Discrimination and Stigma Scale (DISC) version 12
Manual version 3
May 2013

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1. Background to the Discrimination and Stigma Scale (DISC)

The measurement of stigma has largely focused on defining and measuring public stigma i.e. the way in which the general public view and treat people with a diagnosis of a mental illness. A growing body of work concentrates on the individual's expectations of being treated in a devalued manner, as well as the impact of these expectations on their self-image. However, one area which has received relatively little attention is that of experienced discrimination or the individual's actual experiences of stigma and discrimination. The Discrimination and Stigma Scale (DISC) was developed to address the need for a measure of experienced discrimination.

1.1. Purpose of the DISC

The purpose of the DISC is to collect information on how having a diagnosis of mental illness influences an individual's personal and social life. This interview-based instrument collects quantitative and qualitative experiences of discrimination in key areas of everyday life and social participation, including work, marriage, parenting, housing, leisure, and religious activities. It also considers the extent to which participants limit their involvement in areas of life due to anticipated discrimination. The DISC is designed for use by a trained interviewer and the ratings are those reported by the mental health service user.

1.2. Development

The DISC was designed for use by sites collaborating in the International Study of Discrimination and Stigma Outcomes (INDIGO) on schizophrenia (Thornicroft et al, 2009) The Principal Investigator and Study Coordinator was Professor Graham Thornicroft¹.

The Co-Principal Investigators were:
Dr. Diana Rose²
Professor Norman Sartorius³
along with contributions from staff at the participating sites of the INDIGO Study, and study advisors.

The items of the DISC used in INDIGO (version 10) were developed after a detailed literature review, consultation with topic experts and piloting in each INDIGO study site (Thornicroft et al, 2009). The DISC-10 had 39 items the first 32 of which were scored on a 7-point Likert scale which ranged from +3 or 'strong advantage' to -3 or 'strong disadvantage' and covered key areas of everyday life and social participation, including work, marriage, parenting, housing, leisure, and religious activities. The remaining 7 items captured individuals' reactions to having mental illness and were scored on a 3-point Likert scale ‘not at all’, ‘a little’ and ‘a lot’.

1.3. Further validation and new versions

Following on from feedback on the use of DISC-10, further validation work was conducted as part of the SAPPHIRE Research Programme on Stigma and Discrimination in Mental Health (www.sapphire.iop.kcl.ac.uk) (see Brohan, 2012, in press). Feedback from service users and researchers suggested simplifying wording of items, de-emphasising issues regarding diagnosis and reducing the response scale to 4 options. These changes were enacted, generating a new version: DISC-12.

DISC-12 comprises 32 questions that are rated on a 4-point Likert scale: not at all; a little; moderately; a lot. It contains a global scale and 4 subscales:
● Subscale 1 – Unfair treatment
● Subscale 2 – Stopping self
● Subscale 3 – Overcoming stigma
● Subscale 4 – Positive treatment

Detailed psychometric analyses have been undertaken (Brohan, 2012, in press). These analyses have shown that the DISC-12 has good reliability, validity and acceptability. Full details of its psychometric
properties will be available and sent to all enquirers who have contacted us to date when the psychometric paper is in press.

The DISC-12 has since been used in a number of major studies such as:

- International study on experienced discrimination in depression (ASPEN / INDIGO (depression)).
- International study on experienced discrimination in first-episode psychosis (FEDORA).
- National survey as part of evaluation of England’s Time to Change Anti-Stigma Programme (Viewpoint).

1.4. Delivery of the DISC

The DISC was initially developed for use in face-to-face interviews. However, new versions have been developed for:

- self-complete questionnaires (developed by Phoenix in New Zealand www.phoenix.co.nz) (Wyllie and Brown, 2011)

An online version is currently under development as part of the SAPPHIRE Programme by Dr Claire Henderson, and Roger Marlow and Steve Pashley from Health2Works (www.health2works.com).
2. Instructions for use

2.1. Translation of the DISC (if applicable)
Interviewers should prepare a version of DISC in their own language (see Appendix A for instructions), first checking with the DISC developers (see Contact section) whether a translated version has already been made, in which case we will forward this to you for use. Translations should focus on cultural relevance of terms rather than being ‘direct translations’. For example, some countries may not have ‘welfare benefits’ (DISC item 11), or ‘dating’ (DISC item 3) may not be part of the culture. In these situations, cultural equivalents should be found.

2.2. Preparation for use of the DISC
Allocate a unique and confidential identifier number to each service user interviewed. Keep a master list of names and identifier numbers in conditions of security. Ensure that the service user’s name is not attached to any paper scale or to any audio/electronic file of the interview, which use only the service user identifier number. If necessary, ask for the agreement of the treating clinician to have access to interview the service user.

2.3. Conducting the interview
Invite the service user to give written, informed consent to the interview, consistent with the local requirements for ethical approval of the study and consistent with good research practice locally (some sites will need to give a copy of the consent sheet to the patient, keep a copy for the research file, and keep a copy for the clinical file). Inform the service user that what he or she says will be kept confidential and will have no implications for treatment or care received.

Emphasise that the study is intended to gather information on whether the service user feels he or she has been treated unfairly, because of a diagnosis of mental health problems. To do this please read out the information on the front page of the DISC-12. If a service user gives an example which is about being treated unfairly for reasons unrelated to mental health e.g. not being accepted for a job because they are not qualified for it, do not include this and clarify the question to them.

It might be helpful to provide the service user with a laminated copy of the rating guide on Page 11 of DISC-12, to remind them of the available response options.

During the interview, ask the service user to give examples of each experience of stigmatisation or discrimination and ask him or her to be as specific as possible. Make brief notes of these examples on the DISC form. In some studies the interview is audio-recorded to obtain fuller information on the examples given. It is advisable to include these examples as they help to establish the accuracy of responses and can alert the interviewer to times when the service user may need further clarification about what is being asked.

If the interview is being tape-recorded say the question number at the beginning of each question to facilitate the identification of items.
At the end of each question ask the service user to make a rating, and then tick one box on the DISC form to record directly on the data sheet the ratings of the service user.

If any question is not applicable, tick the appropriate ‘Not Applicable box’ and add a brief note to say why this item is not applicable to this particular service user, and then go to next question.

Before starting the study in your site discuss with colleagues how to respond to service users who may be distressed by the interview, and offer such support immediately if any service user is upset in any way by the interview.

2.4. Timeframes
The DISC-12 can be used over different timeframes – for example, lifetime ever, past twelve months or another time period. Most studies have referred to the previous 12 months.

2.5. Checklist to complete before starting the interview

2.5.1. Discuss the purpose of the study
For example, ‘This study is being carried out because we are investigating how stigma and discrimination affect people with a mental health problem. We are interested in how stigma has affected you. For example, you may have felt that people have behaved towards you in an unfair way because of your diagnosis of mental illness. We also want to understand if such experiences have changed your everyday life, for example, in your family, at work, or in leisure activities.’

Give the service user a copy of the study information sheet (where applicable) and consent form to keep.

Tick when completed □

2.5.2. Ask for written consent
Ask for the written, informed consent of the service user to be interviewed and for the anonymised information from the interview to be used for your study.

Tick when completed □

2.5.3. Read through the front page of the DISC-12 to explain the interview process to the participant.

Tick when completed □

2.5.4. Give the service user the rating guide sheet
At the start of the interview tear off the last page of the DISC-12, and give that page to the service user to assist him or her in making ratings for all questions. Alternatively you may wish to make a laminated version of this page.

Tick when completed □
3. Scoring the DISC-12

DISC-12 is a 32-item measure. The 32 items of the DISC are scored to obtain a global scale and 4 subscales as follows:

- **Subscale 1** – Unfair treatment (items 1 - 21)
- **Subscale 2** – Stopping self (items 22 - 25)
- **Subscale 3** – Overcoming stigma (items 26 and 27)
- **Subscale 4** – Positive treatment (items 28-32)

The calculation of both a mean and total score is recommended for each subscale. This allows both the level of stigma in each applicable area of life, and its spread over the different areas to be presented.

Each item is scored as 0 = no difference, 1 = a little, 2 = moderately and 3 = a lot. A 'not applicable' option is available for occasions where the participant was not involved in a situation where they could have experienced discrimination. Code not applicable items as ‘-8’, and missing data as ‘-9’. In some studies researchers have distinguished different types of not applicable responses (i.e., not applicable because: the participant did not disclose diagnosis; it happened before diagnosis; or the participant hasn’t been in that situation in the past year).

### 3.1. Mean scores

A mean score (range 0-3) is calculated for each subscale by adding each item score (0, 1, 2 or 3) and dividing by the number of applicable, non-missing items in the subscale. No items are reverse coded.

### 3.2. Total scores

A total score is calculated for each subscale by counting the number of items for which the participant scores 1 (a little), 2 (moderately) or 3 (a lot) in each subscale. Items which are scored as 0 (no difference), -8 (not applicable) or -9 (missing) are not included in this count. The possible range for each subscale is shown below:

- **Subscale 1** - Unfair treatment (0-21)
- **Subscale 2** - Stopping self (0-4)
- **Subscale 3** - Overcoming stigma (0-2)
- **Subscale 4** - Positive treatment (0-5)

### 3.3. Treatment of missing items

Scores should only be computed if there is a minimal number of missing values, as shown in Table 1 below. Note that, ‘not applicable’ items are not considered ‘missing’. Missing data includes only items for which the participant has not provided a response.

The stricter rules for computation of totals compared to means are because missing values will appear as ‘no stigma’ in totals, and will thus tend to bias any summary statistics downwards. Where only 1 or 2 items are missing this will have negligible effect on subscale 1 and a simple total will be acceptable.

Where 3 or 4 items are missing in subscale 1, prorating may be considered. Prorating is a statistical process where an average of available items is multiplied by the number of actual items. Prorating therefore replaces missing items with the mean of non-missing items. In the case of subscale 1, this would involve using the mean of applicable and non-missing items. Prorating should be backed up with sensitivity analyses if the values appear to be concentrated in a few specific items (e.g. substituting 0s or 1s for the missing items to check that there is no substantial difference in the results).

We do not recommend prorating for subscales 2-4.

### Table 1. Allowable missing items to compute a subscale/global score

<table>
<thead>
<tr>
<th></th>
<th>If more than this number is missing, do not compute the score, but set to 'missing'.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mean</strong></td>
<td><strong>Total</strong></td>
</tr>
<tr>
<td><strong>Subscale 1 Unfair treatment</strong></td>
<td>4</td>
</tr>
<tr>
<td><strong>Subscale 2 Stopping self</strong></td>
<td>1</td>
</tr>
<tr>
<td><strong>Subscale 3 Overcoming stigma</strong></td>
<td>0</td>
</tr>
<tr>
<td><strong>Subscale 4 Positive treatment</strong></td>
<td>1</td>
</tr>
</tbody>
</table>

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3.4. Recording of DISC-12 scores for individuals
Table 2 below is a recommended way of recording DISC-12 scores for each respondent.

3.5. Presentation of summary statistics
The number of applicable and non-applicable items is a statistic of potential interest in its own right, since it indicates the spread of life areas in which respondents engage. It is therefore suggested that summary statistics (such as means, standard deviations, ranges) for samples of respondents should be based on the total number of applicable items, as well as the Mean and Total scores.

3.6. Alternative scoring
In the Viewpoint Study (Henderson, 2012), an alternative scoring method was used. In this study, an overall score for the unfair treatment subscale of the DISC was generated using a binary score for each item.

To do so, for each item convert the scores representing any discrimination into 1 and scores representing no discrimination into 0. The sum of the converted scores is then divided by the amount of applicable answers and multiplied by 100 to generate the percentage score.

For example, if a participant has reported discrimination in 12 life areas and has reported that 2 life areas are not applicable, then the calculation would be: 12/19 x 100 = 63%.

Table 2.
Recommended DISC-12 Summary Scores

<table>
<thead>
<tr>
<th>Subscale 1 Unfair treatment</th>
<th>Mean score</th>
<th>Total score</th>
<th>Number of applicable items</th>
<th>Number of missing items</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subscale 2 Stopping self</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subscale 3 Overcoming stigma</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subscale 4 Positive treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4. Qualitative analysis of DISC responses

For each item, the participant is asked to provide an example. Examples should be recorded on the form or tape-recorded, and provide an opportunity for the interviewer to determine if the participant has understood the question. Importantly, these examples also provide first-person accounts of participants’ experiences of discrimination and are therefore a rich source of additional data.

Some researchers have undertaken qualitative analyses of the examples of discrimination provided by participants. For example Rose and colleagues (2011) conducted a thematic analysis of recorded examples of discrimination reported by people with diagnoses of schizophrenia. This analysis showed how participants’ feelings of humiliation and being ‘shunned’ from society as a result of experienced discrimination, often contributed to further social isolation. Jeffrey, Clement and colleagues (2012) undertook a framework analysis of written examples from the Viewpoint study about discrimination in relation to becoming or being a parent. A qualitative analysis of examples of experienced discrimination reported by people with depression is also underway.

5. Conditions of use

Permission to use the DISC is granted on condition that:
1. No changes are made to wording or format of the DISC.
2. Translations into different languages are done using ‘back-translation’ (see section 2.1 and Appendix A) and a copy of the translated version is sent to Professor Graham Thornicroft (email below) to avoid duplication of effort.
3. The copyright information in the footer of the scale is included on every page and acknowledged in full by all users.
4. The DISC is not passed on to a third party. All interested parties should contact Professor Graham Thornicroft for permission to use the DISC.
5. The DISC is only administered and analysed in accordance with the instructions in this manual.

6. Contacts

For permission to use the DISC or requests to collaborate, please contact Professor Graham Thornicroft (graham.thornicroft@kcl.ac.uk)

For information and queries about the DISC and to share feedback about any of your experiences using the DISC please contact Professor Graham Thornicroft graham.thornicroft@kcl.ac.uk

7. Copyright

The copyright for the DISC is asserted by King’s College London on behalf of the INDIGO partnership.

8. Acknowledgements

The DISC-12 and this manual were developed as part of the SAPPHIRE programme on Stigma and Discrimination in Mental Health. The SAPPHIRE programme is independent research commissioned by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research scheme (RP-PG-0606-1053). Graham Thornicroft is also funded through a NIHR Specialist Mental Health Biomedical Research Centre at the Institute of Psychiatry, King’s College London and the South London and Maudsley NHS Foundation Trust. The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health. Elaine Brohan’s work on the DISC-12 formed part of her PhD.
9. References

The main paper describing the initial development of the DISC and international findings is:

Other relevant publications currently include:
Appendix A: Guidelines for DISC translation, back-translation and concept checking

Translation stage
Please arrange for the DISC-12 to be translated into your local language. Ensure that the translator has the local (target) language as his/her first language, and has English as his/her second language. It is preferable that the translator is not a professional translator, but rather someone with knowledge of the content area. If feasible it may be helpful to have two translators working together. Then discuss this translation within your study team to resolve any disputed items.

If feasible, it is helpful at this stage to have bi-lingual experts read through both versions checking for coherence and cultural applicability.

Back-translation stage
Next back-translate DISC-12 into English, using a different translator whose first language is English and whose second language is your local language. Your study team then meets to discuss this back-translated version and to compare it with the original English version, leading to any further revisions that are necessary, and a list of the remaining disputed items for discussion with the focus group.

You could contact the DISC-12 developers at this stage for any further advice on the intended meaning of the items.

Focus group stage
To carry out what is called ‘concept checking’ (which means validating a group of people similar to those who will be interviewed), it is necessary for you to arrange one focus group. This should include of 6-10 participants of the target group (e.g., with a clinical diagnosis of schizophrenia (or diagnosis of interest)) who meet with 2 coordinators from your study group. The coordinators need to control both the questions to be asked and the group dynamics; one should lead the discussion and another should take notes. It may not be necessary to discuss every item in the DISC. Rather, items requiring further discussion and checking may be identified by the study team after reviewing the back-translated version (we suggest that it is no higher than four or five items discussed in the focus group). The coordinators should introduce the DISC and then to discuss the DISC items in turn, and ask for comments from the service users on the phrasing of the items and how far they are understandable. You should tape-record the meeting and after the meeting prepare a summary outlining the most important ideas and conclusions. Then prepare your final local language version of DISC-12, using the information you have gathered from all these stages.

For more detailed guidance on this procedure please see:

You may also be interested in:

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