

THE UNIVERSITY OF HULL

Constructions of Self-Identity and Experience of Diagnosis in Adults with  
Intellectual Disabilities

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by

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## **Overview**

This thesis portfolio comprises of three parts:

### ***Part one – Systematic Literature Review***

The systematic literature review explored the construction of self-identity in adults with intellectual disabilities. A systematic search identified 30 studies exploring self-identity which were included. A thematic synthesis of findings is presented, including methodological critique. Conclusions and implications for future research are discussed.

### ***Part two – Empirical Paper***

The empirical paper explores the experience of receiving an intellectual disability diagnosis in adulthood. Five individuals participated in semi-structured interviews to aim to understand the meaning of the diagnosis. Three superordinate themes and nine subordinate themes were identified, acknowledging diagnosis was related to understanding of the self, access to support and negotiating stigma. The findings are discussed in relation to empirical and theoretical literature, with implications and avenues for future research discussed.

### ***Part three – Appendices***

The appendices provide information to supplement part one and part two, with the inclusion of an epistemological stance and a reflective statement.

Total word count: 34,664 (including tables, appendices and references)

## Contents

	Page number
Acknowledgements.....	2
Overview.....	3
Contents .....	4
List of Tables and Figures.....	6
Systematic Literature Review .....	8
Abstract.....	9
Introduction.....	10
Method.....	13
Results.....	17
Discussion.....	51
Conclusion .....	59
References.....	59
Empirical Paper.....	74
Abstract.....	74
Introduction.....	75
Method.....	79
Results.....	83
Discussion.....	94
Conclusion .....	101
References.....	101
<i>Appendix A.</i> Author guidelines for ‘Journal of Applied Research in Intellectual Disabilities’ .....	110
<i>Appendix B.</i> NICE (2012) Quality Appraisal Checklist for qualitative studies .....	116
<i>Appendix C.</i> Data extraction form.....	122
<i>Appendix D.</i> Quality assessment ratings for reviewed studies.....	123
<i>Appendix E.</i> Further participant demographic information.....	126
<i>Appendix F.</i> Ethical approval documentation .....	127
Removed for digital archiving. ....	128
<i>Appendix G.</i> Recruitment poster .....	129
<i>Appendix H.</i> Recruitment poster amended for one community learning disability service .....	130
<i>Appendix I.</i> Participant information sheet with visual aids.....	131

<i>Appendix J.</i> Participant information sheet with visual aids adapted for one community learning disability service .....	138
<i>Appendix K.</i> Participant information sheet .....	143
<i>Appendix L.</i> Participant information sheet adapted for one community learning disability service. ....	148
<i>Appendix M.</i> Participant consent form – visual .....	153
<i>Appendix N.</i> Participant consent form.....	156
<i>Appendix O.</i> Participant demographic information form.....	158
<i>Appendix P.</i> Semi-structured interview schedule. ....	161
<i>Appendix Q.</i> Sources of support information for participants.....	163
<i>Appendix R.</i> Thank you letter for people who did not meet inclusion criteria.....	164
<i>Appendix S.</i> Worked example of data analysis from transcript .....	165
<i>Appendix T.</i> Reflective Statement.....	169
<i>Appendix U.</i> Epistemological statement .....	174

**List of Tables and Figures**

*Part One – Systematic Literature Review*

Table 1. Inclusion criteria and rationale..... 15

Table 2. Exclusion criteria and rationale.....15

Figure 1. PRISMA flowchart detailing selection and inclusion of articles..... 19

Table 3.Overview of studies included in the review..... 20

Table 4. Overall quality assessment for the reviewed studies. .... 37

*Part Two – Empirical Paper*

Table 1. Themes relating to the meaning of diagnosis in adulthood ..... 83

## **Part one: Systematic Literature Review**

**Constructions of self-identity in adults with intellectual disabilities: A systematic review.**

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This paper is written in the format ready for submission to the *Journal of Applied Research in Intellectual Disabilities* (see Appendix A for submission guidelines).

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## **Abstract**

*Background:* Research exploring self-identity has focused on the meaning of having an intellectual disability with the risk of overshadowing other aspects that affect how people view themselves.

*Method:* This systematic literature review explores the multifaceted constructions of self-identity in adults with intellectual disabilities. 30 qualitative studies are synthesised thematically, incorporating formal quality assessments.

*Results:* The experience of power through control, dependence and influential narratives and negotiating the self from others, considering autonomy and seeking normality were related to individuals' constructions of their identities. The desire to live a meaningful life considering future hopes, the ability to support others and the experience of connectedness contributed to positive self-identities.

*Conclusions:* Self-identity in adults with intellectual disabilities appears multi-faceted, with a multitude of influences on the construction and expression of identity beyond that of an intellectual disability. The review highlighted a lack of high quality research and indicates the need for further rigorous studies across the literature base.

*Key words:* Intellectual disability; identity, self-concept, self-perception

## **Introduction**

Intellectual disability research has sought to understand how individuals experience labels ascribed to them (Finlay & Lyons, 2005), perceptions by others (Jahoda, Wilson, Stalker & Cairney, 2010) and the subsequent impact on their views, opinions and constructs relating to themselves, namely their self-identity (Ali, Hassiotis, Strydom & King, 2012). Many conceptualisations of self-identity have been presented with definitions centring around the attributes or behaviours of an individual that comprise a social category or socially distinguishing features (Deng, 1995; Erikson, 1968; Hogg & Abraham, 1988; Jenkins, 1996). Terminology has been debated throughout the literature, though self-concept, self-image and self-perception have been used interchangeably (Gecas, 1982), with suggestion that self-identity represents a dynamic and fluid paradigm expressed within the continuity of an individual's past and future (Hall, 2001).

An individual's membership to a group and the subsequent emotional significance of that affiliation is described within social identity theory as contributing to self-identity (Tajfel, 1978). The extent to which personal and group characteristics define an individual's identity is suggested to influence feelings and behaviour (Tajfel & Turner, 1979).

Therefore, individuals who identify as belonging to a group with perceived 'low-status' have been suggested to physically or psychologically leave the group, focus on positive aspects of the in-group, make downward comparisons to others and engage in processes to modify the hierarchy (Hornsey, 2008). Although attempts have been made to distinguish social identity from personal identity and understand them as separate theoretical concepts, it has been argued that identity does not represent a distinct, psychological concept but rather a socially constructed paradigm (Stryker, 1968).

Individuals with intellectual disabilities are often marginalised by society through prejudice and stereotyping (Corrigan, Kerr & Knudsen, 2005) and may internalise these assumptions, thus considering themselves devalued members of society (Beart, Hardy & Buchan, 2005). Labelling theory (Becker, 1963) suggests self-identity is influenced by the descriptive terms used to define someone. For individuals with intellectual disabilities, language used both professionally and informally in relation to their difficulties has historically comprised a range of stigmatised labels such as idiot, imbecile, handicapped and feeble-minded (Rao, 2001; Rix, 2006). Although direct negative connotations to the term ‘intellectual disability’ remain scarce, stigma remains prevalent in society with explicit acts such as prenatal testing (Stainton, 2003) and implicit discourses in society, such as connotations of people as ‘eternal children’ (Starke, Rosqvist & Kuosmanen, 2016).

The social model of disability (Oliver, 1996) attempts to offer a paradigm shift whereby an individual’s personal abilities are considered difficult because of the environment or context, rather due to an intrinsic impairment with themselves. Policies have sought to support individuals with intellectual disabilities to integrate within society with the Community Care Act (House of Commons, 1990) stipulating adults are entitled to a full assessment of their needs and services provided to meet those needs in the community. However, Valuing People (2001) highlighted poor coordination of services, lack of choice and control and Transforming Care (Department of Health, 2015) further highlighted the need for people to be cared for in the community, emphasising the lack of implementation of previous policies.

Whilst both terminology used to describe intellectual disabilities and the associated diagnostic criteria are embedded in social constructionism and dialogical meaning (Rapley, 2004), intellectual disabilities often overshadow other salient aspects of individual’s self-

identity such as their gender (Slater, Ágústsdóttir & Haraldsdóttir, 2018) and sexuality (McCann, Lee & Brown, 2016). Furthermore, perception of stigma in individuals with intellectual disabilities is suggested to be significantly related to negative social comparisons with others (Paterson, McKenzie & Lindsay, 2012). Individuals with intellectual disabilities experience more negative self-concepts, lower self-esteem and more psychopathological symptoms than individuals without (Garaigordobil & Pérez, 2007). Experiences of stigma are perceived to be influential in these outcomes, affecting the extent to which individuals identify with the diagnosis (Ali, Hassiotis, Strydom & King, 2012). Therefore, understanding the way in which individuals construct their self-identities remains important.

Previous reviews have focused on social identity in people with intellectual disabilities in relation to the labels ascribed to them and their awareness of their difficulties (Beart, Hardy & Buchan, 2005; Logeswaran, Hollett, Zala, Richardson & Scior, 2019). However, this review hopes to also capture the multifaceted complexities within self-identity including the intersectionality between gender, sexuality, religion and culture which may often be overshadowed in intellectual disability research. Previous reviews have failed to address the quality and rigor of the studies they addressed. Hence, this review will employ formal quality assessments to consider methodological, design and ethical limitations both for individual studies and the overall evidence base.

#### *Aim for the review*

The systematic review aims to synthesise qualitative studies that sought to explore self-identity directly from the perspective of adults with intellectual disabilities. The review aims to answer the following questions:

1. What aspects of self-identity are salient for people with intellectual disabilities?
2. What are the factors that influence the self-identity of people with intellectual disabilities?
3. How do people with intellectual disabilities construct positive self-identities?

## **Method**

### *Search Strategy*

A systematic search of the literature was conducted in November 2018 using the following electronic databases: PsycINFO, PsycARTICLES, ERIC, CINAHL, MEDLINE, Education Research Complete, Academic Search Premier and Web of Science. The inclusion of subject-specific and broader, generic databases ensured a wide breadth of literature was captured.

Key terms used for ID, both presently and historically, were identified from reviewing literature in the field. Terms around self-identity were also developed from utilising relevant theory and literature based on indication that self-image, self-concept and self-perception may be used interchangeably (Gecas, 1982). The present review aims to synthesis broad constructs of self-identity across the literature base and did not want to impose assumptions as to what aspects of self-identity may be pertinent for individuals. Therefore, no other search terms related to aspects of self-identity, such as sexuality (Medina-Rico, López-Ramos & Quiñonez, 2018) were employed.

Search terms used were:

“learning disab\*” OR “learning difficult\*” OR “learning disorder\*” OR “intellectual\*  
disab\*” OR “intellectual\* difficult\*” OR “mental\* disab\*” OR “mental\* retard\*” OR  
“mental\* handicap\*” OR “mental\* impair\*” OR “mental\* subnorm\*” OR  
“mental\*deficien\*” OR “developmental\* disturb\*” OR “developmental\* disab\*” OR  
“develop\* delay\*” OR “cognitiv\* disab\*” OR “cognitiv\* difficult\*” OR “cognitiv\*  
delay\*”

AND

Identit\* OR “self-identit\*” OR “self-image” OR “self image” OR “self-concept” OR “self  
concept” OR “self-perception” OR “self perception”

English Language, Journal Article, Peer-reviewed limiters were applied to the search. In  
line with the inclusion criteria below, date limiters between 1990-present were also applied.

#### *Inclusion and exclusion criteria*

Initially, papers were reviewed by title with those irrelevant excluded. Abstracts of the  
remaining papers were then assessed for relevance and those irrelevant excluded. Full  
papers of relevant studies were then read and included or excluded based on the exclusion  
criteria. The reference list of a key review was also hand searched (Beart, Hardy & Buchan,  
2005).

*Table 1. Inclusion criteria and rationale*

Inclusion Criterion	Rationale
The study aimed to explore the construction of self-identity in people with intellectual disabilities from their perspective.	The review aimed to explore the construction of and influences on self-identity in people with intellectual disabilities.
The study used qualitative methodology.	To explore the lived experiences of people with intellectual disabilities.
The study was written in the English language	To review papers written in the first language of the author due to financial constraints around translation.
The study was an empirical paper. Reviews, reflections, theoretical papers or case studies were not included.	To ensure the review captured empirical findings rather than secondary data or personal opinions.
The study was published in a peer-reviewed academic journal.	To ensure the quality of the included studies was sufficiently regarded.

*Table 2. Exclusion criteria and rationale*

Exclusion Criterion	Rationale
The study only used quantitative methodology.	The review aimed to develop an understanding of self-identity through direct reports. If mixed methodology was employed, only the qualitative data was extracted for the review.
The study explored the experiences of people with intellectual disabilities from another perspective (i.e. family members, professionals).	To capture the direct experiences of people with intellectual disabilities. If another perspective was included and this could be differentiated, the data from those with

	intellectual disabilities was used.
The study included participants with other conditions where intellectual disabilities were not always present, such as autism or explored specific learning difficulties such as dyslexia.	To ensure the review captured self-identity in adults with intellectual disabilities.
The study recruited participants under the age of 18.	The review sought to explore the experiences of adults, as the influences on self-identity as a child may represent distinctly different experiences from adulthood (Kroger, Martinussen & Marcia, 2010). If a paper included both adults and children, this was excluded if it did not differentiate between these experiences.
The study was published before 1990.	A community model of care for people with intellectual disabilities was introduced in the Community Care Act (1990), which instigated change for the lives of people with intellectual disabilities in the UK (Thornicroft, 1994).
The study did not explore self-identity.	Only self-identity was included in the review. Related concepts such as self-esteem and stigma were only included if they explicitly studied these concepts in relation to self-identity.

### *Quality Assessment*

The studies included in the review were quality assessed by the lead researcher using the National Institute for Health and Clinical Excellence (NICE) Methodology Checklist for

Qualitative Studies (NICE, 2012) (see Appendix B). This checklist encompasses the quality of the theoretical approach, design, method, reflexivity, analysis and ethical considerations; appropriate for assessing qualitative methodology. If a study employed mixed-methodology, only the qualitative research was quality assessed as only these findings were included in the review.

A subset of articles were quality assessed by a peer-reviewer to ensure the reliability of the assessments demonstrated through consistency in ratings and strong inter-rater reliability. Any discrepancies between ratings were discussed and a collaborative decision was made. Papers were not excluded based on their quality to encompass a broad literature base within the review and contextualise the findings (Dixon-Woods et al., 2006). This also allowed for an assessment of the overall methodological strengths and weaknesses across the wider evidence base in this area.

#### *Data Extraction and Synthesis*

Synthesis of the data was achieved through the use of thematic synthesis methodology (described by Thomas & Harden, 2008). The reviewer read the findings of all the studies several times and extracted data relating to self-identity using a bespoke data extraction form (see Appendix C). Line by line coding of the findings of each study was then conducted to develop descriptive themes, similar to the themes in the original empirical studies. Analytical themes were then constructed that translated across studies that synthesised and interpreted the primary data extracted from the literature.

## **Results**

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA

) (Moher, Liberati, Tezloff & Altman, 2009) was used to identify articles for inclusion (Figure 1).

### *Characteristics of Included Studies*

Table 3 provides the main characteristics and relevant findings of the 30 studies that met the inclusion criteria and were thus included in the review.

Database search conducted: 31/10/18

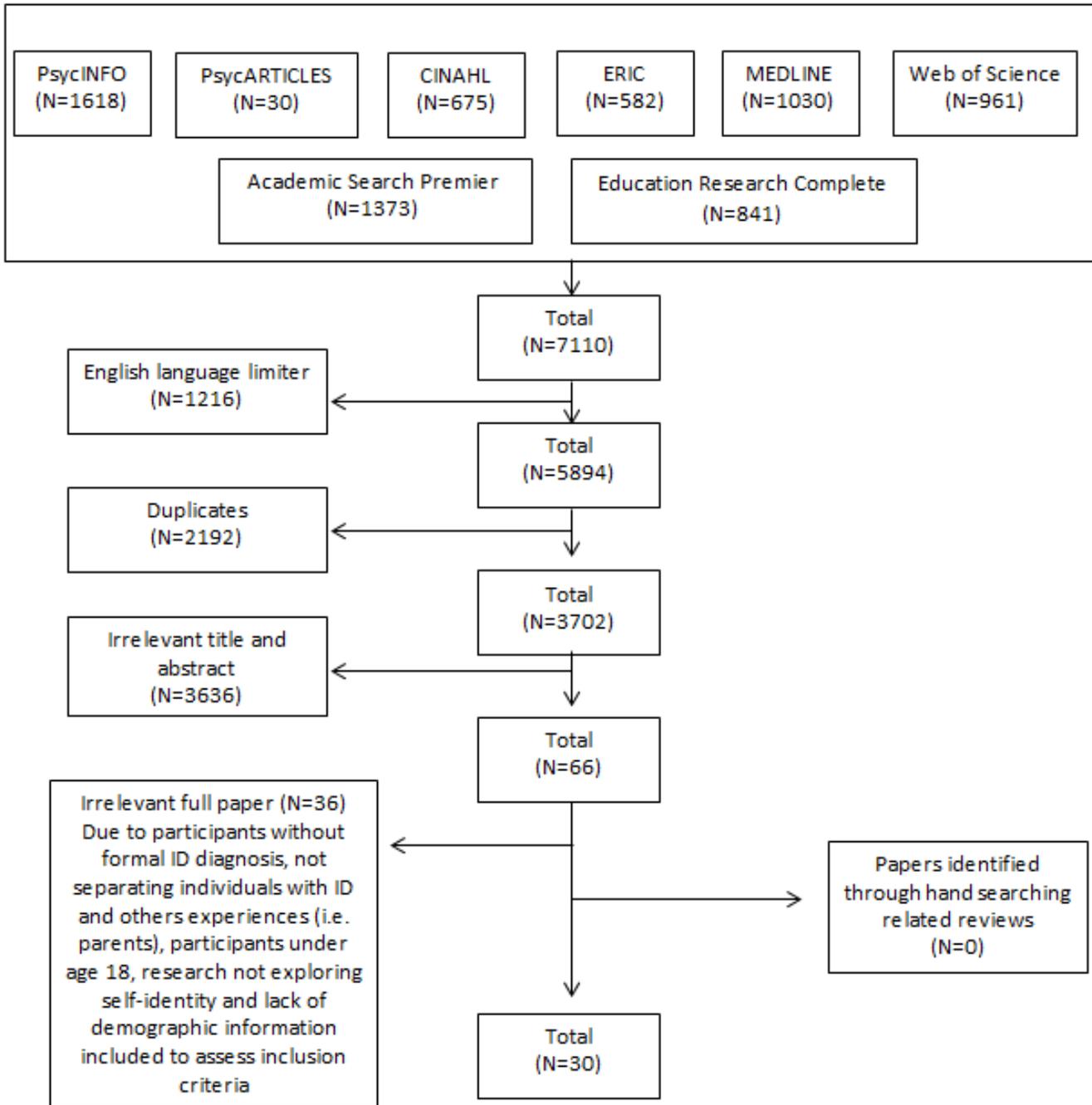


Figure 1. PRISMA flowchart detailing selection and inclusion of articles

*Table 3.* Overview of studies included in the review. Quality rating descriptors (NICE, 2012): ++ = all or most of the criteria achieved, + = most criteria achieved and those missed are unlikely to affect conclusions, - = few or no criteria met, likely to affect conclusions. \* denotes quantitative aspects of the study that were not included in the review.

<b>Author, year, location</b>	<b>Aim(s)</b>	<b>Participant demographics</b>	<b>Recruitment method</b>	<b>Methodology</b>	<b>Findings</b>	<b>NICE Quality Rating</b>
Anderson & Bigby (2017) Australia and UK	To investigate the experience of involvement with self-advocacy groups and the impact of membership on self-identity.	25 members of 6 self-advocacy groups; 2 in Australia, 4 in the UK. 10 female participants (average age 35 years old), 15 male participants (average age 39 years old). Participants described as "relatively able and articulate".	Self-advocacy groups.	Semi-structured interviews were conducted and grounded theory was used to analyse the data.	Individuals reported collegiality, control and ownership as important benefits of self-advocacy involvement. Individuals developed opportunities to try new activities and develop positive identities through experiences of being an expert, business person, independent and a self-advocate.	+
Azzopardi-Lane & Callus (2015) Malta	To explore the perceptions of sexuality for people with intellectual disabilities (pwID) in self-advocacy groups	19 people from a self-advocacy group. Demographics not reported. Self-advocacy group involved 40 members aged between early 20s and late 50s with even membership of males and females. Level of ID not reported.	Self-advocacy group.	Focus groups led by both researchers and members of the self-advocacy groups. Some focus groups separated participants by gender. Thematic analysis was used.	Some individuals accepted sexual norms placed upon them whereas others resisted these. Participants acknowledged barriers to developing sexual identities and the need for more opportunities to have sexual relationships.	-

Bernett (2011) USA	To explore how having an intellectual disability (ID) influences how women experience and express their sexuality	14 women recruited through support services with ID age 18-89. Ethnicities included 3 African American, 10 European American and 1 Native American. Cognitive functioning and adaptive skills "varied greatly".	Assistive and support services.	48 interviews, 28 participant observations and one focus group were used to explore individual's experiences. Analysed with grounded theory	Most women experienced disability centred environments without adopting a disabled identity. Adult identities were expressed with limits on sexual autonomy relating to restrictions and protection from services.	+
Björnsdóttir, Stefánsdóttir & Stefánsdóttir (2017) Iceland	To explore the expression of sexuality, gender and autonomy of Icelanders with intellectual disabilities.	29 participants: 19 women and 10 men with intellectual disabilities. 15 further participants with severe/profound intellectual disabilities were also recruited.	Not reported how participants were recruited.	Interviews and focus groups were undertaken with 19 women and 10 men with intellectual disabilities (ID). Participant observations on 15 individuals with severe/profound ID. Data was analysed using thematic analysis.	Concepts of hegemonic masculinity, emphasised femininity and relational autonomy were employed to explore how normalised roles were adopted. Masculinity was used to contribute to autonomy whereas femininity was resisted to increase autonomy and independence.	-

Bunning and Steel (2007) UK	To explore the self-concept of young people in an inner city area from a Jewish community.	4 individuals (2 male, 2 female). Aged between 18-21 years.	Further education college for Jewish adults with learning disabilities.	Semi-structured interviews were used. Talking Mats were also used to support communication during the interviews. Narrative analysis was used to explore the interview data.	The Jewish community, being young and having a disability were central to the young adults' self-concept.	-
Chou, Lu & Pu (2015) Taiwan	To explore attitudes towards sexuality among individuals with ID in Taiwan using a mixed methods approach.	11 individuals participated in focus groups; 6 men (aged 20s-30s with mild ID) and five women (aged 20-40; 1 with multiple disabilities, 4 with mild ID).  100 individuals with mild-moderate ID (age 18-63) also completed a quantitative part of the research (56 men and 44 women)*.	Two "institutions" and 4 day-care service centres.	Focus groups with 2-3 participants per focus group and analysed using Interpretative Phenomenological Analysis (IPA).  100 adults with mild-moderate ID completed the Attitudes to Sexuality Questionnaire. Data was analysed using a Mann-Whitney U test*.	Individuals described being controlled by parents, staff and society in relation to their sexuality and disabilities, with limited opportunities to develop and explore their sexualities.	+

Clarke, Camilleri & Goding (2015) UK	To explore the experience and meaning of involvement in a self-advocacy group for individuals with intellectual disabilities.	6 adults with ID (3 men, 3 women aged 36-70). All White British.	Self-advocacy group.	Two individual interviews and two focus groups were conducted with each participant. Data were analysed using thematic analysis.	Participants reported the self-advocacy group enabled them to feel part of a group and had positive effects on their self-esteem, self-determination and their sense of empowerment.	++
Craig, Craig, Withers, Hatton and Limb (2002) UK	To explore the relationship that pwID have with an identity related to learning disabilities and the influence of learning disability services on this.	6 adults with ID (5 males, 1 female). All participants were white.	Not reported how participants were recruited, but they all knew each other.	A focus group was facilitated. Before this, an initial audit of referrals was conducted. Following the focus group, a survey of the attitudes of professionals was conducted*. Data was analysed through deriving themes.	Participants expressed discomfort in relation to ID identities and portrayed themselves as non-ID. Downward comparisons to others were made and participants used verbatim repetitions of those used by service providers.	+

Davies & Jenkins (1997) UK	To explore incongruence between an individual's self identity and identity as an individual with ID.	60 individuals with ID (age 18-26), described as having a "range of abilities".  56 parents/carers also interviewed*.	Day centres.	Semi-structured interviews and participant observations were used. People were interviewed several times. Parents/carers were interviewed once*. Data analysis not described.	Participants generally did not associate with an ID identity. Identity was influenced by societal discourses which affected the way in which individuals perceived ID.	-
Dinwoodie, Greenhill & Cookson (2016) UK	To explore how individuals with intellectual disabilities who identify as LGBT experience their sexual identities	5 adults with ID who identified as LGBT (aged 18-47). 3 participants identified as male, 1 trans and 1 female.	Recruited through an LGBT service that ran groups for pwID. 4 participants attended the group for pwID and 1 attended the generic LGBT group.	Individual semi-structured interviews were conducted and analysed using interpretative phenomenological analysis.	Common experiences of discrimination and abuse were reported. Individuals' experience of their own sexual identity was related to other's responses to sexuality, understanding sexuality and acceptance from others.	++

Dorozenko, Roberts & Bishop (2015) Australia	To explore the identity and social role construction of individuals with ID.	18 adults with ID (11 male, 7 female) age 20-45.	Self-advocacy group.	Photovoice was used whereby participants take photographs to illustrate their social roles and identities. Interviewing was also used to supplement the data. Interviews were analysed using causal layered analysis.	Aspects of individuals' lives were conceptualised through relationships, recreational activities and work rather than in terms of their intellectual disability.	+
Elderton, Clarke, Jones and Stacey (2014) UK	To use narrative therapy to explore LGBT identities in individuals with ID.	11 adults (10 men and 1 woman). Age 28-71 with borderline to mild ID recruited from a support group for pwID who identify as LGBT. 10 identified as White British and 1 as Black British.	Support group for pwID who identify as LGBT.	Four 90 minute narrative therapy workshops were run. Participants were interviewed at the end and a feedback form was used. Data was analysed using a narrative approach.	Positive stories of self-identity were strengthened over the duration of the workshops. Individuals also reported feeling connected to others and the ability to support others as benefits of attending.	-

Finlay and Lyons (1998) UK	To understand how differences in whether individuals relate to the ID label affect their evaluation and associations with it.	28 adults with mild-moderate ID. Age range between 19-75 years with a mean on 38.5 years. Gender not reported.	Two services for pwID offering residential, respite and outreach support.	Interviews with open-ended questions about representations of ID and self-descriptions took place at home or in respite accommodation. Data analysis of the interviews was not described. Self-esteem questionnaires and group evaluation measures were also used*.	Individuals showed understanding of the concept of ID, though did not spontaneously refer to this when describing themselves.	+
Finlay & Lyons (2000) UK	To explore how individuals with ID describe and compare themselves in relation to social categorisations.	33 individuals with ID took part - 13 men and 20 women, aged 18-65 (mean 36.5 years). 14 participants were diagnosed with Down's syndrome.	3 services for adults with ID - 1 day centre and 2 social groups.	Individual interviews were conducted and analysed using content analysis.	Individuals expressed more downward and lateral comparisons than upward comparisons in relation to their skills and behaviour compared to both others with ID and those without.	++

Fitzgerald & Withers (2013) UK	To explore how women with intellectual disabilities conceptualise their sexual identity.	10 White British women with ID, ranging from 19-64 years.	Details of recruitment are not provided.	Semi structured individual interviews were conducted and analysed using principles of grounded theory.	Individuals believed others prohibited them from exploring and developing their sexual identities which individuals struggled to conceptualise.	+
Groves, Rayner & Muncer (2018) UK	To explore how women with Down Syndrome's experiences have impacted on their self and shared identities.	Eight women with Down Syndrome; mean age 35 (range 21-49 years old).	NHS community learning disability teams.	Semi-structured individual interviews were conducted - except one person who had a member of staff sit with them. Data was analysed using IPA.	Individuals reported a lack of autonomy and responsibility due to the negative assumptions of others. Many provided fragmented accounts of their identity highlighting a lack of ownership over their own narrative.	++
Hassan (2017) UK	To explore how a choir can contribute to an individual with ID's self-identity.	Demographic details about the participants were not provided, though the research refers to both men and women's experiences.	A choir for pwID.	Participants were observed by the researcher and engaged in a discussion. The research adopted an ethnographic framework.	The formation of the choir, rehearsals and performances aided people to develop empowered self identities.	-

Head, Ellis-Caird, Rhodes & Parkinson (2018) UK	To understand how individuals with ID experience moving out of hospital following "Transforming Care".	11 individuals with mild-moderate ID who had moved into the community between four months and two years ago were interviewed. Nine individuals also participated as Key Support People (parents, social worker, support worker, nurse and home manager). Age and gender of participants was not reported.	Local multidisciplinary Transforming Care team.	Two semi-structured interviews were conducted. The first with the researcher and participant. In the second, a key worker supported the individual with ID and spoke from the individual with ID's perspective using an "internalised other" approach. Data analysis used Grounded Theory.	Moving out of hospital had a positive impact on individuals' relationships with others and their ideas about themselves.	++
Kittelsaa (2014) Norway	To explore how young adults with ID present themselves, understand and relate to the diagnosis.	Seven adults with ID; four women and three men. Inclusion criteria ranged from age 18-30, though ages of recruited participants not detailed.	"Sheltered" workshops.	Participant observations, field conversations and semi-structured interviews were conducted in line with an ethnographic approach to data analysis.	Participants presented a positive image of themselves, had awareness of their impairments, though were not defined by the ID diagnosis.	++

Malik, Unwin, Larkin, Kroese & Rose (2017) UK	To explore the meaning of social care for British South Asian women with ID.	10 British South Asian adult women (age 24-48; average 33 years old) with mild-moderate ID.	Seven organisations including education, social care, local authority, charities, private sector providers and health services.	Seven participants undertook individual interviews and three participants engaged in a focus group. Interpretative analysis was used to analyse data.	Complex identities regarding the intersection of gender, ethnicity and intellectual disability were highlighted, with services generally supporting the development of these.	++
Midjo & Aune (2018) Norway	To explore the self-constructions of young adults with mild intellectual disabilities in everyday life.	4 young adults (2 men, 2 women) with mild ID aged between 18-24 years old. Five mothers of young adults with mild ID and five professionals in the service also took part in the study.	Participation in a habilitation course.	Semi-structured interviews were conducted. In two instances, the young people were interviewed with their mothers. Analysis used meaning interpretation tradition was used.	Young adults constructed themselves in relation to their hopes and dreams and also in relation to housework and their own independence.	+

Mineur, Tideman & Mallander (2017) Sweden	To explore the meaning and importance of engaging in a self-advocacy group for pwID in relation to daily life and identity.	26 adults with ID. Gender and ages of participants not reported.	Six self-advocacy groups: 3 run by one organisation, 3 run by another organisation.	Individual interviews with participants about the meaning and importance of engaging in a self-advocacy groups. Four focus groups were conducted to discuss results and improve credibility. Interviews were analysed using content analysis.	Individuals experienced their self-perception as more social, confident and skilled as a result of engaging in a self-advocacy group.	++
Monteleone & Forrester Jones (2017) UK	To explore how individuals with ID experience their disabilities and the impact of this on social interaction, self-esteem and stigma.	15 adults with ID - 10 male and 5 female (age 19-63; mean 35 years). 13 participants identified as White British, 1 as Irish-Nigerian and 1 as Zimbabwean.	Adult day service - working farm.	Semi-structured individual interviews were conducted and analysed using IPA.	Participants reported pressure to behave in a normative manner, limited knowledge of ID and discomfort around terminology.	++

Neuman & Reiter (2017) Israel	To explore how individuals with ID perceive intellectual disabilities considering quality of life and self-concept	40 men and 40 women with mild-moderate learning disabilities were recruited. Participants ranged from 23-78 years, mean age 46 years). Half of the participants (20 couples) had been in intimate relationships for over a year. The other half had a close relationship with a friend and only took part in the quantitative research).	Assisted living.	Semi-structured interviews and observations were carried out with the 20 couples who were in intimate relationships. Thematic analysis was used to analyse the data.  80 participants completed the Quality of Life Questionnaire and the Tennessee Self Concept Scale.*	Participants described physical and emotional closeness, lifelong partners, planning for the future and secure bases as central to couple relationships. Individuals with ID in intimate relationships scored higher on quality of life and self-concept measures than individuals with close friends.	-
Pestana (2015) UK	To use a qualitative approach to explore self-perception in multiple domains in individuals with mild ID.	8 adults with mild learning disabilities (6 male, 2 female) age 25-56 years.	Learning disability charity.	Individual semi-structured interviews were conducted and data was analysed using IPA.	People described themselves using a range of positive descriptions along with some individuals describing themselves as anxious, slow and not normal.	+

Scior (2003) UK	To explore how women with learning disabilities position themselves in relation to disability and gender.	5 White British women with learning disabilities aged mid-20s to mid-40s. All participants had moderate learning disabilities. One had an additional diagnosis of Down Syndrome.	2 community learning disability teams and 1 self-advocacy group.	Semi-structured interviews using drawings and photographs were used. Each woman took part in two or three interviews. Discourse analysis was used to derive themes from the data.	Gender and disability identities could not be separated with discourses surrounding biological determinism, feminism and pwID as asexual and childlike originating in women's experiences.	+
Shewan, McKenzie, Quayle & Crawley (2012) UK	To explore how parents perceive having an intellectual disability and the impact of this on their parenting role.	8 participants with mild ID between the age of 23-46. (Three mothers and five fathers). The age of their children ranged between 5 months and 30 years old. Six participants had children living with them at the time of the study.	Community learning disability team.	Individual semi-structured interviews were conducted and analysed using Interpretative Phenomenological Analysis.	Participants' identity was explored in three ways – in relation to having a learning disability, in relation to being a parent and their preferences and strengths as an individual, outside of being diagnosed with ID and outside of being a parent.	++

Szivos and Griffiths (1990) UK	To explore group therapy as a method to deal with stigma experiences for individuals with intellectual disabilities.	3 men and 4 women (aged 20-35) with mild intellectual disabilities.	Local "mental retardation" service providers.	Participants were interviewed before commencement of the group and attended group for 13 weeks (videotaped). Phenomenological methodology was used to analyse the data.	Over the course of the group, individuals went through six stages of denial, statement (labels), recognition (discovery), exploration, meaning and acceptance in relation to their identity of intellectual disability diagnosis.	-
Werner & Hochman (2018) Israel	To explore the self-identity of individuals with intellectual disabilities who service in a military project.	31 adults (19 men, 12 women) with intellectual disabilities between 21-30 years old.	Individuals who serve in the Equal in Uniform military project.	49 semi-structured interviews were conducted across 31 participants. 5 individuals also engaged in focus group. Data was analysed through thematic analysis.	Individuals considered participation in the military as an opportunity to engage in meaningful roles and develop a socially valued identity.	++
Wilkinson, Theodore & Raczka (2015) UK	To explore the development of sexual identity for individuals with ID during transition to adulthood.	4 young adults (2 male, 2 female) aged between 19-22. 3 participants were White British, 1 was Black African. Four people with caring roles were also recruited (2 parents, 2 supporters).	Service for pwID.	Individual semi-structured interviews were conducted with individuals with ID and carers/parents. IPA was used to analyse the data.	Individuals with ID struggled to develop "normal" identities, including their sexuality, due to the overshadowing of ID. Carers/parents expressed concerns about risk and protecting the young people.	+

Twenty seven of the studies employed qualitative methodology and three used a mixed methods design (Chou, Lu & Pu, 2015; Finlay & Lyons, 1998; Neuman & Reiter, 2017). The majority of the studies were located in Europe with nineteen in the UK, two in Norway and one respectively in Sweden, Iceland and Malta. Three studies were from Asian countries (Israel and Taiwan), one from the USA and one from Australia. One study was carried out across two countries (UK and Australia).

Participants in twenty five studies were mixed gender samples and five recruited only female participants (Bernett, 2011; Fitzgerald & Withers, 2013; Groves, Rayner & Muncer, 2018; Malik, Unwin & Larkin, Kroese & Rose, 2017; Scior, 2003). Sample sizes ranged from 4-60 participants, though seven studies also recruited additional participants who either undertook a quantitative element (Chou, Lu & Pu, 2015; Finlay & Lyons, 1998; Neuman & Reiter, 2017) or represented a different demographic, such as parents or professionals (Davies & Jenkins, 1997; Head, Ellis-Card, Rhodes & Parkinson, 2018; Midjo & Aune, 2018; Wilkinson, Theodore & Raczka, 2015). One study did not provide the sample size or demographic details of the participants recruited (Hassan, 2017). The age of participants ranged from 18-89 years old across studies that provided this information.

Fifteen studies did not report the level of intellectual disability of participants. Four reported mild intellectual disabilities (Midjo & Aune, 2018; Pestana, 2015; Shewan, McKenzie, Quayle & Crawley, 2012; Szivos and Griffiths, 1990), one reported borderline to mild intellectual disabilities (Elderton, Clarke, Jones & Stacey, 2014) and one alluded to mild severity (Anderson & Bigby, 2017). In one study, all participants in the qualitative aspect reported mild intellectual disabilities except one participant who described themselves as having multiple disabilities (Chou, Lu & Pu, 2015). Four studies reported mild to moderate severity (Finlay & Lyons, 1998; Head, Ellis-Caird, Rhodes & Parkinson,

2018; Malik, Unwin, Larkin, Kroese & Rose, 2017; Neuman & Reiter, 2017) and one reported moderate severity (Scior, 2003). Davies & Jenkins (1997) describe “a range of abilities” and Bernert (2011) reported abilities “varied greatly”. One study described some participants as having “intellectual disabilities”, though distinguished a further 15 participants who were reported to have severe/profound difficulties (Björnsdóttir, Stefánsdóttir & Stefánsdóttir, 2017).

Studies were exploratory in understanding aspects of self-identity with the majority focusing on the impact of the intellectual disability label. Ten explored sexuality and gender, four explored involvement in self-advocacy and two explored ethnicity and religion. Five studies considered the impact of various factors on self-identity such as parenting (Shewan, McKenzie, Quayle & Crawley, 2012), serving in the military (Werner & Hochman, 2018), involvement in a choir (Hassan, 2017), group therapy (Szivos & Griffiths, 1990) and narrative LGBT workshops (Ederton, Clarke, Jones and Stacey, 2014).

Eighteen studies gathered qualitative data through individual interviews only and two used focus groups only (Azzopardi-Lane & Callus, 2015; Chou, Lu & Pu, 2015). Four used individual interviews and focus groups (Clarke, Camilleri & Goding, 2015; Malik, Unwin, Larkin, Kroese & Rose, 2017; Mineur, Tideman & Mallander, 2017; Werner & Hochman, 2018), three used individual interviews and participant observation (Davies & Jenkins, 1997; Hassan, 2017; Szivos and Griffiths, 1990), two employed individual interviews, participant observations and focus groups (Bernett, 2011; Björnsdóttir, Stefánsdóttir & Stefánsdóttir, 2017) and one used individual interviews, participant observations and field conversations (Kittelsaa, 2014).

Nine studies used interpretative phenomenological analysis to interpret data and six used thematic analysis. Grounded theory was used in four (Anderson & Bigby, 2017; Bennett, 2011; Fitzgerald & Withers, 2013; Head, Ellis-Caird, Rhodes & Parkinson, 2018). Narrative approaches (Bunning & Steel, 2007; Elderton, Clarke, Jones & Stacey, 2014) and ethnographic approaches (Hassan, 20017; Kittelsaa, 2014) were used in two studies respectively. Other approaches included discourse analysis (Scior, 2003), content analysis (Mineur, Tideman & Mallander, 2017), meaning interpretation (Midjo & Aune, 2018) and causal layered analysis (Dorozenko, Roberts & Bishop, 2015) . Three studies did not clearly describe how the data were analysed (Craig, Craig, Withers, Hatton & Limb, 2002; Davies & Jenkins, 1997; Finlay & Lyons, 1998).

#### *Quality assessment of methodology*

Table 4 provides the overall quality ratings for each study and a breakdown of methodological quality for the included papers detailed in Appendix D. Nine papers were judged as fulfilling all or most of the criteria, twelve fulfilled most of the criteria unlikely to affect results and nine fulfilled few of the criteria.

Table 4. Overall quality assessment for the reviewed studies.

++	+	-
<i>Studies that were judged as fulfilling all or most of the criteria</i>	<i>Studies that were judged as fulfilling most criteria and unlikely to affect results</i>	<i>Studies that were judged as fulfilling few of the criteria and the conclusions were likely to alter</i>
Clarke, Camilleri & Goding (2015); Dinwoodie, Greenhill & Cookson (2016); Groves, Rayner & Muncer (2018); Kittelsaa (2014), Malik, Unwin, Larkin, Kroese & Rose (2017); Mineur, Tideman & Mallander (2017); Monteleone & Forrester-Jones (2017); Shewan, McKenzie, Quayle & Crawley (2012); Werner & Hochman (2018)	Anderson & Bigby (2017); Bernert (2011); Chou, Lu & Pu (2015); Dorozenko, Roberts & Bishop (2015); Finlay & Lyons (1998); Finlay & Lyons (2000); Fitzgerald & Withers (2013); Head, Ellis-Caird, Rhodes & Parkinson (2018); Midjo & Aune (2018); Pestana (2015); Scior (2003); Wilkinson, Theodore & Raczka (2015)	Azzopardi-Lane & Callus (2015); Björnsdóttir, Stefánsdóttir & Stefánsdóttir (2017); Bunning & Steel (2007); Craig, Craig, Withers, Hatton & Limb (2002); Davies & Jenkins (1997); Elderton, Clarke, Jones & Stacey (2014); Hassan (2017); Neuman & Reiter (2017); Szivos & Griffiths (1990)

Overall, the papers demonstrated varying quality. A qualitative approach was appropriate in all of the studies with relevant aims, objectives, appropriate underpinning literature and theory discussed. Some studies failed to provide adequate rationale and justification for methodological and design procedures, though findings were generally convincing and relevant to the aims of the studies. The papers demonstrated poor reflexivity, with the relationship between the researcher and participants and how research was explained to participants inadequately discussed. Only six studies explicitly discussed reflexivity (the position of the author and potential biases) (Dinwoodie, Greenhill & Cookson, 2016; Finlay & Lyons, 1998; Hassan, 2017; Head, Ellis-Caird, Rhodes & Parkinson, 2018; Mineur,

Tideman & Mallander, 2017; Scior, 2003). The context of the data collection methods and participants' life circumstances were also generally inadequately discussed and therefore there was insufficient consideration of the impact of context bias. The use of methodological triangulation was also mixed across studies and details of data analysis procedures were often lacking, though this may reflect a limitation in reporting rather than inadequate analysis. There was also significant variation in the depth that detail of data and themes were discussed. The clarity of reporting on ethics was generally lacking. The majority of papers adequately discussed that consent was obtained and anonymity was addressed, however the ethical implications of the consequences of the research were rarely mentioned. Many studies also failed to report that the study was approved by an ethical committee.

## **Synthesis of findings**

### **Theme 1: Power**

The first superordinate theme explores the impact of power in relation to the construction of self-identity by individuals with intellectual disabilities. This comprises three subordinate themes of control, dependence and influential narratives.

#### *Control*

A widely discussed idea across the studies in the review was the control, overprotection and lack of privacy available to individuals with intellectual disabilities. Many studies reported a lack of control over decisions and opportunities along with feeling forced into situations (Bernert, 2011; Björnsdóttir, Stefánsdóttir & Stefánsdóttir, 2017; Chou, Lu & Pu, 2015; Dorozenko, Roberts & Bishop, 2015; Fitzgerald & Withers, 2013; Groves, Rayner & Muncer, 2018; Malik, Unwin, Larkin, Kroese & Rose, 2017; Scior, 2003). All of the studies

who only interviewed female participants were represented in the subordinate theme of control, indicating this may be a particularly pertinent issue for women with intellectual disabilities.

Participants spoke of being controlled as a multi-faceted experience, with control from individuals such as parents (Dorozenko, Roberts & Bishop, 2015; Malik, Unwin, Larkin, Kroese & Rose, 2017; Midjo & Aune, 2018), care organisations such as social services (Björnsdóttir, Stefánsdóttir & Stefánsdóttir, 2017; Clarke, Camilleri & Goding, 2015) and at a societal level ( Björnsdóttir, Stefánsdóttir & Stefánsdóttir, 2017; Chou, Lu & Pu, 2015; Clarke, Camilleri & Goding, 2015), with several studies mentioning the “*government*”, “*law*” or MPs: “*You were put in homes for all your life, the government has to push you out*” (Clarke, Camilleri & Goding, 2015, p. 239).

Studies in which participants made reference to control at statutory level were recruited from Iceland, Taiwan and the UK, suggesting these experiences reflect a more global, pervasive issue across political and legal systems: “*my sister spoke with me and she told me that I couldn't move to the group home unless I had the sterilization. I will never forget the day I went there. It was a terrible day*”( Björnsdóttir, Stefánsdóttir & Stefánsdóttir, 2017, p. 304).

The impact of control on romantic relationships was also evident in the literature with participants expressing fear of outside intervention with participants reporting “*I'm scared of you (the caregiver), afraid that you will not let us live together. Do not take him away from me*” (Neuman & Reiter, 2017, p.142).

This was also evident when participants explained they feared consequences of “*getting caught*” having sex with their boyfriends “*they'd stop me from going to see my friend*”

(Fitzgerald & Withers, 2013, p.8). Individuals also expressed others sheltering them, for example by being removed from a sex education class (Björnsdóttir, Stefánsdóttir & Stefánsdóttir, 2017) and telling them “*never do it*” (Fitzgerald & Withers, 2013, p.9.). A lack of privacy in relationships was also expressed:

*“They come back and forth and check up on me, and make sure I don’t do anything wrong. Like fool around the wrong way. Can’t have sex. If you do stuff, he’ll have to go home, and I’ll have to go to my room and spend the rest of the night there.”*

(Bernert, 2011, p. 136).

However, defiance of this also emerged when relationships were discussed with participants reporting “*Parents need to trust us, we are old enough to be in a relationship*”. (Azzopardi-Lane and Callus, 2015, p. 36). Questioning of this applied determinism was also evident for women regarding parenting: “*the law is not fair to us. We are just like any human beings; why can’t we have children?*” (Chou, Lu & Pu, 2015, p. 672).

It was further highlighted how individuals actively defied the control placed upon them engaging in their hobbies and interests “*It got own T.V. Said my parents ‘no T.V.’ so I went in my room. Locked the door and put it on*”. (Bunning & Steel, 2007, p, 47).

### *Dependence*

This subtheme encompasses both actual and perceived dependence individuals reported on others. Participants often spoke of themselves as a receiver of care (Finlay & Lyons, 1998), though participants offered varying attitudes as to whether they felt this was proportionate to the level of support required. For some, this appeared positive and enabled them to ‘get help’ (Anderson & Bigby, 2017). Though others described support as a form of infantilisation. When discussing her identity as an adult, one participant reported “*I feel like*

*I'm a bit of a baby...But it's out, it's my safety, so.*" (Wilkinson, Theodore & Raczka, 2015, p.99). Participants expressed the desire for inclusive support encompassing intellectual disabilities, sexuality, religion and culture (Malik, Unwin, Larkin, Kroese & Rose, 2017), though indicated it was often difficult for all these needs to be met:

*"People say they're there to support you but when you tell them I need support for this [gay sexuality] as well then they don't want to support you with that bit. When you explain that if you can't help me with that [gay sexuality] you can't help me with that either [intellectual disability] because them two things are what collide together"*

(Dinwoodie, Greenhill & Cookson, 2016, p.8)

The impact of dependence on self-identity was discussed across studies that explored experiences of individuals living in long-stay hospitals:

*"Pamela: We were treated like patients*

*Interviewer: What does that mean to you, to be a patient?*

*Pamela: Horrible...it made me feel that I couldn't do anything for myself"*

(Head, Ellis-Caird, Rhodes & Parkinson, 2018, p. 67)

In the community, participants spoke of support to socialise and one participant considered how this affected the development of his sexual identity: *"[the gay bar is] open too late...I need someone who can work that long"* (Wilkinson, Theodore & Raczka, 2015, p. 101).

Participants also expressed financial dependence as a salient aspect of their lives, with a lack of money (Azzopardi-Lane & Callus, 2015, Bernert, 2011; Dorozenko, Roberts & Bishop, 2015; Kittelsaa, 2014; Scior, 2003), reliance on others to be able to access their

money (Malik, Unwin, Larkin, Kroese & Rose, 2017) and financial exploitation (Fitzgerald & Withers, 2013) reported. One participant expressed dependence on a family member to manage their finances. *“My mother keeps it all. My mother keeps my money, ‘cause I’d lose it, ‘cause I’m a handicapped person. And I can’t keep it myself, see. I may lose it”* (Davies and Jenkins, 1997, p. 100).

Individuals who were supported by staff to manage their own finances spoke positively about this experience *“They’re excellent: they help me with money...”* (Malik, Unwin, Larkin, Kroese & Rose, 2017, p.80).

### *Influential narratives*

This subordinate theme relates to the impact of powerful narratives on the identity of individuals with intellectual disabilities, including those held by others close to the individual such as parents and carers, wider societal narratives and individuals’ own narratives of their identity.

Participants spoke of assumptions others made about their ability to read and write (Groves, Rayner & Muncer, 2018) and engage in occupational activities (Werner & Hochman, 2018). Participants also expressed the impact of narratives about individuals with intellectual disabilities developing sexual identities with dialogue indicating that parents hold differing opinions *“my mom says”* (Chou, Lu & Pu, 2015, p. 671), individuals feel scared to discuss sexuality with parents due to their reactions (Shewan, McKenzie, Quayle & Crawley, 2012) and support staff holding restrictive beliefs regarding parenting, (Scior, 2003). This highlights the influence of narratives on the propensity to control individuals with intellectual disabilities within the overarching theme of power.

Participants also reflected on the impact of wider societal narratives including the lack of understanding, stigma and discrimination (Mineur, Tideman & Mallander, 2017), with individuals subsequently feeling uncared for (Groves, Rayner & Muncer, 2018) and angry (Dinwoodie, Greenhill & Cookson, 2016). Participants also reported feeling others looked at them differently, which they perceived as being discriminatory in nature (Dinwoodie, Greenhill & Cookson, 2016; Groves, Rayner & Muncer, 2018; Wilkinson, Theodore & Raczka, 2015).

Participants reported that other aspects of their identity were overshadowed by intellectual disability narratives *“I’m just a normal person that wants a girlfriend”* (Wilkinson, Theodore & Rackza, 2015, p.99). In a Swedish study, participants reflected on the terminology for intellectual disabilities and the stigma attached to the label, which literally translates to “developmentally disturbed” (Mineur, Tideman & Mallander, 2017).

The literature highlighted a dearth of ownership over participants’ own narratives and stories. Many studies emphasised the lack of understanding individuals had about what an intellectual disability is, with participants reporting they do not know or understand (Bernert, 2011; Chou, Lu & Pu, 2015; Craig, Craig, Withers, Hatton & Limb, 2002; Dorozenko, Roberts & Bishop, 2015; Finlay & Lyons, 2000; Fitzgerald & Withers, 2013; Groves, Rayner & Muncer, 2018; Kittelsaa, 2014; Monteleone & Forrester-Jones, 2017; Shewan, McKenzie, Quayle, & Crawley, 2012.). Lack of understandings about sex and sexuality were also highlighted *“I don’t know what a proper woman means”* (Fitzgerald & Withers, 2013, p.10). Whilst it should be considered that levels of verbal language expression may have influenced individuals’ abilities to express and articulate their narratives, one study indicated that sex had never been discussed with them (Chou, Lu & Pu, 2015) and were conversations they felt sheltered from. In a study exploring the

experience of disability, one participant reported *“I know what it is, but I don’t know”* (Monteleone & Forrester-Jones, 2017, p.309), with authors suggesting the possibility that whilst individuals may not be able to verbally articulate the meaning, they emotionally live and experience what it means to have an intellectual disability.

In only one study, participants expressed denial towards an intellectual disability identity (Szivos & Griffiths, 1990). This was the oldest paper included in the literature and may possibly reflect the change in attitudes towards individuals with intellectual disabilities and the subsequent effect on the lived experience and self-stigma. Conversely, strengthening of individuals’ self-identity narratives was evident in a narrative therapy study: *“It was good to hear other people’s comments...understanding that other people have gone through the same experiences and feeling as if they understand me and I felt included”* (Elderton, Clarke, Jones & Stacey, 2014, p305). Participants reported outcomes of increased confidence, bravery and awareness of positive views of themselves held by others.

## **Theme 2: Negotiating the self from others**

This overarching theme encompasses the prevalence of individuals expressing aspects of their identity in relation to others. Subordinate themes include the ability and desire to experience autonomy and seek normality, highlighting the substantial role others contribute to the construction of one’s own identity. All studies in the review encompassed either one or both of the subthemes, with the exception of one study (Fitzgerald & Withers, 2013).

### *Autonomy*

In many studies, participants reflected a desire to be perceived as competent and self-sufficient (Björnsdóttir, Stefánsdóttir & Stefánsdóttir, 2017; Dorozenko, Roberts & Bishop, 2015; Kittelsaa, 2014; Malik, Unwin, Larkin, Kroese & Rose, 2017; Midjo & Aune, 2018;

Mineur, Tideman & Mallander, 2017; Scior, 2003). Participants reported an expression of the importance of independence regarding abilities and skills undertaken; with several referring to household tasks they completed autonomously (Pestana, 2015). Autonomy and ownership over domestic tasks also related to the expression of gender identities in one study: “*Now I want you to look at me and do not help me with it, and if I have problems I ask for help*” (Midjo & Aune, 2018, p41).

Autonomy appeared related to the ability to articulate choices and exert control over decisions (Azzopardi-Lane & Callus, 2015; Chou, Lu & Pu, 2015; Groves, Rayner & Muncer, 2018; Szivos & Griffiths, 1990), such as what to eat for breakfast (Anderson & Bigby, 2017). This also emerged from research that explored the experience of people moving out of hospital, with participants reporting more choice in the community as contributing positively to ideas they held about themselves (Head, Ellis-Caird, Rhodes & Parkinson, 2018).

Attendance at a self-advocacy group (Anderson & Bigby, 2017) and a choir (Hassan, 2017) supported participants to develop confidence and skills leading to increased autonomy and independence, subsequently further increasing confidence. In all studies where the experience of autonomy was reported, expressions were positive and subsequently contributed to a range of other experiences including increased responsibility (Werner & Hochman, 2018), self-confidence (Elderton, Clarke, Jones & Stacey, 2017; Neuman & Reiter, 2017) and happiness (Elderton, Clarke, Jones & Stacey, 2014). One participant reported “*The course made me feel good....it made me feel like a complete, independent soldier...to take responsibility and discover life itself*” (Werner & Hochman, 2018, p. 5).

Conflict was reported when autonomy was challenged (Bernert, 2011), linking the impact of control, dependence, societal narratives and stigma highlighted in the first theme.

### *Seeking normality*

In several studies, participants expressed their self-identities in relation to other people. Participants reflected on wanting to be ‘as normal as possible’ in relation to both adult and sexual identities (Groves, Rayner & Muncer, 2018; Wilkinson, Theodore & Raczka, 2015) indicating this was a desire or something to be achieved, whereas other participants indicated they perceived themselves as ‘normal’ at present and ‘like everyone else’ (Mineur, Tideman & Mallander, 2017). Others used expressions of their independence illustrate ‘normality’: “*As you can see, I live a normal life, just like people who are not intellectually disabled...I can take the bus, and I do everything for myself...*” (Kittelsaa, 2014, p. 35).

Strategies were employed to develop both alignment with ‘normal’ identities and distance from intellectual disability identities through minimisation of their own difficulties (Szivos & Griffiths, 1990; Wilkinson, Theodore & Raczka, 2015) and lateral comparisons with others to express similarity and normality (Finlay & Lyons, 2000). Downward comparisons were also used to portray themselves favourably compared to others (Bernert, 2011; Clarke, Camilleri & Goding, 2015; Craig, Craig, Withers, Hatton & Limb, 2002; Davies & Jenkins, 1997; Monteleone & Forrester –Jones, 2017; Szivos & Griffiths, 1990).

These appraisals were made when expressing aspects of themselves they perceived as positive, such as autonomy and independence: “*I could go to the shops, I could go to work. I could go off...but a lot of them can’t go out coz they need a lot of help*” (Finlay & Lyons, 2000, p.135).

Some individuals described people with intellectual disabilities as dependent on others (Craig, Craig, Withers, Hatton & Limb, 2002; Finlay & Lyons, 1998), however in both of these studies a large proportion of participants personally rejected the label or expressed discomfort towards it, indicating that this may not function as a self-description and may represent a downward comparison to others. Furthermore, these studies were some of the older ones included in the literature review and may reflect a change in attitudes to intellectual disabilities over the previous decades.

Participants also reflected on upward comparisons where they referred to differences, distance from “*normality*” and need for support (Dinwoodie, Greenhill & Cookson, 2016; Finlay & Lyons, 2000; Groves, Rayner & Muncer, 2018; Shewan, McKenzie, Quayle & Crawley, 2012), with individuals describing themselves as “*weird*” (Bunning & Steel, 2007) and “*slow*” (Bernert, 2011; Pestana, 2015). In a study exploring sexual identities of individuals who identified as lesbian, gay, bisexual and transgender, one participant expressed the complexity of feeling different to her family in contrast to the benefit of similarity with friends:

*“Sometimes I get a bit angry having a learning disability because I can’t do things that normal people can do...I don’t want to have a disability...I just want to be normal, but not normal, but, I don’t want to [have a disability], because all my family don’t have one, most of my friends so, so they’re like me, they understand”*

(Dinwoodie, Greenhill & Cookson, 2016, p. 8).

The widespread use of downward, upward and lateral comparisons across studies highlights the complexity of the desire for “normality” concurrently with the acknowledgement of

own support needs, indicating widespread employment of both positive and negative comparisons as a strategy to negotiate one's own sense of self.

### **Theme 3: Living a meaningful life**

This theme relates to the importance of living a meaningful life that was conveyed across studies, with individuals expressing future hopes, the ability to support others and the experience of connectedness through fostering of relationships and shared interests as significant to positive self-perception.

#### *Future hopes*

Hopes and desires for the future were expressed in the context of couple relationships, intimacy and marriage (Azzopardi-Lane & Callus, 2015; Bernert, 2011; Chou, Lu & Pu, 2015; Davies & Jenkins, 1997; Dorozenko, Roberts & Bishop, 2015; Neuman & Reiter, 2017; Wilkinson, Theodore & Raczka, 2015), occupational roles (Davies & Jenkins, 1997; Monteleone & Forrester-Jones, 2017; Werner & Hochman, 2018), living independently (Malik, Unwin, Larkin, Kroese & Rose, 2017; Monteleone & Forrester-Jones, 2017), financial stability (Davies & Jenkins, 1997), developing knowledge (Clarke, Camilleri & Goding, 2015) and engagement in leisure activities (Anderson & Bigby, 2017; Elderton, Clarke, Jones & Stacey, 2014; Midjo & Aune, 2018). The importance of the co-existence of some of these hopes was illustrated:

*AL: I wish I could get married to Caroline and have plenty of money*

*CD: Those two wishes would be enough?*

*AL: Yeah. I could take her out then. To the pictures, or we could go on holidays together*

(Davies & Jenkins, 1997, p.107)

The development of future hopes for relationships through attendance at narrative therapy workshops was also reported “*I feel better and worthwhile and positive...I hope to meet someone special*” (Elderton, Clarke, Jones & Stacey, 2014, p.305), suggesting the benefit of strategies to help individuals foster positive self-identities.

The way in which these hopes were reported suggests that participants’ wish to live a meaningful life was also related to their ability to experience autonomy and a “normal” identity, as illustrated by the following quote from a participant in the military:

*“I’m waiting for service. I’m looking forward to it. Very much looking forward to it. I’m looking forward to enlistment, and I already want to be enlisted. This is my dream and I want to feel like a real soldier”* (Werner & Hochman, 2018, p. 4).

Tension between the desire to move forward and needing support, alongside traditional cultural, family values was indicated as an area of potential conflict (Malik, Unwin, Larkin, Kroese & Rose, 2017).

### *Supporting others*

In several studies, participants expressed enjoyment in being able to support other people including family, friends and at work (Dorozenko, Roberts & Bishop, 2015; Pestana, 2015; Werner & Hochman, 2018). Participants also often referred to helping others with intellectual disabilities with tasks (Clarke, Camilleri & Goding, 2015; Groves, Rayner & Muncer, 2018), which to some extent may function as a downward comparison to others, providing distance from the ‘cared for’ identity, thus link with aspects of the previous themes including perceived dependence and comparisons with others. Supporting others

with intellectual disabilities was also expressed in relation to helping others to speak up for their rights (Anderson & Bigby, 2017; Mineur, Tideman & Mallander, 2017), supporting others at groups (Szivos & Griffiths, 1990) and developing and exploring their sexualities (Dinwoodie, Greenhill & Cookson, 2016; Elderton, Clarke, Jones & Stacey, 2014), with indication this improved confidence.

Shewan, McKenzie, Quayle & Crawley (2012) also explored experiences of parenting, finding participants expressed happiness and pride in relation to raising their children “*I was over the moon*”, with both men and women evidencing their identity as a parent as separate from having an intellectual disability.

### *Connection*

Across studies, participants expressed the importance of feeling connection with others. The opportunity to spend valued time together was significant for individuals who identified as lesbian, gay, bisexual and transgender with ‘*someone that understands you*’ (Dinwoodie, Greenhill & Cookson, 2016).

Connection over a mutual task was also reported, with participants at a self-advocacy group positively illustrating members and support workers “*we just muck in together*” (Anderson & Bigby, 2017, p. 113). Other benefits of developing connection at self-advocacy groups included meeting new people and being part of a group (Clarke, Camilleri & Goding, 2015), developing friendships, feeling cared for and reducing isolation (Mineur, Tideman & Mallander, 2017). Participation in groups when collaboratively working towards a task together also appeared to positively contribute to social connectedness with others, for example choir groups (Hassan, 2017) or dance classes (Kittelsaa, 2014). Social networks

developed at organised groups were also reported to extend outside the groups both in face-to-face interactions and via social media (Mineur, Tideman & Mallander, 2017).

Trusting, understanding relationships with family members (Dorozenko, Roberts & Bishop, 2015), support staff (Head, Ellis-Caird, Rhodes & Parkinson, 2018) and partners (Azzopardi-Lane & Callus, 2015; Neuman & Reiter, 2017) were positively reported.

Physical similarities and shared beliefs were described in relation to family members (Finlay & Lyons, 2000) and physical and emotional closeness were described as important in couple relationships (Neuman & Reiter, 2017). Attendance at places of worship, belonging to a religion and connection with God were also significant to foster a sense of belonging (Bunning & Steel, 2007; Dorozenko, Roberts & Bishop, 2015; Head, Ellis-Caird, Rhodes & Parkinson, 2018; Pestana, 2015).

## **Discussion**

### *Overview and discussion of results*

The review aimed to synthesise and interpret the constructions and influences on self-identity in adults with intellectual disabilities. The literature explored in the review highlights the multi-faceted nature of self-identity highlighting the importance of disability, sexuality, culture, religion and occupation as salient contributors. These findings demonstrate similarity to the wider self-identity literature highlighting the interaction of multiple identities, which are in turn influenced by the how others perceive these and thus form their interactions (Kang & Bodenhausen, 2015). Self-identity literature has received criticism for poorly defined concepts with inconsistent terminology with debates between self-identity, self-concept and self-image (Brown, Dacin, Pratt & Wheeton, 2006). The

literature identified in the present review predominantly used terminology of self-identity and self-concept, though a strength of many of the included studies is that they adopted a constructionist approach to consider the most pertinent aspects of self-identity to an individual, rather than attempt to fit experiences within pre-defined definitions, models or concepts.

Previous reviews have focused on the construction of the self in relation to the experience of an intellectual disability identity (Beart, Hardy & Buchan, 2005; Logeswaran, Hollett, Zala, Richardson & Scior, 2019), though the present findings highlight the importance of a holistic understanding of identity. This challenges discourses suggesting individuals experience a diagnostic overshadowing of other aspects of the self (Ali & Hassiotis, 2008) and assumptions that disability comprises the exclusive identity (Fine & Asch, 1988).

Intersectionality theory has been used to conceptualise the significance of identifying with multiple groups that experience discrimination (Nash, 2008). Although the lived experience of disability is generally lacking in intersectionality literature (Cramer & Plummer, 2009), it is encouraging to see several studies in the present review exploring the experience of other often discriminated against identities for people with intellectual disabilities, such as sexuality and religion.

The three superordinate themes established to understand the reviewed literature represent distinct yet intrinsically related aspects of the construction of and influences on self-identity. The interrelated themes appear to mirror the complexity of self-identity and the fluidity of experiences amongst contexts and environments, though all relate to the experience of the self amongst others. Self-identity theory has long debated the ability to separate personal identity from social identity (Reid & Deaux, 1996), though the present review provides support for the inextricable link of the two. Self-identity literature argues

that the conceptualisation and expression of identity is fluid, dynamic and context-dependent (Combs & Freedman, 2016; Muenchberger, Kendall & Neal, 2008). However, due to a lack of longitudinal studies, further research is required to develop a greater understanding of the changes in self-identity over time.

Findings indicate that for people with intellectual disabilities, self-identities are significantly influenced by experiences of power; particularly the control others may exert in relation to decision-making and opportunities. “Choice” was highlighted as a key principle for people with intellectual disabilities in the Valuing People White Paper in the UK (Department of Health, 2001), though many of the papers reflecting issues around control were recent, indicating the necessity for this to be implemented further. The desire for autonomy, independence and personal agency evident across studies also appears strongly related to lack of choice and decision making (Devi, 2013).

Self-descriptions often related to dependence on others, which supports previous literature proposing individuals with intellectual disabilities construct an ‘overprotected identity’ (Callus, Bonello, Misfud & Fenech, 2019). The concept of being “cared for” also appears prevalent across other populations such as people living with Alzheimer’s disease (Borley & Hardy, 2017), though this likely represents a different experience due to the pervasive nature of intellectual disabilities compared to dementias typically diagnosed later in life.

The lack of narratives individuals held over their stories, experiences and diagnoses was also evident in the review. The absence of sexual narratives emphasised in the present review supports research indicating that education, vocabulary and relational support is needed to advance the human rights of individuals with intellectual disabilities to develop their sexual identities (Turner & Crane, 2016) and parents may feel young adults are too

‘dependent’ to engage in ‘sensitive’ conversations about sexuality (Pownall, Jahoda, Hastings & Kerr, 2011). The present review also highlights the limited ability of individuals to explain what an intellectual disability is, with many reporting they did not know. Whilst this may relate to overprotection from parents, carers and professionals when sharing this information, the present review and previous literature indicate this fails to shelter individuals from the emotional experience of having an intellectual disability (Rapley, Kiernan & Antaki, 1998). The influence of stigmatising narratives on self-identity highlighted in the review show similarities to the wider stigma research (Jahoda, Wilson, Stalker & Cairney, 2010; Scior, 2011), highlighting the need for effective interventions to change public perceptions (Dickinson & Hutchinson, 2019).

Within the review, individuals demonstrated identities that were influenced through the understanding of themselves in relation to others, through the use of comparisons. Whilst this supports other intellectual disability literature (Jahoda & Markova, 2004; Paterson, McKenzie & Lindsay, 2012), comparison as a means to understand oneself is documented widely across self-identity research in people without intellectual disabilities (Ben-Zur, 2016). Although intersectionality of stigmatised identities has been discussed, it is important to balance this with the consideration of the normality of these strategies employed to conceptualise our self-identity to avoid further diagnostic overshadowing in the literature.

The review also highlighted the salient contribution of dependence on others in self-identity, which supports literature indicating that self-determination, choice and control over decision-making are important for individuals with intellectual disabilities to gain confidence in their abilities and develop positive self-concepts (Williams & Porter, 2017).

Meaningful connection, supporting others and hopes for the future were all captured as influencing the construction of positive identities.

Studies within the review encompassing attendance at self-advocacy groups and occupational groups were of good quality and highlighted potentially effective platforms to strengthen positive identities, through empowerment, resilience and belonging (Goodley, 2005). More directive interventions included narrative therapy LGBT groups and a psychodynamic group therapy, however good quality further research is needed to explore the feasibility of possible interventions to develop positive self-identities. However, due to the importance of relations and interactions with others on the experience and meaning of identity, it could be argued that interventions should be targeted at the public, professionals and families, rather than those with intellectual disabilities.

Identification with an intellectual disability diagnosis appeared variable across studies and it should be considered that this may reflect the extent to which the studies explicitly explored intellectual disability identity.

### *Limitations*

Whilst the review offers a useful summary of the multifaceted nature of self-identity for people with intellectual disabilities, a number of limitations should be considered.

Conducting a thematic review of qualitative studies involves construing data that has been interpreted by other researchers, who have interpreted the stories provided by participants based on their own interpretations or their experiences, known as a triple hermeneutic (Weed, 2005). Reviewing the methodological quality of the included studies indicated a lack of reflexivity across the literature base, with limited information detailing the

assumptions, biases and positions of the researchers. Framing of interview questions in the original studies may have also affected the relative disclosure of positive and negative aspects of identity, along with identities prevalent to the individual in the environment where interviews took place. The identity of the first author as a young, White British, female without intellectual disabilities will also have influenced the synthesis of the present review. To mitigate the impact of this, the first author kept a reflective journal to reflect on personal values and assumptions relating to the research.

Quality assessment aimed to provide a judgement on methodological and design limitations in order to critically consider the contribution of the studies within the review (see Table 4). None of the studies met all of the criteria. Understanding these methodological limitations is essential as studies that lack rigorous data collection, analysis, context and reflexivity may fail to accurately portray the experiences of individuals with intellectual disabilities. This emphasises the importance for future research to demonstrate high quality, due to the lack of literature directly recruiting individuals with intellectual disabilities. However, the objectivity of the quality assessment process in the current review is limited due to the implicit assumptions and values of the researcher, though the review endeavoured to mitigate this through the use of a peer-reviewer.

Further limitations exist within the methodology of the studies included in the review. In six studies, participant observation formed part of the data collection, which may contribute to understanding the experiences of people with intellectual disabilities with limited verbal communication. However, interpretation of observations requires a researcher to articulate another individual's experiences potentially leading to bias and subjectivity. Furthermore, the review only incorporated studies directly exploring the perspectives of people with intellectual disabilities. Therefore, it is possible that experiences of individuals with more

profound needs that may be discussed in the literature via the understandings of others around them are not reflected here.

Across the studies, demographic information to contextualise data was generally lacking or inadequate in relation to participants' ages, sex, other diagnoses and living circumstances, highlighting a priority to be addressed across intellectual disability research. Many studies also did not include information about participants' level of intellectual disability.

Ouellette-Kuntz, Burge, Brown & Arsenault (2010) suggest that people with more severe intellectual disabilities are more stigmatised, with others maintaining greater social distance, therefore indicating the lived experiences for different levels of ID may be significantly different and should be addressed in the literature.

The global generalisability of the current review should be cautious as almost two thirds of the studies were conducted in the United Kingdom and thus may reflect a similar experience of attitudes and support systems which may differ across countries and cultures. Furthermore, the current review only incorporated studies published in the English language, therefore may not include research which may have contributed to understanding cultural differences.

#### *Implications and future research*

The findings of the review highlight the need for further research in several areas. Further qualitative research exploring self-identity in individuals with intellectual disabilities is required that demonstrates formal qualitative analysis, participant demographics and transparency around author bias and reflexivity.

Research exploring positive aspects of self-identity in individuals with intellectual disabilities highlighted in the present review is necessary. For example, exploring how the

role of supporting others and the development of meaningful hopes for the future may help individuals to foster positive self identities. Furthermore, an exploration of both direct and indirect interventions to strengthen positive identities is required, for example narrative therapy groups and self-advocacy groups as highlighted in the review. Exploring how individuals can develop, understand and adopt their own narratives, stories and experiences along with understanding how families, friends and professionals can support is also important.

As the review included studies recruiting individuals with a range of demographic variability, exploring the similarities and differences in the influences on self-identity in people with different levels of intellectual disability, differences in living situation and different ages, may be valuable to tailor support.

Furthermore, only literature that explicitly explored self-identity was included in the present review. A future review of the wider research where self-identity may have emerged as significant may contribute further to the understanding of the influence on self-identity.

Previous reviews have indicated the need to support people with intellectual disabilities to develop resilience to negative stigma in society (Logeswaran, Hollett, Zala, Richardson & Scior, 2019). However, the review indicates that experiences of power and control are prevalent from families and professionals in addition to the wider society, highlighting the importance of targeting both explicit and implicit discrimination against people with intellectual disabilities (Keith, Bennetto & Rogge, 2015), rather than expecting people to develop resilience to it.

## **Conclusion**

The present review offers insight into the multifaceted nature of self-identity in adults with intellectual disabilities and highlights the multitude of influences on the construction and expression of identity beyond that of an intellectual disability. The review highlights a lack of high quality research and indicates the need for further rigorous studies across the literature base. Future research is necessary to explore interventions to strengthen positive self-identities and reduce stigma within society.

## **References**

*\* denotes study was included in the systematic review*

Ali, A., & Hassiotis, A. (2008). Illness in people with intellectual disabilities. *BMJ: British Medical Journal*, 336(7644), 570.

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.

\*Anderson, S., & Bigby, C. (2017). Self-advocacy as a means to positive identities for people with intellectual disability: ‘We just help them, be them really’. *Journal of Applied Research in Intellectual Disabilities, 30*(1), 109-120.

\*Azzopardi-Lane, C., & Callus, A. M. (2015). Constructing sexual identities: people with intellectual disability talking about sexuality. *British Journal of Learning Disabilities, 43*(1), 32-37.

Beart, S., Hardy, G., & Buchan, L. (2005). How people with intellectual disabilities view their social identity: A review of the literature. *Journal of Applied Research in Intellectual Disabilities, 18*(1), 47-56.

Becker, H. (1963) *Outsiders*. New York: Free Press.

Ben-Zur, H. (2016). Social and temporal comparisons as moderators of psychological resources associations with wellbeing. *Journal of Individual Differences.*

\*Bernert, D. J. (2011). Sexuality and disability in the lives of women with intellectual disabilities. *Sexuality and Disability, 29*(2), 129-141.

\*Björnsdóttir, K., Stefánsdóttir, Á., & Stefánsdóttir, G. V. (2017). People with intellectual disabilities negotiate autonomy, gender and sexuality. *Sexuality and Disability, 35*(3), 295-311.

- Borley, G., & Hardy, S. (2017). A qualitative study on becoming cared for in Alzheimer's disease: the effects to women's sense of identity. *Aging & mental health*, 21(10), 1017-1022.
- Brown, T. J., Dacin, P. A., Pratt, M. G., & Whetten, D. A. (2006). Identity, intended image, construed image, and reputation: An interdisciplinary framework and suggested terminology. *Journal of the Academy of Marketing Science*, 34(2), 99-106.
- \*Bunning, K., & Steel, G. (2007). Self- concept in young adults with a learning disability from the Jewish community. *British Journal of Learning Disabilities*, 35(1), 43-49.
- Callus, A. M., Bonello, I., Mifsud, C., & Fenech, R. (2019). Overprotection in the lives of people with intellectual disability in Malta: knowing what is control and what is enabling support. *Disability & Society*, 34(3), 345-367.
- \*Chou, Y. C., Lu, Z. Y. J., & Pu, C. Y. (2015). Attitudes toward male and female sexuality among men and women with intellectual disabilities. *Women & health*, 55(6), 663-678.
- \*Clarke, R., Camilleri, K., & Goding, L. (2015). What's in it for me? The meaning of involvement in a self-advocacy group for six people with intellectual disabilities. *Journal of Intellectual Disabilities*, 19(3), 230-250.
- Combs, G., & Freedman, J. (2016). Narrative therapy's relational understanding of identity. *Family Process*, 55(2), 211-224.
- Corrigan, P. W., Kerr, A., & Knudsen, L. (2005). The stigma of mental illness: Explanatory models and methods for change. *Applied and Preventive Psychology*, 11(3), 179-190.

- \*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.
- Cramer, E. P., & Plummer, S. B. (2009). People of color with disabilities: Intersectionality as a framework for analyzing intimate partner violence in social, historical, and political contexts. *Journal of Aggression, Maltreatment & Trauma*, 18(2), 162-181.
- \* Davies, C., & Jenkins, R. (1997). 'She has different fits to me': how people with learning difficulties see themselves. *Disability & Society*, 12(1), 95-110.
- Deng, F. M (1995). *War of Visions: Conflict of Identities in the Sudan*. Washington, DC: Brookings..
- Department of Health. (2001). *Valuing people: A new strategy for learning disability for the 21st century*. London: Department of Health.
- Department of Health. (2015). *Transforming Care*. London: Department of Health.
- Devi, N. (2013). Supported decision-making and personal autonomy for persons with intellectual disabilities: Article 12 of the un convention on the rights of persons with disabilities. *The Journal of Law, Medicine & Ethics*, 41(4), 792-806.
- Dickinson, D., & Hutchinson, N. (2019). Changes in understandings and perceptions of individuals, significant others and community supporters involved in a theatre company for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 32(3), 691-705.

- \*Dinwoodie, R., Greenhill, B., & Cookson, A. (2016). 'Them Two Things are What Collide Together': Understanding the Sexual Identity Experiences of Lesbian, Gay, Bisexual and Trans People Labelled with Intellectual Disability. *Journal of Applied Research in Intellectual Disabilities*.
- Dixon-Woods, M., Cavers, D., Agarwal, S., Annandale, E., Arthur, A., Harvey, J., ... & Riley, R. (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC medical research methodology*, 6(1), 35.
- \*Dorozenko, K. P., Roberts, L. D., & Bishop, B. (2015). The identities and social roles of people with an intellectual disability: Challenging dominant cultural worldviews, values and mythologies. *Disability & Society*, 30(9), 1345-1364.
- \*Elderton, A., Clarke, S., Jones, C., & Stacey, J. (2014). Telling our story: a narrative therapy approach to helping lesbian, gay, bisexual and transgender people with a learning disability identify and strengthen positive self-identity stories. *British Journal of Learning Disabilities*, 42(4), 301-307.
- Erikson, E. (1968) *Identity: Youth and Crisis*. New York: Norton
- Fine, M., & Asch, A. (1988). Disability beyond stigma: Social interaction, discrimination, and activism. *Journal of social issues*, 44(1), 3-21.
- \*Finlay, W. M., & Lyons, E. (1998). Social identity and people with learning difficulties: Implications for self-advocacy groups. *Disability & society*, 13(1), 37-51.

- \*Finlay, W. M., & 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.
- Finlay, W. M. L., & Lyons, E. (2005). Rejecting the label: A social constructionist analysis. *Mental Retardation*, 43(2), 120-134.
- \*Fitzgerald, C., & Withers, P. (2013). 'I don't know what a proper woman means': what women with intellectual disabilities think about sex, sexuality and themselves. *British Journal of Learning Disabilities*, 41(1), 5-12.
- Garaigordobil, M., & Pérez, J. I. (2007). Self-concept, self-esteem and psychopathological symptoms in persons with intellectual disability. *The spanish journal of psychology*, 10(1), 141-150.
- Gecas, V. (1982). The self-concept. *Annual review of sociology*, 8(1), 1-33.
- Goodley, D. (2005). Empowerment, self-advocacy and resilience. *Journal of Intellectual Disabilities*, 9(4), 333-343.
- \*Groves, E., Rayner, K., & Muncer, S. (2018). "It's good, they're like me; the same but different." An interpretative phenomenological analysis of the identities of women with Down's syndrome. *Journal of Applied Research in Intellectual Disabilities*, 31(3), 445-453.
- Hall, R. E. (2001). Identity development across the lifespan: A biracial model. *The Social Science Journal*, 38(1), 119-123.

- \*Hassan, N. (2017). Re-voicing: Community choir participation as a medium for identity formation amongst people with learning disabilities. *International Journal of Community Music*, 10(2), 207-225.
- \*Head, A., Ellis-Caird, H., Rhodes, L., & Parkinson, K. (2018). Transforming identities through Transforming Care: How people with learning disabilities experience moving out of hospital. *British Journal of Learning Disabilities*, 46(1), 64-70.
- Hogg, M. & Abrams, D. (1988). *Social Identifications: A Social Psychology of Intergroup Relations and Group Processes*. London: Routledge.
- Hornsey, M. J. (2008). Social identity theory and self-categorization theory: A historical review. *Social and personality psychology compass*, 2(1), 204-222.
- House of Commons (1990) *The National Health Service and Community Care Act*. 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.
- 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.
- Jenkins, R. (1996). *Social Identity*. London: Routledge.

- Kang, S. K., & Bodenhausen, G. V. (2015). Multiple identities in social perception and interaction: Challenges and opportunities. *Annual review of psychology*, 66, 547-574.
- Keith, J. M., Bennetto, L., & Rogge, R. D. (2015). The relationship between contact and attitudes: Reducing prejudice toward individuals with intellectual and developmental disabilities. *Research in developmental disabilities*, 47, 14-26.
- \* Kittelsaa, A. M. (2014). Self-presentations and intellectual disability. *Scandinavian Journal of Disability Research*, 16(1), 29-44.
- Kroger, J., Martinussen, M., & Marcia, J. E. (2010). Identity status change during adolescence and young adulthood: A meta-analysis. *Journal of adolescence*, 33(5), 683-698.
- Logeswaran, S., Hollett, M., Zala, S., Richardson, L., & Scior, K. (2019). How do people with intellectual disabilities construct their social identity? A review. *Journal of Applied Research in Intellectual Disabilities*, 32(3), 533-542.
- \*Malik, K. J., Unwin, G., Larkin, M., Kroese, B. S., & Rose, J. (2017). The complex role of social care services in supporting the development of sustainable identities: Insights from the experiences of British South Asian women with intellectual disabilities. *Research in developmental disabilities*, 63, 74-84.
- Medina-Rico, M., López-Ramos, H., & Quiñonez, A.H. (2018). Sexuality in People with Intellectual Disability: Review of Literature. *Sexuality and Disability*, 36, 231-248.

- \*Midjo, T., & Aune, K. E. (2018). Identity constructions and transition to adulthood for young people with mild intellectual disabilities. *Journal of Intellectual Disabilities*, 22(1), 33-48.
- \*Mineur, T., Tideman, M., & Mallander, O. (2017). Self-advocacy in Sweden—an analysis of impact on daily life and identity of self-advocates with intellectual disability. *Cogent Social Sciences*, 3(1), 1304513.
- Moher, D., Liberati, A., Tetzlaff, J. & Altman, D. (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *British Medical Journal*, 339, b2535.
- \*Monteleone, R., & Forrester-Jones, R. (2017). ‘Disability Means, um, Dysfunctioning People’: A Qualitative Analysis of the Meaning and Experience of Disability among Adults with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities*, 30(2), 301-315.
- Muenchberger, H., Kendall, E., & Neal, R. (2008). Identity transition following traumatic brain injury: A dynamic process of contraction, expansion and tentative balance. *Brain injury*, 22(12), 979-992.
- Nash, J. C. (2008). Re-thinking intersectionality. *Feminist review*, 89(1), 1-15.
- National Institute for Health and Care Excellence (NICE). (2012). *Methods for the development of NICE public health guidance (3rd ed.)*. London: Author.
- \*Neuman, R., & Reiter, S. (2017). Couple relationships as perceived by people with intellectual disability—implications for quality of life and self-concept. *International Journal of Developmental Disabilities*, 63(3), 138-147.

- Oliver, M. (1996). *Understanding disability: From theory to practice*. New York, NY: Macmillan.
- Ouellette-Kuntz, H., Burge, P., Brown, H. K., & Arsenault, E. (2010). Public attitudes towards individuals with intellectual disabilities as measured by the concept of social distance. *Journal of Applied Research in Intellectual Disabilities*, 23(2), 132-142.
- Paterson, L., McKenzie, K., & Lindsay, B. (2012). Stigma, social comparison and self-esteem in adults with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 25(2), 166-176.
- \*Pestana, C. (2015). Exploring the self-concept of adults with mild learning disabilities. *British Journal of Learning Disabilities*, 43(1), 16-23.
- Pownall, J. D., Jahoda, A., Hastings, R., & Kerr, L. (2011). Sexual understanding and development of young people with intellectual disabilities: Mothers' perspectives of within-family context. *American journal on intellectual and developmental disabilities*, 116(3), 205-219.
- Rao, S. (2001). 'A little inconvenience': perspectives of Bengali families of children with disabilities on labelling and inclusion. *Disability & Society*, 16(4), 531-548.
- Rapley, M. (2004). *The social construction of intellectual disability*. Cambridge University Press.
- Rapley, M., Kiernan, P., & Antaki, C. (1998). Invisible to themselves or negotiating identity? The interactional management of 'being intellectually disabled'. *Disability & Society*, 13(5), 807-827.

- Reid, A., & Deaux, K. (1996). Relationship between social and personal identities: Segregation or integration. *Journal of Personality and Social Psychology*, 71(6), 1084.
- Rix, J. (2006). Does it matter what we call them? Labelling people on the basis of notions of intellect. *Ethical Space: The International Journal of Communication Ethics*, 3(4), 22-28.
- \*Scior, K. (2003). Using discourse analysis to study the experiences of women with learning disabilities. *Disability & Society*, 18(6), 779-795.
- Scior, K. (2011). Public awareness, attitudes and beliefs regarding intellectual disability: A systematic review. *Research in developmental disabilities*, 32(6), 2164-2182.
- \*Shewan, L., McKenzie, K., Quayle, E., & Crawley, R. (2014). A qualitative exploration of the identities of parents with a learning disability. *British Journal of Learning Disabilities*, 42(1), 17-24.
- Slater, J., Ágústsdóttir, E., & Haraldsdóttir, F. (2018). Becoming intelligible woman: Gender, disability and resistance at the border zone of youth. *Feminism & psychology*, 28(3), 409-426.
- Stainton, T. (2003). Identity, difference and the ethical politics of prenatal testing. *Journal of Intellectual Disability Research*, 47(7), 533-539.
- Starke, M., Rosqvist, H. B., & Kuosmanen, J. (2016). Eternal children? Professionals' constructions of women with an intellectual disability who are victims of sexual crime. *Sexuality and disability*, 34(3), 315-328.

- Stryker, S. (1968). Identity salience and role performance: The relevance of symbolic interaction theory for family research. *Journal of Marriage and the Family*, 558-564.
- \* Szivos, S. E., & Griffiths, E. (1990). Group processes involved in coming to terms with a mentally retarded identity. *Mental Retardation*, 28(6), 333.
- Tajfel, H. (1978). *Differentiation between social groups: Studies in the social psychology of intergroup relations*. London: Academic Press.
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC medical research methodology*, 8(1), 45.
- Thornicroft, G. (1994). The NHS and Community Care Act, 1990: Recent government policy and legislation. *Psychiatric Bulletin*, 18(1), 13-17.
- Weed, M. (2005). " Meta Interpretation": A Method for the Interpretive Synthesis of Qualitative Research. *In Forum Qualitative Sozialforschung/Forum: Qualitative Social Research* (Vol. 6, No. 1).
- \*Werner, S. & Hochman, Y. (2018) On self-identity: the process of inclusion of individuals with intellectual disabilities in the military. *Disability and Rehabilitation*. doi: 10.1080/09638288.2018.1443158.
- \*Wilkinson, V. J., Theodore, K., & Raczka, R. (2015). 'As normal as possible': Sexual identity development in people with intellectual disabilities transitioning to adulthood. *Sexuality and Disability*, 33(1), 93-105.

Williams, V., & Porter, S. (2017). The meaning of 'choice and control for people with intellectual disabilities who are planning their social care and support. *Journal of Applied Research in Intellectual Disabilities*, 30(1), 97-108.

## **Part two: Empirical Paper**

**An exploration of the experience of receiving an intellectual disability diagnosis in adulthood.**

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This paper is written in the format ready for submission to the *Journal of Applied Research in Intellectual Disabilities* (see Appendix A for submission guidelines).

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## **Abstract**

*Background:* Individuals are typically diagnosed with intellectual disabilities in childhood; however it is not uncommon for people to receive a diagnosis in adulthood. The present study aims to explore the meaning of receiving a diagnosis in adulthood and the impact on self-identity.

*Method:* Semi-structured interviews were conducted with five individuals who received an intellectual disability diagnosis in adulthood and analysed using Interpretative Phenomenological Analysis.

*Results:* Three superordinate themes and nine subordinate themes were identified. Developed understanding of the self, access to support and negotiating stigma were all highlighted in relation to receiving a diagnosis in adulthood.

*Conclusions:* Both positive and negative experiences were associated with an intellectual disability diagnosis in adulthood, with implications and avenues for future research discussed.

*Key words:* Intellectual disabilities; diagnosis; identity; interpretative phenomenological analysis

## **Introduction**

Approximately 1.5 million people in the United Kingdom are estimated to have an intellectual disability, however only a quarter of these are thought to be known to learning disability services (Emerson & Hatton, 2008; Whitaker, 2004). Most individuals typically receive a diagnosis before the age of 18, though some do not receive a diagnosis until adulthood (Emerson & Hatton, 2008). There is a paucity of literature exploring the mean age that individuals receive a diagnosis and the proportion diagnosed as children or adults respectively.

Eligibility criteria to access specialist learning disability services may require a formal diagnosis and there could be implications regarding legal frameworks associated with a diagnosis, such as fitness to plead in courts (Mental Health Act, Department of Health, 2007), capacity and Deprivation of Liberty Safeguards (Mental Capacity Act; Department of Health, 2005). Consequently, accurate assessment has become increasingly important over recent years, though concerns have been expressed regarding the potential negative consequence of labelling individuals with an intellectual disability in contrast with the advantage of eligibility to access services (The British Psychological Society, 2015). However, no known research has explicitly explored this.

Receiving a diagnosis can be a life-changing event. The impact of receiving a diagnosis has been researched in relation to a range of physical health conditions (Ballard, Lowton & Wright, 2006; Edwards, Barlow & Turner, 2008; Peel, Parry, Douglas & Lawton, 2004), developmental disorders (Young, Bramham, Gray & Rose, 2008) and psychological

difficulties (Inder et al., 2010; Pitt, Kilbride, Welford, Nothard & Morrison, 2009). Across the diagnosis literature, themes relating to adjustment to the diagnosis, seeking information, anger and social experiences such as stigma were evident. Utilising strategies to process the diagnosis, such as support groups was also important (Pembroke, Higgins, Pender & Elliot, 2017). The experiences of individuals' diagnosed with conditions later than typically expected has also been explored. For example, receiving a diagnosis of cystic fibrosis as an adult was related to themes of change, difference, isolation and uncertainty (Widerman, 2008) and receiving an adult diagnosis of autism may lead to increased support and understanding of difficulties (Portway & Johnson, 2005).

Grief models (Kubler-Ross, 1970) have been used to conceptualise psychological processes associated with receiving a range of diagnoses, considering loss of former-life and former-self (Zeligman & Wood, 2017). Parents' experiences of their child being diagnosed with autism spectrum conditions have also drawn upon models relating to resolution of grief reactions (Fernandez-Alcantara et al., 2016). Following the development of the social model of disability, the use and suitability of grief models to understand adjustment to receiving a diagnosis have been criticised (Oliver, 1996). Oliver suggested the use of grief models emerged from beliefs of non-disabled individuals about what it would be like to experience disability, and in reality, individuals find adjusting to the views of others more difficult than expressing grief towards themselves. More recently, social identity theory has been applied to diagnosis based on indication that individuals' sense of self largely relates to group membership schemas (Tajfel, 1978). However, receiving a diagnosis may provide a new group identity, thus affecting schemas and perceived hierarchical positions (Howard, 2000). Social constructionism should also be considered regarding disability and developmental condition diagnoses (Jutel, 2009), whereby individual differences only

become disabling when society fails to account for them. It should therefore be considered whether unmet needs are a catalyst for needing a diagnosis and whether, on a societal level, more should be done to reduce the reliance on diagnosis in order for needs to be met (McCann, 2016).

The experience of intellectual disability diagnosis has only been explored in one known study (Kenyon, Beail & Jackson, 2014), though the proportion diagnosed as children and adults respectively was not stated or explored as separate experiences. Themes relating to awareness of difference, relationships with nondisabled others and coping with stigma were identified within the research. Individuals with intellectual disabilities are suggested to compare themselves to those less able than themselves (Craig, Craig, Withers, Hatton & Limb, 2002), possibly to protect self-esteem (Crocker & Major, 1989). Additionally, literature suggests individuals may not use the diagnosis given to them (Finlay & Lyons, 2000) due to perceiving themselves as ‘ordinary’ and not considering the diagnosis central to their self-identity.

The experiences of individuals with cognitive impairments due to intellectual disabilities, brain injuries, neurological conditions and mental health difficulties suggest that a label or diagnosis often legitimised limitations and difficulties for which there was previously no explanation and which the individual may have been criticised for (Olney & Kim, 2001). This highlights similarities to findings that individuals with intellectual disabilities may find a diagnosis helps them to understanding their own abilities better (Charmaz, 1991). The literature has also considered parents’ experiences suggesting increased knowledge regarding the outcome of the diagnosis provided a sense of control (Cunningham, 1979), made it easier to accept (Lipton & Svarstad, 1977) and provided validation and legitimacy (Makela, Birch, Friedman & Marra, 2009).

Valuing People (Department of Health, 2001) highlighted delay in intellectual disability diagnosis as a ‘problem’ to be addressed and outlined four criteria important for individuals with intellectual disabilities: legal and civil rights; independence; choice and inclusion. However, receipt of a formal diagnosis may be vital for these frameworks to be acknowledged. It has also been suggested that individuals with undiagnosed or ‘borderline’ intellectual disabilities are *‘the forgotten generation’* (Tymchuck, Lakin & Luckasson, 2001) due to the lack of research exploring the experiences of these individuals and their scarcity within learning disability services.

Research exploring the experience of receiving a diagnosis of many conditions later than typically expected indicated that this presents a different experience to receiving a “timely” diagnosis; however this has not been explored in adult diagnosis of intellectual disabilities. The broad aim of the present study is to address this gap in the literature. Developing a greater understanding of the meaning and impact of diagnosis may suggest considerations for professionals’ decisions when considering whether a diagnosis is necessary, appropriate and beneficial to the individual. Furthermore, it may also indicate necessary adaptations and areas for support for individuals during the assessment and post-diagnosis.

Research aims:

1. To gain an understanding of the meaning of the diagnosis to individuals.
2. To gain an understanding of how the process of diagnosis is experienced.
3. To gain an understanding of any impact on the self-identity of participants.

Research questions:

1. What does an Intellectual Disability diagnosis in adulthood mean for an individual?
2. How is the assessment process experienced?
3. What impact does receiving an Intellectual Disability diagnosis have on self-identity?
4. What factors contribute to whether to diagnosis is perceived as beneficial?

## **Method**

### *Design*

The study employed a qualitative design through the use of individual semi-structured interviews to address the primary research questions. Interviews were transcribed by the first author and analysed using Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009) as the study aimed to understand the meaning and experience of diagnosis.

### *Recruitment*

Participants were recruited through volunteer sampling. Individuals were recruited who received a formal intellectual disability diagnosis aged 18 and over, to explore the experience of receiving a diagnosis in adulthood. Participants were included if they received the diagnosis a minimum of 6 months ago to allow for adjustment to the diagnosis and to experience any changes following diagnosis. A maximum time since diagnosis of 10 years was employed due to the rapidly changing legislative and societal experiences of

living with an intellectual disability, in line with Valuing People Now (Department of Health, 2009), to ensure a relatively homogenous participant group. Participants who were English speaking, living in the community and were able to communicate verbally (due to the use of interviews) were included. Individuals were required to have capacity based on the Mental Capacity Act (Department of Health, 2005), were able to consent (see Appendix M-N for consent forms) and were comfortable talking about their experiences of diagnosis.

### *Participants*

Five participants were recruited, in line with recommendations from Smith, Flowers and Larkin (2009) suggesting a sample size of 4-10 participants for doctoral research using IPA. The study recruited through three NHS community learning disability services in the North of England covering a large geographical area and a range of non-NHS community groups, day services and charities. All five participants in the sample were recruited through two community learning disability services. Participants were aged 20-53 years (mean age 29 years) and all identified as White British. Individuals self-reported 1-5 years since diagnosis (mean 2 years) and aged between 19-48 years when diagnosed (mean age 27 years). Two reported living in supported housing, two with family members and one lived independently. Further participant demographic information is presented in Appendix E.

### *Data collection*

The study received full ethical approval from the South Yorkshire branch of the NHS Research Ethics Committee (see Appendix F). Participants who were thought to meet the inclusion criteria were provided with information about the study (see Appendix I-L for participant information sheets) by staff at the community learning disability team and provided consent for their details to be passed to the researcher if they were interested in

participating. The researcher then contacted them via telephone to explain further about the study, answer questions and arrange a convenient time and location for the interview to ensure participants felt at ease. The researcher then went over the information sheet followed by the consent form. All information was provided in simple, short sentences with accompanying visual aids, balanced between sufficient yet concise information (Mental Capacity Act; Department of Health, 2005). This was accompanied by verbal explanations as recommended by Goldsmith and Skirton (2015). Participants were asked to feed back a summary of the information (to demonstrate understanding, weighing up the pros and cons of participating, ability to retain information and communicate their decision to participate) to support the judgement they had capacity.

Information sheets, consent forms and the interview schedule were designed following consultation with an Expert by Experience with an intellectual disability to ensure suitability and accessibility along with speech and language therapists and professionals working within the field. Additional information sheets and consent forms were developed with further information detailed and less visual prompts to accommodate for individuals who may have stronger verbal comprehension skills.

All participants engaged in an interview conducted by the first author, which were guided by a semi-structured interview schedule with questions around the meaning of intellectual disabilities, the diagnostic process and the impact on self-identity (see Appendix P).

Questions were adapted in each interview to capture the experiences pertinent to individuals using open questions with closed prompts if necessary to aid communication (Hollomotz, 2018). Visual emotion flash cards were also available to facilitate conversation, though these were not used by any of the participants. Demographic information was collected using a questionnaire to contextualise the interview data (See

Appendix O). None of the participants knew the researcher before the study and it was explained to participants that they did not work at the learning disability team from which they were recruited.

Three interviews were conducted in participants' homes, one in a community support setting and one in a social space. Two participants chose to have a support worker present in the interview, though their contributions to the interview were excluded from the analysis due to the research aim focusing on individuals with an intellectual disability. The mean length of the interviews was 36 minutes in length (ranging between 22 and 51 minutes). All interviews were audio-recorded and transcribed by the first author.

Participants were asked if they would like to choose a pseudonym to represent their voice within the research and for those who declined, the researcher selected a pseudonym to protect anonymity.

#### *Data analysis*

The principles of IPA were employed for data analysis; considering lived experiences individually within the wider context and then subsequently viewing the data set in its entirety (Smith, Flowers & Larkin, 2009). IPA has been effectively used to explore and understand the experiences of individuals with intellectual disabilities (Rose et al., 2019). The following stages were adhered to (Larkin & Thompson, 2012; Smith, 2004; Smith, Flowers & Larkin, 2009):

1. Reading and re-reading transcripts to increase familiarity of original data.
2. Line by line analysis of each transcript examining descriptive content, linguistic and conceptual level coding (see Appendix S for worked example).

3. Development of emergent themes and patterns for each participant.
4. Mapping connections, commonalities and differences across participants to explore themes across the data set. Relabelling themes, returning to the original data to assess congruence of themes and reconfiguring.
5. An interpretative account of the experiences was then developed underpinned by psychological theory.

Therefore, the interpretation of the data involves participants' and the researcher's beliefs and assumptions, which both subsequently contribute to the analysis and discussion of the phenomenon. The lead researcher maintained a reflective journal throughout to consider reflections on the research (see Appendix T for reflective statement).

## **Results**

Three superordinate themes and nine subordinate themes were identified across the interviews displayed in Table 1. The results indicate three overarching aspects of receiving a diagnosis – developing an understanding of the self, the opportunity to receive support and negotiating stigma from others.

*Table 1.* Themes relating to the meaning of diagnosis in adulthood

Superordinate themes	Subordinate themes
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<i>'If you know, you can talk about it'</i> – developed understanding of self	Making sense of abilities and experiences  Identity oscillating through time  Ownership over own narratives  Others' understanding
<i>'It means you can get help'</i> - diagnosis unlocking support	Practical access to support  Growth in awareness of opportunities  Interpersonal support networks
<i>'It's swings and roundabouts really'</i> – negotiating stigma	Awareness of stigma  Internalisation of stigma

***'If you know, you can talk about it'* – developed understanding of self**

The first superordinate theme encompassed four subordinate themes. Making sense of one's own abilities and experiences was important for participants following diagnosis, along with developing a greater ownership over their own narratives and stories. Importance was also placed on feeling understood by others, which was discussed in relation to positive and negative experiences.

*Making sense of abilities and experiences*

Participants making sense of their abilities and experiences emerged as a subtheme of the research, which was discussed within all interviews. Participants appeared to focus on their own abilities and experiences following diagnosis rather than the diagnostic “label” itself.

Some individuals reported receiving a diagnosis provided them with a better understanding of their abilities, clarifying and confirming their own previous judgments *'it's about me knowing my own disabilities better'* (Emma). Participants also highlighted an interpersonal experience with parents of sense-making prior to diagnosis *'My mum knew. And so I knew. Because my mum always told me that. So we both kind of knew'* (Thomas) and *'I, I knew I had it, but like my mum said, they weren't sure which level, if you know what I mean'* (Emma).

For some participants, the experience of diagnosis appeared initially negative. Richard reported that he *'really weren't expecting it'* and described it as a *'shock'*. Other participants reported feeling *'confused'* (Alice) and *'frustrated and upset'* (Kyle) by the diagnosis, as though they had not previously identified with having an intellectual disability prior to diagnosis. All three of these participants indicated they were unsure why the assessment had been conducted and spoke of questioning themselves following the diagnosis *'I was thinking, what have I done? Does this mean I'm a nasty person?'* (Alice) and *'I just thought why me. Why couldn't it happen to someone else?'* (Richard). Similarly Alice also questioned *'oh no, what's happened to me?'* indicating a change from how she previously viewed herself.

Making sense of abilities appeared to be an ongoing process with Alice reporting *'I've been thinking about it a lot of times'* despite being diagnosed a year ago and Kyle spoke about a change in his feelings towards the diagnosis *'it's ok now. I was upset before though'*. Some participants reported using comparisons to other people as part of the journey of sense making *'I'm different because I can walk and chat to people'* (Kyle).

### *Identity oscillating through time*

In addition to making sense of current abilities following diagnosis, participants also reflected on past and future situations. Some participants spoke about the past and the future in the same sentence highlighting the fluctuations in reflections on experiences when making sense of the diagnosis *'it was such a shock and now I'm stuck in a hole. I can't go back to work and I'd like to find a new job'* (Richard). Only Emma and Thomas reflected on the specific assessment: *'It weren't the best test to have. It was hard. it got easy then harder'* (Emma), indicating that receiving the diagnosis and subsequent consequences were more pertinent for most individuals than the process itself.

Participants spoke of reflecting on and reviewing historical situations, through utilising their developed understanding to make sense of the past. Reflections upon school experiences were present across interviews in relation to friendships *'I didn't have many friends when I was at school because of the way I was or the because of the way I was treated'* (Emma), behavioural difficulties *'I only lasted three days at school. They couldn't handle me'* (Richard) and academic abilities *'I couldn't do anything but my name'* (Kyle). For some participants, reviewing life prior to diagnosis led to a sense of yearning for events they perceived as no longer able to engage in due to having an intellectual disability *'I miss driving, I do. Especially when it's been all your life'* (Richard). Reflections on previous actions and decisions were also evident, with suggestion that an earlier diagnosis would have affected choices made *'Well you would have known about it. So probably you wouldn't have worked so hard. Like, I used to work hard'* (Richard).

Participants also frequently talked about their future and indicated the diagnosis had facilitated them to develop more positive future hopes. Thomas spoke positively about

future opportunities *'I know that I've got these things to go to and these people to help me'* and Emma indicated the diagnosis had increased her confidence that she would be able to live independently:

*"Emma: If I found out any later, it would have been too late. Like if I got found out in my 40s, I don't think there would be any support like there is now kind of thing.*

*Researcher: Ok, why is the support important now in your twenties?*

*Emma: so I know what to expect when I'm older...so if I live on my own, I'll know how to cope on my own. Like if I'm having a bad day [pause] I can just chill and not shout".*

#### *Ownership over own narratives*

Across interviews, participants highlighted the importance of family members in making sense of their difficulties prior to diagnosis, often referring to *'mum'* (Alice and Thomas) and *'grandma'* (Kyle). Following diagnosis, participants indicated that the opportunity to make sense of their own abilities had aided understanding and their ability to communicate this to others, thus developing ownership over their own narratives and stories. Kyle reported the diagnosis had enabled him to *'be able to talk about it. If you know, you can talk about it'* and Emma expressed *'it's about me knowing my own disabilities better'*. Participants also indicated there had been a shift in their own narrative and understanding of self, with Alice highlighting an attempt to move away from a seemingly parent-child narrative within the family: *"well, being an adult. I'm a big lady now. And my mum tells me what to do and I say Mum I'm a big girl now, I don't need to be told what to do'.*

### *Others' understanding*

In addition to participants developing their own understanding of themselves, a shared experience of feeling understood by others was expressed, in relation to employment '*the place understands my disability...my learning disability*' (Thomas), family members '*they know what to do, whereas before they really struggled*' (Emma) and professional teams '*it was so good for other social care team unit people too. It's good they know*' (Kyle).

Participants also reflected on occasions prior to diagnosis when they felt '*no one knew what to do with me before*' (Emma), indicating this had positively changed since diagnosis.

Participants reflected back on the potential benefit of receiving a diagnosis earlier to catalyse the understanding of others around them, such as at school '*It might have helped them. It would have helped for English and Maths*' (Kyle). Participants also considered if an earlier diagnosis would have aided the development of previous friendships '*whereas if I got diagnosed before I could have been hanging round with people who knew me, that kind of thing*' (Emma). All participants spoke about the importance of developing friendships with people who '*can understand me*' (Thomas) and that it is '*probably easier to fit in with other people who have learning disabilities*' (Thomas) as a result. Mutual understanding within friendships was also important with indication of the value of being able to understand others too '*you can like learn what their disabilities are and you can compare with one another. Like if I don't know or struggle with something and they can help me. Or if they struggle I can help them*' (Emma). Richard was '*shocked*' at receiving a diagnosis describing '*it's nothing like me*', though mentioned '*you just have to make friends and keep going, don't you?*' when reflecting on his attendance at a group with other people with intellectual disabilities, indicating value in friendships.

The experience of others developing an understanding and awareness of an individual's difficulties also had negative connotations for participants, with Richard reporting he perceived the diagnosis to have led to him losing his driving licence and subsequent employment *'My learning disability I've got, well, I can't even work with it now, can I? I'd just like to go back to my old job as a wagon driver but I don't think I'll get my licence back'*. Alice also reflected on her mum's understanding of her difficulties *'It makes me quite worried about my mum. I'm worried she doesn't want me anymore'*.

### ***'It means you can get help' - diagnosis unlocking support***

#### *Practical access to services*

All participants reported that receiving a diagnosis had enabled them to receive support that they previously did not have, suggesting it was positive to *'help put things in place'* (Emma) and *'they told me what they had to offer'* (Thomas). Participants also discussed support in relation to the perceived benefit they feel an earlier diagnosis would have had, describing it would *'have been better for me'* (Thomas), *'have been a lot, lot better'* (Emma), *'it would have been better for me'* (Kyle), *'people need to find out when they're children. Children need to know'* (Alice) and *'it would have been nice to know about it'* (Richard). This was also discussed in relation to the lack of support prior to diagnosis *'I didn't get a lot of help before I got diagnosed so it would have been better to be told when I was younger to get help'* (Emma).

Richard reflected on the *'long time'* period between his struggles at school and not being diagnosed until he was in his forties. He also reported parenting difficulties prior to diagnosis, with indication that earlier support would have been valuable for the children *'they'd had to go into erm, what is it, foster placements, and I've missed them growing up'*

(Richard). For participants who were able to recall why a diagnostic assessment had been conducted, individuals referred to the hope that it would lead to support *'my mum thought, they both thought it was a good idea...to do the assessment...and see what there is to offer, is to offer'* (Thomas).

Individuals also referred to further support for employment, highlighting the array of support facilitated through receiving a diagnosis. Richard shared his experience of staff *'been wonderful with me. Everything they help me with. Like going on computers and have a look for a job and that'* and Thomas reported increased support at work *'because my Mum has probably told them that I find things difficult, so they know, so they can help me'*.

Participants also considered the time limited nature of some aspects of support and reflected on occasions where support gained following diagnosis had now ended *'I miss her support. It's freaky without it'* (Kyle). Richard also reported *'then after they saw me every so often. And er, that stopped. So now I'm by myself'*, indicating that support ending was a negative experience which suggests it was likely perceived as valuable.

#### *Growth in awareness of opportunities*

Participants also reported the diagnosis had led to a growth in awareness of opportunities to obtain future support *'Like if I need help on something, I can like ring up, or my Mum can ring up and say I need help with this, can you put it in place for her or things like that'* (Emma), indicating the positive impact of just knowing support is available. Participants also reported developed awareness of groups in the community they could participate with *'I know I've got these things to go to'* (Thomas), suggesting the diagnosis may lead to more systemic opportunities and engagement in the community *'So that I know that there's*

*things out there that for people to help me with and stuff. Things that I can go to and do and stuff. And like things that can help me with'* (Thomas). For other participants, awareness of and access to support led to people feeling able to pursue employment and develop romantic relationships: *'It means you can get help to get to do a job. Get help to go and get married and live with someone who you love so much'* (Alice). Kyle spoke about his hope to live independently *'one day'* reporting the importance of the availability of support *'I'm going to need support but I want to be independent'*.

#### *Interpersonal support networks*

The positive impact on interpersonal support networks was also discussed following diagnosis, including relationships with parents, siblings and friends. Emma reflected that her parents' increased understanding following diagnosis lead to them utilising more beneficial strategies when supporting her: *'Like if I'm like having a tantrum or having a bad day they know what to do. Whereas before, they really struggled. Like now, I can just go out and walk my dog or just have a bit of a breather or go to my bedroom and just scream and get my anger out instead of taking it out on my parents or my sister'*. This highlights the positive impact of diagnosis on family support networks. Increased support within friendships following diagnosis appeared to be appreciated and having *'someone who understands me. And that can help me if I need the help'* (Thomas) was valuable. However, some participants reported feeling overprotected as a result of diagnosis: *'I said to Grandma stop telling me what to do. I'm old enough and I can choose where I go. Stop judging me. I have had one drink, I'm an adult and I'm at the pub'* (Kyle). Some participants also indicated receiving a diagnosis has increased their capacity to utilise personal coping strategies following a developing understanding of themselves *'Now, I am*

*able to know what I can do for myself and instead of getting upset I can just think of something funny or watch a YouTube video and think why were you even upset?’ (Emma).*

### ***‘It’s swings and roundabouts really’ - negotiating stigma***

#### *Awareness of stigma*

Whilst participants all reflected on the positive aspects of diagnosis leading to access to services and availability of support, most individuals also reflected on negative, discriminatory experiences towards them. The majority of examples highlighted related to difficulties with employment, indicating this may be a pertinent struggle with intellectual disability diagnoses. Kyle highlighted the emotional impact of his employment experience: *‘Well he said to me, that I’ve got disability. And the manager said yes I know he has, I can tell. And then, she said to him ‘he won’t be good here’. It was a paid job. I was so so sad’.* Participants’ acknowledgement of their *‘disability’* (Kyle, Emma) when describing stigma suggests they perceived an association between having an intellectual disability and the negative experience directed towards them: *‘I used to volunteer at [name of place] but because of my disability they were, not mean, but they wouldn’t hire me because of my disability’*, with indication this experience has affected future decisions and thus had a lasting impact *‘that’s now put me off wanting to work there’* (Emma). Similarly, Thomas also suggested receiving an intellectual disability diagnosis *‘makes it a bit difficult’* to look for a job, though expressed hope that employment support would be beneficial *‘hopefully when I go through this process it should make it easier’*. Participants also reflected on the nature of interactions with others following diagnosis. One participant described these as *‘swings and roundabouts really. In a good way really I think. But sometimes it’s bad’* (Richard), suggesting a range of both positive and negative experiences were encountered.

One participant discussed understanding and making sense of her abilities following diagnosis increased her confidence to manage experiences of stigma: *'I know I've got the disability, but I don't have to worry about people looking at me differently. Like seeing people in the street going 'she's weird', you can just ignore them now without reacting to them or saying something to them. I just normally ignore them now'* (Emma). This indicates greater self-understanding may have enabled her to develop resilience to stigma through psychological safety and containment.

### *Internalisation of stigma*

In addition to some participants highlighting ways in which they were aware of stigma, participants indicated they may have internalised stigmatising narratives. Language expressed by participants to describe their perceived difficulties was often pejorative towards themselves *'I knew there was something not right'* (Emma), suggesting individuals may have internalised narratives that intellectual disabilities are undesirable. When recalling receiving the diagnosis, Richard reported *'it's nothing like me. Until they tell you it's what you are'* and Alice remarked *'I always think about myself and think oh no what's happened to me'* indicating beliefs that the difficulty lies within themselves rather than a socially-constructed issue. Participants' descriptions of coping with the diagnosis also appeared to reflect negative connotations associated with the diagnosis *'You've got to deal with it. You've got to live with it'* (Richard). Kyle also reported negative perceptions towards the diagnosis *'I didn't want a learning disability. All I want is to be normal. I would like to be normal. Like do normal things'*, suggesting he does not perceive himself as *'normal'* and as a result will not be able to do similar, *'normal things'* to others.

## **Discussion**

### *Overview of findings*

The aim of the study was to explore the experience of receiving an intellectual disability diagnosis in adulthood, with specific aims to gain an understanding of the meaning of diagnosis, the assessment process and the impact on self-identity. The findings indicate that receiving an intellectual disability diagnosis was important for individuals developing their understanding of themselves through making sense of experiences, reflecting on past and future experiences, developing ownership over their own narratives and feeling understood by others. The diagnosis appeared imperative for enabling access to support and awareness of opportunities, with all participants reporting an earlier diagnosis would have provided a catalyst for support earlier in their lives. Participants also appeared to have to negotiate stigma following a diagnosis with increased awareness internalisation of stigmatising discourses into their own constructions of their self-identity.

Only two participants elaborated specifically on the assessment with individuals reflecting more on the emotional experience of receiving a diagnosis. This indicates individuals may place greater meaning on the consequences of the diagnosis rather than the diagnostic process itself, which seems unlikely to relate to memory-recall difficulties (Morales et al., 2017) as all were able to recall pertinent historical experiences.

Receiving an intellectual disability diagnosis was associated with a range of emotions including frustration, sadness and confusion, consistent with diagnosis of other conditions (Wideman, 2008). However, the diagnosis also appeared to lead to the development of a greater understanding of themselves. Some participants reported positive experiences of containment and clarification following diagnosis, mirroring self-identity theories that

demonstrate consistency between self-concept and group identity leads to increase positive self-perceptions and affect (Li, Tam & Man, 2006). This is also consistent with literature highlighting parents' experience of legitimatisation and validation following their child receiving an intellectual disability diagnosis (Makela, Birch, Friedman & Marra, 2009). Furthermore, it appeared that participants felt other people understood them better following diagnosis, which lead to the development of friendships with similar others, mutual support and shared interests. This indicates the diagnosis had contributed to identification with a 'group', subsequently leading to experiences of belonging, acceptance and psychological safety which literature indicates is related to increased social and psychological functioning (Strnadová, Johnson & Walmsley, 2018). It is likely this experience is expedited by the diagnosis unlocking support, highlighted in the second superordinate theme and the increased awareness of opportunities, such as community groups and subsequent prospects of meeting similar others. Participants' increased understanding consequently led to increased ownership over their own narratives. This supports literature indicating that people with disabilities are often overprotected and 'shielded' from harm (Sanders, 2006) prior to diagnosis and thus highlights the positive longer-term consequences of transparency and openness.

Participants' identities appeared to oscillate through time, with participants fluctuating between making sense of the past, present and future. This is consistent with self-identity literature that an individual's sense of self is multifaceted and dynamically fluid over time (Combs & Freedman, 2016). This experience was evident across individuals who were diagnosed relatively recently to those diagnosed five years ago, highlighting the longevity and continual process of constructing self-identities. However, as this was pertinent throughout the interviews, it should be considered that this possibly may represent some

confusion over self-identity or may relate to time perception difficulties (Owen & Wilson, 2006) and indicate that individuals may need further support to process this.

The importance of the diagnosis enabling access to support was positively reported across interviews, demonstrating consistencies with literature suggesting individuals with intellectual disabilities may require additional support for day to day tasks and indicating that individuals may have felt inadequately supported prior to diagnosis. This highlights the need for a timely diagnosis, as recommended by The British Psychological Society (2015). Requirements of NHS learning disability services to formally assess to gain eligibility to services appears to reflect inconsistencies with the social model of disability (Oliver, 1996) and the paradigm shift moving away from diagnostically driven models of care (Roach, 2003). Participants indicated that simply the awareness of available support positively impacted on their hopes for the future, regardless of whether they were directly receiving support at present.

Participants reflected on the awareness of stigma, which is consistent with literature highlighting increased rates of discrimination and stigmatisation for individuals with intellectual disabilities (Paterson, McKenzie & Lindsay 2012). Individuals highlighted negative experiences associated with the diagnosis and expressed self-stigma, which likely relates to the developed self-awareness and identification with the diagnosis (Ali, Hassiotis, Strydom & King, 2012) highlighted in the first superordinate theme. However, reports of coping with stigma demonstrates similarities with experiences of individuals diagnosed in childhood (Kenyon, Beail & Jackson, 2014) indicating this reflects a more widespread concern of diagnosis, rather than specifically adult diagnosis. Participants also reflected on various instances of stigma prior to diagnosis, indicating they may have emotionally

experienced the impact of having an intellectual disability (Jahoda, Wilson, Stalker, Cairney, 2010) in the absence of a formal diagnosis.

### *Limitations*

The study only reflects a small number of stories and all participants who volunteered identified as White British, and therefore the experiences captured here may not reflect those of individuals from different cultural backgrounds. Research indicates varying conceptualisations of intellectual disabilities across cultures (Fatimilehin & Nadirshaw, 1994; Scior, Addai-Davis, Kenyon & Sheridan, 2012), which may contribute to the impact of diagnosis. All participants were in their twenties at the time of the study, with the exception of one who was diagnosed much later in life. This participant appeared the most shocked by the diagnosis and future research may indicate if this experience may be shared across others who were diagnosed later in life. The present study adopted a cross-sectional design and future research using a longitudinal design may be beneficial to explore the impact of receiving a diagnosis over time considering the fluidity of self-identity.

Participants all received diagnoses from two community learning disability services and whilst these covered a large geographical area, their experiences may partly reflect the procedures and protocols of those services. Furthermore, it is possible that participants were assessed by the same professionals and some of their experiences may be affected by the interpersonal style of the assessor.

Volunteer sampling may have led to a self-selection bias, whereby individuals who felt strongly about the diagnosis may have been favoured within the study (Sharma, 2017). The use of professional ‘gate keepers’ to introduce participants to the study may have also led to selection bias, which has been identified as a pervasive concern across intellectual

disability literature (Goldsmith & Skirton, 2015) and may contribute to individuals being denied the opportunity to share their stories and participate in research (Wiles, Crow, Charles & Heath, 2007). It should also be considered that participants may have associated the researcher with the learning disability service due to the use of gate-keepers and avoided discussing certain events or emotions. As participants were incidentally all recruited through community learning disability services and therefore open to the service in some way, this may reflect a particular experience whereby ongoing support is still being received and therefore may not reflect the experiences of those discharged.

The use of interpretative analytical approaches are influenced by the researchers own assumptions, approach and meaning placed on the experiences (see Appendix T for reflective statement) and thus the researcher is open about the multiple possible interpretations of the data.

### *Implications*

Both positive and negative experiences were highlighted in relation to receiving a diagnosis. Access to support and developed understanding of the self were perceived as valuable, though participants also reported feeling shocked, frustrated and upset by the diagnosis, indicating the need for post-diagnostic support by professionals following assessment. Although social models of disability have been widely adopted and there is a paradigm shift away from diagnostic labels, at present a formal diagnosis is generally required to access specialist learning disability services. Whilst this service model still exists, the study highlights the importance of timely diagnosis to enable support structures to be utilised. Many people do not receive a diagnosis until adulthood indicating individuals' difficulties may be missed or overlooked earlier in life. Therefore, further

support may be necessary for a range of professionals such as teachers, doctors and social workers, to support them to identify difficulties and expedite a timely diagnosis. The study also indicates that access to support following diagnosis was consistently highlighted as a positive experience. Consideration should therefore be made to people who do not meet the criteria for a diagnosis and are therefore not eligible to access learning disability services. Signposting to other sources of support such as community groups may be beneficial for increase support networks and connections with others and manage the emotional impact of discrimination.

The study indicates various consequences of receiving a diagnosis in adulthood, which may be beneficial for community learning disability services to consider. Professionals may attempt to avoid distressing individuals by minimising detail, however the research indicates developing self-awareness and making sense of difficulties is beneficial to strengthen individuals narratives and help them to seek connection with similar others, indicating the need for openness, honesty and transparency when discussing the diagnosis. The benefit of having the opportunity to make sense of experiences and foster positive identities is likely to be valuable for individuals who received diagnoses at any time in their lives. Interventions to enable individuals to explore and develop their self-identity may be beneficial, supporting literature indicating that narrative therapy groups help individuals with intellectual disabilities to foster positive self-identities (Elderton, Clarke, Jones & Stacey, 2014).

The present study has highlighted both positive and negative consequences of diagnosis, suggesting ethical principles of beneficence/non-maleficence, consistency and rationality should be considered by professionals when questioning whether an assessment may be valuable (Greenspan, Harris & Woods, 2015). Research suggests that arbitrary diagnostic

'cut-offs' may not represent the level of support required (Arnold, Riches & Stancliffe, 2011), suggesting some individuals that do not meet diagnostic criteria may require more support. Therefore, consideration should be given to whether more should be done to meet the needs of individuals without the reliance on diagnosis (McCann, 2016).

Additionally, there may be implications beyond the intellectual disability field and it is possible that the findings may be relevant for individuals who receive other diagnoses in adulthood, such as autism spectrum conditions, attention deficit disorder and other pervasive difficulties.

### *Future Research*

There remains a paucity in our understanding of the number of individuals who receive an intellectual disability diagnosis in adulthood, the number of people who may not receive a formal diagnosis due to the 'cut-off' of psychometric scores and those who remain undiagnosed and a need to understand this better through further research. Future research is also necessary to consider the experience of diagnosis for individuals who are no longer open service-users for support from community learning disability services. Additionally, as participants were generally diagnosed in their twenties, research exploring the meaning of diagnosis for those later in life would be worthwhile. Exploring the experiences of professionals involved within the diagnostic assessment process would be beneficial in order to gain a deeper understanding of learning disability services rationale, experiences and assumptions around the decision to formally assess and subsequently diagnose an individual.

## **Conclusion**

The study highlights positive and negative experiences following diagnosis in adulthood, including the development in understanding of the self following diagnosis, along with increased access to and opportunities for support. Negotiating stigma also emerged as a challenge following diagnosis. These findings have implications for professionals responsible for providing a diagnosis and question the widespread ethical dilemma of 'labelling' individuals in order for eligibility to access support.

## **Conflict of interest**

None declared.

## **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.
- Arnold, S. R., Riches, V. C., & Stancliffe, R. J. (2011). Intelligence is as intelligence does: Can additional support needs replace disability?. *Journal of Intellectual and Developmental Disability, 36*(4), 258-262.

- Ballard, K., Lowton, K., & Wright, J. (2006). What's the delay? A qualitative study of women's experiences of reaching a diagnosis of endometriosis. *Fertility and Sterility*, 86(5), 1296-1301.
- Charmaz, K. (1991). *Good days, bad days: The self in chronic illness and time*. New Brunswick, NJ: Rutgers University Press.
- Combs, G., & Freedman, J. (2016). Narrative therapy's relational understanding of identity. *Family Process*, 55(2), 211-224.
- Craig, J., Craig, F., Withers, P., Hatton, C. and 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: 61–72.
- Crocker, J., & Major, B. (1989). Social stigma and self-esteem: The self-protective properties of stigma. *Psychological Review*, 96, 608–630.
- Cunningham, C. C. (1979). *Parent Counselling*. In *Tregold's Mental Retardation*. London: Tindall.
- Department of Health. (2001). *Valuing people: A new strategy for learning disability for the 21st century*. London: Department of Health.
- Department of Health (2005). *Mental Capacity Act*. London: Department of Health.
- Department of Health (2007). *Mental Health Act*. London: Department of Health.
- Department of Health (2009). *Valuing People Now: A New Three-year Strategy for People with Learning Disabilities*. London: Department of Health.

- Edwards, R. G., Barlow, J. H., & Turner, A. P. (2008). Experiences of diagnosis and treatment among people with multiple sclerosis. *Journal of Evaluation in Clinical Practice*, 14(3), 460-464.
- Elderton, A., Clarke, S., Jones, C., & Stacey, J. (2014). Telling our story: a narrative therapy approach to helping lesbian, gay, bisexual and transgender people with a learning disability identify and strengthen positive self-identity stories. *British Journal of Learning Disabilities*, 42(4), 301-307.
- Emerson, E. & Hatton, C. (2008) *People with Learning Disabilities in England, Centre for Disability Research, Research Report, CeDR* .
- Fatimilehin, I.A. & Nadirshaw, Z. (1994). A cross-cultural study of parental attitudes and beliefs about learning disability (mental handicap). *Journal of Applied Research in Intellectual Disabilities*, 7(3), 202-227.
- Fernandez-Alcantara, M., Garcia-Caro, M. P., Perez-Marfil, M. N., Hueso-Montoro, C., Laynez, R., C., & Cruz-Quintana, F. (2016). Feelings of loss and grief in parents of children diagnosed with autism spectrum disorder (ASD). *Research in developmental disabilities*, 55(3), 12-21.
- Finlay, W. M. L. and Lyons, E. (2000), Social categorizations, social comparisons and stigma: Presentations of self in people with learning difficulties. *British Journal of Social Psychology*, 39: 129–146.
- Goldsmith, L., & Skirton, H. (2015). Research involving people with a learning disability—methodological challenges and ethical considerations. *Journal of Research in Nursing*, 20(6), 435-446.

- Greenspan, S., Harris, J. C., & Woods, G. W. (2015). Intellectual disability is “a condition, not a number”: Ethics of IQ cut-offs in psychiatry, human services and law. *Ethics, Medicine and Public Health*, 1(3), 312-324.
- Howard, J. A. (2000). Social Psychology of Identities. *Annual Review of Sociology*, 26, 367-393.
- Inder, M. L., Crowe, M. T., Joyce, P. R., Moor, S., Carter, J. D., & Luty, S. E. (2010). “I really don’t know whether it is still there”: Ambivalent acceptance of a diagnosis of bipolar disorder. *Psychiatric Quarterly*, 81(2), 157-165.
- 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.
- Jutel, A. (2009). Sociology of diagnosis: a preliminary review. *Sociology of Health and Illness*, 31(2), 278-299.
- Kenyon, E., Beail, N., & Jackson, T. (2014). Learning disability: experience of diagnosis. *British Journal of Learning Disabilities*, 42(4), 257-263.
- Kubler-Ross, E. (1970). The care of the dying-whose job is it? *The International Journal of Psychiatry in Medicine*, 1(2), 103-107.
- Larkin, M., & Thompson, A. R. (2012). Interpretative phenomenological analysis in mental health and psychotherapy research. *Qualitative research methods in mental health and psychotherapy*, 101-116.

- Li, E. P. Y., Tam, A. S. F., & Man, D. W. K. (2006). Exploring the self-concepts of persons with intellectual disabilities. *Journal of intellectual disabilities*, 10(1), 19-34.
- Lipton, H. L., & Svarstad, B. (1977). Sources of variation in clinicians' communication to parents about mental retardation. *American Journal of Mental Deficiency*, 82, 155-161.
- Makela, N. L., Birch, P. H., Friedman, J. M., & Marra, C. A. (2009). Parental perceived value of a diagnosis for intellectual disability (ID): a qualitative comparison of families with and without a diagnosis for their child's ID. *American Journal of Medical Genetics Part A*, 149 (11), 2393-2402.
- McCann, J. (2016) Is mental illness socially constructed? *Journal of Applied Psychology and Social Science*, 2 (1), 1-11.
- Morales, C., Manzanero, A. L., Wong, A., Gómez-Gutiérrez, M., Iglesias, A. M., Barón, S., & Álvarez, M. (2017). Stability of autobiographical memory in young people with intellectual disabilities. *Anuario de Psicología Jurídica*, 27(1), 79-84.
- Oliver, M. (1996). *Understanding disability: From theory to practice*. New York, NY: Macmillan.
- Olney, M., & Kim, A. (2001). Beyond Adjustment: Integration of cognitive disability into identity. *Disability & Society*, 16(4), 563-583.
- Owen, A. L., & Wilson, R. R. (2006). Unlocking the riddle of time in learning disability. *Journal of Intellectual Disabilities*, 10(1), 9-17.

- Paterson, L., McKenzie, K., & Lindsay, B. (2012). Stigma, social comparison and self-esteem in adults with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 25(2), 166-176.
- Peel, E., Parry, O., Douglas, M., & Lawton, J. (2004). Diagnosis of type 2 diabetes: a qualitative analysis of patients' emotional reactions and views about information provision. *Patient education and counselling*, 53(3), 269-275.
- Pembroke, S., Higgins, A., Pender, N. & Elliott, N. (2017) Becoming comfortable with “my” epilepsy: Strategies that patients use in the journey from diagnosis to acceptance and disclosure. *Epilepsy & Behavior*, 70, 217-223.
- Pitt, L., Kilbride, M., Welford, M., Nothard, S., & Morrison, A. P. (2009). Impact of a diagnosis of psychosis: user-led qualitative study. *Psychiatric Bulletin*, 33(11), 419-423.
- Portway, S. M., Johnson, B. (2005) Do you know I have Asperger's syndrome? Risks of a non-obvious disability. *Health, Risk and Society*. 7(1), 73–83.
- Roach, A. (2003). In search of a paradigm shift: What disability studies can contribute to school psychology. *Disability Studies Quarterly*, 23(3/4).
- Rose, J., Malik, K., Hirata, E., Roughan, H., Aston, K., & Larkin, M. (2019). Is it possible to use interpretative phenomenological analysis in research with people who have intellectual disabilities?. *Journal of Applied Research in Intellectual Disabilities*. doi: 10.1111/jar.12605
- Sanders, K. Y. (2006). Overprotection and lowered expectations of persons with disabilities: The unforeseen consequences. *Work*, 27(2), 181-188.

- Scior, K., Addai-Davis, J., Kenyon, M., & Sheridan, J. C. (2013). Stigma, public awareness about intellectual disability and attitudes to inclusion among different ethnic groups. *Journal of Intellectual Disability Research*, 57(11), 1014-1026.
- Sharma, G. (2017). Pros and cons of different sampling techniques. *International Journal of Applied Research*, 3(7), 749-752.
- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative research in psychology*, 1(1), 39-54.
- Smith, J. A., Flowers, P. & Larkin, M. (2009) *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage Publications.
- Strnadová, I., Johnson, K., & Walmsley, J. (2018). "... but if you're afraid of things, how are you meant to belong?" What belonging means to people with intellectual disabilities? *Journal of Applied Research in Intellectual Disabilities*, 31(6), 1091-1102.
- Tajfel, H. (1978). *Differentiation between social groups: Studies in the social psychology of intergroup relations*. London: Academic Press.
- The British Psychological Society (2015) *Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood*. Leicester: The British Psychological Society.
- Tymchuk, A. J., Lakin, K. C., & Luckasson, R. (2001). *Life at the margins: Intellectual, demographic, economic, and social circumstances of adults with mild cognitive limitations. The forgotten generation*, 21-38.

- Whitaker, S. (2004). Hidden learning disability. *British Journal of Learning Disabilities*, 32(3), 139-143.
- Widerman, E. (2008). The Experience of Receiving a Diagnosis of Cystic Fibrosis After Age 20. *Social Work in Health Care*, 39(3-4), 415-433.
- Wiles, R., Crow, G., Charles, V., & Heath, S. (2007). Informed consent and the research process: following rules or striking balances? *Sociological Research Online*, 12(2), 1-12.
- Young, S., Bramham, J., Gray, K., & Rose, E. (2008). The experience of receiving a diagnosis and treatment of ADHD in adulthood: a qualitative study of clinically referred patients using interpretative phenomenological analysis. *Journal of Attention Disorders*, 11(4), 493-503.
- Zeligman, M., & Wood, A. W. (2017). Conceptualizing an HIV Diagnosis Through a Model of Grief and Bereavement. *Adulthood Journal*, 16(1), 18-30.

## **Part Three: Appendices**

## Appendix A. Author guidelines for 'Journal of Applied Research in Intellectual Disabilities'

### 1. GENERAL

The *Journal of Applied Research in Intellectual Disabilities* is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

Please read the instructions below carefully for details on submission of manuscripts, the journal's requirements and standards as well as information concerning the procedure after a manuscript has been accepted for publication. Authors are encouraged to visit <http://authorservices.wiley.com/bauthor/> for further information on the preparation and submission of articles.

All manuscripts must be submitted solely to this journal and not published, in press, or submitted elsewhere.

### 2. ETHICAL GUIDELINES

Acceptance of papers is based on the understanding that authors have treated research participants with respect and dignity throughout. Please see Section 2.2 below.

#### 2.1 Authorship and Acknowledgements

**Authorship:** Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the collection of data does not justify authorship.

It is a requirement that all authors have been accredited as appropriate under submission of the manuscript. Contributors who do not qualify as authors should be mentioned under Acknowledgements.

**Acknowledgements:** Under Acknowledgements please specify contributors to the article other than the authors accredited. Please also include specifications of the source of funding for the study and any potential conflict of interest if appropriate. Suppliers of materials should be named and their location (town, state/county, country) included.

#### 2.2 Ethical Approvals

Research involving human participants will only be published if such research has been conducted in full accordance with ethical principles, including the [World Medical Association Declaration of Helsinki](#) and the additional requirements, if any, of the country where the research has been carried out. Manuscripts must be accompanied by a statement that the research was undertaken with the understanding and written consent of each participant (or the participant's representative, if they lack capacity), and according to the above mentioned principles. A statement regarding the fact that the study has been independently reviewed and approved by an ethical board should also be included.

All studies using human participants should include an explicit statement in the Material and Methods section identifying the review and ethics committee approval for each study, if applicable. Editors reserve the right to reject papers if there is doubt as to whether appropriate procedures have been used.

Ethics of investigation: Papers not in agreement with the guidelines of the [Helsinki Declaration as revised in 2013](#) will not be accepted for publication.

### 2.3 Clinical Trials

Clinical trials should be reported using the CONSORT guidelines available at [www.consort-statement.org](http://www.consort-statement.org). A CONSORT checklist should also be included in the submission material ([www.consort-statement.org](http://www.consort-statement.org)).

The *Journal of Applied Research in Intellectual Disabilities* encourages authors submitting manuscripts reporting from a clinical trial to register the trials in any of the following free, public trials registries: [www.clinicaltrials.org](http://www.clinicaltrials.org), [www.isrctn.org](http://www.isrctn.org). The clinical trial registration number and name of the trial register will then be published with the paper.

### 2.4 Conflict of Interest and Source of Funding

**Conflict of Interest:** Authors are required to disclose any possible conflict of interest. These include financial (for example patent ownership, stock ownership, consultancies, speaker's fee). Author's conflict of interest (or information specifying the absence of conflict of interest) will be published under a separate heading.

The *Journal of Applied Research in Intellectual Disabilities* requires that sources of institutional, private and corporate financial support for the work within the manuscript must be fully acknowledged, and any potential conflict of interest noted. As of 1st March 2007, this information is a requirement for all manuscripts submitted to the journal and will be published in a highlighted box on the title page of the article. Please include this information under the separate headings of 'Source of Funding' and 'Conflict of Interest' at the end of the manuscript.

If the author does not include a conflict of interest statement in the manuscript, then the following statement will be included by default: 'No conflict of interest has been declared'.

**Source of Funding:** Authors are required to specify the source of funding for their research when submitting a paper. Suppliers of materials should be named and their location (town, state/county, country) included. The information will be disclosed in the published article.

### 2.5 Permissions

If all or parts of previously published illustrations are used, permission must be obtained from the copyright holder concerned. It is the author's responsibility to obtain these in writing and provide copies to the Publishers.

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#### **4. SUBMISSION OF MANUSCRIPTS**

Submissions are now made online using ScholarOne Manuscripts (formerly Manuscript Central). To submit to the journal go to <http://mc.manuscriptcentral.com/jarid>. If this is the first time you have used the system you will be asked to register by clicking on 'create an account'. Full instructions on making your submission are provided. You should receive an acknowledgement within a few minutes. Thereafter, the system will keep you informed of the process of your submission through refereeing, any revisions that are required and a final decision.

##### **4.1 Manuscript Files Accepted**

Manuscripts should be uploaded as Word (.doc) or Rich Text Format (.rft) files (not write-protected) plus separate figure files. GIF, JPEG, PICT or Bitmap files are acceptable for submission, but only high-resolution TIF or EPS files are suitable for printing.

To allow double-blinded review, please upload your manuscript and title page as **separate** files.

Please upload:

1. Your manuscript without title page under the file designation 'main document'.
2. Figure files under the file designation 'figures'.
3. Title page which should include title, authors (including corresponding author contact details), acknowledgements and conflict of interest statement where applicable, should be uploaded under the file designation 'title page'.

All documents uploaded under the file designation 'title page' will not be viewable in the HTML and PDF format you are asked to review at the end of the submission process. The files viewable in the HTML and PDF format are the files available to the reviewer in the review process.

Please note that any manuscripts uploaded as Word 2007 (.docx) will be automatically rejected. Please save any .docx files as .doc before uploading.

##### **4.2 Blinded Review**

All articles submitted to the journal are assessed by at least two anonymous reviewers with expertise in that field. The Editors reserve the right to edit any contribution to ensure that it conforms with the requirements of the journal.

By submitting a manuscript to or reviewing for this publication, your name, email address, and affiliation, and other contact details the publication might require, will be used for the regular operations of the publication, including, when necessary, sharing with the publisher (Wiley) and partners for production and publication. The publication and the publisher recognize the importance of protecting the personal information collected from users in the operation of these services, and have practices in place to ensure that steps are taken to maintain the security, integrity, and privacy of the personal data collected and processed. You can learn more at <https://authorservices.wiley.com/statements/data-protection-policy.html>.

#### **5. MANUSCRIPT TYPES ACCEPTED**

*Original Articles, Review Articles, Brief Reports, Book Reviews* and *Letters to the Editor* are accepted. *Theoretical Papers* are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. Articles are accepted for publication only at the discretion of the Editor. Articles should not exceed 7000 words. Brief Reports should not normally exceed 2000 words. Submissions for the Letters to the Editor section should be no more than 750 words in length. Words in Tables, Table captions/legends, Figures and Figure captions/legends are excluded in the limit.

## 6. MANUSCRIPT FORMAT AND STRUCTURE

### 6.1 Format

**Language:** The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at

[http://authorservices.wiley.com/bauthor/english\\_language.asp](http://authorservices.wiley.com/bauthor/english_language.asp). All services are paid for and arranged by the author, and use of one of these services does not guarantee acceptance or preference for publication.

### 6.2 Structure

All manuscripts submitted to the *Journal of Applied Research in Intellectual Disabilities* should include:

**Cover Page:** A cover page should contain only the title, thereby facilitating anonymous reviewing. The authors' details should be supplied on a separate page and the author for correspondence should be identified clearly, along with full contact details, including e-mail address.

**Running Title:** A short title of not more than fifty characters, including spaces, should be provided.

**Keywords:** Up to six key words to aid indexing should also be provided.

**Main Text:** All papers should have a structured abstract (maximum 150 words) as follows: Background, Method, Results, and Conclusions. The abstract should provide an outline of the research questions, the design, essential findings and main conclusions of the study. Authors should make use of headings within the main paper as follows: Introduction, Method, Results and Discussion. Subheadings can be used as appropriate. All authors must clearly state their research questions, aims or hypotheses clearly at the end of the Introduction. Figures and Tables should be submitted as a separate file.

**Style:** Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:

-Include all figure legends, and tables with their legends if available.

-Do not use the carriage return (enter) at the end of lines within a paragraph.

-Turn the hyphenation option off.

-In the cover email, specify any special characters used to represent non-keyboard characters.

-Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).

-Use a tab, not spaces, to separate data points in tables.

-If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

### 6.3 References

APA - American Psychological Association

References should be prepared according to the Publication Manual of the American Psychological Association (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper.

A sample of the most common entries in reference lists appears below. Please note that a DOI should be provided for all references where available. For more information about APA referencing style, please refer to the [APA FAQ](#). Please note that for journal articles, issue numbers are not included unless each issue in the volume begins with page one.

*Journal article*

Example of reference with 2 to 7 authors

Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. *The American Journal of Psychiatry*, 159, 483–486.  
doi:10.1176/appi.ajp.159.3.483

Ramus, F., Rosen, S., Dakin, S. C., Day, B. L., Castellote, J. M., White, S., & Frith, U. (2003). Theories of developmental dyslexia: Insights from a multiple case study of dyslexic adults. *Brain*, 126(4), 841-865. doi: 10.1093/brain/awg076

#### Example of reference with more than 7 authors

Rutter, M., Caspi, A., Fergusson, D., Horwood, L. J., Goodman, R., Maughan, B., ... Carroll, J. (2004). Sex differences in developmental reading disability: New findings from 4 epidemiological studies. *Journal of the American Medical Association*, 291(16), 2007-2012. doi 10.1001/jama.291.16.2007

#### *Book Edition*

Bradley-Johnson, S. (1994). Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school (2nd ed.). Austin, TX: Pro-ed.

### **6.4 Tables, Figures and Figure Legends**

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.

Figures should be referred to in the text as Figures using Arabic numbers, e.g. Fig.1, Fig.2 etc, in order of appearance. Figures should be clearly labelled with the name of the first author, and the appropriate number. Each figure should have a separate legend; these should be grouped on a separate page at the end of the manuscript. All symbols and abbreviations should be clearly explained. In the full-text online edition of the journal, figure legends may be truncated in abbreviated links to the full screen version. Therefore, the first 100 characters of any legend should inform the reader of key aspects of the figure.

#### **Preparation of Electronic Figures for Publication**

Although low quality images are adequate for review purposes, print publication requires high quality images to prevent the final product being blurred or fuzzy. Submit EPS (line art) or TIFF (halftone/photographs) files only. MS PowerPoint and Word Graphics are unsuitable for printed pictures. Do not use pixel-oriented programmes. Scans (TIFF only) should have a resolution of at least 300 dpi (halftone) or 600 to 1200 dpi (line drawings) in relation to the reproduction size. Please submit the data for figures in black and white or submit a Colour Work Agreement Form. EPS files should be saved with fonts embedded (and with a TIFF preview if possible).

Further information can be obtained at Wiley-Blackwell's guidelines for figures:

<http://authorservices.wiley.com/bauthor/illustration.asp>.

Check your electronic artwork before submitting it:

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[www.adobe.com/products/acrobat/readstep2.html](http://www.adobe.com/products/acrobat/readstep2.html)

This will enable the file to be opened, read on screen, and printed out in order for any corrections to be added. Further instructions will be sent with the proof. Proofs will be posted if no e-mail address is available; in your absence, please arrange for a colleague to access your e-mail to retrieve the proofs.

Proofs must be returned to the Production Editor within 3 days of receipt.

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Appendix B. NICE (2012) Quality Appraisal Checklist for qualitative studies

<b>Study identification:</b> Include author, title, reference, year of publication		
<b>Guidance topic:</b>	<b>Key research question/aim:</b>	
<b>Checklist completed by:</b>		
<b>Theoretical approach</b>		
<b>1. Is a qualitative approach appropriate?</b> For example: <ul style="list-style-type: none"> <li>• Does the research question seek to understand processes or structures, or illuminate subjective experiences or meanings?</li> <li>• Could a quantitative approach better have addressed the research question?</li> </ul>	Appropriate Inappropriate Not sure	Comments:
<b>2. Is the study clear in what it seeks to do?</b> For example: <ul style="list-style-type: none"> <li>• Is the purpose of the study discussed – aims/objectives/research question/s?</li> <li>• Is there adequate/appropriate reference to the literature?</li> <li>• Are underpinning values/assumptions/theory discussed?</li> </ul>	Clear Unclear Mixed	Comments:
<b>Study design</b>		
<b>3. How defensible/rigorous is the research design/methodology?</b>	Defensible Indefensible	Comments:

<p>For example:</p> <ul style="list-style-type: none"> <li>• Is the design appropriate to the research question?</li> <li>• Is a rationale given for using a qualitative approach?</li> <li>• Are there clear accounts of the rationale/justification for the sampling, data collection and data analysis techniques used?</li> <li>• Is the selection of cases/sampling strategy theoretically justified?</li> </ul>	<p>Not sure</p>	
<p><b>Data collection</b></p>		
<p><b>4. How well was the data collection carried out?</b></p> <p>For example:</p> <ul style="list-style-type: none"> <li>• Are the data collection methods clearly described?</li> <li>• Were the appropriate data collected to address the research question?</li> <li>• Was the data collection and record keeping systematic?</li> </ul>	<p>Appropriately</p> <p>Inappropriately</p> <p>Not sure/inadequately reported</p>	<p>Comments:</p>
<p><b>Trustworthiness</b></p>		
<p><b>5. Is the role of the researcher clearly described?</b></p> <p>For example:</p> <ul style="list-style-type: none"> <li>• Has the relationship between the researcher and the participants been adequately considered?</li> <li>• Does the paper describe how the research was</li> </ul>	<p>Clearly described</p> <p>Unclear</p> <p>Not described</p>	<p>Comments:</p>

explained and presented to the participants?		
<p><b>6. Is the context clearly described?</b></p> <p>For example:</p> <ul style="list-style-type: none"> <li>• Are the characteristics of the participants and settings clearly defined?</li> <li>• Were observations made in a sufficient variety of circumstances</li> <li>• Was context bias considered</li> </ul>	<p>Clear</p> <p>Unclear</p> <p>Not sure</p>	Comments:
<p><b>7. Were the methods reliable?</b></p> <p>For example:</p> <ul style="list-style-type: none"> <li>• Was data collected by more than 1 method?</li> <li>• Is there justification for triangulation, or for not triangulating?</li> <li>• Do the methods investigate what they claim to?</li> </ul>	<p>Reliable</p> <p>Unreliable</p> <p>Not sure</p>	Comments:
<b>Analysis</b>		
<p><b>8. Is the data analysis sufficiently rigorous?</b></p> <p>For example:</p> <ul style="list-style-type: none"> <li>• Is the procedure explicit – i.e. is it clear how the data was analysed to arrive at the results?</li> <li>• How systematic is the analysis, is the procedure reliable/dependable?</li> <li>• Is it clear how the themes and concepts were derived from the data?</li> </ul>	<p>Rigorous</p> <p>Not rigorous</p> <p>Not sure/not reported</p>	Comments:
<p><b>9. Is the data 'rich'?</b></p>	<p>Rich</p>	Comments:

<p>For example:</p> <ul style="list-style-type: none"> <li>• How well are the contexts of the data described?</li> <li>• Has the diversity of perspective and content been explored?</li> <li>• How well has the detail and depth been demonstrated?</li> <li>• Are responses compared and contrasted across groups/sites?</li> </ul>	<p>Poor</p> <p>Not sure/not reported</p>	
<p><b>10. Is the analysis reliable?</b></p> <p>For example:</p> <ul style="list-style-type: none"> <li>• Did more than 1 researcher theme and code transcripts/data?</li> <li>• If so, how were differences resolved?</li> <li>• Did participants feed back on the transcripts/data if possible and relevant?</li> <li>• Were negative/discrepant results addressed or ignored?</li> </ul>	<p>Reliable</p> <p>Unreliable</p> <p>Not sure/not reported</p>	<p>Comments:</p>
<p><b>11. Are the findings convincing?</b></p> <p>For example:</p> <ul style="list-style-type: none"> <li>• Are the findings clearly presented?</li> <li>• Are the findings internally coherent?</li> <li>• Are extracts from the original data included?</li> <li>• Are the data appropriately referenced?</li> <li>• Is the reporting clear and coherent?</li> </ul>	<p>Convincing</p> <p>Not convincing</p> <p>Not sure</p>	<p>Comments:</p>

<p><b>12. Are the findings relevant to the aims of the study?</b></p>	<p>Relevant Irrelevant Partially relevant</p>	<p>Comments:</p>
<p><b>13. Conclusions</b></p> <p>For example:</p> <ul style="list-style-type: none"> <li>• How clear are the links between data, interpretation and conclusions?</li> <li>• Are the conclusions plausible and coherent?</li> <li>• Have alternative explanations been explored and discounted?</li> <li>• Does this enhance understanding of the research topic?</li> <li>• Are the implications of the research clearly defined?</li> </ul> <p><b>Is there adequate discussion of any limitations encountered?</b></p>	<p>Adequate Inadequate Not sure</p>	<p>Comments:</p>
<p><b>Ethics</b></p>		
<p><b>14. How clear and coherent is the reporting of ethics?</b></p> <p>For example:</p> <ul style="list-style-type: none"> <li>• Have ethical issues been taken into consideration?</li> <li>• Are they adequately discussed e.g. do they address consent and anonymity?</li> <li>• Have the consequences of the research been considered i.e. raising expectations, changing</li> </ul>	<p>Appropriate Inappropriate Not sure/not reported</p>	<p>Comments:</p>

<p>behaviour?</p> <ul style="list-style-type: none"> <li>Was the study approved by an ethics committee?</li> </ul>		
<p><b>Overall assessment</b></p>		
<p><b>As far as can be ascertained from the paper, how well was the study conducted? (see guidance notes)</b></p>	<p>++ + -</p>	<p>Comments:</p>

*Appendix C. Data extraction form*

**Data extraction form**

Author, year, location of study	
Aim(s)	
Participant demographics	
Level of intellectual disability	
Methodological approach	
Analysis	
Findings of self-identity	
Quality assessment	

Appendix D. Quality assessment ratings for reviewed studies  
(A = appropriate, NR = not reported)

Study	Theoretical approach		Study design	Data collection	Trustworthiness					Analysis			Ethics	Overall	
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	
Anderson & Bigby (2017)	A	Clear	Not sure	Appropriate	Not described	Unclear	Not sure	Rigorous	Not sure	Not reported	Convincing	Relevant	Adequate	A	+
Azzopardi-Lane & Callus (2015)	A	Clear	Indefensible	Inadequately reported	Unclear	Unclear	Not sure	Not rigorous	Poor	Not reported	Not convincing	Partially relevant	Inadequate	Not sure	-
Bernert (2011)	A	Mixed	Not sure	Inadequately reported	Not described	Clear	Not sure	Rigorous	Rich	Not reported	Convincing	Relevant	Adequate	NR	+
Björnsdóttir, (2017)	A	Unclear	Defensible	Appropriately	Not described	Unclear	Reliable	Rigorous	NR	Reliable	Not sure	Relevant	Not sure	NR	-
Bunning & Steel (2007)	A	Clear	Defensible	Appropriate	Inadequately reported	Unclear	Not sure	Rigorous	Poor	Not reported	Not convincing	Partially relevant	Inadequate	A	-
Chou, Lu & Pu (2015)	A	Clear	Defensible	Appropriate	Not described	Unclear	Not sure	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	NR	+
Clarke, Camilleri & Goding (2015)	A	Clear	Defensible	Appropriately	Not described	Clear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	A	++
Craig, Craig, Withers, Hatton & Limb (2002)	A	Clear	Defensible	Appropriate	Not described	Unclear	Not sure	Not reported	Poor	Reliable	Not sure	Relevant	Not sure	Not sure	-
Davies & Jenkins (1997)	A	Clear	Not sure	Inadequately reported	Not described	Unclear	Unreliable	Not rigorous	Poor	Not reported	Not convincing	Partially relevant	Not sure	NR	-
Dinwoodie, Greenhill &	A	Clear	Defensible	Appropriately	Clearly described	Clear	Reliable	Rigorous	Rich	Not reported	Convincing	Relevant	Adequate	A	++

Cookson (2016)																
Dorozenko, Roberts and Bishop (2015) Australia	A	Clear	Defensible	Appropriately	Not described	Unclear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	NR	+	
Elderton, Clarke, Jones & Stacey (2014)	A	Clear	Defensible	Appropriately	Inadequately reported	Unclear	Reliable	Not rigorous	NR	Not reported	Not sure	Relevant	Adequate	NR	-	
Finlay and Lyons (1998)	A	Clear	Defensible	Appropriately	Clearly described	Clear	Reliable	Not reported	NR	Not reported	Not sure	Relevant	Adequate	NR	+	
Finlay and Lyons (2000)	A	Clear	Defensible	Appropriately	Not described	Not sure	Unreliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	NR	+	
Fitzgerald & Withers (2013)	A	Clear	Defensible	Appropriately	Not described	Unclear	Not sure	Not reported	Rich	Not sure	Convincing	Relevant	Adequate	NR	+	
Groves, Rayner & Muncer (2018)	A	Clear	Defensible	Appropriately	Not described	Unclear	Unreliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	A	++	
Hassan (2017)	A	Clear	Defensible	Not sure	Clearly described	Unclear	Reliable	Not rigorous	NR	Unreliable	Not sure	Relevant	Not sure	A	-	
Head, Ellis-Caird, Rhodes & Parkinson (2018)	A	Clear	Defensible	Not sure	Clearly described	Unclear	Reliable	Not reported	Rich	Not reported	Convincing	Relevant	Adequate	A	+	
Kittelsaa (2014)	A	Clear	Defensible	Appropriately	Not described	Unclear	Reliable	Rigorous	Rich	Not reported	Convincing	Relevant	Adequate	A	++	
Malik, Unwin, Larkin, Korese & Rose (2017)	A	Clear	Defensible	Appropriately	Not described	Unclear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	A	++	
Midjo &	A	Clear	Defensible	Appropriately	Not	Unclear	Not	Not sure	Rich	Not	Convincing	Relevant	Adequate	A	+	

Aune (2018)					described		sure			reported						
Mineur, Tideman & Mallander (2017)	A	Clear	Defensible	Appropriately	Clearly described	Unclear	Not sure	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	A	++	
Monteleone & Forrester Jones (2017)	A	Clear	Defensible	Appropriately	Unclear	Not sure	Not sure	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	A	++	
Neuman & Reiter (2017)	A	Clear	Defensible	Unclear	Unclear	Unclear	Not sure	Not reported	NR	Not reported	Not sure	Relevant	Not sure	NR	-	
Pestana (2015)	A	Clear	Defensible	Appropriate	Not described	Unclear	Reliable	Not reported	Not sure	Reliable	Convincing	Relevant	Adequate	A	+	
Scior (2003)	A	Clear	Defensible	Inadequately reported	Clearly described	Clear	Reliable	Not reported	Rich	Not reported	Not sure	Relevant	Adequate	NR	+	
Sherwan, McKenzie, Quayle & Crawley (2012)	A	Clear	Defensible	Appropriately	Unclear	Unclear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	A	++	
Szivos & Griffiths (1990)	A	Clear	Not sure	Inadequately reported	Not described	Unclear	Not sure	Not reported	Poor	Not reported	Not convincing	Partially relevant	Not sure	NR	-	
Werner & Hochman (2018)	A	Clear	Defensible	Appropriate	Unclear	Unclear	Reliable	Rigorous	Rich	Reliable	Convincing	Relevant	Adequate	NR	++	
Wilkinson, Theodore & Raczka (2015)	A	Clear	Defensible	Inadequately reported	Not described	Unclear	Reliable	Rigorous	Rich	Not reported	Convincing	Relevant	Adequate	A	+	

*Appendix E.* Further participant demographic information

<b>Pseudonym</b>	<b>Age</b>	<b>Gender</b>	<b>Ethnic Group</b>	<b>Living situation</b>	<b>Self-reported age diagnosed</b>	<b>Self-reported time since diagnosis</b>	<b>Support received</b>	<b>Employment</b>	<b>Interview location</b>	<b>Length of interview</b>	<b>Anyone present during interview</b>
Thomas	27	Male	White British	Supported housing	25	2	Benefits, family friends, LD service, employment	Paid job and voluntary job	Home	21.5	No
Emma	25	Female	White British	Family home (with parents)	24	1	Benefits, key worker, support from family and friends	Voluntary job	Home	30.01	No
Richard	53	Male	White British	Independently	48	5	Benefits, support from friends and family, support for assisted activities	Voluntary Job	Day centre	36.31	Yes - supporter
Alice	20	Female	White British	Supported housing	19	1	Benefits, support from personal assistants, support from CTLD, employment, assisted activities and Mencap	Voluntary job	Home	39.1	Yes - key worker at end
Kyle	22	Male	White British	Family home (grandparents)	21	1	Benefits, assisted activities, Mencap, employment support,	Paid job	Social space	51.28	No

*Appendix F.* Ethical approval documentation

Removed for digital archiving.

Removed for digital archiving.

			<p>30/05/2018 Recruitment Poster Version 1.1 IRAS ID: 243043</p>
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# Were you diagnosed with a Learning Disability as an adult?

We are interested in hearing about what this was like for you.

I would like to talk to people to find out what it was like when they found out they had a Learning Disability and if anything has changed since they were diagnosed.

### What would I have to do?

If you would like to take part, we would meet at a place and time convenient for you to talk about your experience of being diagnosed with a Learning Disability as an adult.



This will take up to 1 hour.



Taking part will not affect any care or support you receive.

**If you would like to take part, please contact Charlotte Hinsby on:**

**Phone: 07707 869 550**

**Or email: [c.hinsby@2016.hull.ac.uk](mailto:c.hinsby@2016.hull.ac.uk)**









01/02/2019  
Recruitment Poster  
Version 1.2  
IRAS ID: 243043

# Were you diagnosed with a Learning Disability as an adult?

We are interested in hearing about your experience.

I would like to talk to people to find out what it was like when they found out they had a Learning Disability and if anything has changed since they were diagnosed.

**What would I have to do?**

If you want to take part, we can meet at a place and time good for you. We will talk about your experience of being diagnosed with a Learning Disability as an adult.



This will take up to 1 hour.



Taking part will not change any support you get.

**If you would like to take part, please ask at reception or contact Charlotte Hinsby on:**

**Phone: 07707 869 550      Email: [c.hinsby@2016.hull.ac.uk](mailto:c.hinsby@2016.hull.ac.uk)**



*Appendix I. Participant information sheet with visual aids*

Participant Information Sheet

**Title of project: What's it like to find out you have a Learning Disability when you're an adult?**

My name is Charlotte Hinsby and this is some information about my research.

We have given you this information sheet because you might be interested in taking part in the research.



**What is the research about?**

I am going to talk to lots of people who were diagnosed with a Learning Disability when they were an adult.



I am interested to find out how you felt when you found out about your Learning Disability

I want to find out if anything has changed in your life since the diagnosis.



**Why is the research being done?**

I would like to see how you found being diagnosed when you were an adult.

This might help us to know whether it might be useful for other people and what changes might happen for them.



**What will you have to do if you take part?**

I would like to meet with you on your own and ask you some questions.



This will last for about an hour.



What we talk about will be recorded. This will remind me what we talked about.



### **What happens to information about you?**

I will write up what we talk about but I will not use your real name or names of places.

The things we talk about will be private unless I am worried about your safety or someone else's.

If I am worried I will talk to either someone involved in your care, like the Learning Disability Team and/or the Local Safeguarding Team.

This is to make sure you and other people are safe.



### **Where will information be kept?**

The information you tell us will be kept securely at the University of Hull.

Personal information about you, like your name and contact details, are needed so we can speak to you to sort out when we will meet.



This information will be destroyed when I have finished writing up the research.

All typed interviews will be kept securely in a locked cabinet for up to ten years, then they will be destroyed. These will not include your name or personal information.

**Do you have to take part?**

You decide if you want to take part. You can say Yes or No.



You can say Yes and then change your mind up to when I write up my work.

It is ok if you say No. It will not affect any care or support you get.

## What should you do if you want more information?

You can ring me on **07707 869 550**.



You can also ask the staff if you are part of a Learning Disability Service. They might know some answers to your questions.

You can also talk about taking part with someone you feel comfortable with – like a family member or friend.



If you want to take part, please leave your contact details in the space provided below.

I will then contact you to arrange to meet up at a time and place that is good for you.

Name:

.....

Address:

.....

.....

.....

Telephone/ Mobile Phone Number:

.....

What time of day would you like to be contacted?

.....

Signature:.....

Date:.....

**Thank you very much for your interest!**

Appendix J. Participant information sheet with visual aids adapted for one community learning disability service

Participant Information Sheet

**Title of project: What's it like to find out you have a Learning Disability when you're an adult?**

	<p><b>Who am I?</b></p> <p>My name is Charlotte Hinsby and I am a Trainee Clinical Psychologist.</p> <p>I am doing a research project about what it is like to find out you have a Learning Disability when you are an adult.</p>
	<p><b>Why have I been given this information?</b></p> <p>You might be interested in taking part in the research.</p>
	<p><b>What is the research about?</b></p> <p>I am going to talk to lots of people who were diagnosed with a Learning Disability when they were adults.</p>
	<p><b>What do I want to find out?</b></p> <p>I want to know how you felt when you found out about the Learning Disability and if anything changed in your life after.</p>
	<p><b>Why is the research being done?</b></p> <p>It could help us to know if finding out might be useful for other people.</p>

	<p><b>What will you have to do if you take part?</b></p> <p>I would like to meet with you at a time and place that is good for you.</p> <p>I will ask you some questions.</p>
	<p><b>How long will it take?</b></p> <p>It will take up to one hour.</p>
	<p>I will record what we talk about on my laptop. This will remind me what you said.</p>
	<p>I will write up what we talk about but I will not use your real name or names of places.</p> <p>The things we talk about will be private unless I am worried about your safety or someone else's.</p>
	<p>If I am worried I will talk to either someone involved in your care, like the Learning Disability Team and/or the Local Safeguarding Team.</p> <p>This is to make sure you and other people are safe.</p>
	<p><b>Where will information be kept?</b></p> <p>The information you tell us will be kept securely at the University of Hull.</p>

	<p>Your name and contact details are needed so we can speak to you to sort out when we will meet.</p>
	<p>Your personal details will be destroyed when I have finished writing up the research.</p>
	<p>All typed interviews will be kept secure in a locked cabinet for up to 10 years then destroyed.</p> <p>These will not include your name or personal information.</p>
	<p><b>Do you have to take part?</b></p> <p>You decide if you want to take part.</p> <p>You can say yes or no.</p>
	<p><b>What if you change your mind?</b></p> <p>You can say yes and then change your mind up to when I write up my work.</p> <p>It is ok to say no. It will not change any support you get.</p>

	<p><b>What should you do if you want more information?</b></p> <p>You can ring me on 07707 869 550.</p>
	<p>You can email me on <a href="mailto:c.hinsby@2016.hull.ac.uk">c.hinsby@2016.hull.ac.uk</a></p>
<p>[Picture removed for anonymity]</p>	<p>You can also ask at reception at the Learning Disability Team for information.</p>
	<p>If you want to take part, please write your contact details on the next page.</p>
	<p>I will then ring you to give you more information and to sort a time to meet that is good for you.</p>

Name:

.....

Address:

.....

.....

.....

Telephone/ Mobile Phone Number:

.....

What time of day would you like to be contacted?

.....

Signature:.....

Date:.....

**Thank you very much for your interest**

## Participant Information Sheet

### **Title of project: What's it like to find out you have a Learning Disability when you're an adult?**

We would like to invite you to take part in our research study which is looking at the experiences of individuals' who were diagnosed with a Learning Disability as an adult.

Before you decide if you want to take part, we want you to understand why it is being done and what it will involve.

You can talk to others if you would like before you decide.

***The researcher will answer any questions you may have.***

#### What is the purpose of the study?

We know very little about what it is like for people to be diagnosed with a Learning Disability as an adult and how it affects the way they see themselves. This study is looking to understand more about how people find the experience of being diagnosed and how it affects them.

We hope that this will help us to understand more about what it is like to help improve the diagnosis process and how people are supported.

#### Why have I been invited?

This information is given to people who have been diagnosed with a Learning Disability age 18+, between 6 months and 10 years ago. Staff members at Learning Disability Services give this information to people who may be interested in taking part.

#### Do I have to take part?

No –it is up to you if you decide to take part. If you decide you want to, you will need to sign a form to say you agree to take part. You can ask to stop taking part in the study at

any time up to the point where I write up my work. You do not have to give a reason and the decision will not affect any care or support you receive.

What will happen if I decide to take part?

If you agree to take part, please leave your contact details with a member of staff. Then you will be contacted to arrange a meeting at a time and a place convenient for you. You will be asked to answer some short questions about you for example your age and your gender.

You will then have a conversation for up to one hour about your experience of being diagnosed with a Learning Disability and we will audio record the conversation. There are no right or wrong answers; we are just interested in your experience of being diagnosed.

What are the possible disadvantages and risks of taking part?

Taking part will take around one hour which may take up your time. Some people may feel upset or worried when talking about their experience because it might bring up difficult issues. If this happens to you, the researcher will help you and tell you where you can get other support.

What are the possible good reasons for taking part?

There might not be any direct positive reasons to taking part in the study. However, the information you give us will help us to understand more about what it is like to be diagnosed with a Learning Disability as an adult. It may also help to improve the Learning Disability Services and the support available.

What will happen if I decide I no longer wish to take part?

You can stop taking part at any time without giving a reason during the interview. This will not affect any care or support you receive. Any information you have provided will be destroyed. You can change your mind up until the point I write up the research and all your information will be destroyed.

### What if there is a problem?

If you have a concern or worry, you can contact the researcher or their supervisor who will try to answer your questions.

### Will my taking part in this study be kept confidential?

Yes, all personal information will be kept confidential. Any information that could be used to identify you will not be used and real names and places will be changed. The interviews will be typed up and will be stored securely in a locked cabinet at the University of Hull, in keeping with University guidelines, for up to ten years, after which time it will be destroyed. This will not include your personal details.

Your personal information such as your name/contact details and the audio recordings will be destroyed after the research has been written up.

The only time that information cannot be kept confidential is if you say something that suggests you or someone else is at risk of serious harm. If this happens, the researcher will have to contact the Learning Disability Team that you are seen by and/or the local Safeguarding team.

This is to make sure you and other people are safe. It is unlikely that this will happen and the researcher will discuss this with you.

### What will happen to the results of the study?

After the study is complete, we can send you a written summary of the results if you wish. The results will be submitted to be included in an academic journal and used in presentations. We might also tell Learning Disability Services about the results as it might help them to support people better in future.

Some direct quotes from your interview may be used but these will be anonymous and your name will not be used. Your personal details and any identifiable data will not be included.

### Who is organising and funding the research?

The research is part of a doctoral research project in Clinical Psychology. The research is funded and checked by the University of Hull. The University of Hull and other regulatory authorities may check that the right guidance was followed by the researcher.

Who has reviewed the study?

The study is reviewed by an organisation called a Research Ethics Committee. This protects the people who take part in the research.

If you have any further questions, comments or queries, please contact Charlotte Hinsby or Dr Nick Hutchinson:

Email: [c.hinsby@2016.hull.ac.uk](mailto:c.hinsby@2016.hull.ac.uk) or [n.hutchinson@hull.ac.uk](mailto:n.hutchinson@hull.ac.uk)

Address: Charlotte Hinsby/Dr Nick Hutchinson. Clinical Psychology, Aire Building, The University of Hull, Cottingham Road, Hull, HU6 7RX

Thank you for taking the time to read this information.

Yours sincerely,

Charlotte Hinsby

Trainee Clinical Psychologist

Supervised by

Dr Nick Hutchinson

Clinical Psychologist

If you are interested in taking part in the study please leave your contact details in the space provided below. You will be contacted by the researcher to arrange a meeting at a convenient place and time.

Name:

.....

Address:

.....

.....

Telephone/ Mobile Phone Number:

.....

Are there any times of the day that you prefer to be contacted?

.....

Do you have any further comments?

.....

Signature:.....

Date:.....

**Thank you very much for your interest!**

*Appendix L.* Participant information sheet adapted for one community learning disability service.

## **Participant Information Sheet**

### **Title of project: What's it like to find out you have a Learning Disability when you're an adult?**

We would like to invite you to take part in our research study. This is looking at the experiences of people who were diagnosed with a Learning Disability as an adult.

Before you decide if you want to take part, please read why we are doing it and what you will have to do. You can talk to your supporter or family before you decide.

**The researcher will answer any questions you may have.**

#### What is the purpose of the study?

We don't know enough about what it is like for people to be diagnosed with a Learning Disability as an adult. This study looks at how people find it and how it feels.

We hope that this will help us to improve the diagnosis process and how people are supported.

#### Why have I been invited?

We are asking people who have been diagnosed with a Learning Disability age 18+, between 6 months and 10 years ago.

#### Do I have to take part?

No –it is up to you if you decide to take part. If you decide you want to, you will need to sign a form to say you agree to take part. You can ask to stop taking part in the study at any time up to the point where I write up my work. You do not have to give a reason. Your decision will not affect any care or support you receive.

What will happen if I decide to take part?

If you agree to take part, please leave your contact details at reception. I will then contact you to arrange a meeting at a time and place that is good for you. I will ask you some short questions about you, for example your age

We will talk for up to one hour about what it was like to be diagnosed. I will record the conversation with my laptop.

There are no right or wrong answers. I am just interested in your experience.

What are the possible disadvantages and risks of taking part?

Taking part will take around one hour. Some people may feel upset or worried when talking about their experience because it might bring up difficult issues. If this happens I will help you and tell you where you can get other support.

What are the possible good reasons for taking part?

The information you give us will help us to understand more about what it is like to be diagnosed with a Learning Disability as an adult. It may help to improve the Learning Disability Services and the support available.

What will happen if I decide I no longer wish to take part?

You can stop at any time in the interview without giving a reason. It will not affect any support you get. You can change your mind up to the point I write up the research. Anything you have said will be destroyed. This

What if there is a problem?

If you have a concern or worry, you can contact me or my research supervisor who will try to answer your questions.

Will taking part in this study be kept confidential?

Yes, all personal information will be kept confidential. Your real name and names of places will be changed.

Your personal information such as your name/contact details and the laptop recording will be destroyed after the research has been written up.

I will type our conversation up and it will be stored securely in a locked cabinet at the University of Hull. I have to keep this for ten years, then it will be destroyed. This will not include your personal details.

I will keep our conversation confidential, unless I think you or someone else is at risk of harm. I will then have to talk to the Learning Disability Team or Local Safeguarding Team if this happens.

This is to make sure you and other people are safe. I will tell you if I am going to do this.

#### What will happen to the results of the study?

After the study is complete, we can send you a written summary of the results if you want. The results will be submitted to an academic journal and used in presentations. We might also tell Learning Disability Services about the results as it might help them to support people better in future.

Some direct quotes from your interview may be used but your name will not be used. No personal details or information that identifies you will be included.

#### Who is organising and funding the research?

The research is part of a doctoral research project in Clinical Psychology. The research is funded and checked by the University of Hull. The University of Hull and other regulatory authorities may check that the right guidance was followed.

#### Who has reviewed the study?

The study is reviewed by an organisation called a Research Ethics Committee. This protects the people who take part in the research.

#### What should I do if I'm interested in taking part?

Please leave your contact details in the space below. I will then contact you to give you more information and arrange a meeting at a time and place that is good for you.

Thank you for taking the time to read this information.

Yours sincerely,

Charlotte Hinsby (Trainee Clinical Psychologist)  
Email: c.hinsby@2016.hull.ac.uk Phone: 07707 869 550

Supervised by Dr Nick Hutchinson (Clinical Psychologist)  
Email: n.hutchinson@hull.ac.uk

Name:

.....  
..

Address:

.....  
.....  
.....

Telephone/ Mobile Phone Number:

.....

What time of the day would you like to be contacted?

.....

Signature:.....

Date:.....

**Thank you very much for your interest!**

Appendix M. Participant consent form – visual

### CONSENT FORM

**Title of project: What's it like to find out you have a Learning Disability when you're an adult?**

Name of researcher: Charlotte Hinsby

***Participant to circle all they agree with:***

I have read (or had read to me) information about this project



Yes



No

I understand what this project is about



Yes



No

I understand that you can stop taking part at any time without giving a reason, up until the research is written up



Yes



No

I understand that my real name or the names of people or places I have talked will not be used about when the research is written up



Yes



No

When completed: 1 for participant; 1 for researcher site file stored securely at the University of Hull

I understand that my name and contact details will not be passed on to other people



Yes

No



I understand the only people who will have access to information that says who I am will be the researcher who needs to contact me



Yes

No



I understand my personal details will be destroyed once the research has been written up



Yes

No



I have asked all the questions I want



Yes



No

All my questions been answered



Yes



No

When completed: 1 for participant; 1 for researcher site file stored securely at the University of Hull

I understand the interview will be recorded



Yes



No

I am happy to take part



Yes



No

*If you would like to take part, please sign your name below:*

Your name \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_\_

Researchers name \_\_\_\_\_

Signature \_\_\_\_\_

Date \_\_\_\_\_

When completed: 1 for participant; 1 for researcher site file stored securely at the University of Hull

**CONSENT FORM**

**Title of project: What's it like to find out you have a Learning Disability when you're an adult?**

Name of researcher: Charlotte Hinsby

***Participant to circle all they agree with:***

I have read (or had read to me) information about this project Yes/No

I understand what this project is about Yes/No

I understand that I can stop taking part at any time without giving a reason up until the research is written up Yes/No

I understand that my real name or the names of people or places I have talked about will not be used when the research is written up Yes/No

I understand that my name and contact details will be kept confidential and this information will not be passed on to other organisations Yes/No

I understand the only people who will have access to information that says who I am will be the researcher who needs to contact you Yes/No

I understand my personal details will be destroyed once the research has been written up Yes/No

I have asked all the questions I want Yes/No

All my questions have been answered Yes/No

I understand the interview will be recorded Yes/No

I am happy to take part Yes/No

*If you would like to take part, please sign your name below:*

Your name \_\_\_\_\_

Signature \_\_\_\_\_

Date\_\_\_\_\_

Researchers name \_\_\_\_\_

Signature \_\_\_\_\_

Date\_\_\_\_\_

Appendix O. Participant demographic information form

**Demographic Information Form**

Information about you

**1. What is your age in years?**

.....

**2. Are you male or female?**

Male    Female    Prefer not to say

**3. Which ethnic group describes you best?**

- |   |  |
|---|--|
| <input type="checkbox"/> White British          | <input type="checkbox"/> Other Asian background    |
| <input type="checkbox"/> Other White background | <input type="checkbox"/> Black Caribbean and White |
| <input type="checkbox"/> Black British          | <input type="checkbox"/> Black African and White   |
| <input type="checkbox"/> Black African          | <input type="checkbox"/> Asian and White           |
| <input type="checkbox"/> Black Caribbean        | <input type="checkbox"/> Other Dual Heritage       |
| <input type="checkbox"/> Other Black background | <input type="checkbox"/> Chinese                   |
| <input type="checkbox"/> Indian                 | <input type="checkbox"/> Traveller                 |
| <input type="checkbox"/> Pakistani              | <input type="checkbox"/> Bangladeshi               |
| <input type="checkbox"/> Other Ethnic Group     | <input type="checkbox"/> Prefer not to say         |

**4. Where do you live?**

- I live in my family home that I grew up in
- I live in a family member's home
- I live in a residential home
- I live in supported housing
- I live with a friend/friends
- I live independently
- I live with my partner
- I live somewhere else. Please tell us more about this:.....

**5. How old were you when you got diagnosed with a learning disability?**

.....

**6. Do you receive any kind of support related to your learning disability?**

- Yes       No

**If so, please tick the ones that you get:**

- Benefits
- Support from personal assistants/carers/support workers
- Support from family/friends
- Support from a Learning Disability Service
- Support from Community Team for people with Learning Disabilities
- Support for employment
- Support for assisted activities (i.e day centre)
- Support from Mencap
- Support from another organisation. ....

If you have answered yes to any of the above, please provide further information here.

**7. Do you take part in any paid or voluntary work?**

- Yes       No

If yes,

I have a paid job. Please tell us about your job.....

.....

I have a voluntary job. Please tell us about your job.....

.....

**Thank you for completing this questionnaire.**

*Appendix P. Semi-structured interview schedule.*

The interview schedule will not be strictly followed, but rather, used to guide questions and the general direction of the interview.

### **Questions**

#### **1. What does “Learning Disability” or “Intellectual Disability” mean to you?**

*Prompts:*

- How would you describe it?
- Identification with term

#### **2. Tell me about your experience of being diagnosed with a Learning Disability?**

*Prompts:*

- How did you come to be diagnosed?
- Who initiated the referral?
- What was the process of being diagnosed like?
- What did you think it would be like?
- Support from others

#### **3. How did it make you feel? (use visual aid if necessary)**

*Prompts:*

- Happy Sad Angry Scared Worried Surprised

#### **3. How useful do you think the diagnosis was?**

*Prompts:*

- Child or adult diagnosis?

#### **4. How have things changed since you were diagnosed?**

*Prompts:*

- Relationships with others
- Family and friends
- Living arrangements
- Employment

- Activities
- Support
- Self perception / perception of others
- Treated differently
- Behaviour of others

## 5. How has the diagnosis changed the way you view yourself

Prompts:

- Comparison to others
- Fitting in
- Other peoples reactions/behaviour
- Your difficulties
- Capabilities
- Identification with diagnosis

### Visual aid to assist with emotions

happy 	sad 	nervous 	excited 	mad 	frustrated 
sick 	surprised 	tired 	bored 	curious 	sneaky 
confused 	not sure 	funny 	grumpy 	ashamed 	cranky 
moody 	shy 	tense 	flirt 	confident 	interested 
out of control 	special 	comfortable 	mysterious 	panicky 	tough 

Retrieved from [www.boardmakershare.com](http://www.boardmakershare.com)

*Appendix Q. Sources of support information for participants*

**Sources of support and information about Learning Disability diagnosis**

**Mencap** offer support for individuals with a Learning Disability on its website:

[www.mencap.org.uk](http://www.mencap.org.uk)



**Learning disability helpline: 0808 808 1111**

If you have any specific issues about taking part in the study, please contact the **Researcher** on:

**Email:** [c.hinsby@2016.hull.ac.uk](mailto:c.hinsby@2016.hull.ac.uk)



**Phone number:** 07707 869 550

If you would still like further support you can contact **[name] Learning Disability Service** on:



**Phone number:**

[number removed for anonymity]

**Thank you for taking part in the research.**

*Appendix R.* Thank you letter for people who did not meet inclusion criteria

Dear, [name]

Thank you for telling us that you would like to take part in the research.

We have certain things that we have to ask to check if someone is suitable to take part.

**For this research, we are looking for people that:**

1. Were diagnosed with a Learning Disability when they were age 18 or older
2. Were told this between 6 months ago and 10 years ago
3. Understand what they would have to do if they were involved in this research

As you don't fit these three things, unfortunately you cannot take part in the research. Thank you very much for saying you would like to. I really appreciate it.

Kind regards,

Charlotte Hinsby

Supervised by Dr Nick Hutchinson

Appendix S. Worked example of data analysis from transcript

Initial coding	Transcript	Emergent themes
<p>Already had awareness prior to diagnosis</p> <p>Understanding within the family prior to diagnosis?</p> <p>'Something not right' – difference, derogatory</p> <p>Lack of friends. Isolation?</p> <p>'Because of the way I was' – difference</p> <p>Treated differently – stigma?</p> <p>Sadness. Difficulties lead to loneliness and isolation</p> <p>Negative school experience</p>	<p>Researcher: Right ok, and how was it when you found out you had a learning disability?</p> <p>Emma: I, I knew I had it, but like my mum said, they weren't sure which level, if you know what I mean.</p> <p>Researcher: oh right ok, and what made you think that you had a learning disability before?</p> <p>Emma: I think it's, I dunno to be honest. Erm, I knew I was something not right if you know what I mean.</p> <p>Researcher: Right ok, are there any particular differences you notice?</p> <p>Emma: I didn't have many friends when I was at school because of the way I was or the because of the way I was treated.</p> <p>Researcher: so did you feel like you were treated differently?</p> <p>Emma: Yeah</p> <p>Researcher: How did that make you feel?</p> <p>Emma: Sad, I was always on my own and didn't hang around with anyone or anyone at school.</p> <p>Researcher: How was school?</p> <p>Emma: it was [name of school] in [name of place]. It was a Catholic school but it wasn't the best.</p> <p>Researcher: Oh really? Why wasn't it the best?</p>	<p>Struggle to articulate difficulties, parents having ownership</p> <p>LD as unfavourable/people not wanting to be friends/awareness of stigma and discrimination/self-stigma</p> <p>Awareness of differences – lack of belonging or connection</p>

<p>Bullied – “felt like I wasn’t worth” – internalised bullying to self</p> <p>Wanting to be at home- seeking safety, understanding?</p> <p>Running away – escaping, communicating distress?</p>	<p>Emma: It was the headmaster. When I first started it was really good and because the last headmaster left and the other one came, it went downhill. I got bullied and they didn’t do anything about the bullying and yeah, I just felt like, felt like I wasn’t worth being at school. I just always wanted to be at home and on a few occasions, I actually wanted to run away from school.</p> <p>Researcher: oh did you?</p> <p>Emma: Yeah, one day I was actually quite close to walking out of school.</p> <p>Researcher: Oh really. It sounds like that was difficult.</p> <p>Emma: Yeah.</p> <p>Researcher: And how are things now for you?</p> <p>Emma: Fine</p>	<p>World as unsafe place</p> <p>Internalised bullying – self-stigma</p> <p>Seeking to feel understood</p>
<p>Change in circumstances</p>	<p>Researcher: Right ok.</p>	
<p>Lack of friends - different directions – distancing</p>	<p>Emma: I’ve got a few friends but they’ve moved to university. So they’ve gone one way and I’ve gone another and we don’t talk anymore.</p> <p>Researcher: Don’t you? Right. Would you say you’ve got any friends at the minute?</p>	<p>Distance/isolation with friends. Friends who weren’t similar?</p>
<p>Lack of similarity with people around her.</p>	<p>Emma: I have round here, but they’re not my age. It’s more dog walkers and anything else.</p> <p>Researcher: Ah right, so are they people who live locally?</p> <p>Emma: Yeah</p>	
<p>Local/close proximity –</p>	<p>Researcher: ah right. And what was it like when you found out you had to do the learning</p>	

<p>ease</p> <p>Looking forward to assessment – perceived to be positive? not as expected</p> <p>Struggling/not understanding/not explained</p> <p>Something to do with IQ. Awareness of difficulties. Making sense of abilities.</p> <p>Diagnosis via letter (lack of support?)</p>	<p>disability assessments?</p> <p>Emma: I was looking forward to doing the tests and seeing what the tests were, but they were, I weren't enjoying it.</p> <p>Researcher: Right. What made you not enjoy it do you think?</p> <p>Emma: I think it's because I was struggling with them and not understanding how they went. They just put it in front of you and went "do this".</p> <p>Researcher: Oh right. So you weren't always sure what you were doing?</p> <p>Emma: Yeah [laughs]</p> <p>Researcher: some of them are quite tricky aren't they. Can you remember how you ended up having to do those tests? Can you remember who it was who thought it would be a good idea?</p> <p>Emma: No, I think it was something to do with my IQ and to like check my IQ level. Yeah, it weren't the best test to have. It was hard. It got easy then harder.</p> <p>Researcher: So it kept getting harder?</p> <p>Emma: Yeah</p> <p>Researcher: right. Do you remember when they fed back the results?</p> <p>Emma: I think it was through a letter.</p> <p>Researcher: Right. And how was that when you got that letter, can you remember?</p>	<p>Diagnostic process not as expected.</p> <p>Shock – awareness of own abilities– making sense of difficulties</p> <p>Trying to figure out how she was doing – memory of difficulty of tasks – seeking answers? Making sense of abilities?</p>
---	--	--



## *Appendix T. Reflective Statement*

Developing and conducting this thesis over the last three years has been a challenging, yet rewarding rollercoaster.

### *Background to idea*

The idea was built through a number of different experiences throughout my life that have stayed with me. Growing up with a close family member with severe learning disabilities, I have gained a personal understanding of the challenges and stigma, both people with learning disabilities and their families face, alongside great joy, growth and determination, which has fuelled my belief that everyone deserves to live a fulfilling, meaningful life. This has inevitably contributed to my desire to pursue a career in clinical psychology and likely contributes to the foundations upon which the idea for this thesis developed.

Prior to commencing doctoral training, I volunteered at a social group for adults with autism and learning disabilities and found myself surprised by the number of people who had only recently received a formal diagnosis. Whilst these individuals appeared in a unique position, I couldn't help but wonder how receiving a diagnosis affected people's self-identity; a diagnosis that is often unfortunately linked to marginalisation and discrimination.

These thoughts continued to hum away at the back of my mind during my first placement during training working in a community learning disability team. The service adopted a unique model whereby a formal diagnosis was not required for eligibility to access the service. I saw service users receiving support and accessing the service without the need to endure assessments and receive a 'label' and was overwhelmed with the sense of belonging and acceptance service users appeared to gain from the learning disability service. This again led me to question the process of diagnosis and who it served a purpose for?

At this point, curiosity got the better of me and I started to research the experience of intellectual disability diagnosis in adulthood and was shocked to find nothing. Again, this was echoed by peers and professionals in the field: *'I would have thought that there'd*

*already be lots of research on that*’ and *‘are you sure you’re using the right search terms?’* became all too familiar conversations. It was at that point I knew I had a thesis topic.

### *Developing the idea*

Finding a supervisor who was willing to supervise the project and shared the same enthusiasm for the idea was thankfully one of the smoothest aspects of the thesis journey. After spending time talking through the idea with Dr Nick Hutchinson and other professionals working with people with intellectual disabilities, the idea seemed feasible and I was slightly naïve as to the research rollercoaster ahead of me.

In the initial stages of developing the idea, I considered exploring the experience of diagnosis in adulthood from multiple perspectives; individuals with intellectual disabilities, families or supporters and professionals involved in assessing intellectual disabilities. However, when I realised this may be slightly ambitious, I thought about my values and what meant the most to me; quickly deciding that I wanted to find out about the experience from the individuals themselves and provide a platform for their stories and voices to be heard. I have always been drawn to qualitative research methods and immediately knew I wanted to talk to individuals face to face. After consideration of the different methodologies and designs that may be suitable, I decided to use individual interviews to explore individual experiences.

### *Ethics*

Once the idea was sufficiently developed, I submitted my ethics application and shortly found myself attending an NHS ethical review meeting. Although this was generally a lot less daunting than I imagined, I was shocked to hear the committee raise concerns about people becoming upset in interviews, voice difficulties around recruiting from a ‘hard to reach’ population and provide recommendations concerning the procedure and documentation that seemed unsuitable for people with intellectual disabilities. I quickly found myself questioning the likelihood that other intellectual disability research is met

with the same concerns and the barrier this may have for further research in the field. At times, it felt others made assumptions that people would not want to talk about their experiences or may become upset. This made me feel like my research was being silenced and I wondered if this reflected the experiences of the stories of people with intellectual disabilities.

### *Recruitment*

*'You'll only need six people'* was generally the response from peers when I spoke about recruitment for the study and I felt enthusiastic, motivated and it all felt very achievable in the given time frame. Attending meetings at community learning disability services further fuelled my determination when several members of staff identified service users who many wish to talk part. However, my bubble quickly popped when I became aware of the realities up against me when trying to promote my research. Although people appeared excited about research exploring the idea and identified they knew several service users who may wish to share their story within the research, unfortunately due to the demands and commitments within the services I was left feeling unsure as to how many people had initially even been informed of the study.

I also wondered about the potential bias that may be introduced into the study when recruiting through professional 'gate-keepers' and considered the explicit and implicit assumptions that might influence who they discussed the study with. Were they concerned about people becoming upset or distressed? Did they consider if people may share unfavourable stories about their experience of receiving a diagnosis from that service?

I had already made contact with a range of services, groups and charities within the local community to widen the participant pool and decided to continue to broaden this as struggles to recruit from community learning disability services continued.

When connecting with a range of services in the voluntary sector that support individuals with intellectual disabilities, I was surprised by the number of people working within these

groups that were unsure of what an intellectual disability was, asked if I was looking for a particular type of intellectual disability and were unsure if brain injuries, autism and dyslexia were considered intellectual disabilities. This was eye-opening in many ways and challenged my assumptions that people working in this sector were well informed about the difficulties of the people they were working with. However, it led me to consider the echo chamber I'd been surrounded by in clinical psychology concerned with diagnosis, adaptations and considerations for specific difficulties and reflect on the positives of these services adopting an inclusive, person-centred model of services.

#### *Data collection and analysis*

Going to different groups in the community to share my research with them enabled me to develop my awareness of the many different groups and services within the community, meet lots of new people and have exciting conversations with people who were genuinely excited about my research. Meeting participants to hear their stories was the highlight of the research experience, though I was surprised by how many participants were shocked that I was interested in hearing about their experiences and often initially wondered if I may work for the community learning disability team and wanted to do a follow up assessment.

After conducting the interviews, I felt pressurised to analyse the interviews as quickly as possible as a result of the 'feeling behind' others in my cohort due to recruitment difficulties. As the deadline approached (and passed!), I found myself feeling more and more overwhelmed, along with juggling the demands of academic and clinical work in training. However, I quickly realised the process was not one to be rushed and as I developed my tolerance to this, data analysis became an interesting and thought-provoking experience. The next anxiety to manage was my desire to 'get it right'. After several panicked research meetings, I finally accepted that there was no 'right answer' when it came to interpretative phenomenological analysis. It felt powerful to think that the experiences throughout my life that have shaped my beliefs, assumptions and values would influence the way I interpreted the interviews. I was initially sceptical about the benefit of

keeping a reflective journal; though saw how beneficial it was it came to data analysis. It helped me to think about my reactions throughout data collection, my own values and assumptions and how much of “me” I was bringing to the interpretation when analysing transcripts. I was also aware of the overarching link between my empirical paper and systematic literature review and considered how the development of these two papers concurrently would likely influence the interpretation and analysis for each other.

### *The process*

Alongside the research process, I undertook both my final elective placements in secure forensic services and became aware of how many service users in these settings had cognitive difficulties that they had previously received no support or had only just become aware of these difficulties due to recent assessments. This led me to consider the impact of support and likely influenced my positioning of research interview questions around this and I also found myself questioning whether the service users I was working with on placement may have had different journeys in life had they received support. At times during the research journey, it often felt like the research was a self-contained component of training and I really valued the moments when I felt a genuine connection to the clinical work I was doing.

The journey has provided the foundations for future research I may pursue over my career and taught me important lessons about never giving up, even when you might not be winning the race and that the bumpiest journeys are definitely the ones where you learn the most.

## *Appendix U. Epistemological statement*

Epistemology refers to the theory of knowledge, what it is possible to know and how that information is acquired (Ritchie, Lewis, Nicholls & Ormston, 2013; Willig, 2013).

Throughout the research process, epistemology should be acknowledged and considered as the assumptions adopted by the researcher are likely to affect research methodology and analysis. This epistemological statement provides a summary of the epistemological assumptions and beliefs that have influenced the development of this portfolio thesis.

Positivist and realist epistemological stances assume there is objectivity to knowledge and therefore there is a truth to be discovered (Braun & Clarke, 2006). This position appeared to contrast with the overarching aim of the empirical paper aiming to understand the experience and meaning of receiving an intellectual disability diagnosis in adulthood.

Conversely, more constructionist epistemological stances suggest an absence of truth and consider the way in which individuals construct experiences through language and context (Ormston, Spencer, Barnard & Snape, 2013). A range of epistemologies have been used within qualitative research methods with people with intellectual disabilities (Beail & Williams, 2014).

When considering the two extremes of continuum, the researcher is drawn to more constructionist ways of understanding realities and experiences and thus a qualitative approach was initially considered across the portfolio thesis. When considering the broad aims of the research, quantitative approaches felt more consistent with positivist approaches where an objective, predefined concept is being measured or evaluated (Willig, 2013).

Therefore, qualitative methodologies were considered when reflecting on the most appropriate way to understand people's experiences. Interpretative Phenomenological Analysis (IPA) was initially considered due to the focus on understanding lived experiences, reflecting on the wider context and understanding the data set in its entirety (Smith, Flowers & Larkin, 2009). Semi-structured interviews were then considered as an appropriate way of exploring individuals experiences, due to the flexibility to adapt the

interview schedule and communication style to suit the participant and aid the sharing of their experiences. Due to the lack of previous research in this area with individuals with intellectual disabilities and the current research aim to explore participants experiences, grounded theory was discounted, due to the aim to generate theory from the data. Thematic analysis (Braun & Clarke, 2006) is another well regarded qualitative analysis method, however, this was also discounted due to its grounding in phenomenology and generating a description of data, rather than analysing at an interpretative level.

Epistemology should also be considered in relation to the participants recruited to the study, all of whom were diagnosed with intellectual disabilities. Although this in itself was the focus of the research, the assumptions of the researcher around the concept of intellectual disabilities was considered. Willig (2013) acknowledges a debate between relativists, who believe everything lies in discursive constructionism and critical realists, who assume knowledge is constructed through language, though influenced by underlying structures and phenomena. The present research adopts a critical realist stance whereby interpretative constructions are underpinned by social structures and practices. This stance allows participants experiences to be grounded in the reality that societal norms and ways of understanding difficulties are embedded in diagnoses, despite the broader social constructionist values of the researcher when understanding intellectual disabilities through placing difficulties in society rather than within the individual.

This led to consideration around the research aims, which may ask participants to put a 'truth' to their experience and the researcher wondered whether this in turn, could contribute to framing of the diagnosis within the person. However, the relationship and assumptions between the researcher and participant should be acknowledged (Ponterotto, 2005) and the potential for a contrast in epistemological values should also be considered.

Research is underpinned and influenced by the values, assumptions and beliefs of the researcher, which in turn, affects the area of interest, design, methodology and interpretation. The present research will therefore be influenced by the researcher's

personal and professional passion for advocating for the rights of people with intellectual disabilities. Furthermore, the research is likely to be underpinned by the researcher's values of empowering individuals with intellectual disabilities to experience positive, meaningful interactions and experiences, and challenge barriers, negative perceptions and stigma.

## References

- Beail, N., & Williams, K. (2014). Using qualitative methods in research with people who have intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 27(2), 85-96.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Ormston, R., Spencer, L., Barnard, M., & Snape, D. (2014). The foundations of qualitative research. In *Qualitative research practice: A guide for social science students and researchers*, 2, 52-55.
- Ponterotto, J. G. (2005). Qualitative research in counseling psychology: A primer on research paradigms and philosophy of science. *Journal of counseling psychology*, 52(2), 126.
- Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (Eds.). (2013). *Qualitative research practice: A guide for social science students and researchers*. London: Sage.
- Smith, J., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage.
- Willig, C. (2013). *Introducing qualitative research in psychology*. UK: McGraw-Hill Education.