A measure of perceived stigma in people with intellectual disability

Afia Ali, Andre Strydom, Angela Hassiotis, Rachael Williams and Michael King

The British Journal of Psychiatry 2008 193: 410-415
Access the most recent version at doi:10.1192/bjp.bp.107.045823

Supplementary data
"Online supplement" http://bjp.rcpsych.org/cgi/content/full/193/5/410/DC1

Reprints/permissions
To obtain reprints or permission to reproduce material from this paper, please write to permissions@rcpsych.ac.uk

You can respond to this article at http://bjp.rcpsych.org/cgi/eletter-submit/193/5/410

Email alerting service
Receive free email alerts when new articles cite this article - sign up in the box at the top right corner of the article or click here

Downloaded from bjp.rcpsych.org on November 30, 2010
Published by The Royal College of Psychiatrists

To subscribe to The British Journal of Psychiatry go to: http://bjp.rcpsych.org/subscriptions/
Stigma is a ‘mark’ that distinguishes a person as being deviant, flawed, ‘spoiled’ or generally undesirable. A second approach defines stigma as a form of negative social stereotyping or categorisation, where societal attitudes based on social norms and values give rise to stigma.

Intellectual disability (or mental retardation) is defined as a significantly below-average level of intellectual functioning (IQ less than 70) with associated impairments in adaptive functioning (in at least two areas), arising before the age of 18 years. The UK Valuing People White Paper emphasises the need to improve the lives of people with intellectual disability (also known as learning disability in UK health services) through the promotion of rights, choices, independence and social inclusion, including access to mainstream services. However, despite these changes, people with intellectual disability continue to remain socially excluded and encounter stigma, prejudice and major barriers that restrict their human rights.

The stigma of intellectual disability is often neglected by health professionals and researchers. Qualitative research has shown that people with intellectual disability are aware of the stigma of their disability and its social consequences. Those who leave state hospitals or family homes to live in the community, or in independent housing, experience abuse and rejection from others in the community and become aware of the stigma associated with institutions such as hospitals or adult centres for people with intellectual disability. They attempt to hide their disability as a way of avoiding stigmatisation.

There is currently a lack of valid and reliable instruments measuring stigma in people with intellectual disability. Such an instrument would be useful in identifying the extent and severity of stigma encountered by service users with intellectual disability.

**Results**

The instrument was completed by 109 people once and 88 people twice. Items with limited variability in responses and kappa coefficients lower than 0.4 were dropped. Exploratory factor analysis revealed two factors: ‘perceived discrimination’ (seven items) and ‘reaction to discrimination’ (four items). One item loaded onto both factors. Cronbach’s alpha for the ten-item instrument was 0.84.

**Conclusions**

This instrument will further our understanding of the impact of stigma in people with intellectual disability in clinical and research settings.

**Declaration of interest**

None.

**Method**

A literature search was used to generate a list of statements. Professionals, individuals with intellectual disability and carers were consulted about the suitability of statements. An instrument was developed containing statements about stigma with accompanying photographs. Test–retest reliability, internal consistency and the factor structure of the instrument were evaluated.

**Development phase and generation of items**

Development work began with a literature search of the databases EMBASE, Medline and PsycINFO in order to identify validated instruments and questions assessing stigma in people with intellectual disability. Search terms included: stigma OR discrimination AND (learning disability OR mental retardation OR intellectual disability). Two published self-report instruments developed for use in school children and students were identified but both have limitations. The first contains ten items grouped under three categories: feeling different, anxiety and ‘poor in group concept’ (used to describe the low opinion that people with intellectual disability have of others with intellectual disability). The items were chosen on the basis of face validity and reflected feelings about being ‘different’, rather than just negative items.

The instrument had good internal consistency (Cronbach’s alpha=0.81) but test–retest reliability was not conducted by the authors. In a subsequent study, only two items were found to have adequate test–retest reliability. The wording of a number of items is also complex, making the items difficult to understand. The second published instrument is the Experience of Stigma Checklist containing 13 items: 8 items describing stigmatising treatment from key figures (parents, teachers, pupils) and 5 items describing non-threatening items. The internal consistency of the instrument was found to be low (Cronbach’s alpha=0.61) and test–retest reliability was not conducted. Both of these instruments were not developed through consultation with service users or carers, and therefore content validity is questionable. Items from these instruments were not considered suitable for our use owing to the aforementioned problems and our target group being those aged above 18 years.
Key publications on stigma were examined in order to derive new questions. Forty-seven statements were generated including simplified versions of 20 statements from an instrument that had recently been developed to measure the stigma of mental illness. 11

**Determining content validity**

In order to determine face and content validity of the questionnaire, we consulted a number of professionals in the field of intellectual disability, carers of people with intellectual disability and individuals with mild to moderate intellectual disability. As a first step, we led an open discussion about stigma at a meeting of psychiatrists, speech and language therapists, occupational therapists, nurses and psychologists, and asked for their views on the statements that had been generated from the literature search. The professionals were asked to rate the statements for comprehensibility, relevance and suitability; to make suggestions for further statements; and to give us their views on the most useful format for the instrument. We analysed the responses in order to arrive at a core set of statements, which were made into an accessible format using simple illustrations with the help of a speech and language therapist.

The statements were then piloted at a group meeting at a local day centre of people with intellectual disability who were recruited through an intellectual disability service. Four women and two men aged 25–55 with mild to moderate intellectual disability consented to participate. The 90-minute group was facilitated by A.A., an accessible information worker and a member of staff from the local day centre. Participants were asked whether they understood the statements, if they had ever perceived or experienced what was described in each statement and whether or not the illustration by each statement was appropriate and informative. We sought their views on possible response formats (‘yes/no’ answers vs. three- or five-point scales) and the size and style of the font used.

Three carers participated in a meeting at a day centre for people with intellectual disability in which they rated the coverage and relevance of the statements and whether or not the individual they cared for had ever had such experiences or feelings.

Based on this feedback the instrument was developed into a final set of 21 statements, each with an accompanying photo image to illustrate the theme of each statement and a response format of ‘yes’ or ‘no’, which was the preferred choice of the pilot group. The response ‘yes’ was represented pictorially with a ‘thumbs up’ and ‘no’ with a ‘thumbs down’ symbol (full questionnaire available on request from the authors). The instrument contained descriptions of experiences and feelings of stigma and included negative and positive statements to reduce response set bias. Each statement was displayed in size 14 font and the accompanying image was in colour. Cartoon images and symbols were avoided to ensure clarity. The final format was tested by three volunteers with mild intellectual disability who found the instrument easy to understand and therefore no further changes were made.

**Test–retest reliability**

Participants were recruited from a number of different settings including intellectual disability services, out-patient psychiatric clinics, in-patient wards, day centres, social clubs, educational facilities, voluntary organisations for people with intellectual disability (People First, Elfrida) and supported housing schemes. Each participant was asked to complete the instrument on two occasions between 2 and 6 weeks apart. This time period was chosen to balance the possibility that perceived stigma might change over time against the need to avoid recall of previous responses. Although the instrument is self-rated, assistance was provided to participants who had difficulty reading or understanding any of the words. In order to ascertain comprehension of the items, participants were asked to give examples of situations described in the items before selecting an appropriate response.

**Additional information**

We collected data on each participant’s age, gender, ethnicity, accommodation, attendance at day services and physical disabilities. In order to increase the sample size and to improve the external validity of the questionnaire, people with both intellectual disability and mental illness were also included.

**Analysis**

Total stigma scores were obtained for each participant, with higher scores indicating a greater perception of stigma. These were analysed to identify whether there were any differences in the perception of stigma between different socio-demographic and clinical variables. Using the first set of responses to the questionnaire, items with little variation in response (80% or more, selecting one answer or the other) were removed as these would differentiate poorly between people with differing experiences of stigma. The test–retest reliability of each item was estimated using the kappa coefficient. Items with coefficients less than 0.4 were removed. To explore the factor structure underlying the remaining statements, we undertook an exploratory dichotomous factor analysis (given each statement has a binary ‘yes/no’ response) in MPLus using tetrachoric correlations. We used weighted least squares with mean and variance adjustment as the estimation procedure for dichotomous data. We explored orthogonal and oblique rotations of the factors extracted in order to reduce over fitting of the final model. Internal consistency of the final scale (and sub-scales) and whether this improved with any single item removal was estimated using Cronbach’s alpha. The correlations of each statement with the total score and the average correlation with other items were analysed.

**Results**

**Response rates and demographic and clinical data**

A total of 125 people with intellectual disability were approached and 115 agreed to participate. Six individuals were considered unsuitable because they could not give adequate consent, had poor verbal comprehension or difficulties in communication. The remaining 109 (87%) participants completed the instrument once: 84 (77%) were able to do so with either no assistance or minimal assistance. The remainder, most of whom had moderate intellectual disability, required assistance in clarifying the questions. Thus, a total of 62 women and 47 men, with a mean age of 41 years (range 18–73, s.d.=13.6) participated. Ninety-four individuals had mild intellectual disability and 15 had moderate intellectual disability. Eighty individuals were White (Table 1). Forty people had mental illness, of whom 10 had psychotic disorders, 25 had affective disorders, 2 had an anxiety disorder, 2 had substance misuse disorders and 2 had ‘other’ disorders.

Five people refused to complete the instrument on the second occasion and a further 16 people could not be contacted or were not available. The only difference between the 109 participants who completed the instrument once and the 88 who completed it twice was that the former were more likely to have a moderate intellectual disability ($P<0.001$).
There were no differences in the total stigma score (mean 6.50, s.d.=3.73) resulting from level of intellectual disability \((P=0.19)\), gender \((P=0.49)\), age \((P=0.70)\), ethnicity \((P=0.51)\), mental health problems \((P=0.20)\), physical disability \((P=0.13)\), employment status \((P=0.57)\), housing \((P=0.19)\), attendance at college \((P=0.94)\) or day centre \((P=0.58)\) in this sample. There were no differences in the responses given to individual items on the questionnaire by participants with mental illness and those without mental illness (Table 2). Three items were ticked ‘no’ by more than 80% of the sample (items 3, 9, 21) and four items were ticked ‘yes’ by more than 80% of the participants (items 11, 14, 16). These items show little variation in response and are less useful in identifying people with differing levels of stigma. These six items have therefore been removed from the analysis (Table 3). The items that were ticked ‘yes’ by the majority of the sample were ‘positive statements’ such as ‘People like to talk to me’ and ‘People are nice to me’ and may reflect a response set bias.

**Test-retest reliability**

Of the remaining 15 items, two had kappa coefficients below 0.4 and were removed (items 2 and 12). The remaining items had kappa coefficients ranging up to 0.71 (Table 3).

**Factor analysis**

Factor analysis was conducted on the 13 items with acceptable variability in responses and reliability using the 109 responses to the instrument on the first round. Variables with a factor loading of 0.5 or more, where 0.5 is an approximation of the critical value for tetrachoric correlations, were considered to load significantly onto the respective factor. Two factors were sufficient to explain the intercorrelations among the variables \(\chi^2=34.51\), \(P=0.12\) (Table 4). The two rotated solutions were very similar in their factor loadings and thus we report the varimax (orthogonal) rotation as it is easier to interpret. Factor 1 (Table 4) consisted mainly of people’s experiences of discrimination, such as being bullied or ridiculed and was labelled ‘perceived discrimination’. Factor 2 contained statements about people’s emotional reactions to stigma such as anger and embarrassment. This factor was labelled ‘reaction to discrimination’. Item 20 loaded equally on both factors. The two factors together explained 60% of the total variance. Items 4, 7 and 13 did not load onto either factor.

**Internal consistency**

Cronbach’s alpha for the final ten-item instrument (items 1, 5, 6, 8, 10, 15, 17, 18, 19 and 20) was 0.84 (mean score 5.3, s.d.=3.15).
No single item deletion led to an improvement in internal consistency. Cronbach’s alpha was 0.72 (mean score 3.9, s.d.=2.2) for the six-item perceived discrimination sub-scale and 0.69 (mean score 2.4, s.d.=1.4) for the four-item reaction to discrimination sub-scale.

**Table 3** Test–retest reliability of the 15 statements and the percentage of people who responded ‘yes’ to each item

<table>
<thead>
<tr>
<th>Item/statement</th>
<th>( \bar{x} )</th>
<th>Participants responding ‘yes’, %</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. People talk down to me</td>
<td>0.62</td>
<td>60</td>
</tr>
<tr>
<td>2. People think I am not as good as them</td>
<td>0.39</td>
<td>51</td>
</tr>
<tr>
<td>4. I think I am the same as other people</td>
<td>0.44</td>
<td>77</td>
</tr>
<tr>
<td>5. The way people talk to me makes me angry</td>
<td>0.52</td>
<td>62</td>
</tr>
<tr>
<td>6. People make me feel embarrassed</td>
<td>0.41</td>
<td>53</td>
</tr>
<tr>
<td>7. Doctors and nurses have treated me badly</td>
<td>0.40</td>
<td>21</td>
</tr>
<tr>
<td>8. People on the street make fun of me</td>
<td>0.54</td>
<td>45</td>
</tr>
<tr>
<td>10. People on the street look at me in a funny way</td>
<td>0.61</td>
<td>61</td>
</tr>
<tr>
<td>12. People make fun of my family</td>
<td>0.38</td>
<td>21</td>
</tr>
<tr>
<td>13. No one bothers me when I use buses, trains or taxis</td>
<td>0.62</td>
<td>77</td>
</tr>
<tr>
<td>15. People laugh at me because of the way I look</td>
<td>0.51</td>
<td>39</td>
</tr>
<tr>
<td>17. People treat me like a child</td>
<td>0.58</td>
<td>46</td>
</tr>
<tr>
<td>18. I keep away from other people because they are not nice to me</td>
<td>0.47</td>
<td>67</td>
</tr>
<tr>
<td>19. People laugh at me because of the way I talk</td>
<td>0.71</td>
<td>39</td>
</tr>
<tr>
<td>20. I worry about the way people act towards me</td>
<td>0.41</td>
<td>54</td>
</tr>
</tbody>
</table>

The two underlying factors describe useful dimensions of stigma. The ‘perceived discrimination’ sub-scale examines the reactions of others to people with intellectual disability and includes perceived acts of harassment, ridicule and discrimination. Discrimination is one of the three elements of stigma proposed by Thornicroft et al, who describe discrimination as a ‘problem of behaviour’.

**Discussion**

This ten-item self-report instrument for people with mild to moderate intellectual disability has been developed with the detailed input of professionals working with people with intellectual disability, individuals with intellectual disability and carers. It uses an easy-to-understand format with a large font and accompanying photographs illustrating the statements, and takes 5–10 minutes to complete. The ‘yes/no’ format is readily understood and the majority of respondents were able to complete it with minimal assistance (the final version of the instrument is available as an online supplement to this paper). However, participants with moderate intellectual disability may require additional support. It has an acceptable test–retest reliability and high internal consistency indicating that it can be used as a total score.

**Table 4** Items with a factor loading greater than 0.498 following orthogonal rotation

<table>
<thead>
<tr>
<th>Factor</th>
<th>Factor loadings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Factor 1</td>
<td>0.59</td>
</tr>
<tr>
<td>1. People talk down to me</td>
<td>0.59</td>
</tr>
<tr>
<td>8. People on the street make fun of me</td>
<td>0.81</td>
</tr>
<tr>
<td>10. People on the street look at me in a funny way</td>
<td>0.82</td>
</tr>
<tr>
<td>15. People laugh at me because of the way I look</td>
<td>0.90</td>
</tr>
<tr>
<td>17. People treat me like a child</td>
<td>0.69</td>
</tr>
<tr>
<td>19. People laugh at me because of the way I talk</td>
<td>0.70</td>
</tr>
<tr>
<td>20. I worry about the way people act towards me</td>
<td>0.53</td>
</tr>
<tr>
<td>Factor 2</td>
<td>0.79</td>
</tr>
<tr>
<td>5. The way people talk to me makes me angry</td>
<td>0.79</td>
</tr>
<tr>
<td>6. People make me feel embarrassed</td>
<td>0.81</td>
</tr>
<tr>
<td>18. I keep away from other people because they are not nice to me</td>
<td>0.54</td>
</tr>
<tr>
<td>20. I worry about the way people act towards me</td>
<td>0.53</td>
</tr>
</tbody>
</table>
of acquiescence include the desire to please, suggestibility and lack of understanding due to complex questions. Acquiescence is more likely to occur when using ‘yes/no’ questions and is inversely related to IQ. However, Gudjonsson argues that acquiescence is a result of difficult or complex questions rather than a problem of ‘yes/no’ questions per se. In our study, no single participant answered ‘yes’ or ‘no’ to all the questions, suggesting that acquiescence was low. We have also excluded questions that were answered ‘yes’ or ‘no’ by the majority of the participants. One strategy that can be employed to reduce acquiescence is the use of screening questions to exclude participants who are likely to give acquiescent responses. These questions are usually based on nonsense questions and pairs of reverse worded questions but both have limitations: nonsense questions may amuse participants who may say ‘yes’ to play along and reverse worded questions may produce affirmative answers for both versions as they may conjure up different images or situations. Screening questions for acquiescence were not used in our study but participants were asked to give examples to illustrate questions.

Questions on time and frequency of perceived stigma were avoided as the notion of time has been found to be a problem when interviewing people with intellectual disability. We have therefore chosen to look at lifetime experiences of stigma.

The total stigma scores did not vary between socio-demographic and clinical factors in this sample. However, this finding may be explained by our limited sample size. Ethnicity, gender, social class, mental illness and physical disability are factors that may be associated with higher levels of stigma in people with intellectual disability; however, there are few studies looking at this relationship. One qualitative study found that people with intellectual disability were aware of gender and ethnic stereotypes and the disadvantages associated with these. Having an intellectual disability appeared to exacerbate negative gender expectations and detracted from positive ones. This view is contrary to the view of other researchers who suggest that the experience of disability overrides the experiences of other social identities. The relationship between socio-demographic factors and stigma therefore requires further investigation. Our finding that perceived stigma was similar in those with and without mental illness suggests that the instrument is suitable for detecting stigma of intellectual disability, irrespective of the presence of mental illness.

Strengths and limitations
The strengths of the study are that the items and format of the instrument were developed from an extensive search of the literature and consultation with a wide range of people and professionals in the intellectual disability field, including people with intellectual disability themselves. The people with intellectual disability who participated in the field and reliability testing had a range of comorbid problems and were recruited from a number of settings — our sample is therefore comparable with service users aware of stigma among health professionals so that intellectual disability services are better equipped to support the needs of this vulnerable group.

Further research
We are now in the process of developing a version of the instrument for carers of people with intellectual disability with the aim of understanding some of the experiences of people with more severe forms of intellectual disability who are not able to communicate their difficulties. The cultural stability of the instrument also needs to be established to assess its utility in other countries or cultural groups.

Use of the instrument in research and clinical settings
This instrument has potential for use in a number of clinical and research settings such as understanding the part played by stigma in utilisation of intellectual disability services and mental health services, adherence to social or medical interventions and service outcomes in people with intellectual disability. It may help to determine the impact of stigma on mental illness and increase awareness of stigma among health professionals so that intellectual disability services are better equipped to support the needs of this vulnerable group.
References


