

**Imposed Identities and Limited Opportunities: Advocacy Agency Staff  
Perspectives on the Construction of their Clients with Intellectual Disabilities**

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Intellectual disability is commonly conceptualised as stigmatised identity, 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 from the perspective of staff who work closely with people with intellectual disabilities. Informed by a contextualist perspective, this research was based on interviews with five staff of an Advocacy Agency based in a regional area of Australia. Causal layered analysis (CLA) was used to deconstruct the interview data. Analysis of the interactions that emerged across the causal layers revealed a complex dynamic of worldviews which served to dehumanise people with intellectual disabilities and blame them for their own fate (victim blaming). For transformative change to occur, understandings of the ‘problems’ of intellectual disability must be reformulated and those social structures and processes that support the relationship between the powerful and the powerless must be challenged.

## **Introduction**

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, 2004). 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). 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, 1990, 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). Social roles have also been identified as particularly important as they provide expectations for behaviours, emotions and cognitions (Wolfensberger, 1998).

Few studies have investigated the identities and social roles of people with intellectual disabilities (Beart et al., 2005, Beart et al., 2004). Within these studies, intellectual disability is commonly conceptualised as a stigmatised identity, overriding

the alternative identities and social roles an individual may have (Beart et al., 2005, Davies and Jenkins, 1997). However, even within the limited literature examining the identities of people with intellectual disabilities the notion of a stigmatised identity is contested, with reports that at least some people with intellectual disabilities appear to be unaware of this ascribed identity (Todd and Shearn, 1997), whilst others suggest that disability has little resonance with those who live with the label (Jahoda and Markova, 2004, Rapley, 2004).

This research forms part of a larger study which utilised photovoice and conversational interviewing to explore the identities and social roles of Members of an Advocacy Agency for people with intellectual disabilities (Author et al., 2014). The role that dominant cultural worldviews and values played in this construction was of particular interest. During the research process, a number of staff members at the Advocacy Agency expressed interest in being involved in the research.

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.

A key task of staff working with people with intellectual disabilities is assisting them to self-advocate. Self-advocacy was an important movement which emerged in the 1970s which called for ownership, empowerment and control by people with intellectual disabilities (Chapman, 2014). Self-advocacy occurs in many different contexts (formal and informal) and may be with or without the support of others, but most importantly it is a supportive space where people with intellectual disabilities can speak out and be heard (Goodley, 2000, Boxall et al., 2002, Chapman, 2014). Disability agencies may deliver 'self-advocacy training' that focuses on enhancing the interpersonal and communication skills of members with intellectual disabilities, such as understanding body language and assertive communication styles, so that they are able to advocate for their own needs in the community (Boxall et al., 2002). 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 and 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 (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 that 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 that staff have in the lives of people with intellectual disabilities (van Asselt-Goverts et al., 2013).

Given the important role that staff often has in the lives of their clients with intellectual disabilities, it is important to include their perspectives in order to gain a more complete understanding of how people with this label, and intellectual disability more broadly, is socially constructed. The overarching aim of this research was to explore how the staff who work closely with people with intellectual disabilities conceptualise the identities and social roles of their clients. As post-modernist understandings of identity emphasise the degree to which people's identities are constructed in the context of social relations, the role of dominant cultural worldviews and values in this construction was of particular interest (Gergen, 1990, Patel, 2003, Prilleltensky, 1989). It was anticipated that this research may have a role in raising

awareness of the discourses sounding people with intellectual disabilities and how world views, values and assumptions can enter into and shape practice (Szivos and Griffiths, 1992). Consciousness-raising is a transformative process (Freire, 1970) and this research may have a role in informing the way in which services support people with intellectual disabilities.

## **Method**

### **Research design**

Informed by a contextualist perspective (Jaeger and Rosnow, 1988), this research was qualitative and based on semi-structured interviews with the staff at an Advocacy Agency.

### **Participants**

The participants for this study were five staff members (four female and one male) of an Advocacy Agency based in regional Australia. The Advocacy Agency is a non-Government organisation that offers a self-advocacy programme where people with intellectual disabilities in the region can join as Members. Regular Member meetings are held which provide a forum for Members to voice their concerns and share ideas. The Agency offers a number of group sessions which focus on the development of interpersonal and communication skills. The Advocacy Agency also has an ongoing role in individual and systemic advocacy, promoting justice and the human rights of people with intellectual disabilities. The staff members in this study 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 XXX XXXX Human Research Ethics Committee. The interviews with staff members were unstructured, flexible and akin to a conversation. Interviews typically began with the participant describing their position at the Agency and then expanded to include discussion about the Members of the Advocacy Agency 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. Two staff members elected to be interviewed in pairs, and one staff member was interviewed twice.

### **Analysis.**

Causal layered analysis (CLA; Inayatullah, 1998) was used to analyse the interview transcripts. 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 and Dzidic, 2014, Inayatullah, 2004). CLA has the potential to assist in the understanding of people in context and the deeper, more complex social drivers of an issue (Bishop and Dzidic, 2014). Using CLA, social issues are deconstructed into four layers: the litany, the social causative, the discourse/worldview and the myth/metaphor.

The litany is the most proximal layer and refers to most visible or obvious construction of the issue (Bishop and Dzidic, 2014). The social causative 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 are explored at this level (Inayatullah, 2004). At discourse/worldview layer, the deeper social, linguistic and cultural structures that support or legitimise the issue are examined (Inayatullah, 2005). 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.



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 were reworked to ensure each theme had sufficient supporting data and data cohered meaningfully. Quotations were selected to support the claims made. Finally, the findings were reconstructed.

Peer coding was used to ensure research trustworthiness. Two interview transcripts were selected to be coded according to the four causal layers by all three authors independently. Once the interview transcripts were coded, the codes were compared to determine the level of inter coder agreement (Creswell, 2013). Bishop and Dzidic (2014) 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. 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 staff interviewed and the relevant peer-reviewed literature). A reflexive journal was also maintained throughout the research process. Bishop and Dzidic (2014) argued that reflexive journaling is especially important when conducting CLA as inferences are made about the deeper, cultural values influencing an issue. Reflexive journaling can help the researcher become attuned to their own positioning, values and worldviews

(Bishop and Dzidic, 2014). For reflections on the process of conducting this research see Author, Author and Author (2015).

### **Findings**

The themes identified at each causal layer are presented separately with the relevant literature and theory incorporated, prior to reconstruction of the findings. The themes identified at each causal layer are presented in Table 1.

(Insert Table 1 here)

### **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 intellectual disabilities are identified.

### **The Advocacy Agency**

Staff described the role of the Advocacy Agency and the impact it has had on the lives of its Members. Some of the staff members interviewed felt that an important role of the Advocacy Agency was to promote personal development in areas of deficit. Activities of daily living, money management and skills required for social interaction were identified as often needing development; *“It’s about learning who they are, their relationship with the community... how they can change that relationship with the community”*. The Agency was described as having an important role in empowering Members by informing them of their rights and encouraging them to be assertive. 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.*

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. Although advocacy outcomes are said to be difficult to measure, studies have reported positive outcomes including greater independence and autonomy, and improvements in self-esteem and confidence (Peter, 2002, Simons and Carter, 1992).

### **Summary of the Litany Layer**

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, historical, political and environmental factors impact upon people with intellectual disabilities.

#### **The Grouping of People with an Intellectual Disability**

Most of the staff discussed the grouping of people with intellectual disabilities into exclusive groups, as they are at the Advocacy Agency. Staff explained that government departments discourage this practice. This position is based on the principles of social role valorisation (Wolfensberger, 2000) whereby if devalued people associate with valued members of society their social image will be enhanced. The staff, however, argued that the Agency provided a safe space where people with shared experiences could support and learn from each other and form friendships; *“They want to be with people like themselves because they share the same stories, they share the same issues”*. One staff Member 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; *"It's still a big, ugly World out there and the community still has views about people with disability and even their families do"*.

Reflecting this preference, a number of studies have reported that the friendships with other people with intellectual disabilities are very important to people with this label (McVilly et al., 2006, Farmer and Farmer, 1996).

### **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"*. 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.*

Some of the staff also questioned the validity of the concept of intellectual functioning or intelligence and proposed that the ability to adapt to the changeable environment and creativity constituted intelligence. These attributes of intelligence can be likened to the concept of practical intelligence (Wagner, 2000).

### **Summary of the Social Causative Layer**

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. 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.

#### **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. One staff member explained;

*... 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.*

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 (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). Crocker and Major (1989) argued that the visibility of intellectual disability may actually be a protective factor against stigma. 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. In contrast, 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 (2010) hypothesised that this was because the perceiver was receiving inconsistent information about the category or group to which the individual belonged.



### **Low expectations and limited opportunities**

Most of the staff believed that society has low expectations of people with intellectual disabilities and often presumed incompetence or inability. These pervasive societal expectations began once the individual was recognised or formally diagnosed as having an intellectual disability. Many of the staff members distinguished between the actual ability of the person and the disability resulting from lack of opportunity; *“It’s not really about... 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 and 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 and 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’.

#### ***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, such as meaningful employment and close relationships. In the following excerpt, two staff members discuss the lives of people with an intellectual disability;

*Staff member #1: 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 come up against someone calling them something, not being able to get a job... but I think overall... I get the feeling that they have a bloody good life... 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... most of them make the most of what they have.*

*Staff member #2: (interrupting) that's because they've had to though! (laughs).*

*Staff member #1: 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 feel they're a pretty happy bunch of people...*

*Their whole lifestyle, they love their life...*

In this excerpt staff member #2 argues that people with an intellectual disability “*make the most of what they have*” because “*they've had to*”. There is no other option but to accept the status quo. 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*”?

### ***Smiley, happy people***

A related discourse about people with intellectual disabilities being ‘happy’, ‘loving’ and ‘lovable’ also emerged in this analysis. In this excerpt a staff member reflects on a conversation with a man whilst holidaying with the Members abroad;

*He came over to me and he said to me “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... will it be OK? Will it be healthy? Will it have ten fingers and toes?”. He said, “... now I’ve looked at Matty (one of the Members), it doesn’t really matter, I can love him just the way he is”. And I went ‘Wow!’ What a great attitude... There’s still a living human being that can give you love, affection, can do things, can achieve things.*

What is the underlying purpose of the world view that people with an intellectual disability 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). Lerner argued that when the integrity of this belief in a just world is threatened it produces a state of cognitive dissonance. 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, 1980). 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 suffering and deprivation.

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 and Hunyady, 2005).

**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"*. 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. One staff member 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"*.

Interestingly, despite difference being described as common to all, most of the staff interviewed stated that the wider public are often afraid of people with intellectual disabilities *because* they are different. In fact, when compared to other impairments, intellectual disability is often considered the least desirable condition (Thomas, 2000). Scior (2011) reported that people with intellectual disabilities were considered highly undesirable partners for social interactions and that ‘lay people’ generally wanted a greater social distance from people with intellectual disabilities when compared to those with physical disabilities.

### **Pushing the boundaries by being normal**

Staff members described how Members defied stereotypes by ‘being themselves’. By being visible and active within the community the Members were described as challenging the presumptions assigned to people with this label; “*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*”. The skills and abilities of the Members were not surprising to the staff, but they were astonishing to some members of the wider public. The Members were described as presenting a visual challenge to the stamp of difference and otherness that is often affixed to people with the label; “*They’re pushing boundaries by sort of being able to just... be normal*”. Intellectual disability is commonly conceptualised as an unchangeable, naturalised impairment. Genetically-oriented notions of personhood and the assumption of

incompetence limits the likelihood that people with intellectual disabilities are able to be viewed as a 'normal' and 'functional' human beings (Goodley, 2001). As a consequence of this conceptualisation, capacities or competencies are viewed as astonishing. The ordinary becomes the extraordinary in the context of intellectual disability.

### **Summary of the Discourse/Worldview Layer**

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 stories and metaphors which evoke powerful visual images.

#### **Be independent, but in the way we want you to be.**

The exclusive grouping of people with intellectual disabilities was discussed extensively by the staff interviewed. Some staff attempted to explain why people without intellectual disabilities are so uncomfortable with this arrangement; “*I think it’s about ourselves... probably through the guilt of perhaps the way that things were handled in the past... that legacy hangs around in the background*”. Exclusive grouping may be seen as harking back to the days of segregation and congregation. One staff member 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*”.



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 and Nind, 2003, Race et al., 2005). The criticisms of normalisation and image enhancement expressed by some of the staff interviewed are also echoed in the literature (e.g., Chappell, 1992, Culham and Nind, 2003, Oliver, 1999). Despite the positive change these theoretical approaches have been credited to achieving, it has been argued that normalisation lacks 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, is it 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 and Nind, 2003).

In this study, the staff expressed that the Members enjoyed spending time together as a group and rejected the view that exclusive grouping was damaging to the Members image (Wolfensberger, 1998). In contrast, 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

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). It could be argued that this presents an interesting paradox. Services and programmes, such as the Advocacy Agency, created to assist marginalised groups to become more independent and empowered may in fact have the converse effect of perpetuating control and power over people with intellectual disabilities.

### **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'.

### ***Deviancy and Intellectual Disability***

A deviant identity was described as being imposed on people with intellectual disabilities. Difference or deviance is rarely value-free. As Wolfensberger (1975) explained; "... man has been apt to see evil in deviancy" (p. 13, ). One staff member offered the following 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... But then you've got someone that has a disability that doesn't quite understand what's going on but gets aroused... then 'oh he's a weirdo'. He's the one that's pulled out of school... and made to feel really bad. Whereas, the other guys... nothing happens to them. That's just normal growing up.*

As described by staff, if a person without an intellectual disability is involved in a momentary indiscretion, it is not considered symptomatic of any inherent 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).

### ***The Eternal Child***

Another identity that was commonly described by staff as being imposed on people with intellectual disabilities was that of a child. One staff member described how Michelle, who has an intellectual disability, is punished like a child by her brothers;

*They may consider she has been naughty... they will send her to the naughty corner. Another time, she will say to me that she's not allowed to watch TV for three weeks... 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.*

Staff also suggested that members of the wider public are confronted when the Members partake in adult behaviours such as engaging in sexual relationships, getting married and consuming alcohol. Responsibility, independence and autonomy are qualities that are deeply valued in Western society (Wolfensberger, 2000). These qualities are conveyed through holding certain roles, such as being a husband/wife, father/mother or wage-earner (Wolfensberger, 2000). In addition, certain activities are considered 'rites of passage' to adulthood and with adulthood the opportunity to live the 'good life'. The good life, however, is not accessible for all adults (Peter, 2002). Australians with intellectual disabilities are less likely to be employed, married or have a family of their own and have fewer opportunities to make choices and decisions about their lives (Peter, 2002).

### ***Disability as a Master Status***

Some staff described intellectual disability as being all consuming and overriding the other identities that an individual may have. The designation of a master status was described as a common social process; *"It doesn't matter what it is. You know, it's like if you've got cancer, you're the cancer on ward 5.... 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, including low expectations and the provision of fewer opportunities. Interestingly, most staff believed that the Members did not identify as disabled. While the Members were aware that they had been assigned the label, it had little resonance in their lives; "*They actually would identify each other and themselves probably by... who's got certain leadership roles... who's bossy boots... who's ratbag at the pub*".

Echoing these views, it has been argued in the literature that the concept of intellectual disability may have little resonance to the people who live with the label (Jahoda and Markova, 2004, Rapley, 2004). People with intellectual disabilities have many other attributes and social identities beyond that imposed on them by people without intellectual disability (Fine and Asch, 1988).

### **Summary of the Myth/Metaphor Layer**

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**

Overall, the findings of this analysis suggest that people with intellectual disabilities are subjected to a number of powerful underlying processes. 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 intellectual disabilities. One such identity was that of the deviant; a threat to society or a sexual menace. It also 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. Intellectual disability also 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 is reflected in the paucity of disability literature exploring the alternative identities of people with intellectual disabilities, such as gender or ethnic identities (McVittie et al., 2008, Beart et al., 2005).

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. 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*”.

The process of dehumanisation is so powerful and pervasive 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. Interestingly, notions of people with intellectual disabilities being both normal and 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. This finding is supported in the literature (see McManus, 2010, Crocker and Major, 1989). 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 were deemed by staff to have 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. The stigmatisation and dehumanisation experienced by the Members was described as clearly not their fault.



Similarly, the deficits and inadequacies they encountered were 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 the Members are still, nevertheless, different and incompetent. The Members are 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, while on the other hand it contributes to social stigma by reducing their personal control. Examples of this process were evident in the 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 in need of help.

### **Discussion and Conclusion**

Analysis of the complex interactions that emerged across the causal layers revealed the processes of dehumanisation and victim blaming. These findings have important implications for the services that support people with intellectual disabilities. Victim blaming encourages the implementation of strategies focused on changing the individual, rather than those social systems that support the relationship between the powerful and the powerless (Rappaport, 1977, Kielhofner, 2005). It is important to note that strategies designed to support people with intellectual disabilities are well intentioned and rooted in genuine humanitarianism (Kielhofner, 2005). However, worldviews and assumptions about people with intellectual disabilities are so deeply embedded that they may go unnoticed.

To create genuine change, the system that supports the status quo must be challenged (Rappaport, 1977). Developing self-awareness and an understanding of those social structures and social processes, such as dehumanisation and victim blaming, is important but difficult. 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). Such critical reflection and questioning should be encouraged early in the context of professional education and training programmes (Kielhofner, 2005).

The assumption of incompetence and difference may be implicit to the delivery of services that support people with intellectual disabilities. Creating a dialogue with staff that support people with intellectual disabilities and mutually exploring these relationships between the powerless and the powerful represents a useful starting point. Brainstorming practical ways in which the power of their clients could be enhanced by making changes to the service may be beneficial. It is important that people with intellectual disabilities have a strong role in shaping their services and defining the outcomes (Kielhofner, 2005).

Like all qualitative research studies there are limits to the transferability of these findings (Lincoln and Guba, 1985). This study deconstructed the perspectives of staff at an advocacy agency and caution is needed when applying these findings to different contexts (Creswell, 2013). 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 and 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). 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.

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