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Has Social Policy Challenged or Continued Personal Experiences and Understandings of ‘Disability’? A qualitative study of people with Intellectual Disabilities.

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Abstract

Background

Diagnostic labels can impact identity-formation and quality of life for individuals with intellectual disabilities (ID) (Gillman, Heyman, & Swain, 2000). The understanding of the term ‘disability’ to those who experience the ramifications of its clinical and political definition, however, has rarely been explored in depth. Similarly, whilst stigma is a well-studied phenomenon in this population (e.g. Szivos-Bach, 1993; Abraham et al, 2004), few studies qualitatively explore these issues. 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, this study aimed to develop an understanding of how adults with ID experience their own disability and how this impacted their self-esteem, social interactions and stigma. The objective was to illuminate a functional definition of ‘disability’ by those living with ID which may act as a reference point for advocates, practitioners, researchers, and policy-makers. The study addressed the following research questions:

- How do adults with ID interpret ‘disability,’ and does it relate to their understanding of their own disability?
- How do adults with ID compare themselves to typically-developing individuals and other individuals with ID?
- Do adults with ID prefer to associate themselves with those with or without ID?
- To what extent does the understanding of disability effect self-esteem in this population?

Method

This small, exploratory study used semi-structured open-ended interviews. Fifteen adults with ID capable of giving informed consent and currently attending an adult day service (a working farm open to the public) in the United Kingdom participated in one-on-one interviews spanning 10-45 minutes. Interpretive Phenomenological Analysis (Smith, Flowers and Larkin, 2009) was used to understand the idiographic experience of the participants while critically engaging with common themes across their accounts.

Results

Three primary themes were identified following analysis of the transcripts. The first of these addresses the way in which participants conceptualised how to behave, namely by seeking “normal” appearances and comparing themselves favourably against peers with ID. Secondly, participants seemed to develop their own understanding of disability based on a series of intrinsic factors—such as actual cognitive or physical impairment—and extrinsic pressures. Finally, the sample displayed limited, partial, or incorrect understandings of common disability terminology as well as discomfort with the entire line of enquiry.

Conclusions

The implementation of a new national minimum social care eligibility threshold this April (Care Act 2014) may mean changes to accessing social services for many individuals with ID. The impact of this regulation on identity and self-esteem presents a unique challenge during the transition period; an individual who primarily compares himself to other individuals with ID may need increased emotional support if transitioning out of ID-specific social services. Additionally, developing a better understanding of how individuals with ID conceptualise themselves and others is imperative for continuing to ensure genuine person-centred planning (DoH 2001; 2009) within a potentially new era of social care provision.

Introduction

Whilst any disorder may, in part, be socially constructed, (Sampson and Raudenbush, 2004) for the purposes of diagnosis and subsequent application for economic and social care, intellectual disability (ID) is commonly defined as a condition where the person has an IQ of less than 70; impaired functional abilities (e.g. difficulties with communication and/or self-care) and where the onset of the impairment has existed before the age of 18 years (see DSM-V; ICD-10). UK prevalence rates of ID are imprecise due to the lack of a comprehensive national data set, and only include individuals known to ID services. Current estimates suggest that roughly 2% of the UK population may be described as having an ID (DoH 2001; Emerson and Hatton 2004).

Policy

UK government policy in relation to people with ID has reflected a graduated change in attitudes towards, and thinking about the type of care and support individuals with this diagnosis need. Up until the 1950s, care for people with ID was mainly provided in segregated institutions (Mansell and Ericsson 1996). A range of factors however, led to a process of transferring patients from long-stay hospitals into community settings, known as the 'deinstitutionalisation' movement. Push factors away from long-stay hospital care included: 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 stigmatising 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: Farleigh (1971), Normansfield (1978), South Ockendon (1974)), accompanied by radical value shifts of normalisation and social role valorisation (SRV) (Nirje, 1969; Wolfensberger, 1985) as well as studies advocating non-restrictive forms of care (e.g. King, Raynes and Tizard 1971).

The 1971 White Paper Better Services for the Mentally Handicapped 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) advocated that whilst people with ID were physically living in community settings, more needed to be done to support and facilitate opportunities for legal and civil rights, independence, choice and inclusion (p23-24). Legislation including the Sex Discrimination Act 1975; Disability Discrimination Act 1995; Human Rights Act 1998; Race Relations (Amendment) Act 2000 legally protect individuals including those with ID from being socially excluded. Most recently, the Mental Capacity Act 2005 set out provisions to support the presumption of individual decision making for people with ID whilst the Care Act 2014 places a duty on councils to promote self-advocacy and provide independent advocacy (IA) for those who have difficulties or are unable to be involved in the 'process of

care'. It is argued that IA will maximise individual's involvement in decisions about their lives by helping them to express their needs and wishes, secure their rights and represent their interests as well as obtain the care and support they need, thereby promoting 'social inclusion, equality and social justice'. By placing the individual at the heart of the care process, this further acknowledges their personhood and identity (see Care Act 2014 s1 paras 1-3).

Identity, self-esteem and stigma

Although academic work since the early 1960s has suggested that 'understanding, motivation and self-control' is developed through having "a psychologically healthy self-image" or 'identity' (see Goffman's seminal work *Stigma* (1963)), 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. Acceptance and understanding of membership to the social category of people with ID is regarded as a necessary component to "enable realistic self-appraisal" 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 far-flung 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, behaviour, or reputation that is socially discrediting" (Brownet al., 2003; Craig et al., 2002; Goffman, 1963). Stigmatisation can include overt negative categorising and behaviour such as labelling, verbal abuse and rejection as well as more subtle social exclusive behaviour such as compulsory sterilisation, and restricted freedoms and 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 "uncertainty, anxiety, and insecurity" (Szivos-Bach 1993) leading to secondary outcomes such as poor self-image, low confidence, 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 a.,l 2006).

Edgerton (1967) argued that people with ID engage in strategies to appear to 'belong' to a more socially valued group including "passing" as 'neurotypical' but with often poor psychosocial outcomes. More recently, Craig *et al.*, (2002) conducted a focus group of six adults with ID in adult day services, and found that they often expressed great discomfort in identifying with disability, or rationalised their inclusion in disability services in some way that suggested that they did not possess an ID. The choice to accept membership in the socially-stigmatised group of individuals with ID may occur on a conscious or subconscious level, be informed by conscious awareness of stigmatisation or interpretations of experiences that occur at a subliminal level, and may be verbalised or remain unarticulated.

Jahoda *et al.*, (1988), found that the majority of their sample of people with ID recognised their disability as a fundamental fact, but rejected a stigmatised status. Davies and Jenkin (1997) however, in their 3 year longitudinal study found that the knowledge base of ‘disability’ and the application of disability to 60 young adults aged 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 typically-developing teens. 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.

Alternatively, Crocker and Major’s (1989) theory of self-protective properties of stigma suggests that, identifying with a socially stigmatised group can shield an individual from experiencing the poor psychosocial outcomes related to stigmatisation through lateral comparisons and the shift of values toward those more prevalent within the ‘in-group’. Branscombe, Schmitt, and Harvey (1999) further suggest that past experience of discrimination from an ‘outside-group’ increases one’s identification with a stigmatised group, increases cohesion, and serves to protect well-being through insulation. However, Festinger’s (1954) social comparison theory suggests that upward comparisons (that is, appraisals of oneself in contrast to an individual deemed more competent) lead to greater dissatisfaction overall although Finlay and Lyons (2000) argue that upward comparisons rarely occur. 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.

Nevertheless, Zetlin and Turner (1985) argue that the implicit rejection of one’s peer group by non-acknowledgement of similarities is likely to produce poor social outcomes such as fewer relationships and social seclusion, leading to isolation stemming from a systematic rejection of peers with disabilities coinciding with a rejection by typically-developing peers.

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. Therefore, it is imperative to develop a more comprehensive understanding of how individuals view themselves, disability, and other people 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 (Aliet *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).

Aims and objectives

The aim of the study was to develop an understanding of 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 illuminate a functional definition of 'disability' for those living with ID, which could act as a reference point for advocates, practitioners, researchers, and policy-makers. Four research questions guided the study:

- How do adults with ID compare themselves to typically-developing individuals and to others with ID ?
- How do adults with ID interpret 'intellectual/learning' disability and does that abstract definition align with their 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 the site manager and senior staff. Of 17 individuals who were approached to participate, two declined.

Location

The study setting was a working farm open to the public on weekdays, which by its nature, provided many 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's notions of disability had emerged as an unsolicited theme. This led to the opportunity to conduct a more detailed study of the theme 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 and scales concerning stigma and identity, and self-esteem including Rosenberg's Self-Esteem Scale (1965) that addressed the four primary research questions including how participants viewed and interpreted their own disability status.

Analysis

Interpretive Phenomenological Analysis (IPA) was chosen as the best way of gaining an understanding of 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 regarding membership to self-advocacy groups and acceptance of ID 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 of these codes and categories followed until saturation, yielding three final themes and nine subthemes with sixteen categories.

Ethics

The study gained ethical clearance 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 the study and sample. 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. Therefore, the interviewer 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. This was resolved in part, by the interviewer socially interacting with participants (approximately 10-15 minutes) prior to collecting data in addition to meeting all of the attendees and introducing herself on a prior occasion for a day a month before data collection which, it is argued is imperative to collecting rich, meaningful data (Cambridge and Forrester-Jones 2003). In the event that participants became distressed when discussing what it meant to have a disability, they were either directed toward trusted staff members, or the interview was halted until/if the interviewee wished to resume. All participants were also given the option to remove sensitive material from the interview at any point in time; one participant choosing 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 and interviews were purposefully informal, following Prosser and Bromely's (1998) guidelines to encourage all answers and put interviewees at ease by retaining a casual atmosphere. Interviews lasted between 10 minutes and an hour, incorporating breaks as requested or needed. All interviews were recorded rather than annotated in an effort to allow the data collection to be more conversational rather than interrogative. The semi-structured nature of the interview schedule addressed some of the difficulties associated with interviewing individuals with ID such as acquiescence, inconsistency, and low responsiveness by allowing flexibility and reiteration (Stalker, Gilliard, and Downs, 1999; Sigstad, 2014, Heal and Sigelman, 1995).

Results

Sample Characteristics

Fifteen individuals agreed to participate in the research. Over half (66% n=10) were males whilst 33% (n=5) were females. The average age of participants was 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, 3 (20%) lived in community homes (with support from paid staff), 2 (13%) lived alone (1 lived in sheltered housing), 1 lived with a flatmate, and 1 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.

Summary of Themes

Themes	Subthemes	Categories
How to Be (14)	Behaving "normally" (14)	Motivated by Being Good (11)
		Behaviour Signals Difference (8)
	Generic Expectations and Identifiers (14)	Self-defined by Interests (10)
		Job Site as Part of Identity (11)
		Future Expectations Typical (10)
	Downward Social Comparisons (13)	Self-esteem Linked to Status (9)
		Labelling Others (9)
		Distinct from Others (10)
	Self-defined Notions of Disability (14)	Tangible Manifestations or Experiences (13)
Physical Indicators (7)		
Literacy/Communication (8)		
Pejorative Notions of Self (6)		Unfairness Living with ID (6)
		Self-blame or Degradation (3)
Judgement of Others (8)		Bullying (4)
		Undesirable Characteristics (7)
	Job Site Association (6)	
Confused Terminology (14)	Limited Familiarity (10)	
	Unable to Articulate Meaning (11)	
	Discomfort Despite Inarticulation (9)	

NB. Numbers in parentheses represent the number of participants who referenced the theme/category

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. Further examples of this desire to abide by certain cultural norms were broken into two categories: motivated by being “good” or not being “bad,” with poor behaviour as a signal of difference or disability.

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 appeared in eleven of the fifteen transcripts. Participants, most often when asked if they were proud of themselves or if they possessed skills and abilities greater than anyone else, would respond that their helpfulness and cleanliness were major points of pride.

Behaviour signalling difference or disability

In contrast to non-disruptive behaviour as a source of pride, participants reported that “silly” or attention-grabbing behaviour to be a signal that someone was different, and often that the person in question possessed a difficulty or disability. Participant four provided an excellent example of this type of response:

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 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 an ID, 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 that would be expected from a typically-developing adolescent, 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*. As shown above, participant five considers their favourite foods and television programs as facets of their personality, 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 it is paid employment or service provision, is as important a defining characteristic for

these respondents with intellectual disability as it is for typically-developing individuals.

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 Participant 1 was when they fully acknowledged 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, or even details into the process of achieving them, 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]

As understood in the current literature, downward social comparisons are made against an individual or group deemed less socially competent as a way to increase subjective well-being (Wills, 1981). There was significant evidence of this phenomenon occurring in respondents' interpretations of self and others such as the above quote. Additionally, respondents reported several other complimentary 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. Additionally, participants tended to not be able to explain how they were aware of others' disabilities, nor when they discovered them. 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 that 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 typically-developing individuals because they are “*all really that way.*” There appeared then to be a tension between viewing other people with ID as inferior to the typical population 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; seeming to perceive themselves as suspended between the other members of the job site and the staff. As one of the respondents who recognised and embraced their disability status, it is especially interesting that the participant did not regard themselves on the same level with staff or other

service users. Other respondents emphasised their social desirability or their status among their peers by discussing their large number of friends, their good relationships with staff, or their involvement in the more complex or exclusive tasks on the job site.

Theme 2: Self-Defined Notions of Disability

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

Several other participants agreed that a person with a disability meant ‘wheelchair user’ or someone with mobility issues, while others suggested that other physical indicators were clear signals of disability. Regardless of what physical indicator suggested disability to the respondent, the majority were then able to produce 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 an ID tended to produce responses that fell into two categories: assigning blame for difficulties on oneself, or experiencing a broader sense of injustice living with intellectual 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. Participant 15, in contrast, 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 typically-developing individuals 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 typically-developing individuals 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 are about stigma, seem 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

"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

Perhaps the most surprising finding regarding terminology was the discomfort expressed by participants who were not able to define what disability terms mean.

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

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 "rationalised denial" of disability status, and "gnawing self-doubt" when appearances fell short of typically-developing, 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, 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 typically-developing individuals 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 typically-developing individuals. 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) uncovered a similar pattern of response from their participants, arguing that their sample appeared “invisible to themselves.” It was clear that participants experienced feelings of difference and rejection from typically-developing individuals, 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 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.

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 understandings are rooted in similarity of experience. As IPA does not seek to produce a generalizable theory, however, this reality was not viewed as a substantial barrier to quality analysis. 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. A more inclusive sample including individuals with communication difficulties (by using augmentative or assistive communication devices or alternative modes of communication) would undoubtedly enhance the findings.

Additionally, the sample covered a wide age range of 44 years, meaning that older participants likely experienced several shifts in terminology and practices 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 with disabilities 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. Culham and Nind (2003) suggest that these attitudes, which heavily favour "normal" appearance and action, are the vestiges of normalisation in ID services and practices. Normalisation and its successor, social role valorisation, heavily emphasize the need to appear 'as close to typically-developing as possible' in order to assume a more valued social role and thus increase subjective well-being (Wolfensberger, 1985). These concepts were adopted with such fervour, that they became not only a philosophy for service, but a moral code associating "normal" with good. These value-laden judgments can have serious repercussions for individuals with ID who cannot achieve these standards, as evidenced by those participants who self-degrade due to cognitive or behavioural impairments (Culham and

Nind, 2003). The awareness of judgment from others seems to negatively impact self-esteem and cause harsh self-criticism for at least a portion of the sample, which when compounded with difficulty conceptualising disability, could lead to further confusion and self-degradation.

Additionally, 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). Furthermore, Szivos and Griffiths (1990) assert that exploration and discussion of disability can improve outcomes on the personal level. “We should expect that through discussion and exploration,” they write, “the concept of handicap would become less global and more fragmented, enabling a more accurate assessment of strengths and weaknesses” (Szivos and Griffiths, 1990 p?).

Further study into how increasing knowledge and encouraging a cultural shift away from valuing normalcy impact self-concept and understanding of disability would be valuable. It would also be useful to understand how other populations, such as those with physical impairments understand disability, and how it differs from the population with ID. Findings from this study 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. Implementation of the new national minimum social care eligibility threshold introduced this April (Care Act 2014) may mean changes to accessing social services for many individuals with mild- moderate ID. The impact of this regulation on identity and self-esteem presents a unique challenge during the transition period; an individual who primarily compares himself to other individuals with ID may need increased emotional support if transitioning out of ID-specific social services. Additionally, developing a better understanding of how individuals with ID conceptualise themselves and others is imperative for continuing to ensure genuine person-centred planning (DoH 2001; 2009) within a potentially new era of social care provision. Finally, investigation into methods of shifting the cultural understanding of disability is imperative for ensuring the human rights of the population with intellectual disability.

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