

Mental Health Research Network (MHRN) Stigma
and Discrimination Research Group
6 Month Report

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Introduction

The MHRN Stigma and Discrimination Research group forms a British network of those actively interested in research on stigma and discrimination in mental health. Members comprise a multi-disciplinary group of investigators across the fields of: sociology, psychology, geography, health economics, service user research, psychiatry, epidemiology, psychometrics, mental health policy, occupational health, and learning disability. Members come from all over the country from both the public and private sector. This report outlines the progress of the group specifically over the last six months.

MEETING # 4:

As stated in our annual report, our fourth meeting was held in November 2007. At this meeting, it was announced that two clusters, (1. Economic Impact of Stigma, 2. Employment and Stigma) were successful in their protocols receiving funding. These cluster protocols fall under a larger study called the Stigma and discrimination Programme to Promote Healthcare Access & Social Inclusion: Research Evaluation (SAPPHIRE Programme which is funded by a National Institute for Health Research (NIHR) programme grant of 1.95 million pounds. Given the achievement of the quota for the MHRN Stigma and Research Discrimination group timetable this meeting explored the further development of the protocols of other clusters without rushing for the external deadline which has now been met. The relevant aspects of the cluster protocols that are funded under SAPPHIRE are:

A. The financial costs associated with stigma (Proposed by Economic Impact of Stigma Cluster)

The aims of this component are to: (i) develop a theoretical model of the financial costs of stigma, and (ii) to measure these costs for a representative sample of service users. To develop a theoretical model we shall undertake a systematic literature review of the economic impact of stigma. Publications will be identified from the biomedical, psychological and social sciences (including PsychInfo, Medline, EconLit) and from the grey/report literature. We shall identify literature in other areas where stigma may be evident, e.g. epilepsy, TB, and HIV/AIDS. Key issues emerging from the review will be discussed with service users and formal and informal carers in a series of focus groups.

Identification of costs that are a direct result of stigma will be challenging. We might expect delayed treatment for mental health problems to result in high cost services 'downstream' However, for some patients such high cost services may simply reflect needs that would have been there even in the absence of stigma. Similarly, whilst the perception of reduced access to employment of leisure activities may reflect the existence of stigma and discrimination, it may also be caused by other factors, such as the disability consequent upon the mental illness. We shall produce a multiple regression model, where the main independent variable will be the level of stigma experienced by the individual as measured by the DISC. Possible

confounding and clinical measures will also be included. This model will consequently be able to estimate the relationship that exists between the reported level of stigma and costs after holding other factors constant.

B.) Study of decisions of employers in relation to disclosure of psychiatric history (Proposed by Employment and Stigma Cluster)

Disclosure of a mental illness may substantially reduce the likelihood of a job application being successful. We shall therefore undertake an intervention study (to complement the CORAL study to assess the rate of short-listing for employment. Members of the Service User Research Enterprise (SURE) in association with staff of the Human Resources Department of the South London and Maudsley NHS Trust, will develop mock job applications which they will send in response to job vacancies advertised in the South London Press. The applicants' experience and qualifications will be commensurate with the job descriptions given for the vacant posts. A random half of the job applications (n=50) will include no reference to any history of mental illness, while the other half (n=50) will refer to either a history of (i) major depression, or (ii) schizophrenia. If the proportion of short-listing (the primary outcome) in the concealed group is about 30%, this would allow a detection (with 80% power using a significance level of 0.05) of a difference between this and that in the disclosed group of 25%, ie the proportion being short-listed in the disclosed group would be expected to be 5%.

In a linked study we shall undertake a series of 30 qualitative interviews with the appointing officers (ie those doing the short-listing for vacant posts, and who consent to take part in the study) using semi-structured interviews to ascertain: (i) their views about short-listing people with a history of mental illness to posts in their organisation; (ii) their experience of working with people who have been appointed to posts following an episode of mental illness, or who have returned to work following a period of sickness leave because of mental illness; (iii) their knowledge of and views about the 1995 Disability Discrimination Act and its associated Disability Equality Duty (2006); (iv) their views on what measures, singly and in combination, would be likely to change their short-listing a greater proportion of job applicants who disclose a history of mental illness.

CANCELLATION OF 12TH MARCH MEETING

Our fifth meeting was originally to be held on the 12th of March, 2008 however the MHRN conference was also on this day and most of our members were unable to attend the meeting as they would be at the conference. We thus rescheduled the meeting for 28th April, 2008.

ADOPTIONS MEETING

An adoptions meeting for the SAPPHIRE programme as a whole was held on 18th April 2008 with Belinda Williams and Liz Hutt. Also present was the SAPPHIRE programme coordinator Sarah Clement, Elaine Brohan and Aliya Kassam. The costs of study now referred to as Costs of Stigma Inventory (COSI) study and the job shortlisting study will be

adopted by the MHRN as they fall under the SAPPHIRE programme. This also entails meeting the quota for the MHRN clinical research group criteria. The adoption forms have been completed by Sarah Clement and sent to Belinda.

MEETING #5:

Our most recent meeting was held on 28th April 2008. This meeting took on a theme which was Stigma and Discrimination in Employment or the workplace. Apart from regular cluster updates this meeting also discussed other ongoing research projects pertaining to stigma and discrimination in employment such as elements of the Moving People Project as well as the Conceal or Reveal (CORAL) project. Additionally feedback from the group as a whole was sought for the job short listing project. The group felt that hearing about other projects was especially important since stigma and discrimination in employment also touches many other cluster areas such as self stigma and costs of stigma. For example, the self stigma cluster aims to look at *disclosure in mental health* and in particular the situations when mental health service users feel able to disclose details about their mental health problems, and those where they do not. Their proposal is to look at the protective factors that aid disclosure and those that hinder such as self-stigma.

Presentation on stigma and employment projects:

CORAL

- Elaine Brohan presented on the Conceal or Reveal (CORAL) study which looks at concealing or revealing a diagnosis of mental illness in the context of employment or education.
- An output of CORAL involves a Decision Aid Tool and an information booklet with legal standards.
- At present the CORAL team is in discussions with legal colleagues about how little information can legally be disclosed
- It was mentioned that the CORAL study was very much the vision of the Self Stigma group and perhaps will help inform the work of the Self Stigma cluster
- The importance of knowing the DDA was discussed
- The book by Patrick Corrigan 'Don't Call Me Nuts' has a grid about deciding whether or not to conceal/reveal
- Possible partners for the CORAL project and future work could be Job Centre Plus, NHS
- The Shaw trust has done work in this area

Moving People Project and Disclosure

- Legal Mind has 2 ongoing projects
 - 1. Searching case database looking at points of law and discouragement of disclosing
 - 2. Providing legal information on what employees and employers can or can not do

As one of the 6 national aspects of Moving People Minds legal team will be pursuing two avenues to reduce discrimination in the work place:

- Firstly they will aim to take several discrimination cases to the high courts in order to set test cases and legal precedents;
 - Moving People aim to monitor the impact of these cases in terms of their future reference in similar cases, their exposure in the legal media/databases and their exposure in the general media.
- Secondly they will produce and disseminate information on legal rights and obligations to both employees and employers;
 - Moving People aim to evaluate the employers information by building on the Shaw Trust survey carries out in 2006 and may contact employees several months following the receipt of information to gather information on its impact on their practises.

SAPPHIRE Job-Short Listing

- Graham began discussion around the job short listing project which was part of the Employment cluster's original protocol. He went through the various options of how to design the study. The options are being discussed and a proposal will be drafted soon. Additionally, the ethics of this study needs to be considered in more detail.

Further discussion about these issues was warranted and several members of the group acknowledged that they would be happy to meet as part of a cluster on a separate occasion.

Finally, there was much discussion around the area of help seeking and the development of a separate cluster around this topic. Many of the members were interested in this and e-mail addresses were provided in the meeting minutes for a cluster meeting and information exchange via e-mail. The next group meeting will be held in July.

