

School of Psychology and Speech Pathology

**The Identities and Social Roles of People with Intellectual Disabilities: Challenging
Dominant Cultural Worldviews, Values and Mythologies**

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Abstract

Intellectual disability is commonly conceptualised as stigmatised identity with which one has to live. However, within the literature the notion of a damaged or intellectually disabled identity is contested. Numerous studies exploring the identities of people with intellectual disabilities have reported that this ascribed identity has little resonance with those who live with the label and that people with intellectual disabilities reject a stigmatised view of self. In contrast, it has been consistently reported that at least some people with intellectual disabilities appear to be unaware of their ascribed identity. A major criticism of past studies exploring the identities of people with intellectual disabilities is the ascription of a stigmatised identity *a priori* and a failure to consider the alternative identities an individual may embody, beyond that imposed on them by the dominant society. A further limitation of past research exploring the identities and social roles of people with intellectual disabilities (and research more generally) is the failure to include people with intellectual disabilities in the research process.

With these conceptual and methodological limitations in mind, this research was guided by two broad aims. The first aim of this research was to explore the social construction of intellectual disability, particularly the personhood, identities and social roles of people with intellectual disabilities. The role that worldviews, values, mythology and culture play in this construction was of particular interest. The second aim of this research was to increase the control, power and meaningful participation of people with intellectual disabilities in the research process. As such, this research was qualitative and was conducted within a participatory research framework. The co-researchers were 18 Members of an Advocacy Agency that supports people with intellectual disabilities based in the south west region of Western Australia. Photovoice and conversational interviewing were used to collect Member data. In addition, five staff members from the Advocacy Agency who expressed interest in being involved in the research were interviewed. The project spanned one year from initial contact with the Advocacy Agency through to a final reflection session.

Causal layered analysis, an in-depth, multilevel analysis that enables the factors that perpetuate social issues to be identified through the interaction of several different levels of understanding, was used to analyse both the Member and staff interview data. Analysis of the complex interactions that emerged across the causal layers revealed a number of interesting tensions and paradoxes. The identities presented by the Members were derived from the broader social context and reflected the social relations in which they engaged and the social roles they occupied. There was nothing abnormal or extraordinary about the way in which Members conceptualised their identities and social roles and it is suggested that this is in contest with the way in which the dominant culture socially constructs Members. Specifically, further deconstruction of the Member and staff interviews, and a Member life story revealed a complex dynamic of worldviews, values and mythologies which served to construct people with intellectual disabilities as incompetent, inherently different, and not quite human.

The cycle of victim blaming identified in this analysis encourages the implementation of strategies focused on changing people with intellectual disabilities (the victims), rather than broader society. An example of such a strategy is the delivery of educational and skill-building programmes which aim to enhance the independence and autonomy of people with intellectual disabilities, but have the converse effect of contributing to social stigma. For genuine, transformative change to occur, understandings of the 'problems' of intellectual disability must be reformulated and those social structures and social processes that support the relationship between the powerful and the powerless must be challenged.

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Chapter 1: Introduction

She said to her kids once I'm different to them... I think that's just her way of protecting me. She's overprotective of me... Jane, my oldest sister, she said to her "Greg's not stupid! He can do things himself!". That's what she told her... cos she said "Greg's not capable enough to get that cake out of the fridge" (laughs) and Jane said yes I am, "He's not stupid!"... That's what she told her. With her friends, she doesn't... she's embarrassed of me, more or less. But one of her best friends... he told her I'm not stupid. I can do things for myself... that's what he told (her)... "You shouldn't be ashamed of your own brother"... Yeah, but that's just the way she is. She can't change... I think that that's just her way of protecting me... I think that's just her way of doing the best she can, someone said to me... I still love her, like, she's still my sister.

These were the words spoken by Greg, a co-researcher in this project, as we shared a coffee in a local café. Here Greg captures the power of the label intellectual disability. Intellectual disability carries with it clear expectations for behaviours, emotions and cognitions. Because Greg has an intellectual disability he *is* clumsy and incapable. Because of the way he *is*, he evokes feelings of shame and embarrassment in others. In this extract, Greg goes on to contest this ascribed identity and make meaning of his sister's behaviour. The social construction of intellectual disability, particularly how the identities of those bestowed the label are conceptualised, is the focus of this thesis.

Preliminary Thoughts

All research is subjective, value laden and contextually contingent. Researcher subjectivity is considered a strength or resource of qualitative research, and as such it has been argued that the personal motivation of the researcher should be revealed and acknowledged (Creswell, 2013; Crotty, 1998; Schön, 1983). The practice of reflecting on one's personal values, motivations, actions and characteristics is particularly important for researchers exploring the experience of oppression (Vernon, 1997), as I am. The values, orientations and interests of the researcher inevitably influence what they choose to investigate, the research

questions they pose, the worldview underpinning the research, the research design and methodology, the analysis of the data, the their interpretation of the findings (Guillemin & Gillam, 2004; Northway, 2000). As a result, I have included the following section to share with the reader my personal motivation for conducting this research. For me, my interest in the social construction of intellectual disability undoubtedly stems from my personal experience as a sibling of someone with an intellectual disability. My older sister, Emma, has Down syndrome.

When thinking about ‘the moment’ that prompted me to conduct this research, one particular story that my Mother told me comes to mind. Before I was born and when Emma was just a baby, my parents had to make many trips to the city for specialist paediatric appointments. At one particular appointment, the specialist had warned my parents that Emma would probably never be able to talk and that it was likely that she would not be able to achieve very much. The specialist suggested to my parents that it would be best if they just “took Emma home and loved her”. After the appointment, my parents stood outside the entrance to the Children’s Hospital, completely bewildered staring at the baby in the pram. My Father then turned to my Mother and said “so are we going to take that bastard’s advice?”, “no way” she replied. It would seem that the specialist was operating under very different assumptions to that of my parents.

From the perspective of the specialist, Emma presented with an individual, biologically-based pathology; Down syndrome. The presence of a third chromosome on the 21st pair produces a distinctive phenotype which is expressed in over 300 specific characteristics, one of which is the presence of intellectual disability (Berger, 2005; Mulcahy, 1979). According to medical discourses, intellectual disability is conceptualised as impairment in cognitive or intellectual functioning. With Emma’s diagnosis of Down syndrome (and consequent intellectual disability) came the assumption of incompetence and deficit; she would never be able to talk, she would never do well at school and she most certainly would never be able to have a job. Immediately, Emma’s access to alternative identities and valued social roles was diminished. As a naturalised impairment or biology, Emma’s condition was considered to be stable and unchangeable; an undeniable truth (Chappell, Goodley, & Lawthom, 2001; Koegel, 1986). This hopeless prognosis could be made

after just one 15 minute consultation with a four month old baby. Emma was her professionally diagnosed incompetence (Jenkins, 1998).

In contrast, my parents saw no reason why Emma should be hemmed in by her diagnosis of Down syndrome. While acknowledging that Emma would undoubtedly experience some difficulties in the future (as all people do), they assumed that she would be able to live a full and satisfying life. Emma would exceed the dismal expectations imposed on her by others from birth. She would achieve academic success, gain meaningful employment, form friendships and relationships and live independently. Emma would achieve and be successful. Why wouldn't she? For my parents, Down syndrome was only one small part of who Emma was.

Through listening to my Mother tell that particular story and my own experiences as a sibling, I am keenly aware how powerful the label 'intellectually disabled' is. This status is so powerful and pervasive that it can be all-consuming (Beart, Hardy, & Buchan, 2005). The affixing of this stigmatising label can serve to limit access to alternative positive identities and other valued social roles (Wolfensberger, 1998). Often low expectations are assumed and consequently limited opportunities are offered (Jenkins, 1998). Furthermore, people with intellectual disabilities are often cast in roles that are negative and devalued in society (Wolfensberger, 2000). It is these observations and my own personal experiences that culminated in my choosing to research the social construction of intellectual disability, with a focus on the personhood, identities and social roles of people with intellectual disabilities. I was particularly interested in the role of those societal values, attitudes and assumptions toward people with intellectual disabilities that I had encountered. I also wanted to conduct research that enabled the perspective of people with intellectual disabilities to be captured and did not further perpetuate what I saw to be the shortcomings of traditional disability research. My underlying values and assumptions and my role within the research process is explored further in chapter seven.

The Research

This research explores the personhood, identities and social roles of people with intellectual disabilities. The role of worldviews, values and mythologies in this construction was of particular interest. I embarked on the initial stages of thesis

development in 2011. After achieving candidacy, I approached an advocacy agency in the south west region of Western Australia to see if they would be interested in being involved in the research. I was invited to a Member meeting where I presented the research topic to the Members with intellectual disabilities. The Members indicated that the questions 'who am I?', 'what makes me me?' and 'what is important to me?' was something they were interested in investigating.

The title of the research project was 'This Is Me', capturing the research focus of identities and social roles from the perspective of the Members. Photovoice and conversational interviewing were used to collect the Member data. During this process, staff members of the Advocacy Agency expressed interest in being involved in the research, so a second smaller study was developed. Interested staff members were interviewed. Reflecting the wishes of the Members, a public photograph exhibition was held at the local shopping centre displaying the photographs that they had taken as part of the This Is Me project. The project spanned one year from initial contact with the Advocacy Agency through to a final reflection session. After the final session with the Members, I analysed the data from the Member Photovoice interviews and the staff interviews using causal layered analysis.

Research aims and objectives.

This research was guided by two broad aims. The first aim of this research was to explore the social construction of 'intellectual disability', particularly the personhood, identities and social roles of people with intellectual disabilities. The role that worldviews, values, mythology and culture play in this construction was of particular interest. The second aim of this research was to increase the control, power and meaningful participation of people with intellectual disabilities in the research process.

The research objectives were as follows:

1. To explore how people with intellectual disabilities conceptualise their own identities and social roles.
2. To explore how the staff who work closely with people with intellectual disabilities conceptualise the identities and social roles of their clients.

3. To negotiate with the Members the nature and form of the research agenda and process.
4. To support the Members to be co-researchers throughout the research process.
5. To inform clinical psychological practice with people with intellectual disabilities.
6. To inform the way in which services support people with intellectual disabilities.

Changes in the research process are common in research projects that are informed by a contextualist perspective and utilise a participatory research framework (Park, 1993). The researcher must be reflexive and responsive to the needs of the co-researchers. The difference in the research objectives from that proposed initially is the inclusion of research objective number two. As previously noted, during the research project staff members of the Advocacy Agency expressed interest in being involved in the research. In response to this request, a second smaller study was developed. This study explored how the Advocacy Agency staff conceptualised the identities and social roles of the Members. This study is presented in chapter five. In addition, during the analysis of the Member data it became apparent that the subtle and pervasive social processes that impact on the lives of people with intellectual disabilities needed to be illuminated. As such, it was decided that an in-depth lifestory of one of the Members be included to not only illustrate those deeply entrenched social processes but to also humanise the experiences of people with intellectual disabilities. Paul's lifestory is presented in chapter six.

Terminology

The terminology for what is now referred to as 'intellectual disability' has varied enormously over the past 200 years (Cocks & Allen, 1996; Rapley, 2004; Schalock, Luckasson, & Shogren, 2007). In fact, terminology has officially changed nine times in the past century (Harris, 2006). Terms such as 'idiot', 'imbecile' and 'moron' that were once part of the formal classification were gradually replaced with other terms such as 'mental retardation', 'learning disability' and 'mental handicap' (Atkinson & Walmsley, 2010; Harris, 2006). The terminology used reflects the understandings or formulations of intellectual disability of the particular time

(Kuhn, 2012; Rioux, 1997). The shifting ideological frameworks that underpin how disability is perceived, diagnosed and treated are explored further in the following chapter.

At the current time, intellectual disability is the preferred term for the disability historically referred to as mental retardation (Hudson & Radler, 2005; Schalock et al., 2007). This term is preferred as it reflects changes in the construct of disability as disseminated by the American Association on Intellectual and Developmental Disability and the World Health Organisation (Harris, 2006; Luckasson & Schalock, 2013; Schalock et al., 2007). It has been argued that this terminology aligns better with the current emphasis on context and professional practice focused on increasing functional capacity via individualised supports (Luckasson & Schalock, 2013). Furthermore, the term intellectual disability is the least offensive to individuals and their families (Luckasson & Schalock, 2013; Schalock et al., 2007). Intellectual disability is generally consistent with international terminology, with the exception of the United Kingdom where the self-advocacy agency 'People First' has expressed a preference for the term 'learning difficulties' (People First, 2014). When citing research from the United Kingdom I will use the term learning difficulties. In this thesis, I will refer to people with intellectual disabilities in relation to my own research. This will not be abbreviated as to do so would encourage the further alienation of people.

Structure of the Thesis

Following this chapter, I review the literature relevant to this research. Chapter two is divided into three broad sections. First, I provide an overview of the different understandings of intellectual disability. The medical model of disability, the social model of disability and an embodied ontology of disability are presented. A post-modernist posture is then proposed as a framework for exploring how intellectual disability is conceptualised. Second, post-modernist conceptualisations of identity are examined. These approaches to understanding the self and identity emphasise the degree to which people's identities are constructed in the context of social relations (Gergen, 1990b). The importance of social roles as a source of identity is also examined and intellectual disability is presented as a powerful master status. Third, the literature examining the identities and social roles of

people with intellectual disabilities is reviewed. Several key conceptual limitations, particularly the assumption of a stigmatised identity, are presented. Finally, a rationale for conducting this research is presented.

Next, in chapter three I outline the methodology of this study. I begin by restating the aims and objectives of the research and describing the epistemological underpinning of this research; contextualism. I then discuss participatory approaches to disability research, presenting Photovoice and conversational interviewing as methodological options. Information about the co-researchers, the materials and equipment, the research procedure and the approach to data analysis is then provided. The co-researchers involved in the research were Members of an Advocacy Agency for people with intellectual disabilities. Photovoice and conversational interviewing were used to collect Member data. Data were analysed using causal layered analysis (CLA) which corresponds well with contextualism, privileging the socially constructed nature of phenomenon. Finally, ethical considerations relevant to this research are explored and the strategies employed to enhance the trustworthiness of the research are discussed.

In chapters four and five, I present the findings of the CLA of the Member Photovoice interviews and the staff interviews, respectively. The themes emerging from the analysis are then integrated with the existing literature and relevant theory to support my interpretation of the data. Finally, the findings of the analysis are reconstructed and consolidated and some implications are suggested. In chapter six, I present the lifestory of one of the Members, Paul. By presenting the life and experiences of Paul, I illuminate those subtle social processes identified in chapters four and five that are often so deeply embedded in our day-to-day life, that they may go unnoticed.

Following the presentation of the research findings, in chapter seven I reflect on my own experiences of engaging in participatory research with people with intellectual disabilities. This chapter is based on excerpts from my reflexive journal which was maintained throughout the duration of this research. In this chapter, I describe the tensions I experienced juggling two oftentimes conflicting demands; conducting research that met the requirements of the university and the need for the Members to have control and exert power (influence) in the research

process as co-researchers. I also describe the relationship between the Members and myself and question the notion of empowerment. Lastly, I examine my role as a researcher in the co-construction of the data.

Finally in chapter eight, I position the research findings in relation to the two aims of the research; (1) to explore the social construction of 'intellectual disability', particularly the personhood, identities and social roles of people with intellectual disabilities, and (2) to increase the control, power and meaningful participation of people with intellectual disabilities in the research process. By referring to the existing literature and relevant theory, I describe the ways in which my study has made a substantial and novel contribution to both theory and practice with people with intellectual disabilities. The possible implications of, and recommendations from, the findings are suggested. In addition, I outline the strengths and limitations of the study and suggest avenues for future research.

Chapter 2: Literature Review

“We are what we have been told about ourselves. We are the sum of the messages we have received. The true messages. The false messages”

- Donald Barthelme, ‘Snow White’ (Play)

Introduction

This review of the literature is divided into three broad sections. First, understandings of intellectual disability will be explored. Over time, conceptualisations of intellectual disability have undergone periodic revolutions, transitioning from understandings embedded in the medical model of disability, to the social model of disability and most recently, an embodied ontology of disability. Post-modernism is then proposed as a framework for examining worldviews, assumptions and discourses and the role they play in the social construction of intellectual disability. Second, post-modernist conceptualisations of identity and self, particularly symbolic interactionism, are introduced highlighting the importance of social roles in the development of identity. Intellectual disability is described as a powerful and pervasive master status and social role valorisation is presented as a means of enhancing the valued social roles and positive identities of people with intellectual disabilities. Finally, studies examining the identities and social roles of people with intellectual disabilities are reviewed and the limitations of the studies are discussed. Lastly, I conclude with my justification and rationale for the study of the identities and social roles of people with intellectual disabilities from a post-modernist perspective.

Understandings of Intellectual Disability

The nature of intellectual disability and the ways in which we conceptualise intellectual disability have undergone periodic change (Rioux, 1997). Those underlying assumptions and intellectual structures upon which research and development in a field of inquiry are based is referred to as a paradigm (Kuhn, 2012). Paradigms have an ontological, epistemological and methodological basis (Lincoln, Lynham, & Guba, 2011). In the process of exploring an aspect of nature,

anomalies and paradoxes arise which cannot be explained using the methods legitimated by the paradigm. When enough significant anomalies have accrued, the existing paradigm is replaced whole or in part by a new paradigm (Kuhn, 2012). World views change and there is a revolution of ideas and knowledge. New and different things are discovered in familiar places, as well as unfamiliar places. Paradigm shifts appear most obvious in natural sciences which appear mature and stable, such as physics.

However, like the transition from Newtonian mechanics to Einstein's Relativistic worldview, understandings of intellectual disability have too undergone periodic revolutions (Kuhn, 2012). These shifting ideological frameworks underpin the social and scientific formulations of disability, including how disability is perceived, diagnosed and treated and the social responsibility of the broader society toward people with intellectual disabilities as a group (Rioux, 1997). These shifting ideological frameworks not only inform ways of knowing disability, but also the development of research questions, research methodologies, the interpretation of research results and the consequent policies and programmes (Rioux, 1997).

Three different understandings of intellectual disability have been identified in the literature, reflecting changing formulations of disability more generally (McKenzie, 2013; Rioux, 1997). They are; (a) the medical model of disability which formulates disability as resulting from individual pathology, (b) the social model of disability which considers disability to be the consequence of social pathology, and (c) an interactive model of disability which posits that disability reflects a combination of these processes. These different ways of understanding disability (and intellectual disability) are described below.

The medical model of disability.

The medical model was the traditional paradigm of disability (Kuhn, 2012; Shakespeare & Watson, 2001). According to this perspective, disability is conceptualised as being caused by a mental or physical condition; a biological injustice (Fine & Asch, 1988; Rioux, 1997). This understanding of disability as bodily abnormality called for medical, biological and genetic intervention (Prilleltensky, 2006; Rioux, 1997). The disability field abounded in medical expertise and efforts were focused on preventing or ameliorating the condition which was considered an

anomaly and social burden (Rioux, 1997). People with disabilities were commonly viewed as hapless beings requiring the sympathy and care of the non-disabled or 'normal' (Prilleltensky, 2006). Disability became an all-consuming identity. Those who did not despair about their disability or denied the centrality of disability in their lives were believed to be in denial (Prilleltensky, 2006). This is explored further in the section 'Identity and Intellectual Disability' below.

Over the past two decades, understandings of disability evolved from the 'disability as a tragedy' model toward a focus on treating functional incapacity; that is, to reduce the impact of the impairment and maximise functioning of the individual with the disability (Schalock, 2011; Shakespeare & Watson, 2001). Social-ecological perspectives began to infiltrate understandings of disability and prompted this movement (Schalock, 2011). The emphasis of the 'functional approach' is assisting people with disabilities to function more independently and become valued and productive members of society (Rioux, 1997). The principles of normalisation (Nirje, 1969) and social role valorisation (Wolfensberger, 1998) have been central to this movement (see the section 'Social role valorisation' below). Key to this conceptualisation of disability has been the development of services and strategies to assist people with disabilities achieve their fullest potential. Strategies included the movement of people with intellectual disabilities from large, segregated institutions to supported community living and from sheltered workshops to fully integrated employment (Schalock, 2011). The success of services and programmes, such as behaviour modification programmes, are judged on their ability to approximate the lives of people with disabilities to the lives of valued (normal?) people (Rioux, 1997).

At the current time, intellectual disability is viewed as a disability that is characterised by significant limitations in intellectual functioning and adaptive behaviour which manifests during the developmental period (Schalock, 2011). According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-V; American Psychiatric Association, 2013) a diagnosis of intellectual disability requires three criteria to be met. First, there must be a deficit in intellectual functioning (such as working memory, reasoning and verbal comprehension) which is confirmed by both clinical assessment and individualised, standardised intelligence testing. An

intelligence quotient two or more standard deviations below the population mean is considered a deficit in intellectual functioning. Second, there must be a deficit in adaptive functioning as evidenced by how well the individual meets development and sociocultural standards for independence and social responsibility. A deficit in adaptive functioning may reflect difficulties in areas such as communication, social participation and independent living. Adaptive functioning is assessed using both clinical evaluation and individualised, standardised measures. Third, the onset of the intellectual and adaptive deficits must occur during the developmental period (present in childhood or adulthood). The DSM-V also offers an index of severity reflecting the level of adaptive functioning. Intellectual disability must be diagnosed by a professional such as a medical doctor or a psychologist (Gillman, Heyman, & Swain, 2000).

Diagnosing and formally classifying intellectual disability in such a way has enabled people with intellectual disabilities to be identified and granted access to services and supports. Within Australia, citizens aged 16 years or more who have been assessed as having an intellectual disability are able to receive the 'Disability Support Pension' (Department of Human Services, 2014). A maximum support payment of \$751.70 per fortnight enables people identified as intellectually disabled to access the services and supports needed on the basis of their level of adaptive functioning, health status and other contextual factors, such as geographical location (Department of Human Services, 2014; Schalock, 2011). People with intellectual disabilities are also provided with an array of educational, residential, occupational and support services and legal protections (Schalock, 2011). These initiatives have done much to enhance the lives of those diagnosed as intellectually disabled.

Despite these accomplishments, medical formulations of disability have been criticised for their failure to acknowledge the impact of social factors which serve to limit and disable people with mental or physical conditions (Oliver, 1996). It was argued that locating disability solely within the individual with a condition or impairment ignored the social and economic barriers experienced by disabled people. In light of these limitations, there was growing sentiment that the medical model of disability was an inadequate way of understanding and explaining the

experiences of people with disabilities (Kuhn, 2012; Shakespeare & Watson, 2001). This sense of malfunction was the prerequisite for the paradigm shift toward more social models of disability (Kuhn, 2012; Oliver, 1992).

The social model of disability.

The social model of disability was developed in the 1970s by disabled activists in the Union of the Physically Impaired Against Segregation (UPIAS); a self-organised disability movement in Britain (Oliver, 1996). The social model of disability was later given more theoretical shape by academics such as Mike Oliver (1990, 1996), Colin Barnes (2004) and Vic Finkelstein (1980; 1993). Key to the social model of disability is the distinction between impairment and disability (McClimens, 2003). According to this model, impairment is the loss or lack of some functioning part of the body (biological) whereas disability is the meaning society attaches to the impairment (social). Proponents of the social model of disability have argued that disabled people are an oppressed social group and that 'disability' is essentially an artificial and exclusionary social construction that serves to penalise those who do not conform to socially prescribed ideals of appearance and behaviour (Tregaskis, 2002).

The conceptualisation of disability as a social construction has had a number of benefits for disabled people. The social model of disability has been instrumental in the identification, analysis and removal of societal barriers (Shakespeare, 2004). Rather than prioritising medical treatments or rehabilitation, energies were directed toward dismantling societal barriers and creating social change (Prilleltensky, 2006; Shakespeare & Watson, 2001). Priorities for action became the acknowledgement of citizen rights and anti-discrimination legislation. Locating the 'problems of disability' outside of the individual and to the discriminatory society in which people lived was, and continues to be, a liberating experience for disabled people (Shakespeare & Watson, 2001). Ora Prilleltensky argued that this conceptualisation of disability has done much to improve the self-esteem and wellbeing of people with disabilities. People with disabilities could rightfully feel angry and resentful, rather than incompetent and dependent (Shakespeare, 2004). This fuelled a sense of solidarity, resistance and mobilised self-determination and disabled people became empowered to demand their rights (Prilleltensky, 2006;

Shakespeare & Watson, 2001). The improvement witnessed to the lives of disabled people, through anti-discrimination legislation and the removal of other societal barriers has elevated the Social Model of Disability to iconic status (Oliver, 2013; Thomas, 2004a).

Limitations of the social model of disability.

Over the past thirty years the social model of disability has been touted as a powerful organising principle, a rallying cry and practical tool (Thomas, 2004a). Disabled feminist Liz Crow (1996) stated; “My life has two phases: before the social model of disability, and after it” (p. 206), illustrating the profound impact this conceptualisation of disability has had on the lives of people with disabilities. Despite these achievements, as with all theoretical models, the social model of disability is underpinned by social and scientific understandings of disability. As these ideological frameworks shift over time, new theories and frameworks to guide disability practice and research emerge (Rioux, 1997; Shakespeare & Watson, 2001). This is not to invalidate the social model of disability, but rather to acknowledge its limitations and to identify alternative ways of explaining the experience of disability. The main criticisms of the social model of disability are (a) the denial of the relevance of impairment, (b) the binary division between the biological and the social, (c) the assumption of centrality of the ‘disabled’ identity, and (d) the neglect of people with intellectual disabilities by the social model of disability. Each of these criticisms is explored further below.

First, the social model of disability has traditionally avoided or excluded the issue of impairment and focused solely on the impacts of oppressive attitudes and practices (Prilleltensky, 2006; Shakespeare & Watson, 2001). Impairment is completely ‘bracketed’ and relegated to the realm of ‘private life’ (Thomas, 2004b). The denial of the relevance of impairment and the failure of the social model of disability to encompass personal experiences of limitation and pain ignores key dimensions of the disability experience (Shakespeare & Watson, 2001; Thomas, 2004b). Prilleltensky (2006) argued that this may have the unwanted effect of invalidating some people’s struggles with their bodies. Crow (1996) agreed that the tendency to centre on disability disregards the role of impairment in determining the experiences of disabled people. Impairment is not always irrelevant, neutral or

positive and it is important that this part of an individual's biography is explored and shared (Crow, 1996). Ignoring the impairment-related distress experienced by some people with disabilities fails to capture the complexity of the disability experience (Shakespeare & Watson, 2001). To encapsulate the total experience of disability, a recognition of subjective experience of impairment is essential (Crow, 1996). People are disabled by both societal barriers *and* their bodies.

Second, the social model of disability rests on the binary division between the biological (impairment) and the social (disability). Impairment is conceptualised as a loss or lack of some functioning part of the body, while disability is described as the relationship between the person with an impairment and the broader society (Oliver, 1996). Shakespeare and Watson (2001) argued that there are problems inherent to this dualism. Impairment, even though it is situated in biology, is still socially and culturally determined. There is no 'natural' or 'unimpaired' body existing outside of discourse; everything is always social (Shakespeare & Watson, 2001). Further, it is impossible to determine where impairment ends and disability begins; impairment may produce disability (such as, societal oppression and disadvantage) and disability may create or worsen impairment (Shakespeare & Watson, 2001). The socially constructed nature of impairment and the circularity of the relationship between impairment-disability suggest that the binary division is illusory. Disability is complex and variable and cannot be reduced to a single identity (Shakespeare, 2004; Shakespeare & Watson; Thomas, 2004a).

Third, many disabled people do not wish to see themselves as disabled and deny the significance of impairment in their lives (Shakespeare & Watson, 2001). Indeed, many people with intellectual disabilities actively resist being defined as 'disabled' or 'different' and develop a strong identity based on other aspects of their lives (Fine & Asch, 1988; Finlay & Lyons, 1998; Rapley, 2004). The lack of salience of the 'disabled' identity for some people with this label and the multiple, alternative identities of people with intellectual disabilities are explored further in the section 'Salience of the intellectually disabled identity' below. Shakespeare and Watson argued that by assuming disability will always be central to an individual's identity, the social model of disability commits the very same fallacy as the

traditional or medical perspective of disability. People can choose how they wish to identify.

Finally, this social model of disability has its origins in people with physical or sensory impairments and despite its attempts to encompass the experiences of all disabled people, people with intellectual disabilities have been almost entirely ignored (Chappell et al., 2001; Shakespeare, 2004). Chappell (1998) suggested that the social model of disability assumes that the impairment is located in the body, as indicated by the reference to disabled people and able-bodied people. The failure to examine intellectual or cognitive impairment implies that the social model of disability has no explanatory power for people with intellectual disabilities (Chappell, 1998; Shakespeare, 2004). A further indication of the marginalisation of people with intellectual disabilities is the lack of studies exploring the experiences and views of people with intellectual disabilities in the disability literature (Chappell, 1998). There appears to be something unique about 'intellectual disability' that means that it cannot be socialised. The problems experienced by people with intellectual disabilities are perceived as inherent to their impairment, not societal barriers or a disabling society (Chappell et al., 2001). The application of an individualised model of disability to people with intellectual disabilities will be returned to in the section 'Individualism and intellectual disability' below.

In light of these criticisms, it has been suggested that an alternative ontology of disability is required (Shakespeare & Watson, 2001). Calls have been made to move beyond the polarity of the medical model of disability and the social model of disability, to embrace a more eclectic theorising of disability and engage with a post-modernist (crucially questioning) perspective of disability (Crow, 1996; Gabel & Peters, 2004; Goodley & Roets, 2008; Shakespeare, 2004).

A paradigm shift?

For the last decade there has been sustained interest in embodiment and impairment within the field of disability studies (Hughes, 2007; Shakespeare, 2004; Shakespeare & Watson, 2001). Such theorising can prompt new paradigms which are associated with particular assumptions about the world (Gabel & Peters, 2004; Kuhn, 2012). Disability researchers began to engage in post-modernist thinking and question the complex and dialectic nature of disability (Shakespeare & Watson,

2001). The post-modern paradigm negates the likelihood of an objective reality and assumes that everything (including reality itself) is socially constructed (Gabel & Peters, 2004). Post-modernism is reflexive, uncertain and dynamic and posits that there are multiple realities. Through deconstruction it is possible to reveal the tensions or paradoxes of the social world (Gabel & Peters, 2004; Goodley & Roets, 2008). Post-modernism presents a challenge to the assumptions of individual knowledge, objectivity and truth so central to psychology and traditional, medicalised understandings of disability (Gergen, 2001; Oliver, 1996). This approach to theorising or understanding disability also encourages the exploration of the 'third dimension' or the spaces between objectivity and subjectivity (Gabel & Peters, 2004). This is particularly relevant when considering the positioning of medical and social understandings of disability as binary opposites.

Post-modernism has yielded alternatives to the social model of disability, which acknowledge the complex interaction of biological, psychological, cultural and socio-political factors underlying the experience of disability. Shakespeare and Watson (2001) proposed an embodied ontology of disability, whereby it is argued that there is no qualitative difference between disabled and non-disabled people, everyone is impaired. To be frail, limited, vulnerable and mortal is to be alive (Shakespeare & Watson, 2001). Shakespeare (2004) proposed that the rejection and oppression of disabled people by non-disabled people may reflect the tendency of all people to deny their own vulnerability and mortality. As people with intellectual disabilities are perceived to be unacceptably different or deviate too much from those valued cultural norms, they challenge understandings of the World as just and produce an internal state of anxiety and threat (Greenberg et al., 1990; Lerner, 1980). This discomfort and unease is then projected onto disabled people, and they are oppressed by societal practices and attitudes (Ben-Naim, Aviv, & Hirschberger, 2008; Shakespeare, 2004).

It has been argued that this fragility can provide a basis of citizenship for all and can be harnessed to dismantle the divisions between 'the disabled' and the 'normal' (Thomas, 2004a). However, while all human beings are impaired in one way or another, we are not all subjected to disabling barriers or oppression. It would seem that different impairments have different implications (Hughes, 2007).

Social factors can, at the most fundamental level, define what is considered an unacceptable impairment (or human flaw) and what is not (Crow, 1996). Intellectual disability is understood as a deeply stigmatising impairment or difference (Goffman, 1963). Here, I return to my earlier suggestion that there is something unique about intellectual impairment that thwarts it from being conceptualised (socialised) in the same way as physical and sensory impairments. Intellectual disability is an unacceptable difference. This conceptualisation of intellectual disability may reflect its grounding in the disciplines of psychology and medicine where individualism is the dominant discourse.

Individualism and intellectual disability.

Within the field of intellectual disability, medicine and psychology are recognised as the root disciplines (Rapley, 2004; Reid & Valle, 2004). Therefore, it is unsurprising that conceptualisations of intellectual disability embody aspects of the dominant discourses and understandings of these disciplines. Psychology has largely been guided by a modernist world view (Gergen, 1990b). This perspective has four overarching assumptions; (a) the belief in a knowable world, (b) the belief in universal principles and laws that may be discovered, (c) the belief that empirical methods can derive the truth about the nature of the subject matter and (d) the belief in the progressive (forward moving) nature of research (Gergen, 1990b). Most importantly, this world view reinforces the primacy of the individual. When an individual experiences problems, it is thought to be determined primarily by internal psychological events. This belief is known as intrapsychic supremacy (Levine, 1970). Within psychology (and Western society more broadly), individualism is the dominant motif (Gergen, 1990a; Prilleltensky, 1990). Fine (1986) asserted that “the collective has long been out of the intellectual range of psychologists” (p. 110).

The highly individualistic nature of psychology has had a profound impact on understandings of intellectual disability. The reliance on psychological and medical discourses has resulted in biological and individualistic propensities in problem definition (Prilleltensky, 1997; Reid & Valle, 2004). That is, intellectual disability is an individual deficit located within people with intellectual disabilities (Dudley-Marling, 2004). This conceptualisation encourages research from the perspective of

individual pathology and micro level analysis (McKenzie, 2013). The individual is the unit of analysis and is insulated from the broader political, social or cultural context (Reid & Valle, 2004). Further, when subject matter is presumed to exist independently, the surrounding discourse tends to become objectified, making it particularly resistant to change (Gergen, 1990a). Post-modernism offers an alternative conceptualisation of intellectual disability, whereby collectivism and the embedded nature of intellectual disability in the broader historical and cultural context is reinforced.

Post-modernism and intellectual disability.

A post-modernist perspective can identify the different ways in which discourses (such as individualism), worldviews and mythologies create the categories 'disability' and 'impairment' (Thomas, 2004a). As these mainstream perceptions change, people are defined in and out of impairment (Crow, 1996). A post-modernist stance also encourages the examination of the social-relational understandings of disability (Thomas, 2004a). Particular groups of people with impairments are treated in different ways, in different places, at different times. As an example, in Medieval Europe 'fools' (possibly people with intellectual disabilities) were thought to have privileged knowledge about the World and were allowed to wander the country side in search of a higher meaning (Foucault, 1965). In contrast, at the current time Western societies deeply value independence, intelligence, competence, health and beauty, while impairment or disability is deeply devalued (Ben-Naim et al., 2008; Susman, 1994). Human worth is closely associated with ability and as such, people with intellectual disabilities are systematically oppressed and disadvantaged on the basis of their impairment (Emerson & Hatton, 2008; Hughes, 2007). There may be no qualitative difference between the 'fools' of medieval Europe or the people labelled as intellectually disabled today; the meaning assigned to this particular impairment, however, has changed. This brief example illustrates the importance of examining those complex cultural and social factors in the conceptualisation of intellectual disability. Perceptions of norms and differences vary culturally and historically (Crow, 1996).

Post-modernism provides a framework or perspective that permits an understanding of intellectual disability as socially created and changeable (Crow,

1996). Post-modernist methods examine social behaviours enacted between people with intellectual disabilities and people without intellectual disabilities in familial relationships, communal interactions and encounters with social systems or services (Thomas, 2004a). The broader historical, political, social and cultural context is deconstructed, and realities are de-objectified and conventional assumptions are unseated (Gergen, 1990b). The potential of this perspective lies in the opportunity to transform the discourse surrounding intellectual disability and to offer new forms of theory or different interpretations (Gergen, 1990b). The post-modernist paradigm forms the basis of this thesis. Embracing a post-modernist posture encourages the examination of worldviews, values, discourses and mythologies and the role they play in the social construction of intellectual disability, producing a more responsive way of theorising and understanding intellectual disability (Gabel & Peters, 2004).

The Study of Self and Identity

Since the 1970s, within the field of psychology tens of thousands of articles, chapters and books have been devoted to the study of the self and identity (Leary & Price Tangney, 2003). The immense interest in the self and identity reflects the privileging of individualism in psychology and Western society more broadly. Psychology has naturally privileged constructions of the self as individual, independent, autonomous and separate and separable from the social context (Patel, 2003). However, just as disability has been argued to be socially constructed, post-modernist conceptualisations of identity emphasise the degree to which people's identities are constructed in the context of social relations (Gergen, 1990a; Patel, 2003; Prilleltensky, 1989). While individual agency is acknowledged, the self and identity is believed to be inextricably interwoven with the social world (Dudley-Marling, 2004). Gergen (1990a) proposed that there are multiple selves which can be adopted in a chameleon-like fashion to meet the demands of the changeable social world. Post-modernist understandings of the self and identity emphasise the plasticity, changeability and variability of identity (Ryan & Deci, 2003). Similarly, symbolic interactionist conceptualisations emphasise the role of the social world in the development of identity.

Symbolic interactionism.

Symbolic interactionist George Herbert Mead was influential in the study of self and identity as a social process. Mead (1934) proposed that the self is not present at birth, but rather it develops in the process of social relations, interactions and experiential transitions with others. Social processes occur logically prior to the individual experiencing it, and as such the self is emergent from and mirrors society. From a symbolic-interactionist perspective, society is viewed as a mosaic of patterned and durable interactions and relationships. Interactions are embedded in an array of communities, situations, groups, organisations and institutions. Interactions are also coloured by the boundaries of social class, culture, age and gender (Hogg, Terry, & White, 1995; Mead, 1934). The self is an artefact of the reciprocal interactions between the individual and society. Burkitt (1991) has gone as far as to suggest that it is nonsensical to separate personal identity and social identity as all identity is social.

Mead (1934) also posited that an individual's self-concept is ultimately tied to how society (the 'generalised other') responds to them. That is, an individual's self-concept tends to be congruent with how they are appraised by their entire social group. This concept is particularly relevant for people with intellectual disabilities. Based on this theory, it is expected that people who are discriminated against would be likely to internalise a stigmatised view of self (Goffman, 1963; Jahoda, Markova, & Cattermole, 1988). People with intellectual disabilities are systematically rejected and experience social ostracism, victimisation, abuse and oppression and as such, 'intellectual disability' is commonly conceptualised as 'stigmatised identity' with which one has to live (Bogdan & Taylor, 1976; Rapley, Kiernan, & Antaki, 1998). The internalisation of stigma is explored further in the section 'Salience of the intellectually disabled identity' below.

Different identities emerge in different social and cultural contexts (Dudley-Marling, 2004). Goffman (1959) assumed that people are like actors in a play who perform for different audiences. As people take on various identities, the self is merely a consequence, rather than a cause, of the performance, a "product of the scene that comes off" (p. 252). Once people lay claim to an identity, they are obligated to remain 'in character' until they move to the next scene, at which point

the former self is discarded in favor of a self that fits the new context. For Goffman, there was no enduring sense of self. Instead, the self is an ahistorical construction that emerges and vanishes at the whim of the situational cues. In his book, *Stigma: Notes on the Management of Spoiled Identity*, Goffman (1963) further developed the idea that people actively attempt to create desired impressions or appraisals in the minds of others. This feat is achieved by engaging in a number of strategies, including compensating for the stigmatised difference by drawing attention elsewhere or by attempting to pass as a 'normal' (Goffman, 1963). 'Passing' is a concept particularly relevant to people with intellectual disabilities. This is explored further in the section 'Denial and passing' below.

The importance of social roles.

Expanding on the symbolic-interactionist framework of Mead (1934), Stryker (1968) examined the social structural sources of identity. Stryker (1968) argued that identity is a multifaceted social construct that emerges from the roles an individual occupies in society. 'Identities' reflect the social structural role positions that are enacted in ongoing reciprocal relationships that are accepted as self-descriptive (Stryker, 2008; Thoits, 1992). An individual has multiple role identities, as many identities as there are organised systems of role relationships in which they participate (Stryker, 2008). The variation in an individual's self-concept reflects the different social roles they occupy. Examples of role identities include familial identities, such as 'mother' and 'son', and occupational identities, such as 'salesperson' and 'student' (Stryker, 1968).

Related to the concept of multiple role identities is the concept of identity salience. Stryker (1968) suggested that each discrete role identity is arranged in a hierarchy of salience. The distribution of role identities in the salience hierarchy reflects the probability of that identity being invoked within and across particular situations. This is referred to as commitment (Stryker, 1968). Commitment is dependent on the extensiveness (number) and intensiveness (importance) of social relationships built on that identity (Stryker, 1987). For example, for one person the occupational role identity may be the dominant aspect of self which takes precedence over all other role identities (Callero, 1985). The dominant role identity influences general self-perceptions and guides behaviour. Roles provide the

individual with a sense of how they should behave (a 'script') and clear expectations on their rights and obligations to others. Role identities highest on the salience hierarchy are likely to be socioculturally normative and prestigious and can be enacted competently by the individual (Rosenberg, 1979; Thoits, 1991). In contrast, less meaningful (or salient) role identities are likely to be those that are less normative, not associated with prestige or incompetently enacted. Thoits (1991) argued that role identities highest on the salience hierarchy are more important sources of psychological wellbeing, self-worth and existential meaning than those role identities lower in the hierarchy.

Master statuses.

Master statuses are attributes derived from pervasive features of the social structure (Stryker, 1987). Master statuses transcend situations and facilitate (or deter) the formation of particular interactional networks (Stryker, 1987). Examples of primary identifying characteristics or master statuses include age, gender and ethnicity. These master statuses are assigned on the assumption of clear physical or biological conditions and tend to operate in all societies (Barnartt, 2001). Master statuses carry with them clear expectations for behaviours, emotions and cognitions (Barnartt, 2001). Unrelated behaviour displayed by an individual is often attributed to that particular master status, rather than the other social roles s/he may occupy or his/her unique personality characteristics (Barnartt, 2001; Frable, Blackstone, & Scherbaum, 1990). Master statuses often act as 'mechanisms of allocation', dictating an individual's access to other statuses and social roles (Barnartt, 2001). Indeed, master statuses often form the basis for stereotyping, prejudice and discrimination.

A number of authors have argued that the role of 'intellectual disabled' is so powerful and pervasive that it overrides other identities and characteristics the individual may have (Beart et al., 2005; Davies & Jenkins, 1997). The argument that intellectual disability represents a master status has been in reference to its tendency to supersede other recognised master status such as gender, ethnicity and adulthood (Barnartt, 2001; Beart et al., 2005). A person with an intellectual disability *is* their impairment. The perception of intellectual disability as an all-

consuming, stigmatising identity and the implications of conceptualisation are described in more detail later in this chapter.

Social role valorisation.

Wolf Wolfensberger (1972, 1998) agreed that an individual's identity is intimately tied to the social roles he/she occupies. When a person answers the question 'who am I?' it is usually in terms of the positions or roles they hold (Wolfensberger, 2000). In his theory of social role valorisation, Wolfensberger (1998) proposed that the value of each social role is placed on a continuum ranging from highly valued to deeply devalued. People who occupy valued roles are afforded the 'good things of life' such as respect, acceptance, positive relationships with others, integration into the community and access to resources (Wolfensberger, 1998). The social roles that people occupy can be life defining (Wolfensberger, 1998).

People with intellectual disabilities are typically associated with negatively valued roles (Wolfensberger, 2000). Common roles held by people with intellectual disabilities include the eternal child, the object of fear or pity and the sub-human (Wolfensberger, 2000). People with intellectual disabilities are often disqualified from a range of typical, valued social roles (Todd & Shearn, 1997; Wolfensberger, 1998). Most adults with intellectual disabilities are excluded from experiencing a positive sexual life, including sexual expression and relationships (Johnson & Traustadottir, 2005). They are denied the prospect of marriage and parenthood, and employment is a notably absent feature in their lives (May & Simpson, 2003). People with intellectual disabilities are typically isolated from the community and experience loneliness and boredom (Johnson & Traustadottir, 2005). Indeed, people with intellectual disabilities tend to be associated with devalued roles and have limited access to valued roles (Lemay, 1999).

Social role valorisation (Wolfensberger, 1972) emphasises the process of social devaluation and strives to enable, establish and/or maintain valued social roles for people with intellectual disabilities (Wolfensberger & Tullman, 1982). The principles of social role valorisation have been used to guide the design and development of programmes and facilities for people with intellectual disabilities to enhance their life conditions. Such strategies include living and working in the same

environments as valued persons, associating with valued persons and making adjustments to personal appearance (Wolfensberger, 1998). This reflects the current, dominant understanding of disability as a 'functional limitation' and movements to assist people with disabilities to function more like non-disabled people and become valued members of society (Rioux, 1997).

Social role valorisation has been criticised for its emphasis on the need for people with intellectual disabilities to assimilate to fit with the dominant group in society, people without intellectual disabilities (e.g., Beart et al., 2005; Walmsley, 2001). In order to gain valued social roles and positive identities, change is required on the part of people with intellectual disabilities. Despite this criticism, the principles of social role valorisation have permeated disability policy, practice and research and have been influential current conceptualisations of intellectual disability (Walmsley, 2001).

In summary, post-modernist understandings of the self and identity emphasise the interactions between the individual and society in the development of identity (Mead, 1934; Ryan & Deci, 2003). Social roles have been identified as particularly important as they provide expectations for behaviours, emotions and cognitions. Intellectual disability is commonly conceptualised as a master status, overriding the alternative identities and social roles an individual may have. Social role valorisation, a principle that guides much disability practice, has its roots in role theory further illustrating the centrality of social roles in everyday life (Wolfensberger, 2000). The different identities and social roles of people with intellectual disabilities and how they are shaped by the social context in which they are embedded is of particular interest in this thesis. The following section will examine past literature which has explored the identities and social roles of people with intellectual disabilities.

Identity and Intellectual Disability

Few studies have investigated the identities and social roles of people with intellectual disabilities (Beart, Hardy, & Buchan, 2004; Beart et al., 2005). The limited studies that have explored how people with intellectual disabilities conceptualise their identities have tended to focus on two narrow streams of

inquiry: (a) awareness of the label intellectual disability, and (b) salience of the label intellectual disability. The term awareness is used to describe whether the person with an intellectual disability recognises or is aware of the label they have been bestowed by professionals during the process of diagnosis (Beart et al., 2005). In the case of unawareness of the social identity intellectual disability, several mechanisms have been proposed to explain this process. In the literature, the term salience is used to describe the importance or centrality of the label intellectual disability to the people to whom it is given (Beart et al., 2004). In this section, I review the few studies that have explored the identities of people with intellectual disabilities, according to the two foci of the literature; awareness and salience. I will also outline the proposed mechanisms or processes that influence the awareness and salience of the intellectually disabled identity. Finally, I will present the limitations of these past studies and propose that research that explores the identities and social roles of people with intellectual disabilities living in the community from a post-modernist posture is warranted.

Awareness of the intellectually disabled identity.

In the literature, there is a tendency to focus on the awareness or unawareness of the ascribed identity, intellectual disability (Beart et al., 2004). In their review of the literature, Beart et al. (2005) reported that it is consistently found that at least some people with intellectual disabilities appear to be unaware of their intellectually disabled identity. A study conducted by Davies and Jenkins (1997) reported that 43% of the participants with intellectual disabilities interviewed demonstrated a complete incomprehension of 'mental handicap'. Similarly, Finlay and Lyons (1998) found that in open-ended self-descriptions, none of the participants referred to 'intellectual disabilities'. Participants in this study tended to focus on their positive attributes such as abilities and interpersonal traits. Todd and Shearn (1997) concluded that many people with intellectual disabilities are unaware of their membership to the intellectually disabled category and that "... the world in which they operate rejects and discriminates against them" (p. 362). People with intellectual disabilities are effectively 'invisible to themselves' (Todd & Shearn, 1997). Three main hypotheses have been offered to explain the lack of awareness of the 'intellectually disabled' identity amongst individuals categorised

as being members of this group (Beart et al., 2005). They are: (a) the limited cognitive ability of individuals with intellectual disabilities, (b) denial and 'passing' (Edgerton, 1967) as defence mechanisms and (c) the 'protective capsule' (Goffman, 1963) created by the family. These mechanisms are described below.

Limited cognitive ability.

The cognitive development hypothesis borrows from the child developmental literature, citing authors such as Piaget, to posit that a minimal level of cognitive development is necessary to recognise social categorisations (Beart et al., 2005). Harter (1983) proposed that at ages seven or eight years children begin to evaluate themselves across different domains and develop complex and differentiated aspects of self. They also make relative social comparisons and incorporate input from significant others into their self-concept (Evans, 1998; Harter, 1983). According to Harter, children younger than seven or eight years do not have the cognitive ability to evaluate their behaviour across different situations. Their self-concept is global and undifferentiated; they are either all good or all bad (Evans, 1998; Harter, 1999). Children younger than seven or eight years are also unlikely to compare themselves to others and appraise themselves realistically (Harter, 1983).

Based on Harter's (1983) developmental model of self, individuals with an intellectual disability will not be able to understand they have an intellectual disability until a certain level of cognitive development is attained (Beart et al., 2005). Some people with intellectual disability never reach this level of cognitive development. There is substantial evidence that supports the cognitive-developmental model of self-concept and self-categorisation in people with intellectual disability. A study conducted by Cunningham and Glenn (2004) explored the self-awareness of 77 individuals with Down syndrome. In this study, 49% of the participants were rated as having no awareness or recognition of Down syndrome. Level of awareness of Down syndrome and social categorisation was found to be associated with developmental level, with only participants with a verbal mental age (VMA) of approximately eight years and above able to form complex social categories of Down syndrome and disability (Cunningham & Glenn, 2004). Similarly, Cunningham, Glenn, and Fitzpatrick (2000) reported that the majority of young

people with Down syndrome (aged 17 to 24 years) showed no awareness of Down syndrome and disability if their VMA was less than six years. The very nature of intellectual disability precludes some people from developing an awareness of it (Beart et al., 2005; Todd & Shearn, 1997).

Denial and passing.

For individuals with the cognitive capacity necessary to recognise social categories, it has been proposed that the lack of awareness of the intellectually disabled identity may be a function of the psychological defence mechanism known as 'denial' (Beart et al., 2005; Edgerton, 1967; Todd & Shearn, 1997). In his book, *The Cloak of Competence*, Edgerton studied a cohort of individuals with intellectual disabilities following their release from a State institution. Edgerton and his colleagues found that many of the participants refused to accept that they were or were ever 'mentally retarded' and maintained that they never belonged in the institution in the first place. Instead, the participants offered alternative explanations for institutionalisation such as mental illness (nerves), alcoholism, epilepsy and physical illness. Many participants described their release from the institution as evidence of misdiagnosis; they were never 'mentally retarded'. Edgerton hypothesised that "being adjudged a mental retardate" (p. 145) is unacceptable to the individual and all efforts are then directed towards denying the "official fact" (p. 145). The internalisation of this stigmatised identity presents individuals with the need to reconstruct their damaged self-esteem (Edgerton). This is achieved by concerted and well-organised efforts to 'pass' as 'normal' (Goffman, 1963). Examples of 'passing' reported by Edgerton included marriage to an 'outside' man or woman, avoiding public association with people with intellectual disability and concealing their history of institutionalisation (Edgerton, 1967).

More recently, researchers have reported attempts to pass by individuals with intellectual disabilities across a range of settings including day centres, social clubs (Finlay & Lyons, 2000), adult training centres (Jahoda et al., 1988) and special education (Cheston, 1994; Todd, 2000). A study conducted by Cheston explored how pupils leaving special education described themselves. In this study, many of the participants emphasised physical (such as being left handed) or sensory factors when explaining their presence in a segregated schooling environment. Some

participants acknowledged that they experienced difficulties in specific areas (such as reading) whilst others denied that they ever attended a special school (Cheston, 1994). Cheston concluded that the participant's accounts for being in segregated and stigmatising environment served the function of limiting the individuals "psychological liability" (p. 67). In other words, denying membership to the social category 'intellectually disabled' served a protective function. In another study by Davies and Jenkins (1997) 30% of participants could provide a definition of 'learning difficulties', but excluded themselves from this definition. Instead, most participants focused on some physical impairment such as being in a wheelchair, or a specific disability such as not being able to communicate verbally. Given the highly stigmatising nature of the label intellectual disability it is unsurprising that individuals ascribed this label would not want to identify with it (McVittie, Goodall, & McKinlay, 2008).

The protective capsule.

The protective capsule refers to the "charmed circle" (Goffman, 1963, p. 46) in which many people with intellectual disabilities are believed to operate. Here, individuals with intellectual disabilities are unaware of their 'real' socially ascribed toxic identity and view themselves as being competent and "fully qualified ordinary human beings" (Goffman, 1963 p.46). This 'normal' identity is achieved by the careful filtering and control of information by the families of individuals with intellectual disability (Beart et al., 2005; Goffman, 1963). According to Todd and Shearn (1997) parents are the 'gatekeepers' of information concerning their child's intellectual disability. They have a role in both the provision and interpretation of information on intellectual disability to their child (Cunningham et al., 2000). Parents 'protected' their child by non-disclosure, such as providing alternative accounts of the behaviour of others and avoiding the use of obvious terminology. Davies and Jenkins (1997) reported that parents can go to considerable lengths to 'protect' their child with one parent blacking out a reference to Down syndrome in an article published about her son. Parents also achieve a 'normal' identity for their child by constructing and maintaining fictional biographies (Beart et al., 2005; Todd & Shearn, 1997). That is, parents actively support and encourage ambitions, for example living independently and getting married, whilst privately believing that it

will never be possible (Todd & Shearn, 1997). Todd (2000) argued that care staff, such as teachers, also have a role in insulating people with intellectual disability from the stigma associated with being a member of this group. Care staff in this study avoided using the terms 'handicapped' or 'disabled' in the presence of students as they felt it would be potentially disturbing. Todd also reported that the care staff were active collaborators in the students' 'fictional identities' and validated the students' future aspirations.

In these studies, the parents of the individuals with intellectual disabilities explained that they were concerned of the damaging impact that such an identity would have on their child's sense of self (Cunningham et al., 2000; Todd & Shearn, 1997). Some parents regretted not disclosing the 'intellectually disabled status' to their son or daughter sooner, and felt it was too late to do so as "they held deeply entrenched views of themselves as typical social actors" (Todd & Shearn, 1997 p. 356). Other reasons for non-disclosure described by parents included the assumption that their child would not be able to understand and that intellectual disability is irrelevant in their child's life and should not be needlessly dwelled on (Cunningham et al., 2000). In contrast, others (e.g., Rapley, 2004; Rapley et al., 1998) have argued that people with intellectual disabilities are very much aware of their status as a 'stigmatised individual' (Rapley, 2004). Instead, it is suggested that the so-called 'unawareness' reflects a number of social processes: (a) identity ascription a-priori by the researcher, (b) the management of different identities by people with intellectual disabilities in social interactions, and (c) passing as a typical feature of social life. These alternative social processes are discussed below.

Identity ascription a-priori.

A pervasive feature of the literature exploring the identities of people with intellectual disabilities is the taken for grantedness of a 'stigmatised identity' and the assumed centrality of 'intellectual disability' to an individual's identity. This underlying belief that people with intellectual disabilities are 'different' or 'deviant' influences the types of questions that researchers ask. For example, Finlay and Lyons (1998) asked participants 'Can you tell me what learning difficulties means?'. Rapley (2004) argued that in research interviews, a certain identity that the researcher believes constitutes 'intellectually disabled' is offered to the participant.

The power differential that exists between the researcher and the participant in the research interview effectively 'encourages' the participant to admit membership to this social category that the researcher has ascribed *a-priori* (Rapley, 2004). The responses of the participants to these sorts of questions ultimately form the themes that emerge from the data (Rapley et al., 1998). It is possible that the information provided by participants may not have been offered as a response if the question asked was different. The salience of the intellectually disabled identity to the researcher will be returned to later.

Identity management in social interactions.

It has been proposed that people with intellectual disabilities actively resist being defined by others, particularly by researchers who assume the position of power (Rapley, 2004). Rapley et al. (1998) used discourse analysis to reinterpret the data offered by Todd and Shearn (1997), in addition to their own data from a larger qualitative study exploring the quality of life of people with intellectual disabilities. Rapley et al. argued that people with intellectual disabilities are not blinded to their own 'true' natures, but rather negotiate and manage their identities in social interactions. According to Rapley et al. identity is fluid and locally contingent; it can be avowed or disavowed depending on the demands of the social situation. In research interviews, participants with intellectual disabilities are well aware of their so-called 'toxic identity' ascribed *a priori* by academics. Although participants do not offer a textbook definition of 'intellectual disability', closer examination reveals that they have a clear understanding of their status. Participants then go on to express frustration and dissatisfaction with the prejudice associated with their status (Rapley et al., 1998).

Mest (1988) too agreed that people with intellectual disabilities are aware of the stigma attached to them, and although they may internalise some of it, they criticise much of it. Gerber (1990) posited that the accounts of people with intellectual disabilities in Edgerton's (1967) work are interpreted in ways that subvert them. People with intellectual disabilities were not able to analyse their circumstance with any authority. Gerber argued that if Edgerton were to consider the disturbing impacts of institutionalisation and respect the humanity of those

studied, what was considered 'denial' and 'self-delusion' would become explaining, challenging and interpreting their circumstances.

Passing as a feature of social life.

It has been argued that the social action of passing is not unique to people with intellectual disabilities, but rather a pervasive feature of everyday social life (Rapley et al., 1998). All individuals wish to be seen as ordinary, typical social actors and people labelled as intellectually disabled are no exception (Kittelsaa, 2013; Rapley et al., 1998). Furthermore, because the label intellectual disability is so negatively loaded, people with intellectual disabilities would undoubtedly want to avoid being classified as the Other. Distancing oneself from the categorical identity intellectually disabled serves a protective function (Kittelsaa, 2013).

'Passing as normal' is a complex behaviour. To achieve this feat convincingly, the individual with an intellectual disability must be aware of and understand the behaviours of 'competent' others and master these context-specific behaviours (Gerber, 1990). The stigmatised individual must avoid associating with 'stigmatised' others and situations that may threaten exposure, all the while maintaining complete secrecy. Gerber argued that it is paradoxical to claim that people with intellectual disability have severely limited cognitive capacity (Edgerton, 1967) and then suggest that they conceive and practice passing. Passing, by definition, is evidence of learning capacity (Gerber, 1990).

Salience of the intellectually disabled identity

Studies exploring the identities and experiences of stigma of people with intellectual disabilities have reported that the intellectually disabled identity may have little resonance with the people who live with the label (Fine & Asch, 1988; Finlay & Lyons, 1998). Finlay and Lyons (2000) explored the extent to which being allocated as a member of the social category 'learning disabled' was reflected in the way in which participants described themselves and their social worlds. They concluded that the 'learning disabled' identity was not salient and that while participant's self-representations were variable, none included reference to this label. Participants in this study used a range of social categorisations and comparisons which enabled them to present themselves positively. In another study, Jahoda and Markova (2004) explored the experiences of stigma and self-

perceptions of 28 people with mild intellectual disabilities during a period of transition from either the family home and supported housing or an institution into community housing. They reported that while participants acknowledged that they had particular difficulties with learning, they rejected the stigmatising treatment of others and did not view themselves as 'disabled'. Instead, participants emphasised their independence and capabilities to make choices as autonomous individuals.

Similarly, a study by Jahoda et al. (1988) that explored the experiences of stigma and the self-concept of people with intellectual disabilities found that the majority of participants rejected a globally handicapped view of self and considered themselves to be essentially the same as people without intellectual disabilities. Participants were aware of the stigma surrounding them but felt it was unjustified by their *actual* disability which was described as particular difficulties with reading and writing. Further, Jahoda, Wilson, Stalker, and Cairney (2010) reported that people with intellectual disabilities actively disputed the views others had of them, for example incompetent and child-like, and tried to shape their own identities.

Research has also revealed the rich diversity of identities of people with intellectual disability beyond a 'stigmatised identity'. Mest (1988) conducted a series of interviews with people with intellectual disabilities exploring sense of self, beyond stigma. Mest reported that the participants discussed their lives with great enthusiasm and contentment. They developed a positive and strong identity based on their own personal experiences, immediate relationships and achievements. Walmsley (1996) conducted a study which explored how people with intellectual disability experienced and described their relationships with their families. In this study, Walmsley reported that the participants were more than just dependent people who were the recipients of care. The identities of woman/man, son/daughter, parent and sibling were also found to be salient. An anthology collated by Atkinson and Williams (1990) that presented a collection of drawings, paintings, photographs, poetry and writing, and contributions communicated through speech and sign language by people with intellectual disabilities highlighted the different identities of people with intellectual disabilities. The contributors with intellectual disabilities spoke about relationships, caring for others, marriage, employment, learning to drive, owning their own home and improving their skills;

their stories were not primarily about disability. Contributors forged their own identity through their past experiences, belonging and being valued, and by being treated as an adult.

In summary, the intellectually disabled identity is not a particularly salient identity for many of the people categorised as being members of this group. People with intellectual disabilities have many other attributes and social identities beyond that imposed on them by people without intellectual disability (Fine & Asch, 1988). Given the pervasive impact of the label intellectually disabled why is it not a salient identity for those categorised as members of this group? Selective social comparison and the salience of intellectual disability to the researcher offer possible explanations.

Selective social comparison.

According to Festinger's (1954) social comparison theory, an individual's self-evaluation is intimately linked to the nature of the social comparisons they make. The movement towards the integration and inclusion of people with intellectual disabilities into the wider community would create greater opportunity for people with intellectual disabilities to make downward (negative) social comparisons (Dagnan & Sandhu, 1999). Social comparison theory would predict that people with an intellectual disability (a stigmatised social status) may experience poor self-evaluation in the presence of 'more competent' others because of negative frame of reference effects (Crabtree & Rutland, 2001; Dixon, Marsh, & Craven, 2006; MacMahon, Jahoda, & MacLean, 2008). Interestingly, a number of studies have reported no differences in self-concept and self-evaluation when comparing people with intellectual disabilities to people without intellectual disabilities (e.g., Crabtree & Rutland, 2001). Newer developments in social comparison theory have emphasised the flexible and selective nature of social comparisons and categorisations (Crocker & Major, 1989). That is, people with intellectual disabilities actively select who they compare themselves to and on what dimensions (Crabtree & Rutland, 2001; Finlay & Lyons, 2000).

Finlay and Lyons (2000) reported that when describing themselves, people with intellectual disabilities tended to emphasise groups of people with intellectual disabilities who they perceived to be less able than themselves, such as people with

multiple disabilities or those who are unable to talk. They also made downward comparisons to people who behaved in 'morally unacceptable' ways, such as thieves and drunkards. Rarely did people with intellectual disabilities make upward comparisons on qualities relevant to the 'intellectually disabled' categorisation, such as level of independence. Instead, Finlay and Lyons reported that people with intellectual disabilities tend to emphasise their similarities with people without intellectual disabilities. Similarly, Jahoda and Markova (2004) found that participants with intellectual disabilities described themselves as 'better than' less able people with intellectual disabilities or people with physical disabilities. They also considered themselves to be the same as staff members in the services they accessed and people without intellectual disabilities.

A study conducted by Crabtree and Rutland (2001) that examined the self-evaluation of adolescents with intellectual disabilities reported that participants devalued dimensions of self upon which they performed poorly and valued those dimensions on which their group excelled. In this study, participants emphasised their athletic and physical abilities and devalued the importance of scholastic and cognitive ability. Scholastic competence was found to not be related to participants global self-worth. These strategies enabled participants to maintain a relatively positive self-evaluation. Similarly, global self-worth has been found to be more strongly related to physical appearance and social acceptance, than academic competence (Glenn & Cunningham, 2001).

Selective social comparison is described by Crocker and Major (1989) as a 'self-protective property'. Crocker and Major proposed that people with intellectual disabilities protect their self-esteem by selectively devaluing those dimensions in which they fare poorly so that it becomes less psychologically central to their self-definition. Indeed, a study conducted by Dagnan and Sandhu (1999) reported that negative social comparisons were associated with depression in people with intellectual disabilities. Similarly, MacMahon et al. (2008) found that participants with mild to moderate intellectual disabilities who had a current diagnosis of depression made more negative social comparisons than the non-depressed group.

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The centrality of intellectual disability to the researcher.

It has been argued that the social categorisation intellectual disability is more important or salient to the researcher than it is to people bestowed the label (e.g., Fine & Asch, 1988; McVittie et al., 2008). According to the literature, it would appear that many people with intellectual disabilities have not internalised their group membership as an aspect of their self-concept (Tajfel & Turner, 1979). For researchers, on the other hand, it would seem that intellectual disability is a powerful organising principle.

The importance assigned to the social role intellectual disability by researchers (and broader society) is reflected in the paucity of literature exploring the other, alternative identities of people with intellectual disabilities, such as gender and ethnicity (Barron, 2002; Block, Balcazar, & Keys, 2001). The gender identity of men and women with intellectual disabilities has been an area of neglect in disability studies (Barron, 2002; Burns, 2000; Umb-Carlsson & Sonnander, 2006). Feminist scholars have also been accused of overlooking the experiences of women with an intellectual disability and focusing their research on "... more powerful, competent and appealing female icons" (p. 142, Asch & Fine, 1992). Without a gendered place in society, people with an intellectual disability are often not considered male or female, but as gender-neutral or as Burns coined, 'the third sex'. Literature on the ethnic identity of people with intellectual disability is also scarce (Block et al., 2001; Newland, 1999). People with an intellectual disability from ethnic minorities are said to experience a 'double disadvantage'; the stigma associated with having an intellectual disability and the stigma associated with being from an ethnic minority (Baxter, Poonia, Ward, & Nadirshaw, 1990; Singh & Orimalade, 2009).

The assumed centrality of intellectual disability and the neglect of other identities is also evident in disability services. 'Gender blindness' permeates both the provision of services to people with intellectual disability and clinical psychological practice (Burns, 2000). Men and women have different needs, preferences and wishes and it has been argued that there is the need for more advocacy groups specifically for women with intellectual disability and women-only events (Walmsley & Downer, 1997). It has also been argued that gender may also be central to understanding clinical issues such as 'challenging behaviour' (Burns, 2000). Burns argued that if individuals do not have their basic human needs met (such as having a strong identity as oneself as a man or a woman) they compensate for this loss in a variety of ways. For example, a man with an intellectual disability in a supported living environment may exhibit aggression, violence and sexual inappropriateness in response to the emasculation associated with both the label of 'intellectually disabled' and their 'paid-caring' relationship with staff. By adopting an exaggerated, stereotypical male role the individual asserts their masculinity and satisfies their desire to be recognised as male. Burns concluded that the gender of a client (whether they have an intellectual disability or not) is significant and considering clinical problems through the lens of gender is worthwhile.

The neglect of ethnic identity is also evident in the provision of services to people with intellectual disability from ethnic minorities (Singh & Orimalade, 2009). When a person with an intellectual disability enters the service system their disability is defining (a master status) and all other personal characteristics become secondary (Block et al., 2001). These services reflect predominately White values and often fail to consider people's ethnic, cultural and religious needs (Baxter et al., 1990). Disability services need to be responsive to the cultural, dietary and linguistic needs of their clients and their client's carers from minority ethnic communities (Caton, Starling, Burton, Azmi, & Chapman, 2007; Walmsley & Downer, 1997).

Rationale for this Research

Overall, within the literature examining the identities of people with intellectual disabilities the notion of a stigmatised identity is contested. Numerous studies have reported that this ascribed identity has little resonance with those who live with the label and that people with intellectual disabilities reject a stigmatised

view of self. In contrast, it has also been consistently reported that at least some people with intellectual disabilities appear to be unaware of their ascribed identity. There are, however, a number of limitations in the literature exploring the identities and social roles of people with intellectual disability that can be identified. Each of these limitations is described below. The limitations of the past research provide the rationale for the exploration of the identities and social roles of people with intellectual disabilities from a post-modernist perspective in this research.

Limitations of past research.

First, of the studies exploring the identities and social roles of people with intellectual disability, there is a pervasive tendency to assume that identity is static and stable, not dynamic and fluid (Rapley, 2004). As previously discussed, identity is changeable and different identities emerge in different social and cultural contexts (Dudley-Marling, 2004; Gergen, 1990a). By focusing on whether a person with an intellectual disability is aware or unaware of this label, researchers are failing to recognise that identity is negotiable (McVittie et al., 2008; Rapley, 2004). People with intellectual disabilities manage and negotiate their different identities in the context of everyday life. To conclude that many people with intellectual disabilities are unaware of their status as the defective other, is to ignore the complexity of social interactions. The conceptualisation of identity as fixed and stable reflects medical/individualistic understandings of intellectual disability as a naturalised impairment located solely in the heads of people with intellectual disabilities (Dudley-Marling, 2004). Research that appreciates the socially constructed and dynamic nature of identity and intellectual disability is needed (Beart et al., 2004).

Second, many researchers have failed to consider the alternative identities that might be more important and meaningful to people with intellectual disabilities beyond that imposed on them by society (McVittie et al., 2008). This is reflected in the paucity of literature examining the gender and ethnic identities of people with intellectual disabilities. Understandings of disability as an individual, biologically-based pathology (disability as a tragedy) have contributed to these perceptions of intellectual disability as an all-consuming identity. Gergen (1990a) and others have argued that there are multiple and variable selves. In fact, it is possible for an individual to have as many identities as social role relationships in which they

participate (Stryker, 2008). An exploration of the alternative identities, beyond that imposed on people with intellectual disabilities by people without disabilities, should be considered (Beart et al., 2005; McVittie et al., 2008; Walmsley & Downer, 1997).

Third, as previously discussed, it would appear that intellectual disability is in the forefront of many of the minds of researchers examining the area of identity and self. The centrality or salience of intellectual disability to researchers is evident in the mechanisms proposed to explain the unawareness and lack of salience of the intellectually disabled identity (Gerber, 1990; Rapley, 2004; Rapley et al., 1998). Researchers (myself included) bring with them their own orientations and beliefs, shaped by a range of social and historical factors including the dominance of individualism in psychology and Western society, that inevitably enter into and shape their work (Guillemin & Gillam, 2004; Northway, 2000). I would argue that it is imperative for researchers to attempt to understand their own underlying assumptions, values and attitudes and how these may enter into and influence their work, contributing to the oppression of people with intellectual disabilities. This task is particularly difficult as we are so well socialised to these broad social forces that they may go unnoticed (Bishop, Sonn, Drew, & Contos, 2002). The issue of developing self-awareness and an understanding of those social structures and social processes is explored further in the following methodology chapter.

Fourth, few studies exploring the identities of people with intellectual disabilities do so from the viewpoint of people who live it (Beart et al., 2005). More commonly, the perspective of carers and service providers who control the needs and experiences of people with intellectual disabilities are sought (Jurkowski, 2008). For example, Todd and Shearn (1997) interviewed the parents of individuals with intellectual disabilities to ascertain the self-awareness individuals with intellectual disabilities had of their social status and own social identities. Chappell (2000) argues that the people with intellectual disabilities are the best people to ask if researchers want to know their views and experiences. The failure to represent the voices of people with intellectual disabilities in the research process is a pervasive feature of psychological research (Oliver, 1992). Research methodologies that do not perpetuate oppression, but instead challenge power differentials and promote

the meaningful participation of people with intellectual disabilities are needed (Stone & Priestley, 1996). Finally, past literature in this area has tended to include clinical populations (e.g., Jahoda et al., 2010) or populations who have been institutionalised (e.g., Jahoda & Markova, 2004). Jahoda et al. (2010) suggested that future research explore how people with intellectual disabilities, without additional clinical disorders, ordinarily manage and negotiate their identities.

The significance of this research.

With these conceptual limitations in mind, research that explores the identities and social roles of people with intellectual disabilities living in the community from a post-modernist posture is warranted. By examining how intellectual disability is socially constructed; particularly the role of worldviews, values and mythologies; the taken for granted becomes illuminated and paradoxes and inconsistencies in understandings are revealed (Gergen, 2001). This opens the opportunity for new theories or different interpretations to emerge. This research holds potential for new and exciting understandings of intellectual disability and the conceptualisation of identity, beyond the narrow and simplistic focus of awareness or unawareness of the intellectually disabled identity. A reflexive stance and critically questioning and challenging the status quo (Prilleltensky, 1989) is central in shifting the way we as researchers see the world. By de-objectifying existing realities and demonstrating the social and historical embeddedness, it is possible to destabilise ossified (and damaging) understandings of intellectual disability (Gergen, 1990b). Discourses surrounding intellectual disability can be transformed and new, alternative vistas for research and practice can be opened (Gergen, 1990b).

As previously discussed, a significant limitation of past research exploring the identities and social roles of people with intellectual disabilities (and research more generally) is the failure to include people with intellectual disabilities in the research process (Beart et al., 2005). Often the views of parents or carers are sought. This is not to deny the central role those parents and carers play in the lives of people with intellectual disabilities, but by failing to capture viewpoints of the people assigned the label intellectual disability, only a limited understanding of this complex social phenomenon can be garnered (Chappell, 2000). Furthermore, excluding people with intellectual disabilities from the research process altogether

or including people in narrow and superficial ways, research can be said to perpetuate oppression and disadvantage (Oliver, 1997). It is important that research engages people with intellectual disabilities in meaningful ways and promotes valued social roles, autonomy and increased control (power) for people with an intellectual disability (Stone & Priestley, 1996).

This research is informed by a contextualist perspective and is conducted within a participatory research framework. The methodology for this study is discussed at length in the following chapter. In addition, a lifestory exploring the experiences of one of the Members is included (see chapter six). Presenting a lifestory offers an insight into complex social processes in action and may assist in the development of a more nuanced view of reality as experienced by people with intellectual disabilities (Mazumdar & Geis, 2001). Reflecting the importance of support staff in lives of people with intellectual disabilities, the perspectives of the staff at the Advocacy Agency who work closely with the Members will also be explored (Aspis, 1997). Gaining multiple perspectives enables multiple truths to be uncovered (Crotty, 1998). No one perspective is regarded as more 'truthful'; multiple perspectives are needed to capture the complexity of social phenomena (Altman & Rogoff, 1987; Jaeger & Rosnow, 1988). The role that I play as a researcher in the construction of data will also be examined in this thesis. The necessity of researcher reflexivity is examined in the following chapter and chapter seven.

Beyond theoretical significance, this research also has a number of practical implications. First, this research has the potential to inform clinical psychological practice with people with intellectual disabilities. Intellectual disability is a powerful identifying label for not only the individual but also for health care professionals such as psychologists. The power of this label can be seen in the concept of diagnostic overshadowing (Beart et al., 2005). Diagnostic overshadowing is a common clinician bias that refers to the reluctance of clinicians to assign an appropriate diagnosis and recommend an appropriate treatment to people with intellectual disabilities and the tendency to overlook mental health problems as being fundamentally a part of the intellectual disability itself (Jopp & Keys, 2001; Mason & Scior, 2004). That is, in the presence of intellectual disability

accompanying mental health problems become less salient (Mason & Scior). Clinicians tend to view 'intellectual disability' as a master status. Similarly, disability services that support people with intellectual disabilities also tend to neglect other personal characteristics, such as gender and ethnicity (Burns, 2000; Singh & Orimalade, 2009). The permeation of the master status perspective of intellectual disability results in services that not responsive to the unique needs of individuals.

Complex social processes, such as identity ascription, can be so subtle and pervasive that they may go unnoticed. This research may have a role in raising awareness of the discourses surrounding people with intellectual disabilities and their identities and social roles (Szivos & Griffiths, 1992). Consciousness-raising is a transformative process (Freire, 1970). Clinical psychologists and support staff who work with people with intellectual disabilities must be made aware of their own world views, values and assumptions and how this enters into and shapes their practice. To create social movements that produce real social change, raising awareness of the alternative identities and social roles of people with intellectual disabilities is essential (Freire, 1970). This may be achieved through staff education and training. The dissemination of the findings of this research via international conferences and publications will also facilitate in the process of consciousness-raising amongst disability researchers. Small emergent realisations or incremental advances must, however, be reflected on and evaluated (Bishop et al., 2002). Every action creates new challenges and self-awareness and an understanding of those social structures and social processes is crucial to ensure that genuine social change occurs (Bishop et al., 2002; Dalton, Elias, & Wandersman, 2007).

Chapter 3: Research Methodology

“I have never let my schooling interfere with my education” - Mark Twain

Introduction

In this chapter¹, I describe the research methodology for the study with the Members. The methodology for the study with the Advocacy Agency staff members and the life story are presented in chapters five and six, respectively. I begin by restating the research aims and associated research objectives. Next, I will discuss the epistemological assumptions underpinning this research, describe participatory approaches to disability research and introduce Photovoice and conversational interviewing methodologies. I will then describe the research design and introduce the co-researchers involved in this research; Members of an Advocacy Agency for people with intellectual disabilities. The procedures used to collect the data will be outlined and the relevant ethical considerations will be explored. The method of data analysis, causal layered analysis, will be described. Finally, the strategies employed to ensure the trustworthiness of this research will be presented.

Research aims and objectives.

This research was guided by two broad aims. The first aim of this research was to explore the social construction of ‘intellectual disability’, particularly the personhood, identities and social roles of people with intellectual disabilities. The role that worldviews, values, mythology and culture play in this construction was of particular interest. The second aim of this research was to increase the control, power and meaningful participation of people with intellectual disabilities in the research process.

¹ Sections of this chapter have been published in the article:

Povee, K., Bishop, B. J., & Roberts, L. D. (2014). The use of photovoice with people with intellectual disabilities: Reflections, challenges and opportunities. *Disability & Society*, 29, 893-907. doi:10.1080/09687599.2013.874331

The research objectives were as follows:

1. To explore how people with intellectual disabilities conceptualise their own identities and social roles.
2. To explore how the staff who work closely with people with intellectual disabilities conceptualise the identities and social roles of their clients.
3. To negotiate with the Members the nature and form of the research agenda and process.
4. To support the Members to be co-researchers throughout the research process.
5. To inform clinical psychological practice with people with intellectual disabilities.
6. To inform the way in which services support people with intellectual disabilities.

Epistemological assumptions.

When conducting research, it is necessary to be informed by a world view that is compatible with the nature of the research aims. Philosopher Stephen C Pepper (1942) devised four major 'world hypotheses' or conceptual systems that characterise approaches to knowledge and form a typology of research methodologies. The four world hypotheses are formism, mechanism, contextualism and organicism. Each world hypothesis has an accompanying 'root metaphor'; a basic analogy comprised of basic images, principles or concepts from which the world hypothesis developed (Jaeger & Rosnow, 1988; Pepper, 1942). Formism uses similarity as a root metaphor and emphasises the 'essences' or individual differences of phenomena. Pepper's second world hypothesis, mechanism, proposes that phenomena are composed of discrete entities that can be identified, separated and analysed. In contrast, contextualism assumes that the contextual and temporal processes are intrinsically embedded aspects of phenomena. Finally, organicism posits that phenomena reflect underlying organic processes and the whole or system is the focus of understanding. The root metaphor of organicism is the integration of the organism.

These alternative orientations have had implications for psychological inquiry. To describe research and theory in psychology, Altman and Rogoff (1987)

integrated and extended the work of Pepper to develop the taxonomy of world views. The world views are trait, interactional, organismic and transactional and each world view maps onto a world hypothesis by Pepper (see Table 1). Each world view has a number of underlying assumptions in terms of the units of analysis, the role of the observer, environmental and temporal factors and goals (particularly causation) that guide psychological inquiry (Altman & Rogoff, 1987). It is important to note that when studying psychological phenomena no world view is intrinsically better than the other; each approach has unique value in different circumstances (Altman & Rogoff, 1987). Different research questions may require different world views.

The dominant world hypothesis in contemporary psychology is mechanism (Altman & Rogoff, 1987; Oliver, 1992). Mechanism uses the root-metaphor of the world as a machine; discrete structural features responding to stimulation in a static system (Pepper, 1942). According to this world hypothesis, phenomena can be understood by describing its discrete elements and discovering laws of relation (Altman & Rogoff, 1987; Pepper, 1942). The interactional world view builds on Pepper's mechanist perspective and reflects many of the characteristics of the positivist paradigm (Altman & Rogoff, 1987). Key to the interactional perspective is the prediction of unidirectional relationships between antecedent predictor variables and consequent psychological and behavioural outcomes. Reality is understood as an invariable, determinable order and causal inferences can be made (Jaeger & Rosnow, 1988). Contextual factors are viewed as independently defined and operating entities of psychological phenomena that can be controlled (Altman & Rogoff, 1987). Finally, it is assumed that the study of phenomena can be value free; objectivity is the cornerstone of the interactional approach (Altman & Rogoff, 1987; Oliver, 1990). This approach values the testability, generalisability and replicability of research findings. It is assumed that psychological phenomena can be observed objectively and knowledge obtained through the interactional approach is independent of the assumptions underlying it and the methods used to obtain it (Altman & Rogoff, 1987; Oliver, 1990).

Table 1

World Hypotheses by Pepper (1942) and the corresponding World Views by Altman and Rogoff (1987)

World Hypotheses by Pepper	Taxonomy of World Views by Altman and Rogoff
Formism	Trait
Mechanism	Interactional
Contextualism	Transactional
Organicism	Organismic

Epistemological underpinnings in disability research.

Traditionally, mechanistic worldviews have dominated disability research (Oliver, 1992). This approach to psychological inquiry has produced a distorted view of the experience of disability and has had a number of damaging consequences for people with intellectual disabilities (Oliver, 1992). According to the mechanistic/interactional perspective, to maintain objectivity researchers are separate from the psychological phenomena they are investigating. The researcher observes the ‘facts’ of his or her ‘subjects’ actions (Jaeger & Rosnow, 1988). As a consequence, disability research tends to reflect the perspective of academics and professionals or carers and service providers who control the needs and experiences of people with intellectual disabilities (Jurkowski, 2008). Given the emphasis of interactional approaches to psychological inquiry is to identify cause and effect relations, variables must be isolated and controlled by the researcher (Kidder & Fine, 1997). Isolating the individual with a disability from their broader historical, social and cultural context locates the ‘problems’ of disability squarely within the individual (Oliver, 1992). That is, disability is an individual problem; a consequence of personal inadequacies or functional limitations (Oliver, 1992). Other possible explanations for the ‘problems’ of disability (perhaps society?) are rejected. The reductionistic and linear nature of the mechanistic worldview is incompatible with the aims of this research (Gergen, 1990b). To explore the social construction of intellectual disability, a worldview which considers the complexity of social phenomena is required. Similarly, examining the worldviews, values,

mythologies and culture that underlie this social construction requires an appreciation of context and the dynamic nature of social phenomenon.

It is possible that assuming a contextualist worldview may enhance our understandings of the social construction of intellectual disability and the personhood, identities and social roles of people with intellectual disabilities. The contextualist world hypothesis by Pepper (1942) considers contextual and temporal processes to be fundamental aspects of the phenomenon. Contextualism uses the root-metaphor of the world as a historical event; active, dynamic and embedded in the surrounding context which is itself in transition (Jaeger & Rosnow, 1988; Pepper). According to this perspective, knowledge is incomplete and relative as phenomenon is intrinsically bound to context in a reality which is transformative and developmental (Jaeger & Rosnow, 1988). Contextualism corresponds with the transactional world view by Altman and Rogoff (1987). Psychological phenomena are believed to reflect a convergence of psychological and environmental qualities and temporal features. This approach stresses the importance of context and understanding the meanings participants assign to events is fundamental. The observer is viewed as being inseparable from the phenomena and phenomena is seen to be partly defined by the observer. The transactional world view proposes that multiple methods of inquiry are needed to address the complexities of social phenomena (Altman & Rogoff, 1987; Jaeger & Rosnow). The contextualist world view corresponds well with the post-modernist posture assumed for this research, whereby the role of the broader historical, political, social and cultural context in the construction of intellectual disability is of interest.

Citizen participation.

The second aim of this research was to increase the control, power and meaningful participation of people with intellectual disabilities in the research process. One of the most frequently cited models of participation is Arnstein's (1969) Ladder of Citizen Participation. The Ladder of Citizen participation was developed by Arnstein during a period of radical reform in the United States, where government initiatives and other aspects of public life, such as education and housing, were being challenged. The model represents citizen's level of participation in community planning and programmes as being on a continuum or a

ladder. The bottom rung of the ladder represents citizen 'manipulation' or an illusionary form of participation where citizens are not involved in community planning or conducting programmes but rather are 'educated' by powerful stakeholders to engineer their support (Arnstein, 1969). Levels of citizen participation move through significant gradations of participation, through to the top rung of the ladder which represents 'citizen control'. At this level, citizens govern community planning and have managerial power (Arnstein, 1969). Arnstein (1969) acknowledges that in reality more rungs may exist and there are less sharp distinctions between levels of participation.

Central to citizen participation in planning and programme development is the redistribution of power to the 'have-nots'; those who are typically excluded from the community planning process (Aleshire, 1970; Arnstein, 1969). According to Arnstein (1969), genuine participation only occurs when the power balance between the haves and have-nots shifts. Community members are meaningfully engaged in planning, exert influence in the decision making process and are involved in collaborative action (Dalton et al., 2007). This approach is associated with a number of positive outcomes for community members including having a voice in organisational decisions and plans, a sense of pride and accomplishment, and the opportunity to learn new skills (Dalton et al., 2007). While the value of citizen participation in community planning has long been recognised, the use of this model in research with people with intellectual disabilities has been slow to follow (Jurkowski, 2008). This belated movement reflects the stigma associated with disability and the dominant cultural worldviews which construct people with disabilities as incompetent and incapable (Hughes, 2007; Oliver, 1992; Susman, 1994).

Participatory approaches to disability research.

Research is a cultural practice and as such disability research methodologies are underpinned by social and scientific understandings of disability (Rioux, 1997). As understandings of disability and ideological frameworks began to slowly shift, so too did approaches to research with people with intellectual disabilities. In the late 1980s and early 1990s, led by the principles of normalisation (Nirje, 1970) and the values underlying the social model of disability, disability research underwent

dramatic change (Walmsley, 2001). People with disabilities together with academic researchers sought to develop research methodologies that do not perpetuate oppression but instead promote valued social roles, empowerment and autonomy for people with an intellectual disability (Stone & Priestley, 1996). The result was the development of a number of disability research traditions including emancipatory disability research (Oliver, 1992; Zarb, 1992), participatory research (Cocks & Cockram, 1995) and inclusive research (Walmsley & Johnson, 2003). Although each of these approaches to research have different underlying theoretical positions, they do have common features and can be referred to using the umbrella term 'participatory approaches to research'.

Participatory approaches to research with people with an intellectual disability are characterised by greater meaningful participation and influence (control) by people with an intellectual disability in research than has traditionally typified the research process (Turnbull et al., 1998). People with an intellectual disability are involved as more than research subjects or respondents; they are research partners or co-researchers actively engaged in some or all of the research process (Knox, Mok, & Parmenter, 2000; Stalker, 1998; Walmsley, 2001). People with an intellectual disability have the opportunity to exert control and make decisions in the research process (Knox et al., 2000; Walmsley & Johnson, 2003). Rather than a dichotomy between traditional disability research and participatory approaches, there is a continuum with varying degrees of meaningful participation in and control of the research process and outcomes by participants (Finn, 1994).

The role of the person with an intellectual disability and their level of control in the research process can be conceptualised using an adapted version of Arnstein's (1969) Ladder of Citizen Participation and the Continuum of Family Participation in Research by Turnbull et al. (1998) (see Figure 1). In traditional psychological research, the role and level of control of people with intellectual disabilities in research is represented by level one on Figure 1. At this level, people with intellectual disabilities are viewed as 'objects' of research to be tested and analysed (Walmsley, 2001). At levels two and three on Figure 1 people with intellectual disabilities are increasingly involved in the research process. They may review the findings of the research or act as 'consultants', but they have no or little

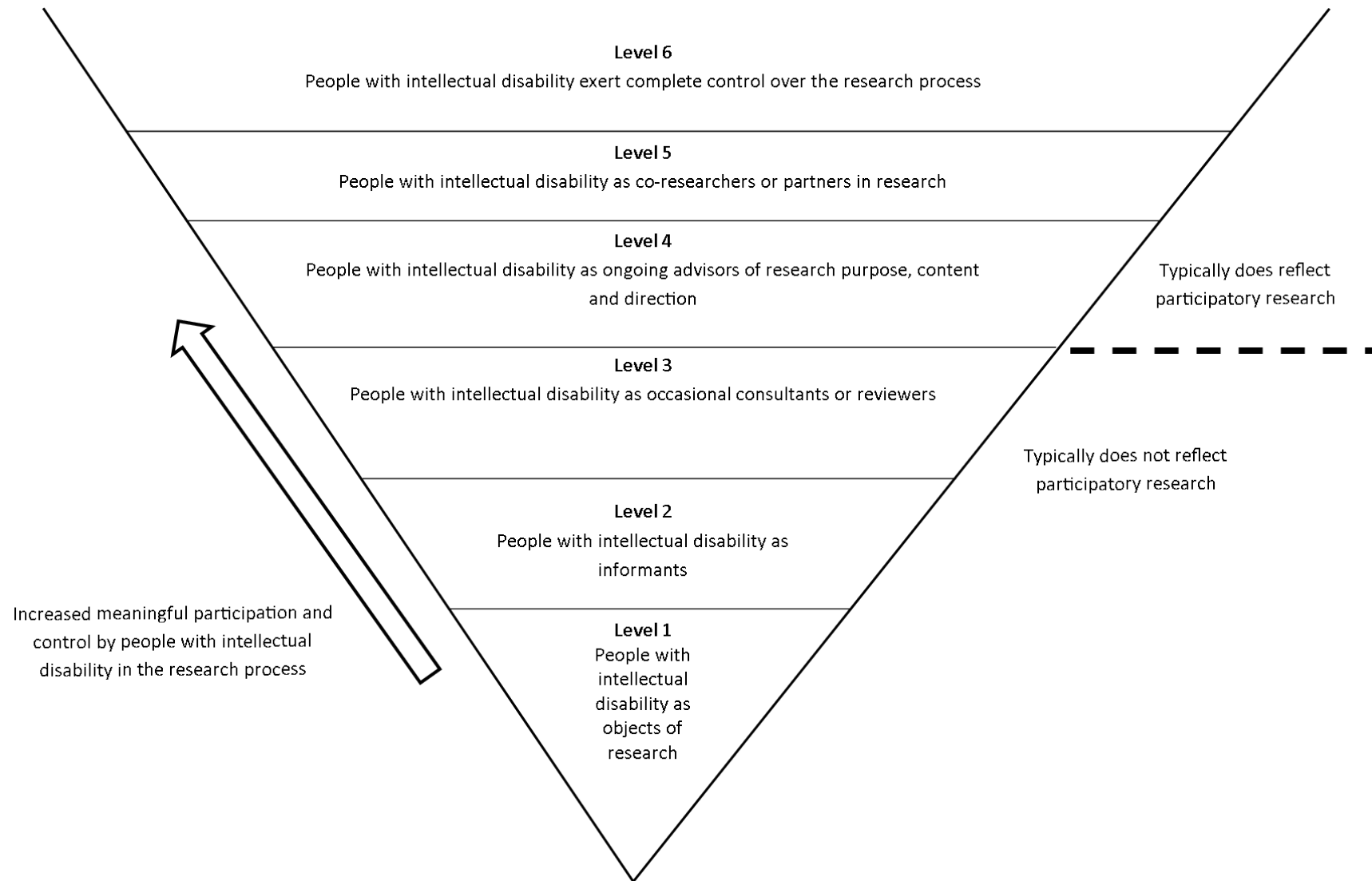


Figure 1. The roles and control of people with intellectual disabilities in research, based on the *Continuum of Family Participation in Research* by Turnbull et al. (1998)

influence over the research design, methods or dissemination (Turnbull et al., 1998). For this reason, level two and three fall short of the definition of participatory research. According to Cocks and Cockram (1995), participatory research involves the formation of an active alliance between the researcher and the participants with intellectual disabilities. There is collaborative decision making and the participants with intellectual disabilities have influence over the design and implementation of the research (Turnbull et al., 1998).

At the participatory research level, represented by level four and five of Figure 1, people with intellectual disabilities can be viewed as ongoing advisors of the research (Turnbull et al., 1998). This may involve people with intellectual disabilities being involved in discussion groups, holding public meetings, establishing research teams and producing educative materials (Cocks & Cockram, 1995). Finally, at level six there is a complete dissolution of the distinction between the researchers and people with intellectual disabilities (Wadsworth, 1993). At this level, people with intellectual disabilities control the research and collaborate in all phases of the research process, including the specification of the research questions, design, data collection, analysis, dissemination and the utilisation of the research findings (Turnbull et al., 1998; Walmsley & Johnson, 2003).

This approach to research has a number of advantages for people with intellectual disabilities. Firstly, the accuracy and meaningfulness of the research contribution is enhanced as people with intellectual disabilities are actively involved at every stage of the research process, including the formulation of a research question (Wadsworth, 1993). Secondly, participatory processes and methodologies are intrinsically empowering as people with intellectual disabilities are able to use research as a media for having their voices heard (Cocks & Cockram, 1995). Thirdly, active participation in research accords people with intellectual disabilities roles of a relatively high social status (Walmsley, 2001). They are the ones asking the questions, not just answering them. Finally, when people with intellectual disabilities are associated with positive images (being a researcher) they are more likely to be afforded positive roles (Wolfensberger, 2000). For this reason, participatory researchers can be viewed as 'citizen advocates' bringing people with

intellectual disabilities into circles of ordinary community life and facilitating social integration (Walmsley, 2001).

This research is situated at level five of the model in Figure 1, where people with intellectual disabilities assumed the role of co-researcher or partner in the research process. The formal requirements and obligations of a PhD placed constraints on the level of participation possible in the research process. This research was not initiated by the Members. I approached the Advocacy Agency and asked if the Members would be interested in being involved in a research project. The research topic (the social construction of intellectual disability) reflects my own interests, not that of the Members. I proposed a research methodology, conducted the analysis of the interview transcripts and wrote this thesis. The Members did not exert complete control over the research process, rather their involvement and level of control fluctuated throughout the research process. For these reasons, this research project could not be situated at level six of the model in Figure 1. The tensions related to participation, control and power that arose in this research are explored further in chapter seven. Although, Members did not exert full control over the research process (level six), they were co-researchers or partners in this research. The role of the Members in this research is described further in the 'Procedure' section below, and in chapter seven.

The use of participatory research approaches with people with an intellectual disability is growing, but still not widespread (Cocks & Cockram, 1995; Jurkowski, 2008). Furthermore, methods for engaging people with an intellectual disability in participatory research tend to be limited to interviews and focus groups (Jurkowski, 2008). This emphasis on the articulated word in intellectual disability research is problematic for those who prefer to use alternative forms of communication (Rojas & Sanahuja, 2011).

Rojas and Sanahuja (2011) called for participatory research approaches with people with an intellectual disability to be broadened beyond the traditional survey or interview to include visual methods. These methods focus on visual, rather than text-based data and may be more accessible to people with an intellectual disability (Boxall & Ralph, 2009). Examples of visual methods used with people with an intellectual disability include the use of video (Rojas & Sanahuja, 2011), digital life-

story narratives (Matthews & Sunderland, 2013), photo elicitation (Fisher, 2009) and Photovoice (Booth & Booth, 2003). There are a number of different terms used to refer to the use of photographs in research. Photo elicitation (also known as PEI and photo-interviewing) refers to the use of photographs in the research interview (Harper, 2002; Mills & Hoerber, 2012). Photographs can be taken and/or selected by both the research participant and the researcher (Epstein, Stevens, McKeever, & Baruchel, 2006). Photovoice only utilises photographs taken by the participants and goes one step further to engage participants and policy makers in a group dialogue for social change (Wang & Burris, 1997).

Like all approaches to research, it is important to acknowledge that the use of Photovoice too reflects (and is limited by) current ideologies and technologies. As technology develops and understandings of disability change, research methods and methodologies will continue to evolve and new methods will emerge. Nevertheless, at the current time Photovoice provides a creative and innovative method that can be used to increase the meaningful participation and control by people with intellectual disabilities in research.

Photovoice

Photovoice aims to capture the reality of people's lives and make these realities accessible to others using photographic images. Photovoice involves the research participants taking photographs to illustrate the research problem or question. The photographs are then supplemented by interview data. Booth and Booth (2003) outlined the six stages of Photovoice:

1. Establishing a group of people interested in conducting research.
2. Collectively identifying a theme to be explored using Photovoice.
3. Taking the photographs.
4. Selecting photographs either individually or as a group which reflect the theme of the project and contextualising or telling stories about the photographs.
5. Codifying or identifying the collective themes, issues and theories which occur across the participants photographs.
6. Targeting an audience beyond the group, such as policy makers.

Developed by Wang and Burris (1994, 1997) Photovoice has traditionally been used in public health settings as a means of conducting participatory needs assessment, participatory evaluation and communicating with policy makers. Wang and Burris (1994; 1997) credit the development of Photovoice to three main sources: Freire and education for critical consciousness, feminist theory, and documentary photography. First, Freire (1970) suggested that one means of stimulating community problem solving, organising and social action is through the visual image. Influenced by Freire's methods, change, participation, personal and social transformation and justice are central to Photovoice (Wang & Burris, 1994). Second, just as feminist theory views women as authorities on their own lives, Photovoice emphasises participants' own voices and visions (Wang & Burris, 1994). Photovoice, like feminist inquiry, values knowledge grounded in experience and attempts to create conditions in which oppressed groups can gain power and stimulate positive social change. Finally, akin to documentary photography, Photovoice uses the visual image to chronicle the social conscience (Booth & Booth, 2003; Wang & Burris, 1994). Photovoice, however, differs from documentary photography in that it places the camera directly in the hands of those who experience powerlessness as their dominant social reality (Wang & Burris, 1997). Wang and Burris (1994; 1997) argued that by actively participating in the recording of their social reality and *owning* the images, participants can be catalysts for change in their own community.

Several published studies have used Photovoice with people with intellectual disabilities and reported a number of benefits (e.g., Booth & Booth, 2003; Brake, Schleien, Miller, & Walton, 2012; Jurkowski, 2008). First, Photovoice captures the view points and social realities of people with an intellectual disability and can improve researchers' understandings of their experiences (Jurkowski, 2008). Using Photovoice, researchers are able to obtain a more rounded insight into how the world of people with an intellectual disability is perceived and experienced as they are granted access to their homes and communities (Jahoda et al., 2010; Jurkowski, 2008). Furthermore, data collection is not restricted to times when the researcher is present. Second, Photovoice affords people with intellectual disabilities the opportunity to develop new skills and confidence (Jurkowski, 2008).

Third, Photovoice offers a novel and interesting way to engage people with an intellectual disability in research. It has been noted in the literature (e.g., Lennox et al., 2005) that it can be difficult to engage people with an intellectual disability in research because of a lack of interest and absence of immediate benefit to the participants. Taking photographs offers an opportunity to be creative and is an enjoyable experience. Finally, Photovoice is accessible to anyone who can be taught to operate a camera and does not require the ability to read or write (Booth & Booth, 2003; Wang & Burris, 1997). During the Photovoice interviews, the photographs taken by the participants can provide a stimulus for conversation. Photographs offer tangible representations of concepts and issues, which corresponds well with the concrete learning style of people with intellectual disabilities (Booth & Booth, 2003; Boxall & Ralph, 2009). Furthermore, emphasising the visual capacity of people with an intellectual disabilities promotes the movement away from the pathological (deficit-focused) perspective of intellectual disability (Aldridge, 2007).

Conversational Interviewing

As outlined above in the six stages of Photovoice, the photographs taken by participants serve as a stimulus for conversation and the photographs themselves are not analysed. An approach to interviewing is needed to assist participants in contextualising or telling stories about the photographs that they have taken. Conversational interviewing is a recursive process whereby the agenda for the interview is established interactively by both the researcher and the participant (Burgess-Limerick & Burgess-Limerick, 1998). The questions asked by the researcher build on the responses provided by the participant to previous questions and in previous interviews as well as the stories told by other participants (Burgess-Limerick & Burgess-Limerick, 1998). Conversational interviewing is a particularly powerful way of gaining access to individuals' unique social worlds as the research is truly grounded in the experiences of the participants (Burgess-Limerick & Burgess-Limerick, 1998). Conversational interviewing also addresses the power imbalance that typically arises between researcher and participant (Burgess-Limerick & Burgess-Limerick, 1998). Using this research methodology, the researcher is responsive to the participant's agenda and the participant has control

over when and where the interview conducted, the duration of the interview and most importantly, the interview content (Limerick, Burgess-Limerick, & Grace, 1996). The researcher and the participant are viewed as partners and collaborators. This is important for people with intellectual disabilities who traditionally have little control and power in research (Walmsley & Johnson, 2003). Conversational interviewing was chosen as a methodology for this research as it complements the use of Photovoice. It enables the unique social worlds of the Members to be accessed and increases their level of control and influence in the research process, consistent with the aims of this research.

Research Design

This research is informed by a contextualist perspective as this approach enables the complexity and contextual factors relevant to the social construction of intellectual disability to be captured. This research was qualitative and was conducted within a participatory research framework. According to Figure 1, this research is situated at level five, where the Members assumed the role co-researchers or partners in research. Providing the Members with the opportunity to exert control and make decisions in the research process, addresses the second aim of this research (Turnbull et al., 1998). Photovoice and conversational interviewing were used to collect Member data. Photovoice enabled the Members to control the subject of the research, while conversational interviewing allowed their reasoning to be given substance and exposure. Data were analysed using causal layered analysis (CLA; discussed below), which corresponds with contextualism which privileges the socially constructed nature of phenomenon, the focus of this thesis.

Co-Researchers

The co-researchers in this study were 18 Members (11 male and 7 female) of an Advocacy Agency that supports people with intellectual disabilities based in the south west region of Western Australia. More information is in the section 'Establishing a group of people interested in conducting research' below.

Materials and Equipment

An information document and consent form was provided to each Member who expressed interest in being involved in the research. These documents are discussed further in the section 'Ethical Considerations' below. Members who were

involved in the 'This Is Me' project were also loaned a digital camera for the duration of the project which was labelled with an identification number. Members were required to sign a register which documented which digital camera they had. A benefit of using digital cameras was that the Members were able to review the photographs before discussing them. In addition, the Members could choose which photographs they would like to have printed, making digital cameras a cost effective option. A series of interview prompts were used to encourage the Members to contextualise or tell a story about the photographs they had taken. The interview prompts used are described in the section 'Selecting and contextualising the photographs' below.

Procedure

The research process of the 'This Is Me' research project followed the six stages of Photovoice identified by Booth and Booth (2003). Each stage will be discussed in detail below.

Stage 1: Establishing a group of people interested in conducting research.

The people involved in this study were Members of an Advocacy Agency that supports people with an intellectual disability living in the south west region of Western Australia. The Agency advocates for the justice and human rights of people with an intellectual disability and values choice, independence, equality of opportunity and social inclusion. The values of the Advocacy Agency are closely aligned with the values underpinning participatory research and as such, the agency was very interested in being involved in the project. Once ethical approval for the project was granted, the advocacy agency was contacted by email to arrange an informal information session for interested Members. All Members of the Advocacy Agency were invited to be involved in the research project. Eighteen Members (11 male and 7 female) aged 20 to 45 years participated in this study. I was well known to the Members of the agency and I had participated in a number of their activities and functions prior to the commencement of this research. Park (1993) argued that when undertaking participatory research, it is important that the researcher knows the community of interest personally as well as scientifically. This increases the acceptability and relevance of the research (Turnbull et al., 1998).

Stage 2: Collectively identifying a theme to be explored using Photovoice.

I was invited by a staff member at the Advocacy Agency to attend the fortnightly Members meeting. At this meeting, I described the research project to the Members, and presented them with a potential research topic (their identities and social roles). It is acceptable for participatory researchers to identify a research problem and bring it to the community to see whether they consider it worthy of investigation (Chappell, 2000). Although not necessarily initiated, the research topic must be owned by people with an intellectual disability (Walmsley & Johnson, 2003). To illustrate the abstract topic 'identities and social roles', I showed the Members a selection of photographs that I had taken of my life; including photographs of my family, home and interests and hobbies and told the Members stories about each photograph. During this process, the Members started to share their own stories and experiences. We collectively discussed those things that were important to us. This discussion generated much excitement and the Members indicated that the topic of their identities and social roles was something that they were interested in investigating.

Stage 3: Taking the photographs.

Members who were interested in being involved in the research project were provided with an information sheet and consent form that utilised simple language, pictures, bullet points and the repetition of information. Members with legal guardians were provided with an information sheet and consent form to take home to have their guardian co-sign. Informed consent was an ongoing process, rather than something only established at the beginning of contact (this is discussed further in the 'Ethical Considerations' section below).

At the second Members meeting, each Member who was interested in being involved in the research project was provided a digital camera. Lending a digital camera demonstrated trust and respect for Members as valued co-researchers. All of the Members were experienced in using a digital camera, but required a little assistance to operate these specific cameras. Members helped and encouraged each other and took practice photographs. Next, we discussed the ethics and responsibilities of camera use, such as obtaining permission before taking someone's photograph. Finally, Members were reminded of the purpose of the

research and encouraged to discuss and think about “Who am I?”, “What makes me me?” and “What is important to me?” Members were given no direction as to what to photograph, as per the Photovoice philosophy.

Members took photographs for a period of three months. Each fortnight, I attended the Members meeting to provide support and guidance to Members who were having difficulties and to see if any of the Members were ready to discuss the photographs that they had taken. The number of photographs taken by each Member ranged from two to 83 photographs, ($M= 32$ photographs, $SD= 24$) taken by each Member. The content of the photographs and videos was diverse. Members took photographs of family, pets, friends, work, their home, their car, their hobbies and their passions, such as supporting the local football team. One Member chose 10 photographs taken on a recent holiday to discuss during the interview. Another Member decided that he would prefer not to take photographs and would like to be interviewed and write letters of his life story. Three Members decided to use the video camera function on the digital camera to take short videos. Five Members were provided with a copy of the photographs that they had taken at their request.

Stage 4: Selecting and contextualising the photographs.

Consistent with the principles of participatory research, the Members had control over where interviews were conducted, who was present during the interviews and the number of interviews conducted. Members were contacted by phone or text message to arrange an interview to discuss their photos and videos at a time and location suitable for them. Members were interviewed at their home, at cafes or at the Advocacy Agency office. Who was present at the interview was determined by the desires of the Member. Thirteen Members chose to be interviewed in pairs or small groups, while others requested that their parent or guardian be present. Ten Members were interviewed once, three Members were interviewed on two occasions, three Members were interviewed on three occasions and one Member was interviewed on four occasions.

At the start of the interview, photographs taken by the Member were uploaded onto a laptop computer. Some Members controlled the laptop to scroll through and select their photographs, while others verbally indicated whether they

wanted to discuss the photograph on the screen. To encourage the Members to contextualise or tell a story about each photograph, they were asked: what made you take this photograph? And, what is happening in the photograph? The interviews were flexible and akin to a conversation, with the questions asked building on the responses provided by the Member to previous questions and in previous interviews as well as the stories told by other Members. This was a particularly powerful way to gain access to the Members unique social worlds and also counteracted the power imbalance that typically arises in research. Members that were not verbal were still able to be involved in the interviews. Some Members pointed at photographs and used facial expressions and gestures to convey their story, while others requested that their parent/guardian be present during the interviews to assist.

Stage 5: Identifying themes that represent the collective experience of the group.

All interviews were audio-recorded and transcribed verbatim. Photographs were inserted into the transcripts for ease of interpretation. Interview transcripts were analysed using CLA (Inayatullah, 1998). CLA is an in-depth, multilevel analysis that enables the factors that perpetuate social issues or problems to be identified through the interaction of several different levels of understanding: the litany, social causes, discourse/worldview, and myth/metaphor (Inayatullah, 1998). This is discussed in detail in the 'Causal Layered Analysis' section below.

Stage 6: Targeting an audience beyond the group.

Reflecting the principles of participatory research, the dissemination of the research findings to the wider public were controlled by and reflected the desires of the Members. Members decided that they would like to display the photographs that they had taken as part of the project in a public display. A meeting was arranged to discuss the logistics of having a public photograph exhibition (timing, location, invitees, advertising, selection and presentation of photographs). Members selected their own photographs for display. Flyers advertising the photograph exhibition were distributed by Members and through the networks of the Advocacy Agency. The public photograph exhibition was held at the local shopping centre with Members involved in setting up the display and working shifts

manning the display. When members of the public approached the display they were met by a Member who walked them through the display talking about the photographs. The photograph exhibition was attended by the local community development officer and representatives of disability agencies in the area.

Simply presenting the photographs taken by the Members enabled the general public to have a glimpse into the realities and experiences of people with an intellectual disability. The photographs taken by the Members presented a diverse range of identities and social roles, beyond that of the 'disabled' or 'stigmatised' identity so commonly assigned to people with an intellectual disability (Rapley, 2004). One person who viewed the This Is Me photograph exhibition commented to me that the Members looked as though they had very fun and full lives. He seemed surprised by the activities, hobbies and holidays enjoyed by the Members. This comment highlights the ability of a photograph (uninfluenced by the voice of the academic researcher) to present a visual challenge to the stamp of difference and otherness so often affixed to people with an intellectual disability and other marginalised groups (Aldridge, 2007; Booth & Booth, 2003). The main action of the photograph exhibition was to facilitate engagement with the community and raise awareness of the many other attributes and social identities people with intellectual disabilities have beyond that imposed on them by people without intellectual disabilities (Fine & Asch, 1988).

The exhibition and the research project more generally received great publicity with the story featuring in two local newspapers, the university website, an independent website and two disability magazines. On the day of the exhibition there was also an interview with the local radio station. Educating others, particularly those in positions of power, to better understand the realities and experiences of the person holding the camera is one of the main goals of Photovoice (Wang & Burris, 1997).

I met with the Members one last time to reflect on the photograph exhibition and the research project more generally. At this meeting I presented the Members with my initial thoughts about their identities and social roles based on the photographs that they had taken and the stories they had told me. Seeking feedback from the Members enabled me to affirm that the findings accurately

reflected their views, feelings, and experiences. At this meeting, the Members were also paid an honorarium of \$100.00 each for the expertise and time that they brought to the project as co-researchers.

Causal Layered Analysis

Wicked problems are complex, difficult to define, intractable and have ambiguous outcomes (Bishop & Dzidic, 2014; Rittel & Webber, 1973). Potential 'solutions' to wicked problems are tangled and complex and may seem unresolvable, overwhelming those attempting to address the issue (Bishop & Dzidic, 2014). The conceptualisation of intellectual disability and the treatment of people assigned this label by society could be considered a wicked problem. As an example, traditional psychological research has contributed to oppression and devaluation of people with intellectual disabilities (Oliver, 1992). Disability researchers have attempted to devise ways to increase the level of control in and meaningful participation by people with intellectual disabilities in research. In the following excerpt, disability researchers Walmsley and Johnson (2003) reflect on their experiences conducting inclusive research with people with intellectual disabilities;

... In our efforts to create a more just society we take on the burden of trying to make our research achieve the goals we would like to see in the broader context. Our research must be democratic, equal, participatory, emancipatory. However hard we try, it never feels as if we have succeeded. How can we? We cannot create a utopia from within our research projects... until we have managed to change the society into a more just place for people with learning disabilities we will continue to feel the guilt and sense of failure of never reaching a desired goal in terms of our research processes (p. 88).

This excerpt illustrates the feelings of hopelessness many disability researchers experience when trying to address the oppression and devaluation of people with intellectual disabilities through inclusive or participatory research practices. When issues (such as, the lack of control and power of people with intellectual disabilities in research) are considered too complex and overwhelming, they are often deemed too difficult, outright ignored (purposefully or incidentally) or only superficially

deconstructed, failing to identify the root of the issue (Bishop & Dzidic, 2014). Complex or wicked social problems, such as societal conceptualisations of intellectual disability and the consequent treatment of people with intellectual disabilities, requires in-depth deconstruction to identify the deeper, underlying cause of the issue (Bishop & Dzidic, 2014). CLA is consistent with the contextualist world hypothesis proposed by Pepper (1942) as contextual and temporal processes are identified as fundamental aspects of the phenomenon. As such, CLA is well suited to analysis of complex data sources, such as the Member (and staff) interviews in this research.

CLA is an emerging methodology within the field of futures (planning) research. Using this approach, complex social issues are examined from multiple and deeper frames of reference to produce transformative spaces for the creation of alternative futures (Bishop & Dzidic, 2014; Inayatullah, 2004). Alternative futures are strategies proposed by the researcher to address the issue(s) being analysed (De Simone, 2004). Bishop and Dzidic argued that CLA has applicability beyond the futures discipline, and could be used to deconstruct complex social phenomenon in the fields of social and community psychology. CLA is inherently ecological and offers an avenue for understanding people in context and the deeper, more complex social drivers of an issue (Bishop & Dzidic, 2014). Where Bishop and Dzidic's conceptualisation of CLA departs from that employed by purist futurists, such as Inayatullah (1998), is the creation of alternative futures. Bishop and Dzidic argued that it is not the position of the researcher to provide a suggested alternative future; this should be determined by the community being studied. This stance is consistent with guiding principles of participatory approaches to disability research (Turnbull et al., 1998; Walmsley & Johnson, 2003).

Using CLA, complex social issues are deconstructed into four layers; the litany, the social causative, the discourse/worldview and the myth/metaphor (see Table 2); with each layer the issue is scrutinised with increasing complexity. The litany is the most proximal layer and refers to most visible or obvious construction of the issue (Bishop & Dzidic, 2014). Analysis at this level requires little analytic capacity as the issue is presented superficially as the uncontested 'truth' and assumptions are rarely questioned (Bishop & Dzidic, 2014; Inayatullah, 2004).

The second layer is the social causative layer. This level of analysis is concerned with the systemic and social causes of the issue, including cultural, economic, political and social factors. Often the role of the Government and other important stakeholders (or 'actors') is explored at this level (Inayatullah, 2004). Although the data is often questioned at this level of analysis, the paradigm within which the issue is framed remains uncontested (Inayatullah, 2004).

The discourse/worldview layer is concerned with the deeper social, linguistic and cultural structures that support or legitimise the issue (Inayatullah, 2005). Worldviews shape our understandings of the issue, and there may be multiple worldviews evident in one data set. Inayatullah (2005) argued that discourses do more than cause or mediate the issue, they constitute it. Discourses express particular worldviews through the words and phrases that are used (Bishop & Dzidic, 2014).

The final layer, the myth/metaphor layer, requires the most analytic investment. At this level of analysis, deep mythical stories, collective archetypes and metaphors (which often operate unconsciously) are identified (Inayatullah, 2004). The myth/metaphor layer often encompasses the emotional level experience or response to the worldview(s) under inquiry. The language used at this level is less specific and may evoke powerful visual images (Inayatullah, 2005). No causal layer is privileged over another; each layer represents a particular frame of knowing that is needed to adequately deconstruct complex social issues (Bishop & Dzidic, 2014; De Simone, 2004). The four causal layers are inherently connected and mutually influential; change in one layer affects all of the other layers (Bishop & Dzidic, 2014; De Simone, 2004).

Table 2

The focus of each causal layer in causal layered analysis

Causal Layer	Focus
Litany	How the issue is typically defined within the public arena. The issue is presented as the uncontested 'truth'.
Social Causative	The systemic causes of the issue, including social, historical, political and environmental factors.
Discourse/Worldview	The underlying values, assumptions, worldviews and ideologies that support or legitimise the issue. How words and phrases are used frame (and constitute) the issue.
Myth/Metaphor	Deep mythical stories, social and cultural archetypes and metaphors. The emotive dimensions of the issue or the paradox.

CLA was undertaken using the method outlined by Bishop and Dzidic (2014). First, the interview transcripts were imported into a qualitative data analysis programme, QSR NVivo 10, for analysis. The transcripts were read through a number of times to familiarise myself with the data. I also took notes; recording nuances, observations and emotional reactions I had in response to the data. Next, to guide analysis I created the pre-existing nodes 'litany', 'social causative', 'discourse/worldview' and 'myth/metaphor'. I then began to code between the causal layers, identifying excerpts of the transcript relevant to the focus of each causal layer. This process was iterative and the codes were revised. At this stage, a sample of interview transcripts were also coded (according to causal layer) by both of my supervisors to ensure the reliability of coding. This process is discussed further in the section 'Ensuring Research Trustworthiness' below. I then coded within each causal layer, identifying trends or patterns in the data relevant to the research question. Potential themes and sub-themes, relevant to the foci of each layer, were then reworked (collapsed, deleted and refined) to ensure each theme had sufficient supporting data and data cohered meaningfully. Quotations were selected from the transcripts to support claims made. Labels for each theme were then determined. Thematic maps were also created to illustrate the overlap and

relationships between themes and the themes relevant to multiple causal layers. As recommended by Bishop and Dzidic, each causal layer is presented independently, with sub-headings representing the themes identified. Existing literature and relevant theory was then incorporated into the findings to support my interpretation of the data. The final stage of CLA is reconstructing the issue (Bishop & Dzidic, 2014). The findings of the CLA were consolidated and reported in the 'Reconstructing the Issue' section of the chapters four and five. The implications of these findings are also suggested.

Ethical Considerations

The traditional regulative principles of research ethics that underline the ethics review processes at most institutions (such as universities), are not suited to the dynamic and changing nature of participatory research approaches within a contextualist paradigm (McLeod, 1996; Smythe & Murray, 2000). Participatory research approaches are open-ended, emergent and intrinsically discovery-oriented (McLeod, 1996). As a researcher, I was unable to anticipate just what would occur throughout the process of the research and detail all these possibilities (and risks) in a comprehensive information document and consent form. For example, the content of the unstructured, Member Photovoice interviews were dependent on the individual Member and the quality of the relationship that we had developed. Josselson (1996) captured the idiosyncratic and open-ended nature of discovery-based approaches to research in the following excerpt:

Merely waving flags about confidentiality and anonymity is a superficial, unthoughtful response. And the concept of *informed consent* is a bit oxymoronic, given that participants can, at the outset, have only the vaguest idea of what they might be consenting to (p. xii-xiii).

Further, traditional ethical principles governing research with human participants tend to conceive research participants as 'data sources', a conception that is not tenable for participatory research approaches which occur in naturalistic settings where long-term, and often close, personal involvement is required (Smythe & Murray, 2000). In addition, my engagement with the Members and multiple role entanglements as a researcher, a friend, a confidant and member of the disability community, encouraged deeply emotional and private accounts from the Members

that could not have been forecast with any degree of accuracy at the outset of this study. It became clear that a different approach to ethics was needed to meet the unique dilemmas associated with participatory approaches to research (Smythe & Murray, 2000). The approach adopted will be discussed according to the main principles of research ethics; free and informed consent, privacy and confidentiality and avoidance of harm (McLeod, 1996; Smythe & Murray, 2000).

Free and informed consent.

Free and informed consent refers to consent to participate in research that is voluntary and not induced using any form of undue influence (Smythe & Murray, 2000). The disclosure of information is pertinent to participant's informed decision to participate in research. An information document and consent form was provided to each Member who expressed interest in being involved in the research. The information documents and consent forms utilised simple language, pictures, bullet points and the repetition of information to ensure understanding. Consent was documented in writing. Given the open-ended and heuristic nature of the research project, this static, one-shot approach to free and informed consent was not sufficient (Smythe & Murray, 2000).

Process consent (Munhall, 1988), whereby informed consent was an ongoing process throughout the duration of the research project, was adopted. At the beginning of each Photovoice interview, the Members were asked if they had any questions or any issues that they would like to discuss. At this time, the concepts of privacy and confidentiality were also re-introduced. Consent was renegotiated with the Members as unexpected events occurred and new permissions were acquired when necessary (Munhall, 1988). The Members were also reminded that it was their choice to be involved in the project and that they can stop their involvement at any time. Members were continually reminded that their remarks were being recorded as research data. This was particularly important when I felt that the Members may have been revealing more than they were consciously willing to share. Some Members used the phrase "off the record" to denote information that was not to be included in this thesis. The consent procedure is described in greater detail in chapter seven.

Privacy and confidentiality.

To meet the principles and standards of privacy and confidentiality in research, personal and identifying information collected from the research participants must be kept private (Smythe & Murray, 2000). Data from this project was stored in a locked cabinet where it will remain until five years following publication. Only my supervisors and I had access to the data. In addition to privacy, research that is released or disseminated must be void of any specific identifying information (Smythe & Murray, 2000). It is particularly difficult to conceal the identity of specific participants in qualitative research as the stories told by the participants are necessarily unique and intimate and saturated with identifying markers (Grafanaki, 1996; Smythe & Murray, 2000). To protect the anonymity of the Members in this study, they were assigned pseudonyms. In some instances, other details which may identify the Members were altered, such as age, gender and relationship status. Photographs taken by the Members that are presented in this thesis have been carefully selected to ensure that the anonymity of the Members is maintained. Photographs featuring people or other identifiable links back to the Members have not been included. In some instances, the photographs were edited to remove personal details, such as names.

Avoidance of harm.

Research should pose no more than minimal risk to research participants (McLeod, 1996). Over the duration of this research, the Members and I developed a close and trusting relationship (this relationship is discussed in detail in chapter seven). Due to the intimate nature of the relationship that I had with the Members, sensitive and highly emotional material was shared. The Members disclosed aspects of their life with a great deal of frankness and honesty. Having a private view of the lives of the Members was a privilege. I had to be receptive to the Members expression of discomfort with the topic being discussed and in instances where the Members became upset, I responded with empathy, respect and integrity. Munhall (1988) captures this perspective; “human beings are being treated as ends and not means” (p. 155). The needs of the Members in this research always superseded the research imperative.

Ensuring Research Trustworthiness

For research that is informed by a constructivist position, the conventional positivist benchmarks for ‘research rigour’ do not apply. Further, disability researchers who engage in participatory research with people with intellectual disability have a unique role and relationship with the co-researchers in the research process that necessitates additional caution to ensure that the research is rigorous and of a high quality (Vernon, 1997). Lincoln and Guba (1985) devised a useful framework which can be used to judge the quality or ‘trustworthiness’ of naturalistic research. Terms such as credibility, transferability, dependability and confirmability replace the traditional quantitative criteria for internal and external validity, reliability and objectivity (see Table 3 below) Lincoln and Guba warned that the equivalent naturalistic criteria is open-ended and can never be satisfied to the extent that the trustworthiness of the research could be considered irrefutable. Instead, it is suggested that researchers adhere to a number of accepted strategies to enhance the trustworthiness of their research and then informed judgments can be made about the quality of the research (Creswell, 2013; Lincoln & Guba, 1985). In this section, I will present the strategies employed to ensure that this research was conducted rigorously, corresponding to each of the naturalistic criteria of trustworthiness specified by Lincoln and Guba.

Table 3

Traditional positivist criteria for research rigour and the equivalent naturalist criteria by Lincoln and Guba (1985)

Traditional Positivist Criteria	Equivalent Naturalist Criteria
Internal Validity	Credibility
External Validity	Transferability
Reliability	Dependability
Objectivity	Confirmability

Credibility.

The credibility of qualitative research refers to the ‘truth value’ of the research findings (Lincoln & Guba, 1985). In this research, a number of strategies

were employed to increase the probability that credible findings would be produced, including; (1) prolonged engagement, (2) the triangulation of sources, (3) member checking and (4) peer debriefing. Close, long-term contact with the participants, rather than a rudimentary acquaintance, is necessary to ensure that a trusting relationship can develop (Lincoln & Guba, 1985). This is particularly important in participatory action research (Park, 1993). Time is also needed to become oriented to the 'culture' and the context in which the phenomenon is embedded (Lincoln & Guba, 1985). A period of prolonged engagement enables distortions to be detected and relevant characteristics and elements of the phenomenon to be identified (Creswell, 2013; Lincoln & Guba, 1985). The This Is Me project officially spanned one year from the initial contact with the Advocacy Agency through to a final reflection session with Members involved in the project after the public photograph exhibition. My engagement with the Advocacy Agency informally, however, began approximately four years prior as a family member. Whilst the Members were taking photographs as part of the project, I visited the Advocacy Agency fortnightly to provide practical support and conduct the Photovoice interviews. This time spent with the Members enabled me to learn more about the context in which they are embedded and gain a more complete understanding of the social construction of intellectual disability. I am still in contact with many of the Members that were involved in this research. The close, trusting relationship that I formed with the Members involved in this study is examined in more detail in chapter seven.

To enhance the credibility of this research, multiple and different sources of data were also sought (Creswell, 2013; Maykut & Morehouse, 1994). Interviewing both the Members and the staff at the Advocacy Agency (see chapters four and five) enabled multiple perspectives to be captured and compared. The convergence of many of the themes lends strong credibility to the findings of this research (Maykut & Morehouse, 1994). In addition, at a final reflection session I presented the Members with my initial thoughts about their identities and social roles based on the photographs that they had taken and the stories they had told me (member checking). This enabled the Members to judge the accuracy and credibility of the account (Creswell, 2013). Finally, peer-debriefing or 'supervision' enabled me to

test working hypotheses, explore meanings, discuss my progress and express my personal feelings. Lincoln and Guba (1985) argued that the peer debriefing process also helps to “keep the inquirer honest” (p. 309) as interpretations are challenged and biases are probed.

Transferability.

The transferability of qualitative research refers to the extent to which the findings can be applied (or transferred) to other contexts (Lincoln & Guba, 1985). In this thesis, I provide a rich, thick description of the co-researchers, the research setting and the research process. Providing a detailed description of how the research was conducted and the analysis and interpretation process enables the reader to determine the extent to which the findings of this study could be applied in a different context because of ‘shared characteristics’ (Burgess-Limerick & Burgess-Limerick, 1998; Creswell, 2013; Lincoln & Guba, 1985). Clear and detailed information about the research aims, participants and methods increases the transparency of the research and invites scrutiny and critical consideration from the reader (Maykut & Morehouse, 1994).

Dependability.

The dependability of qualitative research refers to the consistency or stability of the research findings (Creswell, 2013; Lincoln & Guba, 1985). Lincoln and Guba asserted that there is no credibility without dependability. In this study, dependability was enhanced by the use of multiple coders to analyse the interview transcript data (Creswell, 2013). Bishop and Dzidic (2014) recommended peer coding when conducting CLA to ensure that the claims that are made regarding data interpretation are justifiable. Two interview transcripts were selected to be coded by myself and my two supervisors independently. Each interview transcript was coded according to the four causal layers (the litany, the social causative, the discourse/worldview, and the myth/metaphor). Once the interview transcripts were coded, the codes were compared to determine the level of inter coder agreement (Creswell, 2013). This was a flexible and informal process where each coder was invited to justify their reasoning for coding a section of the transcript at a particular causal layer. Bishop and Dzidic suggested that the conversation surrounding the peer coding process is especially valuable as the data can be discussed, codes can

be challenged and peers can offer alternative interpretations. Across coders, there was sufficient similarity in coding. Regular supervision (or peer-debriefing) further enhanced the dependability of this research, as the themes that were identified through the process of CLA were presented and defended (using quotes from the Members and the relevant peer-reviewed literature).

Confirmability.

The confirmability, or neutrality of the data, was facilitated by the presence of an audit trail (Lincoln & Guba, 1985). My audit trail consisted of a reflexive journal. Bishop and Dzidic (2014) argued that maintaining a reflexive journal is especially important when conducting CLA as inferences are made about the deeper, cultural values influencing an issues and as a researcher, I am too embedded in that culture. Reflexive journaling can help the researcher become attuned to their own positioning, values and worldviews (Bishop & Dzidic, 2014). In my reflexive journal, I also recorded the study schedule and logistics, field notes, summaries, working hypotheses and thematic maps. Methodological decisions and changes were also documented and justified. The reflexive journal was also a personal diary where I recorded my motivations, expectations, thoughts and insights. Reflexive journaling was also an opportunity for catharsis, where I could freely write my feelings and emotions. Lincoln and Guba argued that reflexive journaling can apply to all four of the naturalistic criterion of trustworthiness as important information about both the researcher and the research process are recorded. In chapter seven, I present my thoughts on engaging in this research and critically reflect on my role as a researcher.

Conclusion

In this chapter, I restated the research aims and research objectives and presented the epistemological assumptions that informed the research. Participatory approaches to research with people with intellectual disabilities were examined and the Photovoice methodology was presented. I provided information on the recruitment and demographics of the Members; specified the materials and procedures used to collect the data, and the processes of data analysis used in the research, and emphasised the ethical considerations relevant to this research.

In the following chapter, I present the findings and interpretations from the CLA of the Photovoice interview transcripts with the Members of the Advocacy. The themes identified at each causal layer are presented and then positioned in relation to the research literature, in order to compare and contrast my findings with the existing body of knowledge.

Chapter 4: The Perspectives of the Members

“What’s the use of their having names,” the Gnat said, “if they won’t answer them?”

“No use to *them*,” said Alice; “but it’s useful to the people that name them, I suppose. If not, why do things have names at all?”

- Lewis Carroll, ‘Through the Looking Glass’

Findings

The following is a CLA of the interview transcripts² with the Members of the Advocacy Agency. Fourteen major themes were identified in the data. The themes identified at each causal layer are presented in Table 4 below. The themes emerging from the analysis are then integrated with the existing literature and relevant theory. Finally, the findings of the analysis are reconstructed and consolidated and some implications are suggested.

² In the interview transcript excerpts included in this thesis, I will indicate my dialogue using my first name (‘Kate’).

Table 4

The themes identified at each causal layer from analysis of the Member interview transcripts

Causal Layer	Theme
Litany	Friends, family and pets National/cultural identity The advocacy agency Leisure, recreation and interests Church
Social Causative	Work and employment assistance agencies Housing and welfare
Discourse/Worldview	Proving them wrong People like me Being burdensome Control and contested adulthood
Myth/Metaphor	Doing 'being ordinary' or being ordinary? Problematizing the identities of people with intellectual disabilities Alternative identities and being a human being <ul style="list-style-type: none"> • Love birds and intimate relationships • The carer (not the cared for) • Intelligent and competent • Personal growth

Litany

The litany level refers to the most visible or obvious characteristics of the issue. In this study, the litany encompasses those surface-level issues or aspects of life discussed by the Members. Little analytic capacity is required at this level of analysis (Inayatullah, 2004). Given that the litany refers to the superficial, unquestioned view of reality, in this section I will present the content of the photographs taken by the Members, with little analysis. Five themes were identified at the litany level of analysis; 'Friends, family and pets', 'National/cultural identity', 'The advocacy agency', 'Leisure, recreation and interests' and 'Church'.

Theme: Friends, family and pets.

The personal relationships of the Members were the most featured in photographs and the most commonly discussed aspects of their lives. The majority of the photographs taken by the Members were of their friends. Most of the Members described their friendships and relationships with their fellow Members at the Advocacy Agency or with other people who also had intellectual disabilities. Many of these friendships began in primary school or high school when the Members were in the Education Support Unit. Friends were described as people with whom they could do things. Some Members photographed engaging in activities with friends such as attending the speedway, bowling and fishing (see Figure 2 below).



Figure 2. A photograph taken by Louise of a shovel-nosed shark caught when she was fishing with friends.

Many of the photographs taken by the Members featured their family members. One Member, who is a mother, mostly photographed her two children playing. For the project, some of the Members visited their grandparents and other members of their extended family especially to take a photograph. Members described their position in the family and their relationship with their parents and siblings. These relationships were described positively and were central to the lives of the Members. Some Members chose to photograph and discuss their boyfriend or girlfriend or their husband or wife. These romantic relationships are examined later in this analysis in the theme 'Love birds and intimate relationships'.

Pets also commonly featured in the photographs taken by the Members. Pets were an important member of the family and were a source of companionship and joy for many of the Members. In the following excerpt, Greg and Daniel described their cat Bluey who also features in Figure 3;

Greg: That's my cat. He's very special. My baby. He's about two and a half, nearly three, I think... He is (the) boss of me (laughs).

Daniel: He lets Greg know when he wants to go outside.

Greg: He licks me on my head too. That's not like a cat to do that. I don't know how he picked that up.

Daniel: And he follows you down the road.

Greg: Yeah, follows us down the road (laughs) when we're walking.

Daniel: We're walking, next minute turn around, there's Bluey behind us. He scratches himself on the rose bushes out the front... he copied all the moves of the dog (laughs).



Figure 3. A photograph taken by Greg of his cat Bluey.

Stable and rewarding interpersonal relationships, whether with friends or family, are essential to the wellbeing and quality of life of all people, and people with intellectual disabilities are no different (Knox & Bigby, 2007; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006a). Lacking such social relationships can create feelings of loneliness, exclusion and isolation (Chappell, 1994). Knox and Hickson (2001) interviewed four people with intellectual disabilities to explore their meanings of friendship. Participants in this study all had a 'good mate' that played a

pivotal role in their lives. A good mate was described by participants as being someone you shared common interests with and a reliable, dependable source of support. A sense of shared history and longevity was also common characteristic of these relationships. Participants enjoyed the companionship of their good mate and the relationship was mutually satisfying. McVilly et al. (2006a) explored the friendship experiences and aspirations of 51 people with intellectual disabilities and agreed that friendships can meet a range of both practical and emotional needs. In this study, participants described feeling free to 'be themselves' with their friends.

These findings were also echoed in a larger study of 1452 adults with intellectual disability by Emerson and McVilly (2004). The authors reported that people with intellectual disabilities are more likely to be involved in activities with friends who also have intellectual disabilities, rather than with friends who do not have intellectual disabilities. This finding was comparable to the current study where Members tended to describe their friendships with other Members of the Advocacy Agency. A number of studies have reported that the friendships with other people with intellectual disability are very important to people with intellectual disabilities, as they often have a shared history (e.g., schooling) and common life experiences (Chappell, 1994; McVilly et al., 2006a).

Similarly, family is critically important in the lives of people with intellectual disabilities. Studies have reported that even when they are no longer living at home, people with intellectual disabilities tend to remain very connected to their families and family (particularly parents) continue to play a significant role in their lives (Kraemer, McIntyre, Blacher, & Taylor, 2003). Families are often the main caregivers and supporters of people with intellectual disabilities (Turnbull, Brown, & Turnbull, 2004). Knox and Bigby (2007) explored the meanings of 'family care' and perceptions of family relationships in seven families that included a middle-aged adult with intellectual disability living at home. In this study, care for the family member with an intellectual disability was commonly conceptualised as 'family business'. Family members were highly interdependent and each family member (including the adult with intellectual disability) had specific roles and tasks which served a critical function within the family and ensured that each family member felt important and valued. I would argue that the importance of interpersonal

relationships to the Members as identified in this level of analysis is not an extraordinary or remarkable finding. Like people without the label intellectual disability, the Members identities are bound up in the relations with others. This tension is returned to later in this analysis.

Theme: National/cultural identity.

Some of the Members interviewed spoke enthusiastically about their cultural heritage. Many of the Members had parents or grandparents that were born overseas. Their cultural background seemed to form a very important part of how they saw themselves. Paul explained the origins of his surname;

My surname is a German name and of course my ancestry is English, Scottish, German, Irish and French... My Mother's family fled the guillotine from France and then went to Ireland... My Dad's people were German and English... On my Dad's side, my Great Grandfather was a French man and my Great Grandmother was a German and they used to sneak across the border to see each other. The border guards let them through.

Another Member, David, explained that his parents had migrated to Australia from Hungary following the war. Photographs of his extended family hung on the walls of his unit; *"Yeah... and that's why I've got photo's up of Uncle Edvard and Margot and Margaret, also my Mum and Dad and two of my grandparents... my Dad's side and my Mum's side... They both come from Hungarian"*. David explained that he longed to meet his extended family and was planning a holiday overseas in the future.

National/cultural identity emerged as important to some of the Members in this study. This is not surprising considering multiculturalism has become an integral and essential feature of the contemporary Australian national identity (Moran, 2011; Stratton & Ang, 1994). Most Australians have at least some direct experience with Australia's highly immigrant nature through their own extended families (Moran, 2011). In 2013, the number of overseas-born Australians reached over six million, representing almost a quarter of the total population (Australian Bureau of Statistics, 2013a). A further 20% of people born in Australia had at least one overseas-born parent (Australian Bureau of Statistics, 2013b). In addition, 32% of the population reported more than one ancestry, just as Paul did in this study (Australian Bureau of Statistics, 2013b). The importance of cultural ancestry to the

way in which some of the Members conceptualised their own identities is hardly surprising. As previously discussed in chapter two, post-modernist conceptualisations of identity emphasise the role of an individual's broader historical, social and cultural context in identity formation (Gergen, 1990a). Interestingly, the importance of nationality/culture to identity is not reflected in the disability literature. Beart et al. (2005) argued that the ethnic and cultural identities of people with intellectual disabilities are often obscured by their membership to the category 'intellectual disabled'. The power of this all-consuming master status that overrides the other identities that an individual may have is explored further in the theme 'Alternative identities and being a human being' below.

Theme: The advocacy agency.

The Advocacy Agency featured in most of the Member's photographs. The Members described the activities that they have participated in at the Agency. The majority of the Members stated that they enjoyed attending the camps and the holidays arranged through the Agency the most. Other social occasions facilitated by the Advocacy Agency included karaoke and pool at the local tavern and barbeque picnics on the foreshore. A social ten pin bowling group was also organised by the agency. At the Agency, there were weekly meetings 'just for women' and 'just for men' where sexual health needs and gender-specific issues could be explored in a safe and supportive environment. The majority of the Members described the Advocacy Agency as a place to meet new people and form friendships. The Agency offered a sense of belonging and unity for its Members. For some, the Agency was a space where potential romantic relationships could develop. Stephanie and Mark met at the Advocacy Agency three years ago and have been dating ever since. Stephanie was thankful that she had the opportunity to meet Mark at the Agency; *"It's fun, you meet new people. (Looking at Mark) yeah, I found him so... I wouldn't have met him so"*. Some of the Members formed close relationships with the staff members at the Advocacy Agency. Staff were described as being supportive and helpful;

Greg: She's (Lorraine) really nice.

Daniel: Yeah, she's good. She helps us.

Greg: ... A bit like a mother figure cos I told her some personal stuff... She helps me.

Daniel: If we weren't getting along with people at the Agency we could go up to Lorraine and talk to her about it. Have meetings with Lorraine and that.

The Agency also offered the opportunity to learn important life skills such as cooking and budgeting. Greg explained;

Just to budget and stuff and how things cost and that. Living expenses... we didn't realise you have to pay mortgages. Even the rich, they got their mortgages, their loans. That's what he told us... Having a car... how you got to run it, you got to pay for fuel and this and that. I never thought of that before.

Guest speakers commonly attended the Member meetings. In the following excerpt Jackson described how one guest musician assisted him learning the guitar;

Yeah it's good to catch up with a few different people and share their ideas and I get to share my ideas... I learn a little bit about guitar and there's a lady there... she came from Mandurah, I think, and she... played guitar and she told me a website for guitar playing... I think it's good to have somewhere you can share time with and just chill out or be part of something or whatever it might be.

Most of the Members felt that they had learnt new skills and become more confident through their involvement in the Advocacy Agency. Jimmy has been a Member of the Advocacy agency for six years and credited the Agency for improving his self-esteem; *"Building up my confidence and I've come a long way since I've been there. Yeah and I'm not shy to talk to people cos I was really shy. I'm like (looks down into lap)... Yeah and I was like that".*

The Members in this study are referring to their involvement in a self-advocacy service. Self-advocacy services assist people with intellectual disabilities to develop the skills and confidence necessary to promote, protect and defend their human rights (Cocks & Duffy, 1993; Peter, 2002). By speaking up and representing their own interests, people with intellectual disabilities can challenge the oppression in a disabling society and become a valued and recognised part of the community (Cocks & Duffy, 1993; Goodley, Armstrong, Sutherland, Laurie, & Taylor,

2003). Beyond the opportunity for personal growth and development, self-advocacy agencies can also offer a safe and stable environment where its members can meet with others in a context and at a time that is self-determined (Goodley et al., 2003). Like the Members in this study, self-advocates in a study by Goodley et al. cited forming and maintaining friendships as the main reason for attending their self-advocacy group. McVilly, Stancliffe, Parmenter, and Burton-Smith (2006b) agreed that the shared experience of disability is an important element or basis of friendship. Participants in this study expressed a sense of 'comfort' in their relationships with other people who also had intellectual disabilities as they shared the experience and sociocultural identity of intellectual disability. Goodley et al. noted that comradeship is a quality that is central to new social movements and social action.

Theme: Leisure, recreation and interests.

The majority of the Members chose to photograph the recreation and leisure activities they participate in. Most of the Members played ten pin bowling, both socially and in competitions. Gavin photographed his bowling ball (see Figure 4) and explained; *"Bowling... We do it on Wednesdays"*.



Figure 4. A photograph taken by Gavin of his bowling bowl.

Most of the Members were involved in bowling on Wednesday nights facilitated by the Advocacy Agency. Greg and Daniel explained that they felt more comfortable bowling with their friends from the Agency rather than members of the general public.

Daniel: We used to do the Thursday night one.

Greg: That was, you know, people with not disabilities. And that was pretty good but I like this one better cos the other one with the other people... it's more stressful.

Most of the Members said that they preferred to attend activities facilitated by the Advocacy Agency. This finding was echoed in a study conducted by Buttimer and Tierney (2005) who reported that the leisure activities attended by people with intellectual disabilities also tend to be attached to formal day services or in conjunction with the family (Buttimer & Tierney, 2005; McGuire & McDonnell, 2008).

Two of the Members in this study described how they represented the State in a tenpin bowling competition and won. Their achievement was in the local newspaper and in the newsletter of a disability service agency. These Members proudly showed me their trophy and some photographs from the event. Other activities that the Members engaged in included dancing, horse riding, surfing and skate boarding. One Member photographed cars from when he went to the speedway with his friends. For some of the Members, leisure activities offered the opportunity to be alone and relax. Jackson explained that he plays golf regularly and while it is enjoyable, it can also be frustrating;

I've been playing... for maybe 12 years now. Yeah, it's been good I think with just that way of escaping and just getting away and relaxing but exercising at the same time. I think that's been really good, I think... It can take a lot to improve... Oh it's a weird game. It's so weird cos you think you're doing the right things but you still can't improve. Then it's like what do you do next?



Figure 5. Photographs taken by Anne and David of their West Coast Eagles memorabilia.

Some of the Members were passionate supporters of sporting teams (see Figure 5 above). Being a fan of a sporting team offered a sense of belonging. Paul explained;

I've also been in the Dockers cheer squad for ten years... Well I actually go for both Eagles and Dockers, but Fremantle's my favourite... Dockers were doing very... well, the last few years have done very, very well. They came into the competition in 1995... The day they actually got into the finals I was actually at that match when it happened... So I was part of that history.

A number of Members chose to photograph their television sets and DVDs. Some of the Members described their favourite television series in the interviews. Michelle was a big fan of the television series 'Home and Away'. She explained that she particularly liked the male actors who are often surfing shirtless in the programme;

Michelle: Home and Away! All the time! See it tomorrow... Double episode tonight. They're hot! (Michelle laughs).

Kate: But would it kill em to put a shirt on? They've always got their shirts off.

Michelle: (inaudible) that's the good part! Look when they got no shirts on.

The use of leisure by people with intellectual disabilities has been the focus of much research because of its associated benefits (Buttimer & Tierney, 2005). Numerous studies have reported that leisure and recreation activities can enhance the overall quality of life of people with intellectual disabilities and open pathways toward inclusion in the community (Buttimer & Tierney, 2005; McGuire & McDonnell, 2008; Patterson & Pegg, 2009). Leisure and recreational activities can

have an important role in the facilitation of friendships, the enhancement of self-esteem and confidence and the development of social skills (Duvdevany & Arar, 2004; Patterson & Pegg, 2009). In their study examining the involvement of adolescents and young adults with intellectual disabilities in recreation, McGuire and McDonnell reported that participants that were more actively involved in recreation had higher levels of self-determination. McGuire and McDonnell concluded that recreation can provide a useful platform for enhancing the self-determination of adults with intellectual disabilities as it offers opportunities for independence, risk taking and making choices.

Buttimer and Tierney (2005) also noted that leisure activities can serve an educational function by facilitating the development and generalisation of skills and adaptive behaviours. Beyond the emotional and psychological benefits, recreation and leisure activities can enhance the physical health and fitness of people with intellectual disabilities (Patterson & Pegg, 2009). Some researchers (e.g., Patterson & Pegg) have gone as far as to suggest that serious leisure has comparable benefits to open employment and could serve as a useful substitute to employment for some people with intellectual disabilities. The employment of Members in this study is described in the theme 'Work and employment assistance agencies' at the social causative level.

As exemplified by the above mentioned studies, rather than emphasising the fun or enjoyment of engaging in leisure or recreational activities, research in this area tends to examine the educational, health or psychological benefits of such activities for people with intellectual disabilities. Whereas people without intellectual disabilities may be able to engage in such activities for no reason at all, people with intellectual disabilities are viewed as participating in these activities to develop skills and adaptive behaviours; to remedy their perceived deficits. This is fuelled by fundamental attribution error (Fine & Asch, 1988). The persistent pathologising of intellectual disability and the identities of people with this label is explored in greater detail in the section 'Problematizing the identities of people with intellectual disabilities'.

Theme: Church.

Some of the Members interviewed discussed the role of the Church in their lives. For Paul, attending Church was a way for him to connect with the community and form friendships. He particularly enjoyed the activities and functions organised by the Church;

I love my Church because they're great church members to... get to know and I have lovely friends there too. I'm very happy in my Church and I've got great friends there and... the Church members are great. They are wonderful to hang around with. And there's Church lunches and I love the Church lunches. I'm heading to Church tomorrow and I'm looking forward to that very much.

The above excerpt suggests that Paul appreciates the social aspect of being a member of a Church. Some of the Members had active roles in their Church, such as David who is an Altar Server. For this project, he got a friend to photograph him in his white robes performing his duties at the Sunday service. David described what his role as Altar Server involved;

I give the... Priest the wine to pour into the... chalice and the water in the chalice and then I get this white cloth to put on my arm and... I have to hold this water and he puts his hands into the water and then he takes the cloth and wipe his hands... Monday to Friday at seven in the morning but I go on Sunday the 10 o'clock one cos I carry the cross but the cross they have, I struggle (with) it's heavy... I can't handle it but I can handle the light one.

David explained that he enjoys having a formal and respected role at his Church and was contented to attend six days a week. For some, attending Church was more of a chore. Jackson explained that he attends Church with his parents each Sunday and described Church as 'something to do'; *"It's good, I think. It's just somewhere else to go to. Yeah, I try to go to the 11 o'clock service now. There's a bit more younger people to see... The 9 o'clock service is a bit early for the younger ones (laughs)"*. Michelle's attendance at Church was dependant on when her beloved football team was playing; *"When the football season finish, I go back to church. Football season start, I got back to the football again"*.

Religion has an important role in the lives of millions of people worldwide. It would be expected that religious belief and practice would play a similarly significant role in the lives of people with intellectual disabilities (Selway & Ashman, 1998; Turner, Hatton, Shah, Stansfield, & Rahim, 2004). Shogren and Rye (2005) examined the religious beliefs and practices of 41 people with mild to moderate intellectual disabilities. The majority of participants in this study reported that their religious participation, practices and beliefs were important to them, with participation in religious services being one of the most frequently occurring activities in the participant's lives. Religious participation provided an opportunity to interact with people in the community and form supportive networks. Participants used positive religious coping strategies and the support workers of these participants reported that involvement in religion promoted appropriate social behaviours, such as knowing right from wrong, and enhanced personal competence and control. In another study by Turner et al. (2004) 29 people with intellectual disabilities (with a variety of religious traditions) were interviewed about their religious interests and experiences. Religion was attributed to helping the participants find meaning in their lives and offering a sense of belonging. Although most of the participants were introduced to religion early in their lives by family, Turner et al. concluded that their religiousness was very much the personal choice of the participants. Beyond the family, religious organisations have been integrally involved in the lives of many people with disabilities (Selway & Ashman, 1998). Religious figures and organisations have long been associated with the establishment and provision of health and welfare services for people with disabilities (Selway & Ashman, 1998).

Summary of the litany level.

At the litany level of analysis, the Members presented identities and social roles that were ordinary and unremarkable. The social category intellectual disability was not central to how the Members saw themselves. The most commonly photographed and discussed aspect of the Members lives were their personal relationships. Relationships with family members and friends were described positively and were central to the lives of most of the Members. Cultural heritage was similarly important to some of the Members. Many of the Members

described the Advocacy Agency as a place to meet new people and form friendships. Members enjoyed participating in the various social activities arranged by the Agency and felt that they had become more confident and learnt many useful life skills through their involvement in the group. Leisure activities external to the Advocacy Agency that most of the Members participated in included ten pin bowling and dancing. Other Members were avid sporting fans. Religion featured in the lives of some of the Members. Attending Church was described as an opportunity to engage with the wider community, while others simply saw Church as 'something to do'. In summary, the Members did not conceptualise their own identities as extraordinary or 'abnormal'. Like people without intellectual disabilities, the identities of the Members reflected the social relations they engaged in and the social roles they occupied.

Social Causative

The social causative level of analysis explores the systems and social causes of the phenomenon studied (Inayatullah, 2004). At this level the economic, cultural, historical and political factors that impact on the lives of the Members are explored. Two themes were identified in the social causative layer of analysis; 'Work and employment assistance agencies' and 'Housing and welfare'.

Theme: Work and employment assistance agencies.

Most of the Members discussed or photographed their place of work. Most of the Members in this study worked in open employment organised by employment assistance agencies. They described these agencies as being especially for "*people with disabilities*". Members acknowledged the role of these agencies in assisting them to get a job. Paid jobs undertaken by the Members included delivering catalogues and newspapers, working as a butcher, washing dishes at a café and working at a supermarket; "*Well I collect the trolleys which I've been doing for 15 years... I pick up the baskets from the tills to put them back where they are*" (David). Some of the Members had a number of different jobs. Freya had two different jobs. Her mother explained;

(Looking at Freya) You do newspapers. Newspaper round that she gets paid for... in a Wednesday afternoon... You've been doing it for a long time. You do it with Jess... You go over to the shed and get your papers. You do 185 of

em. Folds em all up and then you go and deliver them... On Wednesday mornings she does the hospital. Works at the hospital volunteering with Jo and Margie, isn't it? They do all the admission folders. Put all the paperwork in the admission folders so when you come in it's already there to go. They make bundles and bundles and bundles of em.

Being occupied by work was described as a way of reducing unwanted behaviours; "She is kept very busy. She has to be kept busy or otherwise... bored and the behaviour comes out" (Freya's mother). Some of the Members worked in sheltered workshops for people with intellectual disabilities making wooden pallets or assembling boxes to carry multiple wine bottles. Working was described as having many benefits. Jimmy enjoyed the financial rewards of being employed as a groundsman at the local trotting track;

Jimmy: I'm a groundsman... a groundsman means that's where you do so many jobs. Yeah, If they want ice, I've got to get ice. If they want drinks, I've got to get drinks. And when the horses go, I do the horse shit.

Kate: Oh do you? (laughs).

Jimmy: (laughs) Yeah! It's good money though. Yeah. It's really good money. I get \$18... I get \$18.50 an hour.

Gavin, who is second in charge at a cleaning company, enjoyed the prestige associated with the position. Some of the Members volunteered for local charity organisations or did unpaid work. One Member expressed frustration at not being financially remunerated for her work.

In Australia, people with intellectual disabilities may be employed in sheltered workshops, open employment or supported employment (Dempsey & Ford, 2009). Employment in sheltered workshops is characterised by repetitive tasks which are relatively easy to learn and perform. Tasks may include assembling, packing and manufacturing. Workers with intellectual disabilities are always subordinated by staff members in sheltered workshops. The introduction of the principles of normalisation and social role valorisation in the 1970s favoured a movement away from segregated sheltered workshops toward more integrated and open employment placements (Dempsey & Ford, 2009; Migliore, Mank, Grossi, & Rogan, 2007). Open employment offers people with intellectual disabilities the

opportunity to experience culturally normative daily routines and typical developmental experiences (Eggleton, Robertson, Ryan, & Kober, 1999). Further, community-based employment enables people with intellectual disabilities to be associated with more positive and valued social roles such as worker, wage-earner and breadwinner (Wolfensberger, 2000).

Indeed, in Western industrialised society, being employed is one of the most valued social roles one can occupy (Eggleton et al., 1999). Guided by the principles of normalisation (and social role valorisation), in the past 40 years over 700 government-funded employment services have been established in Australia, providing employment and training to approximately 65000 people with intellectual disabilities. Open employment services assist people with intellectual disabilities to obtain paid employment in the open labour market (Dempsey & Ford, 2009). This is achieved by identifying possible placements, providing training and offering individualised support. A productivity-based wage is offered (Dempsey & Ford, 2009). Most of the Members in this study have open employment and are serviced by these agencies. The Disability Services Census 2008 (2010) reported that a total of 57 852 consumers were supported by government-funded employment services. Of these consumers, 63.7% were employed in open employment and 36.3% were employed in supported employment (Department of Families Housing Community Services and Indigenous Affairs, 2010). Supported employment services directly employ and pay people with intellectual disabilities or enter into contract agreements with external employers (Dempsey & Ford, 2009).

In a systematic review of community participation, Verdonschot, De Witte, Reichrath, Buntinx and Curfs (2009) reported that people with intellectual disabilities were three to four times more likely to be unemployed than people without disabilities. This is particularly concerning considering the benefits associated with employment. When compared to their unemployed matched counterparts, employed individuals with intellectual disabilities reported a higher quality of life (Eggleton et al., 1999). Eggleton et al. also reported that employment can facilitate social interaction. Further, Kober and Eggleton (2005) found that people with intellectual disabilities employed in open employment had a higher quality of life than those in sheltered employment. These participants displayed

greater community integration, feelings of belonging and increased empowerment and independence. There are also economic benefits associated with people with intellectual disabilities being productive and contributing to society through employment, such as a reduction in government expenditure on disability pensions (Eggleton et al., 1999).

Theme: Housing and welfare.

Most of the Members in this study received a disability support pension from the Government. Many Members described the pension as insufficient and had trouble making their payment last the whole fortnight. Finances were a major worry for Paul. He explained that he had particular difficulties determining when his pension would be paid into his account. To reduce Paul's concerns, he explained that when he goes out to dinner with his friend Lynette they split the bill or Lynette pays.

Just lately me and Lynette have been going out to dinner at the Chinese restaurant... and I must say the food is excellent and we even share the meal together so I don't have the stress... I don't have to worry about 'is my pension in next week?' or you know. It basically means I can enjoy dinner without that worry (of) 'is pension this week or the week after?'. It means I can enjoy dinner without that, you know, worry.

Some of the Members also lived in their own house or unit, which was made possible by the Government Public Housing Assistance. Lynette rents a house from the Department of Housing and enjoys the freedom of being independent;

Lynette: I have my own unit. I have a double size bed and three chairs and I have a table.

Kate: ... How do you like living by yourself?

Lynette: Good... Be on my own. You get to do what you like.

Unlike Lynette, some of the Members in this study had experienced periods of homelessness whilst waiting for Government housing. In the following excerpt, Daniel described 'living rough' while he and a friend were on the waiting list for a house;

Kate: So what were your living arrangements before?

Daniel: Tents, caravan parks, a hotel, then back to the caravan parks and in tents again, then the hotel for six months again...It was raining... it was raining and thundering and lightening and....the tent leaked so all our blankets got wet and... we got work the next morning.

Daniel became quite unwell with pneumonia from living in a tent and was granted priority housing assistance by the Government. He now lives in his own unit with a friend.

Australia has a number of welfare services to support people with intellectual disabilities. The 'Disability Support Pension' is offered to Australian citizens aged 16 years or more, that are permanently blind or have been assessed as having a physical, intellectual, or psychiatric impairment (Department of Human Services, 2014). To be eligible for the pension, the individual must be unable to work, or to be retrained for work for 15 hours or more per week due to the impairment (Department of Human Services, 2014). Most of the Members in this study are single and over the age of 21 years which would entitle them to a maximum support payment of \$751.70 per fortnight (Department of Human Services, 2014). Given that the gross income of most people with intellectual disabilities receiving the Disability Support Pension would be below the Department of Housing's limit, they would also be eligible for public rental housing assistance waitlist (Department of Housing, 2013). Priority housing assistance may be offered in cases where medical conditions are caused or aggravated by the existing housing arrangements (Department of Housing, 2013). This was the case in Daniel's situation described above.

A major survey examining the lives of 2898 people with intellectual disabilities (aged 16 to 91 years) living in England reported that 89% of participants received some form of welfare benefit from the Government (Emerson, Malam, Davies, & Spencer, 2005). Despite receiving a pension, almost half of the respondents reported that they did not have enough money to do the things that they wanted to do, such as go on a holiday or go to the pub. Emerson et al. identified that people with intellectual disabilities who had low support needs and were living independently or with relatives were most likely to experience poverty. Those experiencing poverty were more likely to live in unsuitable accommodation

(like Daniel), be unemployed, have little control over their money and experience poor health. Herein lies a paradox; services and programmes (such as public housing) created to assist marginalised groups to become more independent may in fact have the converse effect of perpetuating control and power over them. This tension is returned to in the following chapter.

Summary of the social causative level.

At the social causative level of analysis, work emerged as an important aspect of the Members lives. Most of the Members were in open employment organised by employment assistance agencies. These Members described the financial benefits of being employed. Other Members worked in sheltered workshops for people with intellectual disabilities, volunteered or did unpaid work. Most of the Members received the Disability Support Pension, although this was described as insufficient. Some of the Members had experienced periods of poverty and homelessness whilst waiting for Government housing. It would seem that Government initiatives (such as supported housing and the provision of a pension) intended to support people with intellectual disabilities to be independent and autonomous paradoxically reduce their freedom and increase their dependence. This tension will be returned to later.

Discourse/Worldview

At the Discourse/Worldview level of analysis, the deeper social, linguistic, and cultural processes are explored (Inayatullah, 2004). Those structures, discourses, values and ideologies that support or legitimise the assumptions made about people with intellectual disability or intellectual disability more broadly are examined. How the Members frame and interpret their world is of particular interest at this level of analysis. Four themes were identified at the Discourse/Worldview level of analysis; 'Proving them wrong', 'People like me', 'Being burdensome' and 'Control and contested adulthood'.

Theme: Proving them wrong.

Some of the Members described that when they were born, doctors and specialists had very low expectations for their development and it was often suggested to their parents that they would be unable to walk or talk. In most cases, the parents of the Members were presented with a very grim forecast of their

future shortly after their birth. In the following excerpt Paul described the poor prognosis given to his parents by a medical specialist when he born;

Paul: The specialist... actually said that I would never.... well, they said that I would never talk but I've certainly proved them wrong... I've certainly proved them wrong.

Kate: You have proved them wrong.

Paul: And... Kate, that makes me feel very good inside.

Here, Paul described the satisfaction he feels in proving the naysayers wrong. Not only is he able to talk, but he also lives independently in his own unit. Paul has far exceeded the dismal expectations imposed on him by others from birth. Many of the Members described this sense of pride and gratification in surpassing these low expectations. Being able to defiantly 'thumb their nose' at the medical establishments was a common discourse throughout many of the Member interviews. In the following excerpt, Felicity and her grandmother described the poor outlook given to Felicity when she was born. This excerpt begins with Felicity, her grandmother and I discussing the itchy, inflamed sores on her body;

Grandmother: Oh it's a part of the disease. Part of the chromosome I think... itching. You're on tablets now for it, aren't you?

Felicity: Yeah.

Kate: (looking at Felicity) is it really itchy?

Grandmother: Nah... she doesn't know.

Felicity: I was born with it.

Grandmother: Yeah, she was born with it and she doesn't realise... part of the complaint... you know what I'm talking about. Actually when she was born (they said she wouldn't) walk, talk or anything.

Felicity: Now look at me now!

Grandmother: Look at you now, yeah.

From being told that she wouldn't be able to do "anything", Felicity now is able to proudly say "look at me now!" which gives her (and her family) a great sense of joy and satisfaction. She has proved them wrong.

The parents of the Members can vividly recall the hopeless prognosis offered by medical professionals and the overwhelming negativity when their child

was diagnosed with an intellectual disability. Barr and Millar (2003) agreed that those early experiences of interactions with health professionals can create lasting impressions and formative in the short term and long term coping and adaptation of parents of children with intellectual disabilities (Barr & Millar). A number of studies have examined the experiences and satisfaction of parents at the time their child was diagnosed as having an intellectual disability. Carmichael, Pembrey, Turner and Barnicoat (1999) interviewed 147 parents of children with Fragile X syndrome to explore their experiences of receiving genetic information about the cause of their child's intellectual disability. In this study, a significant number of parents reported that their experience of genetic counselling was negative. According to a number of parents, the news of their child's diagnosis was delivered in an insensitive and unnecessarily pessimistic way and judgemental comments were made by health professionals about people (and their families) with the condition. Further, parents were offered very limited information about their child's condition and health professionals were not helpful in offering support or facilitating access to services following diagnosis. A qualitative study by Kearney and Griffin (2001) reported that the parents of children with intellectual disabilities initially felt inundated with images of negativity and recounted how health professionals often left no room for hope. This echoes the experience recounted by Felicity's grandmother and Paul in this study.

Using discourse analysis of interview data, Vehkakoski (2007) explored the representations of new born babies with impairments as constructed in the discourse of maternity and paediatric hospital staff. The 'interpretative repertoire' identified that is particularly relevant to this study is the tragedy repertoire. The tragedy repertoire usually occurs in the context of the impairment just being discovered (or possibly diagnosed). This repertoire contained emotive language and many negative expressions that conveyed the birth of these 'shocking babies' as tragic events. Vehkakoski concluded that this particular repertoire served to strengthen the traditional, pathological view of impairment or disability as a chronic loss and an individual tragedy.

According to the individual or personal tragedy theory, people with intellectual disabilities (and their families) are viewed as victims of their

unchangeable and organic impairment (Oliver, 1996). In fact, many of the parents of children with intellectual disabilities in the study by Kearney and Griffin (2001) reported that their expressions of optimism or hope for the future at the time their child was diagnosed as having an intellectual disability were interpreted as maladaptive and pathological by health professionals. Parents who adopted an action-oriented reconceptualisation of their child's disability were also considered 'non-accepting' or 'in denial of reality'; intellectual capacities are fixed and permanently constrained, end of story (Howe, 1997; Kearney & Griffin, 2001).

In this study, the Members are actively resisting this dominant, pathological conceptualisation of intellectual disability as a personal tragedy and challenging the assumptions associated with the label. By doing all those things that health professionals assumed would not be possible, the Members are not conforming to their ascribed identity. They are presenting a threat to the assumed homogeneity of the social category 'intellectually disabled' and the associated assumptions of deficit and incompetence. Through exceeding expectations the Members are not hemmed in by their diagnosis and are able to form identities based on being 'the anomaly' or the one who 'proved them wrong'.

Theme: People like me.

Some of the Members interviewed acknowledged that according to society, they are the collective Other. This was done by using phrases such as "*people like me*", comparing themselves to other people who also have intellectual disabilities and referring to special services and programmes specifically for people with intellectual disabilities. In the following excerpt, Paul discusses his relationship with a local community volunteer; "*He's a very nice bloke and he really cares about people in my situation so I'm happy to have his support*". By referring to "*people in my situation*", Paul is identifying himself as being a member of a discrete social group. In another example, David, who is active at his local church, explained how he became an altar server;

David: Well I'm actually an altar server. Father John, he's a (inaudible) friend... he has a nephew who's exactly like me and that's how I became an altar server.

Kate: So how is his nephew like you?

David: Ummm he's exactly like me. That's how I became an altar server.

In this excerpt, David acknowledges that Father John's nephew is similar to himself ("*he's exactly like me*"), but does not elaborate on *how* they are similar. It is possible to speculate that David and Father John's nephew are similar because they both have Down syndrome. Interestingly, in this excerpt David also goes on to suggest in a matter-of-fact way that Father John bestowed him the position of altar server *because* he is like his nephew ("*That's how I became an altar server*"). That is, because of his being a member of a particular social category he was given this opportunity. This is an example of positive discrimination. In the following excerpt, Mark, Stephanie and I talk about their mutual friend, Lynette.

Mark: I went to high school with her.

Kate: So.... is she your age?

Mark: No, she's younger but...

Stephanie: A bit younger than him.

Mark: But the ed. support unit they always stick everyone in together.

In the above excerpt, Mark acknowledges the grouping of people with intellectual disabilities in the education system; "*... they always stick everyone in together*". Regardless of age, all people with intellectual disabilities within a school are placed in the same classroom. People with intellectual disabilities are a homogenous group, the Other. A number of the Members also described the employment agency through which they got their job as being exclusively for people with disabilities.

The above examples suggest that the Members in this study were aware of their allocation to the social category 'person with an intellectual disability'. In contrast, it is consistently reported in the literature that at least some people with intellectual disabilities appear to be unaware of their 'intellectually disabled' identity (Beart et al., 2005). In their study, Todd and Shearn (1997) interviewed the parents of 33 adults with intellectual disabilities aged 17 to 44 years to explore the nature and meaning of 'co-residence'. Todd and Shearn reported that parents are the 'gatekeepers' of information concerning their child's intellectual disability and protect their child in two ways: non-disclosure (avoiding the use of obvious terminology and providing alternative accounts of the behaviour of others) and through the construction and maintenance of fictional biographies. In this

'conspiracy of silence', parents actively supported and encouraged their child's ambitions, for example getting married, whilst privately believing that it will never be possible. Todd and Shearn concluded that many people with intellectual disabilities are unaware of their membership to the 'intellectually disabled' category and "... the world in which they operate rejects and discriminates against them" (p. 362). Enclosed inside a 'protective capsule' (Goffman, 1963), people with intellectual disabilities are effectively 'invisible to themselves' (Todd & Shearn, 1997).

The assumption that people with intellectual disabilities are unaware of their membership to the 'intellectually disabled' category has been challenged in the literature. Cunningham, Glenn and Fitzpatrick (2000), interviewed 77 young people with Down syndrome to determine their awareness and recognition of Down syndrome. Interestingly, participants' awareness of Down syndrome was not related to parental disclosure of disability. It could be argued that the 'protective capsule' is, in fact, not as effective as suggested by Todd and Shearn (1997). The unique physical features and characteristics of Down syndrome were identified as a 'trigger' which prompted discussion between parents and their offspring with Down syndrome. In addition, differences in schooling environment and attendance at special social clubs often encouraged the discussion and disclosure of Down syndrome. Indeed, people with intellectual disabilities exist in a world external to the 'protective capsule' created by their parents or primary care givers.

In Australia, public services (governed by law and conventions) are organised to increase the access and inclusion of people with intellectual disabilities in society. Most adults with intellectual disabilities are offered special housing, have a supported work placement and attend special social and leisure activities specifically for people with disabilities (Kittelsaa, 2013). Most of the Members in this study referred to the disability agencies that assisted them in securing housing and gaining supported employment. Some Members also discussed their pension that they receive fortnightly from the Government (see the themes 'Work and employment assistance' and 'Housing and welfare' above).

Categorically-based services are a feature of the daily lives for most people with intellectual disabilities. Kittelsaa (2013) argued that such special, segregated

services present an interesting paradox. On the one hand, public policy emphasises self-determination, autonomy, and participation in the community (New South Wales Government, 1993). The diversity of people with intellectual disability is stressed and individuals are to be acknowledged and valued as unique individuals (New South Wales Government, 1993). This rhetoric surrounding difference and how it should to be championed was expressed by some of the staff interviewed as part of this research. This explored in greater detail in the theme 'It's OK to be different (not really)' presented in chapter five. On the other hand, programmes and services are designed and administered specifically to meet the needs to people with intellectual disabilities (New South Wales Government, 1993). These services, by their very nature, effectively exclude people with intellectual disabilities from 'mainstream' society by placing them in the category of service recipients (Kittelsaa).

Theme: Being burdensome

Some of the Members interviewed suggested that they were a burden or an inconvenience to their parents. Most of the Members in this study lived at home and relied on their parents for financial support and transport. The discourse of being a burden is evident in my interview with 20 year old Felicity who lives at home with her family;

Kate: Yep. And what's your mum like? I've spoken to her a few times on the phone.

Felicity: (inaudible). I don't mind her, putting up with me.

The above excerpt suggests that Felicity is thankful for her mother because she tolerates her. In another excerpt, 32 year old Michelle explained that she attends respite regularly to give her mother some relief;

Michelle: I do respite.

Kate: What's... what's that mean?

Michelle: Give mum a break.

Some of the Members interviewed suggested that raising a child with an intellectual disability (and possibly other associated health issues) is particularly difficult and their parents ought to be applauded for their efforts. In the following excerpt, Paul described his parents; "... They're really, really lovely people and... lots of people

have actually said they've done such a great job raising me cos they had to raise me all on their own". By emphasising that his parents raised him "all on their own", Paul is suggesting that this is quite unusual and notable. Paul also mentioned that his parents have been congratulated for parenting Paul by "lots of people". The burden of intellectual disability was described as not only impacting on the immediate family, but also those strangers whom the Members encounter. In an interview with Kelvin (who has Down syndrome) and his mother Jenny, Jenny spoke about their experiences on a recent family skiing holiday in Canada. Jenny, her husband and Kelvin were in a large tour group and Jenny was concerned about how the group would respond to Kelvin's presence; would he be unwanted? Would he be considered a burden? Jenny explained;

... Here we are, this family, we're old and we have Kelvin and we didn't know how they'd tackle us or take us, and some groups would be pretty shirty and make it quite clear that we were the non-crowd... and afterwards.... this chap came up to me and he said "I have a brother who's autistic and he's sixteen and we would never be able to take him like this". He thought it was so marvellous... These people (people with intellectual disabilities) never get to see anything like this because you wouldn't get a group.... they wouldn't take a group there and there would be no other tours they could go on by themselves... He said 'you know, we really, really agree. We think it's amazing that you brought him. We think it's great for the group as well'.

In the above excerpt, Jenny explained that people with intellectual disabilities would not usually be able to go on skiing tours, because tour operators "wouldn't take a group". This could be because people with intellectual disabilities are perceived to be too difficult to accommodate or too much of a liability on the ski slopes. Jenny is surprised by how charitable the people in her tour group were of Kelvin; they were willing to tolerate him on their holiday.

Wolfensberger (1998, 2000) argued that people with intellectual disabilities are often cast in the role of a 'burden of charity', dependent on others (Williams & Robinson, 2001; Wolfensberger, 2000). That is, people with intellectual disabilities lack the resources, ability or power to survive independently and are reliant on others for their care. While others may feel obliged to take care of the person with

intellectual disability, this duty is often resented and performed begrudgingly (Wolfensberger, 1998). In receipt of this sour charity, the dependent is expected to be grateful.

The social construction of people with intellectual disabilities as a 'burden' has been explored in the literature. In her analysis of the interpretative repertoires used by hospital staff when speaking about babies with impairments, Vehkakoski (2007) identified a 'labour repertoire'. In the labour repertoire, maternity and paediatric hospital staff discussed the baby with impairments in relation to his or her parents. The baby was described as demanding and requiring much effort and commitment on the part of the parents, and as such assumed the position of 'burden to parents'. In this repertoire, health professionals also expressed concerns about the capacity of the parents to care for such a fatiguing child as extensive practical skills in the daily management of the child would be required. Indeed, the research agenda in the area of disability typically considers the families, not the individual with an intellectual disability, to be the service users (Priestly, 1998). Priestly argued that such an approach reinforced the belief that families carry the 'burden of care' and people with intellectual disabilities are dependant and require the care, treatment and charity of others. The experiences of people with intellectual disabilities are also not considered.

Studies that examine the impact (or burden?) of having a child or adult with intellectual disability on the family are a dominant theme in current disability research (Blacher, Neece, & Paczkowski, 2005; Povee, Roberts, Bourke, & Leonard, 2012). Early research on the impact of having a child with an intellectual disability on the family reflected a pathological model whereby couples and the family as a whole were assumed to suffer greatly and experience inevitable negative impacts (Cunningham, 1996; Risdal & Singer, 2004). The expectation that the presence of disability would cause inevitable and severe family strain has not been supported in the literature (Blacher et al., 2005; Povee et al., 2012). Despite this finding, Vehkakoski (2007) emphasised the importance of validating the experiences of families that include an individual with an intellectual disability, as they do face unique challenges. While some of the co-researchers in this study had clearly internalised the societal view that they were a burden to their family, a number of

the Members engaged in a range of caregiving activities within their family themselves (see the theme 'The carer (not the cared for)' below. A more expansive, contextual view of families and intellectual disability is warranted (Blacher et al., 2005)

Theme: Control and contested adulthood

Some of the Members described situations in which basic decisions were made on their behalf by parents or guardians. Parents and guardians often controlled much of their daily experiences, leaving the Members with little personal control and autonomy. In the following excerpt, Anne (who is 38 years old) explained how she is no longer allowed to eat at her favourite fast-food restaurant, pictured in Figure 6;

Anne: Hungry Jacks. We always sit there, having lunch.

Kate: How often do you guys go to Hungry Jacks?

Anne: Not anymore now.

Kate: No?

Anne: Cos mum says I've got to lose weight.



Figure 6. A photograph taken by Anne of 'her table' at the fast-food restaurant.

Anne seemed to readily accept the reality that she had to lose weight and did not express any resentment or hostility toward her mother for making decisions for her. Despite living independently with her husband, Anne appeared to accept the control her mother exerts in her life. In another example, I asked Lynette if she would be attending an upcoming camp organised by the Advocacy Agency;

Kate: ... you're going to camp?

Lynette: No, I'm not allowed to.

Kate: You're not allowed to?

Lynette: No.

Kate: No? Why not?

Lynette: I don't know.

Similar to Anne in the previous example, Lynette casually accepted her mother's control over the activities she did and did not participate in, without even requiring a justification as to why. Lynette did not indicate any resentment toward her mother, nor did she express desire to have greater autonomy over her life. Mill, Mayes and McConnell (2010) labelled this approach to negotiating autonomy within the family as 'passive'. This approach is characterised by a casual attitude toward the status quo. Some people with intellectual disabilities are satisfied with the amount of independence they have and do not actively seek out more opportunities to exert control or have greater responsibility. Decisions are often made by the parents and there is little conflict within the family.

Some attempts to negotiate autonomy and control in the family create more palpable tension. In the following excerpt, David and I talk about his engagement to Anne. Although David discussed his desire to marry Anne with his mother, her permission to marry Anne was not formally sought by David. Further, David's mother was not aware that David had proposed to Anne and was engaged until she saw the notice in the local newspaper;

Kate: Were they (the family) really excited when you guys got engaged?

David: Yeah. Well, my mum always get the newspaper and... she open up to that page and she saw our names... the engagement... and I was saying mum didn't get asked for us to get engaged or... (David starts to get teary)... It's true what Tom (David's brother-in-law) was saying in his speech at our wedding reception, 'it's hard for David's Mum' and... it's difficult for my mum and since when all my sisters got married and I'm the last one.

In this example, David acknowledges that seeing a notice in the newspaper was a very upsetting way for his mother to find out that he was getting married.

Reflecting on the events, David was still visibly saddened. David also explained that

he understands that his marriage to Anne was very difficult for his mother to accept; he was the youngest child of five children and was still living at home. Getting married meant that David would be leaving home to live with his wife in another town and his close relationship with his mother would inevitably change. Despite these difficulties, David decided to go against his mother's wishes and marry Anne. His approach to negotiating control and autonomy was very different to that of Lynette and Anne.

The tension experienced in families as people with intellectual disabilities negotiate their autonomy, like the scenario described by David, has been explored in the literature (e.g., Mill et al., 2010; Winik, Zetlin, & Kaufman, 1985). The transition into adulthood is characterised by greater mutuality and less dependence in the parent-child relationship, increased autonomy and becoming a causal agent in one's own life (Mill et al., 2010; Wehmeyer & Bolding, 2001). There are also a number of social markers of adulthood including leaving the family home, gaining employment and financial independence, embarking on intimate relationships, and possibly having a family of one's own (Mill et al., 2010; Todd & Shearn, 1997). When compared to people without intellectual disabilities, people with intellectual disabilities are less likely to be involved with their peers, engage in intimate relationships, marry, have children of their own, and be employed (Mill et al., 2010; Verdonchot et al., 2009). People with intellectual disabilities are also likely to remain in the family home longer (Mill et al., 2010). These factors have been identified by the parents of people with intellectual disabilities as preventing them from obtaining unqualified adult status (Todd & Shearn, 1997). Where people with intellectual disabilities do decide to leave the family home, parents often continue to be the primary source of support and remain heavily involved in their child's life (Winik et al., 1985). This is evident in the current study where despite living out of the family home, Anne's mother still decides where Anne is allowed to eat and Lynette's mother determines what activities Lynette can participate in.

Winik et al. (1985) identified two broad forms of parental involvement in their study of the nature of relationships between parents and their adult children with intellectual disability who live independently. 'Resource' was defined by Winik et al. as parents providing support to their adult children, such as transport, a

supplementary income and emotional support. 'Regulation', on the other hand, was characterised by efforts made by the parents to control the activities of their child, including, managing and controlling their finances and determining their friendships and affiliations. Such parental involvement promotes dependency and obedience (Mill et al., 2010; Winik et al., 1985). The regulation approach is reflected in both Anne and Lynettes' experiences.

Outside of the family home, van Hooren, Widdershoven, van der Bruggen, van den Borne and Curfs (2005) explored the perspectives of caregivers who supported people with Prader-Willi syndrome and reported that they often felt frustrated by the emphasis on self-determination in the care of people with intellectual disabilities. Prader-Willi syndrome is characterised by overeating behaviour (van Hooren et al., 2005). Caregivers in this study expressed concerns about negotiating the need to provide quality care that respected their client's autonomy, while also protecting their client from the risk of obesity and other related conditions which could potentially damage their health. This perspective is particularly relevant to the example in this study of Anne, who was banned from dining at a fast-food restaurant because her mother said she had to lose weight. The parents of young people with intellectual disabilities in a study by Saaltink, MacKinnon, Owen and Tardif-Williams (2012) described their children as lacking flexibility in thinking, complex decision making skills, self-advocacy skills, maturity and confidence. These characteristics led parents to believe that their child was particularly vulnerable to making poor decisions which may place them in unsafe situations or create circumstance where they can be taken advantage of. Parents also argued that parental decision making and offering guidance was normal and natural in all families.

It has been argued in the literature (e.g., Saaltink et al., 2012) that the parents and carers of people with intellectual disabilities are not paternalistic, but rather are attempting to balance the need to respect and promote autonomy and independence for the person with an intellectual disability, whilst also addressing a perceived need for support (or protection). I would argue that the families of the Members in this analysis are not purposively being 'too controlling' but rather are simply responding to what they perceive to be genuine deficits. It is important to

note that the families that include a person with an intellectual disability are socialised to those same dominant worldviews which construct people with intellectual disabilities as vulnerable and incompetent. Supporting or helping their son/daughter by making decisions on their behalf, while done with the best of intentions, can have the unwanted effect of reducing their personal control and power and increasing their dependence. Issues of control and the paradox of support are returned to in chapters five and eight

Summary of discourse/worldview level

At the discourse/worldview level of analysis, how the Members framed and interpreted their world and underlying cultural values and discourses of intellectual disability were of interest. Some of the Members recalled stories of their parents being given a hopeless prognosis by medical professionals who assumed an overwhelmingly negative outlook for their future. Intellectual disability was conceptualised as a personal tragedy and the Members were assumed to be permanently constrained by their 'pathology'. These Members actively resisted this assessment and took great pride in surpassing the low expectations placed on them by others. Some of the Members interviewed acknowledged that according to society, they are the collective Other. This was done by using phrases such as 'people like me' and describing services and schooling arrangements as exclusively for people with intellectual disabilities. This finding presents a challenge to the assertion that many people with intellectual disabilities are unaware of their membership to this stigmatised social category.

Some of the Members who still lived at home suggested that they were a burden to their parents while others applauded the efforts of their parents in raising them. Some Members also described situations where everyday decisions were determined by their parents. It could be argued that the parents of some of the Members are responding to a perceived need for support and protection. Most often the Members passively accepted this level of parental control and did not seek opportunities for greater control and autonomy, reflecting just how pervasive the assumption that people with intellectual disabilities are incompetent, dependent and vulnerable is.

Myth/Metaphor

The myth/metaphor layer refers to the deeper, emotive aspects of how the Members conceptualise their world as told through mythological stories and metaphors which evoke powerful visual images. A gut or emotional response to the worldviews is commonly evoked at this level of analysis (Inayatullah, 1998). Three themes were identified at the myth/metaphor layer; 'Doing 'being ordinary' or being ordinary?', 'Problematising the identities of people with intellectual disabilities' and 'Alternative identities and being a human being', which has the accompanying subthemes; 'The carer (not the cared for)', 'Intelligent and competent' and 'Personal growth'.

Theme: Doing 'being ordinary' or being ordinary?

There was nothing unusual or extraordinary about the content of the photographs taken by the Members and described in the litany level of this analysis. Almost all of the Members photographed and discussed their family, their friends and their beloved pets, suggesting that close relationships were central to all of their lives (this is explored further in the subtheme 'Love birds and intimate relationships' below). Most of the Member described their involvement in the Advocacy Agency and explained how they had formed new friendships and attend camps and holidays. Members discussed their 'working life', whether it be in a paid position or unpaid as a volunteer for local charity organisation. Some Members spoke enthusiastically about their local sporting team or described how they participated in bowling and dancing competitions. Members spoke about their interests and experiences, such as going to the pub with friends or holidaying overseas. Some of the Members attended Church and considered religion to be an important aspect of their lives. The Members were also eager to talk about their hopes and dreams for the future. Overall, through the photographs that they had taken and in the discussions about their lives, the Members presented themselves as 'ordinary'.

Furthermore, when some of the Members were asked to describe themselves, none of the Members referred to intellectual disability in their self-descriptions. Instead, Members described themselves in terms of their physical appearance, their personality, their relationships with others and their future

aspirations. In the following excerpt, Mark describes himself, with a little help from his girlfriend, Stephanie;

Mark: I can be nice and I'm not really sure.

Stephanie: He does get in a shit mood sometimes but he is pretty much good in that respect, but in that respect he really needs to slow down... And he is really friendly too... He's funny, a pretty good looking guy.

Mark: You like my tattoos and that and my body piercings, things like that.

Stephanie: Yeah. It's like, he's a really cool guy.

Mark is described in terms of his interpersonal traits (“nice” and “friendly”) and his unique tattoos and body piercings, which are a form of self-expression. In another example, Jimmy talks about himself; “I’m friendly, outgoing and probably got good manners. Yeah, when I want to (laughs). When I want to. Yeah, otherwise I’m pretty alright”. In his self-description, Jackson included his hopes and desires for his future-self;

Yeah, I'd like to try and be a little more laid-back... can't take it too seriously but knowing that, you know, when things do get difficult you need to sort of try a little harder and just... have to push yourself a bit more (laughs).

Balancing between, sort of taking it easy and also pushing yourself.

Intellectual disability did not feature in any of the Member’s self-descriptions.

Like the Members in this study, a number of researchers have reported that a significant proportion of people labelled as intellectually disabled, do not use the label spontaneously to describe themselves (Finlay, Lyons, & Taylor, 2005). Finlay and Lyons (1998) examined the significance of the label ‘learning difficulties’ to the self-descriptions and self-evaluations of 28 people with learning difficulties aged 19 to 75 years ($M= 38$ years). Similar to the Members in this study, participants did not spontaneously refer to learning difficulties in open-ended self-descriptions. Instead, participants produced over 230 self-descriptors which focused on their interpersonal traits (e.g., “I’m nice”), abilities, habits and personal history. However, when questioned directly, two thirds of the participants ‘admitted’ membership to the category ‘learning disabled’. Finlay and Lyons (1998) concluded that while the participants had an understanding of the label ‘learning difficulties’, it does not serve a descriptive or explanatory purpose in the lives of people with learning

difficulties. In another study, also using self-descriptions, Finlay and Lyons (2000) sought to determine to what extent membership to a stigmatised social category was reflected in the way 33 people with intellectual disabilities described themselves. In this study, the term 'learning difficulties' was rarely invoked by the participants and was not used as interpretative framework for organising their experience. Finlay and Lyons (2000) concluded that participants in this study did not accept the institutional definition of themselves, but rather used a range of comparisons and real-world social categories that were more helpful and meaningful in their lives.

A number of hypotheses have been offered to explain the apparent lack of salience or importance of the 'intellectually disabled' identity amongst individuals categorised as being members of this group (Beart et al., 2005). According to the literature, Members in this study failing to acknowledge the "official fact" (Edgerton, 1967, p. 145) that they indeed are intellectually disabled in their self-descriptions, may be considered a function of the psychological defence mechanism of denial (Beart et al., 2005; Edgerton, 1967; Todd & Shearn, 1997). In his book, *The Cloak of Competence*, Robert Edgerton studied a cohort of individuals with intellectual disabilities following their release from a state institution. Edgerton and his colleagues found that many of the participants refused to accept that they were or were ever 'mentally retarded' and maintained that they never belonged in the institution in the first place. Instead, the participants offered alternative explanations for institutionalisation such as alcoholism or physical illness. They also created new biographies and accumulated personal belongings to give the appearance of normality. Edgerton concluded that:

The label of mental retardation not only serves as a humiliating, frustrating and discrediting stigma on the conduct of one's life in the community, but it also serves to lower one's self-esteem to such a nadir of worthlessness that the life of a person so labelled is scarcely worth living (p. 145).

So unacceptable is being intellectually disabled, that individuals in this study directed all efforts toward denying the "official fact" (Edgerton, 1967, p. 145). Edgerton proposed that reconstructing damaged self-esteem was achieved by donning the 'cloak of competence' and engaging in concerted and well-organised

efforts to 'pass' as 'normal' (Edgerton, 1967; Goffman, 1963). Passing, the management of undisclosed discrediting information about self, is described as a means of protecting ones' self-esteem from stigma (Goffman). Examples of passing noted in Edgerton's analysis included avoiding public association with people with intellectual disabilities and concealing their history of institutionalisation. More recently, Szivos and Griffiths (1992) reflected on their experiences facilitating group therapy for "coming to terms with learning difficulties" (p. 59). Initially, the group members in this study had difficulty acknowledging any form of group identity or recognising any shared focus or common experiences amongst themselves. Many of the group members denied any memory of their childhood or the use of the label 'mentally handicapped' in reference to them. Mental handicap was often denied and group members described themselves in other ways, such as being shy. Szivos and Griffiths noted that the group members engaged in efforts to pass and expressed shame when pushed to reveal biographical information in group therapy. Are the Members in this study in denial of their 'true selves' or is there an alternative explanation for their lack of identification with the label?

It has been proposed in the literature that people with intellectual disabilities actively resist being defined by others, particularly by researchers who assume the position of power (Rapley, 2004; Rapley et al., 1998; Stone & Priestley, 1996). Rapley et al. disputed claims made by Todd and Shearn (1996) that people with intellectual disabilities are blinded to their own 'true' natures, and argued that people with intellectual disabilities negotiate and manage their identities in social interactions. According to Rapley et al. identity is fluid and locally contingent; it can be avowed or disavowed depending on the demands of the social situation. In research interviews, participants with intellectual disabilities are well aware of their so-called 'toxic identity' ascribed *a priori* by academics (Rapley et al.).

Members in this study were aware of my interest in intellectual disability. Intellectual disability was something that I, as a researcher, deemed to be important, but judging by the photographs taken by the Members and the accompanying discussions with the Members, this label had little resonance with them. Furthermore, some of the Members referred to themselves as the Other (see the theme 'People like me' above). Most Members in this study were provided

support in the form of pension payments, housing subsidies and employment assistance on the basis of their membership to the social category intellectually disabled. I would argue that the Members were well aware that according to society they are identified as the Other. It would, however, appear that the notions of abnormality and deviance were more central to how others conceptualised their identities than to how they saw themselves.

Finally, it has also been argued in the literature that the action of passing is not unique to people with intellectual disabilities, but a pervasive feature of everyday social life. All individuals wish to be seen as ordinary, typical social actors. Kittelsaa (2013) agreed that people in general do not want to be perceived as strange or different; everyone hopes to pass as competent. However, when used in the context of people with intellectual disabilities, passing implies a clear intent to mislead and deceive (Rapley et al., 1998). 'Passing as normal' is considered a morally accountable social action because society perceives people with intellectual disabilities to not be normal (Rapley et al., 1998). This is explored further in the following theme.

Theme: Problematising the identities of people with intellectual disabilities

Just as the 'ordinary' or 'non-stigmatised' identities presented by people with intellectual disabilities are considered to be a function of denial or attributed to deliberate and calculated attempts to 'pass as normal', the identities of people with intellectual disabilities are commonly pathologised or problematised (Susman, 1994). In Western societies, independence, intelligence, competence, health and beauty are deeply valued and impairment or disability is commonly considered to be the worst thing that could happen to a person (Ben-Naim et al., 2008; Susman, 1994). Furthermore, a number of studies have reported that when compared to other impairments, intellectual disability is often considered the least desirable condition (Thomas, 2000; Tringo, 1970). Terror management theory (TMT) offers an explanation for this pervasive tendency to reject (or problematise) those who are perceived to be different or deviate from those valued cultural norms (Greenberg et al., 1990). The theory posits that due to sophisticated cognitive abilities, humans possess an awareness of their own vulnerability and mortality. This threat has the potential to arouse overwhelming and paralysing terror (Greenberg et al., 1990;

Rosenblatt, Greenberg, Solomon, Pyszczynski, & Lyon, 1989). According to TMT, to manage this existential threat, humans rely on cultural worldviews to provide a sense of order, meaning and value (Ben-Naim et al., 2008). Cultural worldviews are, however, symbolic representations of reality and are vulnerable to incoming worldview-inconsistent information. Encounters with others, such as people with intellectual disabilities, can present a challenge to one's 'just world' (Lerner, 1980) beliefs, values and cultural conceptions of reality and undermines the ability of the cultural-anxiety buffer to protect against mortality-awareness. TMT therefore posits that people will be punitive to 'moral transgressors' who threaten their source of security in a largely uncontrollable world where the only certainty is death (Ben-Naim et al., 2008; Lerner, 1980).

The conceptualisation of intellectual disability as a naturalised impairment and a fixed, clinical reality impacts the perceived humanness of people with intellectual disability and reduces the likelihood that people with an intellectual disability are able to be viewed as a 'normal' and 'functional' human beings (Goodley, 2001). Indeed, the individual behind the label often gets 'lost' and only the disability remains to be seen (Susman, 1994). Constructing and presenting a positive identity or an identity that is not 'stigmatised' is particularly difficult for people with intellectual disabilities as much of their behaviour is often pathologised and interpreted as being characteristic of their diagnosis or syndrome (Goodley & Rapley, 2001; Kittelsaa, 2013). 'Disability' becomes the powerful lens through which the behaviours and actions of people labelled as 'intellectually disabled' are viewed. Researchers in the field of disability are vulnerable to focusing on the obvious difference and assuming its centrality to an individual's identity and self-identity (Mest, 1988). Distinctive behaviours or patterns of behaviour are also commonly overconfidently assumed to be due to a 'character trait' or internal causal factors (Harman, 1999; Jones & Harris, 1967). This systematic bias in the person-perception process whereby dispositional causes of behaviour are overestimated and the influence of context is underestimated is known as fundamental attribution error (Jones & Harris, 1967; Tetlock, 1985).

To illustrate the process of 'pathologising the ordinary', I will refer to an example from this study. One of the Members who participated in this study is an

avid fan of the cartoon television series, *The Simpsons*. In our discussions, Mark fondly recalled watching the first episode of *The Simpsons* which aired in 1989. He also chose to photograph his collection of *The Simpsons* memorabilia and figurines, much of which was unopened in the packaging (see Figure 7). Mark explained; “*I love Simpsons so much... I’ve got Simpsons everywhere... Yeah, I have a problem (laughs)*”.



Figure 7. Photographs taken by Mark of his *The Simpsons* collection.

Now I will critically examine Mark’s interest and love of *The Simpsons* and his behaviour of collecting *The Simpsons* memorabilia and figurines to illustrate the process of how people with the label ‘intellectual disability’ can become their professionally diagnosed ‘incompetence’ (Jenkins, 1998). One interpretation of Mark’s interest in *The Simpsons* and his collection of toys and figurines is that it is childish and silly. *The Simpsons* is a cartoon with funny characters; it is not a serious television drama or an informative current affairs programme. Further, spending copious amounts of money on this interest could also be considered an irresponsible and immature. Secondly, Mark’s love of *The Simpsons* and his collection could be considered strange or bizarre. Some might feel that it is inappropriate for a 30 year old man to collect stuffed toys and figurines and display them in his bedroom. Mark’s behaviour could be seen as conforming to the ‘eternal child’ or ‘deviant’ identities commonly affixed to people with intellectual disabilities. Viewing Mark’s interest and hobby through the powerful lens of disability, Mark has become his professionally diagnosed ‘incompetence’ (Jenkins, 1998) and his actions are considered confirmation of that diagnosis. But is there another explanation for Mark’s actions and behaviour?

An alternative interpretation of the behaviour displayed by Mark is that it is

ordinary and normal. Although *The Simpsons* is a cartoon, it does contain humour that is specifically targeted at an adult audience. Mark's collection would have taken a great deal of time and money to create, which demonstrates devotion and dedication. People have all sorts of interests and passions and may choose to collect all kinds of items and objects; it is a normal, typical behaviour. According to this alternative interpretation, Mark's interest in *The Simpsons* and his collection is not evidence of intellectual disability, nor is it especially notable or exceptional. It is ordinary behaviour. This process of deconstructing the behaviours of people with the label 'intellectually disabled', illustrates how disability research is essentially a situation of power asymmetry (Rapley et al., 1998). As a researcher, I have the power to determine whether Mark's behaviour is ordinary and unexceptional or whether it is remarkable and evidence of something more sinister, such as a stigmatised identity. As Rapley (2004) noted, researchers have the power to determine what is and what is not sayable as truth.

Theme: Alternative identities and being a human being

When exploring the plurality of alternative identities presented by the Members in this study beyond those imposed by wider society, I needed to adopt a reflexive position. The worldviews and assumptions surrounding 'intellectual disability' and what it is to *be* a person with an intellectual disability are so pervasive and subtle, that they can go unnoticed. The assumption of incompetence as axiomatic in people with intellectual disabilities, in particular, is deeply entrenched in society (Jenkins, 1998). A high level of self-awareness and critical reflection was necessary to uncover the myths underlying understandings of intellectual disability and people with this layer. At this level of analysis, I closely monitored my own personal reactions to the stories told by the Members. Some of the stories told by the Members evoked a strong emotional response. These stories got at the heart of what it is to be a human being. They were unremarkable and ordinary; they weren't about being a person with an intellectual disability, they were about being a person. Many of the alternative identities embodied by the Members in this study were in direct opposition to the identities and social roles typically affixed to people with intellectual disabilities.

As discussed in previous chapters, the label of intellectual disability can conceal a great variety of human experiences and alternative identities (Kittelsaa, 2013; McVittie et al., 2008). A number of studies have explored the identities of people with intellectual disabilities, beyond this powerful and stigmatising label. Kittelsaa explored the self-understanding and experiences of seven young adults with intellectual disabilities (aged 18 to 30 years old) that she observed and interviewed over a period of two years. In this study, participants preferred to present themselves as ordinary and constructed their identities as competent, self-sufficient and active. Participants emphasised that they were living ordinary lives while also noting that they might, at times, require some special assistance or spend time in special environments. The significance of intellectual disability as a defining characteristic was deemphasised by all of the participants. Kittelsaa concluded that by discussing their home, work and leisure activities and highlighting their own personal interests and preferences, the participants emerged as individual human beings.

McVittie et al. (2008) explored how people with intellectual disabilities discursively manage. During talk, participants ascribed deficits to others instead of referring to their own abilities and experiences. Participants consistently avoided or resisted comparisons to deficit proposed by the interviewer and claimed 'normal' attributes while simultaneously distancing themselves from those attributes that might suggest lesser abilities. McVittie et al. argued that the identities of people with intellectual disabilities should not be simply viewed as just the acceptance or rejection of the social category intellectual disability. Rather, identities permeate talk and are bound up in individual's descriptions of themselves, their personal experiences and their relations with other people. Björnsdóttir (2010) agreed that a diverse range of other social categories (beyond disability) including gender, class and religion interact to shape an individual's life experiences. People with intellectual disability cannot be summated to a single identity .

These alternative identities embodied by the Members are presented in the four subthemes; 'Love birds and intimate relationships', 'The carer (not the cared for)', 'Intelligent and competent' and 'Personal growth' below.

Subtheme: Love birds and intimate relationships.

The interpersonal relationships of the Members were commonly featured in their photographs and often discussed. Friendships and family ties were really important to all of the Members (this is discussed in the theme 'Friends, family and pets' above). A number of the Members in this study were in close, intimate relationships. Their role as someone's boyfriend/girlfriend or husband/wife seemed to be very important to their self-concept. Intimate relationships provided the Members with companionship and a sense of belonging and security. Mark and Stephanie met at the Advocacy Agency and began dating soon after;

Mark: I decided to take a photo of my girlfriend... She's sweet, she's nice to me and that's what I want in my life.

Stephanie: I love him to bits. Love him so much.

Mark: Yeah. I saw her. I asked her out. It took me a while....

Stephanie: Yeah, and he kept nagging me for my phone number!

During the interviews, Mark and Stephanie expressed plans to move into their own home and potentially have a family of their own one day. For Mark and Stephanie their relationship was central to their lives. Soon after the completion of this project, Mark proposed to Stephanie on an overseas holiday. They are currently planning their wedding.

Anne and David also met at the Advocacy Agency. They have been married for three years and live together in a small unit in town. Most of the photographs taken by Anne and David for the 'This Is Me' project were photographs of photographs in their home. These photographs featured them as a couple, including some wedding photographs. Throughout the interview, David and Anne had a playful banter and spoke often about their relationship;

Kate: So Anne, tell me a bit about David?

Anne: My first love and now he's my first husband.

Kate: And how is it being married to Dave?

Anne: Good... Yeah, my tummy's OK now.

Kate: Oh OK. So what happened with your tummy?

Anne: Since I got married, I can't believe it.

Kate: Oh. Still got nerves in your tummy?

Anne: Always.

Kate: Really? Is it a good feeling?

Anne: It is... Great. Waited so long... First love I had... Fell in love instantly.

Kate: So what do you think of Anne, Dave?

David: Cute.

(Anne and David kiss).

Kate: Two love birds, aren't you?

Anne: Yes.

David: (smiling at Anne) So cute.

Anne: Be quiet (laughs).

David: You are cute (laughs).

Anne: Quiet, darling! (laughs).

Anne and David were very affectionate and spoke often about the love that they felt for each other and their relationship. Being married was particularly important for Anne, whose younger sister was also married. Being a 'wife' gave Anne a sense of esteem and made her feel valued.

The close, romantic relationships of several of the Members in this study demonstrate that people with intellectual disabilities experience the same feelings of desire and love as do people without this label. Just like people without intellectual disabilities, the Members also aspired to have long-term, mutually satisfying intimate relationships and the possibility of having their own family. The importance of intimate relationships as described by some of the Members in this study has been echoed in the literature. Kelly, Crowley and Hamilton (2009) interviewed 15 people with intellectual disabilities to gain their perspectives on socialising and romantic relationships. Forming an intimate relationship was strongly desired by most of the participants. Relationships were described as being a source of companionship and support and most participants expressed wanting and needing to experience dating, intimacy and sexual interaction. In another study by Healy, McGuire, Evans and Carley (2009) most participants aspired to marriage and children in the future. Engaging in intimate relationships also contributed to the self-esteem of participants in the study.

Why should the finding that the Members in this study (and other studies) valued their close and intimate relationships be remarkable or noteworthy? Sexuality is central to being a human being and love, affection and belongingness are recognised as basic human needs (Gomez, 2012; Maslow, 1970). Sexuality influences all aspects of life including our thoughts, feelings, desires, values, attitudes, behaviours, roles and relationships and encompasses sex and sexual orientation, gender identities and roles, eroticism, pleasure, intimacy and reproduction (Gomez, 2012; World Health Organization, 2006). The right of people with intellectual disabilities to express their sexuality and experience romantic relationships has traditionally been neglected or denied (Siebelink, de Jong, Taal, Roelvink, & Taylor, 2006). Historically, people with intellectual disabilities have been subjected to sexual segregation, marital prohibition and legally-sanctioned sterilisation (Gomez, 2012). Although most of these practices are now prohibited and the right of people with intellectual disabilities to meaningful intimate relationships and sexual expression is becoming increasingly recognised, myths surrounding the sexuality of people with intellectual disabilities continue to operate (Di Giulio, 2003).

Two powerful and pervasive myths, that are somewhat paradoxical, sustain the worldview that the sexuality of people with intellectual disabilities can be ignored or must be suppressed (Milligan & Neufeldt, 2001). The first myth is that people with intellectual disabilities are asexual and do not need or desire loving and fulfilling relationships with others (Siebelink et al., 2006). People with intellectual disabilities are often infantilised by society and considered to be child-like (Jahoda et al., 1988; Todd & Shearn, 1997). As 'eternal children', people with intellectual disabilities lack sexual desire and are disinterested in intimate relationships with others (Anderson & Kitchin, 2000; Siebelink et al., 2006). Further, because of their child-like innocence and immaturity, people with intellectual disabilities are particularly vulnerable to exploitation and abuse and are in need of protection (Anderson & Kitchin, 2000; Stainton, 1998). The second myth, which is completely at odds with the myth of asexuality, is that people with intellectual disabilities are hypersexual and lack sexual restraint (Stainton, 1998). People with intellectual disabilities are often cast in the role of the 'sexual deviant' or 'sexual menace' by

wider society. Men with intellectual disabilities are commonly assumed to be indiscriminating and have a disproportionate sexual urge, while women are often considered promiscuous and prolific in their procreation (Koegel & Whittlemore, 1983; Stainton, 1998). The myth of hypersexuality underlies and maintains the worldview that the sexuality of people with intellectual disabilities is potentially hazardous (Dotson, Stinson, & Christian, 2003; Heyman, 1995). This is explored further in the life story of Paul, presented in chapter six.

Although the myth of asexuality and the myth of hypersexuality are paradoxical, society seems to be able to maintain both 'concerns' about people with intellectual disabilities without any apparent conflict. It would appear that society can simultaneously view people with intellectual disabilities as both vulnerable and menacing without arousing cognitive dissonance.

Subtheme: The carer (not the cared for).

Many of the Members interviewed in this study described scenarios where they adopted the role of carer, actively supporting others. This role presents a challenge to the dominant representation of people with intellectual disabilities as dependent and passive recipients of care (Wolfensberger, 2000). It also contests the common conception of people with intellectual disabilities as vulnerable and in need of care from others, or alternatively as a burden (see the theme 'Being burdensome' above). Here the Members described reciprocal care relationships which require them to support and assist others. Members adopted the role of carer or support person in their relationships with their parents, siblings and friends. Jimmy, aged 45, cares for his elderly Father who has dementia. Jimmy explained that his parents cared for him when he was a small child and now he is returning the favour, caring for his parents as an adult;

Jimmy: Sometimes I can (go to functions). Sometimes I can't. It all depends on my Dad cos my Dad's got dementation...

Kate: So how's your Dad doing?

Jimmy: Pretty alright at the moment... There's certain things... certain things that I got to stay home and help Mum a bit. But otherwise from that... we work around it.

Kate: So what kind of things do you do for your Dad?

Jimmy: I basically... just got to sit there with him sometimes when Mum goes out. Sometimes he can't get up in the chair. I got to get him out the chair and all that stuff. Yeah... He was there for me when I was a little boy so you got to do the right thing... Yep. You've only got one Dad and you've only got one Mum.... And that's what I said to Jess (a friend). I said you've got to have a bit of respect for people cos respect goes a long way. Yeah and that's what I believe in.

Jimmy described a relationship with his parents based on reciprocity. He acknowledges that his parents cared for him as a child, and now as a carer for his Father, Jimmy is required to make the same sacrifices. Jackson, aged 24, described how he is concerned for his younger sister who is studying at university in the city. Jackson explained that his sister is currently experiencing a bout of depression;

She's studying at university... in Medicine.... So yeah, sometimes we see her every now and then... maybe in the holidays or if she has a friend that she wants to see in Town. I think she has been... has a bit of depression at the moment. She has had tablets and gone to the doctor and yeah, it's been a bit ongoing for her at the moment... Yeah. Oh well, she's getting through. Just try and support her when you can.

As a brother, Jackson is worried about his sister and is prepared to support and assist her wherever possible. Jackson is describing an empathy and reciprocity that is central to all human relationships (this is examined in more detail in the previous theme 'Love birds and intimate relationships').

Some of the Members described situations where they supported and cared for their friends. Jimmy is considered an 'older brother' figure for many of the young men at the Advocacy Agency. In this mentoring role, Jimmy provides the other Members with guidance and support, and also assistance with activities of daily living such as toileting and using public transport;

That means that I sort of... (I have) responsibilities cos I can look after them and things like that... I am mentor for the guys... We talk about stuff and yep... A few other things that I got to help out with... If they want to go toilet and things like that. If they have a problem and things like that, I'm there for them. Yep.

In another example of adopting a caring role, Daniel explained how he helps his friend Greg manage his diabetes by reminding him to take his medication, have his insulin injections and prepare his sugar for the day; *"... I ring him at 9:30 in the morning to remind him. I remind him at night time and in the morning from work. He doesn't want to get up that early to do it so... I ring him up at about 9:30 saying do your tablets and your lollies"*.

People with intellectual disabilities are often cast in the role of 'the dependent' or the passive recipient of care (Williams & Robinson, 2001; Wolfensberger, 2000). This world view is supported or legitimised by the assumption of incompetence or inability (Jenkins, 1998). Therefore, as 'incompetent', people with intellectual disabilities would be unable to care for or support others; it is beyond their capabilities. Further, as previously discussed, people with intellectual disabilities are often cast in the role of the eternal child, which is devalued by Western society (Wolfensberger, 2000). As the eternal child, it is assumed that people with intellectual disabilities lack maturity and cognitive ability to be able to care for or support others. A child is 'cared for', not the 'carer'.

Further, research examining the care relationships between people with intellectual disabilities and their primary care givers (often their parents) contributes to this worldview as often only the carer's perspective is sought (Williams & Robinson, 2001). The representation of adults with intellectual disabilities as dependent and a considerable source of burden (see theme 'Being burdensome' above) to their primary caregivers (and society?) ignores the interdependent nature of relationships. Most relationships operate under the norms of reciprocity, whereby emotions and tangible/instrumental services are mutually exchanged which advantage both parties and maintain social ties (Levi-Strauss, 1964; Perkins & Haley, 2013). The simplistic one-way construction of the care relationships between people with intellectual disabilities and their primary caregivers creates a false dichotomy between the carer and the cared for and serves to further reinforce and perpetuate existing stereotypes, failing to enrich our understanding of the lives of people with intellectual disabilities (Fine & Asch, 1988).

The few studies that have examined the care relationships of adults with intellectual disabilities and their primary care givers have provided support for the notion of 'mutual care' and reported that it is far more common than is currently acknowledged (Heller, Miller, & Factor, 1997; Perkins & Haley, 2013; Williams & Robinson, 2001). Just as Jimmy in this study explained that caring for his father was an instinctual means of 'returning the favour', mutual care is both natural and helpful (Williams & Robinson, 2001). Williams and Robinson reported that people with intellectual disabilities (including those with high support needs and very little verbal communication) were performing care tasks for their parents, including physical lifting, carrying, domestic chores and gardening. The participants with intellectual disabilities were also a source of emotional support for their parents. Interestingly, parents and carers in Williams and Robinson's study struggled to accept the concept of mutual dependency and continued to consider themselves to be the sole carers in the relationship.

Similarly, parent carers with primary caregiving responsibility in a study by Perkins and Haley reported receiving considerable support from their adult son or daughter with an intellectual disability. In fact, 22% of carers in this study reported receiving greater support than they gave. This included emotion-based reciprocities such as companionship, expressing affection, sharing activities, and emotional support and tangible reciprocities (physical and instrumental support). In summary, the identity of carer that emerged from this analysis presents a challenge to conceptualisations of people with intellectual disabilities as dependant and burdensome. Something so ordinary as being in a reciprocal or mutually caring relationship must be emphasised to illuminate those dominant, but hidden, worldviews about people with intellectual disabilities.

Subtheme: Intelligent and competent.

The Members presented a challenge to the dominant cultural conceptualisations of people with intellectual disabilities as unintelligent and incompetent. Through the stories that they told, the Members constructed themselves as capable and intelligent. For example, one of the Members, Paul, is particularly interested in Australian politics. In the interviews he expressed very

strong views about Australia disbanding from the Monarchy and becoming a Republic;

I also want to see Australia become a Republic because I think it's time for us to move on from the Monarchy. It's out of touch... I think from Australia's own Head of State... I think a lot of our laws are out of touch. They need to be updated because they don't reflect the Australian climate and European laws just don't work in the Australian climate... That's what I believe... Australian life is great, but could be made better if the Australian laws were made to the Australian way, not the, you know, European... British-way. That's what I believe... On Thursday I get to meet the Governor General and present on why I think Australia should become a Republic.

Paul is an avid viewer of the National news and each time we met, our conversations generally began with discussing the news and current affairs. In the following excerpt Paul explained why a group of Indigenous Australians were protesting on Herrison Island in Perth;

Paul: Did you see the protest on Herrison Island yesterday?

Kate: Yeah.

Paul: It was quite interesting to watch actually. I saw it on the ABC (the National news) last night... It's actually about a land claim over the South West and the Perth Metropolitan area. Apparently they're not very happy with the... State Government and they're trying to get a deal where everyone's happy. And... it doesn't bother me as long as I can still do the things that I can enjoy. That's how I always see it... and I acknowledge those people as the traditional owners of this land.

Initially, my response to these conversations with Paul was surprise. I did not expect him to be interested in politics or have knowledge of current affairs. My assumptions about people with intellectual disabilities were being challenged. Paul was demonstrating intelligence and insight. His capacities, potentials and adequacies were not conforming to the social construct of an intellectually disabled person. The ordinary (listening to the news or reading the newspaper) became extraordinary.

Another Member, Felicity, organised and facilitated a ceramics workshop where she taught interested community members how to work with clay (see Figure 8 below). Felicity advertised the event, purchased the supplies and charged an attendance fee. Over 20 people participated in the workshop, and another has been scheduled for a few months' time. Here Felicity is demonstrating organisational skills, ambition and creativity. Her capacities, potentials and adequacies do not conform to the social construct of a person with an intellectual disability. Situations in which the norms associated with being a person with an intellectual disability are violated are examined further in the theme 'Pushing the boundaries by being normal' in the following chapter.



Figure 8. A photograph taken by Felicity of a sign at the entrance of the ceramics studio.

Watching the National News and engaging in creative pursuits is unremarkable; these behaviours would be expected of *anyone*. The functionality of people with intellectual disabilities, however, has to be presented as extraordinary in order to demonstrate the Othering and dehumanisation of people with this label. The assumption that people with intellectual disabilities are incompetent is so deeply entrenched and ossified because intellectual disability tends to be viewed as a naturalised impairment or biology, rather than a social construction (Goodley & Rapley, 2001). Koegel (1986) conceded; "However much we pay lip service to the influence of socio-cultural factors, we *do* primarily see mental retardation as a biomedical phenomenon and *do*, as a result, tend to attribute incompetent

behaviour exclusively to physiological causes” (p. 47). Physiology or biology can be understood as being stable and unchangeable, and consequently intellectual disability is often considered an undeniable fact or a truth. A naturalised view of impairment locates the problems of disability squarely within the individual. Any difficulties experienced by the individual are interpreted as a direct and inevitable consequence of impairment (Chappell et al., 2001). This has been described as the personal tragedy theory where people with intellectual disabilities are viewed as victims of their unchangeable and organic impairment (Oliver, 1996).

The assumption of intellectual disability as inevitability biological is demonstrated by the neglect of intellectual disability in the social model of disability (Chappell, 1998; Goodley & Rapley, 2001). The social model of disability has been extensively adopted as an explicit framework for analysing the experiences of people with physical and sensory disabilities, but neglects the experiences of people with intellectual disabilities (Chappell, 1998; Goodley, 2001). Why are people with intellectual disabilities not afforded a position in the social model of disability? Why is intellectual, developmental or cognitive (Chappell, 1998) disability understood as a biological deficit, not a cultural, historical, social, relational and discursive phenomenon as is physical or sensory impairment? Gillman, Swain and Heyman (1997) proposed that the exclusion of people with intellectual disabilities from the social model of disability is further confirmation of the lack of *humanity* afforded to people with intellectual disabilities.

At any given historical moment, the content and centrality of ‘abilities of the mind’ (Jenkins, 1998) can change so much that it is possible for one person to be considered intellectually disabled in one context, but not necessarily the other (Goodey, 2011). For example, deafness and cerebral palsy might be considered an intellectual disability depending on the cultural context (Jenkins, 1998). At the present time in Western society, ‘quick thinking’ and intensified productivity are valued and these ideals have become deeply ingrained in our social context and institutions (Goodey, 2011). The administrative and social structures of Western World capitalism place ever increasing importance on the goals of socioeconomic development being achieved sooner rather than later (Goodey, 2011). To achieve the ultimate goal of increased productivity, speed is essential. As a consequence,

social structures have fully engaged with the concept of measurable intelligence and 'intelligence' has occupied a space at the core of modern lives (Goodey, 2011).

Many in the Western world subscribe to the view that intelligence tests provide a measure of inherent mental capacities; in fact, the measurement of intelligence has been touted by as some as one of psychology's greatest achievements (Nisbett et al., 2012). Psychometric tests of intelligence are used widely for selection, diagnosis and evaluation. The results on such tests have been found to effectively predict certain forms of achievement, including school performance ($r = .5$) and adult occupational status ($r = .30$ to $.50$) (Lubinski, 2000; Neisser et al., 1996; Nisbett et al., 2012), solidifying perceptions of intelligence testing as objective. Indeed, psychology has proclaimed intelligence testing to be a neutral scientific instrument with the means of accessing the objective truth of a statistic (Rapley, 2004). An IQ two or more standard deviations below the population mean amounts to a *real* impairment.

Here I return to assertions made earlier in this thesis that all human beings are impaired in one way or another (Shakespeare & Watson, 2001). Despite impairment being universal, we are not all subjected to disabling barriers and oppression; different impairments have different implications (Hughes, 2007). Rather than uncritically accepting realist accounts of internal deficit, it is important to acknowledge that social factors can define what is considered an unacceptable impairment (Crow, 1996). Intelligence and competence is a relative concept.

Subtheme: Personal growth.

Many of the Members interviewed explained that they wanted to better themselves and grow and develop as a person. One such Member was Jimmy, aged 45. After finishing school, Jimmy stayed at home with his elderly parents and his younger brother. He was not employed and participated in few social activities. He became involved in the Advocacy agency six years ago and credited the Agency for enhancing his confidence and self-esteem. Jimmy was encouraged by his peers and staff members at the Advocacy Agency to apply for a position at the local trotting track as a groundsman and was successful;

Kate: How long have you been working at the trots for?

Jimmy: Probably since last year. Yeah.

Kate: And what did you do before the trots?

Jimmy: Nothing. Just... nothing much at all really. Nothing. You can't sit around not do nothin' and twiddle your thumbs.

For Jimmy, working provides a sense of purpose and meaning. Another Member, Jackson describes himself and his goals for the future;

How to describe myself? I think I'm a person who likes to be fair but likes to know more about things as you go along. I like to grow in knowledge and understanding... I like to work things out in a practical pace. I think that it's good to think things through and also consider other people at the same time... when things do get difficult you need to sort of try... a little harder and just have to push yourself a bit more (laughs). You know, just about opening more horizons and doors and avenues. Just the possibilities can just go on... It's about growth. If you're not growing, you're going backwards.

As the above excerpt illustrates, Jackson enjoys expanding his knowledge and understanding. For Jackson, if he is not continually learning and growing as a person, he feels as though he is dwindling as a person or “going backwards”. Some of the Members loved to travel. Mark described how he has travelled all over the world, with his family and with his girlfriend, Stephanie. Mark has been to Thailand three times, Bali, Hong Kong, the Gold Coast and Europe, including Sweden for a wedding. Mark told a story about how he and Stephanie got lost in Thailand. After being lost for quite some time, using a map they eventually found the street that their hotel was on (SK2);

Mark: Yeah, we're over in Thailand, right, we just got to Chiang Mai. Never been there, right, so first night we go for a walk so then we got lost. On the maps, all the streets... on the same road, so very easy to get lost. So we're walking along... and then (we) figure out how to get back, then we found SK2 right.... (on) the road (we) come out (on) there's two men... so 'I take a half an hour by motorbike' and then he goes 'I'm joking! I'm joking. Only a 10 minute walk!'

Kate: (laughs) Only a 10 minute walk?

Stephanie: Yeah! Go straight there!

Kate: So was it like you'd been walking around in circles?

Mark: Yeah!

Mark and Stephanie have a keen sense of adventure. They are independent and enjoy taking risks. Mark and Stephanie explained that they are currently saving to go on another holiday to Thailand.

This finding is hardly surprising; the need for personal growth is universal. In his theory of the 'hierarchy of human needs', Maslow (1943) presented five basic human needs or goals arranged into a hierarchy of pre-potency. That is, once a need is satisfied or gratified, another need emerges. Physiological needs, such as food, water and sleep, are the most pre-potent of all needs and tend to dominate the consciousness of the organism if unsatisfied. The need for self-actualisation rests at the top of the hierarchy and is described as the desire for self-fulfilment and to become all that one is capable of becoming; "What a man *can* be, he *must* be" (Italics in original. Maslow, 1943 p. 383). Beyond these five basic needs, higher needs exist. One such need is the desire to know and understand (Maslow, 1943). This need encompasses the motivational role of curiosity, learning and exploration and the desire to be aware of reality.

Special conditions are required to foster the expression and gratification of these needs (Maslow, 1970). Free choice is described as being central to a self-actualising environment (Maslow, 1970; Seem, 1990). Reflecting on his own experiences as both a patient and a staff member at a State institution for the mentally ill and mentally retarded, Seem concluded that humans possess a tendency toward self-actualisation. Self-actualisation is sought by all people, however, the social context can hamper or impede individual efforts to grow and self-actualise (Seem). Seem argued that the State institution, which encouraged compliant behaviour and dependent, child-like perceptions of self, restricted patients ability to fulfil their growth needs.

Many years later and beyond the walls of State institutions, similarly restrictive worldviews and stereotypes of people with intellectual disabilities exist. McManus (2010) reported that people with intellectual disabilities tend to be perceived as more communal and less agentic. That is, people with intellectual disabilities are seen as warm and friendly, but not particularly skilful, industrious, ambitious, determined or self-sufficient. As such, people with intellectual disabilities

are thought not to require opportunities and contexts to self-actualise. Such worldviews serve to limit the roles requiring competence and independence people with intellectual disabilities have access to and further perpetuate discrimination and prejudice (McManus, 2010).

In this study, Jackson stated; *“It’s about growth. If you’re not growing, you’re going backwards”*. Here Jackson is expressing a motivation or striving toward personal growth and self-actualisation. He also explained that he enjoys learning and is very determined to better himself. Mark and Stephanie’s love of travelling may be motivated by curiosity, learning and exploring. By discovering new destinations abroad, Mark and Stephanie are satisfying their higher order need of wanting to know or understand (Maslow, 1943). Similarly, Jimmy described a comparable feeling of being restless and wanting to do something with his life. He explained *“You can’t sit around not do nothin’ and twiddle your thumbs”*. Not satisfied with being at home, Jimmy sought employment at the trotting track where he now works as a groundsman. Maslow (1970) argued that people are motivated to work because working enables the individual to either directly or indirectly meet their needs. Eggleton et al. (1999) proposed that employment enabled people with intellectual disabilities to satisfy a greater number of basic needs, including self-esteem and self-actualisation, and would contribute to a higher quality of life in those employed individuals when compared to matched individuals who were unemployed. Indeed, those participants who were employed reported a higher quality of life and suggesting that they had more of their basic needs satisfied than those without employment (Eggleton et al., 1999).

Summary of the myth/metaphor level

The myth/metaphor level of analysis examined the deeper, emotive aspects of how the Members conceptualised their world as told through stories and metaphors. As previously discussed, Members photographed and discussed their relationships, their interests (including the Advocacy Agency), their employment, and for some, their religion. Further, Members referred to physical characteristics, personality traits, relationships and future goals when describing themselves and did not use the term intellectual disability in their self-descriptions. This could be interpreted as a calculated attempt to ‘pass as normal’. Alternatively, rather than

attempting to mislead or deceive, the Members lack of 'awareness' or identification with the label intellectual disability could reflect a *real* lack of resonance with this socially created category. So deeply entrenched is the worldview that people with intellectual disabilities are not normal or like *us*, that the presentation of ordinary or 'normal' identities is considered remarkable at best and deceitful at worse. The othering of people with intellectual disabilities is further evidenced by the problematising of the identities of people with this label. This process was demonstrated using the example of Mark and his collection of *The Simpsons* memorabilia. It would appear that in the context of intellectual disability, broader society chooses to misperceive and misrepresent the ordinary.

At this level of analysis, alternative identities and social roles (beyond those imposed on them by wider society) presented by the Members were identified by deconstructing the stories they told. These stories captured what it was to be a human being. The desire for romantic and intimate relationships, engaging in reciprocal relationships (not merely being the passive recipient of care) and striving toward self-actualisation were important aspects of most of the Members lives. These alternative identities presented a challenge to conceptualisations of people with intellectual disability as asexual, a burden and incompetent. Illuminating the ordinary (and essentially human) identities of the Members highlights how the humanness or personhood of people with intellectual disabilities is often denied.

Reconstructing the Issue

CLA was used to deconstruct the Member interviews and uncover how the Members conceptualised their own identities and social roles. Overall, the findings of this analysis suggest that social category intellectual disability was not central to the identities of the Members. The Members presented identities that were not stigmatised or damaged as so often assumed. I would argue that the concept of a stigmatised identity and the view that people with intellectual disabilities are inherently different is *imposed on* people with the label, rather than derived deductively from the broader context. A stigmatised identity and notions of normality and difference are central to people without intellectual disabilities; the labellers. It would be erroneous to assume that those same worldviews must hold true for people with intellectual disabilities; the labelled. This is demonstrated by

comparing the findings at the litany and social causative layers with the findings at the discourse/worldview and myth/metaphor layers.

At the litany layer, the most commonly photographed and discussed aspects of the Members lives were identified. Interpersonal relationships, cultural heritage, leisure and recreational activities and interests and religion emerged as central the identities of the Members. Members had multiple role identities. Social roles identified by the Members as being important included being a mother, a son or daughter, a sister or brother, a friend, a girlfriend or boyfriend, and a wife or husband. Other key social roles embodied by the Members identified at the litany level included being a Member of the Advocacy Agency, an athlete, the fan of a sporting team and the member of a Church. Further, Members referred to personality traits, physical characteristics (such as tattoos and piercings), interpersonal relationships and future goals when describing themselves (see the theme 'Doing 'being ordinary' or being ordinary?' above).

There is nothing unusual or extraordinary about these findings. The identities of the Members are derived from the surrounding context. According to post-modernist conceptualisations, identity is constructed in the context of interactions and experiential transitions with others and emerges from the multiple roles an individual occupies in society (Gergen, 1990a; Mest, 1988; Stryker, 2008). There was nothing abnormal or extraordinary about the way in which Members conceptualised their identities and social roles as identified at the litany level. The embodiment of identities derived from the broader social context would be expected of (or afforded to?) people without intellectual disabilities.

Similarly, at a social causative level, the mundane and ordinary nature of the Members identities and social roles were also apparent. Most of the Members were employed either in open employment or in sheltered workshops for people with intellectual disabilities. Those who were unemployed volunteered in the community. Work was an important aspect of most of the Member's lives. Working afforded the Members positive and valued social roles such as being a wage-earner or a bread winner. This finding is not remarkable or exceptional. In Western society, being employed is one of the most valued social roles one can occupy (Eggleton et al., 1999; Wolfensberger, 2000). Just as people without intellectual disabilities enjoy

the financial benefits and prestige associated with being employed, so too did the Members in this study.

Overall, the findings at the litany and social causative level of this analysis suggest that social category intellectual disability was not central to the identities of the Members. In contrast to previous research which has reported that individuals may be unaware of their intellectual disability or unable to comprehend what is meant by intellectual disability (e.g., Cunningham et al., 2000; Todd & Shearn, 1997), the Members in this study were very much aware of their membership to this stigmatised social category (see the theme 'People like me' above). Members often referred to services being exclusively for people with intellectual disabilities (see the themes 'The advocacy agency', 'Work and employment assistance agencies and 'Housing and welfare'). It would, however, appear that intellectual disability was not a salient aspect of the Member's identity. The Members had multiple and varied selves that emerged from the context of their social relations and social roles.

At a discourse/worldview and myth/metaphor level, the processes that undermined the normalcy of the identities and social roles presented by the Members emerged. Deeper, underlying worldviews, values and mythologies were identified that served to construct people with intellectual disabilities as innately different, which was completely at odds with how the Members conceptualised their own identities. For some of the Members, the assumption that they were different or not normal, begin at birth. Members reported that their families were given a hopeless prognosis by medical professionals who assumed an overwhelmingly negative outlook for their future. Members were identified not only as different, but as a tragedy (see the theme 'Proving them wrong'). There was an overriding assumption that those Members were constrained, and would always be constrained, by their 'pathology'. The Members were defined by their professionally diagnosed incompetence. Indeed, some of the Members internalised these worldviews and felt as though they were a burden to their families ('Being burdensome'). Similarly, the parents of some of the Members exercised a great deal of control over their lives, reflecting the assumption that people with intellectual disabilities are not only incompetent but vulnerable.

The worldview that people with intellectual disabilities are inherently different was challenged at the myth/metaphor level of this analysis. The identities presented by the Members through the emotive stories they told not only challenged the perception of people with intellectual disabilities as fundamentally different, but captured those experiences central to being a human being (see the theme 'Alternative identities and being a human being' and themes presented at the litany level of analysis). Some Members described being in love and their experiences of close, intimate relationships. They described situations where they care for and support others. Members displayed intelligence and competence and were motivated to be all that they could be. I would argue that these experiences are common to us all as human beings. It would, however, appear that within society there is real difficulty in recognising (and accepting) those common aspects of our humanness.

The failure to recognise the humanness of those we categorise as the Other is most obvious in the assumption that people with intellectual disabilities attempt to 'pass as normal' (Rapley, 2004). People with intellectual disabilities can do everything the same as *us*, such as work or be in romantic relationships, but there is the underlying implication that they are trying to hoodwink us by attempting to pass as ordinary, fully fledged human beings. The undermining of the normalcy of the identities and social roles presented by people with intellectual disability is further evident in the assumption that many people with intellectual disabilities are unaware or in denial of their status as an intellectually disabled person. Psychological defences *must be* mobilised by people with intellectual disabilities in order to cope with what researchers feel is not really manageable (Fine & Asch, 1988). It could be argued that researchers are guilty of wanting people with intellectual disabilities to own up or admit to a stigmatised identity. This is described further in the literature review (chapter two).

The othering of people with intellectual disabilities and the myth that people with intellectual disabilities are not quite human is also evident in situations where people with intellectual disabilities present as 'functional' human beings (Goodley, 2001). When people with intellectual disabilities engage in normal or ordinary activities it is considered extraordinary or remarkable. For example, being employed

doesn't make the Members different from other people in society, but because it is a person with an intellectual disability, it *is* remarkable. This process is explored further in the following chapter.

Conclusion

CLA was used to explore how the Members conceptualised their own identities and the role that worldviews, values, mythologies and culture played in this construction. In summary, intellectual disability did not emerge as an identity salient to Members. At a litany and social causative level, the Members did not conceptualise their identities as characterised by a "... humiliating, frustrating and discrediting stigma" (Edgerton, 1967, p. 145). Instead, interpersonal relationships, the Advocacy Agency, leisure and recreational activities and work emerged as important aspects of the Members lives. At a litany and social causative level, there was nothing abnormal or extraordinary about the way in which Members conceptualised their identities and social roles. At a discourse/worldview and myth/metaphor level, however, the dynamics that served to undermine the ordinary identity as presented by the Members emerged. Deeper, underlying worldviews, values and mythologies were identified that served to construct the Members not only as different, but as not quite human. In the following chapter the perspectives of the Advocacy Agency staff who work closely with the Members will be explored.

Chapter 5: The Perspectives of the Advocacy Agency Staff

“If men define situations as real, they are real in their consequences”

(Thomas & Thomas, 1928, p. 572).

Introduction

To gain a more complete understanding of the social construction of intellectual disability, it is important to include the perspectives of staff who work closely with people with intellectual disabilities. Support staff and other paid professionals often have a central role in the lives of people with intellectual disabilities. Hatton and Emerson (2010) noted that staff provide the interface through which disability philosophies and policies are translated into practical action and as such have the ability to directly impact the quality of life of these individuals. The staff at self-advocacy agencies or organisations are required to fulfil a wide range of tasks to support people with intellectual disabilities to make choices, take responsibility and speak up for themselves (Aspis, 1997). Staff at self-advocacy agencies may teach people with intellectual disabilities the skills necessary for participating in formal meetings, such as an understanding of meeting format and structure (Aspis, 1997). Supporting the development of interpersonal and communication skills, including an understanding of body language and assertive (not aggressive or passive) communication styles, so that people with intellectual disabilities can advocate for their own needs in the community is another key role of advocacy agency staff (Aspis, 1997). Advocacy agency staff may also teach people with intellectual disabilities about the importance of valuing personal experiences and opinions and support them to have the self-confidence to make decisions. In addition, the staff who support people with intellectual disabilities also have a central role in facilitating individuals' social inclusion (McConkey & Collins, 2010).

Not only are staff responsible for the delivery of policy, a number of studies have reported that people with intellectual disabilities often consider staff to be an important part of their social network or even their friends (Hastings, 2010). In a study conducted by Miller, Cooper, Cook and Petch (2008) 87 people with

intellectual disabilities and carers were interviewed about the service outcomes they valued. Miller et al. (2008) reported support staff were viewed as central in the social networks of service users and many service users referred to the staff as key friends. The service users in this study also valued the emotional support provided by the staff and their listening. Similarly, a study by van Asselt-Goverts, Embregts and Hendricks (2013) which sought the perspectives of 33 clients with intellectual disabilities from seven different care organisations reported that the staff were their main source of emotional and practical support. On average one quarter of the social network of these participants were professionals (support staff), illustrating the central role staff have in the lives of people with intellectual disabilities (van Asselt-Goverts et al., 2013).

As stated in previous chapters, during the research process I was approached by a number of staff members at the Advocacy Agency who expressed an interest in being involved in the research. In response to this request, a second smaller study was developed. The objective of this study was to explore how the staff who work closely with people with intellectual disabilities conceptualise the identities and social roles of their clients. Once again, the role that worldviews, values, mythology and culture played in this construction was of particular interest.

Method

Research design.

This study was a qualitative study based on unstructured interviews with staff at the Advocacy Agency. The interview transcripts were analysed using CLA.

Participants.

The participants for this study were five staff members from the Advocacy Agency (four female and one male). The staff members held various positions within the organisation from managerial to volunteer roles. All of the staff interviewed had multiple roles within the Agency and extensive work experience in disability services. Several of the participants also had experience as personal carers for someone with a disability. Each participant has been assigned a pseudonym to protect their identity.

Interview procedure.

Prior to the research commencing, ethics approval was obtained from the Curtin University Human Research Ethics Committee. The interviews with staff members were unstructured, flexible and akin to a conversation. The interview generally started with me enquiring about their position at the Advocacy Agency and the role of the Agency and then expanded to include discussion about the Members and intellectual disability more broadly. The questions asked built on the responses provided by the staff members to previous questions and in previous interviews as well as the stories told by other staff members. The length of the interviews ranged from 34 minutes to one hour and 38 minutes ($M =$ one hour and 12 minutes, $SD = 24$). Staff members were interviewed in a private room in the Advocacy Agency. Some staff members elected to be interviewed in pairs, and one staff member was interviewed twice.

Analysis.

All interviews were audio-recorded and transcribed verbatim. The data were then imported into qualitative data analysis programme, QSR NVivo, which provides an efficient means of manipulating, searching, linking and storing textual data (Creswell, 2009). Interview transcripts were analysed using CLA (Inayatullah, 1998). For a more detailed description of CLA see chapter three. To guide analysis, pre-existing nodes based on the four causal layers (the litany, social causative, discourse/worldview, and myth/metaphor) were created. Each interview transcript was read through a number of times to familiarise myself with the content. During this process, potential emergent codes and possible themes were noted in a reflexive journal. Each transcript was then coded (or divided) according to the four corresponding causal layers. Both supervisors also coded two interview transcripts according to the four causal layers, and were compared to my codes to ensure agreement.

Once inter-rater reliability was established, I then systematically worked through each causal layer and inductively produced initial codes. The litany layer had five initial codes; social causative layer, eight initial codes; discourse/worldview layer, 17 initial codes; and myth/metaphor layer, 11 initial codes. Initial codes were then sorted into potential themes and sub-themes, each with accompanying

extracts of data. Thematic maps were developed to illustrate the relationship between potential themes. Themes were then reworked (collapsed, deleted and refined) to ensure each theme had sufficient data to support it and data cohered meaningfully. Descriptions of each theme were then generated and themes were named. A reflexive journal was maintained throughout the process of analysis and I met regularly with my supervisors regularly to discuss the research and analysis, and to confirm agreement of the themes developed.

Findings

The following is a CLA of the interview transcripts with the staff of the Advocacy Agency. Nine major themes were identified in the data. The themes identified at each causal layer are presented in Table 5 below. The themes identified at each causal layer will be presented separately with the relevant literature and theory incorporated. Finally, the findings of the analysis are reconstructed and consolidated and some implications are suggested.

Table 5

The themes identified at each causal layer from analysis of the staff interview transcripts

Causal Layer	Theme
Litany	The role of the advocacy agency
Social Causative	The grouping of people with an intellectual disability The diagnosis of intellectual disability
Discourse/Worldview	Visibility of stigma Low expectations and limited opportunities <ul style="list-style-type: none"> • A bloody good life • Smiley, happy people It's ok to be different (not really) Pushing the boundaries by being normal
Myth/Metaphor	Be independent, but in the way we want you to be Imposed identities <ul style="list-style-type: none"> • Deviancy and intellectual disability • The eternal child • Disability as a master status

Litany

The litany layer refers to how the issue is typically defined within the public arena. At the litany level of analysis the obvious or surface level issues experienced by people with an intellectual disability are identified. At this level, one theme was identified: 'The role of the advocacy agency'.

Theme: The role of the advocacy agency.

Staff described the role of the Advocacy Agency and the impact it has had on the lives of people with intellectual disabilities. The agency has a number of activities, workshops and camps throughout the year which aim to enhance the confidence, self-esteem, independence and autonomy of its Members with intellectual disabilities. Staff also felt that the Agency had an important role in empowering its Members by informing them of their rights and encouraging them

to be assertive. The programmes run by the Advocacy Agency were described as being designed to suit the concrete and visual learning style of people with intellectual disabilities. Lorraine explained;

It's a peer-based programme that encourages self-worth, confidence and leadership and activities are designed around that in the role-play, pictorial method to help the understanding of the people within the programme... Understanding their rights. Their responsibilities. How to have a voice... how to get what they need and what they want in an appropriate way... appropriate behaviour and also we work around the respect model, which is a community model.

Some of the staff members interviewed felt that an important role of the Advocacy Agency was to promote personal development in the areas of 'real' deficit. Skills required for social interaction, such as an understanding of personal space and body language and activities of daily living including personal hygiene and money management, were identified as areas that required further development. Bob in particular felt that Members benefited from learning about relationships and how to improve the way in which they relate to their community:

... There's also a lot of activities... specific activities towards learning and self-development... it (the programme) raises their self-esteem for a lot of them... they learn that they can do things. They learn to explore. They know that if they speak up they can be heard... It's not just about learning to do things. It's about learning who they are, their relationship with the community... how they can change that relationship with the community.

The Advocacy Agency was also described as a safe environment where people with intellectual disabilities could speak and behave freely, without fear of judgment. According to the staff interviewed, the Agency is a space where Members can talk about what they would like for their future, explore who they are and discover alternative identities;

... All of the people connected with the group have been given an opportunity individually to actually just say how they see things, what they want, where they are headed, totally non-judgmentally. And while still being given options to how you might get there, the focus of building on their other

skills, their life skills and understandings of social interaction, themselves, other environments is the ingredient (Liz).

All of the staff interviewed agreed that personal skill development in a non-threatening, non-judgemental environment was imperative for people with intellectual disabilities to be supported in their self-advocacy.

Self-Advocacy has, at least officially, a very short history in Australia (Peter, 2002). In 1986 the Disability Services Act was passed which provided funding for formal advocacy organisations in Australia (Peter, 2002). There are a number of diverse forms of advocacy including; self-advocacy, citizen advocacy, parent advocacy and group advocacy (Cocks & Duffy, 1993). Self-advocacy, which is the underlying philosophy and goal of the Advocacy agency described by the staff interviewed means speaking up for oneself (Simons & Carter, 1992). Self-advocacy agencies, such as the one described in this study, support people with intellectual disabilities to represent their own interests in the community and become a part of the community (Peter, 2002). This goal is achieved by assisting people with intellectual disabilities to develop and maintain the personal skills and self-confidence necessary to advocate for their own needs in the community (Peter; Walmsley, 2002). Although advocacy outcomes are said to be difficult to measure (Peter, 2002), a number of studies have reported that self-advocacy is beneficial for the people with intellectual disabilities involved. Some positive outcomes of self-advocacy include enhanced self-identity, greater independence and autonomy, and improvements in self-esteem and confidence (Mitchell, 1997; Peter, 2002; Simons & Carter, 1992).

Summary of the litany level.

At the litany level, the surface-level issues experienced by people with intellectual disabilities were examined. At this level, the Advocacy Agency was described as addressing the 'real' deficits of its Members with intellectual disability. Issues experienced by the Members identified by the staff interviewed included difficulties in social interactions (particularly being assertive), personal hygiene and grooming and money management. Members were also described as often lacking in confidence and having low self-esteem.

Social Causative

The social causative level of analysis examines how social factors impact upon people with an intellectual disability. Of particular interest in this level of analysis are the social, historical, political and environmental factors which systemically influence the lives of people with an intellectual disability. Two themes were identified in the social causative layer; 'The grouping of people with an intellectual disability' and 'The diagnosis of intellectual disability'.

Theme: The grouping of people with an intellectual disability.

Most of the staff interviewed discussed the grouping of people with intellectual disabilities into exclusive groups, as they are at the Advocacy Agency. Staff explained that government departments (who control funding for the agency) discourage the exclusive grouping of people with intellectual disabilities. The Advocacy Agency has received criticism because membership to the group is reserved exclusively for people with intellectual disabilities. Liz explained; *"this kind of almost fear from particular departments, that if you have a group of people together with a disability, we're harking back to old days of exclusive groups"*. The staff interviewed argued that the Advocacy Agency group provided a safe space where people with shared experiences could offer support to each other, learn from each other and form friendships and relationships. A staff member explained; *"They want to be with people like themselves because they share the same stories, they share the same issues"*. Liz likened the 'grouping' of people with intellectual disabilities to support groups of people who have similar interests and experiences;

We rely on group work and peer work all the time for other experiences, you know cancers, loss of children, other experiences in your life... Being a mother, going to a mothers group or whatever your experiences are... I think that they (the Members) have a genuine interest in each other as a group and I don't think there's anything forced about it at all.

Bob likened people with intellectual disabilities to other minority groups who experience discrimination and prejudice and rely on each other for support:

Aboriginal people, people who come from overseas... I remember when I was young, my parents were from Europe, and they all hung together because they felt safe. They knew what was happening. They could talk about the

issues... religions hang together, Catholics often, Muslims, whatever, they hang together and that's not frowned upon.

Some of the staff interviewed felt that being a member of an exclusive group gave people with an intellectual disability a sense of unity and more power. Being together in the community helped individuals feel safe and accepted in a society which is oftentimes hostile. As Bob explained; *"It's still a big, ugly World out there and the community still has views about people with disability and even their families do"*.

The principles of normalisation (Nirje, 1970) and social role valorisation (Wolfensberger, 1998) are the dominant paradigms in the development of services for people with intellectual disabilities (Chappell, 1992). The popularity of normalisation and social role valorisation has been international and these frameworks have been credited for achieving positive change in services for people with intellectual disabilities (Culham & Nind, 2003; Race, Boxall, & Carson, 2005). In Australia, the influence of normalisation and social role valorisation has waxed and waned, however, the philosophies are still deeply entrenched in the day-to-day practice and thinking of organisations that provide services and support for people with intellectual disabilities (Culham & Nind, 2003; Race et al., 2005). As mentioned by some of the staff interviewed, government agencies often prefer people with intellectual disabilities to associate with valued (or non-disabled) people. This position is based on the principles of social role valorisation (Wolfensberger, 1998) whereby if devalued people associate with valued members of society their social image will be enhanced. The phrase 'people are judged by the company they keep' comes to mind. Therefore, by associating with people without intellectual disabilities or positive images, the image of people with intellectual disabilities may be enhanced and the perceived value of the marked person increased (Wolfensberger, 2000).

The desire for people with intellectual disabilities to associate with other people with intellectual disabilities (as described by the staff interviewed) may reflect the phenomenon 'homophily' (McPherson, Smith-Lovin, & Cook, 2001). Homophily refers to the tendency for people to form relationships or connections with people that are perceived to be similar to one's self (McPherson et al., 2001),

and is reflective of the proverbial expression 'birds of a feather flock together'. Homophily may also be based on the sociodemographic dimensions that stratify society, such as gender, age and ethnicity or acquired characteristics such as education and occupation (McPherson et al., 2001). Farmer and Farmer (1996) reported that children with intellectual disabilities in mainstream classrooms tended to form clusters with children with similar characteristics and similar diagnoses.

Reflecting this preference, a number of studies have reported that the friendships with other people with intellectual disability are very important to people with intellectual disabilities and offer a source of support. McVilly, Stancliffe, Parmenter and Burton-Smith (2006a) conducted a study that explored the experiences of loneliness of 51 people with intellectual disabilities aged 16 to 52 years (mean age: 25 years). McVilly et al. reported that participants' relationships with those associated with or linked to their intellectual disability were very important. Some participants in this study felt that it was easier to form friendships with other people with intellectual disabilities because they shared similar life experiences; "he's just like me, has a disability; but different, I'm goofy and he's quiet" (p. 19), and attended the same educational institutions; "... we have all been through the same things" (McVilly et al., 2006ap. 19).

Theme: The diagnosis of intellectual disability.

Some of the staff interviewed reflected on the label 'intellectually disabled' and had conflicting feelings about its usefulness. On one hand, staff members acknowledged that being labelled 'intellectually disabled' had a powerful and pervasive impact limiting an individual's life opportunities; "*I think because as they were raised as a 'person with an intellectual disability' they weren't given opportunities. It was always assumed that they weren't able to achieve*" (Bob). On the other hand, some staff members acknowledged that a formal diagnosis was a 'necessary evil' required for individuals to get the support they require;

It comes about because of the funding and all these other things and it's about defining people in order to get them the support they need and the services they need... it's just the way this society is. It would be interesting to

look at earlier cultures, and how they defined it, whether there was a name for it, or whatever. I don't know. It's odd. (Dawn)

Some of the staff interviewed questioned the validity of the concept of 'intellectual functioning' or 'intelligence', which is central to the diagnoses of intellectual disability. The process of intelligence testing and obtaining an intelligence quotient, in particular, was criticised by some staff. The 'cut off' score which indicated a deficit in intellectual functioning was described as being arbitrary and meaningless. Bob explained;

Where do you draw that line? Who made that distinction? I mean really, that's ridiculous. Why is it 60... 65 (IQ points) or whatever it might be? Why is it that number? Who created that? I mean why? It's what you do with what you know.

Some of the staff also argued that society has a very narrow definition of intelligence and what is considered 'intelligent behaviour'. The ability to adapt to the changeable environment and creativity were described by some as constituting 'intelligence'. A staff member explained; "A lot of these guys are survivors, they really are. And I think that's creative. I think it's creative that they've survived. So that's intelligence in itself". Interestingly, some of the staff interviewed likened the intelligence displayed by people with intellectual disabilities to that of Aboriginal Australians. Bob explained;

People often say that Aboriginals, how primitive they are. Now who else could've survived out in the middle of the bloody desert with a stick and a couple of bits of rock? No, really? Could we do that? No way. How to find water... I mean that's intelligence.

A staff member added; "Finding water, tracking, all those sorts of things. The skills are amazing".

The rise of psychology and the development of intelligence testing during the early 20th century permitted the official identification and classification of the people with intellectual disabilities (Cocks & Allen, 1996). The language and definition of intellectual disability has undergone many revisions since that time. The current definition of intellectual disability is described in chapter two.

The attributes of intelligence described by some of the staff interviewed, such as creativity and adaptability, can be likened to the concept of 'practical intelligence' in Robert Sternberg's 'triarchic theory of intelligence' (1985). Practical intelligence is distinct from traditional or other forms of intelligence and is never explicitly taught (Wagner, 2000). Practical intelligence is described as those cognitive responses to everyday problems that arise *outside* of the school setting (Wagner, 2000). These problems of everyday life are often poorly defined, have multiple solutions (each with pros and cons) and multiple methods of obtaining a solution (Wagner, 2000). Problems of everyday life require logical thinking, improvisation and the ability to adapt available resources (Wagner, 2000). Practical intelligence or practical 'know-how' is often described as manifesting in unschooled individuals from 'primitive cultures' (Berry & Irvine, 1986; Wagner, 2000). The importance of 'street smarts' as opposed to 'book smarts' is emphasized by some of the staff in this analysis.

Summary of the social causative level.

At the social causative level of analysis, the social factors that influence the lives of people with intellectual disabilities were explored. At this level, the staff interviewed described how Government departments discourage the exclusive grouping of people with intellectual disabilities. Although this practice was consistent with the recommendations of normalisation (and social role valorisation), it was described by the staff interviewed as being at odds with the wishes and desires of the Members. Staff argued that the Members shared similar experiences, formed friendships and relationships, and offered each other support. The privileging of the priorities and perspectives of service providers and professionals over that of people with intellectual disabilities is explored further at the myth/metaphor level of this analysis (see the theme 'Be independent, but in the way we want you to be'). The formal process of diagnosing an individual with an intellectual disability and the definition of 'intelligence' more broadly, was also questioned by some of the staff interviewed.

Discourse/Worldview

The discourse/worldview layer refers to the deeper, unconsciously held value systems of the community about intellectual disability. At this level of

analysis, the discourses, worldviews and ideologies that support or legitimise assumptions about people with an intellectual disability and intellectual disability more broadly are of interest. This level recognises the importance of understanding how people frame and interpret their world. Four themes were identified in the discourse/worldview layer; 'Visibility of stigma', 'Low expectations and limited opportunities' (with the subthemes; 'A bloody good life' and "Smiley, happy people'), 'It's OK to be different (not really)' and 'Pushing the boundaries by being normal'.

Theme: Visibility of stigma.

Most of the staff interviewed distinguished between the individuals with "visible" or "identifiable" intellectual disabilities (such as Down syndrome), and "non-visible" or "non-identifiable" intellectual disabilities. The visibility of an individual's intellectual disability or stigma (Goffman, 1963) influenced the way in which others interacted with the individual. The facial features unique to Down syndrome were described as providing "visual cues" which informed or guided the behaviour of others when interacting with the individual. In these interactions, members of the wider public were described as being more understanding and as making accommodations and allowances. Individuals with non-visible intellectual disabilities, on the other hand, with the absence of these cues to condition the behaviour of others were more likely to experience prejudice and discrimination. Liz explained;

I mean when people can identify disability, their approach is much more conditioned about how they're going to approach someone and the types of things that they will say or not say... someone with an intellectual disability who is less visually disabled, is so much more at risk of idiots.

Two staff members noted this phenomenon in a social situation and contrasted the treatment of Kelvin, who has Down syndrome, and Jim and Matty, who do not have visible intellectual disabilities. Liz explained; "*He (Kelvin) was shirtless, they (the men at the hotel) were shirtless, they were playing pool with him and really being very, very nice*". Another added;

They (the general public) would go 'Oh, hello Kelvin! How are you?'(enthusiastic tone)... and communicate, where with Jim or Matty... it

was 'oh they don't look like they've got a disability, why are they in this group?' ... you could see them thinking and they would go 'oh hello' and they were waiting for their reply as to see...

With the absence of visual cues such as facial features to easily identify intellectual disability and inform behaviour, some people made inferences of disability based on environmental or contextual cues. Liz described a situation with the Members of the Advocacy Agency when she was approached by a woman who assumed that she had an intellectual disability. Liz explained;

So Lorraine and I are sitting there, and she (the elderly woman) comes over and goes to Lorraine, 'I really love what you're doing, darling. Dear it's just wonderful. I just love to see these young people have a really good time'. And then she turns around to me and taps me on the shoulder and she goes, 'And you having a good time dear?', and I thought.... You see? From one extreme to the other! Because I was with the group that Lorraine was obviously leading, by assumption she has been condescending to me. She's trying to be nice, but what she was saying was... 'I'm not quite sure what your disability is darling, but I hope you are having a really good time'.

In this situation, Liz was assumed to have an intellectual disability because she was positioned next to Lorraine who could be easily identified as the group coordinator. The response of the elderly woman was to be "nice" and ask Liz if she was enjoying herself. Reflecting on the situation Liz felt that the woman was being condescending. In contrast to the overly nice treatment encountered by Liz, Lorraine described a situation where Matty (who has a non-visible intellectual disability) was verbally and physically abused by a group of men;

There was an incident which I didn't find out about until two days later when I saw a bruise on the back of Matty's back. They'd thrown him over the balcony... They'd come up, drunk, started teasing Matty and chucked him over the balcony, straight into the big palm tree, and he never said anything cos he felt it was his fault. You know? He feels it's because of his disability that they did what they did.

Liz also described another situation where a Member with a non-visible intellectual disability was met with hostility by a member of the wider public. In this

situation, Gavin (a Member with a non-visible intellectual disability) arrived at the local tavern early and waited for the other Members of the Advocacy Agency;

Gavin had obviously arrived early and been sitting probably for some time... near the bar, near the pool tables with a bunch of five or six young men probably in their early/mid-twenties. Really drunk, really loud, all playing pool, and rugby might have been on, like there was a real scene going on. And I suspect, in retrospect, that actually what had happened for the last 45 minutes, he'd actually been sitting there being the butt of a few jokes, but him not realising... So now we've walked in the other door and I had I think Jess and Felicity were already with me... and Gavin's just got straight up and walked straight over to us. And this big guy has come in and kind of elbowed him out of the way and gone, 'Excuse me, excuse me. You alright here, you alright? I've seen this guy is coming over to you know. He has been sitting over there a while. I'm on to him' and actually I was like, 'Yeah, it's Gavin, we are meeting for dinner'... And then Jacob has come in behind me, and I think Tara has turned up and Anne and David (who all have Down syndrome)... I've watched this penny drop, like he's gone, 'Oh, you're a group of people with disability and I have just...' Like, it was really offensive but he was really drunk, so I wasn't going to make much of it... He just kept falling over himself to apologise and I just sort of said, 'whatever, we're here for dinner, go away'. But it just gave me this really classic image of how different he would've been, if Gavin had of been... his disability was more visual.

Liz added:

He (the man at the tavern) was in this, 'I was trying to keep you away from the weirdo' type thing...he's firstly gone, 'Oh, OK, he's with you?' like... why are you guys hanging out with this guy? And then as our crowd started to gather he's sort of gone, 'Oh! Oh! I am really sorry mate, I am really sorry'.

These examples highlight the role of visual cues of intellectual disability and how this shapes and guides the behaviour of others without an intellectual disability. Without the visual cues to indicate that Gavin had an intellectual disability or was a Member of an Advocacy Agency for people with intellectual disabilities he was assumed to be a “weirdo” and not someone that you would want to associate with.

Liz, Jess and Felicity were assumed to need protecting from Gavin. It was not until Jacob, Anne, David and Tara (who all have Down syndrome) arrived at the tavern providing a visual cue that the man realised that Gavin also had an intellectual disability. Reflecting on the incident at the tavern, Liz mused; *“So in a way it kind of makes their response a little bit manufactured, because they needed that, or do we need that? Do we need that visual response to behave appropriately? Or shouldn’t we be expecting from everybody?”*.

The role of visible differences or stigmas has also been explored extensively in the literature (Allport, 1954; Goffman, 1963). Perceptible appearance-based features are important in distinguishing between in-group and out-group members (Allport, 1954). For example, differences in skin colour, gestures, religious practices or insignia, are visible and conspicuous features that aid in the cognitive process of categorisation (Allport, 1954). Not only do these perceptible differences in appearance aid in assessing whether an individual is a member of the in-group, they also enable attributions about the individual’s personality characteristics to be made (McManus, 2010). As Allport explained; “where visibility does exist, it is almost always thought to be linked with deeper lying traits than is in fact the case” (p. 132). As previously discussed, some intellectual disabilities are associated with particular physical features. Down syndrome, the single most common organic cause of intellectual disability (Bower, Leonard, & Petterson, 2000), is characterised by a unique set of physical and facial features including; almond-shaped eyes (epicanthal folds), a small nose, a large protruding tongue and short stature (Olbrisch, 1982). Similarly, Fragile X syndrome (the second most common chromosomal disorder associated with intellectual disability) is characterised by perceptible differences in appearance including; a long narrow face with protruding ears, ‘lazy’ or ‘crossed’ eyes and low muscle tone (Rudelli et al., 1985). These perceptible differences are immediately visible and convey crucial social information, which may influence or interfere with social interactions (Goffman, 1963; McManus, 2010).

The impact of the visibility or ‘evidentness’ (Goffman, 1963) of an individual’s intellectual disability as described by some the staff interviewed has been explored in the literature. McManus (McManus, 2010) reported that

individuals who obviously appear to have an intellectual disability (such as Down syndrome or Fragile X syndrome) are perceived more positively than individuals who do not appear to have an intellectual disability (such as those with a learning disability). Furthermore, when an individual is identified as having an intellectual disability but does not have the visible indicators of intellectual disability a more negative overall impression is likely to be formed. McManus hypothesised that this was because the perceiver was receiving inconsistent information about the category or group to which the individual belonged. Visibility of intellectual disability may actually be a protective factor against stigma (Crocker & Major, 1989). While people with visible intellectual disabilities may still encounter negative attitudes and discrimination, their appearance could also be protective because some characteristics associated with intellectual disabilities (such as taking longer to process information) could be more acceptable than they would be if the individual had a non-visible intellectual disability.

Theme: Low expectations and limited opportunities.

Most of the staff interviewed believed that society has low expectations of people with intellectual disability and often presumed incompetence or inability. Staff felt that assumptions were often made about the ability of people with intellectual disabilities to achieve academic success, gain meaningful employment, form friendships and relationships, effectively communicate and live independently. These societal expectations were described as beginning once the individual was recognised or formally diagnosed as having an intellectual disability and continued throughout the life of the individual. Low expectations were described as being pervasive, placed on the person with an intellectual disability by their parents, family, teachers and the wider community. Bob described what he saw as the common trajectory of someone with an intellectual disability;

Often the story goes; they were young, small, some sort of disability... intellectual disability, put in the corner and all through their schooling they were kind of held back. Expectations of teachers and parents were very low for them, so opportunities weren't given to them... The school curriculum wasn't designed for their particular learning style... The expectations are they're going to school and not really pass, just go through the school system

and come out the other end and one day go on a pension. Now a lot of these people are coming back, and I'm meeting them out in the field, having particular difficulties. A big part of that is reading and writing, communication... isolation, but a lot of it is because, I feel, not necessarily the degree of disability, it's more societal opportunity and really, the word 'disability' is a misnomer really, I think.

As Bob explained in this excerpt, opportunities to develop skills and abilities and to experience achievement and success were seen as futile. That is, the person with an intellectual disability won't be employable so it is pointless to invest in their education. Assumptions are also made about the ability of a person with an intellectual disability to engage socially. In this example, Bob talked about a Member of the Advocacy agency;

All his life, he's in his twenties, he's been considered not good enough to go out into the community. He just stayed at home, did nothing, watched kiddies videos... he has been able to come along here (to the Advocacy Agency). He is such a social man... he's part of the Men's Group as well and he's at times got up and he can communicate a lot on the board. His gestures, his words....

Many of the staff members interviewed were quick to distinguish between the actual ability of the person with an intellectual disability and the 'disability' resulting from lack of opportunity. Disability was seen as arising from the socially constructed barriers that exclude, disadvantage and discriminate against people with an intellectual disability. Society is disabling by limiting the opportunities afforded to people with an intellectual disability. Bob;

Because they haven't really been given those opportunities to learn life skills... so often I look at that and think well it's not really about that person not having, you know... intellectual disability, so they can't do it because they don't have the intelligence. It's about not being given the opportunity.

Consistent with the reports of limited opportunity described by the staff members interviewed, epidemiological studies consistently report high levels of social and economic disadvantage experienced by people with intellectual disabilities (e.g., Emerson, 2007; Emerson & Hatton, 2008). Adults with intellectual disabilities are at

a significantly greater risk of living in poverty than adults without intellectual disabilities (Emerson, 2007). They are also more likely to experience unemployment and social exclusion (Emerson, 2007; Emerson & Hatton, 2008). The discourses that legitimise the low expectations and limited opportunities afforded to people with intellectual disabilities are described further in the subthemes; 'A bloody good life?' and 'Smiley, happy people'.

Subtheme: A bloody good life?

A discourse surrounding the quality of life of people with intellectual disabilities, including the rhetoric that people with this label lead a good life, was described by some of the staff interviewed. A full and satisfying life was described as being achieved despite the absence of indicators of Western notions of success (Goldberg, Higgins, Raskind, & Herman, 2003), such as meaningful employment and close relationships. In the following excerpt Bob and Lorraine discuss the lives of people with an intellectual disability;

Bob: People with disability might often be seen as being out of work, not having many possessions, not having a lot of friends, don't seem to do a lot and get around a lot as such... then they won't enjoy life, but no, that's not true... So many of my clients, sure they might have problems at times, sure they have certain things that need to be dealt with, but they like life just like we do. They love shows on TV, they like music. They like what they can do, you know what I mean? Sure there are things that they come up against, like we come up against the Government and taxes and all the things that we despise. They come up against someone calling them something, not be able to get a job... but I think overall... I think generally... I get the feeling that they have a bloody good life at times, like anyone. But they don't have to have a good car to do that, they don't have to go overseas to do that or dress in a good suit and go out to the balls... most of them make the most of what they have.

Lorraine: (interrupting) that's because they've had to though! (laughs).

Bob: Well still, it doesn't matter. They might not be able to budget how we do, they might... if they get a pension, they might get a pension and blow it in 3 days and not eat properly, but you know what? They get through week

to week, generally pretty happy. I mean really, around those sorts of things I don't hear a lot of discontent... I feel they're a pretty happy bunch of people... Their whole lifestyle, they love their life... They struggle with one part of their life and that's financial management, otherwise, they have a bloody good time. They go and do things, they have friends, they can sit out on the veranda and watch the world go by and watch TV and discuss things...

In this excerpt Lorraine challenges Bob, arguing that people with an intellectual disability “*make the most of what they have*” because “*they've have to*”. There is no other option but to accept the status quo, people with intellectual disabilities do not have a choice. This raises the question, would being unemployed, having few possessions and not many friends be acceptable for someone *without* an intellectual disability? Would that be considered a “*bloody good life*”? It is also useful to consider other groups in society that experience systemic discrimination, to illustrate the pervasive and often unconscious oppression of people with intellectual disabilities. For example, in the above excerpt consider substituting the terms “people with disability” and “they” with the term “women”;

Women might often be seen as being out of work, not having many possessions, not having a lot of friends, don't seem to do a lot and get around a lot... but I think overall... *they* have a bloody good life.

The excerpt now takes on an entirely new meaning. Society would more than likely be outraged if women as a group were systemically unemployed or unable to eat properly. Why then are we not outraged that people with intellectual disabilities live in these conditions? It would seem that the ‘bar’ is set very low for people with an intellectual disability; society has a lower expectation of what is considered acceptable or a “*bloody good life*” for people with an intellectual disability.

Subtheme: Smiley, happy people.

Related to the worldview of people with intellectual disabilities having a “*bloody good life*” is the discourse about people with this label being ‘happy’, ‘loving’ and ‘lovable’. In society there is a common rhetoric about people with intellectual disabilities having love and affection to offer and being ‘lovable’ (Gilmore, 2006). The discourse is illustrated in an example offered by Lorraine. In

this excerpt Lorraine is reflecting on a conversation she had with a man whilst the Members of the Advocacy Agency were holidaying abroad;

He came over to me and he said to me "It's amazing, isn't it?" He said, "Just look at him (Matty). He's having the time of his life. No different to me when I came over here when I was his age"... I said "I know, it's great, isn't it?" He said, "... My wife's pregnant, she's due to have a baby and... one of the things that you think about when you're pregnant is that, you know, will it be OK, will it be healthy, will it be safe, will it have ten fingers and toes, you know, not have a disability". He said, "... now I've looked at Matty, it doesn't really matter, I can love him just the way he is". And I went 'wow!' who is this man! I want to bottle you! They're human beings and it doesn't matter, you're still going to love them cos they're yours. You know? What a great attitude... You know, it's not so bad. There's still a living human being that can give you love, affection, can do things, can achieve things.

The above excerpt illustrates the worldview that people with intellectual disabilities are able to have fun and can offer love and affection. Despite all of their faults and shortcomings, you still love them because they are your child (and you have to?).

The members with intellectual disabilities were also described by some of the staff as being generally very happy and positive; "*... I feel they're a pretty happy bunch of people*" (Bob). The apparent qualities of people with intellectual disability and the roles that they are able to embody are similar to those proposed by Wolfensberger (2000). Wolfensberger offered some examples of what he described as "*... positive images about, and roles for, retarded people*" (p. 113). Being a "gentle and loving consoler" and finding "joy in the simple things" (p. 113) were identified as valued roles and attributes that people with an intellectual disability may embody (Wolfensberger).

What is the underlying purpose of the world view that people with an intellectual live a "*bloody good life*"? What function does the stereotype of people with intellectual disabilities being happy, affectionate and loving serve? The just world theory by Lerner (1980) and the system justification theory by Jost and Banaji (1994) can provide an explanation. Lerner proposed that the belief in a *just world* where 'people can and do get what they deserve' is both natural and inevitable.

This belief has a central role in meaning making and the organisation of an individual's life (Lerner, 1980). But what happens when people are confronted with evidence that they are not "living in a rose garden" (Lerner, 1980, p. viii) and that undeserved suffering and deprivation is a reality? Lerner proposed that when the integrity of this belief in a just world is threatened it results in a state of cognitive dissonance (this is explored at length in the theme 'It's OK to be different (not really)'). To protect the belief in a just world, people respond in a number of ways to reduce the distress associated with witnessing an injustice. Blaming victims of misfortune for their own fate is a common strategy to re-establish justice (Lerner). Furnham (1995), however, argued that in the case of people who are born with disabilities (and intellectual disabilities), it would be difficult to consider them personally responsible for "their plight" (p. 581) and explanations such as 'original sin' are relatively rare.

An alternative strategy to victim-blaming proposed by Lerner (1980) is to engage in various reinterpretations of the outcome of the injustice so that the victim of the injustice receives compensatory rewards ('everyone gets their share'). Compensatory rewards suggested by Lerner include enjoying the 'simple things in life' and being 'happy go lucky'. The worldview expressed by some of the staff interviewed that people with an intellectual disability make "*the most of what they have*" and that they have a "*bloody good life*" may be an example of reinterpreting the outcome of an injustice. When the injustice is reinterpreted, people can take comfort in images of people with intellectual disabilities being content and satisfied. Jost and Hunyady (2005) expanded on this protective mechanism further in system justification theory to include victim-enhancing stereotypes. Complementary, offsetting stereotypes elevate the victim (which is more socially desirable and less aversive), legitimising the status quo and which helps to restore the belief in a just world (Jost & Hunyady, 2005). Kay and Jost (2003) noted that people often ascribe the virtues of happiness or morality to disadvantaged groups and the virtues of misery and loneliness to advantaged groups. Similarly, in this study some of the staff interviewed described people with an intellectual disability as affectionate and having love to give. This could be considered an offsetting stereotype.

Complimentary stereotypes of people with intellectual disabilities have been examined in the literature. McManus (2010) conducted a study that examined perceptions and behavioural reactions of 120 psychology students towards a target that either appeared to have an intellectual disability or not to have an intellectual disability. The physical facial characteristics of the target picture were adjusted to give the impression of intellectual disability (e.g., a flat nasal bridge, a short and wide neck, and small eye openings). The participants rated whether they believed the target possessed communal qualities or agentic qualities. Agentic traits included being competent, self-sufficient and empowered to manage life goals. In contrast, communal traits included being sociable, emotional, and reliant on others to manage life goals. McManus reported that people who appeared to have an intellectual disability were perceived to possess more communal traits than agentic traits. That is, people with an intellectual disability were more likely to be perceived as friendly, warm and happy, rather than industrious, ambitious skilful and determined.

Similarly, people with Down syndrome are commonly assumed to be 'happy people' (Gilmore, 2006). Gilmore, Campbell and Cuskelly (2003) conducted a study in which 2053 people from the community and 538 experienced teachers were surveyed to assess their knowledge of Down syndrome and to explore their attitudes toward educational inclusion in Australia. In this study, 79% of people in the community sample and 85% of the school teacher sample believed that children with Down syndrome were exceptionally happy and more affectionate than other children .

The use of complimentary stereotypes and compensatory rewards can also be explained using ingroup/outgroup theory (Allport, 1954). Fiske, Cuddy, Glick and Xu (2002) proposed two common dimensions of group stereotype content; warmth (social and moral qualitative) and competence (intellectual and motivational qualities). Most group stereotypes are mixed in nature. That is, negative ratings on one dimension (e.g., competence) are usually accompanied by positive ratings on the other dimension (e.g., warmth). Rohmer and Louvet (2012) argued that people with disabilities are a strongly normatively protected group and as such people are reluctant to make negative evaluations about or appear prejudice toward this

group. In their study Rohmer and Louvet reported that persons with a disability were associated with less competence and more warmth than people without disabilities. Low competence, high warmth groups elicit pitying, paternalistic prejudice (Fiske et al., 2002).

The presumption of compensatory rewards and the existence of complementary stereotypes can have damaging consequences for low status groups such as women (Glick & Fiske, 2001), ethnic minorities (Jost & Hunyady, 2005) and people with an intellectual disability (McManus, 2010). The belief or worldview that people with intellectual disabilities are satisfied or content with a life characterised by unemployment, few possessions and few friends, reduces cognitive dissonance. Furthermore, describing people with intellectual disabilities using communal traits (happy, warm and friendly) implies that they are not capable of fulfilling roles that require intelligence and independence; therefore it is acceptable that their access to such valued social roles is limited. This effectively enhances the perceived legitimacy of the status quo and justifies low expectations and limited opportunities afforded to people with intellectual disabilities (Jost & Hunyady, 2005). When the outcome of the injustice is reinterpreted, the threat of an unjust world is averted, justice is restored and nothing needs to change.

Theme: It's OK to be different (not really).

Across all of the staff interviews there was a common rhetoric about difference. Most of the staff interviewed commented that every individual is different or unique, and that intellectual ability (or disability) is just one way in which people may differ. Lorraine said; *"It's OK to be different. I said 'I'm different', you know? I'm different... I'm not like you, but you're not like me"*. The rhetoric about individual difference expressed by some of the staff interviewed is reminiscent of a scene from the 1979 film 'Life of Brian', where Brian is addressing a crowd;

Brian: Please, please, please listen! I've got one or two things to say.

The Crowd: Tell us! Tell us both of them!

Brian: Look, you've got it all wrong! You don't NEED to follow ME, You don't NEED to follow ANYBODY! You've got to think for your selves! You're ALL individuals!

The Crowd: Yes! We're all individuals!

Brian: You're all different!

The Crowd: Yes, we ARE all different!

Lone Individual: I'm not!

People with an intellectual disability are told emphatically that everyone is unique and different. Difference was described by the staff interviewed as being neutral and not value laden. Difference was not positive (good) or negative (bad), it was just different. Bob spoke of the notion of difference and how it should be championed; *"So at different levels, there's different levels. Some people are surgeons and some people... work on the roads or pick fruit... They're all admirable careers... I think that's great that everyone has to do something different"*. Some of the staff interviewed did not consider this difference to be a barrier to achieving a full and satisfying life; *"OK they (the Members) are different, but they're not that different that they can't have a fulfilling life"* (Lorraine).

Despite 'difference' being described as the only thing common to all people, most of the staff interviewed stated that the wider public are often afraid of people with intellectual disabilities *because they are different*. Bob explained; *"A lot of people are afraid"*. Lorraine added; *"They are. The communication with them. They see them as different, so therefore, we don't like different. That's the way society is"*. The fear of people with intellectual disabilities was attributed to differences in communication and personal interactions and having limited previous experience with people with an intellectual disability. Lorraine explained;

I think it's just lack of understanding. I think it's with any group. Ethnic groups... Aboriginal people... until you actually get to know them or understand where they're coming from, a lot of people are scared about how to approach them.

This uncertainty and apprehension may lead people without intellectual disabilities to avoid interacting or communicating with people with intellectual disabilities. Bob suggested that people without intellectual disabilities shy away from encounters with people with intellectual disabilities to avoid feeling awkward or uncomfortable; *"What do you do if the response isn't what I expect? What do you do? I think people are always afraid of being embarrassed"*. Although there is a recognition of

difference (as evidenced by the rhetoric, “*everyone is different*”) it seems that there is a real intolerance of difference when it comes to people with intellectual disabilities. Difference is not value-free as intended by the dictionary definition. According to the staff interviewed, differences in communication, for example, are unacceptable. Society only tolerates difference within very narrow margins and it seems that “*it’s OK to be different*” is nothing more than a cliché.

The intolerance and fear of intellectual disability as described by the staff interviewed has been extensively reported in the literature. In fact, when compared to other impairments, intellectual disability is often considered the least desirable condition; the ‘worst of the worst’ (Thomas, 2000; Tringo, 1970). Tringo conducted a study which aimed to explore the attitudes toward people from different ‘disability groups’ and to determine if a preference for particular groups existed. Using the Social Distancing Scale (Tringo, 1970) the participants ($n= 455$) had to rate 21 impairments using a nine-point scale ranging from ‘*would marry*’ to ‘*would put to death*’. Tringo concluded that there was a hierarchy of impairment which appeared to be fixed and consistent across all sample groups. Mental retardation (with mental illness, alcoholism, and being an ex-convict) was consistently rated the ‘least preferred’ ‘disability group’ by the non-disabled participants. Tringo proposed that these groups have the most difficulty being accepted in the community. Tringo’s Hierarchy of Preference toward Disability Groups has been found to be relatively stable 30 years later despite efforts to combat such damaging stereotypes (Thomas, 2000).

Feelings of dissonance, tension or discomfort toward people with an intellectual disability described by some of the staff interviewed have also been reported in the literature. Yazbeck, McVilly and Parmenter (2004) conducted a large study ($N= 492$) which examined the attitudes of the Australian public toward people with an intellectual disability. It was reported that people over the age of 40 with a lower level of educational attainment were most likely to feel ‘uncomfortable’ with people with intellectual disabilities in social or work-related settings. Scior (2011) conducted a systemic review of public awareness, attitudes and beliefs regarding intellectual disability in the adult general population. Scior reported that people with an intellectual disability were considered to be highly undesirable partners for

social interactions and 'lay people' generally wanted a greater social distance from people with intellectual disabilities when compared to those with physical disabilities. To reduce the discomfort associated with witnessing an 'injustice' (someone with an intellectual disability), Lerner (1980) proposed that people may use the psychological defence of denial/withdrawal in addition to compensatory rewards and complementary stereotypes. Carefully selecting the information one is exposed to and physically leaving or avoiding situations where the injustice is likely to be encountered can protect the belief in a just world and reduce feelings of distress associated with contradictory evidence (Lerner, 1980).

The model of intergroup anxiety by Stephan and Stephan (1985) also offers a plausible explanation for the apparent reluctance of people without intellectual disabilities to interact and/or communicate with people with intellectual disabilities as described by some of the staff interviewed. Intergroup anxiety refers to feelings of concern and anxiety stemming from the anticipation of contact with outgroup members (Stephan & Stephan, 1985). According to Stephan and Stephan intergroup anxiety may result from a fear of being embarrassed due to feeling incompetent or confused about how to interact with the outgroup (people with intellectual disabilities). Ingroup members (people without intellectual disabilities) may also worry that they will feel guilty if they behave in ways which offend or harm outgroup members. Intergroup anxiety is more likely if the ingroup has had minimal contact with the outgroup (Stephan & Stephan, 1985).

More recently, a study by McManus, Feyes and Saucier (2011) reported that greater *quality* of contact with people with intellectual disabilities, not quantity of contact, was predictive of positive attitudes and behaviours toward this group. Simply having contact with people with intellectual disabilities is not enough to influence attitudes; the contact must be evaluated as a pleasant and enjoyable experience by people without intellectual disabilities McManus et al. (2011). Scripts, norms and other expectations may also increase intergroup anxiety if negative behaviours are anticipated of the outgroup (Stephan & Stephan). Avoidance is the dominant response to intergroup anxiety (Pettigrew & Tropp, 2006; Stephan & Stephan, 1985). As Goffman (1963) observed, people act as though through interaction with the stigmatised (people with intellectual disability) they

will become contaminated by the stigma. Avoiding people with intellectual disabilities in response to fear and anxiety is consistent with the explanation offered by the staff interviewed.

Theme: Pushing the boundaries by being normal.

Most of the staff members interviewed described how the Members of the Advocacy Agency challenged the commonly held assumptions or stereotypes about people with intellectual disabilities by just 'being themselves'. The staff interviewed explained that the Members are very visible within the community as they are engaged in a number of activities such as fundraising, presenting at schools and colleges and participating in the local community events. These activities exposed the wider community to people with intellectual disabilities and created the opportunity to challenge the presumption of incompetence so often assigned to people with this label. Bob explained:

So doing fundraising, getting out in the community, volunteering those types of things... it's only on a small scale but that's where we're affecting change. People are seeing that 'Oh! I didn't know they could cook a sausage on a barbeque!' you know, 'Wow!'... count change, add up, you know, laugh, tell jokes... you know, those sorts of things.

The skills and abilities of the Members were not surprising to the staff interviewed, but they were astonishing to some members of the wider public. Lorraine too was bemused by the response of the wider public when they encountered Members engaging in ordinary activities in the community;

"You've got people saying... 'Look at them. They're not educated', 'Oh didn't realise they could do stuff!' You know, you feel like going (Lorraine pulls face). But, you know, it's still awareness, isn't it? 'oh they can do stuff!' (sarcastic tone)".

The ability of people with intellectual disabilities to perform ordinary tasks such as counting money and everyday social exchanges such as telling jokes is a surprising revelation to people without an intellectual disability. By being active in the community, people with intellectual disabilities present a visual challenge to the stamp of difference and otherness that is so often affixed to people with this label. Liz explained; *"What you're (society) seeing is these perfectly fun, young adults out*

doing very normal things like get together with a bunch of friends, going to the pub, having a couple of drinks, having their meal, playing some pool". Engaging in 'normal' activities challenges the preconceived notion of a 'person with an intellectual disability' because they are viewed as 'not normal'. As Liz puts it; *"they're pushing boundaries by sort of being able to just... be normal"*.

The worldviews that people with intellectual disabilities are 'not like us', are 'not normal' and the presumption of incompetence has been explored extensively in the literature (e.g., Goodley & Rapley, 2001; Jenkins, 1998). Intellectual disability is commonly conceptualised as an unchangeable, naturalised (or biological) impairment (Goodley, 2001). This medicalised and individualised view of 'incompetence' has a profound impact on the perceived humanness of people with intellectual disability and disrupts or prevents people with intellectual disabilities from achieving full personhood in the eyes of people without the label (Jenkins). Put simply, "... we believe the person with a stigma is not quite human" (Goffman, 1963, p. 5). Rigid and inflexible definitions of intellectual disability and the process of formal diagnosis have also contributed to the conceptualisation of 'intellectual disability' as a fixed, clinical reality. The identities of people with intellectual disabilities are determined and governed by institutions such as medicine and psychology and their practices (Goodley & Rapley, 2001). It has been argued that professionals have created parameters for defining and determining intellectual disability that leave no mobility for the person bestowed this label (Jenkins, 1998; Rapley, 2004). Rapley demonstrates the circularity of this process; "How do you know someone is intellectually disabled? Because they are incompetent and stupid, according to our psychometric tests. Why are they stupid and incompetent according to our psychometric tests? Because they are intellectually disabled" (p. 42). The object of this construction (the person labelled as having an intellectual disability) is effectively trapped within a fixed diagnosed disorder (Rapley, 2004). That is, people with intellectual disabilities by definition are defective in intelligence and severely lacking in competence and this is the unchangeable 'truth'.

Genetically-oriented notions of personhood and the assumption of incompetence limits the likelihood that people with an intellectual disability are able to be viewed as a 'normal' and 'functional' human beings (Goodley, 2001).

Competence is generally taken for granted and axiomatic (Jenkins, 1998). That is, it is presumed that an individual is competent unless there is evidence to suggest the contrary (Jenkins). Booth and Booth (1998) argued that this grace is often not extended to people with intellectual disabilities and in this case the presumption of *incompetence* may be axiomatic. The personhood of people with intellectual disabilities is framed in terms of a set of naturalised violations or injuries to their very personhood (Goodley & Rapley, 2001). A person becomes defined in terms of his or her stigma (Goffman, 1963). A person *is* Down syndrome or a person *is* autistic. They become their professionally diagnosed ‘incompetence’ (Jenkins, 1998) and their actions are considered confirmation of that diagnosis. ‘Disability’ becomes the powerful lens through which the behaviours and actions of people labelled as ‘intellectually disabled’ are viewed. It seems that a person with an intellectual disability is rarely just ‘a person’.

But what happens when a person who is labelled ‘intellectually disabled’ demonstrates competence, rather than incompetence? What if the capacities, potentials and adequacies of a person do not conform to the social construct of an ‘intellectually disabled’ person? As explained by some of the staff interviewed in this study, ordinary activities or minor accomplishments such as counting money or cooking a barbeque are assessed as remarkable and noteworthy by the wider public. Capacities, any capacities, are viewed as astonishing considering *the circumstances* (Goffman, 1963); the ordinary becomes the extraordinary in the context of intellectual disability. An example offered by a blind person in the book *Stigma: Management of a Spoiled Identity* by Goffman illustrates this process;

His once most ordinary deeds—walking nonchalantly up the street, locating the peas on his plate, lighting a cigarette—are no longer ordinary. He becomes an unusual person. If he performs them with finesse and assurance they excite the same kind of wonderment inspired by a magician who pulls rabbits out of hats (p. 11).

This phenomenon can be explained using impression formation theory (Asch, 1946). When forming an impression or view of a person, Asch proposed that certain qualities are seen to cooperate, whilst others negate each other. For example, personal qualities such as ‘clumsy’ and ‘slow’ appear to negate the quality ‘helpful’.

Inconsistencies or contradictions create dissonance or a state of inner tension (Asch). When a person with an intellectual disability performs a task with competency and finesse, this characteristic is inconsistent with the general impression of a 'person with an intellectual disability'. They have behaved in a way which is contradictory with respect to their category; things are not as they should be (Asch, 1946; Fiske, Neuberg, Beattie, & Milberg, 1987). As a consequence, people often attempt to gain more information and search for a way for both characteristics (intellectual disability *and* competence or normality) to co-exist harmoniously (Asch). This could possibly involve being reflexive and reframing or reconceptualising notions of intellectual disability. This point is returned to in chapter eight.

Summary of the discourse/worldview level.

At the discourse/worldview level, the language or discourse used by the staff when they spoke of people with intellectual disabilities or intellectual disability more generally was of particular interest, as was the worldview or perspective their words conveyed. Most of the staff interviewed differentiated between visible and non-visible intellectual disabilities and described how the visual cues of intellectual disability shaped and guided the behaviour of those without an intellectual disability. Staff held the perspective that people with non-visible or non-identifiable intellectual disabilities were more likely to be perceived negatively by the general public. This assertion was supported by the literature.

Another underlying societal assumption or worldview identified by the staff at this level of analysis was that people with intellectual disabilities could not succeed, and as a consequence, it was frivolous to offer opportunities to achieve. The low expectations placed on and the limited opportunities afforded to people with intellectual disabilities were supported or legitimised by the discourses that people with this label live "*a bloody good life*" and are "*happy people*". Another discourse identified at this level of analysis was the rhetoric about difference. Difference was described as being "*OK*" and common to all. Paradoxically, many of the staff then went on to say that people are afraid of difference. Another worldview that was identified at the discourse/worldview level of analysis was that people with an intellectual disability are 'not normal'. As a consequence, when

people with intellectual disabilities engaged in 'normal' or competent behaviour it was described as remarkable or noteworthy.

Myth/Metaphor

The myth/metaphor layer refers to the deeper, emotive aspects of how people conceptualise their world as told through mythological stories and metaphors which evoke powerful visual images. The aim of the analysis at the myth/metaphor level is to identify the deeper conceptualisations of intellectual disability which are ingrained into everyday life. Within the myth/metaphor level of analysis, two themes were identified; 'Be independent, but in the way we want you to be' and 'Imposed identities'. The theme 'Imposed identities' had three subthemes; 'Deviancy and intellectual disability', 'The eternal child' and 'Disability as a master status'.

Theme: Be independent, but in the way we want you to be.

The exclusive grouping of people with intellectual disabilities (as they are at the Advocacy Agency) was discussed extensively by most of the staff interviewed. Some of the staff interviewed tried to explore why people without intellectual disabilities are so uncomfortable with the exclusive grouping of people with intellectual disabilities. Liz offered this explanation:

I think it's about ourselves. I think that as a community and probably through the guilt of perhaps the way that things were handled in the past and that... sort of legacy hangs around in the background. I think it's everyone else that doesn't want to see...

According to the staff, the tension or unease experienced by some people without intellectual disabilities when they see people with an intellectual disability grouped together is guilt related to the past treatment of people with intellectual disabilities. The opposition to the exclusive grouping of people with intellectual disabilities is related to shame; we (society) like to think that we have evolved and are 'better than that'. In the past, asylums and institutions were established to congregate, confine and isolate people with intellectual disabilities from the rest of society (Cocks & Allen, 1996). People with intellectual disabilities were subjected to intense surveillance, regiment and had restricted contact with the outside world (Goffman, 1961). The exclusive grouping of people with an intellectual disability may be seen

as harking back to ‘the old days’ of segregation and congregation. Liz reflected; *“People, I think, spend a lot of time worrying about it what's the right way for it to look like we’re treating people with disability”*. This quote captures the sentiment that opposition to the grouping of people with intellectual disabilities is merely an exercise in image control.

Indeed, the ideologies of normalisation and social role valorisation specify that an ‘avenue’ for improving the lives of devalued individuals (or groups) is ‘image enhancement’ (Wolfensberger, 1972, 1998). Wolfensberger and others recognised that the setting, the activities, routines and rhythms and the personal appearance of an individual conveyed important images or messages about a person’s worth or value. Improving an individuals’ social image so that they will be more positively perceived by others is one way in which the plight of societally devalued individuals can be addressed (Wolfensberger, 1998). The criticisms of normalisation expressed by some of the staff interviewed are also echoed in the literature (e.g., Chappell, 1992; Culham & Nind, 2003; Oliver, 1999).

Despite the positive change these theoretical approaches have been credited to achieving in the lives of people with intellectual disabilities, it has been argued that normalisation (and social role valorisation) lacks a critical exploration of opposing interests, inequality and the distribution of power between professionals/service providers and people with intellectual disabilities (Chappell, 1992). Chappell (1992) and Oliver (1999) argued that the underlying values and principles of normalisation may actually reproduce the same conditions that it strives to overturn. For example, it is acceptable for professionals to change the appearance, behaviour, experiences and even the preferences of people with intellectual disabilities in the name of ‘enhancing’ their image in the eyes of people without the label (Culham & Nind, 2003). Professionals hold the power to determine which individual differences are acceptable and which physiognomical features, behaviours and experiences need to be normalised to ‘fit in’ with wider society. People without the label of ‘intellectual disability’ are not held accountable for their discriminatory attitudes and services are not deemed responsible for disabling people with intellectual disabilities. Instead, people with intellectual disabilities are responsible for their own devaluation and need to be normalised.

The opposition to the exclusive grouping of people with intellectual disabilities as described by some of the staff interviewed illustrates this process. According to the principles of normalisation and social role valorisation, large groups of people with intellectual disabilities are undesirable as it conveys the image of a lack of individuality and there are negative associations with the social role of 'service recipient' (Chappell, 1992). To enhance the image of people with intellectual disabilities, social role valorisation prescribes that people with this label avoid engaging in programmes and activities with other devalued people (Wolfensberger, 1998). Friendships with people without intellectual disabilities are also preferable to those with people with intellectual disabilities (Atkinson, 1983). This view reflects the priorities and perspectives of service providers and professionals. The views of people with intellectual disabilities are often assumed and rarely sought (Chappell).

In this study, the staff interviewed felt that the Members of the Advocacy Agency enjoyed spending together as a group. They shared similar experiences, formed friendships and relationships, and offered each other support (this is explored further in the theme 'The grouping of people with an intellectual disability'). But, according to social role valorisation this is not 'what is best' for people with intellectual disabilities. Therein lies the paradox; we (society) want you to be independent and autonomous, and we want you to have control and to exercise power, but as defined by us. Power and control is still being exercised over people with intellectual disabilities in service provision settings and beyond, under the guise of 'doing the right thing' and acting in their 'best interests' (Oliver, 1999). Despite the dominance of the principles of normalisation in the field of intellectual disability and its aim to enhance the life conditions of devalued people, the status quo has remained unchanged (Chappell). Control is still being exercised *over*, and actions are still being taken *on* people with intellectual disabilities.

Despite these criticisms, others have defended the values of social role valorisation. Race et al. (2005) has argued that actions or measures based on social role valorisation are often misinterpreted from what was intended by Wolfensberger (2000). The principles of social role valorisation offer a guide only, and should be applied with careful consideration. For example, an action that would

be likely to reduce the devaluation of people with intellectual disabilities as predicted by social role valorisation (such as discouraging exclusive grouping), might preclude the opportunity for a person with an intellectual disability or a group of people with intellectual disabilities to exercise real choice and control (such as the choice to associate with who you wish). In this instance, Wolfensberger (1995) stated that the benefits and ill effects of reducing devaluation or the lack of choice and control would need to be considered; the Social Role Valorisation specified action would not automatically be chosen.

Theme: Imposed identities.

A theme identified in the myth/metaphor layer was 'Imposed Identities'. Most of the staff interviewed referred to a number of different identities or roles (Wolfensberger, 2000) that are commonly affixed to people with an intellectual disability by people without this label. The roles that people with an intellectual disability are often cast included; the deviant, the child and the disabled. These different identities affixed to people with intellectual disability by people without the label were often brought to the attention of the staff interviewed by incidences of hypocrisy. Within the theme 'Imposed Identities' there are three subthemes which address identities or roles commonly imposed on people with an intellectual disability. The subthemes are; 'Deviancy and intellectual disability', 'The eternal child' and 'Disability as a master status'.

Subtheme: Deviancy and intellectual disability.

A 'deviant' identity was described by some of the staff as being imposed on people with an intellectual disability. 'Deviant' is defined as differing from a norm or from the accepted standards of a society. As previously discussed in the theme 'It's OK to be different (not really)', difference or deviancy is rarely neutral or value-free as intended by the dictionary definition. 'Deviance' identifies something as essentially pathological. As Wolfensberger (1975) asserted "... man has been apt to see evil in deviancy" (p. 13). 'Intellectual disability' is often conceptualised as undesirable 'deviation' and people with this label are often perceived and interpreted as menaces or as a threat to others. As described previously in the theme 'Visibility of stigma', Gavin (who has a non-visible intellectual disability) was assumed to be a "weirdo" or deviant by a man at the tavern. The man at the tavern

also felt that Liz and the other females in her company needed to be 'protected' from him. Dawn offered another example;

Even kids at high school where they have done something inappropriate in terms of a sexual nature, nothing serious... like boys in the boy's toilet... They'll play around and they've got all these different funny things they do to each other you know in fun, in jest. But then you've got someone that has a disability that doesn't quite understand what's going on but gets aroused or what if he does something too and then 'oh he's a weirdo' so somehow he's the one that's pulled out of school... put on detention and made to feel really bad. Whereas, the other guys... nothing happens to them; that's just normal growing up.

In the scenario described by Dawn, the child with an intellectual disability is quickly cast in the role of 'sexual deviant' and punished. In contrast, when the other children (who do not have an intellectual disability) engage in the same behaviour it is considered 'normal growing up'. It seems that in the context of intellectual disability, people are quick to affix the label of deviant.

As described by some of the staff interviewed, if a person without an intellectual disability is involved in a momentary indiscretion, it is not considered symptomatic of any inherent 'deviancy' or blemish of his or her character. In contrast, if a person with an intellectual disability has a similar indiscretion it is interpreted as a direct expression of his or her stigmatised difference (Goffman, 1963). Attribution theory (Heider, 1958; Jones & Davis, 1965; Kelley, 1967) can offer an explanation for this phenomenon. Attribution theory is concerned with how people use information to arrive at casual explanations for the behaviour of others (Fiske & Taylor, 2013). This process involves three key processes (Ross, 1977). First, the observer seeks to identify the cause(s) to which some particular effect can be most reasonably attributed. Second, the observer forms inferences about the attributes of the relevant entities. This may involve making social inferences about the personal dispositions of the actors or the properties of the environment. Third, expectations are formed about future actions or outcomes.

Ross (1977) proposed the existence of a systematic bias in the process of casual judgement and attribution, known as 'the fundamental attribution error'.

The fundamental attribution error refers to the pervasive tendency for observers to overestimate personality or dispositional causes of behaviour and underestimate the influence of situational constraints on behaviour (Ross, 1977). Important qualifying information (such as social norms or social pressures) are ignored and it is assumed that the behaviour reflects a person's stable qualities (Fiske & Taylor, 2013). This widespread bias in social judgement is said to occur because of our reliance on simple, overlearned, judgemental heuristics in social perception tasks (Tetlock, 1985). 'Cognitive busyness' results in a tendency for people to focus on the most compelling and salient aspects of a situation and in turn neglect less salient contextual factors (Fiske & Taylor, 2013).

It is possible that the presence of 'intellectual disability' is considered the most salient and important aspect of a situation, and other contextual factors, such as social norms and expectancies are ignored. Dispositional attributions are then made about the person. For example, the person is engaging in that behaviour because they are "*weird*" or deviant. Similarly, minor failings such as forgetting a detail or repeating information are considered a direct expression of incompetence associated with intellectual disability, not a reflection of situational constraints. Fiske and Taylor noted that if the situational information is not compelling, people are less likely to correct their initial dispositional inference. Related to this notion of stable and well-worn settings and expanding on the work by Ross, Shinn and Toohey (2003) proposed a parallel error in processing known as 'context minimisation error'. Context minimisation error occurs in more enduring contexts, or where situational or personal characteristics are confounded, and is characterised by a tendency to ignore the effects of the context and attribute all shared variance to individuals (Shinn & Toohey, 2003). It is possible that the stereotyping and discrimination experienced by people with intellectual disabilities is so subtle and pervasive (not salient) that it is not recognised. This context minimisation error may result in impoverished disability theory as contextual effects masquerade as effects of individual characteristics, or in this case, incompetencies. It is possible that the social programmes and policies that aim to address the disadvantage experienced by people with intellectual disabilities will fail to

recognise the complex interplay between individuals and the social contexts. This limits the possibility of creating social change (Shinn & Toohey).

According to Ross (1977) the final component of the attribution process is the prediction of future outcomes and behaviour. When a person with an intellectual disability is perceived to be a deviant, that role carries with it particular expectations for behaviour (Wolfensberger, 1972). People tend to play the roles they have been assigned. A 'self-fulfilling prophecy' is created whereby others predict that someone cast in a certain role will display behaviour consistent with that role (Taylor & Bogdan, 1989; Wolfensberger, 1972).

Subtheme: The eternal child.

Another identity that was commonly described by staff as being imposed on people with an intellectual disability was that of a child. People with intellectual disabilities are often cast in the role of the 'eternal child' who never matures into adult status. Despite aging, the behaviours, interests and skills and abilities of people with intellectual disabilities will always remain 'childish'. Children lack maturity and cognitive ability and are subjected to rules and boundaries. Support worker Vicky described how Michelle, who has an intellectual disability, is punished (like a child) by her brothers;

She may get left with them and they are in control of her as they have got to look after her and they may consider she has been naughty... they will send her to the naughty corner. Another time, she will say to me that she hasn't got her TV in her room because she's not allowed to watch TV for three weeks or six months or however long the so-called punishment or she's had a new DVD, and she is not allowed to watch that... And then she will say, 'I tell them I am thirty-three. I'm an adult. I'm an adult.' But this is kind of how she gets treated. So her voice is not heard.

In this example, Michelle clearly identifies herself as an adult, but her brothers consider her to be a child and punish her accordingly. Not only are children subjected to strict rules, they are also not allowed to partake in certain 'adult behaviours' until they reach the age of 18 years. Adult behaviours such as engaging in sexual relationships, getting married and consuming alcohol are reserved for adults and may be considered inappropriate for people with an intellectual

disability who are child-like. Liz described an example of the imposed child-like identity on the Advocacy Agency's trip abroad;

People would come up to us (the staff)... 'You know... that boy over there, he's drinking!' And I was like, 'Yeah'... 'Oh my gosh is he allowed to?' 'Oh, he's 22. Guess so!' And they were like, 'Oh, um... well, of course, yeah, 22, you're allowed to drink aren't you, yeah...' And you see them walk away going, 'Huh?' (laughs)

In this excerpt a member of the wider public is surprised (confronted?) to see an adult with an intellectual disability drinking alcohol and feels the need to inform the 'adults' of the group of this behaviour. People with intellectual disabilities were described by the staff as often being excluded from other markers of adulthood or 'rites of passage'. In the following excerpt Lorraine describes holidaying with friends as a rite of passage;

... (It) is about them having an opportunity for that rite of passage to go on a holiday, because a lot of young people get to go on a holiday. They let their hair down, their parents aren't there, they're there to have a great time. It wasn't my idea of going overseas (laughs) being in the youth hotel... where all the action is... now they might not choose to go to those places, but it's there if they want to... Going away with your friends is the most important thing, cos a few of them have been away... with parents and it's very different.

Similar to the subtheme 'Deviancy and intellectual disability', the notion of 'double-standards' was also a feature of the subtheme 'The eternal child'. One of the staff members interviewed felt that people with intellectual disabilities are often considered to be childish and inappropriate, but if the same behaviour is displayed by someone without an intellectual disability it is considered 'normal'. Lorraine explained;

I remember my lecturer saying to me once... (that) there was a girl that had an intellectual disability, quite severe, and she had this doll... and it was brought up, is it appropriate for her to carry around this doll? Now a 25 year old girl and it probably wasn't appropriate for her to carry around a doll because that attracts attention to society that... this girl needs a doll

whereas the whole class thought the opposite; why couldn't she have the doll? What's wrong with that? Who are you to judge whether she has a doll or not? You know, you see movie stars and God knows what walking around with little handbags that are, you know, designed for Barbie, but that's OK, but someone with a disability doing the same thing, well that's wrong. I can't see the difference, you know?

It seems that two people can engage in the same or similar behaviour, but when the same or similar behaviour is viewed through the lens of disability it takes on a new meaning. The behaviour of an individual with an intellectual disability is pathologised.

According to Wolfensberger (2000) people with an intellectual disability are often cast into roles that are devalued in society. One such role is that of the eternal child, which was a prominent social role identified by staff in this in this analysis. When people with an intellectual disability are cast in the role of the eternal child they are often subjected to a 'pattern of wounding' (Wolfensberger, 2000) that is characterised by a loss of control over their lives and the acquisition of power and decision making by others. Previous literature (e.g., Jahoda et al., 1988; Kittelsaa, 2013; Todd & Shearn, 1997) offers support for the finding in this study that people with an intellectual disability are commonly considered to be child-like by wider society. Todd and Shearn interviewed 33 parents of adult children with an intellectual disability to gain their perspective on a number of topics including the social status of their child and their definitions of 'adulthood'. All of the parents interviewed agreed that their children could not be categorised easily as they were not typical members of the 'child' population or the 'adult' population. Whilst most of the parents recognised that their children were chronologically and physically adults, they believed that they possessed a number of qualities which precluded them from achieving unqualified adult status. A high level of dependency, failure to leave the parental home, limited involvement with peers and the lack of an 'adult perspective' were described as factors that prevented the individual with an intellectual disability from obtaining adult status. Instead, most of the parents interviewed tended to see their adult children as non-adults or adolescents (Todd & Shearn, 1997).

Wolfensberger (2000) also noted that when devalued roles are imposed on an individual (such as the eternal child) valued roles also tend to be withheld. Respect, responsibility, independence, autonomy, strength and power are all qualities that are valued by the Western cultural worldview (Wolfensberger, 2000). These qualities (or messages) can be conveyed through holding certain roles. Being a husband/wife, father/mother, wage-earner, home owner are considered valued social roles (Wolfensberger, 2000). In addition, certain activities including driving a car, drinking alcohol, and having sex are considered 'rites of passage' to adulthood. With adulthood too comes the opportunity to live the 'good life'. The good life encompasses making decisions about your life, being considered a unique individual and contributing to society through work and possibly providing for and supporting a family. These ingredients of a good life are arguably central to an individual's emotional and physical wellbeing (Peter, 2002). The good life, however, is not accessible for all adults. Australians with intellectual disabilities are more likely to be unemployed (and receiving a pension), unable to purchase a home, and have fewer opportunities to make a contribution to broader society through volunteer work with charities and service clubs (Peter, 2002). In fact, people with intellectual disabilities are often the object of charity (Wolfensberger, 2000). Furthermore, people with intellectual disabilities are less likely to marry, live in an intimate relationship with another person and have a family of their own (Peter, 2002). People with intellectual disabilities are also less likely to be recognised as individuals and have fewer opportunities to make choices and decisions about their life (Peter, 2002). It seems that 'intellectual disability' and 'adulthood' are perceived as mutually exclusive in the eyes of society.

Subtheme: Disability as a Master Status

Some staff members described the label of 'intellectual disabled' as being all consuming and overriding the other identities that an individual may have. The 'disabled identity' was described as being imposed on the person with an intellectual disability by others and as being pervasive, influencing all aspects of the individual's life. The designation of a master status was a common social process, as Dawn explained;

It doesn't matter what it is. You know, it's like if you've got cancer, you're the cancer on ward 5. I suppose when I smacked my arm, I was the smacked shoulder on ward 2, or something. I don't know.... it's just the way this society is.

When an individual is seen as 'disabled', without any other identities or social roles, a number of damaging consequences may result. Most notably low expectations are placed on the individual with an intellectual disability, and as a consequence limited opportunities are provided (this is explored in detail in the theme 'Low expectations and limited opportunities'). Limited opportunity for achievement and success may result in the internalisation or incorporation of the 'disabled identity' into the individual's self-image. In cases when the individual with an intellectual disability viewed themselves primarily as 'disabled', low self-esteem and a poor sense of self-worth resulted. Most of the staff interviewed felt that low self-esteem was an issue for some of the Members of the agency. On a recent camp Lorraine noted;

The 'can't do' attitude was very prominent, you know, mum would say or dad would say 'oh you can't do that', 'oh we're going here, but you can't come'... Can't do this, I can't do that. Teachers telling them that. Their peers telling them that. Their family. Their uncles. Their aunties. It came from a wide range of people. People that they volunteer with saying 'oh you can't do that' you know? 'we'll get so- and-so to do that' and not giving them the opportunity... Opportunity is very restrictive.

Age was identified as an important factor related to the incorporation of the 'disabled identity' into an individual's self-concept. Some of the staff interviewed noted that older individuals with an intellectual disability were more likely to have internalised a 'disabled' identity. Lorraine;

The older ones... when it's not going well or if they have not achieved something that they wanted to achieve they do regress back into 'oh well, this is what I can do'... rather than have another go at it... Most of the young ones now, they see that as OK because it is OK to make mistakes and learn from them, whereas the older generation... there's been too much time and a lot of damage.

It was also noted by some of the staff interviewed that the 'disabled identity' was the "default" identity that was often activated enacted during stressful situations or when the individual with an intellectual disability encounters a barrier. Staff described this as a 'regression' whereby the individual with an intellectual disability lapsed back into previous unhelpful thinking patterns (the "can't do attitude" as described by Lorraine). Bob explained;

Those old thoughts and those old experiences come to the surface... I suppose it's through repetition over years of being told who they are and what they can and can't do, even though they've learnt all this now... some of them are taken back there very, very quickly.

In contrast, most of the staff interviewed believed that the Members did not identify as 'disabled'. That is, their *own* identity was different to that imposed on them by the wider society. While the Members were aware that they have been assigned the label of intellectually disabled, it was described as having little resonance or importance in their lives; "*I think mostly they do know and I don't know that it's necessarily something that they dwell on or worry about*" (Dawn). Social roles were described as being more central to an individual's personal identity. Liz; "*They actually would identify each other and themselves probably by more of a social, like their leadership roles, so to them it's about who's got certain leadership roles, about who's bossy boots, about who's ratbag at the pub*".

The notion of intellectual disability as a master status or all-consuming identity is also reflected in the literature (e.g., Aull Davies & Jenkins, 1997; Beart et al., 2005). Hughes (1945) described membership to the intellectually disabled group (as determined by societal mores and/or law mores) as an all-encompassing master status as this identity is thought to be so powerful and pervasive that it engulfs or overrides other identities and characteristics the individual may have, such as gender and social adulthood (Aull Davies & Jenkins, 1997; Beart et al., 2005).

Echoing the views of the some of the staff interviewed, in the literature it has been also argued that the concept of intellectual disability may have little resonance to the people who live with the label (Fine & Asch, 1988; Finlay & Lyons, 1998). Rapley (2004) argued that the lives of people with intellectual disabilities are characterised by fluidity and remarkably ordinary social experiences and

relationships. Mest (1988) conducted a series of interviews with people with intellectual disabilities exploring sense of self, beyond stigma. Mest reported that the participants discussed their lives with great enthusiasm and contentment. They developed a positive and strong identity based on their own personal experiences, immediate relationships and achievements (Mest). A study conducted by Markova and Jahoda (2004) explored the experiences of stigma and self-perceptions of 28 people with mild intellectual disabilities during a period of transition from either the family home and supported housing or an institution into community housing. They reported that while participants acknowledged that they had particular difficulties with learning, they rejected the stigmatising treatment of others and did not view themselves as 'disabled'. Instead, participants emphasised their independence and capabilities to make choices as autonomous individuals. Similarly, a study by Jahoda et al. (1988) that explored the experiences of stigma and the self-concept of people with intellectual disabilities found that the majority of participants rejected a globally handicapped view of self and considered themselves to be essentially the same as people without intellectual disabilities. Participants were aware of the stigma surrounding them but felt it was unjustified by their *actual* disability which was described as particular difficulties with reading and writing. Further, Jahoda, Wilson, Stalker and Cairney (2010) reported that people with intellectual disabilities actively disputed the views others had of them, for example incompetent and child-like, and tried to shape their own identities.

If intellectual disability has little resonance with those who live with the label, why is intellectual disability so salient and central to people without the label? Impression formation theory by Asch (1946) may offer an explanation. Asch argued that when establishing a view or impression of a person not all qualities are given equal weighting. Superordinate categories or central traits (Asch) are the most salient social categories and include gender and ethnicity (Rohmer & Louvet, 2009). Subordinate dimensions are less important and include categories such as occupation and sexual orientation. Superordinate categories are activated automatically and have a profound impact on impression formation (Rohmer & Louvet, 2009). The speed and ease at which category-based processing occurs has been attributed to a number of factors, including; (a) the frequency or regularity

these social categories are activated (b) the clear (visible) physical characteristics that define these categories and (c) the perception of gender and ethnicity as a 'natural' category that is inalterable and stable across time (Rohmer & Louvet).

A recent study by Rohmer and Louvet reported that disability is more salient than the superordinate categories gender or ethnicity in impression formation. In this study, paraplegia (a visible, physical disability) was identified as a superordinate category and a powerful organiser of social perception. It is possible that intellectual disabilities may also have primacy in impression formation (Rohmer & Louvet, 2009). Superordinate traits, such as intellectual disability, have the ability to colour, transform or influence interpretations of other available attributes (Asch, 1946; Fiske et al., 1987). The intellectual disability 'trait' is characterised by incompetence, dependence and pathology (Jenkins, 1998; Wolfensberger, 1975). Other traits that a person may possess such as being humorous or stubborn may be interpreted as symptomatic of 'intellectual disability' to maintain the unity of the impression (Asch, 1946). That is, as a superordinate category intellectual disability determines the content and function of a person's peripheral attributes (Asch, 1946). A person *is* intellectually disabled first and foremost.

Summary of the myth/metaphor level.

At the myth/metaphor level of analysis, intellectual disability and the identities, social roles and personhood of people with this label were explored by deconstructing the stories and metaphors used by the staff interviewed. Feelings of guilt and discomfort were described as being experienced by people without intellectual disabilities when they encountered exclusive groups of people with this label. This tension was described as being related to the shame of the past treatment of people with intellectual disabilities. Deeper exploration of the opposition and discomfort surrounding the exclusive grouping of people with intellectual disabilities revealed an interesting paradox. The principles of normalisation (and later social role valorisation) could be perceived to be perpetuating control and power *over* people with intellectual disabilities; the very atrocities these movements aim to remedy or ameliorate. Analysis at the myth/metaphor level also revealed that people with intellectual disabilities have a number of identities imposed on them by others. These identities were revealed by

deconstructing the stories and metaphors used when describing the interactions between people with and without the label 'intellectually disabled'. These externally projected identities include the deviant, the eternal child and the intellectually disabled; a powerful and all-consuming master status.

Reconstructing the Issue

CLA was used to deconstruct the Advocacy Agency staff interviews to explore how they conceptualised the identities and social roles of their clients with intellectual disabilities and how intellectual disability was constructed more broadly. The role that worldviews, values, mythology and culture played in this construction was of particular interest. Overall, the findings of this analysis suggest that people with intellectual disabilities are subjected to a number of powerful underlying processes including dehumanisation and victim blaming. These processes are revealed by examining the complex interactions across the four causal layers.

Exploration of the metaphors used and the stories told by the Advocacy Agency staff revealed a number of identities imposed on the Members by people without this label. One such identity was that of the deviant; a threat to society or a sexual menace. The imposition of a deviant identity and the damaging consequences of this construction are further illuminated in the lifestory of Paul presented in the following chapter. At the myth/metaphor level of analysis of the staff interviews, it emerged that people with intellectual disabilities are often cast in the role of the eternal child. When considered to be childish, immature and vulnerable, people with intellectual disabilities can rightfully have power and control exercised over them by more capable others. They can also be excluded from markers of adulthood, such as engaging in sexual relationships, getting married or consuming alcohol. Finally, at the myth/metaphor level of analysis, intellectual disability emerged as an all-consuming master status. Staff reported that some of the Members had internalised the externally imposed disabled identity into their self-image, resulting in low self-esteem and poor self-worth. The salience of the intellectually disabled identity to people without this label is reflected in the disability literature. As discussed in the previous chapter, a stigmatised identity is often assumed and people with intellectual disabilities are expected to admit to

their disabled status. Furthermore, there is a paucity of literature exploring the alternative identities of people with intellectual disabilities, such as gender or ethnic identities (Beart et al., 2005; McVittie et al., 2008).

The construction of people with intellectual disabilities as inherently different and the denial of those attributes that make them human reflects the process of dehumanisation (Vail, 1966). Once people with intellectual disabilities are viewed as not quite human the obligation to treat them humanely is moderated (Vail, 1966). The provision of limited opportunities to people with intellectual disabilities and the exercising of control and power over people with intellectual disabilities is a manifestation of this process (see the theme 'Low expectations and limited opportunities'). The limited opportunities afforded to people with intellectual disabilities were further legitimised by discourses that people with intellectual disabilities are happy and led a "*bloody good life*".

So powerful is the process of dehumanisation, that when competence is displayed by a person with an intellectual disability it is considered extraordinary or remarkable. So unexpected is it that people with intellectual disabilities are ordinary and competent human beings that they are able to push the boundaries of society by being normal (see the theme 'Pushing the boundaries by being normal'). Interestingly, notions of being normal and being different were mutually held by the Advocacy Agency staff. At the worldview/discourse level of analysis the rhetoric that difference is OK emerged. Difference was described as being common to all human beings. Paradoxically, staff then went on to say that people (society) are afraid of difference. This was particularly evident in the case of Members with non-visible intellectual disabilities who were subjected to treatment far worse than those Members with visible intellectual disabilities, such as Down syndrome (see the theme 'Visibility of stigma'). This finding is supported in the literature (see Crocker & Major, 1989; McManus, 2010). It would seem that despite difference and variation being common to all human beings and so readily acknowledged in everyday life, this acceptance does not extend to people with intellectual disabilities.

The staff identified that the imposed identities described above and the limited opportunities afforded to the Members produced a number of significant

problems in the lives of the Members. As a result of these unjust societal forces, many of the Members had little confidence and poor self-esteem. Other deficits identified by the staff included difficulties managing money, poor personal hygiene and problems interacting with others socially (see the theme 'The role of the advocacy agency' in the litany level of this analysis). The stigmatisation and dehumanisation of the Members is clearly not their fault. Similarly, the deficits and inadequacies they experience are through no fault of their own. These problems are the consequence of environmental forces and malignant injustice. Although this understanding of intellectual disability shifts the emphasis to environmental causation, nevertheless, the Members are *still* different and incompetent. The Members are still defective, although this shortcoming was derived through social forces. This ideology or phenomenon is known as victim blaming (Ryan, 1971).

Blaming the victim enables society to simultaneously hold vague social forces responsible for the dehumanisation of people with intellectual disabilities while continuing to ignore those victimising social forces (Rappaport, 1977). Ryan (1971) posited that the victim blaming strategy justifies changing its victims (people with intellectual disabilities), rather than broader society. This distortion of reality is unintended, although blaming the victim does serve the interests of those who practice it (Ryan, 1971). This belief system enables people with intellectual disabilities to be helped, without threatening the privileged position of the powerful; people without intellectual disabilities. Society is perpetuated unaltered (Rappaport, 1977).

The process of victim blaming justifies the development of strategies to correct the deficiencies of the individual victim, such as services and programmes that are designed to support people with intellectual disabilities to be independent and autonomous. Ryan (1971) labelled this dynamic, which is rife within the helping professions, the 'giving enemy'. On the one hand, people with intellectual disabilities are given what they need (such as money in the form of a Disability Support Pension), while on the other hand it contributes to social stigma by reducing their personal control. Examples of this process were evident through both the Member and Staff interviews. The educational and skill-building programmes of the Advocacy Agency can have the converse effect of perpetuating the worldview

that people with intellectual disabilities are incompetent and *need* help. This tension also emerged in the analysis of the Members interviews, whereby the provision of a pension and housing served to further reinforce the underlying worldview that people with intellectual disabilities are incompetent and dependant. The life story of Paul presented in the following chapter also exemplifies the 'paradox of support' which emerged through the analysis of the staff interviews. Those formal services intended to support Paul to be independent and autonomous, in fact reinforced his disabled position within society (see the theme 'Behaving and slipping up' in the following chapter). This paradox is inherent to the victim-blaming strategy.

This deconstruction highlights the need for those services that support people with intellectual disabilities (including psychological services) to be made aware of how the assumption of incompetence, deficit and difference may be implicit to service delivery. An understanding of the importance of power is crucial (Rappaport, 1977). For genuine social change to occur, the social structures that support the relationship between the powerful and the powerless must be destabilised. The emphasis must be on changing society, not the individual (the victim). People with intellectual disabilities must have the power to control the social structures that affect their lives as well as control over the outcomes of their own actions (Rappaport, 1977) Power must be redistributed so that the independence and personal control of people with intellectual disabilities can be fostered. This is explored further in chapter eight.

Conclusion

CLA was used to deconstruct the staff interviews to explore how the identities and social roles of their clients and intellectual disability more broadly were socially constructed. Analysis of the complex interactions that emerged across the causal layers revealed a vicious cycle of dehumanisation and victim blaming. At the worldview/discourse and myth/metaphor levels, a number of identities commonly imposed on people with intellectual disabilities were identified. These externally affixed identities, worldviews and overarching myths and were completely at odds with how the Members conceptualised their own identities and social roles and served to construct them as inherently different and not quite

human. Based on the victim blaming ideology, programmes and services are then developed to correct the perceived deficiencies of people with intellectual disabilities (the victim). These solutions which emphasise enhancing the independence and autonomy of people with intellectual disabilities often have the converse effect of contributing to social stigma. For genuine change to occur, those social structures which support the relationship between the powerful and the powerless must be challenged. In the next chapter the lifestory of Paul is presented, further illuminating those deeply embedded social processes identified through the analysis of both the Member and Staff interviews.

Chapter 6: Paul's Lifestory

"I feel as an Australian citizen, I have the right to have... that feeling when I go to bed at night" (Paul).

Introduction

Social phenomena and social processes are multi-faceted and complex (Mazumdar & Geis, 2001). These social processes are often so deeply embedded in our day-to-day life, that they may go unnoticed. The processes by which restricted identities and negatively valued social roles are affixed to people with intellectual disabilities are subtle and pervasive. Similarly, the dehumanisation of people with intellectual disabilities and the denial of full personhood are so deeply entrenched that they may go unnoticed. Life stories can assist in the development of a nuanced view of reality as experienced by people with intellectual disabilities. Life story research aims to investigate the subjective meanings of lives as they are recounted in the narratives or stories of participants (Plummer, 1995). By illuminating the life and experiences of one person in a life story, I hope to provide an insight into these complex social processes in action and the lives of people with intellectual disabilities more broadly.

While people with the label 'intellectual disability' are by no means a homogenous group, they do often share similar histories and common experiences based on their membership to this highly stigmatising social category (Chappell, 1994; McVilly et al., 2006a). Focusing on one case (with tangible, 'real life' examples) and analysing it in-context can ultimately lead to a more holistic and in-depth understanding of the oppression of people with intellectual disabilities (Gilbert, 2004; Mazumdar & Geis, 2001). Furthermore, it has been argued that empathy is central to the comprehension of complex social problems, such as those experienced by people with intellectual disabilities (Mazumdar & Geis, 2001; Stake, 1978). Presenting detailed descriptions of the thoughts and feelings of one Member (as a representative of people with intellectual disabilities) a life story is a powerful way of facilitating an in-depth understanding of social process and encourages social action (Barnes, 1992; Mazumdar & Geis, 2001).

In this chapter, I present the life story of Paul. Paul is a Member of the Advocacy Agency, and while he chose not to take photographs as part of the 'This Is Me' project, he insisted on being interviewed. Paul was formally interviewed three times as part of this project. In these interviews he spoke about his life and his goals for the future. These interviews were audio recorded and transcribed verbatim. My relationship with Paul did not cease following the formal completion of the project. Paul continues to write me letters and send postcards, and we talk on the phone regularly. Where possible we catch up for coffee and attend football matches together. Over the past three years we have developed a close and trusting friendship. For a more detailed discussion of the relationships that developed over the span of the research, please see chapter seven. In this chapter, I will first present Paul's life story. I am by no means attempting to grasp the totality of Paul's life. It is acceptable for a particular issue or theme to be examined in a life story (Plummer, 1995). The issue explored in detail in this lifestory is Paul's desire to live with a female friend. I will then identify the key issues, assumptions, worldviews and myths pertinent to Paul's story. By presenting an in-depth single case, I hope to bring to light those social processes that serve to dehumanise and restrict the identities afforded to people with intellectual disabilities.

Paul's Lifestory

Paul is 40 years old. When he was born, doctors and specialists had very low expectations for his future development and achievement. Paul lived in a group home in a small town from the age of ten until he was 38 years old. He described his time in the group home as shocking and said that the staff would often tell lies. With the support of one particular staff member at the group home, Paul was encouraged to leave the group home and live in the community. Paul stated with apparent pride that leaving the group home was the best decision that he ever made. Paul said that he enjoys the freedom of living independently in his own two bedroom unit which he has done for the past two years.

Paul is an only child. His elderly parents live approximately four hours away in a small farming community. Paul only sees his parents at Easter and Christmas. His Support Worker, Vicky, lives on the same street just five houses away and regularly visits his unit. Paul explained;

She's my support person. She lives just over there. Having her close makes it a lot better because I can sleep better at night, when circumstances come along I can calm down a lot better... She helps me with my planning, with healthy eating but still enjoying myself at the same time. Yeah, and also.... all the things that are important to me, but also in the month to make sure I pay my bills as well. She's wonderful. She's doing a great job.

Paul is not employed. He spends most of his time at the local Adult Day Care Centre or visiting his friends in town. Paul has a keen interest in news and current affairs and is an avid viewer of the National news. Paul explained; *"I reckon you learn a lot from the ABC"*. Paul is currently learning to read and write with the support of his tutor, Mike, who he sees twice a week. Paul is particularly interested in promoting the rights of people with disabilities. In the past, he has presented at large conferences on his experiences and hopes for the future. Paul is also a member of a number of disability committees, Paul explained; *"I enjoy being a part of the Advocacy Agency decision process and I enjoy being a Board Member and helping, supporting the guys"*.

Paul attends Church every Sunday and is involved in Church activities and camps. Some of the members of Paul's Church act as his custodians in his parents' absence, deciding how he spends his money and who he is allowed to associate with. Paul explained that he would prefer that his Church friends did not know that he was talking to me because they would be *"funny"* about it. Paul said that his goal for the future would be to live with a friend, possibly his friends Lynette and Josie. Paul is particularly fond of Lynette and hopes that she could one day become his girlfriend. Paul considered living by himself to be a temporary arrangement and longed for company of a housemate. Paul is currently waiting to attend a 'Planning Day' to be organised by his Disability Services Local Area Coordinator, Sabrina. At the Planning Day, Paul plans to express his desire to live with a female friend to his parents and those people involved in supporting him, such as Vicky and Sabrina. Paul hopes that the Planning Day will set the wheels in motion for him to live with a friend.

The issues and underlying assumptions, worldviews and myths relevant to Paul's life story will be presented in the following sections; 'Loneliness and longing

for a companion', 'The denial of romantic relationships and the paradox of sexuality', 'Behaving and slipping up', 'Getting his reward', 'Waiting and life wasting', and 'Being a human being'. The issues identified in Paul's life story will then be integrated with the relevant literature.

Loneliness and longing for a companion.

Paul has lived independently in his two bedroom unit (with support) for the past two years. Before living in the community, Paul was in a large group home. Although Paul stated that he enjoys the freedom of living in the community he explained that he is lonely living by himself and longed for the company of a housemate. He said that he felt sad and alone coming home to an empty house after being out all day. Paul expressed that he would like to live with either of his close female friends, Lynette and Josie, if they'd agreed to do so;

I don't want to do it forever. I'm hoping one day I can actually find.... One of my... OK, one day out of the two friends... Lynette and my friend, Josie... OK out of the two of them I would like to share a unit with one of them as a friend. Cos I don't want to be on my own forever.

Paul described his current living arrangements as temporary. While he accepted that he had to live on his own in the short-term, this was not his hope for the future;

I'm on my own... its only short term not a, you know, long term cos... one day, you know, if... Lynette wants a friend to move in or my friend Josie... I'd be more than happy, you know, to just share with one of them as a friend because... I said I'm on my own short term, you know, not long term.

For the past year, Paul has repeatedly expressed to his Disability Services Local Area Coordinator that he would like to live with a female friend, but this desire has not yet eventuated.

Loneliness is a central problem or issue as defined by Paul. Loneliness, the unpleasant experience arising from what is perceived to be insufficient social interaction (Peplau & Perlman, 1982), is a common experience for adults with intellectual disabilities (McVilly et al., 2006a). A study conducted by Sheppard-Jones, Prout and Kleinert (2005) reported that adults with intellectual disabilities were more likely to be lonely, afraid in their homes and less likely to have friends

when compared to adults without intellectual disabilities. Similarly, higher levels of loneliness and social exclusion (Mahar, Cobigo, & Stuart, 2013; Sheppard-Jones et al., 2005), are experienced by people with intellectual disabilities than their peers without intellectual disabilities. Loneliness has been identified as an important contributing factor to a number of psychological disorders, including depression and suicidal ideation (Lunsky, 2003, 2004).

Like Paul, more people with intellectual disabilities are moving from large residential institutions to living in very small community residential settings or alone (Kozma, Mansell, Beadle-Brown, & Emerson, 2009). Over the past 50 years the drive toward deinstitutionalisation has seen the majority of people with intellectual disabilities reside outside the formal residential service system (Emerson & Hatton, 2005). In Australia, data from the 'Survey of Disability, Ageing and Carers' identified that of the estimated 239, 900 Australians with intellectual disabilities almost 60% lived in the family home with the support of relatives, approximately 28% lived in their own home and just over 7% lived in establishments, such as institutions and nursing homes (Braddock, Emerson, Felce, & Stancliffe, 2001). With more people with intellectual disabilities living in very small community settings or alone, it has been hypothesised that the risk of loneliness may be greater. Stancliffe et al. (2007) suggested that less contact with other service users (or residents) and less frequent contact with support staff may further contribute to feelings of loneliness and isolation commonly experienced by people with intellectual disabilities.

The denial of romantic relationships and the paradox of sexuality.

During the interviews, Paul explained that some of his "old friends" have been unsupportive of his desire to live with a female friend. Paul has not been offered an explanation as to why his friends do not support his wishes to live with either Lynette or Josie. He explained that this has left him feeling upset and angry. Paul said that he hoped to get some answers at the Planning Day;

Paul: Sometimes I've tried to explain it to the other friends... they won't support it and that can be so, you know, frustrating and annoying because as I said before, you know, if I moved in with Lynette as a friend or Josie, I'd be OK with that and I'd be happy with that. Cos I don't want to be on my own

forever. Only as a short term thing... A lot of old... a lot of friends that know me don't support it.

Kate: So why do you... think that people are against it? Old friends... Why do you think they're against it?

Paul: OK well I think 'cos they're not sure how I'm going to, you know, I think they're not sure... I think, honestly, I've never asked. I don't really know but I'd like.... to find out so we can resolve it once and for all.

The above exchange highlights Paul's confusion and frustration and lack of personal power at being unable to express his sexuality. Paul is describing an opposition to and denial of his sexuality. Sexuality is considered central to being human.

Historically, people with intellectual disabilities were subjected to sexual segregation, sexual confinement and marital prohibition (Gomez, 2012; Siebelink et al., 2006). Legally-sanctioned sterilisation was also introduced in many countries as part of nationwide eugenic programmes to prevent the hereditary transmission of 'feeble mindedness' (Gomez, 2012; Servais, 2006; Wolfensberger, 1975). The emergence of normalisation and social role valorisation in the 1960s and 1970s, created new discourses that were much more favourable towards people with intellectual disabilities (Cocks & Allen, 1996). This ideological shift emphasised the social inclusion, independence and empowerment of people with intellectual disabilities (Scior, 2011). Person-centred planning which shifted the decision-making power from care staff to individuals with intellectual disabilities was promoted and a new rhetoric surrounding empowerment and self-advocacy emerged (Healy et al., 2009; Scior, 2011). The following excerpt illustrates this rhetoric. Here I asked Paul how his Local Area Coordinator, Sabrina, felt about his plans to live with either Lynette or Josie;

Kate: So what's Sabrina's view?

Paul: She supports what I support. She does.

The theoretical drive toward the recognition of the rights of people with intellectual disabilities and the widespread movement to normalise experiences in areas such as employment and living conditions, however, has not been extended to the areas of relationships and sexual expression (Cuskelly & Bryde, 2004; Evans, McGuire, Healy, & Carley, 2009). The promotion of sexual normalisation and sexual autonomy

for people with intellectual disabilities has not been met with the same enthusiasm and negative community attitudes and stigmatising beliefs prevail (Cuskelly & Bryde, 2004; Scior, 2011). The attitudes of parents and carers (or guardians in lieu or Church members?) may continue to directly influence the sexual expression of people with intellectual disabilities (Cuskelly & Bryde, 2004). Healy et al. (2009) argued that the attitudes of many parents and carers of people with intellectual disabilities have failed to progress with changing ideologies of sexual autonomy. Lack of opportunities to interact with the opposite sex and rules limiting physical contact have been identified as barriers to the expression of sexuality for people with intellectual disabilities (Szollos & McCabe, 1995). Further, lack of information and education about sexuality, constant supervision and a lack of privacy also present obstacles to sexual normalisation for people with intellectual disabilities (Healy et al., 2009; Szollos & McCabe, 1995).

Cuskelly and Bryde examined attitudes toward the sexuality of adults with intellectual disabilities in a sample of parents, carers and in a community sample. It was reported that attitudes toward sexual behaviour in people with moderate intellectual disabilities was generally accepted, but older respondents had less liberal attitudes. Some aspects of sexuality, particularly parenthood, were contentious and viewed less positively in the parent and carer samples (Cuskelly & Bryde, 2004). Evans et al. too reported that families of people with intellectual disabilities expressed a preference for low levels of intimacy in relationships and were very accepting of platonic friendships and non-intimate relationships. The conservative attitudes of parents and carers towards the sexuality of adults with intellectual disabilities in the studies presented above are also mirrored in the general public (Cuskelly & Bryde, 2004; Scior, 2011). A large systematic review of public awareness, attitudes and beliefs regarding people with intellectual disabilities conducted by Scior reported that while attitudes towards the sexuality of people with intellectual disabilities were generally positive, once the possibilities of pregnancy and parenthood were considered the general public were less likely to support or endorse people with intellectual disabilities engaging in sexual intercourse.

While ideologically there seems to be a recognition of the rights of people with intellectual disabilities to express aspects of their sexuality, complete sexual 'normalisation' or autonomy for people with intellectual disabilities is contentious (Evans et al., 2009; Healy et al., 2009). The sexual rights of people with intellectual disabilities are supported to *an extent*, but in reality sexual normalisation is rarely achievable (Evans et al., 2009). This reality is often masked by paying lip service to the rhetoric of equal rights and opportunities for people with intellectual disabilities (Szollos & McCabe, 1995). While I am not privy to the reasoning behind Paul's friends and guardian's at the Church objection to his request to live with a female friend, inferences can be made. Examining the subtle and often unconscious worldviews and ideologies that support or legitimise the denial of romantic relationships (as in Paul's case) can be particularly insightful.

As discussed in previous chapters, people with intellectual disabilities are often cast in the role of the eternal child, for whom adult status is never achieved. From this assumption, two conflicting stereotypes (or worldviews) arise with regards to the sexuality and sexual expression of people with intellectual disabilities. The first worldview is that people with intellectual disabilities (particularly males) are essentially children with adult sexual urges and desires that they cannot manage (Di Giulio, 2003). Oversexed and lacking control, men with intellectual disabilities are considered potentially sexually aggressive, while women are promiscuous (Szollos & McCabe, 1995). The second worldview is that people with intellectual disabilities are child-like, dependent and asexual (Di Giulio, 2003). As perpetual children, people with intellectual disabilities lack the capacity to engage in responsible sexual relationships (Szollos & McCabe, 1995). These worldviews are particularly harmful as they imply that the sexual expression of people with intellectual disabilities must be suppressed, or alternatively, that it can be ignored (Dotson et al., 2003). These worldviews and ideologies that support or legitimise the denial of sexual expression in people with intellectual disabilities will be examined in the two sections below; 'People with intellectual disabilities as hypersexual or sexual deviants' and 'People with intellectual disabilities as asexual' below.

People with intellectual disabilities as hypersexual or sexual deviants.

The identity of a 'sexual menace' or 'deviant' is commonly affixed to people with intellectual disabilities, particularly males (Wolfensberger, 2000). As perpetual children with adult sexual urges, people with intellectual disabilities are often considered to be not responsible or mature enough to engage in appropriate sexual expression (Di Giulio, 2003). Men with intellectual disabilities, in particular, may be described as hypersexual or as having an excess of sexual desire (Gomez, 2012). Driven by a disproportionate sexual urge, the sexual deviant has a particular propensity to commit various 'crimes' against others with wilful and evil intent (Wolfensberger, 1975). Such crimes may include inappropriate sexual behaviour such as excessive or public masturbation, paedophilia or sexual victimisation. According to this worldview, Paul is a potential threat or menace and it would be unsafe for him to share a house with a female. Indeed, this point begs the question; would Paul's friends support him if he wanted to live with a male friend?

Notions of sexual deviancy and inappropriate sexual behaviour are not confined to men with intellectual disabilities. Koegal and Whittemore (1983) noted that a central assumption underlying the eugenics movement was that women with intellectual disabilities were particularly promiscuous, amoral and notoriously fertile. To prevent the proliferation of feeble-mindedness, some women with intellectual disabilities were subjected to forced sterilisation (Wolfensberger, 1975). Despite the abolishment of this practice, many negative attitudes about the sexuality and sexual expression of women with intellectual disabilities continue to linger. The majority of special education teachers and administrators in a study conducted by Wolfe (1997) felt that the sterilisation of people with intellectual disabilities should be encouraged. These participants argued that sterilisation would offer protection from unnecessary and inconvenienced menstrual cycles and rape and assault. Participants also suggested that the sterilisation of people with intellectual disabilities would protect offspring from 'mental retardation' and reduce the burden placed on taxpayers who would be required to support these children. The attitudes of teachers and administrators concerning the right of people with intellectual disabilities to have children was reported to be dependent on the 'level of disability' or IQ. More recently, studies exploring the sexuality of

women with intellectual disabilities have tended to emphasise contraception and sexual health, at the exclusion of sexual pleasure (Tepper, 2000). Williams and Nind (1999) agreed that women with intellectual disabilities are commonly considered victims (or potential victims?), rather than active, autonomous sexual beings. It is possible that Paul's friends Josie and Lynette could be considered 'at risk' if they were to live with Paul.

Tepper (2000) argued that the academic literature also contributes to the public discourse that people with intellectual disabilities are hypersexual or sexual deviants, possibly fuelling those erroneous beliefs and negative attitudes about the sexuality of people with intellectual disabilities. Siebelink et al. (2006) reported that the majority of studies examining the sexuality and romantic relationships of people with intellectual disabilities emphasised the potentially negative or problematic aspects of sexual expression such as inappropriate sexual behaviour, sexual abuse and the risk of sexually transmitted diseases. Tepper too agreed that few studies present the sexuality of people with intellectual disabilities in a positive or neutral way. Sexual discourses surrounding desire and pleasure are also lacking in the literature in this area (Tepper, 2000). Further, the application of the 'inappropriate behaviour model of sexuality' by Hingsburger (1991) to people with intellectual disabilities also contributes to this worldview. In this model, the sexuality of people with intellectual disabilities is reduced to basic biological urges and sexual acts. As a 'behaviour emitting entity', emotional intimacy, affection and love are assumed to be beyond the capacity of the individual with an intellectual disability and are disregarded as reasons for wanting to engage in sexual expression (Di Giulio, 2003). Dismissing those basic human needs for affection and belongingness as irrelevant or unimportant, presents people with intellectual disabilities as less than human (Maslow, 1970). This process of dehumanisation is discussed in greater detail in the section 'Being a human being'.

When people with intellectual disabilities are considered to be oversexed and indiscriminating, sexuality is then perceived as a potential hazard (Dotson et al., 2003; Heyman, 1995). As a 'threat', efforts are then often focused on the suppression of sexuality in people with intellectual disabilities (Dotson et al., 2003). Paul wanting to live with a female friend may be assessed by his friends at the

Church as unacceptably hazardous. As a consequence, efforts are made to prevent this desire from eventuating, such as delaying the Planning Day. This is discussed further in the section 'Waiting and life wasting'.

People with intellectual disabilities as asexual.

People with intellectual disabilities are often infantilised by society and viewed as dependent and incompetent (Di Giulio, 2003). As a consequence of this worldview, they are often considered sexually immature or sexually innocent and in need of protection from sexual exploitation (Di Giulio, 2003). Alternatively, people with intellectual disabilities are commonly viewed as asexual without the need for loving and fulfilling relationships with others (Konstantareas & Lunsky, 1997; Tepper, 2000). This worldview supports or legitimises the assumption that sexuality of people with intellectual disabilities can be denied or ignored (Milligan & Neufeldt, 2001). The opposition toward Paul wanting to live with a female friend may reflect this worldview. That is, Paul does not desire close or intimate relationships. He is satisfied being alone.

Interestingly, numerous studies have reported that the attitude of people with intellectual disabilities toward sexuality is rather negative (Siebelink et al., 2006). Lunsky and Konstantareas (1998) conducted a study that examined the sexual knowledge, experiences and interests of people with intellectual disabilities (with and without autism) compared to an age-matched community sample. People with intellectual disabilities were reported to have more conservative and negative attitudes toward dating and sexual activity, particularly with regard to homosexuality, masturbation and pornography. In this same sample, participants that were more knowledgeable about terminology and sexual activities were less likely to endorse sexual activities and were more likely to internalise caregiver concerns about their about sexual vulnerability (Konstantareas & Lunsky, 1997). More recently, a study conducted by Healy et al. (2009) reported that participants with intellectual disabilities felt that family members and staff carers were reluctant to acknowledge their sexual rights. It was also reported that while participants had a sufficient sexual knowledge, most participants had conservative views about their own sexuality. In this study, participants reported a low tolerance of premarital sex and homosexual activity. Healey et al. speculated that participants in this study may

have internalised conservative views of their carers or felt pressured to report traditional views which mirrored that of their carers. Cuskelly and Bryde (2004) agreed that the caregiver concerns about vulnerability and the need to protect from exploitation continue to directly influence the sexual attitudes and behaviours of people with intellectual disabilities.

The influence of religion on the attitudes of people with intellectual disabilities and their parents or carers must too be considered (Healy et al., 2009). In particular, Catholic teachings in Australia have been particularly influential in the education system and social policies, such as same-sex marriage and abortion. In addition, many services for people with intellectual disabilities, such as group homes and larger institutions, are often operated under the auspices of religious organisations (Healy et al., 2009). It is possible that the conservative attitudes of Paul's friends and guardians-in lieu (many of whom are Church members) are related to Catholic teachings on sexuality (Evans et al., 2009). It is also possible that Paul may have internalised these same conservative beliefs regarding his sexuality. Indeed, Paul was eager to keep our interactions private and often emphasised that he wanted to live with either Lynette or Josie "as a friend" and that he would be satisfied "just being friends". The internalisation of prejudicial societal values and attitudes that devalue and disregard the sexuality of people with intellectual disabilities may cause individuals to retreat from intimacy and their sexual nature and adopt a non-sexual lifestyle, in what Milligan and Neufeldt (2001) describe as a self-fulfilling prophecy. The following exchange occurred between Paul and myself after he got off the telephone to his cousin. In this excerpt Paul explains that he did not want his cousin to know that he was meeting with me;

Paul: ... There's certain things that I just don't discuss with certain family members... Just to let you know that so that's why when I was on the phone to my cousin I said 'someone I know'. That's why I did it.

Kate: Yes, yep.

Paul: Cos I said it's been two years since I've seen them so I definitely wanted to show them that I'm managing and coping.

During their telephone conversation, Paul did not disclose to his cousin that he was meeting with me, a female friend. Instead, Paul told his cousin that he was with

'someone that he knew' so that his cousin knew that he was "*managing and coping*". It is possible that Paul considers avoiding interactions with women to be displaying 'good behaviour', suggesting that he may have internalised society's conservative beliefs about his sexuality as a person with an intellectual disability.

Behaving and slipping up.

In my interactions with Paul, he described many instances where control was exerted over him by others. When living at the group home, Paul explained that he was not allowed to make any decisions for himself;

Kate: So before when you were in the group home you weren't allowed to make decisions?

Paul: Nothing... but as I said, I'm pleased I'm doing them now.

Kate: So what kind of decisions do you get to make now?

Paul: Well I basically get to decide what I want to do on a certain day. I get to decide who I see, family or non-family. I get to decide who I get to ring, family or non-family or people I know from Church or whatever. I get to ring whoever... I know from the Advocacy Agency... They all mean a lot to me and they brighten my day and if they ring they always, you know, they always make my day worth enjoying.

Kate: Sounds like you've got a lot more freedom now.

Paul: Well that's right and that's something I really value and treasure.

Paul is now able to decide what he does during the day and who he sees; something that was once determined by the staff at the group home. He values the freedom that he has now living in the community, comparative to the restrictive group home. Despite quite dramatic increases in Paul's autonomy and self-determination since leaving the group home, a great deal of control is still exercised over him by paid disability support workers. Paul explained the arrangement he has with the staff at the group home where his friend still resides;

One of my friends is in a group home but the good news is that me and those staff members... we have an agreement. As long as I work with them, they allow me to catch up with that friend and she's allowed to visit me. That's a pretty good deal to me.

So long as Paul, a 40 year old man, follows the rules and conditions as specified by the staff at the group home, he is allowed to see his friend. There are also expectations for Paul's behaviour and if these expectations are met, he is rewarded. Paul is careful not to "*slip up*" (in the eyes of his paid support worker) and remain on the "*right track*". In the following excerpt, Paul explained that he accompanies his support worker, Vicky, into town as "*a reward*" for his good behaviour;

Her and I often go into town and get things done and... we often make it into a bit of social (thing) and it's all a reward for all the hard work I'm doing. Sure I do have the occasional, you know, slip up but it recent times I've actually handled them a lot better. So I'm pretty pleased I'm on the right track.

Interestingly, Paul is not outraged by the level of control exerted over him by relative strangers. He is not discontented by his own lack of power or resentful of being treated like a child. In fact, Paul seems to accept his reality. Paul even expressed that he is satisfied with the visiting arrangement he has at the group home, considering it to be a "*pretty good deal*". As previously discussed in this thesis, people with intellectual disabilities are often cast in the role of the perpetual child. As the 'eternal child', people with intellectual disabilities experience a loss of control over their life and the acquisition of power and decision making by others who 'know better', such as paid support staff (Wolfensberger, 2000). At the group home, where Paul spent more than 30 years of his life, he was unable to make the most basic decisions such as what he would do on a given day. Although Paul did not elaborate on his time at the group home, he did describe the environment as "*shocking*" and touted leaving the restrictive group home as the "*best decision*" he ever made. With 24 hour staffing, group homes may be characterised by lack of opportunity to express choice, regimentation of daily activities and limited personal privacy (Di Giulio, 2003; Stancliffe & Parmenter, 1999). Although Paul is no longer living in the group home, his dependency on formal services continues to reinforce his disabled position in society. He remains in a vulnerable position with little control and autonomy and obedience and 'good behaviour' are expected.

Based on these experiences, it is probable that Paul has internalised the stigma associated with the label of intellectual disability and has, over time, grown

to endorse society's stereotypes and negative attitudes about his abilities (Ali, Hassiotis, Strydom, & King, 2012; Bos, Pryor, Reeder, & Stutterheim, 2013). Self-stigma is the internalisation or concurrence of those negative societal beliefs and values associated with a stigmatised condition, such as intellectual disability (Bos et al., 2013; Corrigan, Watson, & Barr, 2006). Self-stigma is related to diminished self-esteem, negative self-evaluations and psychiatric symptoms in people with intellectual disabilities (Ali et al., 2012; Corrigan et al., 2006).

Getting his reward.

In most of my interactions with Paul there was a rhetoric surrounding 'being rewarded for his hard work'. Paul explained that he volunteers as a board member on a Disability Council and attends Church because he believes that if he continues to do "good", he will eventually be rewarded and permitted to live with a friend;

As I said, this is only short term not, you know, permanent and that's the way I've always approached living on my own. Cos I want to know that if... I keep doing good like I'm doing with the Council and Church... I just want to know that there's a reward at the end of it... In the meantime, I definitely (want to) keep going good on the Council so those things eventuate... cos as I said, I feel I've come so far. I'm definitely planning to keep on going and that's important.

The above excerpt illustrates Paul's naive optimism that he will eventually have opportunity to live with a friend; something that most people would take for granted. 'Doing good' with the expectation that good will come to him, enables Paul to make meaning of his situation. The 'law of Karma', states that an individual's life condition (current economic, social and physical circumstances, for example) is the summation of all past actions and the improvement of any set of given life conditions occurs when an individual performs actions in life without egoism (Karnik & Suri, 1995). That is, the hope of a better future is based on the individual's right actions or duty. Paul may consider his voluntary work as a board member on a Disability Council and his involvement in the Church as a means of generating 'good karma'. His good deeds will contribute to his future happiness. Alternatively, Paul's optimism that he will eventually get his reward of living with a friend may reflect the belief in a 'Just World' (Lerner, 1980). As previously discussed in this thesis, the

'Just World' hypothesis stipulates that people generally get what they deserve. This belief may allow Paul to make meaning of his current situation or injustice. Paul is a 'good person', therefore, good things will happen for him. He is able to commit himself to this long term goal of living with a female friend because he believes that it will ultimately eventuate for him (Lerner & Miller, 1978). Paul waiting patiently for this opportunity is discussed in the following section.

Waiting and life wasting.

In my all of my interactions with Paul he spoke enthusiastically about his Planning Day that was being organised by his Disability Services Local Area Coordinator. The Planning Day was presented to Paul as an opportunity for him to raise any concerns or issues he had to his parents and the people who supported him (both paid and unpaid). The Planning Day was also an opportunity for Paul to present his goals and plans for the future (to live with a female friend) and create an action plan so he could achieve this goal. The Planning Day was initially scheduled for January, but this was cancelled. Two separate Planning Day meetings were scheduled for April, but unfortunately these meetings were also cancelled because Paul's father had to undergo a major operation. Paul explained;

Sabrina (the Local Area Coordinator) and I thought it would be best, just leave it until August just til, you know, for Dad cos at the moment Dad can't drive long distances... That's why Sabrina and I decided just to, you know, put it off... give Dad a chance to recover... I think with Dad recovering in hospital it wouldn't be a good time to, sort of, bring it up so we're going to let him recover first cos we... Sabrina and I feel it's a sensible way to do it because after an operation I don't want dump on something on him really all at once.

The Planning Day was rescheduled for August so that Paul's parents could travel from the country to attend the meeting. It has been over two years since Paul first mentioned the Planning Day to me and it has still not come to fruition. Paul still remains hopeful that the elusive Planning Day will eventuate; *"I've got some good visions for the future and so far we're on track so I'm hoping the plan will be pulled off in not too long. But they're good positive ones. They are"* .

Across most of my interactions with Paul there was a common rhetoric about waiting. Paul intended to live by himself only in the "short term" only.

Despite the continual postponement of his Planning Day, Paul was convinced that he would have the opportunity to live with a friend “soon”, “one day” or “in the future”. Waiting for opportunities is presented as a negative life experience or ‘wound’ in Wolfensberger’s theory of social role valorisation. The wound of ‘life wasting’ is commonly experienced by people who are systematically rejected devalued, such as people with intellectual disabilities (Wolfensberger, 2000). Annison (1996) proposed that life wasting is the effect of indifference toward people with intellectual disabilities. This indifference is underpinned by the assumption or worldview that people with intellectual disabilities are innately incompetent and unable to develop or self-actualise (Booth & Booth, 1998; Jenkins, 1998; Maslow, 1970). As a result, low (or negative) expectations are held for the person and opportunities for personal development are absent or limited (Annison, 1996). When disability service providers (and family members or guardians in lieu) have no sense of urgency to do for or with their clients, weeks, months and even entire lifetimes can pass, while people with intellectual disabilities wait for opportunities, challenges, experiences, emotional comforts and support services (Annison, 1996; Wolfensberger, 2000).

The wound of life wasting is often associated with the wound of ‘discontinuity’ (Wolfensberger, 1998). Many people (often paid) enter and leave the lives of people with intellectual disabilities. This cycle of social and relationship discontinuity can be likened to a revolving door, where people come and go. Often implicit or explicit promises are made to help or improve the life situation of clients with intellectual disabilities (Wolfensberger, 1998). When these people then leave the lives of their clients, promises are broken adding betrayal to the wound of discontinuity.

This process of wounding is mirrored in the case of Paul. Paul has been waiting for years for his Planning Day; the opportunity to express his hopes for the future to his family members, friends and those paid to provide him with a service. Without the Planning Day, clear and achievable steps or tasks cannot be set to move Paul closer towards this goal. He is left waiting for the opportunity. A lifelong career may be created which essentially wastes the potential of the person and negates any chance of personal development or self-actualisation. Here lies a

paradox. The very services intended to enhance Paul's independence and autonomy within the community in effect reduce his personal control and enhance his dependence. This tension is returned to later in this chapter.

Being a human being.

In my interactions with Paul he often spoke of his vision for his future. Paul explained that he would like to come home to someone at the end of the day. This is a very simple request. In the following excerpt, Paul reiterated that he planned to continue to make the "right decisions" so that he could move closer toward achieving his vision. He also explained that he looked forward to having the opportunity to share his goal for the future at the Planning Day;

In the future it would be nice to come home to either Lynette at night or Josie at night after, you know, being out all day. It would be lovely and it would be nice... to be able to get this out in the open and be able to know that one of those things is going to happen.... I feel it will help me appreciate that goal even more. And it'll help me in my day to day things to, you know, make the right decisions towards that goal. Yes, so I'm pleased that meetings going to come out because I'm so happy I'm going to finally get to say it.

Paul also spoke passionately about his rights as a citizen of Australia. He argued that he, as an Australian Citizen, should be entitled to live how he chooses. Paul explained that sharing a home with his friends Lynette or Josie is his fundamental right and he is allowed to express his wishes, even if others disagree.

I want an Australia where... everyone's entitled to live the way they like (and) still respect the country at the same time. That's how I'd like it to be. I basically feel, you know, about this vision... I'm not going to pretend anymore. There's no point trying to hide it. I think people need to hear it, and they may not like it, but it has to be said. I think sometimes you've got to do what you've got to do... So that's what I'd like my future to be... I feel that as an Australian citizen, I have as much of a right as any Australian citizen.

Here, Paul is clearly advocating for his own interest and defending what he considers to be an impingement on his rights as an Australian citizen. By stating that he has "as much right as any Australian citizen", Paul is asserting that he is entitled to the same liberties and freedoms as people without intellectual disabilities.

I would argue that the right to companionship is not associated with being a citizen of Australia, but is central to being a human being. In Maslow's Hierarchy of Human Needs, the need for love, affection and belongingness are identified as *basic human needs*. The 'love and affection needs' are characterised by feeling needed, important and valued and relatedness and reciprocity, the giving and receiving of feelings, beliefs and love (Mahar et al., 2013; Maslow, 1970). Currently, Paul's need for love and affection is being met with both ambivalence (by staff paid to support him) and opposition (by Church members who act as his guardian). It seems that Paul is not deemed worthy of the gratification of this human need. The attributes that make him human are being denied. This loss of humanity is dehumanisation (Vail, 1966).

To understand the concept dehumanisation first requires an understanding of humanness (Haslam, 2006). That is, what does it mean to be properly human? What separates us from other animals? Fletcher (1988) posed the following questions: "What if an ape had the intelligence and sensibilities of a human, and a human had only the capabilities of an ape? Which would be the human being? The answer is plain; the ape would be the human being" (p. 171). Across theories of humanness, higher cognition is consistently described as an integral and defining aspect of being a human (Bogdan & Taylor, 1989; Jenkins, 1998). Without a minimal level of cerebral function or intellectual capacity, it has been argued that humanness cannot be fully achieved (Fletcher, 1974). More recently, Haslam proposed characteristics that define the boundary that separates human beings from other animals, known as 'uniquely human' characteristics. These include; civility, refinement, moral sensibility, higher cognition (rationality and logic) and maturity.

The centrality of 'intelligence' to definitions of humanness often places people with intellectual disabilities, like Paul on or beyond the border that separates human beings from animals (O'Brien, 2003). According to Haslam (2006), when uniquely human characteristics are denied, the individual or collective group is perceived as uncultured, coarse, lacking in self-restraint, unintelligent and child-like. Words including 'immature' and 'immoral' are often used to describe people who are denied uniquely human characteristics, such as Paul and the other Members

in this study. Further, rationales of consent, choice, independence and autonomy are also underpinned by this accepted view of humanness and intelligence, therefore, control and power can be rightly exercised over people with intellectual disabilities (Goodley, 2001).

Once society accepts that people with intellectual disabilities can be rightly viewed as sub-human or animal entities, the obligation to treat people with the label humanely is moderated or eliminated. Paul's life does not have the same value as someone without an intellectual disability, so it can be wasted.

Conclusion

In this chapter I presented the life story of Paul, a 40 year old man with an intellectual disability, who experienced loneliness and yearned to live with a female friend. The process of dehumanisation, as explored in chapter four and five, is evident within his lifestory. Dominant cultural worldviews serve to construct Paul as deviant, incompetent and not like us. When someone is considered to be inherently different and less than human (as Paul is), the obligation to treat them as human is reduced.

The paradox of support also emerges when Paul's experiences are deconstructed. The formal services designed to support Paul to be independent and autonomous within the community, ironically increase the control and power over him. I would argue that disability services in general tend to operate on the assumption that to enhance a person's independence, their responsibility and control must be taken away until they are 'ready for it'. As illuminated in theme 'Waiting and life wasting' above, rarely are people with intellectual disabilities perceived to be ready or qualified to make their own decisions and have control over their lives. The ability to have control over one's life is fundamental to being a human being (Rappaport, 1977). It has been demonstrated that creating new settings where people marginalised by society can make their own decisions and have personal autonomy can produce enormous impacts on their wellbeing (e.g., Fairweather, Sanders, Maynard, Cressler, & Bleck, 1969). It is clear that a change in thought is needed. This is explored in greater detail in chapter eight.

Chapter 7: Reflections

“Those who create new settings always want to do something new, usually unaware that they are armed with, and will subsequently be disarmed by, categories of thought which help produce the conditions the new setting hopes to remedy” (Sarason, 1974, p. xii).

“Let us give objectivity and other social scientific delusions back to researchers who believe they have no opinions. And let us interject honestly our lives, fears, and passions into our research” (Fine, 1986, p. 118)

Reflexive practice and Disability Research

Reflexivity is the process of critically reflecting on the kind of knowledge produced and how that knowledge is generated (Guillemin & Gillam, 2004). Researchers bring with them their own orientations and values, shaped by a range of social and historical factors, that inevitably enter into and shape their work (Northway, 2000). The values and interests of the researcher influence what they choose to investigate, the research questions posed, the epistemological underpinnings of the research, the research design and methodology, the analysis of the data, the interpretation of their findings and who those findings are available to (Guillemin & Gillam, 2004; Northway, 2000). Research is contextually contingent. Rather than attempting to conceal those values that govern research or maintain a detached, objective role, the reflexive researcher acknowledges that objectivity is impossible (Henwood & Pidgeon, 1992). Instead, subjectivity is considered a strength or resource of the research that should be acknowledged and revealed (Goodley, 1999; Henwood & Pidgeon, 1992; Schön, 1983). Reflexivity is an active, ongoing process that saturates every stage of the research (Guillemin & Gillam, 2004). The process of scrutinising one’s own values, motivations, actions and characteristics in the research process is personally revealing and at times leads to uncomfortable conclusions (Oliver, 1997). However uncomfortable, recognising the limitations of the knowledge produced ultimately enhances the overall quality of the research (Guillemin & Gillam, 2004).

Vernon (1997) argued that reflexive practice is especially critical for researchers exploring the experience of oppression. Furthermore, disability researchers who engage in participatory research have a unique role in the research process that necessitates reflexivity. Disability researchers must be self-critical of their own values, assumptions and practices to ensure that they do not collude with the established hegemony (Northway, 1998; Vernon, 1997). A high level of self-awareness and critical reflection is required to ensure that the existing power relations in traditional disability research (and wider society) are not replicated or reinforced during the research process. Without critical self-reflection disability researchers can (often unknowingly) become accomplices or accessories to the oppression of people with intellectual disabilities (Oliver, 1997). Honest accounts of practice enable the issues and dilemmas to be considered and thereby contribute to theory (Williams, Simons, & Swindon People First Research Team, 2005). Furthermore, reflecting on the process of doing participatory research with people with intellectual disabilities can assist future researchers to create research projects that are both methodologically rigorous and ethically sound and do not perpetuate the shortcomings of traditional disability research, as discussed in chapter three (Walmsley, 2004).

Although there is an extensive body of participatory research projects with people with intellectual disabilities, developed over a period of 35 years or so, there are few published papers that offer reflections of the process of doing such research (Northway, 1998; Walmsley & Johnson, 2003). Bigby and Frawley (2010) agreed that seldom do research projects that claim to be participatory or inclusive offer detailed descriptions of the role of people with intellectual disabilities in the research process (Bigby & Frawley, 2010). The role of the participatory researcher is also rarely canvassed (Walmsley & Johnson, 2003). Remarkably little has been written about the contribution of the researcher in supporting people with intellectual disabilities in participatory research projects (Walmsley, 2004). The factors that influence the construction of knowledge such as the researcher's experiences, assumptions, values and biases are also rarely explored (Ward & Flynn, 1994). Failure to critically reflect on the research process and the role of the researcher not only raises questions of the genuineness and inclusivity of

participatory research projects, but also the role of the research in the maintenance and perpetuation of the oppression of people with intellectual disabilities (Bigby & Frawley, 2010; Vernon, 1997).

In this chapter, I hope to contribute to this area of research by reflecting on my own experiences of engaging in participatory research with people with intellectual disabilities. To foster my own self-awareness throughout the This Is Me project I maintained a reflexive journal. A reflexive journal is a personal diary that provides an account or 'paper trail' of the researchers interests, values, assumptions and logs any methodological decisions and their accompanying rationales (Henwood & Pidgeon, 1992). From the conceptualisation of the research project through to the final write-up of the thesis, I documented my thoughts, concerns and insights, emotional responses and actions. Walmsley (2004) cautioned that this process involves reflecting on the research and acknowledging what actually happened, not what we as an academic researcher, wished had happened. Unfortunately, as is evident from my own reflections of engaging in participatory research with people with intellectual disabilities, "intent is no guarantee of outcome" (Barton, 1996, p. 6). Based on my own observations, this chapter is divided into the following sections; 'The role of the academic researcher (with the subsections 'Participatory research: An impossible dream?', 'Sharing control and tolerating uncertainty' and 'The issue of informed consent'), 'Who Gains?' (with the subsections 'Reciprocity and challenging traditional research relationships and 'Empowerment?'), and 'Knowledge as a Co-Construction' (with the subsection 'Identities discursively produced and feelings of guilt').

The Role of the Academic Researcher

Academic researchers have a crucial role in supporting people with intellectual disabilities to be involved in research (Walmsley, 2004). Despite this, researchers rarely specify their involvement or clarify their role and often dismiss or discount the skills and experience they bring to the research project (Walmsley, 2004). Walmsley argued that this is often done with the best of intentions, suggesting that participatory researchers in the field of disability are driven by the desire to erase difference. That is, researchers with intellectual disabilities are exactly the same as researchers without intellectual disabilities. Diminishing their

role in the research process also elevates and enhances the role of the co-researchers with intellectual disability (as per the principles of social role valorisation; Walmsley, 2004). However, to enhance the quality and rigor of participatory research with people with intellectual disabilities, scholars have urged researchers to be unapologetic for their expertise and instead be more transparent and recognise and describe their role and contribution in the research process honestly. In the section 'Participatory research: An impossible dream?' below, I will identify and make explicit my involvement in the This Is Me project from the conceptualisation of the research to its completion. I will also examine some of the tensions related to control and power that arose during the research process. Oftentimes, these tensions were further compounded by the official requirements of a PhD. In the section 'Sharing control and tolerating uncertainty', I will explore the difficulties I experienced divesting control throughout the research process and managing the feelings of uncertainty and insecurity associated with this.

Participatory research: An impossible dream?

I had hoped that the research project would be truly participatory; led by people with intellectual disabilities with the sharing of power and control throughout the whole process. Unfortunately, the reality of the research project fell short of my initial expectations. To ensure that the research met the requirements of a PhD candidacy research proposal, I was required to propose a specific research aim with corresponding research questions. I had to include a comprehensive literature review which included a strong rationale for conducting the research. The methodology and methods, and probably most challenging, a clear budget and timeline were required. The structured and predetermined nature of the project was completely at odds with the guiding principles of participatory research with people with intellectual disabilities (Turnbull et al., 1998). Participatory research requires collaboration; here I was the one calling the shots, not the Members. The constraints of the academic system in which I was indoctrinated, meant that that the aims of the research had to be recalibrated. Rather than recreating participatory research in its ideal or purest form, my focus throughout the research process then became one of creating opportunities for the Members to make decisions and exert control wherever possible. For example, before drafting the research proposal I had

begun a dialogue with the Advocacy Agency to ascertain their interest in being involved in research. During these informal conversations, possible research topics and potential methodologies were discussed.

Once the research had been formally approved by the University, I contacted the Advocacy Agency to arrange to meet with the Members. At this meeting I proposed a research topic to the Members and presented them with some methodological options (including the possibility of individual interviews, focus groups or Photovoice) for exploring their 'identities and social roles'. My thoughts and feelings following this initial meeting with the Members is presented in the section 'Sharing control and tolerating uncertainty' below. All of the Members expressed interest in using photography to capture their experiences. The process of establishing consent with the Members is described in the section 'The issue of informed consent' below.

Once 'consent' was established, I provided the digital cameras to the Members for the project and once the Members had finished collecting the data, I arranged times to meet with each Member to discuss the photographs with them. Throughout the project, I had to make sure that progress was being made according to the proposed timeline. At the same time, establishing close and trusting relationships with each of the Members and working at a pace suitable for them was really crucial. The time frame of participatory research projects is at the least medium-term and usually long-term (Cocks & Cockram, 1995). With this, I constantly felt as though I was juggling two demands; ensuring the Members were in control as much as possible and meeting the obligations of a PhD. that needed to be completed within a specified timeframe

Once all the data (photographs and interviews) had been collected, I transcribed each interview and began the process of analysis. The Members were not involved in the analysis of the data and had no role in the writing of this thesis (the issues associated with representing the views of others are discussed in the section 'Knowledge as a Co-Construction' below). At the same time, I had to acknowledge that I did have certain skills and expertise that lent itself to research. I was experienced at writing literature reviews, analysing qualitative data and publishing research reports. I also really enjoyed the process of 'doing research'. It

would be self-effacing (and dishonest) to deny my contribution to this particular part of the research project.

Bigby and Frawley (2010) reflected on their experiences supporting a co-researcher with an intellectual disability in a research project that explored community living following the closure of a large institution for people with intellectual disabilities. Supported by a 'research mentor', the co-researcher was to examine the concept of 'homeliness'. The co-researcher with an intellectual disability was initially treated the same as a "new, relatively inexperienced research assistant" (p. 56) and attempts were made to orient him to the project and educate him in matters of research methodology. Throughout this process, the co-researcher commented that he was having difficulties sustaining interest and was struggling with understanding the complexities of the research. Bigby and Frawley conceded that they were so fixated on the prerequisites of 'being a researcher' and expecting the co-researcher to 'pass' (Goffman, 1963) as a researcher, that they completely disempowered and alienated him. Bigby and Frawley concluded that it is important to recognise the strengths of co-researchers with intellectual disabilities as 'experts by experience' (Grant & Ramcharan, 2007). Commonly, participatory researchers attempt to 'mould' their co-researchers with intellectual disabilities into the ideal of an 'establishment researcher' to legitimise or justify their involvement in the research project (Bigby & Frawley, 2010; Williams, 1999).

In this research, the Members were authorities on their own lived experiences. They were experts on their own lives, experiences, feelings and views. They were interested and motivated to be involved in the This Is Me project and they had a wide range of skills that were invaluable to the project. The Members involvement on the research process, however, fluctuated and did not always represent the ideal of participatory research. I would argue that there is not a dichotomy between traditional disability research and the ideal (or dream) of participatory research. Instead, a continuum exists with varying degrees of meaningful participation in and control of the research process and outcomes by people with intellectual disabilities (Finn, 1994). Participatory research is an evolving process, rather than a clear cut, measurable objective. The aim of this research project became increasing the control, power and meaningful participation

of the Members wherever possible rather than reproducing ideal participatory research. Creating opportunities where the Members could move up Arnstein's (1969) Ladder of Citizen Participation to a place where they felt comfortable was key.

For the final phase of the research project ('Acting on the Research') the Members decided that they would like to display the photographs they had taken in a public photograph exhibition. The Members were really enthusiastic to have this exhibition and wanted it to be done immediately. I was hoping to delay the exhibition for a few months as my schedule at University was particularly demanding at that time. However, in the interests of participatory research, the wishes of the Members superseded my own and together, we began the process of organising the public photograph exhibition. I booked the space in the shopping centre, organised partitioning, printed the photographs selected by the Members and made flyers and signage. The Members distributed flyers through their networks and invited members of the community. An excerpt from my reflexive journal highlights just how busy (and stressful) this stage of the research project was for me;

Today I've been crazy busy sending emails regarding the display. I have emailed the local newspaper, the Executive Assistant to the CEO of the Town (asking her to invite the CEO or a Community Development Officer to open the display) and the University PR department (I sent her quotes from the Members to include in the media release). I am starting to feel quite overwhelmed with the amount of work that is required for this display! It is so much. To be honest, I will be pleased when it is all over!

As is evident from the above excerpt, my involvement in the 'Acting on the Research' stage of the This Is Me project was particularly demanding. Reflecting on the research process as a whole, however, my contribution and level of involvement fluctuated and evolved. My feelings of control and certainty also waxed and waned throughout the process. This is discussed below.

Sharing control and tolerating uncertainty.

In order to move this research along the continuum toward 'participatory research', wherever possible I tried to divest myself of power so that the Members

could take control of the research process (see the above section 'Empowerment?' for a more detailed discussion). The sharing control and power in the research process and recognising and tolerating uncertainty was one of the most challenging aspects of this research. Having been socialised to a positivist worldview and quantitative methodologies, in which predetermined, tightly controlled methods are valued, this was really difficult. These excerpts from my reflexive journal following the first meeting with the Members highlight this struggle;

This was not what I was expecting. In my mind I imagined everyone sitting around quietly, exchanging ideas and asking questions. It did not happen like that at all, it was complete chaos. I was trying to talk to the group about how to use the cameras and I had one Member tugging on my shirt and dismantling my pens. I feel as though the project is completely derailed. I think my expectations were unrealistic. I was being naïve to think that this project would be easy.

And another;

I am finding the lack of control really difficult. I am worried about not having an interview schedule planned. Will the digital cameras be returned? Will the Members want to talk to me? Will the photos work as a stimulus for conversation? Will I have enough information?

As the above excerpt illustrates, I experienced considerable anxiety and feelings of uncertainty. This sense of losing professional power and control was really challenging, but very necessary. For people with intellectual disabilities to regain their own power in the research process, the researcher must be prepared to divest some of their power. Participatory researchers in the field of disability must be able to recognise the shift in power and control that occurs as the research evolves and be able to cope with the redefinition of their role. This allows the researcher to be part of the empowering process.

The issue of informed consent.

Establishing informed consent was also another challenge that emerged throughout the research process. After the Members indicated that they were interested in being involved in the research at the initial meeting they were provided with an information sheet and consent form, as per the University

requirements. As described in chapter three, the information sheet and consent forms I created for the project utilised simple language, bullet points, pictures and the repetition of information. I read through the documents aloud and asked the Members if they needed anything clarified or had any questions. At this time I emphasised that participation was completely voluntary. The Members interested in being involved in the research project were then provided with an information sheet and consent form to sign. This process was particularly alarming for me and after the meeting I reflected;

When completing the consent forms, some of the Members did not know how to write their name or write numbers for the date. Members could not recall their own phone number in a lot of cases. I am also not sure that the Members knew what they were agreeing to. It was a very crude and abrupt process. There was no time or space to go over the consent procedure again. The Members just signed because they were told to. Informed consent is a real concern of mine. I do not feel that the Members have given informed consent.

It quickly became obvious to me that the static, one-shot approach to free and informed consent (although modified to meet the needs of people with intellectual disabilities) was not appropriate. Although this method to obtain consent was approved by the University research ethics committee; it was clearly insufficient. This was an issue that was not anticipated. 'Ethics in practice' (Guillemin & Gillam, 2004), instead was required. In light of these limitations, process consent whereby establishing informed consent was an ongoing process throughout the duration of the research project, was adopted (Munhall, 1988). Process consent is described further in the 'Ethical Considerations' section in chapter three.

Who Gains?

Individuals with disabilities rarely experience the benefits of research such as improved outcomes or more equitable access services and resources (Petersen, 2011). Furthermore, the actual research process has been criticised for contributing to the oppression experienced by people with intellectual disabilities (Dowse, 2009; Vernon, 1997). Initially guided by the principles of the social model of disability

(Oliver, 1992), I entered into this project with the desire to redress some of what I perceived to be the wrongs of traditional disability research (see chapter three for a more detailed discussion). I hoped that this research would be beneficial and helpful to Members engaged in the This Is Me project. But did the Members actually benefit by being involved in the This Is Me project? The question of who stands to gain from the research is indeed an important one. Upon much reflection I have concluded that I am undoubtedly the main beneficiary of this research. I have obtained data to complete my PhD. I am the first author of a publication utilising this data and will likely publish further. I have had the opportunity to present this research at two international conferences. Throughout the research project I also feel that I have learnt a great deal and gained a better understanding of myself. On the other hand, whether the Members who were involved in the research benefitted is much more difficult to determine. Knowing that I was going to be the main beneficiary of this research, I was particularly concerned by the need to avoid exploitation, make the research more equitable and enhance the opportunity for positive outcomes for the Members involved. How I attempted to do this is explored further in the following sections; 'Reciprocity and Challenging Traditional Research Relationships' and 'Empowerment?'

Reciprocity and challenging traditional research relationships.

Participatory approaches to research with people with intellectual disabilities are characterised by greater meaningful participation and influence (control) by people with intellectual disabilities in research than has traditionally typified the research process (Turnbull et al., 1998). People with an intellectual disability are involved as more than research subjects or respondents; they are research partners or co-researchers actively engaged in some or all of the research process (Knox et al., 2000; Stalker, 1998; Walmsley, 2001). People with an intellectual disability have the opportunity to exert control and make decisions in the research process (Knox et al., 2000; Walmsley & Johnson, 2003). Guided by these principles, I attempted to forge a relationship with each Member based on respect and reciprocity. According to Ribbens (1989), reciprocity in research can be described as a researcher's willingness to introduce some vulnerability through self-exposure and the mutual exchange of personal information. This involves being

prepared to respond to direct questions asked by the interviewee, voluntarily revealing information about ourselves without being asked, and a willingness to really listen (Ribbens, 1989; Vernon, 1997). Conversational interviewing (Burgess-Limerick & Burgess-Limerick, 1998) really facilitated this process.

As discussed in chapter three, conversational interviewing is a recursive process whereby the agenda for the interview is established interactively by both the researcher and the participant (Burgess-Limerick & Burgess-Limerick, 1998). I did not enter the Member interviews with a predetermined interview schedule. The questions I asked the Members built on their responses to previous questions and in previous interviews as well as the stories told by other Members that I had interviewed. The interviews were informal, flexible and akin to a conversation. I made myself vulnerable by sharing personal information and stories with the Members. The Members often enquired about my family and asked about how my studies were going. Being vulnerable through self-exposure (in the same way I was asking the Members to be) created a space where the Members felt comfortable to speak openly and freely with me. For some, the interview process was cathartic; an opportunity to speak honestly about their feelings, thoughts and concerns. Rapport was easily established with each of the Members I interviewed and long-term friendships have developed with some of the Members involved in the study.

Ribbens (1989) and Vernon (1997) also describe reciprocity in research as a willingness to help or assist participants in ways that are not directly tied to the research. In this research, I was able to help the Members by buying items in the city that were unavailable in the country town where they lived on their behalf, creating personal DVDs of their photographs to music, driving them to work or to the shops and being available for a chat. This conveyed a sense of value for the person and partially addressed the power imbalance that typically arises between researcher and participant in research with people with intellectual disabilities.

In the This Is Me project I considered the Members to be partners and collaborators in the research. Our roles changed and evolved throughout the research process. In the beginning, I was involved in the preparation and planning of the research project. I formulated the research aim and research questions and selected different methods that would be appropriate to explore the research

question. In the data collection phase of the project, my role as a 'researcher' experienced a significant shift. During this phase, the Members assumed control and executed all of the data collection. They took photographs, videos, wrote letters and told stories of their experiences. The Members were valued co-researchers and experts in their own experiences. In the final phase of the project, the holding of a public photograph exhibition, the relationship between the Members and myself was collaborative. Members took control and initiated the public photograph exhibition, and I facilitated and organised the event. I began to feel that I was no longer the 'expert', but rather an observer and facilitator. Reiff (1968) described this role as being a 'participant-conceptualiser'. As a participant-conceptualiser, the researcher is actively involved in the processes, while also attempting to conceptualise or understand them (Elias, 1994). Reiff argued that only by participation and involvement can theory and intervention be enriched.

Empowerment?

When I drafted the proposal for this research project in my naivety, one of the key objectives was to '*empower people with intellectual disabilities by being active participants in research*'. The concept of empowerment in research, particularly disability research, is contentious and not universally accepted (e.g., Stalker, 1998; Zarb, 1992). Oliver (1992) argued that empowerment is not a gift to be bestowed by the privileged to those deemed less fortunate. Attempting to empower the Members is akin those strategies that emerge from the victim-blaming ideology discussed in chapters four, five and six. Inherent to the concept of empowerment in disability research is the assumption of deficit; the Members *needed* to be empowered by me.

Rather than aiming to empower the Members, I instead attempted to embrace the presumption of competence and ability (Fairweather et al., 1969). This approach involved recognising the strengths and competencies that each Member possessed and supporting them in their desire to be empowered (Petersen, 2011). From the outset, I was mindful to acknowledge the voices, needs, and wants of the Members. Read and Wallcraft (1992) offered a definition of empowerment which I found particularly useful to refer to throughout the research process; "No one can give power to another person, but they can stop taking their power away. They can

also help people to regain their own power. This is what we mean by empowerment” (p. 5). Petersen (2011) suggested that to promote and facilitate this process, participants must be offered opportunities to exert control, make decisions and share power. Learning and practicing skills, working with others toward a common goal and developing leadership skills is also essentially empowering (Zimmerman, 1995).

With this in mind, respecting the abilities of the Members and enhancing opportunities for personal development and growth (and possibly empowerment) became crucial (Fairweather, 1967). When reflecting on the This Is Me research project, the Members exerted control over the photography process, taking as many photographs of whatever they deemed important over an unrestricted period of time. Some Members used the black-and-white function, while others took short videos. Members also exerted control during the Photovoice interviews, with some choosing to control the laptop and scroll through the photographs. The public photograph exhibition was also driven by the Members. Control and ownership of the photographs and the narratives they elicit fostered a sense of pride amongst the Members, as Jimmy (aged 45) explained:

Basically, what the thing was all about was people getting to know what we can do ...and all I can say is well done guys cos you have got some really good skills there with the camera and I'm really proud of ya's.

Over the duration of the project, Members also developed new skills and increased confidence. One of the Members, Jimmy, explained:

I reckon it was really good cos some of the shots I done on the camera, I didn't think I can do and it's really good ... Some of the shots that I did was just unbelievable... cos with the camera, I figured it out how to do the video on it. Yeah, so I figured it all out how to do the video.

Some Members also took on a mentoring role, teaching and supporting other Members to use the digital cameras.

In summary, it is difficult to determine whether the Members were empowered by being involved in this research project. In my role as the academic researcher, I attempted to challenge the traditional research 'setting' (Sarason, 1974) as much as possible. The skills and abilities of the Members were emphasised

and I attempted to provide the Members with many opportunities to exert power and control in the research process. It is, however, difficult to say definitively whether the Members were empowered through their involvement in the This Is Me project.

Knowledge as a Co-Construction

Research is socially co-constructed (Rioux, 1997). Soviet philosopher and linguist Bakhtin (1981) noted that all human beings are connected and socially interdependent and conversations (or research interviews) are context-specific, multi-sided events. According to Bakhtin, “Language is not neutral medium that passes freely and easily into the private property of the speakers intentions; it is populated – overpopulated with the intentions of others” (1981, p. 294). The values and assumptions of the researcher undoubtedly influence the construction of data and the knowledge produced (Dowse, 2009). In the below section, ‘Identities Discursively Produced and Feelings of Guilt’, I will critically reflect on a selection of excerpts from my interviews with the Members, highlighting my role in discursively producing the identities of the Members.

Identities discursively produced and feelings of guilt.

In this section it is not my intention to conduct a thorough conversation analysis on all of the interview transcripts of my interactions with the Members, complete with transcription notation. Rather, I wish to critically reflect on a few example interview excerpts of my interactions with the Members. When analysing the Member interview transcripts, some of the interactions made me feel uneasy. I decided to create a node in QSR NVivo entitled ‘Uncomfortable’ where I placed interview transcript excerpts that made me cringe with embarrassment. The following is a brief examination of these uncomfortable moments. Through this process (however shameful it may be) I am able to examine how I, as a researcher, both produce and maintain the same restricted identities imposed on people with intellectual disabilities discussed in previous chapters. The identities of people with intellectual disabilities discursively produced in interactions and the Member interviews included people with intellectual disabilities as incompetent, people with

intellectual disabilities as vulnerable and child-like, and people with intellectual disabilities as happy and the Down syndrome stereotype.

People with intellectual disabilities as incompetent.

The label of 'intellectually disabled' is often conceptualised as a master status that is so pervasive that it overrides all other identities or social roles that the individual may have (Aull Davies & Jenkins, 1997; Beart, Hardy, & Buchan, 2005). With this master status comes the assumption of incompetence, low expectations and limited opportunities. Upon reflecting on some of the 'uncomfortable' interactions I had with the Members, I soon realised that the low expectations placed on people with intellectual disabilities and the presumption of incompetence or inability was mirrored in my own interaction with the Members. The ascription of an incompetent identity that I explored (and criticised) in my analysis of the staff interviews was produced and perpetuated in my interactions with the Members. The following excerpt is from my interview with Freya. Before the interview I was under the impression that Freya participated in Wednesday night bowling, and asked her about this. Despite Freya asserting that she does not do bowling, I adamantly continued to question her further two times;

Kate: Do you do bowling with Liz?

Freya: Nah.

Kate: You don't do bowling?

Freya: Nope.

Kate: You don't do bowling on Wednesdays?

Freya: Nah.

As illustrated by above the excerpt, I assumed that Freya was incompetent and automatically deemed her unable to accurately report on her whereabouts or what activities she participates in. The answer Freya offered to my question was erroneous; Freya *does* do bowling on a Wednesday night, she just doesn't know it. Her answer (as a person with an intellectual disability) could not be trusted, I knew better. The following excerpt illustrates my presumption that Louise, who has an intellectual disability, would be unable to travel independently to her poker competition at the local tavern using public transport;

Kate: And how do you get to the venue?

Louise: I normally get a bus or a friend to take me and bring me home.

Kate: Yep. And how are you with going on the buses?

Louise: Good. Yeah. Yep.

In this example, I assumed that Louise would have difficulties using public transport and felt compelled to ask her how she managed. Would I ask someone without an intellectual disability how they fare riding the bus? Probably not. It seems that in the case of intellectual disability the presumption of *incompetence* is axiomatic (Booth & Booth, 1998; Jenkins, 1998). This assumption is also evident in my interaction with Michelle, where I expected that managing finances would be a challenge for her;

Kate: How do you go with your budgeting in everything? Are you good with, you know, doing your bills...

Michelle: Nah.

Kate: No. It's hard, isn't it?

(Michelle nods).

Kate: Yeah, it can be tough.

Would I ask a 32 year old woman without an intellectual disability if they could budget? Probably not. This excerpt once again highlights the low expectations afforded to people with intellectual disabilities and the presumption of incompetence or inability. Furthermore, in this example not only am I questioning Michelle's ability to manage her money, I am also asking her about a very private matter; her personal finances. This excerpt is revealing of the (often unconscious) ascription of a child-like identity to people with intellectual disabilities. This is discussed further in the following section 'People with Intellectual Disabilities as Vulnerable and the Eternal Child'.

People with intellectual disabilities as vulnerable and the eternal child.

As explored in previous chapters, people with intellectual disabilities are often cast in the role of the eternal child. As the eternal child, a person with an intellectual disability never achieves adult status and is expected to have childish abilities, skills behaviours and interests (for a more detailed discussion, please see the subtheme 'The eternal child' presented in chapter four). Upon re-reading the interview transcripts and reflecting on my own emotional reactions during the

interviews, I realised that I too at times (unknowingly) imposed the eternal child identity on the Members that I interviewed. This identity was discursively produced in a subtle and pervasive way. My presumption of a child-like identity (and the accompanying sense of vulnerability) is evident in my interaction with Jacob, a 22 year old man with Down syndrome.



Figure 9. Two photographs taken by Jacob of his *Kill Bill* memorabilia; Samurai swords and a figurine.



Figure 10. A photograph taken by Jacob of his collection of thriller/horror movies and television series.

For the This Is Me project, Jacob took a photograph of his collection of memorabilia from the film *Kill Bill*, which included a number of Samurai swords and

a figurine (see Figure 9). *Kill Bill* is a gory action/thriller film directed by Quentin Tarantino that is infamous for its violent and graphic nature. When Jacob showed me these photographs during the interview, I was shocked that he had seen the film. The film is far too violent and too scary for Jacob. Similarly, when Jacob showed me a photograph that displayed his collection of thriller/horror movies and television series (see Figure 10), I was equally surprised. Jacob couldn't possibly have adult interests? The following exchange accompanied these photographs;

Kate: Dusk Til Dawn. Do you like the scary ones?

Jacob: Yeah.

Kate: Yeah. You don't get nightmares?

Jacob: No.

*Kate: No? I do (laughs)... I think it took me about ten years to get over *Scream* it was that scary (laughs).*

In the above excerpt, I asked Jacob if he got nightmares from watching horror movies. Although Jacob is 22 years old, I assumed that he would find horror movies frightening, because after all, horror movies are for adults. By saying that "*it took me about ten years to get over *Scream* it was that scary*", I am attempting to empathise with Jacob, and normalise this experience. Not only did I find adult interests (such as liking horror movies) confronting, markers of adulthood also presented a challenge to my understanding of a person with an intellectual disability. In the following excerpt I am talking with Lynette about her living arrangements;

Kate: Is it just you most of the time?

Lynette: Most of the time, yeah.

Kate: Yeah? And how do you feel about that?

Lynette: Not too bad.

Kate: Don't get scared at night or anything like that? (laughs)

Lynette: (laughs and shakes head). No.

Kate: It must just be me. I think I'm a bit of a wuss.

Lynette: (laughs).

By living independently, Lynette presents a challenge to the child-like status so often affixed to adults with intellectual disabilities. Surprised by this living

arrangement, I ask Lynette if she feels nervous living by herself. Once again, I assumed that Lynette, living independently, was particularly vulnerable. I also expected that she would have difficulties with this arrangement.

People with intellectual disabilities as happy and the Down syndrome stereotype.

A common rhetoric is that people with intellectual disabilities “*make the most of what they have*” and generally have a “*bloody good life*”. People with intellectual disabilities, particularly people with Down syndrome, are also commonly stereotyped as being happy and loving (for a more comprehensive discussion, please see the subthemes ‘A bloody good life?’ and ‘Smiley, happy people’ presented in chapter five). This very same phenomenon that I observed (and criticised) in my interviews with the staff was being reproduced in my own interactions with the Members. In some of the interviews, I asked the Members to describe themselves. This question was often met with a long pause, after which I offered an example answer, pre-empting their response. Here is an example excerpt from my interview with Jacob, who has Down syndrome;

Kate: So did you have anything else that you wanted to tell me about you?

Jacob: (silence)

Kate: About what you... What do you think you're like?

Jacob: (silence)

Kate: Do you think you're a pretty happy person?

Jacob: Yeah.

Here Jacob did not offer a prompt reply to my question, so I presented him an example answer (“*happy*”) which primed a particular response from Jacob (“*yeah*”). Coaching a response from Jacob in such a way treated him as deficient and unable to describe some of his own personal qualities. In addition, offering the example answer “*happy*” also perpetuates the assumption that people with Down syndrome are joyful, good-natured and easy (Wishart & Johnston, 1990). In my interactions with the Members, complimentary or positive stereotypes were not limited to those Members with Down syndrome.

Kate: So if you were thinking about what you're like as a person, how would you describe yourself? It's a hard question, isn't it?

Freya: Yeah.

Kate: What do you think you're like? I think if I think about myself I think I'd be pretty happy. I love to hang out with my friends...

Freya: Yeah me too.

Kate: My family... are you the same?

(Freya nods).

Once again, I offered the example response (“*happy*”), to which Freya agrees. Interestingly, I didn’t offer Freya other example characteristics such as athletic, intelligent or artistic. This implies that Freya (and all people with intellectual disabilities alike) experience limited emotions (happiness only). As discussed in previous chapters, this stereotype may result in low demands or expectations being placed on people with intellectual disabilities and limited opportunities because it is assumed that regardless they will be satisfied or content (Wishart & Johnston, 1990). In addition, offering the example answer “*I love to hang out with my friends... my family*”, to which Freya agrees, further implies a restricted identity; people with intellectual disabilities have limited interests (family and friends only).

This finding is comparable to a study conducted by Antaki, Walton and Finlay (2007) that examined how staff at residential homes for people with intellectual disabilities proposed outside activities and offered choices to residents. It was reported that when staff introduced an activity to a resident the social aspect of the activity was emphasised (e.g., associating it with a given person), but often failed to mention the intrinsic qualities of the activity or important aspects, such as its location or what is involved. Antaki et al. argued that framing outside activities and choices by emphasising its social aspects may have the unwelcome effect of negating the ability of the resident to choose an activity based on other characteristics, such as the timing and location of the activity or whether the activity offers an intellectual challenge. Antaki et al. concluded that staff interactions with residents with intellectual disabilities perpetuated the assumption that the identities and interests of people with intellectual disabilities are primarily social, with little appreciation of other aspects of life.



Figure 11. A photograph taken by Jacob of his CD player.

Another well-established stereotype that wasn't identified in the analysis of the staff interviews is that people with Down syndrome are musical or interested in music (Wishart, 2001). Although there is little evidence for the responsiveness of people with Down syndrome to music, this stereotype very much remains widely accepted (Wishart & Johnston, 1990). Of all of my 'uncomfortable moments' throughout the duration of this research project, the most significant to me is shown by the following interaction between Jacob (who has Down syndrome) and myself. This exchange accompanied the photograph presented in Figure 11;

Jacob: Hmmmmm. Music.

Kate: Music?

Jacob: Yeah.

Kate: You like your music?

(Jacob nods).

Kate: Yeah. Just like Emma. She loves it.

In this excerpt I am drawing comparisons between Jacob and my sister who also has Down syndrome. By declaring that Jacob likes music "*just like Emma*", I am endorsing the stereotype that all people with Down syndrome love music. This implies a complete lack of individuality; people with Down syndrome have the same positive personality attributes, preferences and interests. Surprisingly, a study conducted by Wishart and Johnston (1990) that examined personality stereotyping in Down syndrome, reported that mothers of children with Down syndrome also endorsed the positive, music-loving stereotype. Wishart and Johnston hypothesised

that although the mothers in the study had high levels of experience and contact with children with Down syndrome, endorsement of this myth may be due to repeated experience of this stereotype being applied by others.

Scrutinising and critically reflecting on my interactions with the Members, I did not explicitly call a Member 'intellectually disabled', nor did I allude to 'having difficulties learning' in any of the interactions. However, as the above examples illustrate, a disabled identity can be affixed not just by naming, but by treating someone as disabled. I noted that the imposition of a restricted identity (e.g., the eternal Child or incompetent) was more likely to occur in my interactions with Members that were non-verbal. In these interactions I was more likely to ask leading questions or offer example answers that were biased by my own values and assumptions. Reflecting on these interactions I felt like an accessory or an accomplice to the restricted identities so commonly attached to people with intellectual disabilities. This led me to feel a great deal of guilt and question my own values. Interestingly, during the interviews and immediately following, I did not feel uncomfortable or as though I had behaved inappropriately. Interestingly, the Members and their parents/guardians (who were at times present at the interviews) did not appear to be upset by the overtones of my comments. It was only when the exchanges between myself and the Members were presented in stark, plain black text completely devoid of context that I realised that I too affixed a restricted identity to the Members. This demonstrates just how socialised we all are to those deeply embedded and pervasive processes that serve to construct people with intellectual disabilities as the Other.

Feeling disheartened and hopeless, I asked a fellow student (who is also in the area of disability studies) to read the transcript excerpts so she could see what a 'bad person' I was. Her reaction was to sigh and say; *"I know. I did the exact same thing in my interviews. I'm a bad person too"*. Smith (2006) warned of this potentially negative self-regulatory function of critical reflection and reflexivity. Excessive reflection and rhetorical awareness of decisions and actions in research can serve to isolate the individual (the researcher) from the broader social context in which they occurred. Judging one's actions completely divorced from social context in which they inhabit the can produce a state of self-criticism and self-

condemnation (Dowling, 2006; Smith). Over self-critical introspection can serve as a barrier to authentic learning and impact on motivation to persist with research (Smith).

Conclusion

Reflections on the process of doing participatory research with people with intellectual disabilities are notably absent from the disability research literature (Northway, 1998; Walmsley & Johnson, 2003). Reflexive accounts of research make evident that researchers are always products of their culture and history and bring with them their own orientations and values that undoubtedly enter into and shape the research (Northway, 2000). Observations made by researchers are always limited and partial, just as understandings are always complex and contradictory (Kirsch, 1999). Research accounts are always open to reinterpretation and revision (Kirsch, 1999). Dowse (2009) argued that it is crucial that reflexive accounts of doing participatory research with people with intellectual disabilities are made overt, so that these experiences can become legitimate and fruitful objects of study. Being reflexive requires the researcher to become the 'other'; another subject of their own objective gaze (Navarro & Zeni, 2004). In this chapter, I have endeavoured to place myself under scrutiny and honestly reflect on the challenges and tensions I experienced engaging in participatory research with people with intellectual disabilities.

One of the most difficult challenges was juggling two oftentimes conflicting requirements; conducting research that met the criteria of academic rigor and accountability required by the university, while being guided by the principles of participatory research that emphasises greater meaningful participation and influence (control) by people with intellectual disabilities in the research process. At times during the research, concessions needed to be made which swung the pendulum of control and power firmly in my direction as the academic researcher. These tensions prompted me to question whether truly participatory research with people with intellectual disabilities was attainable or just an 'impossible dream'. Reflecting on this challenge, I came to realise that participatory research requires an acknowledgement and appreciation of the expertise and knowledge that *both* the co-researchers with intellectual disabilities and the academic researcher bring to

the research process. The academic researcher has experience in writing literature reviews, analysing data and publishing research reports, while the co-researchers with intellectual disabilities are authorities on their own lived experience. The roles and contributions of the academic researcher and the participants with intellectual disabilities in the research process fluctuate and change. Traditional disability research and participatory research are not binary opposites. At other times during the research process the pendulum of control and power swung in the direction of the Members. As a researcher indoctrinated to a certain understanding of the research process, I was left feeling uncertain and anxious. This uneasiness was, however, necessary so that I could be a part of the empowering process.

Actively 'othering' myself when examining the transcripts of my interviews with the Members was particularly confronting. In some of these interviews, I was unknowingly reproducing the same damaging interactional patterns and social relationships with the Members and affixing the same restricted identities, which I as a researcher, had hoped to remedy. This prompted me to re-examine my own assumptions and values and threatened my own positive self-image. After much reflection I adopted a more balanced critical perspective, and concluded that it is impossible to completely 'bracket out' assumptions or be an 'invisible researcher' (Navarro & Zeni, 2004). Our values, attitudes, personal histories and the broader social context in which we inhabit, will inevitably enter into and shape our work. Even as a researcher with an awareness and understanding of the oppression experienced by people with intellectual disabilities, I was still not immune to committing this fallacy. Unknowingly, my decisions and actions in this research were reflective of the dominant culture, illustrating just how subtle and pervasive these oppressive social processes can be and the importance of attempting to develop self-awareness. Navarro and Zeni (2004) capture the essence of this process; "Research means learning and authentic learning transforms us in transactive ways".

Chapter 8: Overall Discussion and Conclusion

If anybody ever asked me wherein my thinking has any distinctiveness, I would say it was in taking the obvious seriously. American psychology has had trouble recognising the obvious, perhaps because so much attention has been given to the distractions of theory (Sarason, 1982, p. 234).

This research was guided by two overarching aims. They were (1) to explore the social construction of 'intellectual disability', particularly the personhood, identities and social roles of people with intellectual disabilities, and (2) to increase the control, power and meaningful participation of people with intellectual disabilities in the research process. This chapter is structured according to these research aims. First, I provide a summary of the data and interpretations (from chapters four, five and six), that address the social construction of intellectual disability, particularly the identities of people with this label (research aim one). Particular emphasis will be given to the processes of dehumanisation and victim blaming which were identified across the Member interviews, the staff interviews and the life story. Second, I will critically examine the research process, particularly the control, power and meaningful participation of the Members in this study (research aim two). Next, I discuss the implications of these findings for the services that support people with intellectual disabilities and clinical psychological practice with people with this label. I then outline the strengths and limitations of the study. Finally, I suggest avenues for future research.

The Social Construction of Intellectual Disability

The first aim of this research was to explore the social construction of intellectual disability, particularly the personhood, identities and social roles of people with intellectual disabilities. Multiple perspectives were sought to enable multiple truths to be uncovered. Analysis of the Member interviews (presented in chapter four) revealed a number of interesting tensions and paradoxes. Intellectual disability did not emerge as an identity salient to Members. Contrary to dominant discourses within the literature that suggest that intellectual disability is central (and damaging) to those with the label, there was nothing abnormal or

extraordinary about the way in which Members conceptualised their identities and social roles. The identities presented by the Members were derived from the broader social context and reflected the social relations in which they engaged and the social roles they occupied. Interpersonal relationships, the Advocacy Agency, leisure and recreational activities and work emerged as important aspects of the Members lives. The Members emphasised those elements of their identities which they shared with others. As previously discussed, all individuals wish to be seen as ordinary, typical social actors. Given that the label intellectual disability is so negatively loaded, it is not surprising that the Members wanted to distance themselves from those aspects that make them 'different' in the eyes of broader society. It would appear that the concept of a stigmatised identity and the view that people with intellectual disabilities are inherently different is imposed on people with the label, rather than derived deductively from the broader context.

Further deconstruction of the Member data, however, revealed a number of complex dynamics that served to undermine how the Members conceptualised their own identities. Deeper, underlying worldviews, values and mythologies were identified that othered the Members, constructing them as incompetent, a burden and innately different. Examples of these processes include the worldview that people with intellectual disabilities will inevitably be constrained by their pathology and the assumption that people with intellectual disabilities are 'passing as normal'.

Similarly, in the analysis of the staff interviews (presented in chapter five), a number of discrepancies between the ways in which the Members constructed their own identities and how they were perceived (and treated) by society emerged. A number of identities commonly imposed on people with intellectual disabilities were identified including that of the deviant, the eternal child and the all-consuming master status. Most of the staff felt that those Members with non-visible or non-identifiable intellectual disabilities were even more likely to be perceived negatively by the general public. Another worldview identified by the staff was that people with intellectual disabilities could not succeed, and as a consequence, it was frivolous to offer opportunities to achieve. This treatment was legitimised by discourses that people with intellectual disabilities are happy and led a "bloody good life". So pervasive were these dehumanising processes and the

assumption of incompetence that when the Members displayed functional behaviour, it was considered remarkable. The worldview that people with intellectual disabilities are not like us also emerged in Paul's lifestory (presented in chapter six) where he was effectively being denied his need for love, affection and companionship. As Paul was viewed as not quite human the obligation to treat him (and others with the label intellectual disability) humanely was moderated or eliminated.

The staff identified that those stigmatising identities imposed on the Members and the limited opportunities afforded to them produced a number of significant problems in the Members lives, including difficulties interacting with others and other activities of daily living such as money management and personal hygiene). Some Members, particularly those with non-visible intellectual disabilities, experienced hostility and bullying by people without intellectual disabilities and others were described as having low self-confidence and poor self-esteem. Although these shortcomings were recognised as being derived through social forces, the Members were constructed as deficient. While this understanding of intellectual disability shifts the emphasis to environmental causation (the broad social forces of stigmatisation and dehumanisation), the Members are *still* nevertheless considered different and incompetent. This phenomenon is known as victim blaming (Ryan, 1971).

Based on the victim blaming ideology, programmes and services are then developed to correct the perceived deficiencies of people with intellectual disabilities (the victim). These solutions which emphasise enhancing the independence and autonomy of people with intellectual disabilities often have the converse effect of contributing to social stigma. As such, the helping professions have been touted the giving enemy (Ryan, 1971). For example, the educational and skill-building programmes of the Advocacy Agency can have the converse effect of perpetuating the worldview that people with intellectual disabilities are incompetent and *need* help. This paradox also emerged in the analysis of Paul's lifestory, whereby the formal services intended to support him to be independent and autonomous, in fact reinforced his disabled position within society by limiting

his personal control and freedom. The implications of victim blaming identified in this analysis are discussed below.

The Research Process

The second aim of this research was to increase the control, power and meaningful participation of people with intellectual disabilities in the research process. In the This Is Me project the Members assumed the role of co-researcher or partner in the research process (level five of the model presented in Figure 1). The control and level of involvement of both myself and the Members fluctuated and evolved throughout the duration of the research process. While this research was not initiated by the Members, the Members indicated that the research topic and methodology was of interest to them. The Members assumed control and executed all of the data collection including taking photographs, videos, writing letters and telling stories of their experiences. Further, the dissemination of the research findings to the wider public was controlled by and reflected the desires of the Members. The relationship between myself and the Members was characterised by respect and reciprocity and many long-term friendships have developed as a result of this project. The role of the Members in the research process is discussed in greater detail in the section 'Strengths and Limitations of This Study' below.

While the Members did have greater meaningful participation and influence (control) than does traditionally typify the research process, this research was to a large extent predetermined and structured. As discussed in chapter seven, difficulties were encountered when attempting to juggle the requirements of academic rigor and accountability by the University, while being faithful to the principles of participatory research. Unfortunately, some concessions had to be made. The impositions of the academic system required the submission of a comprehensive research proposal, including specific research aims and corresponding research objectives, a detailed literature review and a specified methodology and method before the research could commence. Once the data had been collected, I transcribed and analysed the interview data and wrote this thesis. The budgetary and time constraints of a PhD presented a further challenge to the participatory research ideal.

Ideally, people with intellectual disabilities would control the research and collaborate in all phases of the research process, including the specification of the research questions, design, data collection, analysis, dissemination and the utilisation of the research findings (Turnbull et al., 1998; Walmsley & Johnson, 2003). This research, however, represents a compromise between the demands and constraints of the academic system I was indoctrinated into and the requirements of ideal or 'true' participatory research. Rather than an objective or outcome, participatory research was an evolving process. The aim of this research project became increasing the control, power and meaningful participation of the Members wherever possible. These opportunities to move up Arnstein's (1969) Ladder of Citizen Participation are outlined in greater detail in chapter seven.

Implications of This Research

The findings of this research have important implications for the services that support people with intellectual disabilities and clinical psychological practice with people with this label. The cycle of victim blaming identified in the analysis of both the Member and staff interviews, encourages the implementation of strategies focused on changing the individual (the victim), rather than those social systems that support the relationship between the powerful and the powerless (Kielhofner, 2005; Rappaport, 1977). People with intellectual disabilities are provided with a pension, housing, and services and programmes (such as the Advocacy Agency) to make them less vulnerable and improve their wellbeing, while at the same time those social relationships that perpetuate the control over people with intellectual disabilities and maintain their dependence remain essentially unaltered. In effect, people with intellectual disabilities are blamed for their own victimisation while those power dynamics identified in this analysis continue to operate unchanged (Ryan, 1971). Solutions generated from the analysis of individuals (such as people with intellectual disabilities) represent first order change (Watzlawick, Weakland, & Fisch, 1974). First order changes are often based on common sense and may create or exacerbate the problem (Rappaport, 1977; Watzlawick et al., 1974).

It is important to note that the strategies and interventions designed to support and improve the wellbeing of people with intellectual disabilities are well

intentioned (Kielhofner, 2005). Disability service providers that support people with intellectual disabilities, such as the Advocacy Agency, are rooted in genuine humanitarianism. Valid scholarship, science and data are utilised to produce interventions aimed at addressing the injustice experienced by people with intellectual disabilities (Rappaport, 1977). Education and training for people with intellectual disabilities are academically and socially respectable solutions (Rappaport, 1977). Similarly, the parents/guardians and families of people with intellectual disabilities often have the very best of intentions and a deep concern and care for the wellbeing of the individual with an intellectual disability. I would argue that parents/guardians are not intentionally controlling or overprotective, but are simply responding to those prevailing worldviews and myths that construct people with intellectual disabilities as vulnerable and child-like. As described in this analysis, we are all so socialised to those deeply embedded worldviews and assumptions about people with intellectual disabilities, that even those with an awareness and understanding of the processes of social injustice can fall victim (see chapter seven). These misguided assumptions serve to perpetuate the process of disablement and disempower people with intellectual disabilities (Fine, 1986; Kielhofner, 2005).

To create genuine or second order change, the system that supports the status quo must be questioned and challenged (Rappaport, 1977; Watzlawick et al., 1974). We must look beyond the individual to the collective. Fine (1986) argued that decontextualized research produces a distorted understanding of the social relationships and structures that shape unjust relationships, such as that between people with intellectual disabilities and people without intellectual disabilities. This approach reinforces psychological beliefs in individualism and internal control, neglecting the role of the environment (Fine, 1986; Kielhofner, 2005). It is the 'rules of the game' that govern the social relationships between people with intellectual disabilities and people without the label that need to be changed (Watzlawick et al., 1974). Interventions need to be aimed at changing the 'setting' (Sarason, 1974), rather than addressing the perceived deficits or weaknesses of those othered by society (Rappaport, 1977).

This subtle but profound shift in emphasis from weaknesses to strengths is exemplified in the work of George Fairweather and colleagues. Fairweather proposed that a sense of personal accomplishment and opportunities for involvement in participating social statuses within the community were central to all human beings (Fairweather et al., 1969; Fairweather & Tornatzky, 1977). With this humanitarian value orientation at the forefront, the Fairweather Lodge Program was created. Small sub communities with independent living and working facilities were developed where individuals identified as chronically 'mentally ill' could live and work autonomously (Fairweather, 1967). This approach enabled the role relationships between these individuals (the subordinate) and society (the superordinate) to be changed and created opportunities for Lodge members to be upwardly mobile socially (Fairweather, 1967). Fairweather empirically demonstrated that by providing social conditions that were fitted to human needs and capitalised on potential capabilities, those individuals identified as chronically mentally ill were more likely to remain living productively in the community and less likely to return to hospital (Rappaport, 1977). Further, the cost of the Lodge Program was considerably less than that of regular aftercare services (Fairweather et al., 1969).

It is not my intention to propose a drastic social innovation, such as that implemented by Fairweather. To do so without a comprehensive understanding of context, particularly the relationships and structures that perpetuate injustice, would be frivolous (Fine, 1986). It is crucial that the rules of the game (the social systems) are examined before any intervention is implemented (Watzlawick et al., 1974). In addition to determining how to intervene, we must also consider where to intervene in a system and how gradually or abruptly change should be introduced (Rappaport, 1977). It is also important that the potential consequences of an intervention be considered before an action is taken. Failure to do so may have the unintended effect of further exacerbating the difficulties experienced by people with intellectual disabilities. The work of Fairweather does, however, provide a useful orientation when considering the difficulties experienced by people with intellectual disabilities.

How issues are defined and conceptualised has major implications for the solutions that follow. The ideology of blaming the victim identified in this analysis produces first order change. For genuine change to occur, the 'problems' of intellectual disability must be reformulated and the tenets of the social system that support these relationships between the powerless and the powerful must be challenged. Developing self-awareness and an understanding of those social structures and social processes, such as dehumanisation and victim blaming, is important but very difficult (Bishop et al., 2002). We are so well socialised to these social forces, that they can go unnoticed. An ability to observe the broad trends or the obvious that are obscured by dominant worldviews is fundamental, as is an understanding of context (Bishop et al., 2002).

This research may have a role in raising awareness amongst scholars, disciplines, professions, systems and society at large of the complex social processes of dehumanisation and victim-blaming experienced by people with intellectual disabilities as identified in this analysis. Looking beyond the individual and attending to all the aspects of context raises new questions. Simply accepting the powerful role of the environment (worldviews, values and mythologies) in the construction of people with intellectual disabilities, encourages us to consider what a just allocation of power would be, opening up new possibilities (Fine, 1986). I would urge people to be critical of current systems, rather than just passively accepting them and their consequences as a given (Fine & Asch, 1988). Such critical reflection and questioning should be encouraged early in the context of professional education programmes, whether that be disability or psychology studies (Kielhofner, 2005). In addition, further incorporating the voices of people with intellectual disabilities into the psychology knowledge base would be beneficial for both students and clinicians. This would enable those professional understandings and discourses surrounding disability to be challenged.

As previously discussed, the assumption of incompetence, deficit and difference may be implicit to the delivery of services that support people with intellectual disabilities. Establishing a dialogue with service providers who support people with intellectual disabilities (including psychological services) around issues of power and control and questioning assumptions inherent to their 'helping role'

could be useful (Beaulaurier & Taylor, 2001). It would be particularly important to alert service providers to the issues abounding the concept of empowerment, for example; do their clients want to be empowered? Who determines whether a programme or a strategy is empowering? Brainstorming practical ways in which the power of their clients could be enhanced by making changes to the service may be beneficial. This would need to be done in a collaborative way with their clients with intellectual disabilities (to the extent to which they want to be involved and feel comfortable). It is important that people with intellectual disabilities have a strong role in shaping their services and defining the outcomes that they want (Kielhofner, 2005).

I would argue that the humanitarian perspective advocated by Fairweather, whereby there is a deep and continued concern about the value of human life, has important implications for disability services and clinical psychological practice with people with intellectual disabilities (Fairweather, 1967). Services and programmes for people with intellectual disabilities should emphasise and respect existing abilities and enhance opportunities for personal development and growth (Beaulaurier & Taylor, 2001; Fairweather et al., 1969; Rappaport, 1977). Programmes and services must support genuine autonomy and value human diversity. The role of staff within these services becomes one of assisting people with intellectual disabilities to obtain their rights and mobilise their resources, especially their power (Rappaport, 1977).

Strengths and Limitations of This Study

In this section, I address the strengths and limitations of the study with a particular emphasis on methodology and methods utilised in the study. As identified in chapter two, previous studies exploring the identities of people with intellectual disabilities tended to assume that identity was stable and static, not changeable and dependent on context (Gergen, 1990a; Rapley, 2004). As a consequence of this conceptualisation of identity, studies tended to focus on whether or not an individual was aware of their status as a person with an intellectual disability. This creates a narrow and impartial understanding of the identities and social roles of people with this label. Furthermore, reflecting the worldviews and values identified in this research, past studies examining the

identities of people with intellectual disabilities have tended to assume a stigmatised identity, neglecting the alternative identities that an individual may have (Barron, 2002; Block et al., 2001). While it is not possible to bracket these worldviews due to the powerful nature of process of socialisation, adopting a post-modernist/contextualist posture can assist in capturing the complexity and paradoxical nature of social phenomena, such as intellectual disability (Crow, 1996; Gergen, 1990b; Pepper, 1942). Deconstructing the broader historical, political, social and cultural context, produces a more responsive way of theorising and understanding the social construction of intellectual disability and the identities and social roles of people with intellectual disabilities (Gabel & Peters, 2004). Further, including the perspectives of the Advocacy Agency staff and Paul's life story enabled multiple truths to be uncovered, strengthening confidence in the findings of this research (Crotty, 1998). It is, however, important to note that like all qualitative research studies there are limits to the transferability of these findings (Lincoln & Guba, 1985). Caution is needed when applying these findings to different contexts (Creswell, 2013).

As noted in chapter three, the use of participatory research approaches with people with an intellectual disability is growing, but still not widespread (Cocks & Cockram, 1995; Jurkowski, 2008). Further, within the field of disability studies calls had been made for participatory research approaches with people with intellectual disabilities to be broadened beyond the traditional survey or interview to include visual methods (e.g., Rojas & Sanahuja, 2011). This research represents a contribution to this growing body of research. There were a number benefits associated with the use of a methodology characterised by greater meaningful participation and influence for the Members. As research partners or co-researchers the Members were afforded many opportunities to exert control and make decisions in the research process. This enabled the power imbalance that typically arises between researcher and participant in research with people with intellectual disabilities to be challenged. As described in chapter seven, the notion of empowerment in disability research is contentious. In this research, I focused on the strengths and abilities of the Members and attempted to support them to make

their own decisions in the research process. I cannot determine whether the Members were empowered through their involvement in the This Is Me project.

As previously noted, few studies exploring the identities of people with intellectual disabilities do so from the viewpoint of people who live it (Beart et al., 2005). Typically, the views of parents, carers and support workers are sought (Jurkowski, 2008). In this study, parents/guardians were only included in the interview process at the request of the Members. The Members were considered experts on their own lives, experiences, feelings and views. The view points and social realities of the Members were captured and their voices were acknowledged, addressing what has been identified as a shortcoming of traditional disability research (Walmsley & Johnson, 2003). There is, however, difficulty determining whether the findings presented in this thesis accurately represent the perspectives of the Members. Ensuring that I accurately captured the views, feelings and experiences of those Members who were non-verbal or had a parent/guardian speak on their behalf in the Photovoice interview was particularly difficult and represents a limitation of this research. In an attempt to enhance the credibility or truth value of my findings, I presented my initial thoughts/findings to the Members in the final reflection session for their feedback (Burgess-Limerick & Burgess-Limerick, 1998). The Members affirmed that I had accurately captured their experiences. Further, I was engaged with the Members for a prolonged period of time both formally as a researcher and informally as a family member which enabled me to gain a greater understanding of the phenomenon I was observing in context (Creswell, 2013).

In addition to the redistribution of power inherent to a participatory research framework, there were a number of advantages unique to the use of Photovoice. First, Photovoice emphasises the visual capacities of people with intellectual disabilities and does not require the ability to read or write. Members who were non-verbal were able to meaningfully participate in the research project. These Members pointed at photographs and used gestures to convey their story. Second, the Members developed new skills and increased confidence through their involvement in the This Is Me Project. Control and ownership of the photographs, the narratives they elicit and the public photograph exhibition fostered a sense of

pride amongst the Members. Third, the photograph exhibition facilitated engagement with the community and enabled the Members to challenge the identities commonly affixed to people with the label intellectually disabled. Finally, Photovoice was a novel and interesting way to engage the Members and enjoyable experience. For these reasons, I would advocate the use of Photovoice within a participatory research framework for future research with people with intellectual disabilities.

Further, the reflections presented in chapter seven on the process of conducting participatory research and Photovoice with people with intellectual disabilities can assist future participatory researchers to create projects that increase the control, power and meaningful participation of people with intellectual disabilities in the research process. Questioning and reflexivity is fundamental to the principle of developing ethical research (Bishop, 2007). Publishing the procedural material, as well as accounts of the challenges and tensions associated with this type of research, ensures that this information is readily available to future researchers.

Lastly, the use of CLA to analyse both the Member and staff interviews represents a further strength of this study. This study represents a contribution to the body of research using this emerging methodology within the field of psychology. Deconstructing the data according to the four deeper frames of reference enabled some of the complex social drivers of societal conceptualisations of intellectual disability and people with this label to be identified. Identifying the deeper, underlying root cause of the dehumanisation of people with intellectual disabilities is more likely to produce genuine, transformative social change (Bishop & Dzidic, 2014; Watzlawick et al., 1974).

Avenues for Future Research

As discussed previously, in order to produce second order change, the tenets of the social system that support the relationships between the powerless and the powerful must be changed. Disability researchers must change the way in which research is conducted to avoid academic exploitation (Fine, 1986). Participatory research approaches offer the opportunity to challenge the power differential that

arises between the researcher and the researched in traditional disability research. In addition, this approach creates genuine opportunities for people with intellectual disabilities to exert control and make decisions in the research process. Further, the use of Photovoice capitalises on the strengths and abilities of people with intellectual disabilities and enhances opportunities for personal development and growth. I advocate the use of participatory research approaches and Photovoice in future studies with people with intellectual disabilities. It would also be useful for future research to examine other ways in which the control and power of people with intellectual disabilities could be increased through the research process.

In this research, intellectual disability did not emerge as a salient identity for the Members. Their identities reflected the broader context; the social relations in which they engaged and the social roles they occupied. The identities of the Members were not stigmatised or damaged as so often assumed. I support the calls made by Beart et al. (2005), McVittie et al. (2008) and others that the alternative identities embodied by people with intellectual disabilities (beyond that imposed by people without disabilities) warrant further investigation. As discussed previously, there is a paucity of literature examining the multiple and variable selves of people in this powerful social category. Research exploring the gender, sexual, religious and ethnic identities of people with intellectual disabilities is recommended.

Further research exploring those complex social structures or rules of the game (Watzlawick et al., 1974) that serve to dehumanise and blame people with intellectual disabilities for their experiences is needed. It may be useful to examine the dominant cultural world views, values and mythologies in other settings, such as education and employment. As previously discussed, within disability research (and psychology more broadly), there is an individualistic propensity in problem definition. A post-modernist/contextualist posture is suggested for future studies as it emphasises collectivism and the embedded nature of intellectual disability in the broader historical and cultural context. Disability needs to be studied as a process that transforms and changes over time and context (Fine & Asch, 1988). By revealing tensions or paradoxes, understandings of intellectual disability can be destabilised opening up the opportunity for new theories or different interpretations to emerge (Gergen, 1985; Prilleltensky, 1989). Furthermore, an

awareness and understanding of the social systems that govern and support the relationship between the powerful and the powerless is needed before any intervention or social innovation (Fairweather, 1967) aimed at changing the setting can be implemented. The use of CLA is also advocated as a means of analysing qualitative data as it enables the in-depth deconstruction of complex issues, such as conceptualisations of intellectual disability and people with this label. Understanding people in context and revealing the complex social drivers of an issue supports the generation of genuine, transformative change.

Conclusion

The broad aims of this research were to explore the social construction of intellectual disability and to increase the control, power and meaningful participation of people with intellectual disabilities in the research process. Deconstruction of the Member and staff interviews, and the life story revealed a complex labyrinth of worldviews, values and mythologies which served to dehumanise people with intellectual disabilities and blame them for their own fate (victim blaming). Those complex dynamics presented in this thesis that construct people with intellectual disabilities as incompetent, different and not quite human explain the experiences of people with this label. These meanings of intellectual disability are social and therefore changeable. Intellectual disability is a social construction, not an immutable reality. Genuine, transformative social change, however, is a slow process. Developing self-awareness and an understanding of those social structures and social processes, such as dehumanisation and victim blaming, is crucial, but challenging. Creating a dialogue with the staff that support people with intellectual disabilities and mutually exploring these relationships between the powerless and the powerful represents a useful starting point. Further, the adoption of participatory research approaches can create opportunities for people with intellectual disabilities to have a voice, exert control and make decisions in the research process. Directly challenging this power imbalance enables researchers and the field of disability research more broadly, to be part of the empowering process.

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Appendix A

I, Kate Povee, contributed to the conception and design of research project, the collection and analysis of data, the interpretation of the results, and drafted and revised significant parts of the publication entitled 'The use of photovoice with people with intellectual disabilities: Reflections, challenges and opportunities' (reference listed below).

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I, as a co-author, endorse that this level of contribution by the candidate indicated above is appropriate. As co-author, I contributed advice on the research design, analyses and the interpretation of the data and provided feedback on the manuscript.

Associate Professor Brian Bishop

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Associate Professor Lynne Roberts

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Povee, K., Bishop, B. J., & Roberts, L. D. (2014). The use of photovoice with people with intellectual disabilities: Reflections, challenges and opportunities. *Disability & Society*, 29, 893-907. doi:10.1080/09687599.2013.874331

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