

# **How do people with intellectual disabilities construct their social identity? A review**

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## Abstract

**Background:** A 2005 review by Beart, Hardy and Buchan, asking how people with intellectual disabilities view their social identities, has been widely cited, indicating this important topic needs an updated review. This review covers research on how people with intellectual disabilities view their ascribed label; to what extent they ascribe it to themselves; and whether they recognise it as devalued in society.

**Method:** Rapid review methodology using PsycINFO, citation- and hand-searching identified relevant studies.

**Results:** The 16 studies identified indicate that the majority are aware of their ascribed label, or acknowledge they are 'different'. Others reject it, focusing on alternative attributes or roles. Most recognise others view the label negatively and express feelings of shame, anger and powerlessness.

**Conclusions:** The review advances our understanding of social identity formation in people with intellectual disabilities, with implications for future research and practice to support construction of positive social identities and stigma resistance.

## 1. Introduction

While we have witnessed positive shifts in attitudes towards people with disabilities over recent decades, the label of ‘intellectual disability’ continues to be a dominant and stigmatising one. Labelling theory (Becker, 1963; Link & Phelan, 1999) suggests that humans manage the world around them through categorisation and by applying labels to themselves and to individuals or groups around them. These labels can acquire negative valence where the labelled group is considered deviant from cultural norms. The labels, due to their stigmatising nature, can negatively influence individuals’ self-identity and behaviour. As such, labelling has been criticised for instigating and maintaining stigma and activists with intellectual disabilities have called to “label jars, not people”.

Social identity theory (Tajfel & Turner, 1979) focuses on the notion that group membership and identification with one’s in-group can shape a person’s sense of self through comparisons with out-groups. Thus, belonging to a stigmatised group has implications, likely negative ones, for how individuals feel about themselves. This can lead to rejection or denial of group membership in order to save face or avoid prejudice as discussed by Finlay and Lyons (2005), or alternatively, some individuals may try to raise their self-esteem through engaging in collective action to bring about social change (Anderson & Bigby, 2017) – this would however require individuals to accept the label. Branscombe, Schmitt, and Harvey (1999) suggest that experiencing a sense of belonging in a stigmatised group can buffer against negative experiences such as prejudice and discrimination, through social support.

The question of how people with intellectual disabilities should deal with their intellectual disability and the devalued status in society associated with this label has been the focus of debate for several decades. Social role valorisation (Wolfensberger, 1983) proposed that by adopting socially valued roles, people with intellectual disabilities would be able to

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‘pass’ and thus escape their deviant status. These ideas were highly influential in the intellectual disability field but much criticised by some for apparently failing to challenge the status quo, and implicitly accepting the lower value assigned to anyone with an intellectual disability (e.g., Szivos & Griffiths, 1990). In response, Szivos and Griffiths (1990) proposed that the answer for dealing with a stigmatised identity is not to attempt to ‘pass’ but rather to enable those affected to examine the meaning of the disability and to ‘own’ it through a process of increasing self-acceptance. They also noted that dealing with a stigmatised identity by trying to assimilate into mainstream society can have potential negative consequences, not least derogation of members own group and concomitant social isolation. However, the suggestion of consciousness raising as a positive paradigm was rejected, for example, by Emerson (1990) who questioned the merits of boosting individuals’ sense of self by focusing on their membership of a group defined by impairment, and suggested instead we should focus on the multiple roles and identities people with intellectual disabilities have, or should have, access to. Adopting an understanding of identity as socially constructed and fluid rather than fixed (Gergen, 1977) and moving away from group-based definitions of self can go some way to avoid the somewhat black and white tone of some such debates. This is in line with systemic ideas regarding human behaviour being embedded within relational contexts (Bateson, 1972). Accordingly, individuals are described to have a relational sense of self; for example, someone may view themselves as having an intellectual disability in some contexts, while in others this label purporting membership of a group of people with intellectual disabilities may seem irrelevant.

Nonetheless, whether a person deemed by others to have an intellectual disability views themselves as having an intellectual disability, at least in some contexts and at some times, has implications, for example, for engagement with initiatives and support services targeting this population, including efforts to engage them in self-advocacy. If one does not

identify with the intellectual disability label, one may well regard such initiatives as of little or no personal relevance and reject all support associated with the label, which may have benefits but also negative consequences. Furthermore, the centrality (or lack thereof) of intellectual disability to one's social identity is likely to affect how one makes sense of others' negative reactions. For example, one may view them as a sign of disablism and respond with righteous anger, or alternatively one may feel personally rejected and attribute this either to others' negative traits or states (e.g., 'they are not nice' or 'they are drunk') or to other aspects of one's own social identity (e.g., ethnic minority status). Self-reported stigma associated with having an intellectual disability has been found to be positively associated with psychological distress and negatively with quality of life (Ali, King, Strydom & Hassiotis, 2015). It stands to reason that a prerequisite for relating hostility and prejudicial actions to one's intellectual disability is that one views oneself as having such a disability, and/or an awareness that others view one in this vein.

Beart, Hardy, and Buchan (2005) reviewed research that attempted to answer the question of how people with intellectual disabilities construct their social identity, and centrally how, or rather whether, they view 'intellectual disability' as part of their identity. Their much cited review concluded that many people with intellectual disabilities seem unaware of their 'intellectual disability' status or do not see it as applicable to them. They put forward various explanations for this, including a wish to distance oneself from belonging to a stigmatised group, or the use of denial as a defence mechanism.

### ***1.3. This review***

Given that Beart et al.'s (2005) review has been widely cited (114 citations in Google Scholar as of August 2017) and that its conclusions have important implications, we felt it

timely to review empirical work on this topic published over the intervening years. Our review set out to answer the following questions:

- 1) To what extent are people with intellectual disabilities aware that they have an intellectual disability?
- 2) How do they feel about the ‘intellectual disability’ label ascribed to them?
- 3) Are they aware that others view the label negatively?

## **2. Method**

### ***2.1. Search strategy***

Rapid review methodology (Ganann, Ciliska, & Thomas, 2010) was used to identify literature via three main sources: the PsycINFO database, a citation search for Beart et al.’s (2005) review article, and hand-searching of reference lists of studies identified for inclusion in this review. PsycINFO was chosen as it has the most comprehensive coverage of attitudinal research, and was searched in August 2017 using the following search terms: intellectual disab\* or learning disab\* or developmental disab\* or mental disab\* or mental retard\* or Down Syndrome or intellectually disabled. This was combined with the following search terms:

- 1) (aware\* or self-aware\* or know\* or accept\*) and identity;
- 2) (feel\* or view\* or \*perception or perceive\* or experience\* or identity\*);
- 3) (aware\* or knowledge\* or acknowledge\* or conscious\*) and (stigma\* or label\*) and (attitude\* or opinion\*)

Studies were included in the review if they were published in English in a peer-reviewed journal since 2004, but not included in Beart et al.’s (2005) review, to account for time lag in publications. Articles were included if they reported relevant original empirical work, regardless of methodology. Articles that were concerned with the impact of

involvement in self-advocacy or participatory research (e.g., Beart et al., 2004; Tilly, 2015), even though relevant to our focus, were excluded from this review.

### **2.2. Review process**

The database searches produced 483 articles. These were assessed for eligibility on the basis of the title, where indicated abstract, and full-text. Only five articles identified through the PsycINFO searches met the inclusion criteria. An additional six articles were identified via a citation search for Beart et al. (2005). A search of the reference lists of all 11 articles thus identified yielded a further five relevant studies. The process of selecting studies for inclusion in the review and reasons for excluding studies is presented in Figure 1.

## **3. Results**

In total, 16 articles reporting on 16 separate studies were included in the present review. A summary of these studies is provided in Table 1.

### **3.1. Overview of studies**

The 16 studies identified were carried out in six different countries: most in the UK ( $n=11$ ), and one each in the USA, South Africa, Australia, Norway, and Taiwan. Twelve studies employed qualitative methods, which included semi-structured interviews ( $n=9$ ), photo voice and conversational interviews ( $n=1$ ), focus groups ( $n=1$ ), and participant observations ( $n=1$ ). Three studies employed quantitative methods, which involved self-report measures. One study employed a mixed methods design, using both interviews and questionnaires.

The sample sizes of the sixteen studies ranged from 2 to 229 participants. The total number of participants from all of the studies was 784, which included adults ( $n=581$ ), young people aged between 15 and 22 years ( $n=102$ ), and children aged between 10 and 14 years ( $n=101$ ). Participants were recruited from various different settings including community

services, agencies, day centres, schools, special educational programmes, self-advocacy groups, community housing and hospitals.

-Insert Table 1 here-

### **3.2. Main findings**

The main findings of the studies are summarised below in relation to the three questions guiding this review. While we have attempted to answer the review questions separately, many of the studies answered these questions simultaneously.

#### **3.2.1. *Are people with intellectual disability aware that they have an intellectual disability?***

Across the studies identified, most people with intellectual disabilities appeared aware of their diagnosis, or acknowledged that they were in some way ‘different’. This awareness was sometimes the result of receiving a formal diagnosis from a professional, and/or receiving support from or attending intellectual disability or other specialist services (e.g., Chen & Shu, 2012; Corr, McEvoy, & Keenan, 2014). Awareness was often present from a young age (i.e. primary school years) but appeared to increase as individuals got older and learned to negotiate their intellectual disability label (Kenyon et al., 2013; Norwich & Kelly, 2004).

The level of individuals’ awareness of their disability differed across studies, with some suggesting a high proportion of individuals were aware that they had an intellectual disability (e.g., over 90% of participants in Norwich and Kelly’s 2004 study). Other studies concluded that people with intellectual disabilities had little awareness of their intellectual disability, or were uncertain or confused (e.g., believing that they “sometimes” have disability). A few studies suggested people appeared to have no awareness, e.g., rejecting the label altogether as of no personal relevance (Corr McEvoy & Keenan, 2014; Finlay & Lyons, 2005). These different responses suggest that whilst many may be aware that they have an



intellectual disability (i.e. having been given a diagnosis or the label was ascribed in other ways), they may consciously or unconsciously reject the label, or may struggle to understand the concept and its implications. This is demonstrated by a marked lack of articulation and clarity in studies where individuals were asked to describe what an intellectual disability is, what it means to have this label, and whether it applies to them (Corr McEvoy & Keenan, 2014; Finlay & Lyons, 2005; Jones, 2012; Monteleone & Forrester-Jones, 2016).

Further to this, despite most people being aware of their intellectual disability (irrespective of the actual level of awareness and understanding), the results from many of the studies suggest that it may not be considered an important part of their identity. Instead, they often focus on other attributes, roles, and competencies when describing themselves, and rarely refer to their intellectual disability in self-presentations (e.g., Davidson et al., 2014; Dorozenko et al., 2015; Kittelsaa, 2014). Finlay and Lyons (2005) found that when individuals with intellectual disabilities were asked to describe themselves (but were not asked specifically about their intellectual disability) in an interview, only four out of 36 participants used the label (or a synonym) when referring to themselves. Even when specifically asked about their intellectual disability (in follow up interviews a year later), only 13 interviewees applied this label to themselves, whereas 13 others rejected it. As such, the literature suggests that regardless of the level of awareness of carrying the label, many do not see their intellectual disability as an important or meaningful part of their identity. This has implications for social interactions with others whose central focus may well be the intellectual disability.

### ***3.2.2. How do they feel about the intellectual disability label ascribed to them?***

The majority of the studies suggest that people with intellectual disabilities feel negatively about the intellectual disability label ascribed to them. Feelings such as shame,

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embarrassment and dejection were commonly reported, with individuals showing obvious discomfort when discussing this topic (e.g., Monteleone & Forrester-Jones, 2016). People associated the label with inability and demonstrated a reluctance to reveal their intellectual disability to others (e.g., Corr McEvoy & Keenan, 2014; Kenyon et al., 2013; Chen & Shu, 2012; Jones, 2012). The label was also associated with feelings of anger, powerlessness and frustration (e.g., Jahoda et al., 2010; Jahoda & Markova, 2004; Norwich & Kelly, 2004).and conflict between accepting and rejecting this label was observed (Jahoda et al., 2010). In line with this, the results suggest that individuals felt that the label had a negative effect on many aspects of their lives, as it made them feel isolated and different to other people, restricted them from having relationships with others, limited their independence and decision-making, and increased the likelihood of being a target for insults (Corr McEvoy & Keenan, 2014; Finlay & Lyons, 2005; Jahoda et al., 2010; Kenyon et al., 2013). As such, some felt that it was unhelpful to label themselves and other people with intellectual disabilities (Kenyon et al., 2013).

These negative feelings about the intellectual disability label in turn increased feelings of unhappiness and discontent, which led some individuals to dissociate or distance themselves from the label. This was achieved through seeking to create a new identity for themselves (e.g., Jahoda et al., 2010; Jahoda & Makrova, 2004), resisting any inference that they have an intellectual disability (e.g., ascribing deficit to others and claiming 'normal' attributes for themselves; McVittie et al., 2008), rarely using the label in reference to themselves, or even rejecting it completely (Finlay & Lyons, 2005).

However, it is also important to note that not all people with intellectual disabilities felt negatively about the label they had been given. For example, Norwich & Kelly (2004) found that whilst the majority of participants felt sad, hurt, upset or frustrated about having an intellectual disability, 23% expressed neutral feelings (i.e., no concerns were reported related

to it). Furthermore, the label was sometimes viewed in a positive light; it can allow individuals with intellectual disabilities to have access to support and resources that are contingent on this label (Chen & Shu, 2012; Corr McEvoy & Keenan, 2014). However, the focus of the studies identified in this review was rarely on positive perceptions or implications of the label. This is important as the stance of these studies by their very nature may be seen as focusing on intellectual disabilities as problematic.

### ***3.2.3. Are individuals with intellectual disabilities aware that others view this label negatively?***

The findings from the identified studies suggest that many people with intellectual disabilities are aware that others view this label negatively. This awareness is often the result of negative treatment and interactions they have experienced, for example, people laughing at them, subjecting them to insults, treating them differently, ignoring or rejecting them (Ali et al., 2016; Ali et al., 2015; Corr McEvoy & Keenan, 2014; Chen & Shu, 2012; Finlay & Lyons, 2005; Jahoda & Markova, 2004; Monteleone & Forrester-Jones, 2016; Norwich & Kelly, 2004). Kenyon et al. (2013) found that many participants expected the ‘mainstream world’ to treat them poorly and unfairly due to previous experiences.

This awareness of others’ negative views appears to be present from a young age; children and young people aged 15-17 from both mainstream and special schools showed awareness of the stigma attached to their intellectual disability label within society (Cooney et al., 2006). Additionally, those attending a mainstream school reported stigmatising treatment (e.g., rejection and ridicule from others) at school, as well as by society in general, particularly from their non-disabled peers. Interestingly, Ali et al. (2016) found age and severity of intellectual disabilities to be associated with self-reported stigma. Older participants and those with moderate intellectual disabilities (compared to participants who

were younger or had mild intellectual disabilities) reported more negative experiences and discrimination, such as being mocked or treated differently.

Further evidence that many people with intellectual disabilities are aware that this label is viewed negatively comes from other sources, including aforementioned findings that many want to dissociate themselves from the label and create a new and separate identity for themselves (e.g., Jahoda et al., 2010; Jahoda & Markova, 2004). It is also evident in findings that many resist any inference that might lead them being labelled as having an intellectual disability (e.g., ascribing deficits to others whilst claiming 'normal' attributes for themselves; McVittie et al., 2008), rarely identify with or use the label in reference to themselves (e.g., Kittelsaa, 2014), or reject it altogether (e.g., Finlay & Lyons, 2005). Research also suggests that people with intellectual disabilities often engage in downward social comparisons to distance themselves from others who have an intellectual disability and to present themselves in a better light (e.g., Jahoda & Markova, 2004; Monteleone & Forrester-Jones, 2016). Taken together these findings suggest that they are aware of the negative connotations and stigma attached to the label.

In addition to these results, evidence cited above that many people with intellectual disabilities feel ashamed and embarrassed about their ascribed label, are reluctant to reveal their identity to others, and often experience tension and/or conflict in accepting that they may need support due to their disability, adds to the idea that they understand that the intellectual disability is viewed negatively within society.

### ***3.3. Limitations of the studies***

One significant limitation of the studies included in this review concerns their sample sizes. Five of the 16 studies had less than 10 participants, limiting the generalisability of the findings. For example, Jahoda et al. (2010) examined data from two case studies. Whilst case

studies can offer in-depth insights, caution must be exercised when interpreting their findings. However, some studies had much larger sample sizes (e.g., 229 participants; Ali et al., 2016).

The use of opportunity sampling in the majority of the studies is another limitation. Many participants were recruited through day centres or the equivalent and self-advocacy groups, and as such, the results may not be generalisable beyond these particular samples. Findings from studies that involved members of self-advocacy groups (e.g., Dorozenko et al., 2015; Kenyon et al., 2013), for example, may give an overly positive picture as such participants are more likely to be aware of and to feel more positively about their intellectual disability label, having been part of a group that advocates for greater equality.

Caution should also be exercised in generalising the findings of Chen and Shu's (2012) study to cultural contexts that are dissimilar to Taiwan, the study's setting. Whilst many young people in their study were aware of their intellectual disability, the authors note that Taiwan has a strong emphasis on academic success, and as such, intellectual disability may be viewed more negatively than in cultures that place less pressure on academic success.

The definition of intellectual disability used across studies was often inconsistent and at least some studies included people with 'borderline' intellectual disabilities (e.g., Cooney et al., 2006). Furthermore, in some studies researchers inferred that participants believed themselves to be treated negatively because of their disability without explicitly asking this; for example, Ali et al. (2015; 2016) assessed responses to statements such as "people look at me funny..." without checking whether participants felt others responded to them negatively *because* of their disability, which compromises the interpretation of the results.

It is also important to point out that 'double' stigma may have been present in some studies. Many participants may have also experienced stigma for additional reasons, for example, emotional/mental health problems (Jahoda et al., 2010), other disabilities or

conditions (e.g., Jones, 2012), or perhaps due to racism (e.g., Ali et al., 2015). Thus, caution should be exercised when interpreting the results purely in terms of carrying an intellectual disability label. Furthermore, the lack of longitudinal studies in this review is a prominent limitation; the static results reflect awareness and feelings about individuals' intellectual disabilities and the label at one point in time, rather than capturing views across different time points and thus are limited in what they tell us about the process of identity development.

### **4. Discussion**

The results from the 16 studies included in this review indicate that most people with intellectual disabilities appear aware of the intellectual label ascribed to them, or that they view themselves as in some way 'different'. Some clearly reject any such suggestion though. Of note, they commonly present their intellectual disability to researchers as of little relevance to their self-image and instead focus on other attributes, roles, or characteristics when describing themselves, suggesting that intellectual disability is not a central or dominant aspect of their identity. This finding is in line with identity process theory (Jaspal & Breakwell, 2014), which suggests that we all have a 'constellation of identities' and go through a process of assimilation/accommodation and evaluation in forming our identities. The theory also proposes that a threatened identity may result in the use of coping mechanisms to manage threat, in line with the finding that some individuals distance themselves from the label.

Most studies in the current review concluded that people with intellectual disabilities feel negatively about their ascribed label, and experience shame, discomfort, but also anger, powerlessness and frustration when discussing the label. However, this was not the case for all. Beyond the reasons cited in the literature for neutral or positive views of the label, such as entitlement to use specialist services and access to scarce resources, giving positive meaning to the label is also central to the self-advocacy movement and collective action by people

with intellectual disabilities (Anderson & Bigby, 2017). The integrated social identity model of stress (Haslam, 2004) postulates that social groupings can foster a sense of belonging in a stigmatised group, which can buffer against negative experiences such as prejudice and discrimination (see also Branscombe et al., 1999). Crabtree, Mandy and Mustard (2016) draw similar conclusions, suggesting this involves complex mechanisms for people with intellectual disabilities which operate through in-group comparisons with those who are less able, moderating the value placed on various attributes salient in providing an alternative self-evaluation and a shared group identity with which to reject stigma.

Finally, most people with intellectual disabilities seem well aware that others view the intellectual disability label negatively, often as a direct result of negative social interactions they have experienced across their life course. This emphasises the important role the social sphere has in the construction of social identity for people with intellectual disabilities (Crabtree, Mandy, & Mustard, 2016; Rapley, 2004) and provides evidence for developmental systems theory models which emphasise that individuals are both a product and a producer in the development of their social identity through the bidirectional relationship between the individual and the environment or context (Bronfenbrenner, 2005). What needs to be considered next is how this model might inform effective interventions to enable the construction of positive social identities.

### ***4.2. Limitations of the Review***

Whilst this review has contributed to gaining an insight into how people with intellectual disabilities view the label they have been given, the limitations must be carefully considered before drawing strong conclusions from the results. Firstly, only the PsycINFO database was searched due to the rapid review methodology adopted. Therefore relevant papers published in journals not included in PsycINFO may have been missed. Secondly, we are limited to results yielded from the search terms and criteria utilised; for example we

included only research published in English. Thirdly, no formal appraisal of the quality of the research was conducted but the limitations of the studies have been outlined. Finally, we focus on how social identity is constructed relating to intellectual disability; thus, broader influences on social identity construction were not synthesised in the present review.

### ***4.3 Conclusions and Implications***

Whilst people with intellectual disabilities generally appear aware of the label ascribed to them, some distance themselves from the label or reject it altogether. Overall, having an intellectual disability mostly appears not to be a dominant feature of their identity, although it may be in others' eyes and therefore the most widely researched. Whilst many have described negative feelings associated with the label, ascribing the label to oneself can also have positive consequences, such as enabling access to support, resources, and liberation via self-advocacy.

The findings of this review have implications for both research and practice. There is a need for more robust evidence to inform interventions aimed at attitude change and stigma reduction. Future research should explore the role of group identification, social support and peer support in making people with intellectual disabilities more resilient to the negative consequences of stigma. Studies employing longitudinal designs would allow an understanding of identity development that goes beyond a snapshot at one point in time and a richer consideration of the many and varied factors that contribute to identity formation in people with intellectual disabilities.

In terms of practice, the early cultivation of advocacy, citizenship and rights approaches in educational programmes with young people with intellectual disabilities seems vital if young people are to be resilient in the face of stigma associated with their disabilities. Fostering empowerment, confidence and positive schemas during adolescence could help sow the seeds of not only a positive identity, but also higher aspirations. Clinically, an



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understanding of social identity formation may serve to improve and refine both the formulation of psychosocial difficulties and the selection of appropriate interventions, for example, narrative approaches may be highly appropriate in deconstructing dominant narratives and the power relations that underpin them and may be helpful in promoting a positive sense of self (Scior & Werner, 2016). Indications that people with intellectual disabilities can be buffered against the stress of a stigmatised identity through coming together as a group, emphasise the value of self-advocacy groups and suggest a need for more group-based interventions for people with intellectual disabilities.

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### **Conflict of Interest**

No conflict of interest has been declared.

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Table 1. *Overview of studies included in the review*

Study (Year) Location	Sample	N	Method	Key Findings
Ali, King, Strydom & Hassiotis (2016) UK	Adults with mild or moderate intellectual disabilities from community intellectual disability services	229	Self-report measure of perceived stigma (Ali, Strydom, Hassiotis, Williams, & King, 2008); information on physical disability and socio-demographic variables also collected using a structured form	<ul style="list-style-type: none"> <li>- More stigmatising experiences reported by older adults than young adults</li> <li>- More stigmatising experiences reported by: <ul style="list-style-type: none"> <li>- adults with moderate intellectual disabilities than with mild intellectual disabilities;</li> <li>- males with moderate intellectual disabilities than females with moderate intellectual disabilities;</li> <li>- older adults with moderate intellectual disabilities than young people with moderate intellectual disabilities</li> </ul> </li> <li>- No association found between physical disability and stigma</li> </ul>
Ali, Kock, Molteno, Mfiki, King & Strydom (2015) South Africa	Adults with mild to moderate intellectual disabilities from 3 ethnic backgrounds: Black African, Caucasian & Mixed	191	South African version of the Perceived Stigma of Intellectual Disability tool (Kock <i>et al.</i> , 2012)	<ul style="list-style-type: none"> <li>- No differences across the ethnicities in total stigma reported</li> <li>- Significant interaction between ethnicity and severity of intellectual disability: Black African participants with mild intellectual disabilities reported higher stigma level than those with moderate intellectual disabilities</li> <li>- Black African participants more likely to report being attacked and more likely to report being the same as other people than Caucasian and Mixed participants</li> </ul>
Chen & Shu (2012) Taiwan	Young people with mild to moderate intellectual disabilities (age range 17-22) from a special educational programme	14	Semi-structured interviews about experiences of stigma, views about stigmatizing treatments and responses to treatment.	<ul style="list-style-type: none"> <li>- Participants aware of 'intellectual disability' label and stigma from others, due to educational and social welfare systems</li> <li>- Reports of feeling ashamed, embarrassed, unhappy, different, ill or sick</li> <li>- Reports of engaging in avoidance and isolation to manage stigma</li> </ul>



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Study (Year) Location	Sample	N	Method	Results
Cooney, Jahoda, Gumley & Knott (2006) UK	Young people with mild-moderate intellectual disabilities (age range 15-17) from mainstream and special schools	60	Perceptions of stigma measured using the “Experience of Stigma Checklist” (developed for study); “Modified Life in School Checklist” (Arora, 1987)	<ul style="list-style-type: none"> <li>- Participants in both schools aware of stigma in wider society; those in mainstream school also experience stigma at school</li> <li>- No relationship found between social comparison and future aspirations, nor between future aspirations and stigma</li> </ul>
Corr McEvoy & Keenan (2014) UK	Adults with intellectual disabilities attending an agency	41	Seven focus groups about treatment and experiences in everyday life	<ul style="list-style-type: none"> <li>- Mixed responses to whether they have an intellectual disability: many knew they had a disability due to assessment results or because they access disability services, but were often unclear about what it means</li> <li>- Negative views of label: participants linked it to ‘inability’</li> <li>- Reports of feeling ashamed and being called names (with awareness of stigma) and reports of public treating them well</li> </ul>
Davidson, Smith & Burns (2014) UK	Adults with intellectual disabilities (age range 17-37) who have completed a cognitive assessment within last 6 months	5	Semi-structured interview about participant experience of completing a cognitive assessment and influence on identity	<ul style="list-style-type: none"> <li>- Even in context of IQ assessment (central to the label of intellectual disability), participants did not use the label in reference to themselves</li> <li>- Diagnosis of intellectual disability not thought to be a salient part of their cognitive assessment</li> </ul>
Dorozenko, Roberts & Bishop (2015) Australia	Adults from a self-advocacy group for people with intellectual disabilities (age range 20-25)	18	Photovoice & conversational interviewing	<ul style="list-style-type: none"> <li>- Most aware of their intellectual disability label and their membership of this stigmatised category, but not thought to be an important aspect of their identity</li> <li>- Participants often emphasised other identities/characteristics</li> </ul>
Finlay & Lyons (2005) UK	Adults with mild or moderate intellectual disabilities (age range 16-65)	36	Semi-structured, conversational interviews about themselves at T1 and about the label of intellectual disability at T2 (1 year later)	<ul style="list-style-type: none"> <li>- Only 4 adults used label to describe themselves; 13 accepted label as personally applicable 1 year later</li> <li>- Negative perceptions of label, awareness of stigma seen; many reluctant to use label in self-descriptions</li> <li>- Authors suggest rejection of label is due to lack of relevance to social identity rather than denial</li> </ul>

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Study (Year) Location	Sample	N	Method	Results
Jahoda & Markova (2004) UK	Adults with mild intellectual disabilities; 10 making transition from family home to live more independently; 18 moving from long-stay hospital to live in community housing	28	Semi-structured interviews about awareness and responses to stigma	<ul style="list-style-type: none"> <li>- Both groups aware of membership to a devalued social category and aware of discriminatory treatment and stigma associated with intellectual disabilities</li> <li>- Wanting to break away from stigmatised past: hospital group distanced themselves from the institution; housing group emphasised their achievement in leaving home</li> <li>- Some showed sense of powerless, frustration, anger</li> <li>- Both groups made downward social comparisons and had difficulties retaining positive views of self</li> </ul>
Jahoda, Wilson, Stalker & Cairney (2010). UK	Young people with mild to moderate intellectual disabilities, drawn from a larger ethnographic project	2	Case study: semi-structured interviews of individuals and family/careers; using disposable cameras and video camera	<ul style="list-style-type: none"> <li>- Themes identified about their own awareness of stigma, sense of emptiness and recognition seeking</li> </ul>
Jones (2012) USA	Adolescents with mild to moderate intellectual disabilities (mean age = 15.97)	21	Mixed methods: interviews on knowledge of self and disability, and measures of global self-worth and social acceptance	<ul style="list-style-type: none"> <li>- 55% aware of their intellectual disability, but lacked affirmative language when describing disability</li> <li>- Those who denied the label felt shame or embarrassment</li> <li>- Most felt excluded due to separate classrooms</li> </ul>
Norwich & Kelly (2004) UK	Children with intellectual disabilities from mainstream or special school (age ranges = 10-11 & 13-14)	101	Semi-structured interview about self-perceptions and evaluations of labels	<ul style="list-style-type: none"> <li>- Over 90% aware of their intellectual disability (no differences between special and mainstream school)</li> <li>- 44% expressed negative feelings about their intellectual disability; 23% were 'not bothered'; 33% had mixed feelings</li> <li>- Special school pupils had more positive views of own educational abilities than mainstream school pupils</li> <li>- 15% of pupils minimised or denied their intellectual disability: secondary school pupils more likely to than primary school pupils</li> <li>- Common labels (e.g., 'stupid') were negatively evaluated, particularly by secondary school pupils</li> </ul>

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Study (Year) Location	Sample	N	Method	Results
Kenyon, Beail & Jackson (2013) UK	Adults from self-advocacy group and day centres (mean age = 47, age range = 25-63)	8	Semi-structured interviews about individuals' experience of diagnosis	<ul style="list-style-type: none"> <li>- Three major themes emerged:               <ol style="list-style-type: none"> <li>1. Developing awareness of difference: all aware of intellectual disability label but this awareness grew as they got older. Reports of feeling miserable and shame.</li> <li>2. Relationship with non-disabled others: belief that they should not be labelled or set apart from others, and had expectations of poor treatment from the public</li> <li>3. Living with an impairment: belief that they have to learn to cope with their disability</li> </ol> </li> </ul>
Kittelsaa (2014) Norway	Young adults with mild intellectual disabilities (age range = 18-30)	7	Participant observation, field conversations and interviews about self-understanding and daily life experiences	<ul style="list-style-type: none"> <li>- No one identified intellectual disability as a primary aspect of identity: not included in self-presentations</li> <li>- Emphasised other identities in self-presentations</li> <li>- Understood intellectual disability is viewed negatively by others</li> </ul>
McVittie, Goodall & McKinlay (2008) UK	Individuals with intellectual disabilities from a local community centre	8	Semi-structured interviews about ascription of abilities and disabilities relative to others	<ul style="list-style-type: none"> <li>- Three main findings:               <ol style="list-style-type: none"> <li>1. Ascribing deficits to others: emphasised differences between themselves and others so as to normalise abilities</li> <li>2. Resisting comparisons of deficit: avoided conversations about intellectual disabilities</li> <li>3. Claiming 'normal' attributes: referred to experiences of people with intellectual disabilities but without reference to first-hand knowledge</li> </ol> </li> </ul>
Monteleone & Forrester-Jones (2016) UK	Adults with intellectual disabilities	15	Semi-structured interviews about disability, social interactions and self-esteem	<ul style="list-style-type: none"> <li>- Some identified themselves as having a disability</li> <li>- Feelings of difference experienced, despite lack of articulation</li> <li>- Some aware of stigma and others' negative views – they showed discomfort with topic of disability</li> <li>- Feelings of unfairness, blame and rejection expressed</li> </ul>