

## VOLUME IV

# Compendium of Programmes Aiming to Reduce Stigma and Discrimination Because of Schizophrenia or Mental Illness in General

Revised October 2002

### Introduction

This volume contains information on current and recent anti-stigma programmes worldwide collected by means of a postal survey and email inquiries. This information should help those implementing the WPA Programme design their own project and decide on the media materials to be used. The compendium may provide a basis for networking and may facilitate collaboration and sharing of knowledge and experience between people implementing programmes around the world.

The compendium focuses on programmes of public information or education and of political action. Programmes which are primarily clinical, but which may nevertheless have an element of public education aimed at reducing stigma, are not included in the compendium as a rule. Programmes fighting stigma and discrimination as part of the WPA Programme are described in Volume III.

The survey is ongoing and it is expected that many more programmes will be included as information about them is received. This volume is a revision of the earlier Volume 4 published in 1999 and includes programmes that have begun since that time.

### Request for further contributions

The WPA would be delighted to receive further contributions to this programme. If you wish to propose a programme or materials for inclusion in the compendium, please contact Professor Norman Sartorius at the address below.

Prof. Norman Sartorius  
H.U.G., Belle-Idée  
2, chemin du Petit-Bel-Air  
1225 Chêne-Bourg/Genève  
Switzerland

email: [Norman.Sartorius@hcuge.ch](mailto:Norman.Sartorius@hcuge.ch)  
Phone: +41-22-305 57 41  
Fax: +41-22-305 57 49

## **Acknowledgements**

The WPA wishes to thank all contributors to the survey for their interest, time, and effort. Their input has been extremely valuable to the WPA Programme. We thank Mrs. Radha Murthy, for conducting the survey and preparing the compendium.

## TABLE OF CONTENTS

### Programmes organized by Country

Australia	4
Belgium	17
Canada	19
Greece	22
Japan	27
New Zealand	30
Norway	33
Slovenia	37
Spain	42
United Kingdom	44
United States	52

# AUSTRALIA

## There is Hope: Schizophrenia Awareness Program

Managed by:	SANE Australia
Program type:	Public education campaign
Focus:	Schizophrenia
Target audience:	General public with a particular focus on young people
Location:	Australia
Start date:	November 1998
Projected end date:	May 1999
Languages:	English
Funding:	Friends of SANE Australia and the pharmaceutical company Eli Lilly and Company
Contact Person:	Ms. Barbara Hocking, Executive Director SANE Australia PO Box 226 South Melbourne Victoria 3205, Australia Tel: 61 3 9682 5933 Fax: 61 3 9682 5944 Email: barbara.hocking@sane.org

### Aims

To develop positive and supporting attitudes towards people with the illness. To increase awareness of:

- early warning signs and symptoms of schizophrenia
- effective treatments.

### Description

SANE Australia approached the editor and scriptwriters of a popular teenage soap *Home and Away*, to ask them to introduce a story line on schizophrenia. They agreed and worked with SANE and clinical specialists to develop the story and script. One of the regular characters then developed the illness. The story ran over 4 months and reflected accurately and sympathetically real life events. A positive and optimistic outcome demonstrated the effectiveness of modern treatments. This soap then was used as a springboard for a national campaign. A poster and pamphlet were developed using the image of 'Joey,' the character in the TV program, and were distributed via GPs, schools and clinics. Through media publicity using Joey, SANE Australia staff and clinical experts provided additional awareness.

## Materials produced

*Home and Away*, TV program primarily aimed at young people 12-30 yrs old, introducing schizophrenia by having one of the regular characters developing the illness. These episodes ran over a 4 month period in early 1999.

*'Schizophrenia' Pamphlet*, appropriate for a wider audience including family, friends, students and interested general community members. The pamphlet 'Schizophrenia' is part of a series of pamphlets called 'Understanding Mental Illness.' Other titles available are 'Bipolar Disorder,' 'Depression' and 'Anxiety Disorders' and 'Something is not quite right — getting help early for mental illness.' They are distributed via GPs, clinics, schools etc. as a first base information resource, containing basic information about schizophrenia, symptoms, causes, treatments, where to get more information and help etc.

Available from SANE Australia, PO Box 226

South Melbourne, Vic 3205 Australia

Aus\$ 16.50 per 100 plus P&P

Copyright: SANE Australia, can be used with clear acknowledgement.

Web site: [www.sane.org](http://www.sane.org)

Poster: no longer produced

## Evaluation and feedback

No formal evaluations have been conducted, mainly due to financial constraints. Informal measures of success in the 3 months following the campaign include:

- Extensive national mass media coverage
- 100% increase in Helpline & HelplineOnline contacts
- 50,000 pamphlets and 3,000 Posters distributed — via SANE to community groups and Eli Lilly reps to GPs — 100,000 pamphlets distributed in total in 9 months (pop 20m)
- SANE had increased contact from GPs re: other resources
- Schools now see the issue as relevant and request resources and even raise money to support our work!
- Acclaim from people with schizophrenia, reports of consumers heeding advice given to Joey and cooperating with treatment
- Positive experience for *Home and Away* team, who received congratulatory, unsolicited feedback from viewers, and won a Special Commendation in National media competition

## SANE Stigma Watch Programme

Managed by:	SANE Australia
Program type:	Media Education campaign – ongoing
Focus:	Mental illness generally
Target audience:	Mass media, students, general community
Location:	Australia
Start date:	August 1999
Projected end date:	Ongoing
Languages:	English
Funding:	Friends of SANE, Federal Department of Health and Aging
Contact Person:	Ms. Barbara Hocking, Executive Director SANE Australia PO Box 226 South Melbourne Victoria 3205, Australia Tel: 61 3 9682 5933 Fax: 61 3 9682 5944 Email: <a href="mailto:barbara.hocking@sane.org">barbara.hocking@sane.org</a>

### Aims

To promote accurate, respectful and positive reporting of mental illness in the media.

### Description

The media is one of the strongest influences over how people see life, and unfortunately it gets it wrong far too often on mental illness. SANE Australia's StigmaWatch program is an innovative and successful stigma reduction activity based on SANE's award-winning web site.

StigmaWatch provides an easily understood way to fight back against stigmatising and disrespectful reporting of mental illness in the media, and to applaud appropriate reporting.

Anyone can make a StigmaWatch report outlining their concerns and 'offending' broadcasters, journalists, or advertisers are approached, the nature of the complaint is outlined and they are asked to clarify/explain their actions. Education resources about mental illness are also enclosed. Reports are documented on the StigmaLog with responses from those approached. There is also a Good News Log which documents positive, accurate media reports.

As a result of StigmaWatch activity, Samboy *Psycho* strength chips are no longer sold, the video promotion for the film *Me, Myself & Irene* has been changed and Sony has made major changes to its offensive PlayStation game *Twisted Metal Black* (removing all references to mental illness).

### **Materials produced**

SANE StigmaWatch is based on SANE's website at [www.sane.org](http://www.sane.org)

The SANE *Guide to Fighting Stigma*, which provides information and guidance for interested community members about tackling stigma in their local areas, will be available in July 2002.

An annual SANE *StigmaWatch Report Card* will be produced in June each year, reporting to the media on how well it is doing in reporting mental illness.

### **Evaluation**

Informal measures of success include:

- Number and nature of StigmaWatch reports
- Responses received from media who have been reported
- General media interest in the site and stigma issues for stories and features
- The production and distribution of the SANE *Guide to Fighting Stigma*
- Great acclaim from all parts of the mental health sector for Stigma Watch for its unifying work for the mental health community
- SANE Australia's StigmaWatch program received a Gold Award from the Mental Health Services Conference of Australia and New Zealand in 2001

# Empowerment, Education, Awareness: A framework for addressing the stigma of mental illness

## Australian National Mental Health Strategy

Managed by:	Mental Health and Special Programs Branch, Commonwealth Department of Health and Aged Care, Australia
Program type:	Public education; training; research
Focus:	Mental illness generally
Target audience:	General public, (mental) health professionals, media, users, families of users and carers, young people
Location:	Australia
Start date:	1992
Projected end date:	Ongoing
Languages:	English
Funding:	From Commonwealth Government, Department of Health and Aged Care under the National Mental Health Strategy and the National Suicide Prevention Strategy
Contact Person:	Dermot Casey, Assistant Secretary Department of Health and Aged Care Mental Health & Special Programs Branch Ground Floor Alexander Annex MDP 37 GPO Box 9848 Canberra ACT 2601 Australia Tel: (02) 6289 7343 Fax: (02) 6289 7703 Email: <a href="mailto:dermot.casey@health.gov.au">dermot.casey@health.gov.au</a>

### Aims

To address the stigma of mental illness by utilising the framework provided by the National Mental Health Strategy.

### Description

The framework offers a strategic approach to address the stigma of mental illness. It focuses on increasing mental health literacy, information dissemination and exchange, professional development and education, promoting service user and carer involvement and empowerment, and improving quality and effectiveness of service provision. It supports a range of initiatives across a number of domains using key strategies to address identified target groups.



### **Public education projects by the Mental Health and Special Programs Branch include:**

- Rotary Health Research Fund: a series of community forums and television advertisements are being conducted to help de-stigmatise mental illness and to raise awareness about issues related to mental illness. Contact details: Email: joygillet@rotarnet.com.au; Postal: Australian Rotary Health Research Fund, PO Box 779, PARRAMATTA NSW 2124; Website: www.rotarnet.com.au.
- AusEinet: A national network helping to inform and educate mental health and other sectors about the concepts and practice of mental health promotion, prevention, early intervention and suicide prevention. Contact details: AusEinet, CAMHS, Flinders Medical Centre, BEDFORD PARK SA 5042; Website: <http://auseinet.flinders.edu.au>

It is furthermore supporting other agencies and projects, described in more detail the following pages: MindMatters, Mental Health Council of Australia (MHCA), and Training New Professionals.

### **Materials produced**

**Mental Health Information Brochures:** Six easy to understand information brochures (6 pages, foldout format) designed to increase mental health literacy in the community (developed 1996) have been updated and distributed nationally in 1999. These brochures are entitled: *Mental Illness–The Facts*, *What is Depression?*, *What is an Eating Disorder?*, *What is Schizophrenia?*, *What is Bipolar Disorder?*, and *What are Anxiety Disorders?* Two million brochures have been printed and distributed to general practitioners, pharmacists, schools and the general public since October 1999. These promotional materials have been widely accepted and continue to be in strong demand.

### **Achieving the Balance: A Resource Kit for Australian Media Professionals for the Reporting and Portrayal of Suicide and Mental Illness.**

Working closely with media industry representatives, health professionals and researchers, *Achieving the Balance* was developed to ensure that a wise and compassionate approach is adopted in the reporting of suicide and mental illnesses. This valuable reference document aims to assist media professionals to cover these issues in a sensitive and constructive way. The kit consists of two sets (one for suicide, one for mental illness) of 15 page strategy booklets, 31 page resource booklets and quick reference cards.

### **Evaluation and feedback**

The Mental Health and Special Programs Branch produces an Annual National Mental Health Report and Survey of Mental Health Services. Feedback on materials produced include high utility ratings on the Mental Health Information Brochures.

## MindMatters: A Mental Health Promotion Program for Australian Secondary Schools

Managed by:	Australian Principals Associations Professional Development Council (APAPDC) and Curriculum Corporation
Program type:	Public education
Focus:	Mental health generally
Target audience:	Secondary schools—staff, students communities
Location:	Australia
Start date:	30 March 2000
Projected end date:	Ongoing
Languages:	English
Funding:	Funded by Australian Commonwealth Department of Health and Aged Care under the National Mental Health Strategy and the National Suicide Prevention Strategy
Contact Person:	Susan Boucher APAPDC Education Development Centre Milner Street Hindmarsh, South Australia 5007 Tel: (+61 8) 8463 5860 Fax: (+61 8) 8463 5865 Email: sboucher@ozemail.com.au

### Aims

- To enhance the development of school environments where young people feel safe, valued, engaged and purposeful
- To increase knowledge and understanding about mental illness and promote early help seeking

### Description

MindMatters is a landmark initiative developed in recognition of the need to support the mental health and well-being of all young Australians. It is grounded in resilience research, aiming to enhance the development of school environments where young people feel safe, valued, engaged and purposeful. To do this, MindMatters uses a whole school approach, which recognises the interaction and connection between its curriculum, policies, practices and partnerships.

MindMatters is available free of charge to every Australian school with secondary enrollments, providing a range of school support and teaching materials as well as an initial two-day professional development program. There is also a dedicated website as an additional and ongoing resource: <http://www.curriculum.edu.au/mindmatters>.

## **Material Produced**

**MindMatters:** A Mental Health Resource for Secondary Schools, Published by Commonwealth of Australia. Curriculum Corporation. PO Box 177, Carlton South VIC 3053, Australia. The resource kit consists of 8 booklets of approx. 70 pages each, and one 36-min. video:

### **Booklets:**

- SchoolMatters: Mapping and Managing Mental Health in Schools
- Community Matters: Working with Diversity for Well-being in Schools
- Educating for Life: A Guide for School Based Responses to Preventing Self Harm and Suicide
- Enhancing Resilience 1: Communication, Changes and Challenges
- Enhancing Resilience 2: Stress and Coping
- A Whole School Approach to Dealing with Bullying and Harassment
- Understanding Mental Illness
- Loss and Grief

### **Video:**

- Understanding mental illness

## **Evaluation and feedback**

MindMatters is the result of the successful evaluation of an initial pilot program conducted to trial the curriculum and support materials. Ongoing evaluation is currently being undertaken, focussing both on the professional development being provided and the effectiveness of MindMatters in a number of case study schools. Interim results of this evaluation will be available regularly on the MindMatters website, with the final report due in 2004.

## Mental Health Council of Australia (MHCA)

Managed by:	Mental Health Council of Australia
Program type:	The MHCA is the peak, national, non-government organisation established to represent and promote the Australian mental health sector, with the mission of promoting the mental health of all Australians.
Focus:	Promotion of mental health and prevention of mental illness
Target audience:	The Australian mental health sector including consumers, carers, clinical service providers, special needs groups (rural/remote, Transcultural), private mental health service providers, non-government organisations, Aboriginal and Torres Strait Islander groups, and State/Territory based peak bodies. In addition, the MHCA also targets governments, political parties, and the general community.
Location:	Australia
Start date:	The MHCA was established in 1997, with the Secretariat established in May 1999.
End date:	Ongoing
Languages:	English
Funding:	The MHCA receives core funding from the Commonwealth Community Sector Support Scheme and National Mental Health Strategy funds through the Commonwealth Department of Health and Aged Care. Core funding is supplemented with the undertaking of national projects, sponsorships, and membership fees.
Contact Details:	Mental Health Council of Australia PO Box 174 DEAKIN WEST ACT 2600 AUSTRALIA Tel: (02) 6285 3100 Fax: (02) 6285 2166 Email: <a href="mailto:admin@mhca.com.au">admin@mhca.com.au</a> Website: <a href="http://www.mhca.com.au">http://www.mhca.com.au</a> Chairperson: Mr. John McGrath CEO: Mr. Des Graham

## **Description**

The Mental Health Council of Australia (MHCA) was established under the National Mental Health Strategy and was incorporated in June 1998. The MHCA is the peak, national non-government organisation representing and promoting the interests of the Australian mental health sector. It also provides advice to the Minister on mental health issues and works with the Department to progress reform initiatives at the grass roots community level. The Council has a broad constituency comprising organisations representing all key stakeholders including consumer, carers, special needs groups, clinical service providers, private mental health service providers, non-government organisations, Aboriginal and Torres Strait Islander groups, and State/Territory based peak bodies. The MHCA currently has 33 member organisations which are national bodies in their own right.

## **MHCA Board**

The activities of the MHCA are managed by a Board of 27 representatives (capacity of 30 representatives) with membership taken from MHCA member organisations.

## **MHCA Committees**

The MHCA Board is divided into 5 committees, each chaired by a member of the MHCA Executive and each with at least one consumer and one carer representative included in the membership. The committees include: Executive Committee, Research, Policy and Project Committee, Legal and Membership Committee, Finance Committee, Consumer and Carer Committee.

## **Activities of the MHCA**

Since the formation of the Secretariat in May 1999, the MHCA has undertaken management of the following national projects and initiatives:

### **Community Development Project and 'The Kit'**

Consumers and carers are increasingly asking for an enhanced role within the mental health sector as well as taking their place as community leaders in the struggle against stigma and discrimination. The Community Development Project (CDP) is a national project, funded in two phases by the Commonwealth Department of Health and Aged Care. The aim of the CDP is to put in place strategies and resources to enable consumers and carers to participate more actively through the development of community advocacy skills.

During the first phase of the project, The Kit – a guide to the advocacy we choose to do – was developed. The second phase of the CDP is being undertaken by the MHCA. The MHCA has identified key areas in undertaking management of the CDP: dissemination of The Kit, access, consultation and development, support, training, and evaluation.

The MHCA is about to commence delivery of a national curriculum program based on initial national consultations with consumers, carers and service providers about the needs of stakeholders in progressing community development. Five curriculum modules have been produced.

#### **Enhancing Relationships between Health Professionals and Consumers and Carers Project**

The Enhancing Relationships between Health Professionals and Consumers and Carers Project provides an overview of current issues, policy and initiatives which impact on consumers, carers, and health professionals and their ability to work in collaboration to improve mental health outcomes. Five key areas of direction for the Enhancing Relationships Project were identified as consumer and carer participation; continuous quality improvement; legislation; workplace reform; and education and training.

#### **Carers of People with Mental Illness Project**

The Carers of People with Mental Illness Project is an innovative partnership project funded by the Commonwealth Department of Health and Aged Care, and jointly undertaken by the MHCA and the Carers Association of Australia. The primary goal of the project was to identify priority actions to better support and recognise the roles of carers of people with mental illness across Australia. Stage 2 of this project, focussing on implementation of the recommendations, is currently being negotiated.

#### **World Mental Health Day 1999, 2000 and 2001**

World Mental Health Day is an annual international event, celebrated since 1992, that is co-ordinated by the World Federation for Mental Health and co-sponsored by the World Health Organisation, a specialised agency of the United Nations. Over the past 3 years the MHCA has developed a campaign for World Mental Health Day based on the international theme for the day: Mental Health and Work.

#### **World Health Day 2001: Stop Exclusion – Dare to Care**

The MHCA undertook the national co-ordination of World Health Day (held by the World Health Organisation) activities in Australia on 7 April 2001. The theme of the event was dedicated to mental health issues, and its prime objective was to impact public opinion and stimulate debate on how to improve the current condition of mental health around the world. The role of the MHCA included a national media campaign, a national ministerial launch, national distribution of promotional materials, development of a website and co-ordination of State-based activities in collaboration with local organisations.

### **Alleged Discrimination by Insurance Companies**

The MHCA has recently undertaken an investigation of alleged insurance discrimination against those who either have, or have had, a mental illness. This investigation is being undertaken in partnership with beyondblue: the national depression initiative.

### **Establishment of a National Consumer and Carer Forum**

With the proposed closure of the Network of Australian Community Advisory Groups (NOAC), the MHCA has been working with NOAC to develop a proposal to maintain the national network of consumers and carers established through NOAC. A National Consumer and Carer Forum is the proposed model to be co-ordinated by the MHCA in partnership with States/Territories. This proposal was unanimously endorsed by the Australian Health Ministers Advisory Council National Mental Health Working Group (AHMAC NMHWG) on 7 September 2001 with agreed funding of \$121,000 per year. The MHCA informed the AHMAC NMHWG final endorsement of the proposal would be considered by the MHCA Board at the meeting on 18 September 2001.

### **Materials Produced**

- The Kit: A Guide to the Advocacy we Choose to Do
- Final Report of the Carers of People with a Mental Illness Project
- Final Report of the Enhancing Relationships between Health Professionals and Consumers and Carers Project: Identifies barriers to enhancing relationships along with a series of strategies to overcome these barriers.
- Promoting the Mental Health of all Australians – A Federal Election 2001 Submission
- Flannel Flower package – 1 Flannel Flower lapel pin and one Flannel Flower postcard: As part of the World Mental Health Day campaign, the MHCA developed an enduring national symbol for mental health – the Flannel Flower. This native Australian plant represents the resilience, adaptability to change and sensitivity that is important in each individual's mental health life.
- Promotional materials (e.g. posters, brochures, fact sheets etc.) for World Mental Health Day and World Health Day
- MHCA Annual Report (1999 - 2001), Strategic Plan (1999- 2001), Sponsorship brochure, and quarterly newsletters.
- Copies of all MHCA policy submissions, project reports, and other materials are available on the MHCA Website, [www.mhca.com.au](http://www.mhca.com.au).

## Response Ability: University Curriculum Resources

Managed by:	Hunter Institute of Mental Health Australia
Program type:	Training
Focus:	Mental illness, mental health promotion, and suicide prevention
Target audience:	University students in the disciplines of secondary education and journalism
Location:	Australia
Start date:	2000 [Phase Two]
Projected end date:	2002
Languages:	English
Funding:	Funded through the Commonwealth Department of Health and Aged Care, under the National Mental Health Strategy and National Suicide Prevention Strategy
Contact Person:	Hunter Institute of Mental Health PO Box 833 NEWCASTLE NSW 2300 Tel: (02) 4924 6721 Fax: (02) 4924 6724 Website Address: <a href="http://www.himh.org.au">http://www.himh.org.au</a> Email: <a href="mailto:himh@hunterlink.net.au">himh@hunterlink.net.au</a>

### Aims

To disseminate mental health promotion and suicide prevention resources to universities, for use with students in the disciplines of secondary education and journalism.

### Description

The Hunter Institute of Mental Health, based in Newcastle, is being funded to further develop and disseminate mental health promotion and suicide prevention resources for the training of new professionals, in secondary education and journalism. The resources are available to academics teaching in each of these disciplines and to students via the Internet.

### Materials produced

- *Response...Ability: Curriculum Resources on the Issue of Youth Suicide*. [Phase one Materials]. Published on the Internet, developed for use in tertiary education courses of professionals (nurses, high school teachers, journalists) in Australia. Available at [www.himh.org.au](http://www.himh.org.au).
- *Response Ability: Curriculum Resources Teacher Education Youth AND Response Ability: Curriculum Resources for Journalism Education* [Phase Two Materials]. Published primarily in CD-ROM format with additional materials on the internet, developed for use in tertiary education courses of professionals (high school teachers and journalists) in Australia. Available at [www.responseability.org](http://www.responseability.org).



# BELGIUM

## Changing community attitudes on community care for the severely mentally ill

Program type:	Education and information in an interactive way targeted at groups of lay people
Focus:	Changing community attitudes on community care for the severely mentally ill
Target groups:	Lay people, informal volunteer carers, police, students
Location:	Sint-Niklaas (Oost-Vlaanderen, Belgium)
Research:	Katholieke Universiteit Leuven, Belgium
Start date:	January 1st, 2000
Projected end date:	December 30th, 2002
Languages:	Dutch
Funding:	Grant from the 'Ministerie van de Vlaamse Gemeenschap, Administratie Wetenschap en Innovatie, Afdeling Wetenschappen' (PBO98/27/73)
Contact Person:	Katleen De Rick Prof. Dr. Chantal Van Audenhove LUCAS (Katholieke Universiteit Leuven) Kapucijnenvoer 35 B-3000 Leuven Belgium katleen.derick@med.kuleuven.ac.be chantal.vanaudenhove@med.kuleuven.ac.be Tel :+ 32 16 33 69 10 Fax :+ 32 16 33 69 22 Website address: <a href="http://www.kuleuven.ac.be/lucas/">http://www.kuleuven.ac.be/lucas/</a>

### Aims

To enhance knowledge about the origin and courses of severe and enduring mental illnesses and about the disabilities and skills of the severely mentally ill to encourage positive attitudes towards the severely mentally ill towards care in the community.

### Description

Two complementary evening meetings (each lasting two hours), which include a lecture and talk, theoretical information on the causes and consequences of mental illnesses, experiences of a client and a family member (both interviewed by a professional caregiver), a conducted tour of mental health services, introduction to different therapies (group therapy, music therapy, sports therapy) introduction to different forms

of community care (sheltered living, drop-in centre, centre for ambulatory health care, vocational rehabilitation) and question time and ‘stay and talk.’

#### **Program features**

- Active involvement of three groups of stakeholders: clients, family members and professionals
- Active involvement of the lay people (e.g. group therapy)
- Interaction between stakeholders and lay people (question time and ‘stay and talk’)
- Involvement of all regional services for the severely mentally ill (psychiatric hospitals, centre for ambulatory mental health care, centre for vocational rehabilitation, drop-in centre, sheltered living)

#### **Materials produced**

Dutch translation of the questionnaire ‘Community Attitudes toward the Mentally Ill (CAMI) (Taylor & Dear, 1979).

#### **Evaluation**

##### **POSITIVE**

##### **for the clients :**

- participating can contribute to the recovery process
- enhances empowerment
- enhances self esteem
- is satisfying
- makes the client a positive role model

##### **for the professionals:**

- participating makes the professionals aware of the possibility of engaging clients
- encourages intra-organisational collaboration

##### **for the lay people:**

- participating breaks stereotype images
- enhances knowledge
- encourages a positive attitude

##### **NEGATIVE**

##### **for the clients:**

- participating is very burdensome
- endangers privacy
- can cause envy from the other clients

##### **for the professionals :**

- participating is very time consuming

# CANADA

## Partnership Programme

Managed by:	Schizophrenia Society of Nova Scotia Canada
Program type:	Public education
Focus:	Schizophrenia
Target audience:	General public, secondary school students (high school students), families of mental health service users
Location:	Nova Scotia (and other Canadian provinces)
Start date:	Mid 1995
Projected end date:	Ongoing
Languages:	Mostly English, some French
Funding:	Individual fund raising, private donations, with initial funds at under \$1000
Contact Person:	Mr. Dion Moulant B.Sc, DHSA, MHSA(pending) Executive Director Schizophrenia Society of Nova Scotia P.O. Box 1004 Dartmouth Nova Scotia B2Y 3Z9 Nova Scotia, Canada Tel: +1(902) 465-2601 Fax: +1(902) 465-5479

### Aims

To promote a better understanding of the illness of schizophrenia and to reduce stigma.

### Description

The Partnership Program is a public educational programme in which people suffering from schizophrenia, members of their families and mental health professionals jointly deliver presentations on schizophrenia to a variety of audiences. In each presentation a person with schizophrenia and a family member talk about the difficulties in living with schizophrenia. Their personal stories help to humanize the illness and add compassion to their plight. The mental health professional lends his/her medical expertise to the presentation. Discussion generally includes the onset of the illness and early signs, surviving the illness, treatments and their side effects, and relapses.

The presentation may involve viewing of some audio-visual material, such as the locally produced video “Walk Beside Me” in which service users talk about their personal experiences with the illness.

This public educational model was developed by the Schizophrenia Society of Alberta where a Partnership Program has been in operation since January

1994. It has spread to other provinces in Canada subsequently. These joint presentations are felt to be a very dramatic and effective way to educate.

### **Materials produced**

“Walk Beside Me.” This video describes the experience of living with schizophrenia in several rural and urban communities in Nova Scotia. It features people with schizophrenia and their families filmed in their home environment describing in their own words what contributes to, and detracts from, their quality of life as they live with the illness. 35 Minutes. Jointly produced by New Beginnings and Schizophrenia Society of Nova Scotia, Canada, 1994.

### **Evaluation and feedback**

In Nova Scotia presentations were given to at least seven schools, the Rotary Club Dartmouth, and the Petty Officers' Club Halifax, since mid 1995. More than 100 videos have been sold. Evaluation sheets were passed out during each presentation and feedback has generally been very positive. Many students have approached the Schizophrenia Society for more information having decided to do a project on the subject and many of those achieved high marks. Overall, these presentations were felt to bring the Society much closer to the general public and to high school students, than any other means used.

## Televised Schizophrenia Awareness and Fund Raising Auctions

Managed by:	Schizophrenia Society of Nova Scotia Bridgewater Chapter, Lunenburg County Canada
Program type:	Public education (combined with fund raising)
Focus:	Schizophrenia
Target audience:	General public
Location:	Lunenburg County, Nova Scotia
Start date:	August 1995
Projected end date:	Ongoing
Languages:	English
Funding:	Local firms donate gifts to be sold on the auction; local TV/Radio network is providing its services free of charge
Contact Person:	Ruth and Bruce Herridge Representatives, Bridgewater Chapter Schizophrenia Society of Nova Scotia Box 271 Mahone Bay, Nova Scotia B0J 2E0 Canada Tel: +1 (902) 624-8904 Fax: +1 (902) 624-8784

### Aims

To increase awareness of schizophrenia and to reduce stigma.

### Description

One or two weeks before Christmas an auction of donated goods is held, broadcast on local television. The auction element is alternated with entertainment by local artists and discussions on schizophrenia by service users, their families and local mental health workers. Viewers can call in to the station to make their bids for goods auctioned or to join the discussions. Over 5000 viewers are tuned in to the auction at any given time.

### Evaluation and feedback

Two auctions have been held so far, raising over \$10,000. Following these broadcasts more sufferers have been coming forward, contacting the Schizophrenia Society for more information and support. As a direct result, the Schizophrenia Society's " Schizophrenia: A Handbook for Families" had to be reordered and reprinted to meet demands.

# Greece

## Association of Families for Mental Health (SOPSI)

Association type:	Voluntary organization
Focus:	Stigma associated with mental illness
Target audience:	General public, as well as families of people with mental illness
Location:	Nationwide in Greece
Start date:	1993
Languages:	Greek and English
Funding:	Self-funding
Contact:	SOPSI Dilou 3 Vironas 16231 Greece Tel: +301 7640277 Fax: +301 7640277 E-mail: dandronikos@Ath.forthnet.gr

### Description

The Association of Families for Mental Health was established in 1993 in Athens by a few families who were not only seeking help in order to better cope with the illness of their relatives, but also to confront societal discrimination against persons suffering from a mental illness and their family members. These days, SOPSI has members nationwide and has contributed to the establishment of local organizations in the major cities of Greece. It is a voting member of the National Confederation of Disabled Persons of Greece, the European Federation of Associations of Families of Mentally ill (EUFAMI), the World Association of Psychosocial Rehabilitation (W.A.P.R.) and of the World Schizophrenia Fellowship (W.S.F.). Moreover, SOPSI maintains contacts with the World Health Organisation (W.H.O.), as well as with local organizations helping Greek people in several countries and especially in Greece.

Members of SOPSI can be either physical or legal entities. Family members of persons suffering from mental illness are voting members, but friends, mental health professionals and all persons interested in the association's activities are also welcomed as members.

The administrative members are made up of the General Assembly, the Board of Directors, the Scientific Committee and the Reviewing Committee. All administrative members are elected by the General

Assembly every second year. The Board of Directors nominates the Scientific Council and its role is advisory and consultative.

### **Objectives**

The main objectives of SOPSI are to support its members in various ways, to reduce fear and anxiety and any kind of discrimination against those who suffer from mental illness and their families and to fight stigma.

### **Activities**

In order to achieve its goals, SOPSI increases public awareness and understanding of mental illness by publishing information leaflets and organizing lectures, seminars and campaigns. In addition to that, SOPSI runs psychoeducational groups as well as support and self-help groups for relatives.

## Association Against the Prejudice of Mental Disorders “Anagennisi”

Managed by	U.M.H.R.I.
Programme type:	Training and education of patients, advocacy, public education, research
Focus:	Mental Illness Generally
Target Audience:	Patients, friends, relatives, general public, health care professionals
Start date:	1984
Funding:	Self-funded, small funding from the participation of the Association in European Programs, support from the U.M.H.R.I. and human resources provided by friends of the Association
Contact:	4, Eginitou street 115 28 Ilissia Athens, Greece Tel: 0030 10 7292888 Fax: 0030 10 6170917 Email: vkaridi@compulink.gr

### Description

The Association Against the Prejudice of Mental Disorders (originally named “Synechia”) was founded in 1984 by people with mental disorders. It was the first such association to participate in pilot programmes for vocational preparatory work and training. The Association, with the support of the University Mental Health Research Institute (U.M.H.R.I.) offers its members various forms of assistance, strengthens the mutual help and solidarity between them and is opposed to all kinds of prejudice, social rejection and isolation surrounding mental disorders.

In 1994, the Association was expanded with the participation of employees of the psychosocial rehabilitation programmes of the U.M.H.R.I., friends, relatives and volunteers and was re-established as “Anagennisi,” with the basic goal of becoming more effective against social stigmatization and self-stigmatization on a national and European level. The newly-formed Association proved to be more functional, flexible and effective regarding its main purpose and its additional goals for people with mental disorders.

### Goals

The basic goal of Anagennisi is the improvement of social sensitivity towards mental illness, as well as the fight against self-stigmatization (the stigma that the patient holds for himself/herself).



#### **Additional goals of the Association are:**

- To develop common activities and actions against stigma and to promote a change in attitudes in local European societies. Since 1998, the Association, with the support of U.M.H.R.I., has pursued this goal through participation in programmes of the European Union and by the organization of a European network of associations for people with mental disorders.
- Improvement of the quality of life for people with mental disorders (including use of leisure time, pursuit of occupational motives, participation in programs or activities with family members).
- Development of meaningful relationships between the members and their families.
- Organization of volunteer support and self-help groups (e.g. visits in guests' houses of chronic patients, operation of a "support-fund").
- To improve the awareness of health-care professionals and the general public about mental illness.
- Patient psychoeducation in order to develop more positive attitudes towards various therapy methods and also to reconcile the illness with its social perspectives.
- Formation of volunteer groups and committees which can pursue the goals of the Association and the organization of social, cultural and recreational activities.

#### **Past and future activities**

- Publication of informational pamphlets about the activities of the Association. The pamphlets have been distributed during meetings and conferences dealing with mental health, as well as to relevant groups.
- Organization of recreational and cultural activities under the scope of quality of life improvement and relationship strengthening among members on a stable basis.
- Establishment of open voluntary groups that help primarily in crisis prevention and in emergency situations which may occur with some of the members of the Association (e.g. lonely individuals in relapse, loss of a relative, loss of job etc.).
- Psychoeducation in small groups of patients and relatives. (Professionals that work with these groups are always volunteers, members of UMHRI).
- Participation of the Association in research programmes: a) Patients have administered questionnaires to a large number of employers in order to explore the attitudes towards the illness and towards patients, and with the aim to sensitize through direct contact, and b) All patients have completed questionnaires for a UMHRI's study regarding self-stigmatization.
- Participation of the Association in conferences, meetings and events.

- Participation of the Association in the recognition of European programmes as an equal partner with national and international bodies.
- A network of patient associations has been formed in Scotland, Austria and Greece aiming to record attitudes, develop mutual activities and actions for the fight against stigma and to improve the attitudes of local communities in Europe.
- Participation in art events, mainly painting exhibitions organized on a local and national level. The art works of the patients are often sold or awarded.
- Organization of patient networks, health units and guest houses on a national level.

### **Evaluation**

While the Association has undoubtedly made major progress in many areas since its inception in 1984, perhaps the most important transformation has occurred with the Association members themselves. Through the years of hard work, there has been a progressive elimination of the concept of “they, the healthy ones – us, the patients,” an adoption of the perception that “we are all human beings with individual differences and weaknesses” and the tendency towards the attitude that “we are fighting for the prevalence and expansion of our strong points.” A patient from the Association “Revival” recently exemplified this shift in concept in an answer given at the Associations’ meeting in Austria (program “An enabled voice in mental health”):

*When we are ill we cannot express our opinion because we are confused and upset... As we recover we become capable of participating in decision-making... It is exciting... We all must remember to enjoy every experience and mainly to show tolerance among each other. If we cannot do that among us how could we expect others to be tolerant towards us?*

The Association is seeking funding from private and public bodies in order to accomplish the outlined goals.

# JAPAN

## Committee on Concepts and Terminology of Psychiatric Diseases

Managed by:	The Japanese Society of Psychiatry and Neurology Japan
Program type:	Training (political action)
Focus:	Schizophrenia
Target audience:	Mental health workers, physicians, students, politicians
Location:	Japan (Bukyo-ku, Tokyo)
Start date:	27 March, 1993
Projected end date:	Ongoing
Languages:	Japanese (some proceedings available in English)
Funding:	Japanese Society of Psychiatry and Neurology
Contact Person:	Yuki S. Nishimura M.D., Ph.D. National Research Institute of Police Science 6-3-1, Kashwanoha, Kashiwa city Chiba 277-0882 JAPAN Tel: 81-471-35-8001 Fax: 81-471-33-9184 Email:satsumi@nrrips.go.jp

### Aims

To rethink the term schizophrenia (so-called "Seishin-Bunretsu-byo" in Japanese, meaning "splitting of spirit") and possibly reducing stigma by changing this term. Proposals for alternatives were considered and at the WPA World Congress in Yokohama, Japan, August 2002, the Japanese term for schizophrenia was officially changed from "seishi buntetsu byo," which means "split-mind disorder," to "togo schiccho sho," which means "loss of coordination disorder."

### Description

The Committee on Concepts and Terminology of Psychiatric Disorder was set up in 1993 by the Japanese Society of Psychiatry and Neurology (JSPN). The committee consists of 10 members of JSPN who are psychiatrists, and one lawyer. A subcommittee called "Committee on Rethinking the Term Schizophrenia" is focusing on schizophrenia, while another subcommittee "Committee on Disease Concepts and Terms" is focusing on mental illness more generally. A preliminary study, the results of which were presented during the Xth World Congress of Psychiatry in Madrid in 1996, explored the preconceptions Japanese Psychiatrists harbour, how they use the term schizophrenia in practice, and how they manage various issues surrounding this stigmatized

diagnosis. It brought out the reality of stigma attached to the term schizophrenia. They planned a symposium entitled “Rethinking the term Schizophrenia” during the XIth World Congress of Psychiatry in Hamburg in 1999, and the results of their field study were presented.

The Committee on Changing the Term Schizophrenia (CCTS) and the Special Committee for Anti-stigma (SCA) were set up in 2000 by JSPN. In response to the results described in the above study, the Committee is researching some of the issues faced by people with mental disorders, such as their recognition of their own diagnosis, how they had known the diagnosis, what they expect of mental health care. In the course of publications and presentations, the Committee is aiming to stimulate discussion on the term schizophrenia and the stigma attached, and is promoting the generation of possible alternative terms, in the hope of reducing stigma.

In June 2001, the Committee on Changing the Term Schizophrenia investigated alternatives to the Japanese term for schizophrenia.

On November 11th 2001, the Committee on Changing the Term Schizophrenia held a public hearing entitled “Public Hearing to rethink the term schizophrenia.” The meeting consisted of a nurse, a PSW, a psychiatrist from an outpatient clinic, a psychiatrist from a psychiatric hospital, a lawyer, a reporter from Asahi Newspaper, a specialist of medical ethics, an individual suffering from schizophrenia, a family member from the National Federation of Families with the Mentally Ill in Japan (NFFMIJ), a member of the general public, and a director of secretariat of FFMIJ (as an observer).

Between 2001 and 2003, Dr. Nishimura Y., a member of both committees, has been granted a subsidy from the Ministry of Health and Welfare for the “Study on reducing the stigma of people with mental illness.” Based on this fund, the CCTS has a project to study the negative image subjected to people with schizophrenia, and several names to replace the Japanese term for schizophrenia.

CCTS and SCA planned a symposium consisting of 2 sections at the XIIth World Congress of Psychiatry in Yokohama in 2002: “Beyond the term schizophrenia;” “The term schizophrenia and stigma.” In the first section, 5 researchers (Italy, UK, Germany, Japan) held a discussion based on their own data. In the second section, a president of World Fellowship for Schizophrenia and Allied Disorders, a family member from NFFMIJ, and Korean, Chinese and Japanese psychiatrists discussed the issues of stigma in their own countries.

## Materials produced

Publications by the Committee:

- 1) Report of Questionnaire on the concept and the term of schizophrenia; part 1, *Japanese Journal of Psychiatry and Neurology*, 98(4), 1996 (IN JAPANESE)
- 2) Report of Questionnaire on the concept and the term of schizophrenia; part 2, *Japanese Journal of Psychiatry and Neurology*, 99(8), 1997 (IN JAPANESE)
- 3) "Schizophrenia: Is there a term to replace the term?" *Psychiatry and Clinical Neurosciences*, 53: 335-341, 1999
- 4) Impact of the term schizophrenia on the culture of ideograph: The Japanese experience.; *Schizophrenia Bulletin*, 27(2):181-187, 2001

## Evaluation and feedback

The initial survey of members of the JSPN in September 1996 indicated that a majority of members felt the term "schizophrenia" should be changed. This conviction was strongly related to members witnessing great difficulties experienced by patients and/or their families in accepting the diagnosis of schizophrenia. It also was found to be strongly related to the problems experienced in giving a certificate for absence from work, or explaining the diagnosis and/or its prognosis to third parties.

During symposiums at Annual Meetings of the Japanese Society of Psychiatry and Neurology, including a poster session at the Xth WPA Congress in Madrid, August 1996, a lively response from the audience was encountered on this theme. Patients suffering from schizophrenia, present at any of the Conferences or presentations, confirmed that they had been waiting for a long time for this kind of action and that it was "the most important thing." Psychiatrists wishing to see the term changed sent in journal articles or manuscripts with encouraging words. Great interest was expressed in whether it would be likely or not that the term would be changed in the future. At the WPA World Congress in Yokohama, Japan, August 2002, the Japanese term for schizophrenia was officially changed from "seishi buntetsu byo," which means "split-mind disorder," to "togo schiccho sho," which means "loss of coordination disorder."

## NEW ZEALAND

### Like Minds, Like Mine: Project to Counter Stigma and Discrimination Associated with Mental Illness

Managed by:	Ministry of Health New Zealand
Program type:	Public education
Focus:	Changing attitudes and behaviour towards people with experience of mental illness
Target audience:	General public, mental health workers, other public sector agencies with frequent contact with people with experience of mental illness, media, other opinion leaders (e.g. politicians, church leaders)
Location:	New Zealand
Start date:	1996
Projected end date:	Ongoing
Languages:	English, New Zealand Maori, Samoan, Tongan, Cook Islands Maori, Niuean
Funding:	Government funding
Contact Person:	Gerard Vaughan Ministry of Health PO Box 5013 Wellington New Zealand Tel: +64 4 496 2064 Fax: +64 4 496 2340 Email: gerard.vaughan@moh.govt.nz

#### Aims

- To empower people with experience of mental illness to gain equality, respect and rights
- To put mental health on people's agendas
- To educate people about what mental illness is
- To promote greater understanding of, acceptance of and support for people with mental illness
- To change public and private sector policy to reflect the above
- To communicate the above effectively with all key groups in New Zealand

#### Description

“Like Minds, Like Mine” is a comprehensive health promotion programme, including the development of organisational policy guidelines for government agencies, a mass media campaign to create a supportive social environment, and a number of regional educational programmes.

The latter aim at providing training and developing resources to support community action, to promote communication and advocacy skills of people with experience of mental illness and to re-orient health services to eliminate discriminatory attitudes and behaviour.

The project's vision is to work towards creating a nation that values and includes people with mental illness.

Regional service providers develop networks and infra-structure in order to empower people with experience of mental illness by involving them in the project and develop educational programmes to meet local needs, targeting the mental health sector, key opinion leaders, news media, schools and communities.

National service providers develop organisational policy guidelines and service quality standards to ensure people with mental illness are treated with equality and respect and mount a mass media campaign to raise public awareness. They are responsible for evaluation of the project.

## **Evaluation and feedback**

### **Formal evaluations completed:**

- 1) Formative evaluation 1996: Survey of public knowledge of and attitudes to mental health and mental illness. Business Research Centre for Ministry of Health.
- 2) Pretesting of National Advertising Campaign. October 1999 Phoenix Research for Health Funding Authority (Testing of four creative concepts for the campaign).
- 3) Process evaluations 1999, 2000. Nona Milburn and Phoenix Research for Health Funding Authority. (Evaluations completed in the different regional areas of the community education work and other activities carried out by the contracted providers).
- 4) National media campaign benchmark survey of general public attitudes to mental illness, March 2000. Phoenix Research for Health Funding Authority.
- 5) National media campaign tracking survey against benchmarks of general public attitudes to mental illness, January 2001. Phoenix Research for Health Funding Authority.
- 6) Public response to national media campaign - tracking surveys carried out in April 2000, August 2000 and June 2001. Phoenix Research for Health Funding Authority.
- 7) Report on response of people with experience of mental illness to the National Mass Media Campaign. March 2001. Phoenix Research for Health Funding Authority.

**Formal evaluations planned:**

1. Two further tracking surveys of general public attitudes to mental illness are planned for phase two of the national mass media campaign that will run in 2002.
2. Two further tracking surveys are planned for the public's response to the national media campaign.
3. A further evaluation of the response of people with experience of mental illness to phase two of the National Mass Media Campaign is planned for 2002.
4. Further process and impact evaluations will be completed in 2001 and 2002 around the work of the regionally contracted providers and some national projects.

Informal feedback was received in a number of ways. Numerous requests for information about mental illness and personal help came in through the toll-free counselling and information service accompanying the mass media campaign. An increased demand for community education services and resources for schools came to the fore, as well as an increased news media interest in the television advertising (as part of the mass media campaign), especially regarding the experiences of celebrities with experience of mental illness involved in the advertising.



## NORWAY

### TIPS: Tidlig-Intervensjon ved Psykose (early Treatment and Intervention in Psychosis)

Managed by:	Rogaland Psychiatric Hospital Rogaland County, Norway
Program type:	Public education campaigns in context of clinical programme
Focus:	Mental illness in young people (early psychosis)
Target audience:	General public, students, mental health consumers and their families, mental health professionals, physicians etc.
Location:	Rogaland County, Norway
Start date:	1987
Projected end date:	2006
Languages:	Norwegian, Danish, English
Funding:	Public funds (cost of information campaigns NOK 1 million/year or £80,000/year)
Contact Person:	Jan Olav Johannessen, Chief Psychiatrist Rogaland Psychiatric Hospital Armauer Hansensvei 20 Postboks 1163 Hillevåg 4004 Stavanger, Norway Tel: +47 (51) 515151 Fax: +47 (51) 515205 Email: <a href="mailto:joj@rps.no">joj@rps.no</a> Web site: <a href="http://www.TIPS-info.com">http://www.TIPS-info.com</a> <a href="http://www.schizofrenidagene.no">http://www.schizofrenidagene.no</a> <a href="http://www.psykopp.no">http://www.psykopp.no</a>

#### Introductory note

While the central aim of the programme may be clinical, it has been included in this compendium because of its significant public education component, which consists of an extensive and sustained campaign targeting young people especially. Anti-stigma campaigns as part of public information strategies are considered necessary components of early intervention strategies.

#### Aims

- To reduce fear and stigma of mental illness and of the psychiatric services in order to facilitate access to the psychiatric services.
- To reduce duration of untreated first episode psychosis (clinical aim).

## Description

The TIPS Programme consists of a highly responsive mental health services programme for early detection and treatment of first onset psychosis.

With unfavourable outcome (longer and more chronic disturbance) being considered a possible consequence of delayed treatment of early schizophrenia, development of an early intervention service became a priority in Rogaland by the late 1980's. The first public education campaigns grew out of the need to reduce the barriers to the mental health services so as to reach young people with first episode psychosis earlier.

A study evaluating the programme's impact on 'Duration of Untreated Psychosis' (DUP) was launched in January 1997 to last for four years. An intensified public education campaign in Rogaland forms part of this study. The results in Rogaland are compared with results of two further study sites without major public education campaigns in Oslo County in Norway and Roskilde county in Denmark.

### Public education campaigns:

1. Schizophrenia Days: Since 1989, a week-long conference about psychoses for professionals and the public, is held each year in the middle of Stavanger in the town's cultural centre. It includes arts such as theatre, cinema and picture exhibitions, lectures for the public, political conferences etc. Schools are invited to attend special lectures and to develop projects around psychiatric and psychological themes. Television as well as local newspapers cover the events. The Schizophrenia Days are now visited by approximately 1000 professional people and 2000-4000 lay people each year. A diversity of people have become involved in the organising committee, including the town mayor, the theatre director, librarians, cinema director, schoolteachers and representatives for national and local health authorities, clinicians, patients and relatives.
2. The Psychiatric Information Foundation: This non-profit organisation originated within Rogaland Psychiatric Hospital. It publishes and distributes information about psychiatric disorders and mental health services for patients, relatives, health workers, social workers, schools, and the public.
3. TIPS Education Programme: As part of the TIPS study a more intensive education programme was launched in January 1997.

### Targeting the general public:

In January 1997 all households in the county (180,000) received a 12-page brochure with information about the TIPS project including general information about the early symptoms of psychosis and information on how to get in touch with the Detection Teams. Further information is distributed through the media by means of radio, television, cinema and newspaper advertising, and through

distribution of postcards, flyers, car stickers and T-shirts as well as 4-page brochures with general information on psychosis and schizophrenia.

**Targeting schools:**

Special educational programmes for all teachers, counsellors, and educational psychologists, as well as students. For example, educational videos like “Something is wrong with Monica” showing the gradual drifting into psychosis of a 16 year old girl; brochure on early signs of serious psychiatric disorders, and information on how to seek help distributed to all high school students on an annual basis; posters, flyers and specifically designed newspaper advertisements etc.

**Targeting professionals:**

Seminars for GP’s, psychiatric nurses and other health professionals consisting of information on the TIPS project and instructions on the use of a prodromal symptoms checklist and rating manual developed for the TIPS programme.

**Materials produced**

**Brochures:** 12-page brochure with information about the TIPS project and general information about the early symptoms of psychosis; 4-page brochures with general information on psychosis and schizophrenia; brochure targeting young people specifically.

**Posters, postcards, flyers, car stickers and T-shirts.**

**Newspaper advertisements:** Including a series of whole page advertisements on the theme “Myths and Reality,” where each ad carries a scene from the movie “One flew over the cuckoo’s nest” (Myth) juxtaposed to a picture of people working in the TIPS programme (Reality).

**Video:** “Something is wrong with Monica,” featuring a gradual drifting into psychosis of a 16 year old girl. Norwegian. 22 minutes. Produced in co-operation with the school authorities.

**Cinema trailer:** Domino, a 30 second trailer in black-and-white featuring domino blocks falling over, portraits of young people fading in and out and symptoms of mental distress such as “anxiety” being flashed onto the screen. It ends with the message “seek help” and telephone numbers for TIPS Detection teams. Norwegian/English.

**Educational materials:** Includes books on family work, “What is psychosis” and overhead sets with pre-made lectures etc.

**Booklet:** Complete and detailed summary booklet of all marketing and information strategies and elements. [www.psykoop.no](http://www.psykoop.no)

## Evaluation and feedback

Many thousands of leaflets have been distributed and the interest in the videos produced has been considerable.

Opinion polls conducted prior to and one year into the study show that general knowledge about psychosis among the population of Rogaland county was significantly better after one year of information campaigns. The main source of people's knowledge was the newspapers. Preliminary results of the TIPS study show that the duration of untreated psychosis (DUP) has been reduced from 114 weeks in 1997 to 20 weeks in 1999.

## References:

1. *Early detection strategies for untreated first episode psychosis.* Johannessen JO, McGlashan TH, Larsen TK et al. *Schizophrenia Research* 51 (2000) 39-46.
2. *Early Recognition and intervention. The key to success in the treatment of schizophrenia.* Johannessen JO, *Disease Management & Health Outcomes* 2001; 9(6):317-327

# SLOVENIA

## Help and Self Help for People with Mental Health Problems

Managed by:	Slovenian Association for Mental Health
Program type:	Public education; Training
Focus:	Mental illness generally
Target audience:	Mental health workers, physicians, students, relatives and carers of people with chronic psychotic disorders, users of mental health services
Location:	Slovenia (three different regions)
Start date:	1997
Projected end date:	Ongoing
Languages:	Slovene
Funding:	MATRA program until June 2000
Contact Person:	Dr. Vesna Svab Psychiatric Hospital Ljubljana Studenec 48 1000 Ljubljana Slovenia Vilharjeva 22, 1000 Ljubljana, Slovenija, Tel: +386 61 131 94 18, Fax: +386 61 131 94 08, Email: sent@siol.net Web Site: <a href="http://come.to/sent">http://come.to/sent</a> Director: Nace Kovec Email: nace.kovec@siol.net

### Aims

- To improve knowledge about mental health in the community
- To improve professionals' attitudes and therapeutic relationships with users
- To promote multidisciplinary communication among different services and different professions
- To promote empowerment of users
- To explore ethical issues
- To promote human rights across different parts of the country

### Description

A series of seminars was offered to three different groups of participants: users, relatives and professionals. For all three groups the following themes were dealt with, adapted to previous levels of knowledge: basic education about mental health and mental illness; care management; self-help; human rights and rights of users of mental health services and legal procedures; team and multidisciplinary work; social skills training; and vocational rehabilitation. The professional group also attended a course on supervision.

## Materials produced

- Leaflets about the programme were sent to: Centers for social work, non-government rehabilitation organizations, GP practices all over Slovenia, asylums, hospitals, schools.
- The book *Schizophrenia: information for families*, Division of Mental Health, World Health Organization, Geneva, was used, 1996, reprinted in 1999.
- *From the inside out*, published by, Ljubljana, 1997.
- *Information for patients (Zyprexa)*, published by Eli Lilly, Ljubljana, 1999.
- *Schizophrenia – Manual for patients, carers and professionals*, published 2001.

Language in all publications is Slovene.

## Evaluation and feedback

After the seminar professionals reported perceiving much less stress and fear when working with users of psychiatric services and they found the programme of utmost importance. The most important consequence of the education seems to be improved communication among the three groups of participants – users, relatives and professionals. This was reported in every group we conducted and we believe that the programme actually enabled better participation and involvement of users and their families in the process of treatment and rehabilitation. All the groups also reported a need for continuing education and to have regular meetings aimed at co-coordinating their activities and establishing a ongoing form of support and supervision.

The most commonly observed problems were some organizational issues: late information and lack of accurate information. Furthermore, the group of educators was not very cohesive.

The overall satisfaction of participants was very good for all the three groups. Some dissatisfaction was reported with less than optimal co-ordination of leaders. A need was expressed for further education and supervision. Each group's cohesion was strengthened.

Participants expressed a need to form an ongoing alliance. They wish to form a body with professional and political goals: to influence the planning and the establishment of mental health services, their financing, their integration and to broaden the community perspective of care in Slovenia.

The National Forum of Relatives was consequently formed in 1999. A serial of round tables about mental illness and stigma are organized in the capital Congress Center, attended by patients, relatives and profes-

sional, media and other public. They are widely recognized and usually attended by more than hundred people.

An advanced course on counseling and an extension of seminars to other regions was held in September 2000 in Ljubljana and in a central region (Postojna). In 2001 the seminar took place in the central psychiatric hospital: Psychiatric Clinic Ljubljana. Nurses, social workers and occupational therapists attended lectures and workshops described above.

Seminars for users and relatives take place every two months in Psychiatric Clinic Ljubljana from February 2000.

## What Is Mental Illness – How Do You Get Mentally Ill

Managed by:	Slovenian Association for Mental Health
Program type:	Public education campaign
Focus:	Mental illness generally
Target audience:	Young people (primary and secondary school pupils)
Location:	Slovenia (starting in Ljubljana)
Start date:	School year 2001-2002
Projected end date:	Ongoing
Languages:	Slovene
Funding:	FIHO (Slovenian Lottery Foundaton)
Contact Person:	Barbara Purkart SENT Vilharjeva 22, 1000 Ljubljana, Slovenija Tel: +386 1 431 94 18 Fax: +386 1 431 94 08 Email: sent@siol.net Home page: <a href="http://come.to/sent">http://come.to/sent</a> Director: Dr.Vesna Svab

### Aims

- To reduce stigma and fear of mental illness among young people
- To promote understanding, tolerance and self-help

### Description

The program is designed for school children in late primary and secondary school (between 12 and 17 year old youngsters). The programme consists of a series of age-adapted interactive workshops, where children are given basic information about mental illness, mental health, and problems that people have who suffer from mental illness. It is explained how frequently mental illness occurs and who the children can turn to if it occurs in their circle of relatives and friends. The children are given a lot of opportunity to form their own opinions on the issues of mental health and mental illness using the information provided. The programme explores the ways in which the lives of people with mental health problems are different from other individuals and in which way they are the same.



The program will start in Ljubljana, and be extended to other Slovenian regions subsequently. SENT will send information about the programme to different schools and perhaps in the first instance participate in “Activity Days,” a programme of special activities customary to Slovenian schools. Activity Days are frequently dedicated to social themes.

### **Materials produced**

A handbook on the basis of the workshops is planned. It will be appropriate for work with youngsters.

Materials used: The book *Schizophrenia: youths greatest disabler* (information for families), Division of Mental Health, World Health Organization, Geneva, published in Slovene by SENT, Ljubljana, 1996.

### **Evaluation and feedback**

The programme will evaluate the knowledge that youngsters have before and after the workshops. It will also evaluate their opinions on some specific problems.

# SPAIN

## Hagamos Una Locura

Managed by:	Association Madrilenya de Rehabilitacion Psicosocial (AMRP) Spain
Program type:	Public education (Musical event)
Focus:	Severe mental illness
Target audience:	General public, but especially young people and the media
Location:	Madrid
Start date:	1998
Projected end date:	Yearly event.
Languages:	Spanish
Funding:	Various kinds of alliances among Professionals (AMRP, AMSM), and families and Associations (FEMASAM)
Contact Person:	Dr. Ricardo Guinea AMRP(Actual) President (Madrid Association for Psychiatric Rehabilitation) Hospital de Dia Madrid c/ Manuel Maranon, 4. Madrid 28043 Spain Tel: + 34 (1) 759-6692 Fax: + 34 (1) 300-3355 Email: guineateam@inicia.es www.terra.es/personal/a.m.r.p.

### Aims

To change the way people with mental illnesses are perceived by society and by the media.

### Description

This programme organizes charity concerts of popular music folk song-writers (“Cantautores”) during which messages challenging stigma of mental illness are delivered. Several artists are contacted and asked to participate at no cost to the organisation. A theatre is hired and involvement of the media is ensured to maximize publicity. The first event was held in the "Monumental Theatre" in Madrid on 30 May 1998. All through the event messages were sent out in different ways:

1. FEMASAM's spokespersons explained the relatives' perspective. Their message centered on a complaint about the status quo which forces families of mentally ill people to provide care no matter what. They asked for a better understanding of their predicament and more effective financial and practical support.

- 2) The artists themselves explained their point of view: “All of us are a little crazy every now and then.” This message was welcomed by mental health service users and general public alike.
- 3) The presenter of the event, a well-known radio personality and professional journalist, with work experience in mental health as a psychiatric social worker in the past, was able to bring the musical elements and messages together and contributed substantially to the event’s success.

No printed materials were distributed during the event.

### **Materials produced**

Pamphlets and poster advertising the concert. T-shirts with a slogan.

### **Evaluation and feedback**

Very good effect and the media receives it as a positive and entertaining event. The first event on 30 May 1998 was very successful and about 1700 people attended the event. The event was organised by a very small team (a FEMASAM delegate, a professionals delegate and a media delegate) with FEMASAM’s economic and social support, and resulted in no cost for the organisers. The event was reported on 20 separate occasions on radio and TV.

The second one, in 1999, was organised by FEMASAM exclusively (the families league) and was successful, but the cost was high.

The third event was organised on the 2000 WPFMH mental health day by the Madrid Association for Mental Health (AMSM) and Madrid Association for Psychiatric Rehabilitation (AMRP), as a small model (about 500 people), with no financial cost/burden for organisers. T-shirts with a slogan “Si a la atencion, no a la exclusion” were sold at a small cost to help the funding. The results were good.

# United Kingdom

## Respect Campaign

Managed by:	MIND (National Association for Mental Health) United Kingdom
Program type:	Public education, Political action
Focus:	Mental illness generally
Target audience:	General public, students, employers, politicians, the media, service users
Location:	England and Wales
Start date:	June 1997
Projected end date:	Ongoing programme
Languages:	English (materials also available in Welsh, Bengali, Urdu, Cantonese, Chinese, Vietnamese, Punjabi, Turkish, Gujarati, Hindi, Somali, Greek and Arabic)
Funding:	MIND
Contact person:	Policy Director MIND (National Association for Mental Health) The Granta House 15-19 Broadway, Stratford London E15 4BQ UK Tel: +44 208 -215 2264 Fax: +44 208 522-1725 Email: m.wilson@mind.org.uk

### Aims

The aims of the Respect Campaign are to increase opportunities for users of mental health services to be part of communities, workplaces, families, social circles – and to reduce the rejections that keep so many people trapped on the social margins.

The peg for the campaign was to promote ‘a fair deal’:

- in the public eye
- in working life
- as citizens.

### A fair deal in the public eye

The goal was that by 1999, MIND aimed to have created a measurable shift in media coverage, with less ‘mad axeman’ and stereotyped coverage, and more examples which illuminate the different realities of people’s lives. MIND also aimed to have implemented an effective school education programme.

### **A fair deal in working life**

The goal was that by 1999, MIND aimed to have increased knowledge amongst employers of 'reasonable adjustments' in the workplace and good practice generally for people with mental health problems; to have informed the public that disability discrimination law includes mental health service users; and to have built the basis of a strategy to increase the employment rates for service users. (Note: 'reasonable adjustment' is the term used in the Disability Discrimination Act (DDA), 1995, for flexible working hours, additional support at work and other adaptations to improve access to work for people defined as 'disabled' under the Act.)

### **A fair deal as citizens**

The goal was that by 1999, MIND aimed to have succeeded in extending anti-discrimination law, through lobbying and test cases; and to have publicised the realities of discrimination to the general public.

### **Description**

The Respect Campaign was launched in June 1997 with a central mission to reduce discrimination on mental health grounds, including multiple discrimination. It is a broad-based campaign around a single theme.

Broad-based campaigns, with a number of targets, can take account of the complexity of what actually creates change. For instance, new law alone, if not accompanied by pressure for changes in local practice, is ineffective in areas where policy is largely delegated to local commissioners/practitioners. Choosing several targets – if change really is dependent on all of them – can make change deeper and more lasting.

MIND's Stress on Women campaign is an example. By targeting Government, parliament, professional bodies, the media and local services, there was a cumulative effect, which shifted both policy and practice (Sayce 1996). This will facilitate an entrepreneurial approach, enabling people locally and nationally to link into the campaign in a variety of ways and to develop new, creative ideas.

Some of the achievements were:

A fair deal in the public eye – incorporating:

- a. The Campaign to Complain – about mental health in the media.  
This was launched in November 1999.

A fair deal in working life – including work on Employment.

This resulted in:

- a. The publication of *How to Survive Working Life*, a training pack for employers and information booklet for employees (May 2000).
- b. Setting up of Work Net – to promote employment opportunities for people with mental health problems.

A fair deal as citizens – incorporating:

- a. The Arts Project initiative – September/October 1999 [posters and postcards were distributed nationally through regional offices, Diverse Minds and Mindlink.]
- b. Older People – which included a Debate of the Age contribution (1999/2000).
- c. Mental Health Act Review work, which resulted in the publication of *Mind the Law*, MIND’s authoritative response to the government’s consultation on the Mental Health Act Review (1999); and work with other mental health organisations – including formation of the Mental Health Alliance – to influence new legislation.
- d. Social Inclusion (Phase 1) – including publication of a comprehensive report *Creating Accepting Communities*, on the social exclusion of people with mental health problems (November 1999).
- e. Social Inclusion (Phase 2) – Developing and promoting good practice – based on the *Creating Accepting Communities* report (April 2000) and ongoing.

### **Evaluation feedback**

It has been noted that campaigning is a difficult activity to evaluate because (a) reliable indicators of progress are often hard to find and (b) social change is typically caused by a complete set of inter-related events and a direct causal link between campaign actions and a change in the policy or practice of the target is often difficult to establish (Lattimer 1994).

There are, however, some parameters to which we can look in the Respect Campaign to at least begin to contextualise its impact.

### **Tangible changes**

The impact of a campaign can be gauged on the basis of the tangible gains or activity associated with it (e.g. number of events held nationally, locally and regionally; number of mentions/stories in the media; number of enquiries, etc.) These are largely to do with issues of visibility – for MIND, for raising and providing information on the issue.

Examples of the Respect Campaign’s success in this area include:

- The launch of ‘Not Just Sticks and Stones’ (1996 – stigma and discrimination); ‘Tall Stories in the Backyard’ (1997 – nimbyism), and ‘Raised Voices’ (1997 – issues for black and minority ethnic communities) – all of which generated high profile national, regional and local attention and media coverage on the multiplicity of stigma and discrimination faced by a range of mental health service users.
- The Arts Project – produced posters and postcards and a Year 2000 calendar which were widely distributed and informative and served to raise the profile of MIND and the needs of people with mental health

problems in general. In MIND's Northern Region e.g. the police commissioned their own reprint of the languages poster to go up in police stations. The project work also promoted positive aspects of mental health.

- The Campaign to Complain has attracted more than 300 groups and individuals onto the network and has issued alerts aimed at countering stigma and discrimination in the media.
- In MIND Cymru there was wide media coverage for 'Ten Tips for Employers' on discrimination at work; increased work on mental health awareness addressing race and culture, as well as rural issues.
- The Education Pack was launched in September 1999 and achieved national media coverage. Copies were sent to named teachers in 4000 schools, and by agreement with the Qualifications and Curriculum Authority to 220 schools involved in piloting NVQ Health and Social Care. Publicity material was sent to all other schools in England.
- A related collaboration took place with the Health Education Authority to run the 'Stigma Partnership' aimed at addressing issues of stigma and discrimination around mental health issues which are prevalent amongst the 16 to 24 age group.

In this context, Liz Sayce (formerly MIND's Policy Director) has noted that 'the campaign has succeeded in its ambition to use a relatively small amount of money – £30,000 – to spearhead change and harness energies to a common purpose,' and that its first year revealed 'a huge wealth of activity at local and national level.'

### **Intangible change**

The other aspect on which a campaign's success or failure can be judged is more intangible – the extent to which public opinion is changed; the degree to which the public policy agenda is changed; the degree to which alliances shift and partnerships emerge. Though the intangibles may be less overt, and more within the realm of subjectivity, there is evidence, nevertheless, to suggest that the Respect Campaign's impact can again be felt. Examples of this include:

- Increased links with the disability movement, which in turn helps to ensure that mental health is considered a natural part of that agenda.
- The *Creating Accepting Communities* Inquiry and its effect in raising issues of social exclusion/inclusion (and thereby awareness of the impact on people with mental health problems) across a wide range of constituencies – including the statutory sector, business, religious groups and government.
- Influencing and working with psychiatric professionals e.g. the Royal College of Psychiatrists' 'Changing Minds' campaign, launched in October 1998.
- Likewise collaboration with the World Psychiatric Association's educational programme to reduce the stigma and discrimination faced by people with a diagnosis of schizophrenia was also an aspect.

- The ‘Campaign to Complain’ has contributed to greater awareness about how common the incidence of people being in mental distress is. It has helped to foster the view that it is no longer acceptable to use (or at the very least that there should be a degree of discomfort about using) negative or disparaging terms in the media. MIND’s press office, for example, complained about the title of a Channel 4 series ‘Psychos’ and was consulted about an advertising campaign associated with it. In the longer term, such input can be expected to impact favourably on public opinion, through more positive portrayals of people with mental health problems.
- Mental Health Act Review. MIND’s response to this review and the associated consultations, networking (both at a grassroots and Parliamentary level), as well as raising the issues regarding compulsory treatment in the community at ministerial level has served to broaden the public policy agenda. The stance we have taken in our work around the review has helped to create a climate in which those who would argue for compulsory treatment can no longer do so on the basis that it is the obvious solution. It can be argued that we have extended the parameters of the debate to ensure that the needs of people with mental health problems (even if some of those people are ‘difficult’) nevertheless should be taken into account in a real and meaningful way; and in such a way that their human rights are not disregarded or violated.
- The MIND Inquiry – with its theme of ‘Creating Accepting Communities’ – has also served to broaden public understanding of the complexities of social exclusion/inclusion for people with mental health problems. The Inquiry has also helped to change the focus from merely being one of exclusion to that of inclusion.
- The Fair Deal in Working Life Employment Project tackles stigma and discrimination on the economic front – with the publication of a training pack to educate employers about good practice and the setting up of a network to foster employment opportunities for people with mental health problems.
- Yellow Card – aimed at highlighting side effects of medication from a user perspective (First report 1998; Second report with a focus on black and minority ethnic communities published in September 2001).

## References

- Sayce, L. (1996) *Campaigning for change*. In: Abel K et al.(eds) *Planning Community Mental Health Services for Women*. London: Routledge.
- Lattimer M (1994) *The Campaigning Handbook: Directory of Social Change*.



## Changing Minds - Every family in the land

Managed by:	Royal College of Psychiatrists
Program type:	Public education
Focus:	Mental illness generally
Target audience:	General public and also specific target groups: young people, physicians, employers, ethnic minorities, politicians, the media
Location:	UK and Republic of Ireland
Start date:	October 1998
Projected end date:	October 2003
Languages:	English
Funding:	Initial funding from the Royal College of Psychiatrists. Ongoing and project funding by sponsorship from external sources.
Contact Person:	Ms. Liz Cowan Campaign Administrator, "Changing Minds" Royal College of Psychiatrists 17, Belgrave Square London SW1X 8PG UK Tel: +44 (171) 235-2351 ext 122 Fax: +44 (171) 235-1935 Email: stigma@rcpsych.ac.uk Web site: www.changingminds.co.uk Campaign Chairman: Professor Arthur Crisp

### Aims

- To increase public and professional understanding of mental disorders;
- To reduce stigmatisation of, and discrimination against, people who suffer from mental disorders.

### Description

A major five-year campaign, co-ordinated by the Royal College of Psychiatrists, the 'Changing Minds' Campaign aims to increase public and professional understanding of mental health problems and reduce the stigma and discrimination associated with them. Individual projects target specific groups of people: doctors, employers, journalists, teachers, children, and young adults. The campaign is focusing on six of the most common mental health problems: depression, anxiety, schizophrenia, Alzheimer's disease and dementia, eating disorders, and alcohol and drug misuse.

## Materials produced

### Websites

[www.changingminds.co.uk](http://www.changingminds.co.uk)

Campaign information, Campaign booklets, “1 in 4” video, references to published articles on stigma.

[www.stigma.org](http://www.stigma.org)

80 author, 200,000 word, 90 article book ‘Every Family in the Land.’ An in-depth study of the stigmatisation of people with mental illnesses.

### Videos

Stigma (10-minutes)

Aimed at the general public and mental health professionals. Explores the nature and origins of the stigma of mental illness and how it affects us all.

“1 in 4” (2-minutes)

Aimed at young people aged 15 - 25. Has been shown during the trailer session in cinemas throughout the UK.

### Materials to Download or Available on CD-Rom

‘Every Family in the Land.’ Internet book available as CD-Rom or on [www.stigma.org](http://www.stigma.org) (see above). Aimed at healthcare professionals, academics, service users/providers and the general public.

Campaign booklets: Series of seven booklets challenging people to reconsider their attitudes towards those suffering from anxiety, depression, anorexia and bulimia, schizophrenia, Alzheimer’s disease, or drug and alcohol addiction. Aimed at the general public. Available on [www.changingminds.co.uk](http://www.changingminds.co.uk).

Opinion survey: Results and full analysis of national survey of public attitudes, carried out by the Office for National Statistics, 1998. Published by Crisp et al, British Journal of Psychiatry (177) 4-7. Available on [www.changingminds.co.uk](http://www.changingminds.co.uk).

Declaration of Intent: Signatures are invited from those supporting the aims of the campaign. Available on [www.changingminds.co.uk](http://www.changingminds.co.uk).

### Printed Materials

For children and young people

- *Reading Lights*: Four booklets for children aged 4 – 7, addressing what it is like to be different.
- *Headstuff*: Leaflet for 14 – 17 year olds, to increase understanding of mental health problems.

#### **For medical professionals**

- Mental Illness: Stigmatisation and discrimination within the medical profession: Joint report between the Royal College of Psychiatrists, the British Medical Association and the Royal College of Physicians.
- Leaflets for GPs: Published in conjunction with the Campaign Roadshow for primary healthcare workers, taking place throughout the UK November 2000 – April 2002.

#### **Relating to the media**

- Guide for Journalists and Broadcasters Reporting on Schizophrenia. Booklet with facts about schizophrenia, produced in association with the National Union of Journalists.
- Practical guidance on responding to the media: Fact sheet on how to complain about inaccurate representation of mental illness in the media. For use by members of the College and the general public.

#### **General information**

- Campaign update: Information sheet about the 'Changing Minds' Campaign and the projects being undertaken.

#### **Evaluation and feedback**

A baseline survey of attitudes among the general public was conducted in July 1998 by the Office of National Statistics on behalf of the 'Changing Minds' Campaign. The results showed that stigmatising attitudes were common. A full analysis of the survey has been published in *The British Journal of Psychiatry* (2000) 177, 4-7, and can be downloaded from [www.changingminds.co.uk](http://www.changingminds.co.uk). The impact of the campaign will be evaluated by repeating the survey in October 2003, at the end of its five year duration.

# UNITED STATES

## Rosalynn Carter Fellowships Mental Health Journalism

Managed by:	The Carter Center Mental Health Task Force
Program type:	Training (mentored fellowship); public education
Focus:	Mental illness generally
Target audience:	Media (working journalists)
Start date:	September 1997
Projected end date:	None
Languages:	English
Funding:	The Annenberg Foundation, Bass Hotels & Resorts, Center for the Advancement of Children's Mental Health at Columbia University, The Philip L. Graham Fund, The William Randolph Hearst Foundation, The Charles and Betti Saunders Foundation, Walter H. and Phillis J. Shorenstein Foundation, and SmithKline Beecham Corporation.
Contact person:	Gregory L. Fricchione, M.D., Director Carter Center Mental Health Program The Carter Centre One Copenhill Atlanta, GA30307 USA Tel: +1-404-420-5165 Fax: +1-404-420-5158 Web address: <a href="http://www.cartercenter.org/mentalhealth.html">http://www.cartercenter.org/mentalhealth.html</a> Email: <a href="mailto:ccmhp@emory.edu">ccmhp@emory.edu</a>

### Aims

To increase public understanding of mental illness and reduce stigma by creating a cadre of journalists who are knowledgeable about mental illness and the issues in depicting it and by supporting these journalists in projects that will communicate important information to the public about mental illness.

## **Description**

Each year, the program's staff and Board of Advisors select six working journalists from the United States and two from New Zealand to receive Fellowship stipends for support of projects they have proposed relating to mental health. The Fellows meet with Advisory Board members at the Carter Center to learn more about mental illness and issues related to journalistic coverage of psychiatric disorders. Each journalist is matched with a mentor from the Advisory Board who will be available to help them with projects, providing ideas, information, and contacts for them. At the end of the fellowship year, Fellows present the results of the efforts to the Advisory Board, the Carter Center Mental Health Task Force, and newly selected Fellows.

## **Materials produced**

Products are the end results of journalist projects. They have included newspaper articles, radio reports, televised news stories, and book proposals.

## **Evaluation and feedback**

Participants in the Fellowships for Mental Health Journalism program have succeeded in having their work appear in major newspapers and on national and local radio and television news programs. Two of these works were nominated for Pulitzer prizes and received other prestigious awards, such as ones from the American Psychiatric Association and Amnesty International. A 1998-99 Fellow has expanded his project into a book on the mental illness of Abraham Lincoln, which holds much promise for challenging negative stereotypes about mental illness. An additional indicator of the success of the program is that funding has rapidly expanded as funders have eagerly sought to become involved with the program.

## The Anti-Stigma Project

Managed by	On Our Own of Maryland, Inc.
Program type:	Public education
Focus:	Mental illness generally
Target audience:	Mental health professionals, service users, families, policy makers
Location:	United States
Start date:	1993
Projected end date:	Ongoing
Languages:	English
Funding:	Maryland Mental Hygiene Administration, the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services
Contact person:	Jennifer Brown, Project Director The Anti-Stigma Project 1521 South Edgewood Street, Suite C Baltimore, MD 21227-1139 Tel: +1-410-646-0262 or +1-800-704-0262 Fax: +1-410-646-0264

### Aims

To reduce stigmatizing attitudes, behaviors, and practices within the mental health and substance abuse community by raising awareness, facilitating ongoing discussions, searching for creative solutions, and educating service providers and other members of the mental health community.

### Description

The project is a collaborative effort among mental health consumers, family members, providers, educators, and administrators to confront the ways those within the mental health field may contribute to stigma. Through handouts, workshops, and a video, the project tries to foster open discussion regarding the issue of stigma within the mental health system and to increase awareness of how stigma affects everyone in that system, including themselves. The project also challenges people to critically appraise their own possibly stigmatizing attitudes and behavior and to find ways to reduce stigma. There are three basic workshops, conducted by staff from the Project, for mental health service providers, consumers, family members, and others. The first, about 3-hours in length, provides an intensive look at stigma in the mental health field.

The second is a longer one that focuses on solutions to stigma within the mental health system and builds upon suggestions from the first. The third, about 1 hour-long, focuses specifically on language used to refer to mental illness and treatment.

### **Materials produced**

**Poster and handout:** A one page poster/handout, *Stigma: Language Matters*, discusses stigma and gives examples of respectful and disrespectful references to mental illness. It also provides some “rules of thumb” for avoiding stigmatizing (e.g., “Don’t use generic labels.”).

**Video:** *Stigma...in Our Work, in Our Lives* is a compilation of interviews with people who are members of the mental health and substance abuse communities. Interviewees give their thoughts and views regarding the issue of stigma in the mental health and substance abuse systems – its manifestations, its effects, and possible solutions. The video is intended as a stimulus for discussion of the issue of stigma within the mental health and substance abuse community. Included with the video package is a booklet that includes a self-inventory of stigmatizing perceptions and attitudes, discussion questions, and a list of books, articles, and organizations that provide additional information.

### **Evaluation and feedback**

Representatives of the Anti-Stigma Project have facilitated hundreds of workshops. In addition, many have been introduced to the Project through presentations and adapted workshops at various conferences. Comments from workshop participants on evaluation questionnaires given at the end of workshops have been largely positive, often indicating that the workshops had helped the individual be more aware of his/her own stigmatizing attitudes and behaviors.

## National Stigma Clearinghouse

Managed by:	National Stigma Clearinghouse
Program type:	Public education, advocacy
Focus:	Mental illness generally (media depiction)
Target audience:	Mental health advocates, media professionals
Location:	United States
Start date:	November 1989
Projected end date:	Ongoing
Languages:	English
Funding:	Personal and private contributions, project income from Center for Mental Health Services
Contact person:	Jean Arnold or Nora Weinerth 245 Eighth Avenue, #213 New York, NY 10011 Tel: 1-212-255-4411 Web site: <a href="http://community.webtv.net/stigmanet">http://community.webtv.net/stigmanet</a>

### Aims

To end exploitation of mental illness for humor or sensationalism, encourage balanced and sensitive portrayals of people with psychiatric vulnerabilities, promote accuracy in the use of medical terms associated with psychiatric conditions, and thereby change public attitudes about people who have psychiatric conditions.

### Description

Participants in the all-volunteer National Stigma Clearinghouse monitor the presentation of mental illness in popular media – newspapers, films, television, advertising, etc. The Clearinghouse encourages media watchers to mobilize local “stigmabusters” groups and issues “Stigma Alerts” to organizations and individuals to encourage broader response when depictions are particularly stigmatizing or when media representatives are unresponsive to initial contacts. The Clearinghouse hub in New York City furnishes information on request from its clippings and articles file to consumer/survivor groups, the media, mental health organizations, lawyers, researchers, families, and professionals in the mental health field. Occasionally, the Clearinghouse will organize demonstrations or file complaints with trade and regulatory organizations. Praise to media professionals for positive and accurate treatment of mental illness is provided and encouraged as well.



## **Materials produced**

Fact sheets: (e.g., about schizophrenia and about the distinction between psychosis and psychopathy) for use in communication with media personnel.

Writers' Guide: A reference card with advice to writers and reporters about coverage of mental illness, including terms to be avoided (e.g., lunatic) and preferred terms (e.g., people with schizophrenia). The guide also includes brief information about schizophrenia, bipolar disorder, and major depression.

Consensus Statement on Violence and Mental Illness: A statement, endorsed by major researchers, concerning what is known about the (weak) relationship between mental illness and violence. This statement became the core of a brochure produced by Policy Research Associates, "What Do We Know About Mental Disorder and Violence?"

Reports for the Center for Mental Health Services: "Media stereotypes of mental illness, their role in promoting stigma, and advocacy efforts to overcome such stereotypes and stigma" was completed in 1995. An anti-stigma guide, "Challenging Stereotypes: An Action Guide" was published in February 2001, DHHS Publication No. (SMA) 01-3513.

Internet web site: The Clearinghouse has established an internet web site on which information about the Clearinghouse, stigma alerts, and links to other anti-stigma sites are provided.

Internet address: <http://community.webtv/stigmanet>

## **Evaluation and feedback**

From 1990 until 1997, the Clearinghouse issued 64 monthly reports containing 640 examples of stigma submitted by its nationwide network of stigmabusters. The Clearinghouse has become widely known among both mental health advocates and media professionals. Most resource guides for improving understanding of mental illness (e.g., one for journalists in the Jan./Feb. 1998 Columbia Journalism Review) include the National Stigma Clearinghouse, and the work of the Clearinghouse has been reported as part of stories in newspapers, magazines, and television news programs. Their participants have also succeeded in bringing the issues of media depiction and stigma to public attention by having many letters to the editor published in local and national newspapers. Finally, the Clearinghouse has had numerous successes in getting advertisers and retailers to change or discontinue products that ridicule or misrepresent mental illness.

## Stamp Out Stigma (Educational Presentations)

Managed by:	Stamp Out Stigma (SOS) (associated with Caminar/CLC, San Mateo)
Program type:	Public education, Training programme
Focus:	Mental illness generally
Target audience:	General public, families of mental health service users, politicians, students, mental health professionals, crisis-line volunteers, physicians, nursing and medical students, police
Location:	California, United States of America
Start date:	October 1990
Projected end date:	Ongoing
Languages:	English
Funding:	Small community grants, fees, honorariums, donations and support from San Mateo County Department of Mental Health
Contact Person:	Ms. Carmen A. Lee Chair Stamp out Stigma 1572 Winding Way Suite A Belmont, CA 94002 - 1953 USA Tel: +1 (650) 592-2345 Email: carmenSOS@aol.com

### Aims

To dispel the common myths and stereotypes of mental illness, thereby creating a more informed and supportive community; to contribute to the training of future clinicians and crisis-line volunteers etc.

### Description

SOS delivers educational presentations by 4 or 5 members of SOS, all of whom are mental health clients diagnosed with severe mental illness. They give a brief bio-sketch of how mental illness has affected their lives, relating their own experience with stigma, putting a human face on mental illness. The audience is encouraged to ask questions early on, promoting a group discussion that is the most valuable part of each presentation. If addressing community leaders, the presentation is tailored to raise "voter issues" like the increase of homeless mentally ill, the cutbacks in mental health programs, and the plight of returning to gainful employment. Presentations to professionals focus on what is helpful in a therapeutic relationship e.g. in the recovery process. SOS

regularly presents at five San Francisco Bay Area's Suicide Prevention Centers for volunteer training, with a focus on what is helpful in a crisis situation.

### **Materials produced**

Promotional leaflets (brochures): Distributed for advertising or informational purposes, the brochure describes the SOS programme and its primary goals. Comments from various audience participants are included.

SOS Demonstration video: This video introduces the SOS programme and shows excerpts from a number of presentations including members talking about their personal experiences, as well as members enacting a role-play of a crisis situation for training purposes. The video is intended to entice general and professional audiences. 12 Minutes. Produced by SOS, 1992.

Non-broadcast quality video recordings of actual presentations: Full length SOS presentations recorded by various organisations to use as a training tool or for their video library. 1990 -1994.

*Train-the-Trainer: A Beginners Guide:* A 12 page booklet giving step-by-step practical advice on how to begin a similar programme based on the experience of setting up SOS. It deals with public speaking training, funding, contacting organisations, managing presentations and includes a "Mental Illness Myth and Reality" hand-out and sample evaluation form. Produced by SOS, 1994. Cost: \$10.00 + postage.

### **Evaluation and feedback**

Wherever presentations have been made, the response has been overwhelmingly positive, with many groups asking SOS to present on a regular basis. All requests for presentations are from "word-of-mouth" advertising. Responses to evaluation questionnaires by audience attendees are generally very positive. Nearly 700 presentations have been made to date, amounting to about 60-70 presentations/year. SOS has acquired some contacts with police departments, where SOS presentations will be a regular part of the Police Academy Training Programs in San Francisco, and also in police departments in other countries. Many requests for repeats are received. SOS has been featured in several national publications, and has been on local radio and TV. Other client groups in the USA are starting their own SOS program.

## The Stigma of Mental Illness: a Model Curriculum.

Managed by:	Dr. Ken Duckworth, Harvard Medical School
Programme type:	Training programme
Focus:	Mental illness generally
Target audience:	Mental health or medical professionals, including trainees
Location:	Massachusetts, USA (including some international distribution)
Start date:	1997
Projected end date:	Ongoing
Languages:	English
Funding:	National Alliance for the Mentally Ill (for publication and free distribution of the curriculum to teachers/trainers of health care professionals)
Contact Person:	Dr. Ken Duckworth Assistant Professor of Psychiatry Harvard Medical School Massachusetts Mental Health Center 74 Fenwood Road Boston, MA 02115 USA Tel: +1(617) 626-9589 Voice mail: +1(617)734-3182 Fax: +1(617)626-9591 Email: Lois.Mastrangelo@DMH.state.ma.us

### Aims

To address the stigma of psychiatric illness and how cultural stereotypes can impact clinical decision-making.

### Description

The curriculum is designed for use in a workshop format training session. It consists of a quiz of knowledge and attitudes about major mental illness, a 15-minute video, and a series of discussion questions.

The video includes media clips (advertising, cartoons, films) of stereotypical portrayals and presents an organisational framework of stereotypes to aid recognition. Stereotypes are then countered and ways in which the viewer(s) can impact this important social problem are

suggested. The video contains commentary by prominent people about the effect of stigma on their lives and the presenter, Dr. Ken Duckworth, relates his personal childhood experience of stigma having a father with bipolar illness.

After taking the quiz and viewing the video, viewers engage in discussion focusing on their response to the video and quiz, and are encouraged to reflect on their own experiences and fears about mental illness.

### **Materials produced**

Video with accompanying printed material (description as above).

### **Evaluation and feedback**

Feedback from workshops based on this curriculum include the observations that stereotypical portrayals on TV are often noted, as are comments by colleagues about “crazy people.” Personal and family experiences may be conveyed to the group. A realisation of how cultural stereotypes affect attitudes and care can be achieved and then offers a powerful new perspective to the workshop participants.

Close to 500 copies of the curriculum have been distributed nationally and internationally.

## Stigma Watch Program

Managed by:	National Mental Health Association
Programme type:	Public education, advocacy
Focus:	Mental illness generally (media depiction)
Target audience:	General public, mental health advocates, media
Location:	United States
Start date:	May 1996
Projected end date:	Ongoing
Languages:	English/Spanish
Funding:	Individual donors, general operating budget
Contact person:	Michelle Pruett Director, Media Relations National Mental Health Association 1021 Prince Street Alexandria, VA 22314 Tel: 1-703-838-7538, or 1-800-969-NMHA Fax: 703-684-5968 Web site: <a href="http://www.nmha.org">http://www.nmha.org</a>

### Aims

To reduce mental illness stigma, challenge stigmatizing portrayals of mental illness, and increase public understanding both of mental illness and issues of stigma.

### Description

The National Mental Health Association (NMHA) Stigma Watch program has several components, as follows:

1. Newsletter columns: Brief articles concerning issues related to stigma are included in NMHA's affiliate and advocacy network. Topics so far have included media images of mental illness, the violence stereotype, straitjacket images in advertising and cartoons, the importance of People First language, and the impact of stigma on children. These articles are also posted on the NMHA web site.
2. Stigma Watch: Through its newsletter, internet site, and workshops, the NMHA has encouraged its members and affiliates to monitor and report stigmatizing media depictions of mental illness. The NMHA maintains a toll-free Stigma Watch phone number through which people can alert the NMHA to problem depictions. NMHA staff then respond to those depictions that involve national media and encourage/assist members to respond to local instances of media stigmatizing. In addition, stigma alerts about stigmatizing media depictions – and information about NMHA responses to them – is often included on the organization's internet site, distributed

through an e-mail alert system, to NMHA's affiliate and advocacy network.

3. **Media Awards:** The NMHA gives annual awards to people in the media who have contributed presentations about mental illness that are accurate, empathic, and likely to increase public understanding. Media professionals submit their work for award consideration and a panel of judges pick the winners in several different categories, such as Print, Broadcast (radio and television), and Overall Coverage. The awards are given, with considerable fanfare, at a dinner at the NMHA annual meeting in June.

### **Materials produced**

**Brochures:** The NMHA has brochures about a variety of mental disorders and mental health issues available at no charge through its Information Center. This includes brochures on schizophrenia and on stigma. The brochure on schizophrenia provides facts about the symptoms, subtypes, causes, and treatments of schizophrenia, as well as coping guidelines for caretakers and organizations and readings that can provide more information. The stigma brochure, titled *Stigma: Awareness and understanding of mental illness*, contains information on common misconceptions about mental illness, suggested readings, and addresses and web sites for other organizations. It also provides the toll-free Stigma Watch phone number (800-969-6642). The NMHA also offers numerous other information brochures (e.g., on depression, stress, bipolar disorder), and provides referrals to local services, through its Information Center.

**Newsletter articles/ fact sheets:** NMHA is developing several new fact-sheets for advocates and journalists on stigma issues. NMHA has developed fact sheets for the entertainment industry on how to accurately and sensitively depict people with mental illness in television and film, which are available both on-line and through their Information Center.

### **Evaluation and feedback**

The NMHA has received an increasing number of calls on its Stigma Watch line and has responded to several hundred instances of media stigmatization. Moreover, the NMHA has had several successes from contacting media professionals about stigmatizing images. An advertising campaign for the TV show *Frasier*, for example, was modified in response to concerns expressed by NMHA. The number of entries for the Media Awards program has increased steadily, indicating interest in journalists and producers in providing and being recognized for positive depictions of mental illness. In 2000, the NMHA distributed over 500,000 brochures to the general public. The Stigma and Schizophrenia brochures continue to be among the most requested titles.







For more information on the  
WPA global programme to fight  
the stigma and discrimination  
because of schizophrenia, please contact:

Professor Norman Sartorius  
H.U.G. Belle-Idée 2, chemin du Petit-Bel-Air  
1225 Chêne-Bourg/Genève  
Phone: (41) 22-305-5741 | Fax: (41) 22-305-5749  
Norman.Sartorius@hcuge.ch

Supported by an unrestricted educational  
grant from Eli Lilly and Company