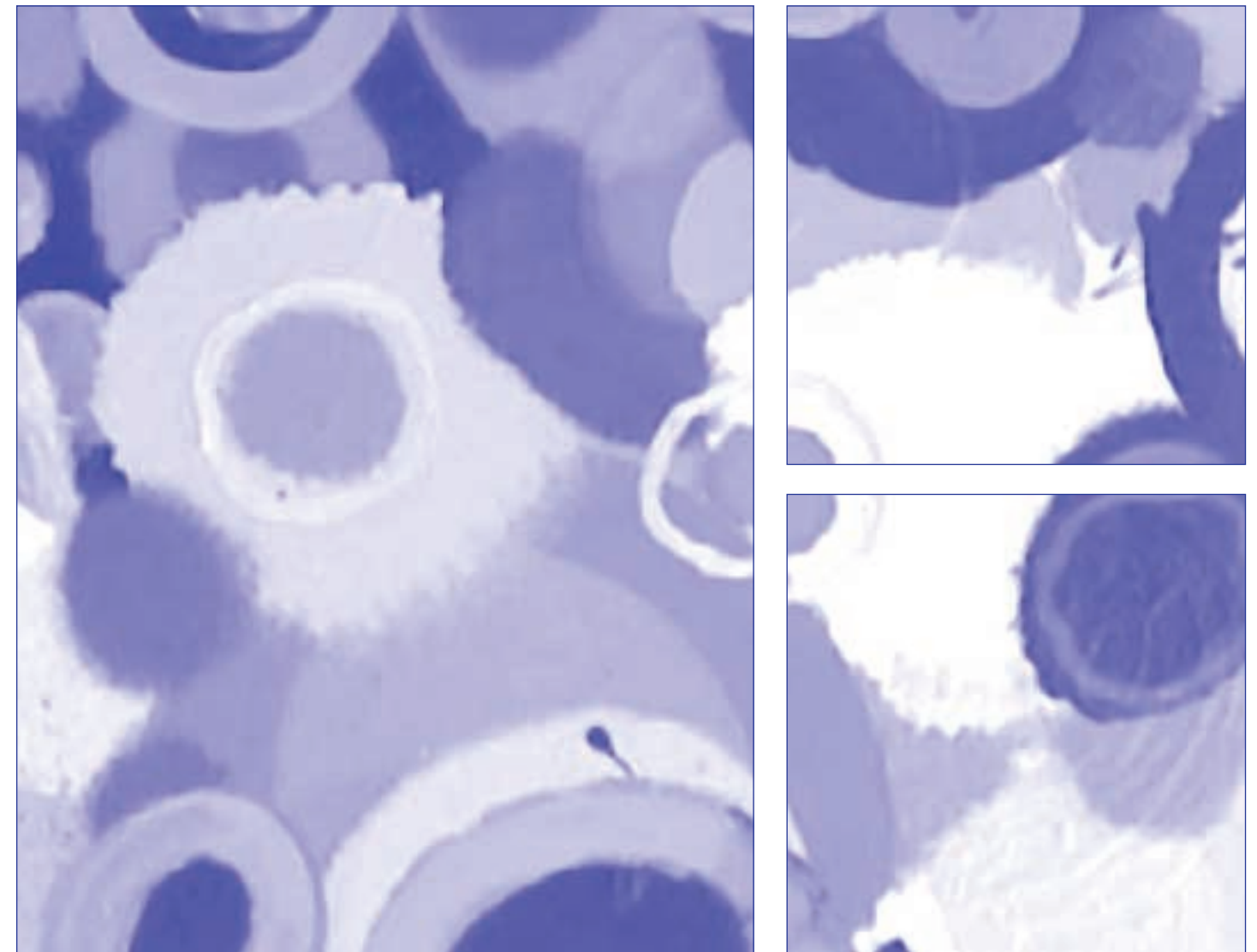




National Institute for Mental Health in England

Executive Summary, April 2004

Scoping Review on Mental Health Anti Stigma and Discrimination – Current Activities and What Works



For more copies of this document, please contact your local development centre or the central team in Leeds.

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mental health questions? **ask NIMHE**

www.nimhe.org.uk

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Foreword

People with mental health problems consistently identify stigma and discrimination as major issues affecting their lives. They can make it more difficult for people to find or stay in work, to receive health and social care services or adequate housing, for example, and to generally enjoy life. In addition, while mental health problems are usually time limited, stigma and discrimination are persistent, often affecting people long after the symptoms of mental distress have been resolved. Discrimination can lead to relapses in mental health problems, and can intensify existing symptoms.

The National Institute for Mental Health in England (NIMHE) is responsible for the Department of Health's activities on mental health stigma and discrimination, working in partnership with other public agencies and the voluntary sector. We are committed to doing what will work best, what we understand will have the most positive impact on how people are treated in their every day lives, and how we support each other to feel valued as equal citizens.

All around the country, and internationally, there are pockets of expertise and experience about what works most effectively in changing people's attitudes and behaviour towards mental health issues. This scoping review aims to begin bringing together this rich learning. It describes types of research evidence, principles underpinning initiatives and an overview of activities included in the review. The full version of the review is web based, available on www.nimhe.org.uk/stigma&disc, which we will continue developing to help share evidence of what works (and what doesn't) in this country and abroad on an ongoing basis.

We would like to thank mentality, Mental Health Media and Rethink who collaborated to produce the review. We are also grateful to the NIMHE's Board of Advisors for their support and advice in the project. The Board will play an important role in overseeing the strategic direction and implementation of NIMHE's future activities in this important area of work (see appendix 1).

NIMHE will use the learning and key messages in this review to shape a three year strategic plan which will be published this summer. The plan will set out a vision, aims and objectives including priorities for action and a framework for evaluation. It will include activities in response to the David Bennett and Daksha Emson Inquiries.

We hope that you find this review a useful and stimulating resource, and look forward to keeping in touch with you in the future.



Ingrid Steele
Director of Underpinning Strategies

DH INFORMATION READER BOX	
Policy	Equality
HR / Workforce	Performance
Management	IM & T
Planning	Finance
Clinical	Partnership Working
Document Purpose Best Practice Guidance	
ROCR Ref:	Gateway Ref: 2961
Title	What Works in Anti Stigma and Discrimination - A Literature Review
Author	National Institute for Mental Health in England
Publication Date	April-04
Target Audience	PCT CEOs, NHS Trusts CEOs, SHA CEOs, Care Trusts CEOs, Directors of PH, PCT PHC Chairs, NHS Trust Board Chairs, GPs, Communications Leads
Circulation List	Local Authority CEOs, Ds of Social Services, Voluntary Organisations
Description	The publication is a literature review of what works in anti stigma and discrimination. It has reviewed existing work happening locally, nationally and internationally. It is the first publication of its kind world wide.
Cross Ref	N/A
Superseded Docs	N/A
Action Required	NIMHE's national programme will build in the learning and key messages into the future national programme
Timing	N/A
Contact Details	Ingrid Steele NIMHE Blenheim House Duncombe Street LS1 4PL 0113 254 3811 (Divina Davidson - secretary)
For Recipients Use	

Current Evidence Base

All types of evidence have strengths and weaknesses. In our review, the 'what works' evidence falls into five main categories:

- Nature & prevalence of stigma and discrimination: establishing the scale of the issue including literature reviews
- Expert opinion: providing the views and experiences of users and carers who live with stigma and discrimination
- Public attitudes: this gives a broad perspective on what the public thinks of mental illness and people with mental health problems
- Models of change: dedicated to understanding the stigma process and examining ways in which our knowledge, attitudes and behaviours can change to reduce the prejudices, ignorance and fears surrounding mental health problems

- Assessments of anti-discrimination programmes and projects: looks at the effectiveness of work and different ways of measuring this.

We have looked at all types of evidence to provide a review of what works. There are few 'randomised controlled trials' (RCTs) and no systematic reviews on the effectiveness of anti-discrimination activities in mental health. The majority of evidence is found in programme reports, attitude surveys, quasi-experimental studies, qualitative research projects and review papers. This learning provides us with a good basis for understanding what is working on the ground and although this is not a well-researched area, we are making significant progress, which will need to be built upon by subsequent nationally co-ordinated work.

Underpinning Principles

The review has uncovered a range of effective approaches to challenging stigma and discrimination. From current evidence we have identified six key principles that underpin best-practice mental health anti-discrimination programmes. These principles are described below and the supporting evidence for each can be found in the full report www.nimhe.org.uk/stigma&disc

(i) Users and carers are involved throughout the design, delivery, monitoring and evaluation of anti-discrimination programmes

Mental health service users and carers should not only be consulted about the effects of discrimination, priority areas and potential target audiences but they themselves provide an important means of challenging stigma and dispelling stereotypes. There are numerous examples of user-led work that are successful because the target audience learn from those who are experts by experience.

(ii) National programmes that support local activity demonstrate the most potent combination for efficacy

Multi-faceted, multi level approaches are the most effective way of reducing stigma and discrimination. Using a combination of approaches and intervention methods, at a variety of different times in a range of appropriate settings, was shown to be effective in New Zealand and across the World Psychiatric Association (WPA) global network of stigma projects.

(iii) Programmes should address behaviour change with a range of approaches

Raising awareness and changing attitudes does not necessarily lead to a reduction in stigma or discrimination. Programmes that aim to reduce stigma and discrimination must address discriminatory actions by individuals, groups and organisations. Effective approaches include social inclusion and empowerment, providing support and skills to individuals required to adapt, developing an environment of intolerance to prejudice and ensuring change is sustainable and supported by policy and legislation.

(iv) Clear consistent messages are delivered in targeted ways to specific audiences

The role of clear and consistent messages is fundamental to having the desired impact. A coherent and co-ordinated approach is essential, especially as there is a large mental health community with very different starting points, aims, perspectives and activities.

To deliver effective messages the main recommendations from current work are:

- 1) Define your approach – for example are you taking a rights based stance or working with the bio-medical model?
- 2) Address anti-discrimination activities explicitly and not as part of general health programmes or mental well-being programmes.
- 3) Adopt social marketing principles to segment your target audience.
- 4) Focus on a limited number of target audiences or projects.
- 5) Know your audience well.

Review of Current Activity

(v) Long term planning and funding underpins programme sustainability

Changing the behaviour of the population is a long term goal and it will not be achieved overnight. Programmes which are most effective and contribute most effectively to the evidence base are those which are planned, delivered and monitored over a number of years. With time positive practice can be adapted to suit localities and replicated ensuring consistency and coverage.

(vi) Programmes should be appropriately monitored and evaluated

As the published evidence for effective practice is limited in this area it will be important for future programmes to add to the knowledge base by providing further information on best practice. The monitoring and evaluation of programmes should be considered when the aims and objectives of the programmes are established to ensure that indicators are relevant and relate to the chosen outcomes. Funders should allocate an appropriate resource to support the evaluation of anti-discrimination activities.

The task of reviewing all anti-stigma and discrimination activities is a tough one because many are embedded in other pieces of work including mental health service provision and mental health promotion. In the UK there are activities associated with World Mental Health Day – 10th October, education projects providing mental health training, media projects addressing media representations of mental illness, activities to reform discriminatory policy and legislation, public mental health awareness advertising campaigns to name a few. All we have been able to do in the review is to detail the main campaigns and identify a number of local projects in England. Even in this short summary it is not possible to do justice to all the work we have found but we list below the largest projects and direct you to the main report for a fuller review of current activities www.nimhe.org.uk/stigma&disc. Not all of the projects and campaigns included in this part of the review have included a robust evaluation component in their work but their experiences provide valuable insight into the implementation of anti-discrimination goals.

UK national programmes

Mind Out for Mental Health, England

The programme has targeted the media, youth and employer audiences. It has produced a range of communications materials, run workshops and events and networks with other agencies to achieve change. Communications materials include toolkits and resource packs, postcards and posters, newsletters, an ambassadors programme and web sites. www.mindout.net

'see me', Scotland

The campaign combines an award-winning national publicity programme with local and national anti-stigma action developed in partnership with like-minded groups and individuals across all sectors of Scottish life. Individuals who have experienced stigma are involved in many aspects of the campaign including those prepared to talk to the media about the impact stigma has had on their lives. www.seemescotland.org

Final Remarks

UK local anti-discrimination projects

We have had contact with 75 projects in the UK that are dedicated to reducing stigma and discrimination in mental health. For a summary of these groups and their approach to reducing discrimination please see www.openuptoolkit.net

National programmes overseas

MindMatters, Australia

The programme targets secondary schools and offers free resources kit for every Australian school and two-day professional development programme. www.apapdc.edu.au

Stigma Watch: Media Education Campaign, Australia

Target groups include the general public, advertisers and the Australian media. www.sane.org

Like Minds, Like Mine, New Zealand

The programme targets the general public, mental health workers, public sector agencies with frequent contact with people with experience of mental illness, media and other opinion leaders (e.g. politicians, church leaders). www.likeminds.govt.nz

National Stigma Clearinghouse, United States

Created to track and respond to stigmatising media images of mental illness and to provide information about stigma. Participants in the all-volunteer National Stigma Clearinghouse monitor the presentation of mental illness in popular media – newspapers, films, television, advertising. <http://community-2.webtv.net/stigmanet>

International Programme

Open the Doors, World Psychiatric Association

This is an umbrella programme for anti-discrimination programmes operating in 20 countries including Canada, Germany, Brazil, India, Turkey and Japan. Each country develops projects for a range of target audiences. A full report on the effectiveness of the programme in each country was presented in 2002. www.openthedoors.com

*"There is no single solution to discrimination, but different elements to potential 'solutions' exist. What is needed is to bring different strands of work together. In particular it would be helpful to force a stronger synthesis between, on the one hand, securing legislative improvement and enforcement and, on the other, promoting universal benefits of a more inclusive society. Each complements the other."*¹

Sayce, 2003

To develop and deliver effective anti-stigma and discrimination programmes in the UK it will be essential for the mental health promotion community to be supported. Building expert capacity nationally, and locally, to deliver and evaluate programmes will ensure the sustainability of effective practice. Appropriate programme management at all levels, real consultation, expert by experience involvement and investing in evidence based practice will over time support the delivery of a national programme for England. It is essential that we learn from our experiences of anti-discrimination work collectively, and form effective partnership to ensure our goals are attainable and measured. All research and evaluation should add to the evidence base for this important work, whether it aims to improve the quality of life of people with mental health problems, build local capacity to challenge discrimination, support citizenship and the human rights agenda, enhance inclusion and participation in local communities and/or promote mental health.

In the time available for our review it was only possible to reach a small number of the many anti-discrimination programmes operating in the UK. We would be keen to hear from other people who are engaged in these activities, and encourage you to contact us through the 'take Action' section of new web site: www.openuptoolkit.net and through the full published review resource on www.nimhe.org.uk/stigma&disc

¹ Sayce L (2003) *Beyond good intentions: making anti-discrimination strategies work. Disability & Society, 18 (5): 625-642.*

Appendix 1

NIMHE Anti Stigma and Discrimination Board of Advisors

The Board of Advisors to the programme at the time of publication of the scoping review were (in alphabetical order):

Andy Bell – Sainsbury Centre for Mental Health

Philip Brooks – NIMHE South East and Faculty of Public Health

Jenny Bywaters – NIMHE

David Crepaz-Keay – Mental Health Media

Margaret Edwards – SANE

Paul Farmer – Rethink

Keith Foster – NIMHE

Elizabeth Gale – mentality

Kate O'Hara – NIMHE West Midlands

Deborah Hart – Royal College of Psychiatrists

Gil Hitchon – Maca

Liz Main – Social Exclusion Unit

Chris Manning – PRIMHE

Karen Mattison – Independent Consultant

John Scott – NIMHE

Ruth Stanier – Social Exclusion Unit

Jude Stansfield – NIMHE North West

Ingrid Steele – NIMHE (and chair of board)

Adrian Thomas – Mind

Jan Wallcraft – NIMHE

Jackie Wilkinson – The Samaritans

Toby Williamson – Mental Health Foundation

The terms of reference for the Board are also on www.nimhe.org.uk