“Disability Means, um, Dysfunctioning People”:

A Qualitative Analysis of the Meaning and Experience of Disability among Adults with Intellectual Disabilities

Key words: Intellectual disability; self-perception; adulthood (18 & older); interpretive phenomenological analysis; experience

Abstract

Background: There has been little qualitative analysis of the experience of stigma, social comparisons, and conception of identity among adults with intellectual disabilities (ID). The following study aims to develop an understanding of how adults with ID experience their own disability, and any implications relating to self-esteem, stigma, and social interactions. **Materials and Methods**: Fifteen adults with ID were interviewed using semi-structured, open-ended questions regarding disability, social interactions, and self-esteem. Interviews were analysed independently by two researchers using Interpretive Phenomenological Analysis. **Results**: Three major themes emerged during analysis, exploring pressure on participants to behave in a socially normative way, tendency to produce personal definitions of disability, and consistently limited knowledge of and discomfort around common disability terminology. **Conclusions**: Participants' clearly experienced feelings of difference, despite a lack of articulation. Limited understanding of both terminology and conceptualisation of disability status could negatively impact self-esteem, person-centred actions, and political movement.

Introduction

Whilst it is understood that diagnostic labels can have an impact on identity-formation and experience of stigma for individuals with intellectual disabilities (ID), the way in which this population encounters these labels has rarely been explored in depth (Gillman, Heyman and Swain, 2000).

Policy

Historically, individuals classified as having an intellectual disability in the United Kingdom were cared for in large, segregated long-stay hospitals (Mansell and Ericsson, 1996). An increasing demand for ID residential places against a backdrop of overcrowded and costly ID hospitals (Report of the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency, 1954-57 (1957)); post-war societal reactionism to labelling and stigmatizing people with disorders (e.g. Lemert, 1951; Becker, 1963); anti-institutionalism which viewed hospital practices as oppressive and institutionalising (Foucault, 1961; Szasz, 1961; Goffman) and a series of public scandals in institutions (see Reports of the Committees of Inquiry at: Ely (1969), Farleigh (1971), Normansfield (1978), South Ockendon (1974)),

accompanied by radical value shifts of normalisation and social role valorisation (SRV) (Nirje, 1969; Wolfensberger, 1985) and studies advocating non-restrictive forms of care (e.g. King, Raynes and Tizard 1971) led to the transfer of hospital patients to community settings in what is now known as the 'deinstitutionalisation movement'

The 1971 White Paper Better Services for the Mentally Handicapped, which was devised as a response to the first major institution scandal at Ely Hospital in Cardiff (1969), was followed by a series of initiatives including transferring funds from the Health Service to local government; and 'Care in the Community' centrally funded demonstration projects. The 1990 Health and Community Care Act led to the mass closure of hospitals, and a mixed-economy, (though one which is now arguably mainly privatised), care provision in the community currently exists.

The White Paper *Valuing People* (2001) and its successor, *Valuing People Now* (2009) argue that professionals and practitioners need to facilitate opportunities for legal and civil rights, independence, choice and inclusion. Legislation including the Disability

Discrimination Act of 1995 and the Equality Act of 2010 set out legal protections from social exclusion for those with ID, and the Mental Capacity Act of 2005 provides a framework for facilitating individual decision-making for people previously viewed as lacking capacity due to diagnosis. Most recently, the Care Act 2014 places a duty on councils to position the individual at the heart of the care process and establishes a national threshold of eligibility for services.

Identity, self-esteem and stigma

Although academic work since the 1960s has suggested that "understanding, motivation and self-control" are developed through having "a psychologically healthy self-image" or "identity" (Goffman, 1974), socially disenfranchised groups such as those with ID can experience exclusion from the dominant culture which often leads to the creation of a distinctly separate identity favouring characteristics not readily accepted by the prevailing culture (ibid). Acceptance and understanding of membership to the social category of people with ID is regarded as a necessary component to realistically formulate one's self-concept and to develop relevant and effective coping mechanisms when

interacting with a world that socially devalues disability (Szivos and Griffiths, 1990). Yet, whilst professionals, policy makers, and researchers agree that the definitions used to categorise adults with ID have important and wide-ranging implications, very little research exists which has sought to understand the meaning of both the terminology of 'disability', and the embodied experience of it (Schalock and Luckasson, 2013) from the viewpoint of the individuals with ID themselves.

There is evidence, however that people with ID—regardless of their awareness of their own disability status—experience stigma, or social treatment based on an "attribute that is deeply discrediting" (Goffman, 1974, p.13; Brown *et al*., 2003; Craig *et al.*, 2002). Stigmatisation can include overt negative categorising and behaviour such as labelling, verbal abuse and rejection as well as more insidious social exclusive behaviour such as compulsory sterilisation, and restricted opportunities (Jahoda *et al.*, 2010; Szivos and Griffiths, 1990). A lack of coherent understanding of why one occupies a socially devalued role, can result in poor self-confidence (Szivos and Griffiths, 1990) leading to

secondary outcomes such as poor self-image, poor social development and relationships, difficulties in or gaining employment, self- or societally-imposed restrictions, (Jahoda and Markova, 2004), and a lack of social support, and/or sense of belonging (Forrester-Jones *et al,* 2006).

Edgerton (1967) argued that people with ID engage in strategies to 'belong' to a more socially valued group including "passing" as a non-disabled person but often with poor psychosocial outcomes. More recently, in a focus group of six adults with ID using a day centre, Craig *et al.,* (2002) found that individuals often expressed great discomfort in identifying with disability.

Jahoda *et al*., (1988), similarly found that people with ID recognised their disability as a fundamental fact, but rejected a stigmatised status. Davies and Jenkins (1997) however, in their 3 year longitudinal study found that the knowledge and application of disability to 60 young adults (18 to 26 years) was relatively infrequent. Todd (2000) also found that adolescents with severe ID were generally unaware of their stigmatised and potentially limiting status, despite the acquisition of that status occurring at birth. When interviewed, the

majority of the sample did not acknowledge disability, and seemed to envision a future very similar to that of teens without disabilities. Similarly, Cunningham and Glenn (2004), found through a series of semi-structured interviews with young people diagnosed with Down Syndrome and their parents, that recognition of one's status as a person with ID occurred infrequently, with awareness and verbal expression of experience of stigma even less likely to occur.

Crocker and Major's (1989) offer a theory of self-protection through identification with a socially stigmatised group, arguing that such a strategy can shield an individual from stigmatisation. Branscombe, Schmitt, and Harvey (1999) further suggest that past experience of discrimination from an 'out-group' increases one's identification with a stigmatised group, increases cohesion, and serves to protect well-being through insulation. Wills (1981) argues that 'downward social comparisons' or judgements made against a person or category of people who are deemed less competent or socially valued in order to improve subjective well-being also serves the same end of protecting self-esteem of the 'with-out' group.

Todd and Shearn (1997) caution against the dangers of a partial or incorrectly-defined disability identity, stating that if people with ID are "unaware that the world they operate in rejects and discriminates against them, [they] are unable to present a challenge to that world." (ibid p.362). Albeit, service user self-advocacy and involvement in provision and planning of services cannot be executed effectively if the terminology being used is inaccessible to them, nor if the service users are unaware of common barriers to full inclusion and access. It is therefore imperative to develop a more comprehensive understanding of how individuals view themselves, disability, and others in order to see the strengths and weaknesses of self-advocacy promotion and person-centred action, identify areas of concerns regarding social relationships, and ensure better, more accessible delivery of information and services.

A systematic review (Ali *et al*., 2012) identified seventeen studies worldwide examining stigma experienced by individuals with ID. Eight of these studies were quantitative, six were qualitative, and three utilised mixed-methods. Of the mixed-methods

and qualitative studies, only five used adult participants, with two of these including adolescents in addition. At least one of the studies (Finlay and Lyons, 2000) addressed social comparisons. Some studies suggested that many of the participants were aware of their disability and stigmatised status and felt the negative ramifications associated with it (e.g. Li, 2004; Jahoda and Markova, 2004) while others argued that there was very little understanding of either (e.g. Cunningham and Glenn, 2004; Todd, 2000). Within this small body of work then, there is no clear consensus on how adults with ID understand disability and stigma despite this area being identified as important (Schalock and Luckasson, 2013). The purpose of this study was to move towards such a consensus.

Aims and objectives

The aim of this study was to understand how adults with ID experience their own disability, and whether their experience impacts on their own notions of stigma, self-esteem and social interactions. The objective was to attempt to elucidate a functional definition of 'disability' for those living with ID. It was hoped that such a

definition might act as a reference point for advocates, practitioners, researchers, and policy-makers.

It should be noted that this study uses the concepts “disability” and “intellectual disability” interchangeably unless explicitly specified. The reason for this ambiguity is two-fold: first, this project was informed by the social model of disability, which concerns the restrictions caused by societal perceptions rather than physical or cognitive impairment (UPIAS, 1976). Therefore, the social constraint or “disability” does not specifically refer to the cognitive impairment of the individual. Secondly, these concepts are often conflagrated and ambiguously defined in practical application; the distinction between the two was not obviously or spontaneously articulated by the majority of participants in the study. Both concepts were introduced independently during the study, but there was no significant difference in how participants responded to either. Nevertheless, whilst the study primarily explored what “disability” meant to the individuals interviewed, there was an opportunity to look more specifically at ID when discussing terminology

and relationships. Where this occurred, the term ID was explicitly used in the naming of themes and subthemes.

Five research questions guided the study:

- How do adults with ID compare themselves to individuals without disabilities and to others with ID?
- How do adults with ID interpret 'intellectual/learning' disability?
- Does the abstract definition of disability align with participants' understanding of their own disability?
- Who do adults with ID prefer to associate with, those with or without ID?
- To what extent does the understanding of one's disability effect self-esteem?

Method

Design

In order to delineate the 'emic' or 'insider' understandings of 'disability', a small, in-depth, exploratory study design using qualitative methods was used.

Sample

The small sample size (*n*=15) was purposively chosen to include adults with ID who were capable of granting informed consent and currently participating in an adult day service designed to be socially inclusive. With the exception of one who approached the researcher independently, all were recruited only after referral by senior staff. Of 17 individuals invited to participate, two declined.

Location

The study setting was a working farm open to the public on weekdays, which by its nature, provided opportunities for attendees with ID to interact with visitors without ID. The setting choice was also born out of convenience since the second author had recently completed a broader evaluation of adult social care day services in the county and the issue of individual notions of disability had emerged as an unsolicited theme. This led to the opportunity to conduct a more detailed study of disability as an abstract concept and how it related to experiences of individuals with ID, and was welcomed by those commissioning and delivering the day activities/opportunities

Measure

An open-ended semi-structured interview schedule was developed from previous relevant literature concerning stigma and identity, and self-esteem including Rosenberg's *Self-Esteem Scale* (1965) that addressed the five primary research questions.

Analysis

Interpretive Phenomenological Analysis (IPA) was chosen as the best way of gaining insight into participants' thoughts, ideas, and experiences of social constructions of disability and stigma, as well as their reactions to and/or interpretations of those experiences (Smith, Flower and Larkin, 2009). An inductive process, IPA seeks to produce themes from the data rather than confirming or disproving a preconceived theory. A handful of studies of ID self-advocacy groups have used IPA (e.g. Rosetti and Henderson, 2013), but these studies remain rare and do not directly address stigma or knowledge of ID terminology.

The raw data was transcribed verbatim by the lead researcher. Next, both authors read through the transcripts several times and the data was independently coded and categorised. As IPA is an iterative process,

each emergent category led to a review of all transcripts. The authors then compared codes, categories and emerging sub-themes to ensure inter-thematic reliability. There was a 58% agreement (22 of 38 initial codes) between the researchers. Elongated discussions between the authors of these codes and categories followed until saturation, yielding three final themes and nine subthemes with sixteen categories.

Ethics

The study gained a favourable ethical opinion from the University of Kent Ethics Committee (November 2014). Informed consent, voluntariness, confidentiality and the sensitive nature of the questions around stigma and identity (which might evoke sensitivities and emotions) were the ethical issues of particular relevance to this study. One month prior to beginning interviews, an accessible words and symbols information sheet, designed following guidelines for Easy Read formatting (Turnpenny and Richardson, 2013) was provided to the site manager to share with potential participants. It is not known to what extent this information was made available, although awareness of the project appeared low upon arrival. The interviewer therefore verbally

explained the nature and details of the project including confidentiality and anonymity (particularly important here due to the small sample size) to each individual in turn before asking them to participate and sign a consent form. Perry (2004) posits that sole interviews with people with ID may fail to safeguard their interests due to the distribution of authority between researcher and participant. The interviewer attempted to resolve some of these issues by socially interacting with participants for a brief time (approximately 10-15 minutes) prior to data collection, (including sharing general details about their lives with participants to put them at ease) but it is unknown to what extent power differentials were addressed given the short time available. According to Cambridge and Forrester-Jones (2003), establishing familiarity is essential to facilitate rich, meaningful data. The short time for familiarisation between participants and the researcher in this study (due to the packed timetables of participants as well as the limited timescale of the researcher) must be acknowledged as a limitation and something which should be addressed in any future study. In the event that participants became distressed during the

interview process, they were either directed toward trusted staff members, or the interview was halted until/if the interviewee wished to resume. Participants were also given the option to remove sensitive material from the interview at any point in time; one participant chose to remove several lines of the transcript following their interview.

All interviews were conducted on site in a relaxed environment identified by the participants themselves (including an office made available to participants at their request and a quiet corner of the canteen) and interviews were purposefully informal, following Prosser and Bromley's (1998) guidelines to encourage all answers and put interviewees at ease by retaining a casual atmosphere. Each interviews lasted on average for about one hour, incorporating breaks as requested.

Results

Participant Characteristics

Fifteen individuals agreed to participate in the research. Over half (66% n=10) were males and 33% (n=5) were females with an average age of 35years (with a range

from 19yrs to 63yrs). The majority of participants (87%, n=13) identified themselves as White British, with the remaining two identifying as Irish-Nigerian and Zimbabwean. Just over half of the participants (53%) lived with family members, three (20%) lived in community homes (with support from paid staff), two (13%) lived alone (one of which lived in sheltered housing), one lived with a flatmate, and one lived with their spouse.

Three primary themes, all evident in at least thirteen of the fifteen transcripts were delineated. Because this study was not quantitative, no restriction was put on how often a theme or subtheme must occur to be included. Rather, themes, sub-themes, and categories were chosen for their idiographic nature and sought to capture the full range of interpretations and experiences of all participants (see Table 1).

[Table 1.]

Theme 1: How to Be: *"As that's what peoples do."*

[P.10, L. 99-100]

Participants expressed a need to behave in a certain, societally-acceptable way that included behaviour and

appearance, and tended to compare themselves favourably against their peers with ID.

Subtheme A: The Need to Behave Normally.

> *Participant 02: I'm not naughty on the [job site], I'm not. [P.02, L.99]*

The first subtheme dealt with expectations relating to behaviour. Participant 2, in the above quote, had been asked what other people (a category that was left ambiguous intentionally) did better than they. The response avoided addressing shortcomings, and displayed a simplistic understanding of good and bad, as well as a firm ideation of what is appropriate work behaviour.

> ***Motivation derived from being "good" or not being "bad."***
>
> *Interviewer: Are you proud of yourself?*
>
> *Participant 08: Yeah [Laughs].*
>
> *Interviewer: Yeah? What makes you proud of yourself?*
>
> *Participant 08: Good. Tidy.* [P.08, L. 51-54]

The desire to be perceived as nice, clean, or quiet was a theme that emerged from eleven transcripts;

participants cited their helpfulness or cleanliness as major points of pride.

Behaviour signalling difference or disability

> *Participant 4: I don't even understand what I'm doing sometimes. Ah! That is a learning difficulties. What I was telling you!*
>
> *Interviewer: Can you say it one more time? What's a learning difficulty?*
>
> *Participant 4: What I just said! Yeah. Because sometimes I don't listen to anyone. And that's my problem. I love to play up. And push 'em. I want to push 'em too far. Yeah…I can't do that. And that's learning difficulties.* [P.04, L. 252-257, 259]

Non-adherence to so-called cultural mores, which most often included behaviours such as fighting, losing one's temper, not following directions, and poor hygiene were often used to exemplify individuals whose behaviour signalled difficulties. Similarly, these were markers used to gauge if someone had a disability, thereby establishing a link between cultural devaluation of disability and other undesirable characteristics.

Subtheme B: Generic Expectations and Identifiers

> *Participant 15: I'm hoping to get a house, like to get a house of my own one day. Not sure when exactly, but it will take a while to start planning.* [P.15, L. 670-671]

The majority of the participants did not consider disability to be a factor when identifying themselves nor their future expectations. In fact, as exemplified in the categories below, individuals largely recognised their occupation on the job site and their leisure-time activities as their primary identifiers. When considering future plans, participants often indicated non-specific goals such as marriage (regardless of current relationship status) and paid work.

Self-defined by interests

> *Interviewer: Great. So tell me about yourself. Your life, and your personality, and anything else you can think of.*
> *Participant 5: I like watching TV. I like Strictly Come Dancing, EastEnders, um, The X-Factor. I like food. Pizza, chips, burgers. I still like Chinese. I like chicken curry. It's nice…uh. I like Christmas*. [P.05, L. 13-17, 20]

When asked to describe their personalities or their lifestyles, the majority of participants, (ten of fifteen) used leisure-time preferences as their primary identifier. Moreover, it was often not what participants *did* during that time that gained the status of identifier, but rather what they *consumed,* suggesting a lack (or perhaps a lack of opportunity for) introspection.

Job site as part of identity

Many participants often considered their experiences on the job site as an important identifier when communicating who they see themselves as. It seems that productive work—regardless of whether it is paid employment or service provision—is as important a defining characteristic for these respondents with intellectual disability as it is for individuals without disabilities.

> *Interviewer: Okay. Can you tell me a little bit about yourself, what you like to do?*
> *Participant 14: I like w-w-working farm.*
> *Interviewer: Why do you like working on the farm?*
> *Participant 14: It's nice. [P.14, L. 20-24]*

Non-specific and typical future expectations

> *Interviewer: What are your future plans?*
> *Participant 10: Well, I want to go get a, um, a job.*
> *Interviewer: A job? What kind of job?*
> *Participant 10: A better job that I can work with, and get a lot of money* [P.10, L. 333-337]

Lines of inquiry regarding the future yielded very similar results across the majority of participants. Either they were unsure or uninterested, as exemplified by Participant 1 who said that they "*didn't thought about that*," or future goals were the vague expectations of an adolescent such as getting married, owning a home, or simply being "happy and healthy" [P.01, L. 212; P.03,

L.164]. When probed about the feasibility of these plans, many of the respondents were unable to further examine their answers.

Subtheme C: Social Comparisons

Participant 6: I work hard better. [P.06, L. 86]

There was significant evidence of downward social comparisons in respondents' interpretations of self and others. Additionally, respondents reported several other associated thought processes, such as labelling others as having a disability, categorising oneself as distinct from peers with ID , and using one's perceived status among peers as a means of bolstering self-esteem.

Distinct from others with intellectual disabilities

Participant 2: [Long pause]. Hm. I think. [Pause]. I'm a good boy on the job site. Everyone else is very silly. [P.02, L. 112-113]

The type of sweeping generalisation made above, which clearly distinguishes the respondent from peers with ID working alongside them on the job site, was found in two-thirds of the transcripts analysed. Interestingly, this kind of broad judgement only occurred when respondents compared themselves to other service

users on the job site, as opposed to the general population.

Labelling others as having a disability

A common occurrence throughout the interview process was the tendency to label others as having a disability, regardless of ability to articulate what that disability might be. When asked how to identify someone with a disability, Participant 11 explained:

> *Participant 11: Um, I wouldn't normally know, and, without getting used to them first. And then you do know that obviously they've got something strange about them, but gradually you know why. You don't know, when you meet someone new, you don't always know immediately. They're just a normal person—'cause I've met people who treat us quite normal. We're all really that way. I've never really got to know immediately about their disability. Immediately.* [P.11, L. 265-271].

Implicit in P11´s response are two contrasting beliefs about disability: that it is inherently abnormal, and easily identified by "strange" behaviour, and that people with disability should be treated as "normal" or individuals without disabilities because they are "*all really that way*." There appeared then to be a tension between viewing other people with ID as inferior to the population without disabilities and viewing oneself as "normal" despite identifying as having a disability.

Self-esteem linked to perceived status and work

Interviewer: Why are you proud of yourself?

Participant 15: 'Cause I know I do a really good job, I know I can do it to high standards. Most people need a bit of encouragement from me and the staff as well to do it. Me, I know what their standards are, and if you don't do it, you have to do it over and again and again. Till it happens, till it's right. And you won't move on to the next job. [P.15, L. 89-94]

Participant 15 was clearly aligning themselves with staff in the above quote. As one of the respondents who recognised and embraced their disability status, it is especially interesting that this participant did not regard themselves on level with either staff or other service users.

Theme 2: Self-Defined Notions of Disability

The second theme considered the way in which respondents understood disability in themselves and in others. Identification of disability primarily relied on physical or tangible experiences of disability. The experience of disability in oneself was often accompanied by self-degradation or feelings of injustice,

and the judgement of others played a role in perceptions.

Subtheme A: Tangible Manifestations and Experiences of Disability

> *Participant 4: Aw come on,* come on, *look at me! I know about disability.* [P.04, L.106]

The manifestation of physical features or behaviours was largely agreed as indicative of disability to thirteen of the fifteen respondents. While some participants believed that specific physical impairments such as wheelchair use suggested disability, others considered more abstract concepts such as poor or abnormal communication or literacy skills, and the presence of staff or carers.

Physical Indicators

> *Participant 11: For, I do have a friend who's a bit disabled because, and she's, she's not being able to walk without the aid of crutches. Or…since she were born practically.* [P.11, L. 199-200]

Regardless of what physical indicator (ranging from wheelchair use to epilepsy) suggested disability to the respondent, the majority produced an anecdote relating themselves or someone they knew who possessed that feature. The importance of physically experiencing

one's own or other individuals' disabilities seemed key to producing an understanding of what disability is.

Literacy, school skills, and communication

> *Interviewer: Can you tell me what [learning disability] means?*
>
> *Participant 3: Yo—I'm—[pause]*
>
> *Interviewer: Or some examples of what it's like?*
>
> *Participant: Some people won't be able to read. Writing. Um, talk. Um, see, um—not talking to somebody. Yeah. What else? Can't say if they're ill or not. If they're not very well they won't be able to say, will they? They won't be able to tell nobody, will they?* [P.03, L. 67-73]

Difficulties with reading, writing, and communication also acted as markers of disability for many participants. These features seemed to be related to ID more than disability in general, and participants tended to distance themselves using "they" rather than "we."

Receiving help and support

The final physical manifestation of disability that respondents reported frequently was the presence of staff or assistance.

> *Participant 15: Um, disability means, um, dysfunctioning people, which just means people who depend on more help as they get older and older, for people to help them. [P. 15, L. 272-274]*

What distinguishes this category is that eight of the nine respondents who made mention of receiving assistance, including Participant 15 in subsequent extracts, referred to receiving assistance for disability in the context of themselves. There is evidently something less stigmatising about receiving assistance than the previously mentioned indicators, perhaps because assistance manifests itself in greater ability due to support.

Subtheme B: Pejorative Notions of Self

Respondents who identified as having a disability tended to produce responses that fell into two categories: assigning blame for difficulties on oneself, or experiencing a broader sense of injustice living with disability without applying blame to any specific cause.

Unfairness or difficulty living with intellectual disability

Participant 10: Uh, I don't understand why I've got autism. I feel upset by it.

Interviewer: Why does it upset you?

Participant 10: It does.

Interviewer: Why?

Participant 10: 'Cause I just don't, I just, I shouldn't have it in the first place?

> *Interviewer: Why not?*
>
> *Participant 10: Um, because it just feels not fair to me, I honestly feel like I'm not there or something.* [P.10, L. 115-123]

Participant 10's dissatisfaction with their disability appeared to extend from an understanding that their autism is something that coexists in their body rather than an intrinsic part of themselves.

Self-blame or self-degradation

A portion of participants who identified as having an ID blamed their difficulty with social interactions or adaptive behaviour on themselves.

> *Participant 7: Disgusting for me.*
> *Interviewer: Disgusting?*
> *Participant 7: 'Cause everyone's always taking the mick out of me and everyone's more clever than me. [P.07, L. 285-289]*

The participant here continued to reiterate that they are not well-liked due to their ID, and their past experiences with bullying and rejection were directly related to their disability status. Another participant blamed themselves for the anxiety and difficulty experienced by their parents and professional support workers. While only three respondents discussed their experiences with self-blame and self-degradation, it is included here as a unique interpretation of disability and perception of

their own disability status and how they interact with the world.

Subtheme C: Judgement by Others

> *Participant 4: I get told I'm a waste of space* [P.15, L. 451]

Outside pressures from other people's perceptions seemed to play a role in the development of identity and interpretation of ID. Interestingly, the "other" making judgement was both individuals without disabilities and the respondents themselves appraising their peers with ID.

Bullying

Four participants shared extensively about their experiences with bullying, all occurring in integrated settings, most often in mainstreamed schools. Frequent interactions with individuals without disabilities seemed to be related to more encounters with bullying and harassment as well as poor self-image among respondents:

> *Interviewer: Yeah? And what is 'it'? What is autism like?*
>
> *Participant 10: Not very nice.*
>
> *Interviewer: In what way?*

> *Participant 10: Like, people call you names, take the mick out of you.* [P.10, L. 132-135]

Intellectual disability associated with socially undesirable characteristics

> *Participant 2: That's—X done it before. X. You met him on the bus.*
>
> *Interviewer: X has a learning disability? Can you—what's he like?*
>
> *Participant 2: He's fine. He's very [motion] like that.*
>
> *Interviewer: What is the word for that?*
>
> *Participant 2: He's very fat.* [P.02, L. 202-206]

One association that came up multiple times across half of the participants was the connection between ID and socially undesirable characteristics such as being overweight or talking excessively. Respondents, regardless of how articulate they were about stigma, seemed to understand on some level that ID is a devalued trait in society.

Job site indicative of intellectual disability

The final extrinsic factor that participants related to ID was the job site itself. Respondents were often aware that their employment was not typical—particularly that they were not paid and the job site was funded by the local authority, and was offered only to individuals

with ID. Respondents were also often aware that staff were not service users and did not have the same needs.

> *Participant 4: Yeah. And that's why we're on the farm. It is for learning difficulties as well.* [P.04, 175-176]

Theme 3: Confused Terminology

> *Participant 1: I do know what it is, but I don't know.* [P.01, L. 112]

The final theme deals with how participants defined conventional disability terminology. The vast majority, fourteen of fifteen interviewees, had partial, incorrect, or very limited knowledge of terminology that is commonly used in services.

Subtheme A: Very Limited Familiarity with Terminology

Ten respondents had no or very limited knowledge of at least some of the terminology presented. "Intellectual disability" or "learning disability" were the least accessible terms to this population, although some, like Participant 6, were not familiar with euphemistic terms either:

> *Participant 6: Special needs? What's that?* [P.06, L. 248]

Subtheme B: Familiarity but Unable to Articulate Meaning

The second subset of respondents had some knowledge of the terms, often citing that they had heard them from staff or informal carers, but were unable to provide a meaning for them. Several respondents reported that they had learned disability terms while in school, but now that they were no longer in an educational environment, they couldn't recall the meaning.

> *Interviewer: And so, do you know the word 'disability'?*
>
> *Participant 7: No. I've heard it lots of times.*
>
> *Interviewer: Yeah, so, you've heard it lots of times, do you know what it means? […]*
>
> *Participant 07: My mum told me something about it, but I forgot.* [P.07, L. 196-199, 202]

Subtheme 3: Discomfort Despite Inarticulation

Participants were almost universally uncomfortable discussing disability terminology, regardless of the ability to define the meaning of the terms.

> *Participant 9: I have heard it before. Disab-abilities.*
>
> *Interviewer: Do you know what it means?*
>
> *Participant 9: Uh, um. [Pause].Hm. I don't know. I don't want to answer that.* [P.09, L. 132-134]

Respondents who expressed discomfort seemed to have a perception that disability was a taboo subject that should not be discussed in depth. Perhaps if participants had been more familiar with the researcher, they would have been more forthright with opinions, but as it stood, it appeared that the nine participants who responded in this way did not find disability an appropriate subject for discussion.

Discussion and Conclusions

The findings indicated that although participants were not always able to articulate feelings of difference verbally, many seemed to experience stigmatisation and "otherness." The response to these experiences most often appeared to be adherence to behaviours and social norms that suggest "non-otherness." These "passing" behaviours, which were born of justified rejection of disability status and overwhelming self-doubt when appearances fell short of non-disabled, were a method to appear to belong to a more highly valued social group (Edgerton, 1967). The desire to appear "normal" was further developed by the identification of the "other" among friends and

colleagues with ID. Additionally, the typical future expectations, primarily paid, meaningful employment and deeper personal relationships, suggested a desire to obtain a more socially valid role. Despite the fact that these expectations are very nearly identical to those found by Forrester-Jones and colleagues (2002) and Todd (2000) when interviewing a similar population, it is still exceptionally rare for adults with ID to achieve either, and very little change has occurred in services to support these goals.

As expected, downward social comparisons occurred frequently throughout interviews. Participants who favoured this type of comparison seemed to have excellent self-esteem, and the small number of participants who made comparisons between themselves and individuals without disabilities reported poorer self-esteem and greater overall dissatisfaction. These findings are in line with previous literature (Finlay and Lyons, 2000; Festinger, 1954; Wills, 1981). Participants strongly associated their identity with how they were perceived by their peers and on the job site, very rarely drawing from experiences outside of activities and services specific to people with ID.

Additionally, Finlay and Lyons (2000) found that when downward comparisons were made, they most likely involved appraisals of good versus bad or bizarre behaviour. The current study also found these value-laden judgements, with participants almost exclusively judging themselves and their peers on the basis of behaviour on the job site. With the exception of Participant 15, who appeared to have broader experiences in integrated settings than the other respondents, no comparisons were made against individuals without disabilities. These findings support the concept that membership in a stigmatised group can act as a protection from the effects of stigma by insulating oneself from more competent social groups.

Respondents often experienced difficulty with self-reflection, seemingly having limited past experiences answering questions that require introspection and self-examination. Participant 5 provides a tangible example of this difficulty:

> *Interviewer: What's your personality like?*
>
> *Participant 5: Um. [Sighs]. I haven't got a clue.* [P.05, L. 28-29]

Todd and Shearn (1997) reported a similar pattern of response from their participants, arguing that their sample appeared "invisible to themselves" (p. 363).Despite this, it was clear that participants experienced feelings of difference and rejection from individuals without disabilities, which was perhaps exasperated by an inability to express their feelings in those situations. Furthermore, participants' obvious discomfort with the topic of disability suggested that regardless of the ability to verbally express it, disability status is experienced on some level. Craig, *et al* (2002) found a similar phenomenon.

Finally, disability as a concept seemed to develop for these individuals via a collection of intrinsic and extrinsic factors. The intrinsic factors included phenomena such as actual physical or cognitive impairment and the extrinsic were primarily the appraisals made by others. In combination, these factors influenced the development of an interpretation of disability that includes both its topography and its connotations. The directionality of the relationship between judgement coming from self and judgement coming from others, however, is not known. The poor

psychosocial outcomes experienced by some participants may be the result of a self-fulfilling prophecy, or a set of beliefs that triggers a behaviour change that inadvertently proves the belief (Merton, 1948). Beck (1967) alternatively suggests that individuals who already possess low self-esteem may be "hypersensitive to negative feedback" and therefore become entrapped in a cycle of self-degradation and perceptions of negative judgements from others. Further study is necessary to better understand the relationship between internal and external factors in the development of self-concept and understanding of disability.

Towards a Theory of Subjective ´Disability´

While the ultimate aim of Interpretive Phenomenological Analysis, in its truest form, is not to develop generalizable theory based on the idiographic findings, it is the belief that the data here supports a possible theoretical relationship between the major themes and subthemes, which is illustrated in Figure 1 below.

[Figure 1.]

The above figure represents a basic flow of negative self-image and understanding of disability stemming from an initial confusion surrounding disability terminology. Without a clear comprehension of disability and associated terms and diagnoses, one is forced to develop one's own notions of disability based on tangible manifestations, external pressure from others, and pejorative self-degradation. A decidedly negative connotation is attached to disability conceptualisation, which encourages behaviours that dissociate one from the label. These factors simultaneously impact and are impacted by one's interpretations of how to be. The cyclical feedback pattern represented above is indicative of the aforementioned relationship between these two factors, whose directionality is not well-understood. Smaller arrows represent additional interplay between certain factors. The desire to behave normally, when not achievable, further contributes to pejorative notions of self. Building from the theory that downward social comparisons are a mechanism used to increase subjective well-being, judgement by others on an individual, which lowers subjective well-being, will

influence the prevalence of downward social comparisons. Additionally, a strict adherence to social norms is likely to increase discomfort when talking about disability, particularly disability relating to oneself. By avoiding further discussion, one perpetuates misunderstandings around disability, and the cycle continues. In this model, the confusion and subsequent discomfort with terminology acts as an entry point to a cycle of self-degradation, judgement from others, and pressure to conform to socially-valued and non-disruptive behaviours. Using this conceptualisation, one could theorise thereby that improving one's understanding of disability, an alternative cycle with more positive outcomes could be activated. A visual representation of this virtuous cycle can be seen below in Figure 2.

[Figure 2.]

Limitations

Firstly, all participants were recruited from a single service with a limited number of staff and engagement with others, which undoubtedly limited the scope of experiences that participants had. It is possible that similarity of understanding is rooted in similarity of

experience. Secondly, the nature of the farm day centre was one that required a certain amount of physical exertion and coordination from service users, who were also capable of excellent expressive communication, which likely biased the sample toward individuals with milder disabilities, fewer adaptive behaviour deficits, and less medical health problems. Additionally, inclusion in an ID-specific service was taken as de facto evidence of intellectual disability, which may not be accurate (Whitaker, 2008). A sample with more rigorous inclusion criteria that includes individuals with communication difficulties would undoubtedly enhance the findings.

The sample covered an age range of 44 years, meaning that older participants likely experienced several shifts in terminology and practice throughout their lifetimes. Differences in schooling and living arrangements also likely impacted experiences and interpretations. With a relatively small sample size, it is impossible to stratify the data in a useful way—a follow-up study with a greater number of participants purposively selected to analyse variations in experiences based on these characteristics would likely

yield an even greater understanding of how individuals formulate their identities and conceptualise disability.

Regarding researcher variables, the interviewer in this study was North American, while the study was conducted in the United Kingdom; the accent and pronunciation of certain terms seemed to influence understanding of questions in several participants.

Implications

In the light of specialist social policies for people with ID such as Valuing People (2001) and Valuing People Now (2009), which foster rights, independence, choice and social inclusion, knowledge and understanding about how people with ID view themselves in terms of their social desirability, status, and self-esteem as well as their perception of their own and others' disabilities is important. Additionally, addressing the taboo nature of disability at an individual level can facilitate conversation among policy makers, practitioners, and service users to break the vicious cycle of socially normative behaviour and inaccurate, negatively connoted understanding of intellectual disability.

Recent austerity policies in the United Kingdom disproportionately affect individuals with disabilities (Atkinson, *et al.,* 2012). Sudden loss of services due to funding cuts or ineligibility resulting from the national threshold implemented with the Care Act 2014 could have wide-ranging social and psychological implications. Individuals who have primarily developed their sense of intellectual disability and themselves in the social environment of ID-specific services are likely to experience anxiety, confusion, and poor self-esteem when forced into a social context that systematically discriminates against them. Better understanding of how individuals with ID conceptualise themselves and intellectual disability is key to safeguarding their interests and psycho-social health in the midst of fluctuating service provision. Additionally, empowering individuals with ID to develop vocabulary and understanding is necessary to facilitate their participation in the national dialogue about policies with massive consequences on their quality of life.

At a systems level partial or non-existent terminology could pose a serious challenge to person-centred action, choice-making, and political movement

in this population. As Oliver and Barnes (1998) suggest, the self-advocacy movement cannot thrive unless its participants are capable of engaging in discourse and challenging unjust paradigms. Moving from the experiential understanding of disability into the discursive understanding is a key to furthering the disability rights movement (Oliver and Barnes, 1998). Beart (2005) suggests that the primary barriers to individuals claiming the label of "disabled" amongst that population are "people with learning disabilities not having access to the meanings and discussions about 'learning disabilities' and the emotional impact of the label" (p. 129). These two components, which are essentially the poor comprehension of disability terminology and self-degradation stemming from negative judgements of others as reported in this study, appear repeatedly in the literature as obstacles to healthy and comprehensive identification with disability (e.g Cunnigham & Glenn, 2004; Li, 2004; Jahoda & Markova, 2004). The interplay between these variables is mediated by the maladaptive definitions of disability produced by individuals without access to more positive models, as exemplified in the theory produced above.

Further study into how increasing knowledge and encouraging a cultural shift away from valuing normalcy impacts self-concept and understanding of disability is a valuable next step after the conclusion of this study. Findings from this study and past literature suggest that conceptualising disability in a more precise manner could pose a challenge to the negative appraisals made by oneself and others, which in turn may limit the value placed on behaviour that appears “normal” and encourage self-expression and individuality. Investigation into methods of shifting the cultural understanding of disability is imperative for ensuring the human rights of the population with ID. A comprehension of ID and self situated in the context of disability are essential to full inclusion, equality, and rejection of discrimination for all people with ID.

References

Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012).Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review.*Research in Developmental Disabilities, 33*(6), 2122-2140. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2012-24108-050&site=ehost-live

Atkinson, W., Roberts, S., & Savage, M. (.). (2012). *Class inequality in austerity britain: Power, difference and suffering*. Basingstoke: Palgrave Macmillan.

Beart, S. (2005). 'I won't think of meself as a learning disability. but I have': Social identity and self-advocacy. *British Journal of Learning Disabilities, 33*(3), 128-131. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2005-08923-008&site=ehost-live

Beck, A. (1967).*Depression: Clinical, experimental and theoretical aspects*. New York: Hoeber.

Becker, H. S. (1963). *Outsiders: Studies in the sociology of deviance*. Oxford, England: Free Press Glencoe. Retrieved

from http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=1965-08393-000&site=ehost-live

Branscombe, N. R., Schmitt, M. T., & Harvey, R. D. (1999). Perceiving pervasive discrimination among africanamericans: Implications for group identification and well-being. *Journal of Personality and Social Psychology, 77*(1), 135-149. doi:10.1037/0022-3514.77.1.135

Brown, M. R., Higgins, K., Pierce, T., Hong, E., &Thoma, C. (2003). Secondary students' perceptions of school life with regard to alienation: The effects of disability, gender and race. *Learning Disability Quarterly, 26*(4), 227-238. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2004-10529-001&site=ehost-live

Cambridge, P., & Forrester-Jones, R. (2003).Using individualized communication for interviewing people with intellectual disability: A case study of user-centred research. *Journal of Intellectual and Developmental Disability, 28*(1), 5-23. doi:10.1080/136682503100008687

Care act 2014, London: HMSO

Craig, J., Craig, F., Withers, P., Hatton, C., & Limb, K. (2002). Identity conflict in people with intellectual disabilities: What role do service-providers play in mediating stigma? *Journal of Applied Research in Intellectual Disabilities, 15*(1), 61-72. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2002-02321-006&site=ehost-live

Crocker, J., & Major, B. (1989). Social stigma and self-esteem: The self-protective properties of stigma. *Psychological Review, 96*(4), 608-630. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=1990-04498-001&site=ehost-live

Cunningham, C., & Glenn, S. (2004). Self-awareness in young adults with down syndrome: I. awareness of down syndrome and disability. *International Journal of Disability, Development and Education, 51*(4), 335-361. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2004-21756-002&site=ehost-live

Davies, C. A., & Jenkins, R. (1997). 'She has different fits to me': How people with learning difficulties see themselves. *Disability & Society, 12*(1), 95-109. Retrieved from

http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=1997-07252-006&site=ehost-live

Department of Health (DoH).(1971). *Better services for the mentally handicapped.* (). London: HMSO.

Valuing people now, London: The Stationary Office (2009).

Disability discrimination act 1995, London: HMSO

Edgerton, R. B. (1967). *The cloak of competence: Stigma in the lives of the mentally retarded*. San Francisco, CA: University of California Press.

Equality act 2010, HMSO: LondonU.S.C.

Festinger, L. (1954). A theory of social comparison processes. *Human Relations, 7*, 117-140.

Finlay, W. M. L., & Lyons, E. (2000). Social categorizations, social comparisons and stigma: Presentations of self in people with learning difficulties. *British Journal of Social Psychology, 39*(1), 129-146. doi:10.1348/014466600164372

Forrester-Jones, R., Carpenter, J., Cambridge, P., Tate, A., Hallam, A., Knapp, M., & Beecham, J. (2002). The quality of life of people 12 years after resettlement from long

stay hospitals: Users' views on their living environment, daily activities and future aspirations. *Disability & Society, 17*(7), 741-758. doi:10.1080/0968759021000068469

Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P., Cambridge, P., Tate, A., Beecham, J., Wooff, D. (2006). The social networks of people with intellectual disability living in the community 12 years after resettlement from long-stay hospitals. *Journal of Applied Research in Intellectual Disabilities, 19*(4), 285-295. doi:10.1111/j.1468-3148.2006.00263.x

Foucault, M. (1961).*Madness and civilisation: A history of insanity in the age of reason*. New York: Random House.

Gillman, M., Heyman, B., & Swain, J. (2000). What's in a name? the implications of diagnosis for people with learning difficulties and their family carers. *Disability & Society, 15*(3), 389-409. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2000-07929-001&site=ehost-live

Goffman, E. (1974). *Stigma; notes on the management of spoiled identity.* New York: Jason Aronson.

Heal, L. W., & Sigelman, C. K. (1990). Methodological issues in measuring the quality of life of individuals with mental retardation. In R. L. Schalock, M. J. Begab (Eds.), *Quality of life: Perspectives and issues* (pp. 161-176). Washington, DC, US: American Association on Mental Retardation. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=1990-98020-010&site=ehost-live

Health and community care act 1990, London: HMSO

Jahoda, A., & Markova, I. (2004).Coping with social stigma: People with intellectual disabilities moving from institutions and family home. *Journal of Intellectual Disability Research, 48*(8), 719-729. doi:10.1111/j.1365-2788.2003.00561.x

Jahoda, A., Markova, I., & Cattermole, M. (1988).Stigma and the self-concept of people with a mild mental handicap. *Journal of Mental Deficiency Research, 32*(2), 103-115. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=1988-29993-001&site=ehost-live

Jahoda, A., Wilson, A., Stalker, K., & Cairney, A. (2010). Living with stigma and the self-perceptions of people with mild

intellectual disabilities. *Journal of Social Issues, 66*(3), 521-534. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=2010-18517-007&site=ehost-live

Lemert, E. (1951). *Social pathology: A systematic approach to the theory of sociopathic behavior*. Michigan, USA: McGraw-Hill.

Li, E. (2004). Self perceived equal opportunities for people with intellectual disability. *International Journal of Rehabilitation Research, 27*, 241-245.

Mansell, J., & Ericsson, K. (.). (1996). *Deinstitutionalization and independent living: Intellectual disability services in britain, scandinavia, and the USA*. London: Chapman and Hall.

Mental capacity act 2005, London: HMSO

Merton, R. (1948). The self-fulfilling prophecy. *The Antioch Review, 8*(2), 193-210.

Nirje, B. (1969). The normalization principle and its human management implications.In R. Kugel, & W. Wolfensberger (Eds.), *Changing patterns in residential*

services for the mentally retarded. Washington, DC: Author.

Oliver, M. & Barnes, C. (1998).*Disabled people and social policy*. New York: Addison Wesley Longman.

Perry, J. (2004). Interviewing people with intellectual disabilities. In E. Emerson , C. Hatton , T. Thompson & T. Parmenter (Eds.), *The international handbook of applied research with intellectual disabilities*. United Kingdom: Wiley & Sons.

Prosser, H., & Bromley, J. (1998).Interviewing people with intellectual disabilities. In E. Emerson, C. Hatton, J. Bromley, A. Caine, E. New York, NY, US: John Wiley & Sons Ltd. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=1998-06692-005&site=ehost-live

Report of the committee of inquiry at ely hospital (cmnd 3975). (1969). London: HMSO.

Report of the committee of inquiry at farleigh hospital (cmnd 4557). (1971). London: HMSO.

Report of the committee of inquiry at normansfield hospital (cmnd 7537). (1978). London: HMSO.

Report of the committee of inquiry into south ockendon hospital. (1974). London: HMSO.

Rosenberg, M. (1965).*Society and adolescent self-image*. Princeton, NJ: Princeton University Press.

Rosetti, C., & Henderson, S. (2013). Lived experiences of adolescents with learning disabilities. *The Qualitative Report, 18*, 1-17.

Royal commission on the law relating to mental illness and mental deficiency (percy commission): Minutes, papers and reports (1957). (). Great Britain: The National Archives.

Schalock, R. L., & Luckasson, R. (2013). What's at stake in the lives of people with intellectual disability? part I: The power of naming, defining, diagnosing, classifying, and planning supports. *Intellectual and Developmental Disabilities, 51*(2), 86-93. doi:10.1352/1934-9556-51.2.086

Sigstad, H. M. H. (2014). Characteristic interviews, different strategies: Methodological challenges in qualitative interviewing among respondents with mild intellectual disabilities. *Journal of Intellectual Disabilities, 18*(2), 188-202. doi: 10.1177/1744629514523159

Smith, J., Flower, P., & Larkin, M. (2009).*Interpretative phenomenological analysis: Theory, method and research.* London: Sage Publications.

Stalker, K., Gilliard, J., & Downs, M. G. (1999).Eliciting user perspectives on what works. *International Journal of Geriatric Psychiatry, 14*(2), 120-131. doi:10.1002/(SICI)1099-1166(199902)14:2<120::AID-GPS947>3.0.CO;2-9

Szasz, T. (1961).*The myth of mental illness*. New York: Harper and Row.

Szivos, S., & Griffiths, E. (1990). Consciousness raising and social identity theory: A challenge to nomalization. *Clinical Psychology Forum, 28*

Szivos-Bach, S. (1993). Social comparisons, stigma and mainstreaming: The self esteem of young adults with a mild mental handicap. *Mental Handicap Research, 6*(3), 217-236. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=1994-06159-001&site=ehost-live

Valuing people: A new strategy for learning disability for the 21st century, London: The Stationary Office (2001).

Todd, S. (2000). Working in the public and private domains: Staff management of community activities for and the identities of people with intellectual disability. *Journal of Intellectual Disability Research, 44*(5), 600-620. doi:10.1046/j.1365-2788.2000.00281.x

Todd, S., &Shearn, J. (1997). Family dilemmas and secrets: Parents' disclosure of information to their adult offspring with learning disabilities. *Disability & Society, 12*(3), 341-366. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=1997-06838-002&site=ehost-live

Turnpenny, A., & Richardson, L. (2013). *How to produce easy read information: A review of available guidance.* Tizard Centre, University of Kent.

UPIAS (1976) Fundamental Principles of Disability.Union of the Physically Impaired Against Segregation.

Wills, T. A. (1981).Downward comparison principles in social psychology. *Psychological Bulletin, 90*(2), 245-271. doi:10.1037/0033-2909.90.2.245

Wolfensberger, W. (1985). Social role valorisation: A new insight, and a new term, for normalisation. *Australian Association for the Mentally Retarded Journal, 9*(1), 4-11.

Zetlin, A. G., & Turner, J. L. (1985). Transition from adolescence to adulthood: Perspectives of mentally retarded individuals and their families. *American Journal of Mental Deficiency, 89*(6), 570-579. Retrieved from http://search.ebscohost.com/login.aspx?direct=true&db=psyh&AN=1985-25745-001&site=ehost-live