# Development and psychometric evaluation of the Discrimination and Stigma Scale (DISC)

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## ABSTRACT

Mental illness is associated with unfair treatment in a number of areas of life. There is currently no psychometrically validated measure that has been developed to specifically focus on such experienced discrimination. This study aimed to finalise the Discrimination and Stigma Scale (DISC) and establish its psychometric properties. The DISC was further developed using (1) service user and interviewer focus groups; (2) reading ease testing; and (3) cognitive debriefing interviews. The revised scale then underwent psychometric testing to establish the following properties: reliability; validity; precision; acceptability; and feasibility. The final 22-item DISC demonstrated good psychometric properties ($n=86$) including inter-rater reliability (weighted kappa range: 0.62–0.95), internal consistency ($\alpha=0.78$) and test–retest reliability ($n=46$) (weighted kappa range: 0.56–0.89). Feasibility, validity and acceptability were also established. In conclusion, the 22-item DISC is recommended for use in measuring experienced stigma and discrimination. Additional work to develop a measure of anticipated stigma is recommended.

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## 1. Introduction

Stigma is defined as a characteristic which individuals possess (or are believed to possess) that conveys an identity which is devalued in a particular social context (Crocker et al., 1998). Mental illness is associated with devaluation in a number of social contexts including: the workplace; healthcare settings; acting as a parent; and personal relationships (King et al., 2007; Link et al., 1997; Ritsher et al., 2003; Wahl, 1999). Three elements of stigma can be considered: (1) perceived stigma or the belief that the public hold negative attitudes towards people with a mental health problem, (2) experienced stigma or reported instances of unfair treatment or discrimination due to having a mental health problem and (3) self-stigma or adopting a stigmatised view of oneself (Yanos et al., 2008). Stigma research has largely focused on the measurement of perceived stigma. A recent review of studies using survey-based measures ($n=52$) reported that 79% used a measure of perceived stigma, 46% a measure of experienced stigma and 33% a measure of self-stigma (Brohan et al., 2010b). This review further suggests that, although several survey measures have addressed aspects of experienced stigma, there is currently no psychometrically validated measure that was developed with a specific focus on understanding the scope and content of these experiences.

The Discrimination and Stigma Scale (DISC) was developed to address this gap. It is based on the definition of Thornicroft et al. (2007), who present stigma as an overarching term including three elements: (1) problems of knowledge (ignorance or misinformation); (2) problems of attitudes (prejudice); and (3) problems of behaviour (discrimination) (Thornicroft et al., 2007). This definition moves the stigma focus from the characteristics of the individual to the problems that perpetuate stigma. The DISC focuses on the third aspect of stigma: problems of behaviour or discrimination. It is an interview-based measure which collects qualitative and quantitative data to provide a rating of the degree to which discrimination has been experienced in various areas of life including work, relationships, parenting, housing, leisure, and religious activities. The qualitative aspect of the scale asks respondents, for each domain, to give an example of how they have been treated differently (or not) from other people because of their diagnosis of mental illness. Participants are then asked to given a Likert scale rating for each item, which is the quantitative aspect of the scale.

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A preliminary version of the DISC was developed as part of the International Study on Discrimination and Stigma Outcomes (INDIGO) (Thornicroft et al., 2009). In scale development, face and content validity were established through a literature review, Delphi consultation and pilot testing of the draft scale were carried out within research teams at 28 participant study sites in 27 countries. Twenty-five interviews were conducted at each site (total $n=732$) with five of the interviews at each site audio-taped, transcribed verbatim, translated into English and qualitatively analysed by members of the study team (Rose et al., 2011). The results of this study suggested that negative discrimination was frequently experienced. For example, 344 (47%) reported discrimination in making or keeping friends, 315 (43%) in relationships with family members, and 209 (29%) in finding a job. Discrimination was also frequently anticipated, with 469 (64%) inhibiting themselves from applying for work, training, or education and 402 (55%) stopping themselves from looking for a close relationship for this reason. This initial version of the scale also provided the opportunity for participants to record any experiences of positive discrimination (i.e. situations where they had been treated more positively because of their mental health problem). Reports of positive experienced discrimination were rare. The qualitative and quantitative analysis of the data collected suggested that the scale may benefit from further developmental work to improve the relevance and ease of use of items and response options. This article details this work and further work to establish the psychometric properties of the revised scale.

### 1.1. Aims

This study aims to

(1) complete the developmental work to maximise the acceptability and feasibility of the DISC, leading to a finalised version of the scale (Phase 1); and
(2) establish the psychometric properties of the revised DISC (Phase 2).

## 2. Methods

### 2.1. Methods for completing the development of the DISC

Firstly, the corrections indicated by the INDIGO data analyses were incorporated, as described elsewhere (Rose et al., 2011; Thornicroft et al., 2009). As mentioned in Section 1, this focus improved the relevance and ease of use of items and response options. This included restructuring the response options from a 7-point Likert scale that allowed a rating of positive or negative discrimination on each items to a 4-point scale that allowed ratings of negative discrimination only. An additional positive discrimination subscale was introduced to allow participants to provide ratings on this aspect for several areas of life in which it was most frequently reported.

This was followed by three stages of evidence gathering to support further development: (1) service user and interviewer focus groups ($n=4$ groups); (2) reading ease testing; and (3) cognitive debriefing. Evidence from stage 1 was used to create a draft DISC, which was considered in stages 2–3.

#### 2.1.1. Stage 1: service user and interviewer focus groups
Two semi-structured focus groups were conducted with mental health service users. Eligible participants were identified by the clinical team at a day centre service. Participants were asked to complete the DISC at the beginning of the focus group and then discuss aspects of the scale including: overall ease of completion; relevance of items and response options, time taken to complete and recommendations for improvement. Two focus groups were also separately conducted with interviewers who had experience in using the DISC as part of other studies run by colleagues at the Institute of Psychiatry. Group discussion focused on experience of using the scale and recommendations for improvement.

#### 2.1.2. Stage 2: reading ease testing
The Flesch Reading Ease score and Flesch–Kincaid Grade level were assessed using MS Word. These are widely used tools which assess readability based on the syllabic and sentence structure of the text (Kalk and Pothier, 2008). The Flesch Reading Ease score ranges from 0 to 100 with higher scores being easier to read. The Flesch–Kincaid Grade level provides an indication of the US educational grade to which the material is most appropriate (range 0–17) (Flesch, 1974).

#### 2.1.3. Stage 3: cognitive debriefing
Cognitive debriefing involves a small interview study, providing qualitative data on the mental processes that respondents use to answer questions (Ojanen and Gogates, 2006). Once changes had been made following the recommendations of stages 1 and 2, cognitive debriefing interviews were conducted as a check to ensure conceptual clarity and ease of meaning in the final DISC. Five individuals were recruited from a day centre service using the methods described in the service user focus groups.

### 2.2. Methods for the psychometric evaluation of the DISC

#### 2.2.1. Design
A cross-sectional study design was used, with participants being interviewed at one point in time. A sub-sample of participants also completed the DISC again 7–14 days following initial administration to establish the test–retest reliability. This study, and the earlier work described in stages 1–3 above, received National Research Ethics Service (NRES) approval from the Camden and Islington Community Local Research Ethics Committee (REC ref: 08/H0722/40).

#### 2.2.2. Sample
A sample size of 90 was chosen as it is sufficient to establish that the inter-rater reliability is at least 0.7 (assuming that the true level is 0.8) (Walter et al., 1998). Sample size was calculated based on inter-rater reliability as this was the property which required the largest sample. The sample of 90 was also sufficient to establish the other properties under consideration (e.g. convergent and discrimination validity analyses). Convenience sampling was used. All participants were aged 18 years or over and had used a community mental health team in the past 12 months.

#### 2.2.3. Procedure
Interviews were conducted by a team of six researchers. Each researcher participated in a half-day training session led by EB. During the participant interviews, DISC responses were digitally recorded. A second member of the research team listened to the interview and recorded a score for each DISC item. This was compared with the original interview scores to calculate inter-rater reliability. Every seond participant in this study was asked to repeat the DISC interview again 7–14 days following initial administration. The study measures are detailed below.

#### 2.2.4. Measures
2.2.4.1. Discrimination and Stigma Scale (DISC). The revised DISC is a 35-item, interview-based, measure. All items are scored on a 4-point Likert scale ranging from 0=not at all to 3=a lot. It comprises a global scale and four subscales, each of which is scored separately. The four subscales are: (1) Unfair treatment (22 items); (2) Stopping self (4 items); (3) Overcoming stigma (2 items) and (4) Positive treatment (7 items). The qualitative aspects of the scale were retained, with respondents asked, for each item, to give an example of how they have been treated differently (or not) from other people because of their diagnosis of mental illness. Both a mean and a total score are calculated for each subscale and the global scale. This allows both the typical level of stigma in each applicable area of life, and its spread over the different areas to be encompassed.

2.2.4.2. The Stigma Scale (SS). The SS is a 28-item self-completed measure. It has three subscales: disclosure (11 items), discrimination (12 items) and positive aspects (5 items) (King et al., 2007). The scale has good test–retest reliability (kappa range 0.49–0.71) and internal consistency ($\alpha=0.87$).

2.2.4.3. Internalised Stigma of Mental Illness Scale (ISMI). The ISMI is a 29-item self-completed measure that assesses mental health service users' experience of internalised stigma (Ritsher et al., 2003). It is composed of five subscales: Alienation, Stereotype Endorsement, Perceived Discrimination, Social Withdrawal and Stigma Resistance. Strong internal consistency ($\alpha=0.90$) and test–retest reliability ($r=0.92$) have been reported.

2.2.4.4. Brief Psychiatric Rating Scale (BPRS). The BPRS measures psychiatric symptomatology, including positive symptoms, general psychopathology and affective symptoms (Overall and Gorham, 1962). The 18-item version of the scale was used in this study (Lukoff et al., 1986). Items 1–10 are rated by the participant during an interview, while items 11–18 are rated by the researcher following observation of