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

Intellectual disability is commonly conceptualised as stigmatised identity with which one has to live. However, within the literature the notion of a damaged identity is contested. The aim of this research was to explore the social construction of intellectual disability, with an emphasis on the identities and social roles of people with an intellectual disability. Informed by a contextualist perspective, this research was conducted within a participatory framework. The co-researchers involved in this research were 18 Members of an Advocacy Agency. Photovoice and conversational interviewing were used to collect data and causal layered analysis was used to deconstruct the data. Analysis of the interactions that emerged across the causal layers revealed a complex dynamic of worldviews which served to construct people with an intellectual disability as incompetent, inherently different, and not quite human. For genuine, transformative change to occur, developing an awareness and understanding of social processes, such as dehumanisation, is crucial.

Keywords: Intellectual disability, identity, stigma, worldviews, Photovoice, causal layered analysis.

"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').

Introduction

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 and 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). Reflecting the privileging of a modernist world view where individualism is the dominant motif (Gergen 1990b, a) and intellectual disability is defined as a 'naturalised impairment' (Goodley and Rapley 2001), past studies exploring the identities of people with an intellectual disability have tended to focus on a narrow stream of inquiry; the awareness of the label intellectual disability, and the denial of this label.

In their review of the literature, Beart, Hardy, and Buchan (2005) reported that it is consistently found that at least some people with an intellectual disability appear to be unaware of their intellectually disabled identity. Three main hypotheses have been offered to explain apparent unawareness. First, 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, Hardy, and Buchan 2005). The very nature of intellectual disability precludes some people from developing an awareness of it (Beart, Hardy, and Buchan 2005, Todd and Shearn 1997). Second, it has been proposed that people with an intellectual disability operate within a 'protective capsule' where information is careful filtered and controlled by their families who act as the gatekeepers' of information concerning their child's intellectual disability (Goffman 1963, Beart, Hardy, and Buchan 2005, Todd and Shearn 1997, Cunningham, Glenn, and Fitzpatrick 2000). Finally, 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 denial (Edgerton 1967, Beart, Hardy, and Buchan 2005, Todd and Shearn 1997). The internalisation of this stigmatised identity presents individuals with the need to reconstruct their damaged self-esteem (Edgerton, 1967). This is achieved by concerted and well-organised efforts to 'pass' as 'normal' (Goffman 1963).

More recent studies extend beyond the awareness of and denial of label intellectual disability to posit that identities are constructed in the context of social and power relations (Gergen 1990a, Patel 2003, Prilleltensky 1989). Just as disability has been argued to be socially constructed (Oliver 1996), post-modernist conceptualisations of identity emphasise the role of social relations and structures, and the plasticity, changeability and variability of identity (Ryan and Deci 2003, Mead 1934, Stryker 1968). These studies have reported that people with an intellectual disability are indeed aware of their membership to this deeply devalued social category and actively resist being defined as 'disabled' or 'different' and develop a

strong identity based on other aspects of their lives (Rapley 2004, Jahoda and Markova 2004, Jahoda et al. 2010, Kittelsaa 2013a). Whether or not these self-presentations are accepted as trustworthy, however, is a matter of who has the power to define the situation. Adopting a post-modernist stance attuned to power allocation and social processes, allows notions such as 'passing as normal' and 'denial' to be challenged and reinterpreted in a number of ways.

First, it has been suggested that label ID is central or salient to researchers examining the area of identity and self, and that many researchers have failed to consider the alternative identities that might be more important and meaningful to people with an ID beyond that imposed on them by society (McVittie, Goodall, and McKinlay 2008). The importance assigned to the social category of intellectual disability is also reflected in the paucity of literature examining the alternative identities that people with an intellectual disability may embody, including gendered and ethnic identities (McVittie, Goodall, and McKinlay 2008, Block, Balcazar, and Keys 2001). Second, 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, Goodall, and McKinlay 2008, Rapley 2004). Identities can be vowed or disavowed depending on the demands of the social situation and people with an intellectual disability may actively resist being defined by others, particularly by researchers who assume the position of power (Rapley 2004, McVittie, Goodall, and McKinlay 2008). Finally, it has been argued that the social action of passing is not unique to people with an intellectual disability, but rather a pervasive feature of everyday social life (Rapley, Kiernan, and Antaki 1998). All individuals wish to be seen as ordinary, typical social actors and 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, and McKinlay 2008, Kittelsaa 2013a).

We argue that deconstructing the broader historical, political, social and cultural context, produces a more responsive way of theorising and understanding intellectual disability (Gabel and Peters 2004). 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 contributes to the growing body of work which adopts a more nuanced and

expansive way of understanding the identities and social roles of people with an intellectual disability.

Research Methodology

Research Design

Informed by a contextualist perspective, this research was qualitative and conducted within a participatory research framework. Participatory research in its purest or ideal form involves people with an intellectual disability adopting the role of co-researcher and controlling the research and collaborating 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, Friesen, & Ramirez, 1998; Walmsley & Johnson, 2003). It has been argued, however, that participatory research can be conceptualised as a continuum with varying degrees of meaningful participation in and control of the research process and outcomes by people with an intellectual disability (Bigby et al., 2014; Strnadová et al., 2014). This research falls on the continuum of participatory research and focus throughout the research process was one of creating opportunities for the Members to make decisions and exert control wherever possible. For our reflections on attempting to engage in participatory research with people with an intellectual disability and a more detailed description of the research process, see (Dorozenko, Bishop, and Roberts 2015).

Co-Researchers

The co-researchers in this study were 18 Members (11 male and 7 female), aged 20 to 45 years, of an Advocacy Agency that supports people with an intellectual disability based in a regional area of Australia.

Procedure

Photovoice and conversational interviewing were used to collect Member data. Photovoice involves the co-researchers taking photographs to illustrate the research problem or question; their social roles and identities. These photographs are then supplemented by interview data. Conversational interviewing, recursive process whereby the agenda for the interview is established interactively by both the researcher and the participant, (Burgess-Limerick & Burgess-Limerick, 1998), was used to engage with the Members. The photographs taken by the Members acted as a stimulus for the conversational interviews, which were informal and

flexible. For a detailed description of the procedure, including and the challenges and opportunities associated with the use of Photovoice with people with an intellectual disability, please see Povee, Bishop, and Roberts (2014). All interviews were audio-recorded, transcribed verbatim and analysed using causal layered analysis (Inayatullah 1998). The photographs taken by the Members were not analysed, however, the content of the photographs is described at the Litany layer of the findings section.

Analysis

Causal layered analysis (CLA) is inherently ecological and offers an avenue for understanding people in context and the deeper, more complex social drivers of an issue (Bishop and Dzidic 2014). Using CLA, complex social issues are deconstructed into four layers: the litany, the social causative, the discourse/worldview and the myth/metaphor (see Table 1). With each layer the issue is scrutinised with increasing complexity. CLA was undertaken using the method outlined by Bishop and Dzidic (2014). Interview transcripts were read multiple times before coding between and within each causal layer. Potential themes and sub-themes, relevant to the foci of each layer were then reworked to ensure each theme had sufficient supporting data and data cohered meaningfully. Quotations were selected from the transcripts to support claims made. Finally, the findings of the CLA were reconstructed creating alternative vistas for research and practice. Member checking and peer coding was used to ensure research trustworthiness and a reflexive journal was maintained.

Table 1: *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.

Findings

The following is a CLA of the interview transcripts[1] with the Members of the Advocacy Agency. The themes emerging from the analysis are then integrated with the existing literature and finally reconstructed.

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. The content of the photographs taken by the Members (with little analysis) form the litany of this analysis.

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 were of friends, many of whom also had an intellectual disability, and family members. Pets also commonly featured in the photographs and were described as a source of companionship and joy; "*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)*" (Greg).

National/cultural identity

Some of the Members interviewed spoke enthusiastically about their cultural heritage which 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*". National/cultural identity emerged as important to some of the Members in this study.

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[1] In the interview transcript excerpts, the dialogue of the first author will be indicated using 'Kate'. The names of Members have been changed.

The Advocacy Agency

The Advocacy Agency featured in many photographs. The majority of the Members stated that they enjoyed attending the camps and the holidays arranged through the Agency and described the Agency as a place to meet people and form friendships and relationships. 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… 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.*

Leisure, recreation and interests

The majority of the Members chose to photograph recreation and leisure activities. 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.

Church

Some of the Members interviewed discussed the role of the Church in their lives. For some, attending Church was a way to connect with the community and form friendships. Other Members had active roles in their Church, such as David who is an Altar Server;

> *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…*

David explained that he enjoys having a formal and respected role at his Church.

Overall, 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 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.

Work and employment assistance agencies
Most of the Members discussed or photographed their place of work. Most worked in open employment organised by employment assistance agencies. They described these agencies as being especially for "*people with disabilities*". Paid jobs included delivering catalogues and newspapers, butchering, washing dishes and supermarket work. Some worked in sheltered workshops for people with disabilities making wooden pallets or assembling boxes. Working was described as having many benefits; *"I'm a groundsman... a groundsman means that's where you do so many jobs... It's good money though. Yeah. It's really good money. I get $18... I get $18.50 an hour".* Some of the Members volunteered for local charity organisations or did unpaid work.

Housing and welfare
Most of the Members in this study received a disability support pension from the Government. The pension was described as insufficient and many had trouble making their payment last the whole fortnight. Some of the Members also lived in their own house or unit, which was made possible by the Government Public Housing Assistance. Two 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;

> *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 and thundering and lightening... 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.

Discourse/Worldview
At the Discourse/Worldview level of analysis, those structures, discourses, values and ideologies that support or legitimise the assumptions made about the Members, or people with an intellectual disability or intellectual disability more broadly, are examined.

Proving them wrong

Some 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 were presented with a very grim forecast shortly after birth; *"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… and… Kate, that makes me feel very good inside"* (Paul). 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 from birth. Many of the Members described this sense of pride and gratification in surpassing these low expectations.

Members are actively resisting the 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'.

People like me

Some Members interviewed acknowledged that according to society, they are the collective other. 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, 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, but does not elaborate on *how* they are similar. Interestingly, 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. The above examples suggest that some of the Members in this study were aware of their allocation to the social category 'person with an intellectual disability'. It is, however, important to note that this does not exclude the possibility of other people with intellectual disability being unaware of this label or wanting to deny those aspects that make them 'different' in the eyes of broader society. Indeed, the label 'intellectually disabled' is so negatively loaded that distancing oneself from this categorical identity can serve a protective function (Kittelsaa 2013).

Being burdensome

Some Members interviewed spoke of being a burden or an inconvenience to their parents, suggesting that they had internalised a stigmatised view of self. Most lived at home and relied on 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: *... I don't mind her, putting up with me.*

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. 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. Indeed, early research exploring the impact of having a child with an intellectual disability on the family tended to reflect a pathological model whereby couples and the family as a whole were assumed to suffer greatly and experience inevitable negative impacts (Risdal and Singer 2004). Nowadays, research in this area adopts a more expansive, contextual view of families and intellectual disability that is cognisant of the philosophies of the social model of disability (Maul and Singer 2009).

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;

> *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.*

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. Some attempts to negotiate autonomy and control in the family created 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;

> *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 difficult for my mum and since when all my sisters got married and I'm the last one.*

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. It has been argued in the literature (e.g., Saaltink et al. 2012) that the parents and carers of people with an intellectual disability 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).

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. In the context of CLA, myths are not considered falsehoods, but rather provide the foundation of issues.

Doing 'being ordinary' or being ordinary?

As presented in the Litany layer of this analysis, there was nothing unusual or extraordinary about the content of the photographs taken by the Members. Almost all Members photographed and discussed their family, friends and pets, suggesting that close relationships were central to their lives. Most described their involvement in the Agency, their 'working life', interests and experiences and were also eager to talk about their hopes and dreams for the future. Furthermore, when asked to describe themselves, none referred to intellectual disability, instead referring to physical appearance, personality, relationships with others and 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.*

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.*

Like the Members in this study, researchers have reported that a significant proportion of people labelled as intellectually disabled, do not use the label spontaneously to describe themselves (Finlay, Lyons, and Taylor 2005, Finlay and Lyons 2000). As previously discussed, this lack of awareness of the intellectually disability identity has been understood as denial or attempts to pass as normal (Edgerton 1967, Beart, Hardy, and Buchan 2005, Todd and Shearn 1997). We argue that this interpretation is too simplistic and illuminates the taken for grantedness of a stigmatised identity and the assumed centrality of intellectual disability to an individual's identity.

Problematising the identities of people with an intellectual disabilities
Just as the ordinary or non-stigmatised identities presented by people with an intellectual disability are often considered to be a function of denial or attributed to deliberate attempts to 'pass as normal', the identities of people with an intellectual disability are commonly pathologised (Susman 1994). In Western societies, independence, intelligence and competence are deeply valued and impairment or disability is commonly considered to be the worst thing that could happen to a person (Susman 1994, Ben-Naim, Aviv, and Hirschberger 2008). Furthermore, it has been reported that when compared to other impairments, intellectual disability is often considered the least desirable condition (Thomas 2000).

Constructing and presenting a positive identity or an identity that is not 'stigmatised' is particularly difficult for people with an intellectual disability as much of their behaviour is often pathologised and interpreted as being characteristic of their diagnosis or syndrome (Goodley and Rapley 2001). To illustrate this process, we refer to an example from this study. Mark is an avid fan of the cartoon television series, *The Simpsons*. Mark chose to photograph his collection of The Simpsons memorabilia and figurines, much of which was unopened in the packaging. He explained; *"I love Simpsons so much… I've got Simpsons everywhere… Yeah, I have a problem (laughs)"*. One interpretation of Mark's interest in *The Simpsons* and his collection of toys and figurines is that it is childish and silly. Further, spending copious amounts of money on this interest could also be considered an irresponsible and immature. Viewing Mark's interest through the powerful lens of disability, he becomes his professionally diagnosed 'incompetence' (Jenkins 1998) and his actions are considered confirmation of that diagnosis.

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 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. 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. This process of deconstructing the behaviours of people with the label illustrates how disability research is essentially a situation of power asymmetry (Rapley, Kiernan, and Antaki 1998). Researchers have the power to determine whether behaviour is ordinary or evidence of a stigmatised identity.

Alternative identities and being a human being

The label of intellectual disability can conceal a great variety of human experiences and alternative identities (McVittie, Goodall, and McKinlay 2008, Kittelsaa 2013). Some of the stories told by the Members got at the heart of what it is to be human. They were unremarkable and ordinary; they weren't about being a person with an intellectual disability, they were about being a person. The alternative identities and roles embodied by the Members are presented in the four subthemes below.

Intimate relationships.

The interpersonal relationships of the Members were commonly featured in their photographs and often discussed. A number of Members were in close, intimate relationships, with the role of boyfriend/girlfriend or husband/wife important to their self-concept and providing 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. Another member, Anne, expressed that being married and someone's wife gave her a sense of esteem and made her feel valued. Of her husband she said; "*My first love and now he's my first husband*".

Sexuality is central to being a human being and love, affection and belongingness are recognised as basic human needs (Gomez 2012, Maslow 1970). Traditionally, the right of people with an intellectual disability to express their sexuality and experience romantic relationships has been neglected or denied (Siebelink et al. 2006). Two powerful and pervasive myths sustain the worldview that the sexuality of people with an intellectual disability can be ignored or suppressed. The first myth is that people with an intellectual disability are asexual and do not need or desire loving and fulfilling relationships (Siebelink et al. 2006). The second myth is that people with an intellectual disability are hypersexual

and lack sexual restraint (Stainton 1998). Although the myth of asexuality and hypersexuality are paradoxical, society seems to be able to maintain both concerns about people with an intellectual disability without arousing cognitive dissonance.

The carer (not the cared for).

Many 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 an intellectual disability as dependent and passive recipients of care (Wolfensberger, 2000). 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;

> "*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…*"

Daniel 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… saying do your tablets and your lollies*".

Research examining the care relationships between people with an intellectual disability and their primary care givers contributes to the worldview of people with an intellectual disability as dependent as often only the carer's perspective is sought (Williams and Robinson 2001). The representation of adults with an intellectual disability as dependent and a source of burden ignores the interdependent nature of relationships. The simplistic one-way construction creates a false dichotomy and serves to further perpetuate existing stereotypes (Fine and Asch 1988). Something as ordinary as being in a reciprocal or mutually caring relationship must be emphasised to illuminate those dominant, but hidden, worldviews about people with an intellectual disability.

Intelligent and competent.

The Members presented a challenge to the dominant cultural conceptualisations of people with an intellectual disability as unintelligent and incompetent. Through their stories, the Members presented themselves as capable and intelligent. For example, one of the Members

is particularly interested in Australian politics; *"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 form Australia's own Head of State..."*. Another Member organised and facilitated a ceramics teaching interested community members how to work with clay, demonstrating organisational skills, ambition and creativity. Having an interest in politics or engaging in creative pursuits is unremarkable. These behaviours would be expected of *anyone*. The functionality of people with an intellectual disability, however, often has to be presented as extraordinary in order to demonstrate the othering and dehumanisation of people with this label. The assumption that people with an intellectual disability are incompetent is so deeply entrenched because intellectual disability tends to be viewed as a naturalised impairment or biology, rather than a social construction (Goodley and Rapley 2001). However, 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). 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).

Personal growth.

Many Members interviewed wanted to better themselves and grow and develop as a person. For example, Jackson described 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... 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.*

Jackson is expressing a motivation or striving toward personal growth and self-actualisation. Another Member credited the Agency for enhancing his confidence and self-esteem, by encouraging him to seek employment. For this Member working provides a sense of purpose and meaning; *"You can't sit around not do nothin' and twiddle your thumbs"*. Despite the need for personal growth being universal (Maslow, 1943) restrictive worldviews and stereotypes of people with an intellectual disability exist. McManus (2010) reported that people with an intellectual disability tend to be perceived as more communal and less agentic. That is, people with an intellectual disability are seen as warm and friendly, but not

particularly skilful, industrious or ambitious. As such, people with an intellectual disability are thought not to require opportunities and contexts to self-actualise. Such worldviews limit the roles requiring competence and independence people with an intellectual disability have access to and further perpetuate prejudice (McManus 2010).

Reconstructing the Issue

Overall, the findings of this analysis suggest that the social category intellectual disability was not central to the identities of the Members. These findings are consistent with that of other studies that the intellectually disabled identity may have little resonance with the people who live with the label (Fine and Asch 1988, Finlay and Lyons 1998). We argue that the concept of a stigmatised identity and the view that people with an intellectual disability 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 an intellectual disability; the labellers. It would be erroneous to assume that those same worldviews must hold true for people with an intellectual disability; 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.

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 1990, Mest

1988, Stryker 2008). There was nothing 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 an intellectual disability. 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. 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 an intellectual disability 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., Todd and Shearn 1997, Cunningham, Glenn, and Fitzpatrick 2000), the Members in this study were very much aware of their membership to this stigmatised social category. 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 disability as inherently 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, began 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. There was an overriding assumption that those Members were

constrained, and would always be constrained, by their 'pathology'. Indeed, some of the Members internalised these worldviews and felt as though they were a burden to their families. This was particularly true for the older Members (Dorozenko, Roberts, and Bishop 2015).

The worldview that people with an intellectual disability 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 an intellectual disability as fundamentally different, but captured those experiences central to being a human being. 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. We 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 an intellectual disability attempt to 'pass as normal' (Rapley 2004). People with an intellectual disability 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 an intellectual disability is further evident in the assumption that many people with an intellectual disability are unaware or in denial of their status as an intellectually disabled person. Psychological defences *must be* mobilised by people with an intellectual disability in order to cope with what researchers feel is not really manageable (Fine and Asch 1988). It could be argued that researchers are guilty of wanting people with an intellectual disability to own up or admit to a stigmatised identity.

The othering of people with an intellectual disability and the myth that people with this label are not quite human is also evident in situations where people with an intellectual disability present as 'functional' human beings (Goodley 2001). Often when people with an intellectual disability engage in normal or ordinary activities it is considered extraordinary or remarkable,

reflecting the axiomatic assumption of incompetence that is deeply entrenched in society (Dorozenko, Roberts, and Bishop 2015, Jenkins 1998).

Discussion and Conclusion

In this research we explored how the Members conceptualised their own identities and the role that worldviews, values, mythologies and culture played in this construction. Contrary to some previous research and discourses within the literature that suggest that intellectual disability is central (and damaging) to those with the label, intellectual disability did not emerge as an identity salient to Members. Instead, 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. Deeper deconstruction, 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 dehumanised and othered the Members, constructing them as incompetent, a burden and innately different

This research may have a role in raising awareness amongst scholars, disciplines, professions, systems and society at large of the complex social process of dehumanisation experienced by people with an intellectual disability. Looking beyond the individual and attending to all the aspects of context, including the allocation of power, raises new questions. Simply accepting the commanding role of the environment (worldviews, values and mythologies) in the construction of people with an intellectual disability, encourages us to consider what a just allocation of power would be, opening up new possibilities (Fine 1986). 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). We support the calls made by Beart, Hardy, and Buchan (2005), McVittie, Goodall, and McKinlay (2008) and others that the alternative identities embodied by people with an intellectual disability, such as gender, sexual, religious and ethnic identities warrant further investigation. Finally, the use of CLA is 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 (Bishop and Dzidic 2014).

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