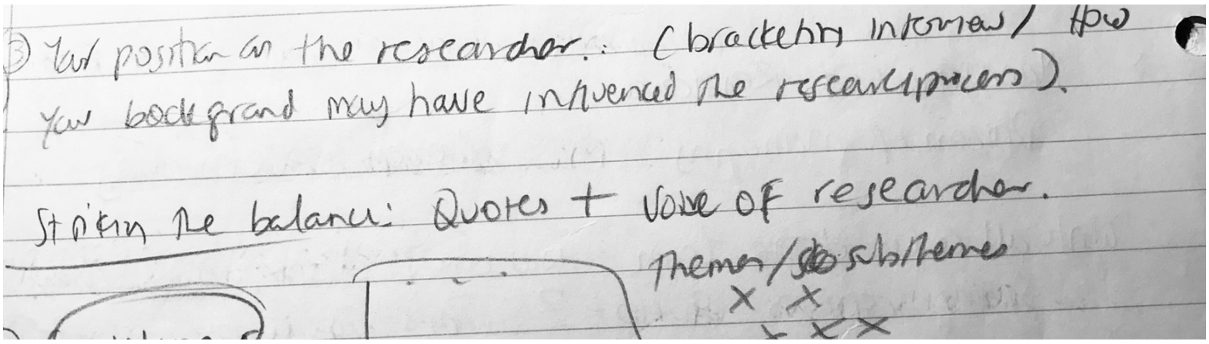
cause I'm ~~integrating~~ integrating knowledge scholarly approach

from many sources

evidence in the field & approach my lens

-> foundation for future research to look more at ~~[illegible]~~ the nuances eg. feelings, behind it, social - psychological elements.

Future research to look at nuances eg feeli behind it.



③ Your position as the researcher: (bracketing interview / How your background may have influenced the research process).

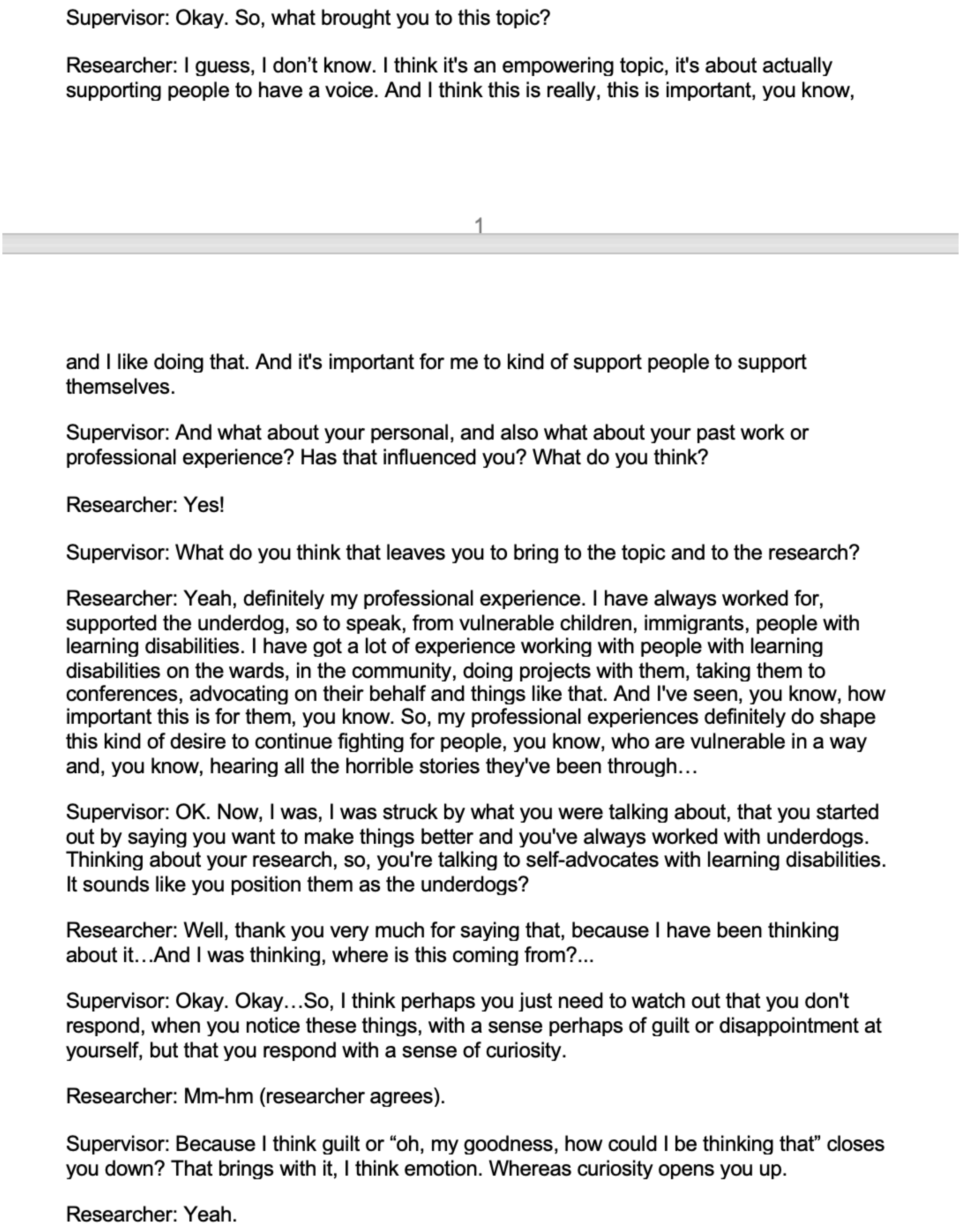
Striking the balance: Quotes + voice of researcher.

Themes / ~~sb~~ subthemes

X X

X X X

Appendix O: Sample of bracketing interview of the researcher. N.B. Ellipses (…) are used where sensitive information is omitted.



Supervisor: Okay. So, what brought you to this topic?

Researcher: I guess, I don’t know. I think it's an empowering topic, it's about actually supporting people to have a voice. And I think this is really, this is important, you know, and I like doing that. And it's important for me to kind of support people to support themselves.

Supervisor: And what about your personal, and also what about your past work or professional experience? Has that influenced you? What do you think?

Researcher: Yes!

Supervisor: What do you think that leaves you to bring to the topic and to the research?

Researcher: Yeah, definitely my professional experience. I have always worked for, supported the underdog, so to speak, from vulnerable children, immigrants, people with learning disabilities. I have got a lot of experience working with people with learning disabilities on the wards, in the community, doing projects with them, taking them to conferences, advocating on their behalf and things like that. And I've seen, you know, how important this is for them, you know. So, my professional experiences definitely do shape this kind of desire to continue fighting for people, you know, who are vulnerable in a way and, you know, hearing all the horrible stories they've been through…

Supervisor: OK. Now, I was, I was struck by what you were talking about, that you started out by saying you want to make things better and you've always worked with underdogs. Thinking about your research, so, you're talking to self-advocates with learning disabilities. It sounds like you position them as the underdogs?

Researcher: Well, thank you very much for saying that, because I have been thinking about it…And I was thinking, where is this coming from?...

Supervisor: Okay. Okay…So, I think perhaps you just need to watch out that you don't respond, when you notice these things, with a sense perhaps of guilt or disappointment at yourself, but that you respond with a sense of curiosity.

Researcher: Mm-hm (researcher agrees).

Supervisor: Because I think guilt or “oh, my goodness, how could I be thinking that” closes you down? That brings with it, I think emotion. Whereas curiosity opens you up.

Researcher: Yeah.

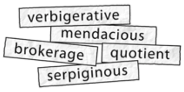
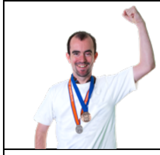
Appendix P: Accessible report with the findings of the study

	Easy read report with the findings of the research.
	In 2020, you took part in my university research.
	Research means finding out about things. Below are some reasons why we did the research.
	Some people with learning disabilities feel bad because of how others think of them or behave towards them.
	I wanted to find out what people with learning disabilities do when others treat them unfairly.
	I wanted to find out what gives people the confidence to stand up for themselves or prove others wrong.
	I also wanted to find out what makes it difficult for people to stand up for themselves.
	I asked you to take part because you go to a self-advocacy or speaking-up group for people with learning disabilities.

	I interviewed 16 self-advocates with learning disabilities on Zoom. Here is what everyone said.
	**Things that people with learning disabilities do to stand up for themselves or prove others wrong.**
 	Some may tell those who treat them badly to stop it or go away. But they do that only if it's safe. Some report the bad treatment to a family member, police or their support worker.
	Some state their needs or rights. For example, they ask for easy read materials. If they feel safe and comfortable, some also ask others to treat them well.
	Many show people what they can do.
	Some also do public speaking. For example, they speak up at conferences or people's parliament

	Sometimes, people join protests and campaigns. For example, they write to government to complain about things not being right.
	Some educate others about learning disabilities. For example, they speak to nurses, doctors, teachers.
	Many support their peers by listening to them.
	People may work with others to change things. For example, they work with their peers, MPs and other professionals.
	People may also take on responsibilities. Some become trustees for their self-advocacy groups. Others become consultant workers or have many jobs.
	People often work hard to achieve their goals. For example, they do competitive sports, travel independently or gain skills.
	Many do not believe negative things others may say about them. Instead, “they put their head up high” as one participant said.

	Many ignore or walk away from bad treatment or bullying. This is in order to stay safe.
	**Things that make it hard for people with learning disabilities to stand up for themselves or prove others wrong.**
	Not understanding things. For example, not understanding what their rights are or questions on a form.
	Not knowing how to stand up for themselves.
	Not having the confidence to stand up for themselves. Not believing in themselves.
	Fearing other people's responses.
	Bottling up their own feelings or getting down on themselves.

	Other people's bad attitudes and behaviours. For example, being told that they can't achieve things.
	Lack of support. For example, not getting the right help to do things.
 	Not having access to computers. Not having access to transport.
	Jargon words. For example, in information leaflets or on forms.
	**Things that make it easy for people with learning disabilities to stand up for themselves or prove others wrong.**
	Believing in themselves and not caring about what others think.
	Learning from others how to do things. Also, learning from their own experiences is helpful.

	Knowing what their rights are. For example, that they have the right to be respected and treated equally.
	Acting in line with what they believe is right. For example, helping others to stick up for themselves.
	Having the support from others. This could be from friends, family, partners, support workers, self-advocacy group.
 	Having access to easy read information. Having access to a computer.
	Being prepared. For example, preparing what to say in a presentation.
	**Here is the advice that participants wanted to share with other people about how to stand up for themselves.**
	Make sure that you find a person to talk to, especially if you are stressed.

	Say to people: You don’t have the right to say that to me. But only say that if you feel comfortable and safe.
	You have to do it not just for yourself, but for others.
	Have the confidence to do it. You can make a big difference in the community.
	Get other people from the group to support you.
 	Don’t react to that person and just walk away. Speak your mind, but only if you are safe.
	Never give up, even if people put you down.
	Get your own confidence to stand up for yourself.

	Have trust in yourself and speak up.
	Ask for support.
	Keep yourself to yourself. But if you have a problem, talk to someone outside of the place, like an advocate.
	If you've got a problem, get some help from an organisation, or your support worker or family. And don't be scared, because if you live behind your fear, you will get nowhere.
	Just pluck up the courage, if you've got to go anywhere. Say to others: 'I'm just as good as anybody else. Please listen to me and respect me'.
	Thank you again for taking part in the study.
	And good luck with the rest of your advocacy work.