Stigma and Self-perceptions Among Individuals with Intellectual Disabilities

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Chapter 1: Systematic Review

Individuals with Intellectual Disabilities' Experiences of Stigma and its Relationship with Sense of Self: A Thematic Synthesis of Qualitative Studies

Prepared in accordance with the author requirements for The Journal of Applied Research in Intellectual Disabilities (JARID)

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Abstract

Background: Individuals with intellectual disabilities continue to experience stigma despite improvements in community supports. There is a body of research which has sought to understand how stigma impacts aspects such as self-esteem. However, the findings are not consistent. To our knowledge no systematic review has examined the qualitative research regarding individuals' own experiences of stigma and how this might relate to sense of self.

Method: Articles were searched for in electronic databases. Ten articles were identified for review and subjected to quality appraisal. The results were synthesised using thematic synthesis.

Results: Four analytical themes were identified: living with stigma, the emotional impact of awareness of difference, 'I'm not like that at all', and a multifaceted identity can be protective. The results suggested that individuals with intellectual disabilities continue to experience stigma and that this can have a negative emotional impact on their sense of self. The results also show that some people sought to distance themselves from the stigmatised label by rejecting this or concealing elements of their identity. The context of the studies included in the review was taken into consideration and highlighted themes specific to these contexts.

Conclusions: Policy development and initiatives are required at a societal and service level to reduce the stigma that people with intellectual disabilities experience in their daily lives. This could have a positive impact on wellbeing and quality of life for individuals with intellectual disabilities.

Key words: Intellectual disabilities, stigma, self-concept

Introduction

Stigma, wrote Erving Goffman (1963), is "an attribute that is deeply discrediting" (p.3). It is a social phenomenon which occurs in the context of perception of difference and power differentials, and results in negative stereotyping and decreased social status (Pescosolido & Martin, 2015). Intellectual disability may be considered a stigmatised label as individuals with intellectual disabilities, in differing from the dominant cultural group, may possess or display characteristics which are negatively perceived by society (Goffman, 1963). Due to this, individuals with intellectual disabilities are often seen unfavourably by others and can be subjected to prejudicial or discriminatory attitudes and behaviours. Stigma can take the form of explicit verbal and physical abuse directed towards individuals with intellectual disabilities, but it can also take a more systemic form, through societal exclusion and limited opportunities for participation (Ali et al., 2012).

Despite progress regarding the community support and acceptance of individuals with intellectual disabilities (Scior et al., 2022), they continue to face stigmatisation leading to labelling, stereotyping, loss of status, and discrimination (Link & Phelan, 2001). Indeed, research has shown that individuals with intellectual disabilities are often aware of their stigmatised identity (Norwich & Kelly, 2004; Ali et al., 2012). However, it should also be acknowledged that individual experiences and perceptions of stigma vary within a stereotyped group. It has been argued that the extent to which individuals believe they will be stereotyped depends on how negatively impacted they are by experiences of stigma (Daley & Rappolt-Schlichtmann, 2018).

Responses to Stigma

Research has shown that experiences of stigma can be associated with lower self-esteem and poorer emotional wellbeing among individuals with intellectual disabilities (Dagnan & Waring, 2004; Ali et al., 2012). However, this is not a consistent finding. For example, some research has suggested that while an awareness of stigma is associated with lower-self-esteem and psychopathology in people with intellectual disabilities, not everyone with an intellectual disability reports low levels of self-esteem (Paterson et al.,

2012). This suggests that more complex processes are at play regarding the perception and impact of stigmatising experiences. Thomson & McKenzie (2005) found that while individuals with intellectual disabilities are more likely to have lower self-esteem than those who do not have an intellectual disability, they do not necessarily believe that having an intellectual disability is negative. Hence, people with intellectual disabilities' views of self are not necessarily determined by their social experience.

It has also been found that individuals with intellectual disabilities who perceived higher levels of stigma, made more upwards social comparisons (Patterson et al., 2012) resulting in lower-self-esteem. Others made more downwards social comparisons, seeing themselves favourably in comparison to others which bolstered self-esteem (Finlay & Lyons, 2000). The perception of stigma and its impact on sense of self and wellbeing is clearly a complex process and one that elicits varied responses from individuals.

Few reviews have sought to examine the impact of stigma on individuals with intellectual disabilities' self-perceptions. Lee and colleagues (2023) conducted a systematic review examining the negative effects of low self-esteem on depression and anxiety among adults with intellectual disabilities. It concluded that levels of self-esteem among individuals with intellectual disabilities varied depending on factors such as age and clinical setting. For some people, being able to work and feeling included contributed to higher self-esteem. However, some people appeared to internalise negative attributions related to an awareness of their stigmatised label and treatment which resulted in lower self-esteem.

Another systematic review (Ali et al., 2012) found that individuals with intellectual disabilities were largely aware of their stigmatised identity, but that this did not necessarily result in internalised stigma. The review also concluded that self-stigma was associated with lower self-esteem and poorer psychological wellbeing indicator outcomes such as psychiatric symptoms. Overall, much of the research included in these reviews has been quantitative and cross-sectional in nature, making it difficult to infer causality. It is also the case that research in this area has drawn on questionnaire

measures to examine this phenomenon which perhaps reduces these experiences and processes to psychometric outcomes.

To our knowledge, no previous systematic review has examined qualitative research regarding individuals with intellectual disabilities' experiences of stigma. Other reviews (Lee et al., 2023; Ali et al., 2012) have examined the impact of stigma on factors such as mental health and wellbeing among individuals with intellectual disabilities. However, these reviews included mixed methods and quantitative studies which often utilised outcome measures. The unique contribution of this review was to examine people's experiences of stigma solely through qualitative data to provide rich descriptive insights of these lived realities. Furthermore, another distinctive aspect of this review was to examine how individuals respond to stigma experiences and explore how these influence sense of self. There is a limited understanding of the influence of stigma on the self-perceptions of people with intellectual disabilities and how they respond to stigma. This meta synthesis of qualitative studies aims to draw together the available literature to provide a more in-depth insight into the impact of stigma on people with intellectual disabilities' view of self and the way they respond to these experiences.

Method

Registration

In accordance with PRISMA guidelines, this systematic review protocol was registered with the International Prospective Register of Systematic Reviews (PROSPERO) on 05 August 2024 (CRD42024563444) and was written in accordance with the enhancing transparency in the reporting of qualitative health research (ENTREQ) reporting guidelines (Tong et al., 2012; see Appendix 1.1).

Search Strategy

Searches of four databases were completed on 16 August 2024. The identified databases included OVID interface (MEDLINE, EMBASE, PsychINFO) and EBSCO (CINAHL). The search strategy was formulated using the SPIDER framework, developed in consultation with a subject specialist librarian and amended for each database as required (see Appendix 1.2). The search strategy for the intellectual disability and stigma main subject terms were based on those from published Cochrane systematic reviews (Coren et al.,, 2018; Clement et al., 2013). For the qualitative research main subject component of the search strategy, a validated qualitative research search filter (Shaw et al., 2004) was used as recommended by the specialist librarian. The search strategy included:

1. Key word searches related to main subject terms:

- **Intellectual disabilities:** intellectual* disab* OR impair* OR learning disab* OR difficult* OR Cognitive disab* OR mental* retard* OR mental* disab* OR mental* impair* OR down* syndrome OR mental* deficie* OR fragile X OR prader willi
- **Stigma:** public* attitude OR community attitude OR prejudice OR hostil* OR intolderan* or marginalis* OR social stigma OR rejection OR self concept OR self esteem OR self identit* OR view* OR stigma
- **Qualitative research:** discourse analysis OR content analysis OR ethnographic research OR ethnological research OR qualitative OR observational method* OR phenomenological research OR life experience* OR grounded theor* OR life

stor* OR women's stor* OR theme* OR thematic OR field stud* OR focus group* OR questionnaire* OR thematic analysis OR interview* OR qualitative

2. The use of MeSH/Subject Headings to map articles to main subject terms.
3. The use of Boolean operators such as OR to combine lines for each main subject and AND to combine the three main subject terms.

Inclusion Criteria

- Studies that recruited individuals with intellectual disabilities who were 16 years old and over from any setting.
- Any qualitative research design that explored individuals' experiences of stigma or how stigmatising experiences have affected the participants' sense of self.
- Studies published between 2000 and 2024 as stigma experiences may be temporally sensitive due to changes in service provision and evolving public attitudes. The period for this review was chosen to coincide with the closure of long stay hospitals in a number of countries, including the United Kingdom (UK) and Canada, and the shift to community-based supports.

Exclusion Criteria

- Studies not published in full in the English language.
- Unpublished, non-peer reviewed articles.
- Studies that only include quantitative data.
- Studies investigating specific learning difficulties (e.g. Dyslexia) without a diagnosis of intellectual disabilities.

Review Process

Study screening

Figure 1.1 shows that 7332 articles were identified from the initial database searches, and 2587 duplicates were removed electronically. The remaining 4745 articles were title and abstract screened in line with the inclusion and exclusion criteria, and 4675 articles were removed. Where it was unclear if an article should be included, the full article was retrieved. This resulted in 70 articles eligible for full-text screening and 100% of the

articles were checked by a second reviewer to ensure they met the inclusion and exclusion criteria.

Of the remaining 70 articles for full-text review, 60 articles were excluded for a variety of reasons detailed in Figure 1.1, including having a focus on a different population, not being concerned with stigma and being quantitative studies. The full texts for two articles were not available. A scoping search of Google Scholar found two additional articles that also met the eligibility criteria. In total, 10 articles were identified for inclusion in the qualitative synthesis. All 10 articles were reviewed by the first author and the second reviewer against the inclusion and exclusion criteria and were deemed to be appropriate for inclusion in the review.

Data extraction

Information was extracted from the included articles by hand and included:

- Study characteristics: authors, year of publication, aims, data collection method, analysis method.
- Study sample: sample size, gender, age range, setting.
- Study findings: all direct participant quotations from the articles were extracted and transferred to a Word document.

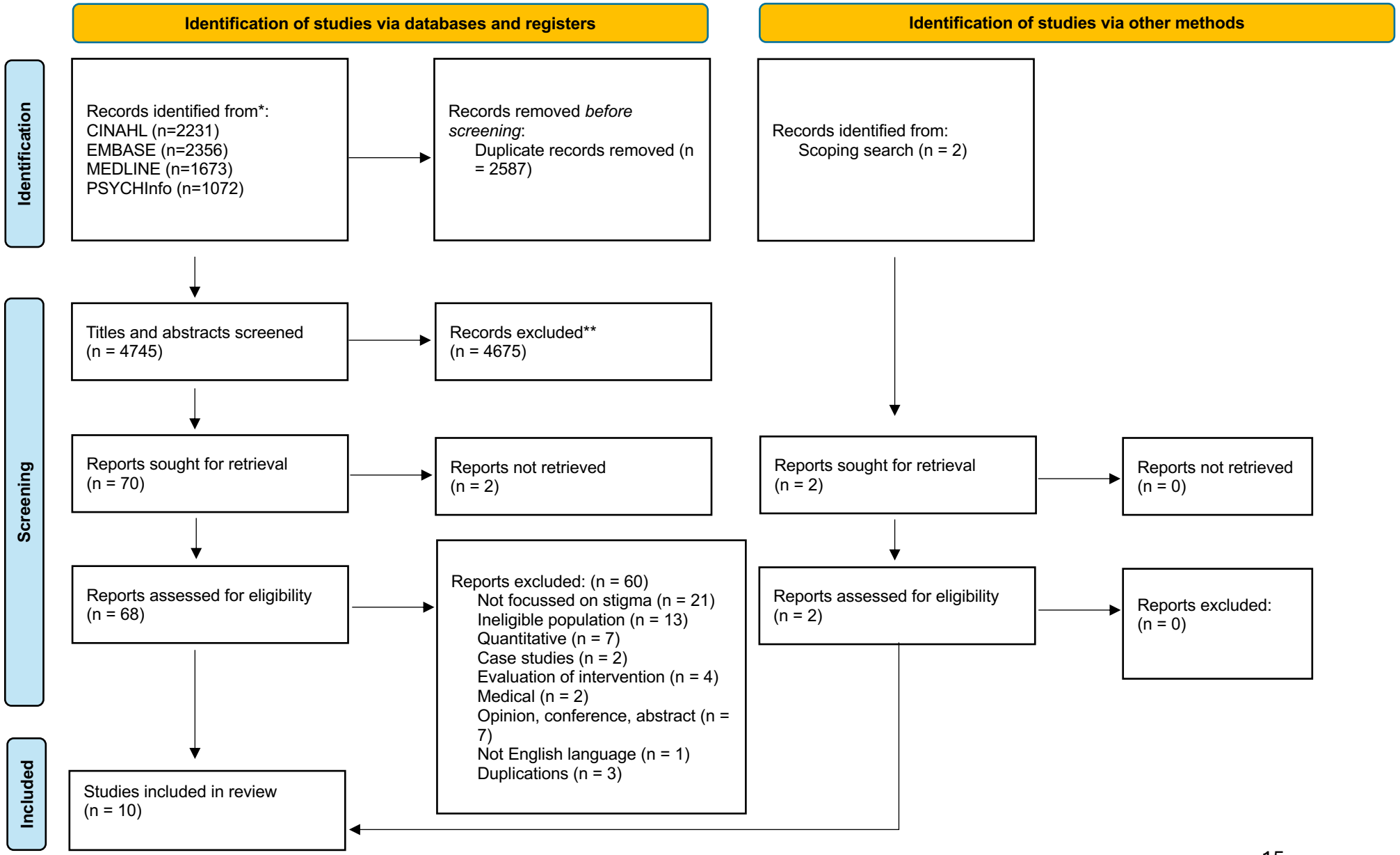

Figure 1.1 PRISMA (2020) Diagram

Quality Appraisal

The Critical Appraisal Skills Programme UK (CASP) Qualitative Studies Checklist is a tool used for critically appraising qualitative research (Appendix 1.3). The checklist includes ten questions regarding different aspects of qualitative research methods such as design, analysis, and researcher reflexivity. The CASP Qualitative Studies Checklist was chosen for this review as it has been endorsed by Cochrane for use in qualitative evidence syntheses (Long et al., 2020) and is recommended by the ENTREQ guidelines (Tong et al., 2012).

The CASP was used to assess the strengths and limitations of the studies included in the review rather than to eliminate studies from the review based on a quality threshold. This tool has been found to be a good measure of research transparency and reporting standards (Long et al., 2020). All studies were rated by the first author and three articles (30%) were selected at random to be appraised by a second reviewer to ensure reliability. Concordance was 24/30 (80%). Discrepancies in ratings between the first author and second reviewer were noted and were resolved through verbal discussions. Some discrepancies in ratings could be attributed to subjective interpretation of the items included in the CASP tool, other discrepancies were due to information being missed in the initial reading of articles.

Method of Synthesis

Thematic synthesis was chosen as the method of qualitative synthesis as it was developed to address questions about people's experiences and perspectives (Thomas & Harden, 2008). Thus, this method is appropriate for the current review which aimed to develop a further understanding of experiences of stigma and how these may relate to sense of self. Thematic synthesis is a flexible approach, suitable for analysing a range of qualitative data and epistemologies, and is recommended by Cochrane (McMahon et al., 2022).

Thematic synthesis is based on techniques adopted from Thematic Analysis (Braun & Clarke, 2006) and seeks to identify prominent or recurring themes by integrating findings from several primary studies (Maeda et al., 2022). Thematic synthesis has been argued

to be a technique which has much in common with other established methods such as meta-ethnography (Noblit & Hare, 1988) and consists of three phases of analysis: line-by-line coding of text; developing descriptive themes; and generating analytical themes (Thomas & Harden, 2008). While descriptive themes remain close to the data included in the papers, analytical themes require the researcher to generate new interpretations of the data to address the review questions (McMahon et al., 2022).

The process of thematic synthesis was based on the description by Thomas and Harden (2008). The first stage consisted of line-by-line coding of participants' direct quotes from the primary studies included in the review. This was an iterative process which involved developing a set of codes and applying them to subsequent studies, developing new codes when necessary. Each sentence of data was assigned at least one code. Stage two consisted of developing descriptive themes by grouping similar codes together, generating 17 descriptive themes (Appendix 1.4). Due to the different contextual environments of the articles, stage one and stage two of analysis were completed with these contexts in mind, creating three subsets of articles to be analysed: 1) articles from Indonesia and Taiwan; 2) articles from UK and the Netherlands; and 3) articles concerned with specific environments or roles such as employment, maternity services and parenting.

Stage three concerned the development of analytical codes to address the review questions. The descriptive themes from the three separate subsets of articles were aggregated due to the similarity of the themes developed. The process of generating analytical themes was inductive and involved examining the descriptive themes that were developed across the three subsets of studies, grouping these based on similar meanings (Appendix 1.5), and then examining them in light of the review aims. This process highlighted themes that were pertinent across all articles included in the review but also indicated themes that were specific to context. This process continued until the analytical themes sufficiently captured the relationships between descriptive themes and the inferences made regarding the review aims and questions. The research team was consulted through supervision to support the generation of themes and reflexivity.

Researcher Reflexivity

The researcher is a Trainee Clinical Psychologist who has worked with individuals with intellectual disabilities in a professional capacity. From clinical practice, the researcher was aware of the negative social experiences individuals with intellectual disabilities can experience and the emotional difficulties that can occur as a result of these. It was therefore important to consider the potential influence that working in mental health settings could have on data analysis and the interpretation of results. To address this, discussions in supervision encouraged reflection on the review process and on the development of themes to increase awareness of potential bias.

Results

Data Extraction

Table 1.1 outlines the study characteristics of the ten papers included in the review. Studies were published between 2004 and 2022. Seven studies were published in the UK, one study was published in the Netherlands, one in Indonesia, and one in Taiwan. All papers collected their data via individual interviews with participants, and one study (Jahoda et al., 2010) used photographs taken by the participants, an ethnographic method called photovoice, as the basis for their individual interviews.

There were 127 participants across all studies and their ages ranged from 17-63 years old. All participants were considered to have an intellectual disability that could be described within a range of mild to moderate. However, one study (Monteleone & Forrester-Jones, 2017) did not report the level of intellectual disability and another study (Franklin et al., 2022) included participants who self-identified as having an intellectual disability without formal assessment data. All participants resided in community settings. Two studies were from Indonesia and Taiwan, and some studies were concerned with specific aspects of community living or services such as work or education placements, experiences of maternity care, and parenting. These contexts were considered important for the meta-synthesis and therefore, were acknowledged in the analysis of the aggregated data.

Table 1.1 Study Characteristics

Study Citation and Country	Aims	Data collection method	Analysis	Participant, gender, age	Themes and sub-themes
(Jahoda & Markova, 2004) **Scotland, UK**	To ascertain whether participants believe they face prejudice or discrimination, how they adapt to social circumstances and present themselves.	Individual semi-structured interviews	Content analysis, qualitative analysis (Edgerton, 1967, 1984)	n=28 (M=18 (64.3%), F=10 (35.7%)) with mild ID Age range: 20-55 years old Community residents, 18 participants left long stay hospitals during the study.	i. Experience of stigma ii. Presentation of self
(Jahoda *et al.*, 2010) **Scotland, UK**	To use novel methods to gain insight into experiences that may be difficult to express. To ascertain experiences of stigma and how participants sought to establish their identities.	Individual semi-structured interviews and other ethnographic methods such as photovoice and use of video filming	Non-specific qualitative	n=2 (M=1 (50%), F=1(50%)) with mild to moderate ID Age range: 18-20 years old Community residents with mental health difficulties.	i. A sense of emptiness ii. Seeking recognition iii. Awareness of stigma iv. Negotiating adulthood
(Chen & Shu, 2012) **Eastern Taiwan**	To gain an understanding of the experience and process of stigmatisation	Individual interviews	Grounded theory	n=14 (M=8 (57%), F=6 (43%)) with mild to moderate ID	i. Being labelled ii. Perceiving oneself iii. Living with the labelling

	among Taiwanese youth with ID.			Age range: 17-22 years old Community residents who attended or had graduated from a special education high school.		
(Kenyon *et al.*, 2014) **UK**	To qualitatively explore participants' experiences of ID diagnosis.	Individual semi-structured interviews	Interpretative Phenomenological analysis	n=8 (M=7 (87.5%), F=1 (22.5%)) with likely mild ID Age range: 25-63 years old Community residents who were involved with self-advocacy organisations.	i. ii. iii.	Developing awareness of difference Relationships with non-disabled others Coping skills
(Malouf *et al.*, 2017) **UK**	To better understand the individual experiences of maternity care for women with ID	Individual semi-structured interviews	Interpretative Phenomenological analysis	n=9 (M=0 (0%), F=9 (100%)) with mild to moderate ID. One participant reported to have 'severe' ID by their family member. Age range: 25-39 years old Community residents who had	i. ii. iii. iv.	I hate being treated differently I find it harder to understand than other people We've had to prove ourselves Make sure you've got good support around you

				experienced maternity care.		
(Monteleone & Forrester-Jones, 2017) **UK**	To understand how adults with ID experience their own disability, and whether their experience impacts on their own notions of stigma, self-esteem, and social interactions.	Individual semi-structured interviews	Interpretative Phenomenological analysis	n=15 (M=10 (66.6%), F=5 (33.4%)) with ID (level not reported) Age range: 19-63 years old Community residents.	i. ii. iii.	How to be Self-defined notions of disability Confused terminology
(Groves *et al.*, 2018) **UK**	To explore experiences of women with down syndrome to understand how these have impacted on individuals and shared identities.	Individual semi-structured interviews	Interpretative Phenomenological analysis	n=8 (M=0 (0%), F=8 (100%)) with Down's Syndrome Age range: 21-49 years old Community residents.	i. ii. iii. iv.	Negative assumptions of others Oppression Lack of ownership over own narrative Finding a place in society
(Voermans *et al.*, 2021) **Netherlands**	To provide an examination of the lived experience of people with ID in competitive employment.	Individual semi-structured interviews	Interpretative Phenomenological analysis	n=6 (M=4 (66.6%), F=2 (33.4%)) with mild ID Age range: 26-36 years old Community residents who participated in paid work experience.	i. ii. iii.	Building on my life experiences My place at work Being a valuable member of society like everyone else

(Franklin *et al.*, 2022) **England, UK**	To have a specific focus on what learning-disabled parents' experiences tell us about the operation of stigma in their everyday lives.	Individual interviews conducted by co-researchers	Thematic Analysis	n=22 (M=5 (22.7%), F=17 (77.3%)) who self-identified as having an ID Age range: 26-60 years old Community residents who have had experience of being a parent.	i. ii. iii. iv.	Positions of powerlessness Assumptions of incompetence Challenging assumptions and proving competence Claiming power
(Handoyo *et al.*, 2022) **Indonesia**	To explore the experiences of stigma in the Indonesian cultural context, and how do these experiences affect individuals, and inclusion in society.	Individual semi-structured interviews	Thematic Analysis	n=15 (M=7 (46.7%), F=8 (53.3%)) with mild to moderate ID. Age range: 17-45 years old Residing in family house (n=6) and residing in 'special institutions' (n=9)	i. ii. iii. iv.	Discrimination and poor treatment Reaction to and impact of stigma Limited social life and activities Wish of a normal life

M = males, F = females

Quality Appraisal

Quality appraisal ratings are outlined in Table 1.2. Overall, the 10 studies included in the review were of generally good quality and met quality standards as assessed by the CASP tool. It is recognised that qualitative research employs a range of methods which can make it difficult to identify significant methodological flaws and that identified quality issues may be due to publication requirements (Long et al., 2020) For example, journal word limits may constrain the detail provided regarding the data analysis process or reflexivity considerations of authors. There was little variation in the quality of the studies included in the review and these ratings did not influence the results of the thematic synthesis.

Almost all studies included in the review had clear research aims which could be addressed using qualitative methods. Franklin et al. (2022) did not set their research aims out clearly in their study, but these were decipherable from the body of the text in their paper. Most authors provided a justification for the study design they used. Only Kenyon et al. (2014) failed to provide such a justification. The recruitment and data collection methods used by most of the researchers were deemed appropriate. However, some studies (Groves et al., 2018; Jahoda et al., 2010) provided limited information about recruitment processes and (Kenyon et al., 2014) failed to provide details about the content of their interview schedule or information about the setting in which data was collected. Most studies included a clear statement about their findings, their contribution to the field and implications for policy. However, some papers lacked discussion about the strengths and limitations of the research (Kenyon et al., 2014; Jahoda & Markova, 2004) or an account of clinical or practical considerations, beyond suggesting general future research (Groves et al., 2018),

Regarding ethical considerations, few papers explicitly stated that the studies had received ethical approval, provided sufficient details regarding the process of obtaining consent or acknowledgment of potential harms of taking part in the research. However, this is not to say that researchers had not considered or done these things but rather that this information was absent in the reporting. The process of analysing the data was reported inconsistently. Handoya et al. (2022) provided a thorough outline of their

analysis and sufficient data to support the development of themes. However, other papers provided insufficient descriptions of the data analysis (Jahoda et al., 2010) or limited information and evidence supporting how themes were developed by the researcher (Voermans et al., 2021). Very few studies considered the relationship between the researcher and the participants, in terms of reflexivity, apart from Kenyon et al. (2014), who used a journal to monitor influences on data collection and analysis. Franklin et al. (2022) considered how their previous experience had influenced their research.

Table 1.2 Quality Appraisal tool (CASP) Ratings

	(Jahoda & Markova, 2004)	**(Jahoda *et al.*, 2010)**	**(Chen & Shu, 2012)**	**(Kenyon *et al.*, 2014)**	**(Malouf *et al.*, 2017)**	**(Monteleone & Forrester, 2017)**	**(Groves *et al.*, 2018)**	**(Voermans *et al.*, 2021)**	**(Franklin *et al.*, 2022)**	**(Handoyo *et al.*, 2022)**
1. Clear statement of aims?	✓	✓	✓	✓	✓	✓	✓	✓	/	✓
2. Is qualitative methodology appropriate?	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
3. Research design appropriate?	✓	✓	✓	×	✓	✓	✓	✓	✓	✓
4. Recruitment strategy appropriate?	✓	/	✓	✓	✓	✓	/	✓	✓	✓
5. Data collected to address research issue?	✓	✓	✓	/	✓	✓	✓	✓	✓	✓
6. Relationship between research and participants	×	×	×	✓	×	×	×	×	✓	×

7. Ethical issues	✗	✓	✓	/	/	✓	✗	/	✓	✗
8. Rigorous data analysis	/	/	✓	✗	✓	✓	/	/	/	✓
9. Clear statement of findings	/	✓	✓	✗	✓	/	✓	✓	✓	✓
10. How valuable is the research?	✓	✓	✓	/	/	✓	✗	✓	✓	✓

Code: ✓= Present, ✗= Absent, / = Unable to ascertain

Results of Thematic Synthesis

The thematic synthesis elicited four analytical themes concerning individuals with intellectual disabilities' experience of stigma and how this relates to their sense of self: 1) living with stigma, 2) emotional impact of a sense of difference, 3) "I don't think I'm like that at all", and 4) a multifaceted identity can be protective. The analysis is split across two sections: i) common analytical themes across articles, and ii) themes accounting for the context of the articles included in the review.

1. **Common analytical themes across articles**

Analytical Theme 1: Living with stigma

Across all articles included in the review was the prevalence of stigma individuals with intellectual disabilities experienced and lived with. Individuals' narratives regarding these experiences tended to acknowledge and reflect on explicit discrimination in the form of name-calling, being *"mocked"* (Handoyo et al., 2022) and being negatively judged by others. This occurred across a variety of settings in the community and in educational, workplace, and health facilities. Participants spoke about these experiences like they were common occurrences and as though there was little they could do to change this. Discriminatory behaviour was perpetrated by seemingly

unknown individuals in the communities in which participants lived but could also be perpetrated by peers at school.

> *"I'm a person who has got a learning difficulty problem with Down's Syndrome… Because I'm different, sometimes they discriminate me for who I am."* (Groves et al., 2018).

> *"Special needs was not a nice thing to have. I mean, you get bullied no matter what you do."* (Franklin et al., 2022).

Within this theme, participants often reported that the explicit discrimination they were subjected to was being judged by others as being incapable or *"useless"* (Handoyo et al., 2022). Two studies included quotations from participants who referred to being told they were a "waste of space" (Kenyon et al., 2014; Monteleone & Forrester-Jones, 2017) Participants were negatively judged regarding their intellectual abilities and practical skills.

> *"'Cause everyone's always taking the mick out of me and everyone's more clever than me."* (Monteleone & Forrester-Jones, 2017).

> *"They assume you've got a disability and we can't do things."* (Kenyon et al., 2014).

Negative judgements regarding ability was a prominent issue raised in the articles concerning individuals with intellectual disabilities' parenting and maternity service experiences. Participants experienced being judged by professionals and family members with regards to their ability to parent a child based on their label of having an intellectual disability. Participants' quotes suggest that this was the most salient factor in how people perceived their ability to parent.

> *"People aren't seeing past the learning disability…There's no reason for you to judge me on whether I can understand how to look after a baby or not."* (Malouf et al., 2017).

> *"They don't think I can cope, because I have got a learning disability…it always came back to that."* (Franklin et al., 2022).

Participants also seemed to experience stigma in more implicit ways compared to explicit discrimination or judgement. This was often in the form of exclusion and being treated as though they were 'invisible'.

> *"Social Services talked to them [other professionals] more than they talked to me…when they did talk, they treat us like a two-year-old, talking down to us…"* (Franklin et al., 2022)

> *"[they] think you're stupid…treat you as though you don't exist."* (Malouf et al., 2017).

These quotes illustrated how individuals with intellectual disabilities felt excluded by professionals from discussions and decision-making regarding their own lives. Therefore, participants may have felt a lack of agency and control as professionals did not deem them capable of having an opinion.

> *"Sometimes they don't talk to me, they just look at me, it's weird. I don't know why. Makes me think they don't take me seriously or really care."* (Groves et al., 2018).

This subtle process of othering through exclusion is felt by individuals with intellectual disabilities as another form of stigma which discredits their standing in society and reduces their participation in 'normal' social life.

Analytical Theme 2: Emotional impact of a sense of difference

Participants reported an awareness of their identity being related to having an intellectual disability and therefore, had an awareness of being considered different from other people. Participants' awareness of their label *"people like me"* (Malouf et al., 2017) appeared to result in feelings of shame, frustration, and concern regarding how others viewed them, perhaps due to their experiences of stigma.

> *"I felt, well, miserable. I felt, well, shame in a way [regarding being diagnosed with an intellectual disability]."* (Kenyon et al., 2014).

> *"How come I'm different from my brothers and I'm stupid, and how come my nephew can count and I can't and he's seven."* (Jahoda et al., 2010).

The quotes from participants illustrated their awareness of difference from other people and the emotional impact of this. It can also be seen that the language used by some participants might reinforce this notion of difference. Indeed, a number of participants used language to juxtapose their sense of identity to 'normal' others.

> *"Why did I become like this?...I want to be normal."* (Chen & Shu, 2012).

> *"Women who have LD are not classed as normal."* (Malouf et al., 2017).

Participants also referred to certain environments such as educational facilities, workplaces, and hospitals, and specific objects which they thought conveyed their difference.

> *"Having a handicapped card makes us feel embarrassed. I am not happy; I felt ashamed to have a handicapped card."* (Chen & Shu, 2012).

These quotes suggest that participants were aware of how certain objects and environments could be construed as symbols of their intellectual disability to other people. These indicators were visible to others, reinforcing the participants' awareness of being 'different' and at times resulting in feelings of shame. Participants also showed an awareness of being considered different resulted in differential treatment; something they wished to avoid.

> *"I just want to be treated normally, like anyone else…that happens an awful lot, because, if they know that you have a disability, they'll start treating you very differently, and that's not always good."* (Voermans et al., 2021).

2. Themes accounting for the context of the articles included in the review

While two analytical themes were generated through the development of descriptive themes and translating these across all articles, there were also some points of difference that became apparent when considering the specific contexts of the articles included in the review, such as different countries and papers specifically concerned with different roles. This section seeks to address how contextual factors could impact on individuals with intellectual disabilities' sense of self and responses to stigma.

Analytical Theme 3: 'I don't think I am like that at all'

In response to awareness of a stigmatised identity, participants responded in a variety of ways that served to distance themselves from the label or related stereotypes. These different responses were captured across articles included in the review. Some participants explicitly rejected being labelled, and others rejected the specific label of a disability being conflated with their individuality, perhaps in an attempt to avoid stigma.

> *"We shouldn't be labelled because we are all equal at the end. You're a human being for God's sake…The person is still a person so don't label them."* (Kenyon et al., 2014).

> *"I'm a person who has got a learning difficulty prob-lem with Down's Syndrome, but outside this world I don't think I am like that at all. I'm a person in my own right…"* (Groves et al., 2018).

Other participants attempted to distance themselves from a stigmatised identity by *"hiding their disability"* (Voermans et al., 2021); concealing tangible elements of this identity such as their school or place of work. Participants also attempted to conceal their identity by withdrawing from social situations, perhaps limiting their exposure to stigmatising experiences.

> *"…people might come up and say to you. – Where do you come from? – and you hate telling them, you've got to try and keep it to yourself."* (Jahoda & Markova, 2004).

> *"I am afraid of being out alone. I am afraid of misspeaking, and I am afraid of being mocked; that is why I go straight to home after work. I never go outside…It's better for me to stay in my room."* (Hadoyo et al., 2022).

The quotations suggest that participants made choices that limited their social interactions due to feelings of shame about their identity and of elements that conferred a stigmatised identity.

Another response to a perceived stigmatised identity found in the articles was participants presenting their resilience to stigma. However, the presence of this is an interesting point of comparison when considering the different geographical origins of the articles. Resilience appeared more in articles from the UK and was absent in the articles from Indonesia and Taiwan. This could be a feature of different cultural contexts and how these might impact on how individuals express their sense of self and respond to stigma. It might also be that the interview questions in these articles did not ask questions that elicited responses about participants' resilience to stigma.

Resilience could be active or more passive. Within the articles included in the review active resilience appeared to be illustrated by participants attempting to *"prove"* (Malouf et al., 2017) their capabilities to others and engaging in downward social comparisons in order to bolster their sense of self.

> *"…I know I do a really good job, I know I can do it to high standards. Most people need a bit of encouragement from me and the staff as well to do it."* (Monteleone & Forrester-Jones, 2017).

> *"Some people with disabilities they are swearing and shouting, a lot, um they are. Can't control themselves. I'm not like that."* (Groves et al., 2018).

Passive resilience appeared to take the form of participants accepting stigmatised treatment but also presenting themselves as being unaffected by this. Participants spoke of how they did not *"let it [stigma] bother"* them (Kenyon et al., 2014) and others presented themselves as being able to 'cope' with stigma, perhaps to try and prevent further emotional discomfort or further perceived judgement about not being able to cope.

> *"It's harder to cope when you're younger because you get stigmatised by members of the public…you learn to build that inner shell."* (Kenyon et al., 2014).

This quote summarises how one participant felt they were more able to cope with stigma as they got older by building a 'shell'. This suggests an awareness of the negative emotional impact such treatment can cause but also this participant's resilience to its impact.

Analytical Theme 4: A multifaceted identity can be protective

A subset of articles included in the current review had a specific focus on certain roles and environments - parenting and employment. Again, this provided an interesting point of comparison regarding how papers concerned with specific roles or environments may positively influence the sense of self of participants. It was noted that this subset

of papers lacked discussion about shame in response to a stigmatised identity. Indeed, this could be due to the questions asked of participants in these articles. However, what was highlighted was the potentially protective influence of identities conferred by roles such as being in employment or being a parent, which could be protective against stigma. Such roles appeared to have a positive impact on individuals with intellectual disabilities' sense of self by promoting an identity that was *"useful"* (Voermans et al., 2021) and beyond that of a potentially stigmatised one.

> *"They accept me more…they react normally to me, just like they do with other people…"* (Voermans et al., 2021).

> *"Yeah, if I didn't work, what would I do then? I think that I would just sit at home all day. It would be harder…"* (Voermans et al., 2021).

These quotes illustrate how employment provided opportunities for occupation and to interact with others which contributed to a multifaceted identity for participants.

Having a multifaceted identity also appeared to have a positive impact on participants' self-esteem in the face of stigmatising experiences. This was a particular feature found in the quotes from individuals who were parents.

> *"You don't have to listen to the negative stuff…you're just as good as anybody else."* (Franklin et al., 2022).

> *"I speak up more for myself now than I used to…if you keep quiet that's when you get picked on."* (Franklin et al., 2022).

These quotes illustrate how different roles and identities may positively impact on individuals' ability to advocate for themselves or feel more able ask for support and "help with learning difficulties…there's nothing wrong with that" (Franklin et al., 2022).

Discussion

Overview of findings

This review synthesised the available qualitative research regarding individuals with intellectual disabilities' experiences of stigma and how this relates to sense of self. Thematic synthesis elicited four analytical themes which captured individuals' experiences of living with stigma, the emotional impact of this, and how they might respond in relation to sense of self. Many participants spoke about how they attempted to distance themselves from a stigmatised identity by either rejecting the label or concealing elements of their identity. Such responses may serve to avoid stigmatising experiences and the consequent emotional distress. This may be achieved through cognitive mechanisms such as those outlined in social identity theory (Tajfel & Turner, 1979) in which individuals may seek to preserve self-esteem by rejecting their association with a group that is perceived to be stigmatised.

Other participants chose to highlight their capabilities as a form of active resilience to stigma. It may be that individuals generated a more positive sense of self from engaging in downward social comparisons (Finlay & Lyons, 2000). Or perhaps for some individuals, their intellectual disability identity feels imposed and incompatible with how they view themselves. This may result in cognitive dissonance (Festinger, 1957) and therefore individuals chose to promote their skills and abilities in accordance with their view of self. Furthermore, promoting one's sense of competence and autonomy may maintain positive self-perceptions and wellbeing. This idea is central to self-determination theory (Deci & Ryan, 2012) and may promote individuals' ability to cope with stigma and result in less emotional distress. It appeared resilience in response to stigmatisation was more of a feature in articles from the UK in comparison to those from Indonesia and Taiwan.

The review also highlighted that individuals with intellectual disabilities' experiences of different roles can contribute to a multifaceted identity which may be protective in response to stigma and for promoting a positive sense of self. Again, this novel insight draws parallels to social psychological theory such as social identity theory (Tajfel & Turner, 1979) in which individuals' participation and inclusion in different social groups

contributes to their overall self-concept. Individuals may protect positive self-perceptions by aligning their sense of self with membership of different groups or roles, instead of identifying with a more stigmatised group, such as intellectual disability.

Relevance to existing literature

The findings of the review highlight that individuals with intellectual disabilities continue to experience stigma despite the advances in service provision and public attitudes (Scior et al., 2022). The review only included articles published since 2000, indicating that the experiences of individuals with intellectual disabilities have not vastly improved since the closure of long stay hospitals. This is perhaps not surprising given research which suggests individuals with intellectual disabilities remain a socially excluded group in society (Ali et al., 2012; Wilson et al., 2017).

Participants from the studies included in the review appeared to have an awareness of a stigmatised identity and their 'difference' to others which lends support to findings discussed across studies (Norwich & Kelly, 2004; Ali et al., 2012). As discussed in a review by Beart et al., (2005), although individuals with intellectual disabilities may have problems understanding or choose not to use the label, they are often aware of stigma attached to this identity and experience stigma through their social interactions.

Our results also suggest that awareness and experiences of stigma can result in negative emotional experiences which supports previous research that suggests stigma may be associated with lower self-esteem and psychopathology (Dagnan and Waring, 2004; Thomson & McKenzie, 2005; Ali et al., 2012). However, it should also be noted that research has also suggested that the relationship between stigma and self-esteem is more complex and that individuals with intellectual disabilities may engage in downward social comparisons to promote self-esteem (Finlay & Lyons, 2000; Paterson et al., 2012). This can also be seen in the findings of the current review whereby some participants attempted to prove their capabilities to others and compare themselves favourably to peers.

An interesting finding from the current review was the potential protective aspects of multifaceted identities that developed through work opportunities or specific roles, such as being parents. For example, papers which focussed on these roles appeared to enable participants to discuss themselves in more positive ways which aligns with the findings of a review by Lee et al. (2023) in which social inclusion including opportunities for work contributed to higher self-esteem among individuals with intellectual disabilities.

Strengths and limitations

This review presents a synthesis of the qualitative research published since 2000 regarding individuals with intellectual disabilities' experiences of stigma and how this may relate to sense of self. The consistency of themes regarding the experience and emotional impact of stigma across all studies suggests that little improvement has occurred despite progression in care and policy.

Due to resource constraints, the review only included published peer-reviewed articles which may have introduced a publication bias by excluding relevant studies. With regards to quality ratings, these were not used to exclude articles from the review as it is acknowledged that publication requirements may impose limitations on the level of details researchers can provide in their articles (Long et al., 2020). This may have introduced some bias to the review as it is unclear whether quality issues of the articles are due to weaknesses with design and methods or publication constraints.

Non-English papers were excluded which may have discounted valuable insights from different countries and cultures. An additional limitation of this review is the underrepresentation of diverse cultural groups. The majority of articles were from the UK and one from the Netherlands. Only two articles were from outwith Europe (Chen & Shu, 2012; Handoyo et al., 2022). Therefore, the review may overwhelmingly represent the account of individuals living in Europe, where deinstitutionalisation and the subsequent drive to enhance community provisions has promoted the social inclusion and participation of individuals with intellectual disabilities.

Implications for policy, practice, and future research

This review has implications for practice regarding individuals with intellectual disabilities and wider implications at a societal level. The review highlighted that experiences of stigma continue to be a frequent occurrence for people with intellectual disabilities. There is a need for policymakers to think about stigma using a public health approach and initiatives to challenge stigma at a societal level to reduce the health and social inequalities that individuals with intellectual disabilities face and to improve their quality of life (Emersen et al., 2011). It was clear from the two papers included in the review in which individuals with intellectual disabilities had contact with professionals from maternity services (Malouf et al., 2017) and health and social care services (Franklin et al., 2022), that they did not feel listened to and were excluded from decision-making. Services across the health and social care sector should increase their awareness of intellectual disabilities through staff training and communicating in an accessible way so that individuals with intellectual disabilities are informed of processes and are able to participate in discussions, to address some issues in the disparity of care.

Research has shown that experiences of stigma can have a detrimental impact on emotional wellbeing. Clinical Psychologists working in services for adults with intellectual disabilities should consider perceptions of stigma at an individual and systemic level. This may allow for different professions often involved in supporting individuals to increase their awareness of the impact of stigma. It may also support considerations about the importance of engagement in meaningful activity and different roles. This aligns with social cure theory (Haslam et al., 2018) which posits that involvement and belonging to social groups provides psychological benefits that can mitigate the impact of stress and adversity. The “constellation of identities” conferred by identifying with different groups or roles may provide a mechanism for coping with stigma and have a positive effect on sense of self (Jaspal & Breakwell, 2014). More recently, there have been positive outcomes regarding the feasibility of interventions for stigma resistance among individuals with intellectual disabilities (Scior et al., 2022) which aim to equip people to manage and cope with stigma experiences in their daily lives. The findings of this review would support the need for these interventions being

offered and the need for professionals to engage in discussions with individuals about their experiences of stigma and encourage the development of skills to cope with difficult emotional experiences.

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Chapter 2: Major Research Project

An Exploratory Study of Self-Perception Among Individuals with Intellectual Disabilities

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Plain Language Summary

Background: Individuals with intellectual disabilities frequently experience stigma which can take many forms including discrimination, bullying, and exclusion. It is thought that these experiences may mean that individuals with intellectual disabilities think negatively about themselves, and research has shown lower self-esteem amongst this group (Logeswaran et al., 2019). However, many people with intellectual disabilities have different relationships in their lives, some of which are positive and may promote a more positive sense of self. This research explored what individuals with intellectual disabilities think about themselves, what they think others would say about them, and how important the views of others were to them.

Method: Thirty adults with intellectual disabilities, aged between 20 and 84 were recruited from a social enterprise in the west of Scotland. Participants took part in a task (Deakin et al., 2018) in which they were shown a series of pictures showing things that people might say about themselves (e.g. happy, sad, friendly, unfriendly). Participants were asked to select pictures that described themselves, and described how other people would view them. They were then asked a series of questions about what they liked and disliked about themselves, and their experience of what others have said about them.

Main findings: The participants in this study generally held positive views of themselves and thought that someone they knew and had a positive relationship with would describe them more positively than someone that did not know them. Participants also thought it was more important what someone they knew thought about them in comparison to someone they didn't know. Participants commented on the things they liked about themselves and the positive comments they received from others regarding their appearance or personal qualities. Participants found it more difficult to talk about the negative aspects of themselves.

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Abstract

Objectives: Individuals with intellectual disabilities continue to experience stigmatising treatment and the potential impact of this on sense of self has been well-documented. The aim of this study was to examine the self-perceptions of individuals with intellectual disabilities and how they believe that they are viewed by others.

Method: Thirty adults with intellectual disabilities, aged between 20 and 84, were recruited from a community enterprise for individuals with intellectual disabilities in the west of Scotland. Participants took part in a novel exploratory task in which they were shown pictorial representations of attributes and asked to make a forced-choice between the positive and negative dimension of each attribute. Participants selected attributes to describe themselves, how they thought they would be described by a supportive-other, and an unknown-other. Participants also took part in a sentence completion task.

Results: Participants selected significantly more positive attributes to describe themselves compared with how they reported being described by unknown-others. The participants also indicated that supportive others would select more positive attributes to describe them compared to unknown-others. Participants rated the views of supportive-others as more important than those of unknown-others.

Conclusions: While individuals with intellectual disabilities may be aware of the potentially stigmatising views of others, the current study suggested that individuals with intellectual disabilities have positive views about themselves and place emphasis on the positive views of individuals that they have supportive relationships with. These results suggest the important role of supportive relationships in developing positive self-perceptions.

Key words: Intellectual disabilities, self-perceptions, relationships

Introduction

Stigma is a social phenomenon in which characteristics are perceived negatively by society and shape people's overall views of a person or group of people (Goffman, 1963). Intellectual disability could be described as a stigmatised label as individuals with intellectual disabilities are likely to experience stigmatising attitudes, discrimination, and inequalities despite positive societal changes in attitudes (Scior, et al., 2022; Ali et al., 2015). Research has shown that individuals are often aware of their stigmatised identity and experiences of stigmatising treatment (Norwich & Kelly, 2004; Ali et al., 2012). It has been suggested that negative interpersonal life events, such as stigma experiences, may be associated with lower self-esteem in individuals with intellectual disabilities across genders (Paterson et al., 2012; Lee et al., 2023) and therefore, may contribute to a negative sense of self. Sense of self is often seen as a relational concept in which aspects of one's identity are shaped by dynamic experiences and systems of relationships (Fogel, 2001) but sense of self can also be characterised in relation to others (Chen et al., 2011). Thus, it has been suggested that individuals with intellectual disabilities' sense of self may be shaped by interactions with the environment and through the incorporation of negative social attributes (Crocker & Major, 1989).

Much of the existing research has focussed on whether stigmatising experiences result in self-stigma or 'internalised' stigma (Scior et al., 2022), whereby individuals with intellectual disabilities may come to view themselves in a way that is consistent with their potentially stigmatised identity. Negative self-concept and self-stigma have been associated with poorer emotional wellbeing and lower self-esteem in individuals with intellectual disabilities (Ali et al., 2012; Dagnan & Waring, 2004). However, the extent to which individuals hold a prominently stigmatised identity is unclear as not all people with an intellectual disability report low self-esteem (Paterson et al., 2012). Furthermore, while individuals with intellectual disabilities are more likely to have lower self-esteem scores than typically developing peers, they do not necessarily believe that having an intellectual disability is negative or defines them (Thomson & McKenzie, 2005). Therefore, the evidence regarding the impact of stigma on individuals with intellectual disabilities' self-perceptions is equivocal.

Research has suggested that people with intellectual disabilities cope or deal with stigma in different ways, which may serve to mitigate the psychological impact of stigma and promote a more positive sense of self. For example, a review examining the formation of social identities among individuals with intellectual disabilities by Logeswaran et al. (2019) highlighted that individuals with intellectual disabilities have an awareness of negative views held by others. However, they reported that having an intellectual disability was not an important part of their identity and focussed on other competencies and attributes when describing themselves, such as having friends or engagement in leisure activities (Dorozenko et al., 2015). Other research has shown that individuals with intellectual disabilities made more downward social comparisons, seeing themselves favourably in comparison to others which bolstered self-esteem (Finlay & Lyons, 2000). Another review (Beart et al., 2005) concluded that many individuals saw the label of intellectual disability as unapplicable to them and they engaged in processes such as denial or distancing oneself from the label to promote a more positive sense of self. The perception of stigma and its impact on sense of self is clearly a complex process and one that elicits varied responses from individuals. The findings of previous research suggest a more dynamic relationship between awareness of stigma and self-perceptions among individuals with intellectual disabilities.

As mentioned, much of the existing research has focussed on the impact of negative and stigmatising experiences for individuals with intellectual disabilities. However, this does not account for people's other social experiences and relationships. The self-perceptions of individuals with intellectual disabilities are also influenced by positive social experiences and relationships with significant others (Callus, 2017), which may help to foster a more positive sense of self (Jahoda et al., 2010; Finlay & Lyons, 2000).

As such, the focus of this study draws on social constructionist theories of the self (Gergen, 2011) which concern people's relative view of self and the role of others in developing this sense of self. For example, symbolic interactionism (Mead, 1934) argues that sense of self is grounded in social processes and interactions with others. Such theories would posit that individuals' significant relationships have the potential to

positively impact on one's self-perceptions compared to how one might think they are viewed by unknown others who might hold stigmatised views. While external social influences may impact on how individuals view themselves, there are also internal cognitive processes theorised to be involved in the shaping of one's self-perceptions. For example, the self-schemas individuals develop about themselves guide how experiential information relating to the self is interpreted (Markus, 1977). This may influence what information an individual values or otherwise discounts to maintain a consistent and stable sense of self (Green & Sedikides, 2001). In addition, attribution theory (Zwickert & Rieger, 2013) has been used to study stigmatising attitudes to a variety of health and mental health conditions. This theory suggests that the perception of responsibility and control regarding a condition, whether this is internal or external, is related to self-perceptions. For example, attributing negative experiences such as stigmatisation to internal factors can result in more negative self-esteem and self-stigma (Zwickert & Rieger, 2013). Therefore, the construction of self-perceptions is likely a complex combination of both external and internal processes and responses to experiences.

Examining how individuals with intellectual disabilities view themselves and how they believe they are viewed by others in an open way has methodological challenges due to discrepancies in language capabilities and cognitive ability (Huck et al., 2010). One approach to this is outlined in Deakin et al., (2018) whereby they investigated the self-perceptions of children with Down Syndrome using a novel experimental method in which participants selected pictorial attributes to describe themselves and typically developing peers. They found that the children were more likely to assign positive attributes to photographs of typically developing children than photographs of children with Down Syndrome. However, despite having negative views of their peers with Down Syndrome they held more positive views of themselves.

The current study builds on the research of Deakin et al. (2018), extending this to a broader sample of adults with intellectual disabilities to examine self-perceptions and inter-personal perceptions from the perspective of a potentially stigmatising view and a more supportive view. Therefore, the specific aims of the study are to examine the self-

perceptions of individuals with intellectual disabilities, gain understanding of how they believe they are viewed by others, and to understand the value placed on these views.

Research Questions

The current study sought to examine if individuals with intellectual disabilities attribute more positive attributes to themselves compared to how they think they are viewed by others. It was also of interest to examine if individuals with intellectual disabilities thought supportive-others would attribute more positive attributes to them compared to unknown-others. An additional question was concerned with the importance individuals with intellectual disabilities place on the views of supportive-others and unknown-others.

Method

Design

This exploratory study used a within-subjects design and an experimental task with three conditions to examine: i) the nature of the participants' self-perceptions, and how they think they are perceived by ii) a supportive-other in their lives whom they have a positive relationship with; and iii) a potentially prejudiced, unknown individual they might encounter in the community.

A sentence completion task was also used to provide a more open approach to exploring the nature of the participants' self and inter-personal perceptions.

Participants

Thirty participants with intellectual disabilities were recruited from a community enterprise which provides day opportunities for individuals with intellectual disabilities in the west of Scotland. All participants were over 18 years of age. Potential participants were identified with the help of staff at the organisation who knew the individuals well. To help establish whether potential participants had the communicative ability to complete the experimental task the staff used the following items from the Adaptive Behaviour Scale (ABS-RC-2; Nihira et al., 1993): being able to talk to others about sports, family, group activities etc.; sometimes use complex sentences containing 'because', 'but' etc.; and answer simple questions such as 'what is your name?' or 'what are you doing?'. Participants were excluded if they had experienced recent significant mental health difficulties or had a sensory impairment which would have impacted on their ability to complete the task. One person was unable take part in the study as they were unable to provide informed consent.

Experimental Task and Measures

The participants completed the following questionnaires, experimental tasks and measures in the order presented below.

Background information: Participants were asked about their age, gender, ethnicity, and socio-economic status. Socio-economic status was measured using the Scottish Index

of Multiple Deprivation (SIMD; Scottish Government, 2020), which ranks postcodes into quintiles of deprivation. Rankings of 1 represent the most deprived areas and rankings of 5 the least deprived areas.

Glasgow Depression Scale – Learning Disabilities: The Glasgow Depression Scale for people with a Learning Disability (GDS-LD; Cuthill et al., 2003) was used as a screening tool for mood difficulties, to ensure that negative self-perceptions were not a consequence of depressive mood. The GDS-LD is a 20-item questionnaire which gathers ratings on a three-point scale about symptoms of low mood experienced in the previous week. The psychometric properties of the GDS-LD include good test-retest reliability (r=0.97), strong internal consistency (Cronbach's α=0.90), and a cut-off score (13) yielded 96% sensitivity and 90% specificity for clinical depression (Cuthill et al., 2003).

Attribution Task: Self and inter-personal perceptions

The experimental task was an adaptation of the 'attribution task' developed by Deakin et al. (2018). The task is based on a set of bi-polar attributes shown in Table 2.1 below, with a positive and negative dimension. The attributes included in Deakin et al. (2018) were chosen to reflect societal attitudes towards people with intellectual disabilities (Enea-Drapeau et al., 2012). The attributes were represented pictorially.

The pictures used to depict the different attributes in the attribution task were adapted for use with adults from Deakin et al.'s (2018) study with children. The adaptation of the pictures had three phases: i) collecting feedback from a group of clinicians regarding the aspects of the pictures (i.e. clothing and background features) deemed as unsuitable for use with adults and removing or altering these; ii) discussion with the research team concerning age-appropriate background features such as home and community locations, and incorporating these to assist in providing context and engaging participants; iii) a focus group with five experts by experience focussing on the comprehensibility of the adapted pictures. The adaptations that were made following this focus group consisted of making pictures clearer by increasing the size of images, removing features which could be visually distracting, and changing the name of one

attribute to ‘is struggling’. A complete set of pictures used in the study is shown in Appendix 2.5.

Table 2.1 Attribute pairs included in the attribution task

Positive dimension of attribute	**Negative dimension of attribute**
Feels happy most of the time	Feels sad most of the time
Is good	Is bad
Can do lots of things alone	Needs help to do things
Is clever	Is struggling
Has lots of friends	Lonely
Friendly	Unfriendly
Doesn’t get called names	Gets called names

The attribution task was used to examine self-perceptions across three conditions: i) self-attributions, ii) supportive-other attributions, and iii) unknown-other attributions. For each condition, participants were presented with seven pictorial attribute pairs. Participants were required to make a forced-choice regarding the positive or negative dimension of each attribute pair in turn. Once participants selected an attribute, they would then place their chosen attribute into the appropriate ‘post-box’ denoted with either ‘this is me’ or ‘this is not me’, as shown in Figure 2.1.

Prior to starting the attribution task, the participants were asked to complete a trial selection task, using food items, to ensure they understood the procedure with the post boxes.

i) *Self-attribution condition*: participants were asked for each attribution pair “what would you say about yourself” e.g. “would you say you were friendly or unfriendly?”.

ii) *Supportive-other condition*: participants were asked to choose someone they had a positive relationship with and provide a brief description of this person and their relationship (see Appendix 2.6). Participants were asked “what do

you think this person would say about you", e.g. "would they say you are friendly or unfriendly?".

iii) *Unknown-other condition*: participants were read a brief vignette describing a group of teenagers in the town centre who looked at the participant as they walked past (see Appendix 2.6). As above, for each attribute the participants were asked "what do you think this person would say about you", e.g. "would they say you are friendly or unfriendly?".

The order in which the supportive-other and unknown-other conditions were administered was alternated for each successive participant, to control for order-effects.

Figure 2.1 Attribution task

Importance Ratings

Following both the supportive-other and unknown-other conditions, participants were asked to rate how much importance they placed on the target person's views. A five-

point visual Likert scale was used, from 'not at all important' to 'really important' (Appendix 2.7). The visual Likert scale was developed for use with individuals with intellectual disabilities based on the principles outlined in Hartley & MacLean (2006), with pictorial representations and short response descriptors of each scale point.

Sentence Completion Task: Exploration of self and inter-personal perceptions
The sentence completion task was an adaptation of Jahoda et al.'s (1998) 'word-stem' task. The aim was to allow the participants to generate their own responses about the nature of their self and inter-personal perceptions. The sentence completion task consisted of 11 sentence stems (Appendix 2.8) that were read aloud and discussed verbally with participants following the attribution task. Two sentence stems were about the participants' positive views of themselves ("the thing I like most about myself is…") and other people's positive comments ("the best thing someone has said about me is…"). Two sentence stems were about participants' negative view of themselves ("the thing I don't like about myself is…") and other people's negative comments ("the most upsetting thing someone has said about me is…").

In order to prevent the participants becoming caught in a positive or negative response set and to maintain rapport, the sentence stems concerning the participants' self-and inter-personal perceptions were interspersed with seven sentence stems about their likes and dislikes (e.g. "my favourite music to listen to is…"). These sentences stems served to maintain participant engagement and to conclude the research session in a positive and less demanding manner.

Wechsler Abbreviated Scale of Intelligence (WASI-II; Wechsler 2011)
The WASI-II was used as a measure of cognitive functioning. The two-subtest form of the assessment was used, which consists of the Vocabulary and Matrix Reasoning subscales. The WASI-II reports good to excellent test-retest reliability across subtests (0.83 – 0.94) and composite scores (0.90 – 0.96), a high level of internal reliability (0.90 – 0.92), and acceptable (0.71) to excellent (0.92) concurrent validity. This assessment was administered last to encourage the participants to feel they can be open during the main components of the research session.

Procedure

The researcher met with participants in a private room at the organisation they attended, at a time convenient to them. Participants were seen on their own and no participants elected to have a member of staff join their research session. At the start of the session time was taken to build rapport with participants. Participants were initially presented with the participant information sheet which outlined the purpose of the study, participation requirements, voluntary status of the study, and participants' right to withdraw from the study. Any questions regarding this and checks regarding participants' ability to understand and consent to taking part in the study were discussed before taking consent. The participants information sheet and consent form were both provided in an accessible 'easy-read' format (see Appendix 2.4).

At the end of the session, participants were able to ask any questions and provide feedback on their experience of the study. The attribution task and sentence completion task were audio recorded to help ensure the participants' responses were recorded accurately and allow the researcher to focus her attention on completing the tasks with the participant.

Sample size

This exploratory study of self and inter-personal perceptions involved the adaptation of a novel approach that has not been used in prior research with adults with intellectual disabilities. The sample size of 30 was based on reviewing comparable studies which utilised novel experimental tasks and recruited samples of individuals with intellectual disabilities (Deakin et al., 2018; Donnachie et al., 2021).

Analysis

1. *Self and inter-personal perceptions: Comparison of positive attributes selected across three conditions*

The data obtained from the attribution task were frequency counts and did not meet assumptions for parametric statistical analysis, therefore non-parametric tests were used to answer the research questions.

To examine if individuals with intellectual disabilities attribute more positive attributes to themselves compared to how they are viewed by others, and to examine if individuals with intellectual disabilities thought supportive-others would attribute more positive attributes to them compared to unknown-others, a Friedman test was used as an omnibus test to examine if there was a difference in the number of positive attributes selected by participants across the three conditions.

Following this, pairwise comparisons were analysed using Wilcoxon Signed Rank tests and Sign tests with Bonferroni corrections for multiple comparisons, to reduce the chance of Type I error.

2. *Comparison of importance ratings between supportive other and unknown-other*

The data from the importance ratings were ordinal. To examine the importance participants placed on the views of supportive-others and unknown-others, Wilcoxon signed rank tests were used to examine if there was a difference in how participants rated the importance of other people's views about them. One participant did not complete this part of the study due to it being developed further in piloting. All statistical analysis was 2-tailed due to the exploratory nature of the research questions.

3. *Exploration of self and inter-personal perceptions*

In addition, participants' responses to the sentence completion task were transcribed verbatim and content analysed (Strauss, 1987). Content analysis was deemed appropriate as the participants' responses were short and lacking the rich detail for other qualitative approaches. This process involved categorising the short responses that participants provided to the four target sentences. Categories were developed to reflect participants views about themselves and their experience of what others have said about them.

Ethics

Ethical approval was obtained from the University of Glasgow College of Medical, Veterinary and Life Sciences Ethics committee (Ref: 200230233) based on research proposal (Appendix 2.3).

Results

1. Participant characteristics

Table 2.2 shows the socio-demographic characteristics of the 30 participants who took part in the study. Nineteen male and 11 female participants all identified as white British/Scottish. The age of participants spanned from 20 to 84 years old, however there was only one participant who was over 70 years old. The mean age was 43 years old. Fourteen participants lived with their family while nine stayed in their own tenancy and seven in shared accommodation. The WASI-II scores indicated the cognitive abilities of participants and the mean shows this was in the mild to moderate intellectual disability range. One participant scored in the low average range. Given that this participant had lifelong experiences of services for people with intellectual disabilities, it was decided that they should be included in the sample of individuals with intellectual disabilities. Most scores on the GDS-LD were below the clinical threshold for depression. However, five participants had elevated scores on this measure. The socio-economic status of the areas where the participants lived (as categorised by SIMD) was spread across the range of quintiles, but most participants lived in the most deprived areas. The SIMD was not calculated for six participants as they did not provide a postcode.

Table 2.2 Participant characteristics

Demographic/characteristic	**Participants (n=30)**
Age	Mean = 43 SD = 17.19 Range = 20 – 84
Gender	
Male	19 (63.7%)
Female	11 (36.7%)
Ethnicity	
White	30 (100.0%)
Living situation	
Own home	9 (30.0%)
Family home	14 (46.7%)
Shared accommodation	7 (23.3%)
WASI-II score	Mean = 58.77 SD = 8.10 Range = 45 – 87
GDS-LD score	Mean = 7.66 SD = 5.36

	Range = 0 – 19
SIMD Quintiles	(n= 24)
1 most deprived	10 (41.7%)
2	7 (29.2%)
3	3 (12.5%)
4	1 (4.2%)
5 least deprived	3 (12.5%)

2. Selection of supportive-other relationship target person

For the supportive-other condition of the attribution task, participants were asked to select a supportive individual and then asked to think about how this person might describe them when completing the attribute task. Table 2.3 shows the types of relationships participants selected. Most participants chose a friend as a supportive-other, and this was often a friend that attended the same organisation. Some participants chose support staff either at home or at the organisation as their supportive-other, suggesting the opportunities for positive relationships at such organisations.

Table 2.3 Relationships selected by participants for supportive-other condition

Description of relationship	**Number of participants**
Friend	4
Friend at organisation	14
Family	2
Support staff	3
Support staff at organisation	4
Romantic relationship	2
Neighbour	1

3. Attribution task: Analysis of Self and inter-personal perceptions

3.1. Comparison of positive attributes selected across self, supportive-other, and unknown-other conditions

The number of positive attributes selected by each participant across the three conditions of the attribute task (self, supportive-other, and unknown-other) was examined. A Friedman test was conducted as an omnibus test which confirmed there was a statistically significant difference between the mean ranks of the three conditions, $\chi^2(2) = 9.651$, $p = 0.008$ with a small effect size (Kendall's $W = 0.16$; Cohen,1992).

3.2. Do individuals with intellectual disabilities select more positive attributes to describe themselves compared to how they think they are viewed by others?

To determine where the differences occur within the significant Friedman test, post-hoc analysis was conducted using Wilcoxon signed-rank tests for pairwise comparisons and Bonferroni correction applied resulting in a significance level set at $p < 0.017$ to account for multiple comparisons. There was no significant difference between the number of positive attributes selected for the supportive-other conditions and the self condition ($Z = -.728$, $p = 0.467$). However, there was a significant difference between unknown-other condition (mean = 5.23; SD = 1.74; median = 6.00; IQR = 2.25) and the self condition (mean = 6.03; SD = 0.89; median = 6.00; IQR = 2.00), $Z = -2.869$, $p = 0.004$ with a standardised effect size of $r = 0.37$ indicating a medium effect (Cohen, 1992). This shows that participants selected more positive attributes to describe themselves compared to the how they thought they would be described by an unknown-other.

3.3. Do individuals with intellectual disabilities think they are viewed more positively by a supportive-other or unknown-other?

For the comparison between the number of positive attributes selected by participants in the unknown-other and supportive-other conditions, examining the change in residuals showed a skewness value of greater than ±2 (Hair et al., 2010; Kim, 2013) which violated the symmetry assumption of the Wilcoxon Signed Rank test, meaning conducting a Sign test[1] was more appropriate statistical test to use. There was a

[1] Wilcoxon signed-rank test was also conducted to determine if this made a difference to the analysis. The results of this show a significant difference ($Z = -2.804$, $p = 0.005$), with a medium standardised effect size $r = 0.36$.

statistically significant difference in the number of positive attributes selected between the unknown-other condition (mean = 5.23; SD = 1.74; median = 6.00; IQR = 2.25) compared to the supportive-other condition (mean = 5.93; SD= 1.02; median = 6.00; IQR = 2.00), $p = 0.013$. This suggests more positive attributes were selected in the supportive-other condition than in the unknown-other condition, meaning that the participants believed they were viewed more positively by supportive others.

3.4. Positive attribute selection across self, supportive-other, and unknown-other conditions

Figure 2.2 shows the number of participants that selected the positive dimension of each of the seven attribute pairs across the three conditions of the task: self, supportive-other, and unknown-other.

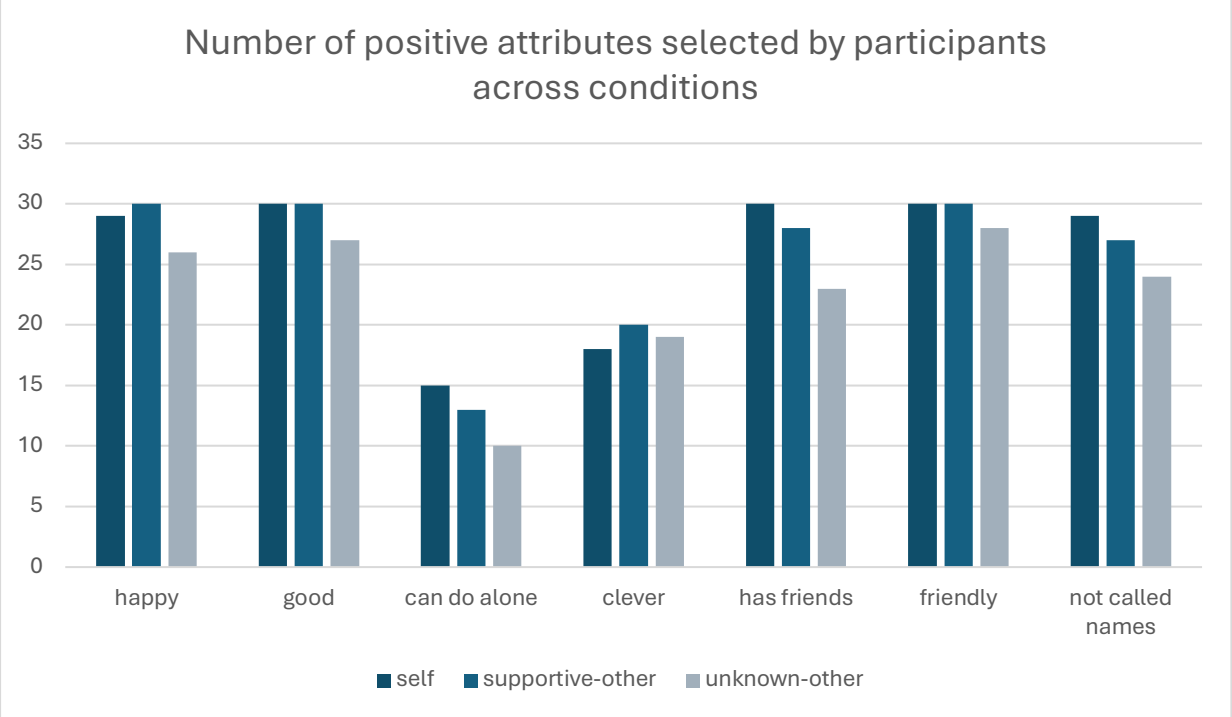

Figure 2.2 Bar chart showing the number of participants that selected the positive dimension of each attribute pair, across three conditions

Figure 2.2 shows that in general participants described themselves using positive attributes across the seven attribute pairs. Participants tended to describe themselves more positively than how they thought they would be viewed by an unknown-other. Participants also described themselves using more, or equivalent number of positive

attributes to how they thought they would be viewed by a supportive-other. The one exception to this was that participants selected the attribute 'happy' more when describing how a supportive other might view them in comparison to how they viewed themselves. Notably, the selection of positive attributes by participants was lower for 'can do things alone' and 'clever' attributes across all three conditions which may reflect participants' real-life experiences of requiring more support for certain tasks and feeling less able.

4. **Importance ratings: is there a difference in how individuals with intellectual disabilities rate the importance of views of an unknown-other compared to a supportive-other?**

To address the research question regarding if there was a difference in how participants rated the importance of views of an unknown-other compared to supportive-other, a Wilcoxon Signed Rank test was used to compare participants' ratings. Ratings regarding the importance participants of unknown-others' views (mean = 2.17; SD = 1.20; median = 2.00; IQR = 2.00) was compared to the ratings concerning supportive-others' views (mean = 3.79; SD = 0.73; median = 4.00; IQR = 0.00). There was a significant difference in the ratings of how important the participants rated the views of others (Z = -4.256, p < 0.001) with a standardised effect size of r = 0.55 indicating a large effect (Cohen, 1992). Participants rated that it was more important what the supportive-other thought about them compared to an unknown-other.

5. **Accounting for elevated depression scores in the findings**

Data from five participants who obtained elevated scores on the GDS-LD, indicating clinical depression, were removed to conduct further analysis. This was in order to account for the potential impact of depression on the findings of the current study as there is some evidence to suggest a correlation between low self-esteem and depressive symptoms (Lee et al., 2023). The analysis below details the findings of the statistical analysis excluding the data of the five participants.

5.1. Comparison of positive attributes selected across self, supportive-other, and unknown-other conditions

The number of positive attributes selected by each participant across the three conditions of the attribute task (self, supportive-other, and unknown-other) was examined. Removal of the data from five participants who exceeded the threshold of the GDS-LD showed the Friedman test remained significant $\chi^2(2) = 7.28$, $p = 0.026$, with a small effect size (Kendall's $W = 0.15$; Cohen, 1992) and confirmed there was a statistically significant difference between the mean ranks of the three conditions

5.2. Do individuals with intellectual disabilities select more positive attributes to describe themselves compared to how they think they are viewed by others?

As was found in the previous statistical analysis conducted including the data from all 30 participants, there was no significant difference between the number of positive attributes selected for the supportive-other conditions and the self condition ($Z = -.632$, $p = 0.527$).

The Wilcoxon signed rank tests remained significant after excluding participants with elevated GDS-LD scores for the comparison between the number of positive attributes selected in the unknown-other condition (mean = 5.44; SD = 1.47; median = 6.00; IQR = 2.50) and self condition (mean = 6.04; SD = 0.94; median = 6.00; IQR = 2.00), $Z = -2.438$, $p = 0.015$ with a standardised effect size of $r = 0.31$ indicating a medium effect (Cohen, 1992). This shows that participants selected more positive attributes to describe themselves compared to the how they thought they would be described by an unknown-other.

5.3. Do individuals with intellectual disabilities think they are viewed more positively by a supportive-other or unknown-other?

Regarding the comparison between the number of positive attributes selected by participants in the unknown-other (mean = 5.44; SD = 1.47; median = 6.00; IQR = 2.50) and supportive-other conditions (mean = 5.96; SD = 0.98; median = 6.00; IQR = 2.00), the Wilcoxon signed rank test remained significant after excluding participants with

elevated GDS-LD scores (Z = -2.506, p = 0.012) with a standardised effect size of r = 0.35 indicating a medium effect (Cohen, 1992). This suggests more positive attributes were selected in the supportive-other condition than in the unknown-other condition, meaning that the participants believed they were viewed more positively by supportive others.

5.4. Importance ratings: is there a difference in how individuals with intellectual disabilities rate the importance of views of a supportive-other compared to an unknown-other?

Regarding the comparison of the importance ratings for the unknown-other condition (mean = 2.12; SD = 1.22; median = 2.00; IQR = 2.00) and the supportive-other condition (mean = 3.75; SD = 0.79; median = 4.00; IQR = 0.00), the Wilcoxon signed rank test remained significant after excluding participants with elevated GDS-LD scores (Z = -3.882, p < 0.001) with a standardised effect size of r = 0.56 indicating a large effect (Cohen, 1992). Participants rated that it was more important what the supportive-other thought about them compared to an unknown-other.

6. Sentence Completion Task: Exploration of self and inter-personal perceptions

The section below illustrates the responses to the sentence completion task in which participants were asked to provide a response to four target sentence stems: 1) the thing I like most about myself, 2) the best thing someone has said about me, 3) the thing I don't like about myself, and 4) the most upsetting thing someone has said about me.

6.1. What participants value about themselves and positive comments from others

Table 2.4 shows that participants cited personal qualities related to their personality or temperament, such as being 'kind' as their most favoured features. Appearance and engagement in hobbies or activities were also commonly mentioned by participants.

Table 2.4 Content of responses to 'The thing I like most about myself'

Like about self	Example response	Number participants mentioned
Abilities	*I'm independent*	3
Appearance	*I'm handsome*	7
Having friends	*being myself and having more friends*	2
Hobbies	*being sporty and getting out in the environment*	8
Personal qualities	*To be polite and nice*	10

Table 2.5 illustrates that many participants received positive comments from others regarding their personal qualities and their abilities in specific hobbies or interests. This echoes the responses provided by participants regarding what they liked about themselves. Three participants cited others talking to them or spending time with them as a positive action enacted by others. Only one participant was unable to provide a response to this part of the task.

Table 2.5 Content of responses to 'The best thing someone has said about me'

Positive comment from others	Example response	Number participants mentioned
Abilities and hobbies	*being very good at stuff - drama and mosaics*	7
Achievements	*that I have good achievements like the national games and the Olympics*	1
Appearance	*I look nice*	6
Personal qualities	*I'm friendly and funny*	12
Spending time with others	*someone coming over to talk to me*	3
Unable to provide response		1

6.2. What participants dislike about themselves and negative comments from others

Table 2.6 illustrates participants responses to the target sentence stem regarding negative self-perceptions. Only one participant explicitly discussed their disability as something that they felt negatively about. Other participants mentioned physical difficulties and experiencing negative emotions. However, perhaps what was most noteworthy was that half of the participants stated that either there was nothing they didn't like about themselves, elected to provide a positive response, or were unable to provide a response.

Table 2.6 Content of responses to 'The thing I don't like about myself'

Dislike about self	Example response	Number participants mentioned
Appearance	*my glasses*	2
Being talked about	*people talking about me*	1
Having a disability	*a wee bit disabled. I have mild brain damage sometimes I wish I wasn't and sometimes I don't give it a thought*	1
Experiencing negative emotions	*don't like being sad*	3
Occupation and chores	*don't like ironing clothes*	3
Physical difficulties	*wanting my hip done*	2
Other	*get better at decisions*	3
Provided positive comments	*I like everything*	3
Nothing		7
Unable to provide response		5

Table 2.7 shows that while almost half of the participants spoke about their experience of abuse, including being seen as 'stupid', the remaining participants said that nothing upsetting had been said to them or were unable to provide a response.

Table 2.7 Content of responses to 'The most upsetting thing someone has said to me'

Negative comment from others	Example response	Number participants mentioned
Appearance	*you're fat*	3
Being called names	*called names, saying I said something*	1
Being talked about	*passing on stories about me*	2
Inability	*are you stupid?*	2
Physical assault	*got a doin' one time*	1
Other	*swearing at me*	4
Nothing		6
Unable to provide response		11

Discussion

The findings showed that individuals with intellectual disabilities generally selected positive attributes to describe themselves. However, as can be seen in Figure 2.2 participants selected the positive dimension of the attribute pair less frequently for 'can do things alone' and 'clever'. This suggests that participants recognised that there were aspects of themselves that they did not feel as positive about. The responses to these items may indeed reflect participants' real-life experiences and difficulties. However, their selection of positive attributes on other items suggested that participants did not define themselves by their difficulties as they also emphasised their positive qualities (Crocker & Major, 1989; Logeswaran et al., 2019). This may allude to the presence of a self-serving bias as a form of resilience to stigma. Participants may have sought to maintain a positive view of themselves and present this view to others by attributing positive qualities to internal factors such as personality (Shepperd et al., 2008). Participants may have also been engaging in the cognitive process of downward social comparisons (Finlay & Lyons, 2000) towards their peers and this promoted a more positive sense of self.

When participants were asked to select attributes based on what others might think about them, participants thought they would be described more positively by supportive-others compared to unknown-others. This might suggest that participants were aware that unknown-individuals might hold more negative views about people with intellectual disabilities. This would support previous research that has found that individuals with intellectual disabilities are often aware of the potentially prejudiced and stigmatising views society holds (Logeswaran et al., 2019). This finding also appears in research conducted with other stigmatised groups and has implications for wellbeing outcomes. For example, research conducted with people with significant mental illness (Corrigan & Rao, 2012) showed that individuals often had an awareness of stereotypical views about this group and could be more vulnerable to self-stigma if they identified as belonging to this group. This vulnerability to self-stigma has been shown to be related to poorer mental health outcomes, reduced social networks and access to housing and employment (Livingstone & Boyd, 2010).

Participants also rated the views of supportive-others as more important than those of unknown-others. This examination of the role of positive relationships in the construction of a relative view of self (Crabtree et al., 2016) may highlight another strategy for coping with stigma and promoting a more positive sense of self among individuals with intellectual disabilities. This aligns with positive identity development and the importance of meaningful opportunities for inclusion, community engagement and forming relationships in shaping of a positive identity for individuals with intellectual disabilities (Rodriquez et al., 2023). Similar considerations have arisen from research conducted with individuals with substance use disorders (Grønnestad & Sagvaag, 2016). Social marginalisation and labelling have been cited as factors which can impede recovery. This is partly due to the sense of inclusion and respect individuals gain from substance-use associations and the absence of these opportunities in wider society. Therefore, social marginalisation may be a maintenance factor in continued substance use and engagement with related social groups as they provide a sense of improved self-worth (Grønnestad & Sagvaag, 2016).

For the positive items in the sentence completion task, participants provided responses relating to appearance, social qualities, and inclusion through hobbies and activities. This reflects previous research in which individuals with disabilities tended to focus on such attributes when describing themselves (Dorozenko et al., 2015) and suggests these are important indicators for the development of positive self-worth and self-esteem (Kloomok & Cosden, 1994; Lee et al., 2023). With regard to negative self and inter-personal perceptions examined by the sentence completion task, the notion of 'disability' was not prominent in participants' responses and only appeared once. This is a similar finding to Finlay & Lyons's (2000) study which found that individuals did not tend to describe themselves using such labels. This may also reflect aspects of discussion in Beart et al., (2005) which queried the prominence of the label 'intellectual disability' in forming part of one's identity. Such findings draw parallels to social identity theory (Tajfel & Turner, 1979). Participants may have chosen to identify themselves based on their abilities and interests, instead of aligning themselves with the label of intellectual disability in an attempt to avoid, or resist, stigma and promote positive self and inter-personal perceptions.

Participants in the current study were more likely to respond with experiences of being laughed at, talked about, or in the case of one participant, physically assaulted which suggests living with stigma is a very real experience for individuals with intellectual disabilities (Ali et al., 2012). However, it should also be noted that it was difficult for many participants to provide responses for the negative items in the sentence completion task. Although speculative, this may illustrate a sensitivity among participants to discussing more negative aspects of their self-perceptions and inter-personal perceptions. Again, this may be attributable to a self-serving bias (Shepperd et al., 2008). Participants may have anticipated feeling a sense of discomfort when discussing more negative aspects of their self-perceptions and so chose not to provide this information. This might have served to maintain a consistent and positive sense of self, in line with that which they had already presented during the experimental task. It may also illustrate that the methods were unsuitable and perhaps a more in-depth qualitative approach would have been more appropriate to explore these sensitive aspects.

It is also important to consider social desirability with regards to the results of the study. The researcher was required to develop a positive, albeit short, relationship with participants to facilitate participation in the study. In turn, this may have impacted on the responses that participants provided and it is possible that participants provided responses or presented themselves in such a way that upheld a positive sense of self rather than responses which reflected their beliefs (Alexander et al., 2025).

Strengths and limitations

The current study used a novel method to explore people with intellectual disabilities' self and inter-personal perceptions. The advantage of this approach is that it is an active and engaging task which is less reliant on people's abilities to articulate their views. This method may have the potential to be developed for use as an assessment tool, although this would require careful psychometric investigation and further consideration of attributes.

Although the current study has shown promise regarding the utility of the methods used, the sample size was small, and the results are not generalisable to a larger population. A larger sample would have been beneficial to conduct meaningful analysis regarding gender differences, for example. The understanding of the influence of gender in intellectual disabilities research is limited as few studies examine this (Umb-Carlsson & Sonnander, 2006). Although the current study intended to reach a representative sample, all participants were white Scottish/British. Research has shown there may be additional challenges pertaining to stigma, socio-economic disadvantage, and access to appropriate services for individuals with intellectual disabilities from other ethnic backgrounds (Ali, Kock, Molteno, et al., 2015; Dùra-Vilà & Hodes, 2012) which may also influence self-perceptions. Another limitation is the large age range included in the current study. It is possible that there is a disparity of views and experiences between younger and older participants which would likely inform self-perceptions. For example, older adults with intellectual disabilities may have had different experiences over their life course compared to younger adults. Older participants' identity may also comprise of aspects regarding the cultural context of ageing (Kåhlin et al., 2015). It therefore seems valid to consider how gender, age, and other aspects of intersectionality may impact on how individuals experience the social world and consequently, influence self-perceptions.

Future research

Much of the research examining self-perceptions of individuals with intellectual disabilities has focussed on the negative impact of stigma. This exploratory study suggests that individuals with intellectual disabilities often view themselves positively despite some awareness of the more negative views held by wider society. This suggests the importance of positive relationships in potentially contributing to people's positive self-perceptions and the value of replicating this research with a larger sample to examine the influences of factors such as gender, age, and ethnicity. Another important area of future research would be to extend the current study to include a wider variety of attributes. Although consideration was given to include lived experience contributions in the development of the current study, it would be beneficial to generate a wider range of attributes through consultation with individuals with lived experiences

of intellectual disabilities and their families. It would also be beneficial to consider a longitudinal approach to examine the impact of relationships throughout developmental stages on sense of self.

Implications

This study furthered insights into the self-perceptions of individuals with intellectual disabilities and how they believe they are viewed by others by not only focussing of the impact of stigma but acknowledging the other relationships people have in their lives (Crabtree et al., 2016). This study was novel and permitted the exploration of aspects relating to stigma and self-perceptions that contribute to existing knowledge. To our knowledge, no previous study has shown that the views of supportive-others are more important to individuals with intellectual disabilities than those of unknown-others. While not surprising, these results suggest the importance of individuals with intellectual disabilities having access to community resources and activities which provide opportunities for positive social interactions with others. This bidirectional relationship between individuals and their environment or context (Bronfenbrenner, 2005) may serve the development of a positive sense of self.

As discussed, some previous research has implied that there is a direct impact of stigma on self-worth. However, the results of this study shed light on some of the complexities involved in the process of perceiving stigma and the impact this has on sense of self for individuals with intellectual disabilities. Specifically, this study concluded that the impact of stigma may depend on the individuals' relationship with the person who might treat them in a stigmatising way, and whether the views of this person are considered important.

Tackling stigma towards individuals with intellectual disabilities is a priority at a societal level to reduce inequalities and discrimination. This involves not only the physical inclusion in communities but also acceptance and social inclusion (Scior et al., 2020) which may provide opportunities for positive relational experiences. At an intrapersonal level, interventions which seek to promote self-advocacy and resistance to stigma (Scior et al., 2022) have shown promise in developing self-efficacy and skills to manage

stigma. Regardless of how we attempt to reduce stigma, what the results of this study have shown is that individuals with intellectual disabilities have the ability to make the distinction between the behaviour and attitudes of people who know and support them, and those who don't. It is important to take this finding into account when developing interventions or strategies to reduce or resist stigma as this will ensure a holistic understanding of an individual and their social network. As well as recognising the detrimental impact of stigma, there is a need to recognise the variety of relationships individuals with intellectual disabilities have and the multifaceted nature of self-perceptions based on these relationships. In doing so, we move beyond a reductionist view of stigma and instead acknowledge individuals' agency in how they view themselves and how they present themselves to others.

Conclusions

The current study examined self-perceptions and inter-personal perceptions among a sample of adults with intellectual disabilities. This study took into consideration the different relationships individuals with intellectual disabilities experience and how these may influence how they view themselves. The results suggested that participants had an awareness of the potentially stigmatising views held by society and individuals they do not know. Despite this, participants had generally positive views of themselves, discussed their positive qualities, and believed they were seen as positively by their chosen supportive relationship. This highlights the importance of promoting opportunities for individuals with intellectual disabilities to experience positive social interaction and activities. These experiences may contribute to a more positive sense of self.

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Appendices

Appendix 1.1: The ENTREQ checklist

Item	Guide and description	Reported on page #
Aim	State the research question the synthesis addresses	13
Synthesis methodology	Identify the synthesis methodology or theoretical framework which underpins the synthesis, and describe the rationale for choice of methodology (e.g. metaethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).	18
Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until theoretical saturation is achieved).	14
Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type).	15
Data sources	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psychINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar), hand searching, reference lists) and when the searches were conducted; provide the rationale for using the data sources.	14
Electronic Search strategy	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research and search limits).	14, Appendix 1.2
Study screening methods	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies)	15, 16
Study characteristics	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).	21 - 25
Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e.g. for comprehensive searching, provide numbers of studies screened and reasons for exclusion	17

	indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications t the research question and/or contribution to theory development).	
Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings).	18
Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).	18
Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required.	18
Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale	26, 27
Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. all text under the headings "results /conclusions" were extracted electronically and entered into a computer software).	16, 19
Software	State the computer software used, if any.	N/A
Number of reviewers	Identify who was involved in coding and analysis.	19
Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts).	19
Study comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary).	19
Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	19
Quotations	Provide quotations from the primary studies to illustrate themes/constructs, and identify whether the quotations were participant quotations or the author's interpretation	28 – 35
Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual	28 – 39

	models, analytical framework, development of a new theory or construct).	

Appendix 1.2: Search Terms

PsycInfo (OVID)

1. Qualitative Methods/
2. Questionnaires/
3. exp Attitudes/
4. Focus Group/
5. discourse analysis.mp.
6. content analysis.mp.
7. ethnographic research.mp.
8. ethnological research.mp.
9. ethnonursing research.mp.
10. constant comparative method.mp.
11. qualitative validity.mp.
12. purposive sample.mp.
13. observational method$.mp.
14. field stud$.mp.
15. theoretical sampl$.mp.
16. phenomenology/
17. phenomenological research.mp.
18. life experience$.mp.
19. cluster sampl$.mp.
20. or/1-19
21. ethnonursing.af.
22. ethnograph$.mp.
23. phenomenol$.af.
24. grounded theory.mp.
25. (grounded adj (theor$ or study or studies or research or analys?s)).af.
26. (life stor$ or women's stor$).af.
27. (emic or etic or hermeneutic$ or heuristic$ or semiotic$).af. or (data adj1 saturat$).tw. or participant observ$.tw.
28. (social construct$ or (postmodern$ or post-structural$) or (post structural$ or poststructural$) or post modern$ or post-modern$ or feminis$ or interpret$).mp.
29. (action research or cooperative inquir$ or co operative inquir$ or co-operative inquir$).mp.
30. (humanistic or existential or experiential or paradigm$).mp.
31. (field adj (study or studies or research)).tw.
32. human science.tw.
33. biographical method.tw.
34. qualitative validity.af.
35. purposive sampl$.af.
36. theoretical sampl$.af.
37. ((purpos$ adj4 sampl$) or (focus adj group$)).af.
38. (account or accounts or unstructured or open-ended or open ended or text$ or narrative$).mp.

39. (life world or life-world or conversation analys?s or personal experience$ or theoretical saturation).mp.
40. lived experience$.tw.
41. life experience$.mp.
42. cluster sampl$.mp.
43. (theme$ or thematic).mp.
44. categor$.mp.
45. categor$.mp.
46. observational method$.af.
47. field stud$.mp.
48. focus group$.af.
49. questionnaire$.mp.
50. content analysis.af.
51. thematic analysis.af.
52. constant comparative.af.
53. discourse analys?s.af.
54. ((discourse$ or discurs$) adj3 analys?s).tw.
55. (constant adj (comparative or comparison)).af.
56. narrative analys?s.af.
57. heidegger$.tw.
58. colaizzi$.tw.
59. speigelberg$.tw.
60. (van adj manen$).tw.
61. (van adj kaam$).tw.
62. (merleau adj ponty$).tw.
63. husserl$.tw.
64. giorgi$.tw.
65. foucault$.tw.
66. (corbin$ adj2 strauss$).tw.
67. (strauss$ adj2 corbin$).tw.
68. (glaser$ adj2 strauss$).tw.
69. glaser$.tw.
70. or/21-69
71. findings.af.
72. interview$.af. or Interviews/
73. qualitative.af.
74. or/71-73
75. 20 or 70 or 74
76. intellectual development disorder/
77. (intellectual$ adj3 disab$).tw.
78. (intellectual$ adj3 impair$).tw.
79. (learning adj3 disab$).tw.
80. (learning adj3 difficult$).tw.
81. (cognit$ adj3 disab$).tw.
82. mental$ retard$.tw.
83. (mental$ adj3 disab$).tw.
84. (mental$ adj3 impair$).tw.

85. down$ syndrome.tw.
86. (mental$ adj3 deficie$).tw.
87. idiocy.tw.
88. fragile x.tw.
89. prader willi.tw.
90. or/76-89
91. stereotyped attitudes/
92. social perception/
93. stigma/
94. public opinion/
95. prejudice/
96. attitudes/
97. ((public* or community or social or popular) adj attitude*).tw.
98. (((negative or positive or chang*) adj3 attitude*) or prejudice* or hostil* or intoleran* or marginalis* or stigma*).tw.
99. self-concept/
100. self-esteem/
101. ((perception* or identit* or view* or esteem) adj2 self).tw.
102. or/91-101
103. 75 and 90 and 102
104. limit 103 to english language
105. limit 104 to yr="2000 -Current"

MEDLINE (OVID)

1. Qualitative Research/
2. Nursing Methodology Research/
3. Questionnaires/
4. exp Attitude/
5. Focus Groups/
6. discourse analysis.mp.
7. content analysis.mp.
8. ethnographic research.mp.
9. ethnological research.mp.
10. ethnonursing research.mp.
11. constant comparative method.mp.
12. qualitative validity.mp.
13. purposive sample.mp.
14. observational method$.mp.
15. field stud$.mp.
16. theoretical sampl$.mp.
17. phenomenology/
18. phenomenological research.mp.
19. life experience$.mp.
20. cluster sampl$.mp.
21. or/1-20

22. ethnonursing.af.
23. ethnograph$.mp.
24. phenomenol$.af.
25. grounded theory.mp.
26. (grounded adj (theor$ or study or studies or research or analys?s)).af.
27. (life stor$ or women's stor$).mp.
28. (life stor$ or women's stor$).mp.
29. (emic or etic or hermeneutic$ or heuristic$ or semiotic$).af. or (data adj1 saturat$).tw. or participant observ$.tw.
30. (social construct$ or (postmodern$ or post-structural$) or (post structural$ or poststructural$) or post modern$ or post-modern$ or feminis$ or interpret$).mp.
31. (action research or cooperative inquir$ or co operative inquir$ or co-operative inquir$).mp.
32. (humanistic or existential or experiential or paradigm$).mp.
33. (field adj (study or studies or research)).tw.
34. human science.tw.
35. biographical method.tw.
36. qualitative validity.af.
37. purposive sampl$.af.
38. theoretical sampl$.af.
39. ((purpos$ adj4 sampl$) or (focus adj group$)).af.
40. (account or accounts or unstructured or open-ended or open ended or text$ or narrative$).mp.
41. (life world or life-world or conversation analys?s or personal experience$ or theoretical saturation).mp.
42. lived experience$.tw.
43. life experience$.mp.
44. cluster sampl$.mp.
45. (theme$ or thematic).mp.
46. categor$.mp.
47. observational method$.af.
48. field stud$.mp.
49. focus group$.af.
50. questionnaire$.mp.
51. content analysis.af.
52. thematic analysis.af.
53. constant comparative.af.
54. discourse analys?s.af.
55. ((discourse$ or discurs$) adj3 analys?s).tw.
56. (constant adj (comparative or comparison)).af.
57. narrative analys?s.af.
58. heidegger$.tw.
59. colaizzi$.tw.
60. speigelberg$.tw.
61. (van adj manen$).tw.
62. (van adj kaam$).tw.
63. (merleau adj ponty$).tw.

64. husserl$.tw.
65. giorgi$.tw.
66. foucault$.tw.
67. (corbin$ adj2 strauss$).tw.
68. (strauss$ adj2 corbin$).tw.
69. (glaser$ adj2 strauss$).tw.
70. glaser$.tw.
71. or/22-70
72. findings.af.
73. interview$.af. or Interviews/
74. qualitative.af.
75. or/72-74
76. 21 or 71 or 75
77. exp Intellectual Disability/
78. (intellectual$ adj3 disab$).tw.
79. (intellectual$ adj3 impair$).tw.
80. (learning adj3 disab$).tw.
81. (learning adj3 difficult$).tw.
82. (cognit$ adj3 disab$).tw.
83. mental$ retard$.tw.
84. (mental$ adj3 disab$).tw.
85. (mental$ adj3 impair$).tw.
86. down$ syndrome.tw.
87. (mental$ adj3 deficie$).tw.
88. idiocy.tw.
89. fragile x.tw.
90. prader willi.tw.
91. or/77-90
92. stereotyping/
93. exp social perception/
94. public opinion/
95. prejudice/
96. attitude/
97. ((public* or community or social or popular) adj attitude*).tw.
98. (((negative or positive or chang*) adj3 attitude*) or prejudice* or hostil* or intoleran* or marginalis*).tw.
99. social stigma/
100. rejection, psychology/
101. Self Concept/
102. self esteem.tw.
103. ((perception* or identit* or view* or esteem) adj2 self).tw.
104. stigma*.tw.
105. or/92-104
106. 76 and 91 and 105
107. limit 106 to english language
108. limit 107 to yr="2000 -Current"

EMBASE (OVID)

1. qualitative stud$.mp.
2. nursing methodology research.mp.
3. questionnaire/
4. attitude/
5. focus group$.mp.
6. discourse analysis.mp.
7. content analysis.mp.
8. ethnographic research.mp.
9. ethnological research.mp.
10. ethnonursing research.mp.
11. constant comparative method.mp.
12. qualitative validity.mp.
13. purposive sample.mp.
14. observational method$.mp.
15. field stud$.mp.
16. theoretical sampl$.mp.
17. phenomenology/
18. phenomenological research.mp.
19. life experience$.mp.
20. cluster sampl$.mp.
21. or/1-20
22. ethnonursing.af.
23. ethnograph$.mp.
24. phenomenol$.af.
25. grounded theory.mp.
26. (grounded adj (theor$ or study or studies or research or analys?s)).af.
27. (emic or etic or hermeneutic$ or heuristic$ or semiotic$).af. or (data adj1 saturat$).tw. or participant observ$.tw.
28. (social construct$ or (postmodern$ or post-structural$) or (post structural$ or poststructural$) or (post modern$ or post-modern$) or feminis$ or interpret$).mp.
29. (action research or cooperative inquir$ or co operative inquir$ or co-operative inquir$).mp.
30. (humanistic or existential or experiential or paradigm$).mp.
31. (field adj (study or studies or research)).tw.
32. human science.tw.
33. biographical method.tw.
34. qualitative validity.af.
35. purposive sampl$.af.
36. theoretical sampl$.af.
37. ((purpos$ adj4 sampl$) or (focus adj group$)).af.
38. (account or accounts or unstructured or open-ended or open ended or text$ or narrative$).mp.
39. (life world or life-world or conversation analys?s or personal experience$ or theoretical saturation).mp.

40. lived experience$.tw.
41. life experience$.mp.
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43. (theme$ or thematic).mp.
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50. thematic analysis.af.
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52. discourse analys?s.af.
53. ((discourse$ or discurs$) adj3 analys?s).tw.
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58. speigelberg$.tw.
59. (van adj manen$).tw.
60. (van adj kaam$).tw.
61. (merleau adj ponty$).tw.
62. husserl$.tw.
63. giorgi$.tw.
64. foucault$.tw.
65. (corbin$ adj2 strauss$).tw.
66. (strauss$ adj2 corbin$).tw.
67. (glaser$ adj2 strauss$).tw.
68. glaser$.tw.
69. or/22-68
70. findings.af.
71. interview$.af. or Interviews/
72. qualitative.af.
73. or/70-72
74. 21 or 69 or 73
75. intellectual impairment/
76. (intellectual$ adj3 disab$).tw.
77. (intellectual$ adj3 impair$).tw.
78. (learning adj3 disab$).tw.
79. (learning adj3 difficult$).tw.
80. (cognit$ adj3 disab$).tw.
81. mental$ retard$.tw.
82. (mental$ adj3 disab$).tw.
83. (mental$ adj3 impair$).tw.
84. down$ syndrome.tw.
85. (mental$ adj3 deficie$).tw.
86. idiocy.tw.

87. "fragile x".tw.
88. "prader willi".tw.
89. or/75-88
90. stereotyping/
91. public opinion/
92. prejudice/
93. attitude/
94. ((public* or community or social or popular) adj attitude*).tw.
95. (((negative or positive or chang*) adj3 attitude*) or prejudice* or hostil* or intoleran* or marginalis*).tw.
96. stigma/
97. social stigma/
98. self concept/
99. self esteem/
100. ((perception* or identit* or view* or esteem) adj2 self).tw.
101. or/90-100
102. 74 and 89 and 101
103. limit 102 to english language
104. limit 103 to yr="2000 -Current"

CINAHL (EBSCOhost)

#	Query
S1	(MH "Qualitative Studies")
S2	(MH "Research Nursing") OR (MH "Research, Nursing")
S3	(MH "Questionnaires+")
S4	(MH "Attitude+")
S5	(MH "Focus Groups")
S6	(MH "Discourse Analysis")
S7	(MH "Content Analysis")
S8	(MH "Ethnographic Research")
S9	(MH "Ethnological Research")
S10	(MH "Ethnonursing Research")
S11	(MH "Constant Comparative Method")
S12	(MH "Qualitative Validity+")
S13	(MH "Purposive Sample")
S14	(MH "Observational Methods+")
S15	(MH "Field Studies")
S16	(MH "Theoretical Sample")

S17	(MH "Phenomenology")
S18	(MH "Phenomenological Research")
S19	(MH "Life Experiences+")
S20	(MH "Cluster Sample+")
S21	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20
S22	TX ethnonursing
S23	TX ethnograph*
S24	TX phenomenol*
S25	TX "grounded theory"
S26	TX((grounded w1 (theor* or study or studies or research or analys#s)))
S27	TX ((("life stor*") or ("women's stor*")))
S28	TX (emic or etic or hermeneutic* or heuristic* or semiotic*) or TI (data n1 saturat*) or AB (data n1 saturat*) or TI ("participant observ*") or AB ("participant observ*")
S29	TX ((("social construct*" or (postmodern* or "post-structural*") or ("post structural*" or poststructural*) or ("post modern*") or "post-modern*" or feminis* or interpret*))
S30	TX (("action research" or "cooperative inquir*" or ("co operative inquir*") or ("co-operative inquir*")))
S31	TX ((humanistic or existential or experiential or paradigm*))
S32	TI ((field w1 (study or studies or research)) OR AB ((field w1 (study or studies or research))
S33	TI ("human science") OR AB ("human science")
S34	TI ("biographical method") OR AB ("biographical method")
S35	TX ("qualitative validity")
S36	TX ("purposive sampl*")
S37	TX ("theoretical sampl*")
S38	TX (((purpos* n3 sampl*) or (focus w group*)))
S39	TX (((account or accounts or unstructured or "open-ended" or ("open ended") or text* or narrative*))
S40	TX ((("life world") or "life-world" or "conversation analys#s" or "personal experience*" or "theoretical saturation"))
S41	TI ("lived experience*") OR AB ("lived experience*")
S42	TX ("life experience*")

S43	TX ("cluster sampl*")
S44	TX ((theme* or thematic))
S45	TX categor*
S46	TX "observational method*"
S47	TX "field stud*"
S48	TX "focus group*"
S49	TX questionnaire*
S50	TX ("content analysis")
S51	TX ("thematic analysis")
S52	TX ("constant comparative")
S53	TX ("discourse analys#s")
S54	TI (((discourse* or discurs*) n2 analys#s)) OR AB (((discourse* or discurs*) n2 analys#s))
S55	TX ((constant w1 (comparative or comparison)))
S56	TX ("narrative analys#s")
S57	TI heidegger* OR AB heidegger*
S58	TI colaizzi* OR AB colaizzi*
S59	TI speigelberg* OR AB speigelberg*
S60	TI (van w1 manen*) OR AB (van w1 manen*)
S61	TI (van w1 kaam*) OR AB (van w1 kaam*)
S62	TI (merleau w1 ponty*) OR AB (merleau w1 ponty*)
S63	TI husserl* OR AB husserl*
S64	TI giorgi* OR AB giorgi*
S65	TI foucault* OR AB foucault*
S66	TI (corbin* n1 strauss*) OR AB (corbin* n1 strauss*)
S67	TI (strauss* n1 corbin*) OR AB (strauss* n1 corbin*)
S68	TI (glaser* n1 strauss*) OR AB (glaser* n1 strauss*)
S69	TI glaser* OR AB glaser*
S70	S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S64 OR S65 OR S66 OR S67 OR S68 OR S69

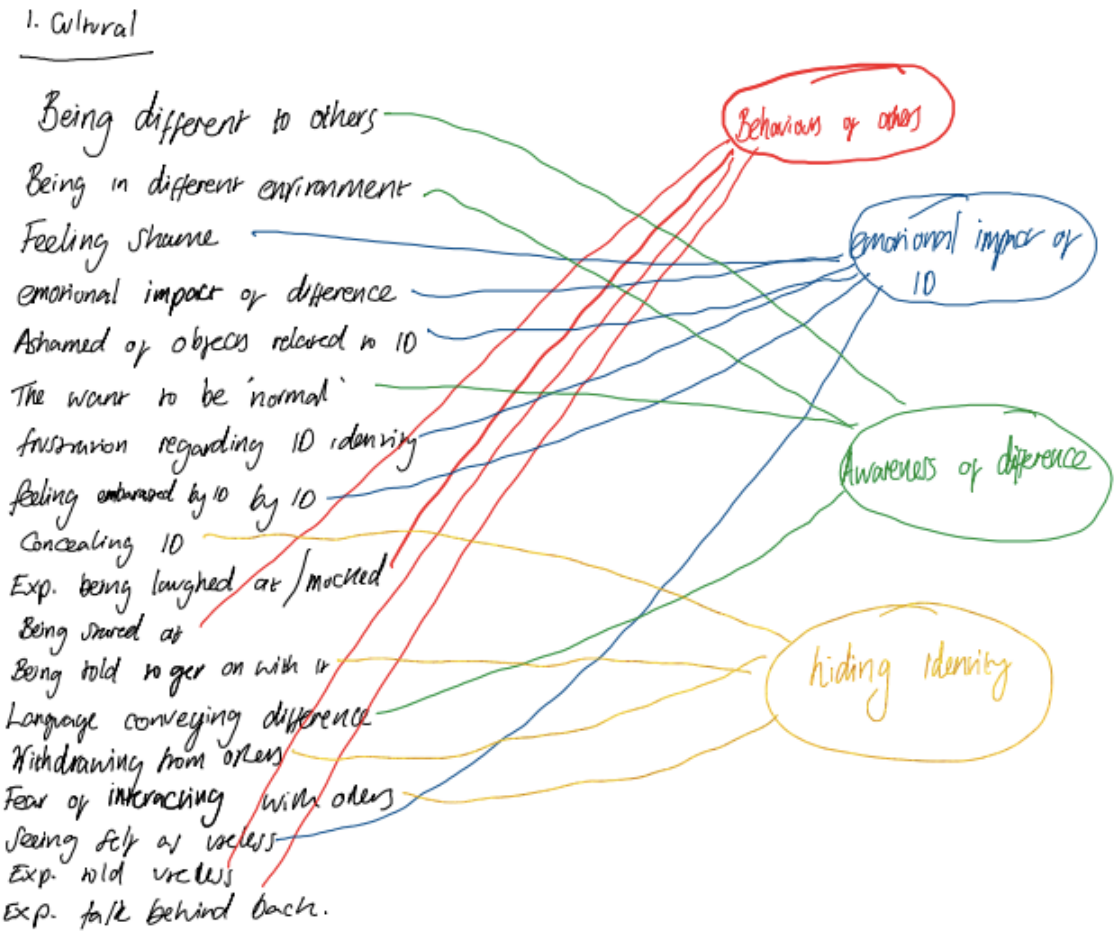
S71	TX findings
S72	(MH "Interviews+")
S73	TX interview*
S74	TX qualitative
S75	S71 OR S72 OR S73 OR S74
S76	S21 OR S70 OR S75
S77	(MH "Intellectual Disability+")
S78	TX (intellectual* n3 disab*)
S79	TX (intellectual* n3 impair*)
S80	TX (learning n3 disab*)
S81	TX (learning n3 difficult*)
S82	TX (cognit* n3 disab*)
S83	TX (mental* retard*)
S84	TX (mental* n3 disab*)
S85	TX (mental* n3 impair*)
S86	TX (mental* n3 deficie*)
S87	TX idiocy
S88	TX "fragile-x"
S89	TX "prader-willi"
S90	TX "down# syndrome"
S91	S77 OR S78 OR S79 OR S80 OR S81 OR S82 OR S83 OR S84 OR S85 OR S86 OR S87 OR S88 OR S89 OR S90
S92	(MH "Stereotyping")
S93	(MH "Social Perception")
S94	(MH "Public Opinion")
S95	(MH "Prejudice")
S96	(MH "Attitude")
S97	(MH "Stigma")
S98	TX ((public* or community or social or popular) n1 attitude*)
S99	TX (((negative or positive or change) n3 attitude*) or prejudice* or hostil* or intoleran* or marginalis*)
S100	(MH "Self Concept")
S101	TX "self-esteem"

S102	TX ((perception or identit* or view*) n2 self)
S103	TX stigma*
S104	S92 OR S93 OR S94 OR S95 OR S96 OR S97 OR S98 OR S99 OR S100 OR S101 OR S102 OR S103
S105	S76 AND S91 AND S104
S106	S76 AND S91 AND S104
S107	S76 AND S91 AND S104

Appendix 1.3: CASP checklist

https://casp-uk.net/casp-tools-checklists/qualitative-studies-checklist/

Appendix 1.4: Development of descriptive themes



2. General

Favourable comparisons to others – being more negative about others.	Others telling them they are incapable.
Aligning self with "normal"	Experience of being called names
Highlighting their abilities	feeling upset about others' perceptions of them
Negative comparisons to others – intellect.	Feeling othered and less powerful
Experience of others taking the mick	Not having a voice or being listened to
Experience of being told waste of space	Feeling shame about their identity
Not wanting others to find out about ID	Identity being visible to others
Feeling shame in relation to ID diagnosis	Wanting to conceal identity
Anger as a response to ID identity	Physical environment indicating ID identity and this would result in stigma
Acting in a way that rejected ID identity	Trying to distance self from physical environment and associated identity
Not wanting to be labelled	Not being able to do what they want, being treated as a child
Wanting ID to be seen as equals to others	Rejecting the label of being a child
Assumptions that people with ID are not capable	Experience of being considered stupid by others.
Perception that people with ID dont have opinions	A wish to be accepted by other people that dont have disabilities
Experience of being told they are useless	Experience of being excluded
Shrugging off experiences of stigma – to appear unbothered by it/resilient.	Experiecne of being discriminated for ID
Building up armour of resilience to stigma experiences happens as you age.	Wanting to be seen as equal, a person in their own right
Awareness of difference to other people	Describing self as more able than people think
Perception that others will see her as stupid	Experience of others assuming they are not able to read write etc.
Being excluded from work activity and environments, this causing distress	Not feeling important or listened to
Frustration regarding difference to others and intellectul ability.	Others having control over what they do, becoming involved in their lives
	Distancing self from others with ID

Being told not odd - power/agency/exclusion

Promoting self in positive light

Distancing self from label, others & environment

Awareness of ID and how others respond

Dealing with stigma

Experiences of being mocked/discriminated ~~as being stupid~~ or incapable

3. specific settings

Being told they arent capable	Acquiescing to professionals.
Doing things to show they are capable and prove others wrong	Experience of being treated differently compared to others by staff
Hiding disability in order to be treated normally	Experience of being excluded from spaces and knowledge
Experience of being treated differently when others are aware of disability	Being treated like a 'disabled person'
Role environment being seen as useful/good	Not being spoken to by professionals
Favourable social comparisons to 'regular' co-workers, ability to produce same work.	Information not being shared by professionals to people with LD
Distancing self from sheltered workshops and individuals there with ID.	People not taking time to explain things
Noticing difference from 'ordinary' company.	Awareness of difference 'people like me'
Having a problem working with other people with ID 'got on nerves'. Despite recognising they had a disability themselves.	Having to prove they are good enough parents to professionals
Using the word 'very mild' to create distance from others with more 'severe' disabilities	others having low expectations of them as parents
Awareness of not being classed as normal.	Others not being pleased with the fact they are parents
Experience of being discriminated against, staff thinking they are stupid	Feeling judged by professionals in parenting skills/ability
Not being involved or spoken to Being treated like they dont exist	Being told they are not going to do well when young
Feeling invisible	People with LD not speaking up, being frightened to
Being excluded from decision making	Stating they are as good as anyone else
Feeling pressured to make decisions with little time to understand or think.	Not listening to negative others
Advocating for speaking up to ask for help	Asking family and friends for help and guidance

Being negatively judged by others regarding their abilities

Being excluded from discussions and decision-making – feeling invisible

Awareness of difference and receiving different treatment due to ID.

distancing self from ID identity

Proving themselves to others

Role or environment as protective

Subset of Articles and References	Descriptive Themes	Contributing codes
South and Southeastern Asia Chen & Shu (2012) Handoyo et al. (2022)	• Experiencing discriminatory behaviour from others. • The ID label is something that individuals feel shame and frustration about. • Awareness of difference to others and the want to be 'normal', conveyed by use of language and environment. • Concealing ID identity and withdrawing from others.	• Being different to other people • Being in a different environment to others • Feeling shame • Emotional impact of being different • Ashamed of physical indicators of ID • The want to be 'normal' • Frustration regarding ID identity • Feeling embarrassed by ID • Concealing ID • Experience of being laughed at/mocked by others • Being stared at • Being told to persevere with regards to difference • Use of language conveying difference • Withdrawing from others • Fear of interacting with others • Seeing self as useless • Experience of being told they are useless • Experience of people talking behind their back
Northwestern Europe Monteleone & Forrester-Jones (2017) Kenyon et al. (2013) Jahoda et al. (2010) Jahoda & Markova (2004) Groves et al. (2018)	• Experiences of being mocked and discriminated against. • Others seeing people with ID as stupid and incapable. • Individuals with ID are aware of ID identity. This results in shame, frustration, and worry about what others think of them. • Being excluded from social life by not being listened to and not having agency.	• Favourable comparisons to others – being more negative about others. • Aligning self with 'normal' • Highlighting their abilities • Negative comparisons to others – intellect. • Experience of others taking the mick • Experience of being told waste of space • Not wanting others to find out about ID • Feeling shame in relation to ID diagnosis • Anger as a response to ID identity

- People with ID present themselves as being able and wanting to be seen as 'normal'.
- Rejecting the ID label by distancing themselves from environments and individuals associated with ID label.
- Expecting and accepting stigma but responding with resilience.

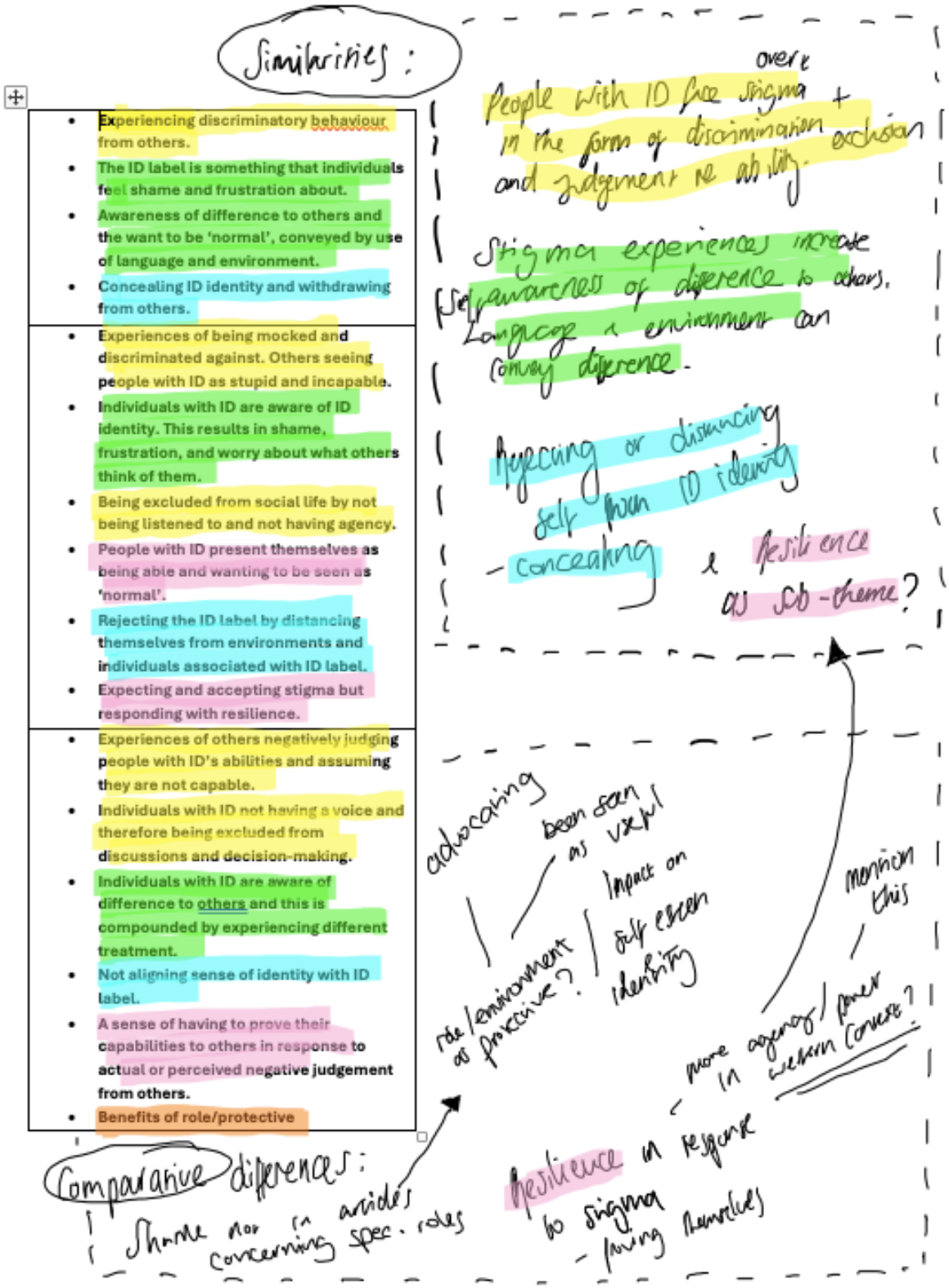
- Acting in a way that rejected ID identity
- Not wanting to be labelled
- Wanting ID to be seen as equals to others
- Assumptions that people with ID are not capable
- Perception that people with ID dont have opinions
- Experience of being told they are useless
- Shrugging off experiences of stigma – to appear unbothered by it/resilient.
- Building up armour of resilience to stigma experiences happens as you age.
- Awareness of difference to other people
- Perception that others will see her as stupid
- Being excluded from work activity and environments, this causing distress
- Frustration regarding difference to others and intellectual ability.
- Others telling them they are incapable.
- Experience of being called names
- feeling upset about others' perceptions of them
- Feeling othered and less powerful
- Not having a voice or being listened to
- Feeling shame about their identity
- Identity being visible to others
- Wanting to conceal identity
- Physical environment indicating ID identity and this would result in stigma
- Trying to distance self from physical environment and associated identity

		• Net being able to do what they want, being treated as a child • Rejecting the label of being a child • Experience of being considered stupid by others. • A wish to be accepted by other people that don't have disabilities • Experience of being excluded • Experience of being discriminated for ID • Wanting to be seen as equal, a person in their own right • Describing self as more able than people think • Experience of others assuming they are not able to read write etc. • Not feeling important or listened to • Others having control over what they do, becoming involved in their lives • Distancing self from others with ID
Articles from specific environments and roles Voermans et al. (2020) Malouf et al. (2017) Franklin et al., (2022)	• Experiences of others negatively judging people with ID's abilities and assuming they are not capable. • Individuals with ID not having a voice and therefore being excluded from discussions and decision-making. • Individuals with ID are aware of difference to others and this is compounded by experiencing different treatment. • Not aligning sense of identity with ID label.	• Being told they arent capable • Doing things to show they are capable and prove others wrong • Hiding disability in order to be treated normally • Experience of being treated differently when others are aware of disability • Finding it harder to meet people with little opportunities for activity. • Favourable social comparisons to 'regular' co-workers, ability to produce same work. • Distancing self from sheltered workshops and individuals there with ID. • Noticing difference from 'ordinary' company.

	• A sense of having to prove their capabilities to others in response to actual or perceived negative judgement from others • Protective roles	• Having a problem working with other people with ID 'got on nerves'. Despite recognising they had a disability themselves. • Using the word 'very mild' to create distance from others with more 'severe' disabilities • Awareness of not being classed as normal. • Experience of being discriminated against, staff thinking they are stupid • Not being involved or spoken to Being treated like they dont exist • Feeling invisible • Being excluded from decision making • Feeling pressured to make decisions with little time to understand or think. • Advocating for speaking up to ask for help • Acquiescing to professionals. • Experience of being treated differently compared to others by staff • Experience of being excluded from spaces and knowledge • Being treated like a 'disabled person' • Not being spoken to by professionals • Information not being shared by professionals to people with LD • People not taking time to explain things • Awareness of difference 'people like me' • Having to prove they are good enough parents to professionals • others having low expectations of them as parents • Others not being pleased with the fact they are parents • Feeling judged by professionals in parenting skills/ability

	• Being told they are not going to do well when young • People with LD not speaking up, being frightened to • Stating they are as good as anyone else • Not listening to negative others • Asking family and friends for help and guidance

Appendix 1.5: Development of analytical themes



Appendix 2.1: Reporting guideline STROBE Statement

	Item	Recommendation	Page no.
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	45, 48
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	48
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	49 – 51
Objectives	3	State specific objectives, including any prespecified hypotheses	51
Methods			
Study design	4	Present key elements of study design early in the paper	52
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	52
Participants	6	(*a*) *Cohort study*—Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up *Case-control study*—Give the eligibility criteria, and the sources and methods of case ascertainment and control selection. Give the rationale for the choice of cases and controls *Cross-sectional study*—Give the eligibility criteria, and the sources and methods of selection of participants	52
		(*b*) *Cohort study*—For matched studies, give matching criteria and number of exposed and unexposed *Case-control study*—For matched studies, give matching criteria and the number of controls per case	N/A
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	52 – 56
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	52 – 56
Bias	9	Describe any efforts to address potential sources of bias	55
Study size	10	Explain how the study size was arrived at	57
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	57 – 58
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	57 – 58
		(*b*) Describe any methods used to examine subgroups and interactions	N/A
		(*c*) Explain how missing data were addressed	58
		(*d*) *Cohort study*—If applicable, explain how loss to follow-up was addressed *Case-control study*—If applicable, explain how matching of cases and controls was addressed *Cross-sectional study*—If applicable, describe analytical methods taking account of sampling strategy	N/A

		(e) Describe any sensitivity analyses	

Continued on next page

Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	59
		(b) Give reasons for non-participation at each stage	N/A
		(c) Consider use of a flow diagram	N/A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	59 – 60
		(b) Indicate number of participants with missing data for each variable of interest	58
		(c) *Cohort study*—Summarise follow-up time (eg, average and total amount)	N/A
Outcome data	15*	*Cohort study*—Report numbers of outcome events or summary measures over time	N/A
		Case-control study—Report numbers in each exposure category, or summary measures of exposure	N/A
		Cross-sectional study—Report numbers of outcome events or summary measures	62
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	60 – 68
		(*b*) Report category boundaries when continuous variables were categorized	N/A
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	63 – 65
Discussion			
Key results	18	Summarise key results with reference to study objectives	69 – 72
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	70 – 71
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	69 – 72
Generalisability	21	Discuss the generalisability (external validity) of the study results	70, 72
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	N/A

*Give information separately for cases and controls in case-control studies and, if applicable, for exposed and unexposed groups in cohort and cross-sectional studies

Appendix 2.2: Final approved MRP proposal

https://osf.io/ea8ns

Appendix 2.3: Ethical approval letter

Ethical approval letter removed due to confidentiality issues.

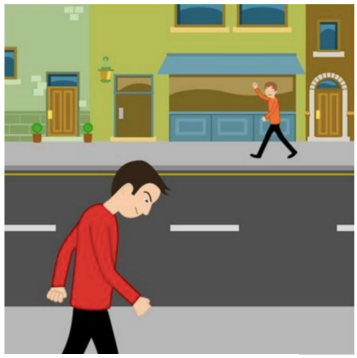
Appendix 2.4: Study documentation

Participant information sheet: https://osf.io/m86fw

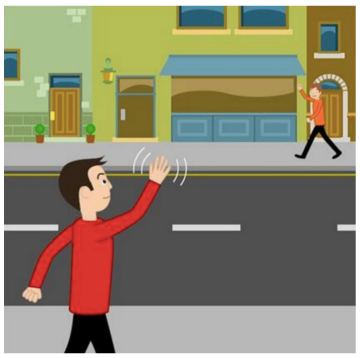
Consent form: https://osf.io/wcfj7

Privacy notice: https://osf.io/m4jx7

Appendix 2.5: Complete set of pictures used in the attribution task



Unfriendly



Friendly

Struggling

Clever

Sad

Happy

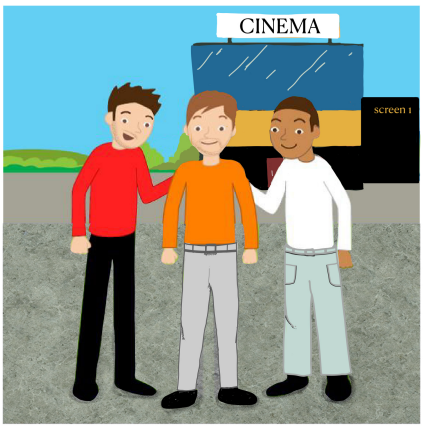
Lonely

Has lots of friends

Needs help to do things

Can do things alone

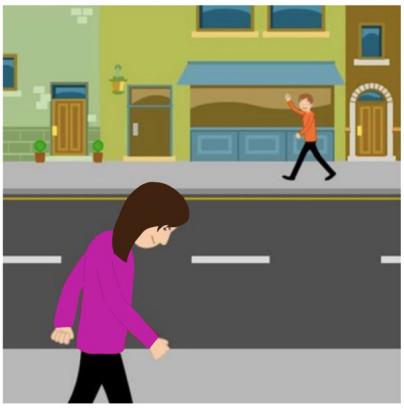
Gets called names



Doesn't get called names

Bad

Good



Unfriendly

Friendly

Struggling

Clever

Sad

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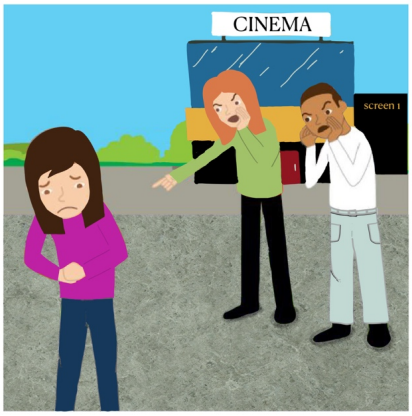
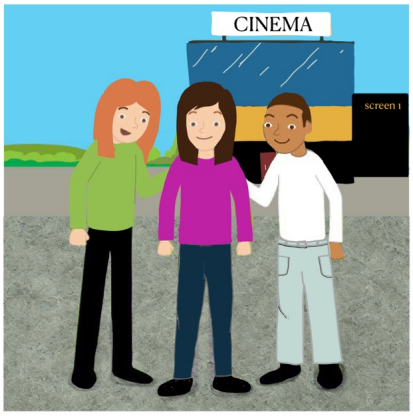


Gets called names



Doesn't get called names

Bad

Good

Appendix 2.6: Vignette for supportive-other and unknown-other

Supportive other:

I would like you to choose someone. It can be anyone you like and get on well with.

Who did you choose? Can you tell me a wee bit about them?

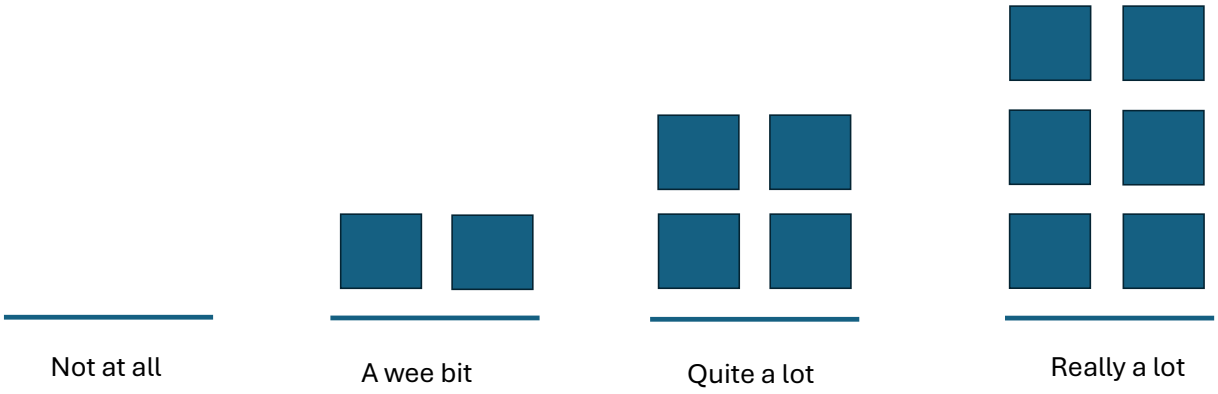
What would this person [name] say about you?

Unknown other:

I want you to imagine you are out for a walk in the town centre in the afternoon. You walk past a group of five teenagers who are being loud and laughing. They look at you as you pass but they don't say anything.

What do you think these people would say about you?

Appendix 2.7: Visual for importance ratings



Appendix 2.8: Sentence stems from sentence completion task

My favourite television programme to watch is…
The flavour of crisps I don't like the most is…
The thing I like most about myself is…
I don't like listening to … music
The thing I don't like about myself is…
I am most excited about doing…this week
The most upsetting thing someone has said about me is…
My favourite colour is…
The best thing someone has said about me is…
The animal I'm most scared of is…
The animal I think is the cutest/best is…

Appendix 2.9: Data analysis plan

https://osf.io/wmyc7

Appendix 2.10: Data analysis syntax

Attribute data: https://osf.io/h8jxc

Importance ratings: https://osf.io/kes6m

Analysis re-run (removing 5 participants with elevated depression scores):

https://osf.io/vf94w

Appendix 2.11: Data availability statement

As outlined in the data management plan (which can be found in Appendix 2.2), the study data was collected with the sole purpose of the current study and will be held by the research team. Third parties can contact the research team for information pertaining to the study data.