

CHAPTER 4

Term of Reference D: Community participation in, and integration of, mental health services

- (i) Levels of community, consumers and carer participation in local and state mental health service planning and decision-making.

The level of consumer and carer participation at the local level is well documented in the National Mental Health Reports. The results suggest that the involvement of consumers and carers in planning and decision making is increasing. The mid-term review of the Second National Mental Health Plan has reported on the way forward for consumers and carers as follows:

- Expand and enhance the consumer and carer network, ensuring their ongoing involvement in policy and programme planning and fund the necessary administrative capacity.
- Rejoin the battle for stigma reduction in Australian society.
- Organise and offer respite care and other practical support measures for carers of people with disabling mental health problems.
- Fund training for consumers, carers and mental health advocates.¹

In 1994, a total of 137 organisations throughout Australia, including 43 in NSW, provided responses to questions concerning their level of participation in mental health service development. The numbers have increased to 226 and 96 respectively in 2000.

Figure:D:1 Levels of consumer participation, 1999-2000, by jurisdiction

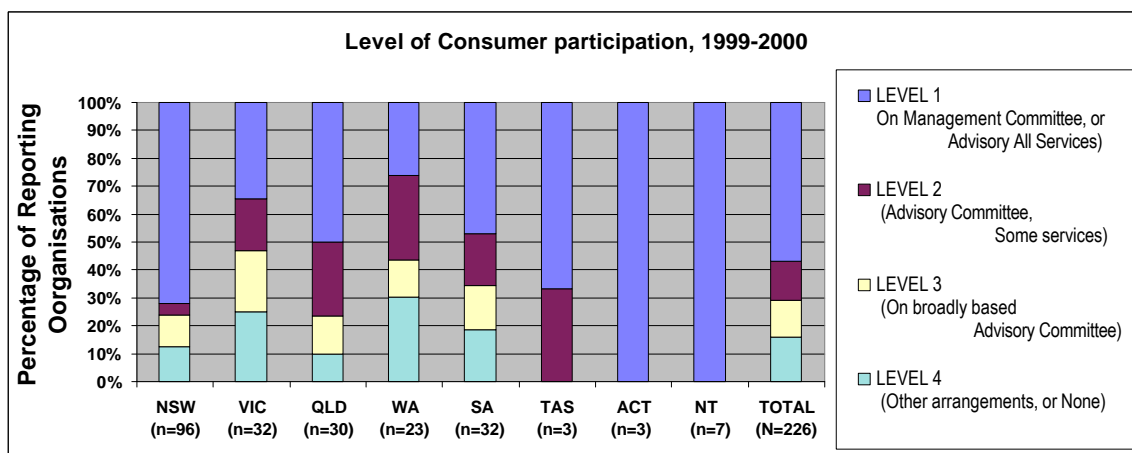


Figure D:1 includes data from the draft tables of the National Mental Health Report 2002. Interstate data are under Commonwealth embargo until publication of the Report, due June 2002.

The proportion of organisations in NSW reporting some formal type of mechanism for consumer participation in 2000 was 88%. The figure has steadily increased from a baseline of 68% in 1994. Of particular note is the fact that the percentage of services with Level 1 involvement in NSW has increased from 19% in 1994 to 71% in 2000.

Each organisation was also asked whether it had a charter, mission statement or other means of informing consumers about what to expect from its service and whether it routinely sought feedback from consumers on the provision of mental health services. In 1998, 93% of NSW respondents stated that they inform consumers and carers about what to expect from their mental health services and 94% that they seek consumers' views about service provision.

The *NSW Consumer and Carer Mental Health Framework for Participation and Prevention* emphasises working with the broader community and mainstream services to improve access, and increase the pathways to full participation in the community. Guidelines have been developed to assist each area in developing a Consumer and Carer Participation Plan. Strategies are identified to assist consumers and carers to reduce isolation and prevent or reduce disability.

Examples of involvement at the local level are:

- The Northern Rivers Area Mental Health Service Council is a combination of a number of consumer/carer and community groups that meet on a monthly basis with Board members, the Chief Executive Officer and management of mental health services. The role of the Council is to assess, plan and determine ways forward for mental health services within the Area Health Service. The Council reports directly to the Board. This level of consumer and care participation provides a comprehensive framework for all groups within the mental health services to be represented at the highest level within the Area.
- The Western Sydney Area Health Service Community Consultative Committee includes representatives from consumers, carers, other government agencies and NGOs. The Committee's Terms of Reference and membership have been reviewed and modified recently to strengthen the level of participation of external agencies in the planning, delivery and evaluation of mental health services. The Committee meets bimonthly.

At the State level, the New South Wales Consumer Advisory Group (NSWCAG) was established in 1992. Its main objectives are to ensure that consumers and carers have input into local and national policy development and to consult with, and advocate for, consumer and carer rights.

Priorities identified by NSWCAG include:

- Participation on national bodies to ensure ongoing input to the implementation of the National Health Plan
- Establishment of an 'Information Link' to enable consumers and carers to have access to relevant information and advice
- Development of a policy and procedures document and a communication strategy to enable enhanced accountability and responses to requests

In the 1999/2000 State Budget, \$12.9 million over four years was committed to enhance supports for carers. Of this amount, \$1 million recurrent was allocated for supporting carers of people with mental illness.

The Centre for Mental Health administers this component of the budget and participates in mental health planning for carers. The Centre for Mental Health administers funding focussing on the following areas: personal supports for carers, including support, training and counselling; practical supports for carers, including respite and transport; and building better responses to carers on the part of health and community care workers.

The Mental Health Implementation Group has been established to steer the planning of the State's mental health services. The Group brings together consumers, carers, psychiatrists, nurses, allied health professionals and non-government organisations. The Group's achievements and progress include:

- Release of the Disaster Mental Health Response Handbook providing all area health services with supporting training material
- Completion of the Mental Health for Emergency Departments Manual
- Completion and release of 'Getting in Early: A Framework for Early Intervention and Prevention in Mental Health for Young People in NSW'
- Issuing the Mental Health-Clinical care and Prevention model
- Implementing the Mental Health Information Development Program and the Mental Health Outcomes and Assessment Training Program

This group has a consumer and carer subcommittee working to develop a Mental Health Consumer Participation Strategy aligned to the broader departmental strategy.

(ii) The effects of mainstreaming policies within mental health services and their impact on the community and consumers of mental health services

The integration of mental health services into primary health care is in line with the global trends. The division between psychiatric and medical facilities resulted in significant disadvantage to people with mental health problems, particularly those with coexisting medical problems. Repeated studies have demonstrated that the rate of mental health problems in those with long term medical illnesses is two to three fold the rate of mental health problems in the general population. The division of psychiatric and medical facilities in the past has resulted in significant disadvantage to people with mental health problems and contributed to isolation and stigmatisation.

Mainstreaming has been achieved by the development of inpatient units attached to local general hospitals and supported by integrated community health services. This has meant proximity of assessment and treatment for people from local communities and better partnerships between mental health services and general medical services especially emergency departments. Mainstreaming has also resulted in better partnerships between mental health services and general practitioners, although the degree to which these initiatives have been successful is variable across the state and depends on multiple factors.

Mainstreaming of mental health care is critical because:

- the complex nature of mental illnesses with the involvement of brain and physical health pathology
- the high co-morbidity of major physical and mental health problems that are not adequately dealt with in stand alone psychiatric hospitals
- the need for complex investigations in the diagnosis and treatment of mental illnesses.

The provision of acute and long-term inpatient services for people with a mental illness in locally based units is preferred from both clinical and management perspectives and is part of national and international mental health policy directions.²

(iii) Effectiveness of community education/integration programs at a local, state and national level, which aim to reduce the stigma associated with mental illness

In the first *National Mental Health Plan*, promotion and prevention components focused on increasing public awareness of the extent of mental disorders and reducing stigma. The *Second National Mental Health Plan* extended this to include reducing stigmatising attitudes within the helping services and increasing mental health literacy in key settings, such as schools, and among strategic groups.

The *National Action Plan for Promotion, Prevention and Early Intervention for Mental Health* (2000) includes the identification of effective approaches to improving mental health literacy as a National Action item. This includes reviewing population health programs for effective approaches and partnerships that can shift attitudes, increase mental health knowledge and reduce the stigma of mental health problems and mental disorders in the community.

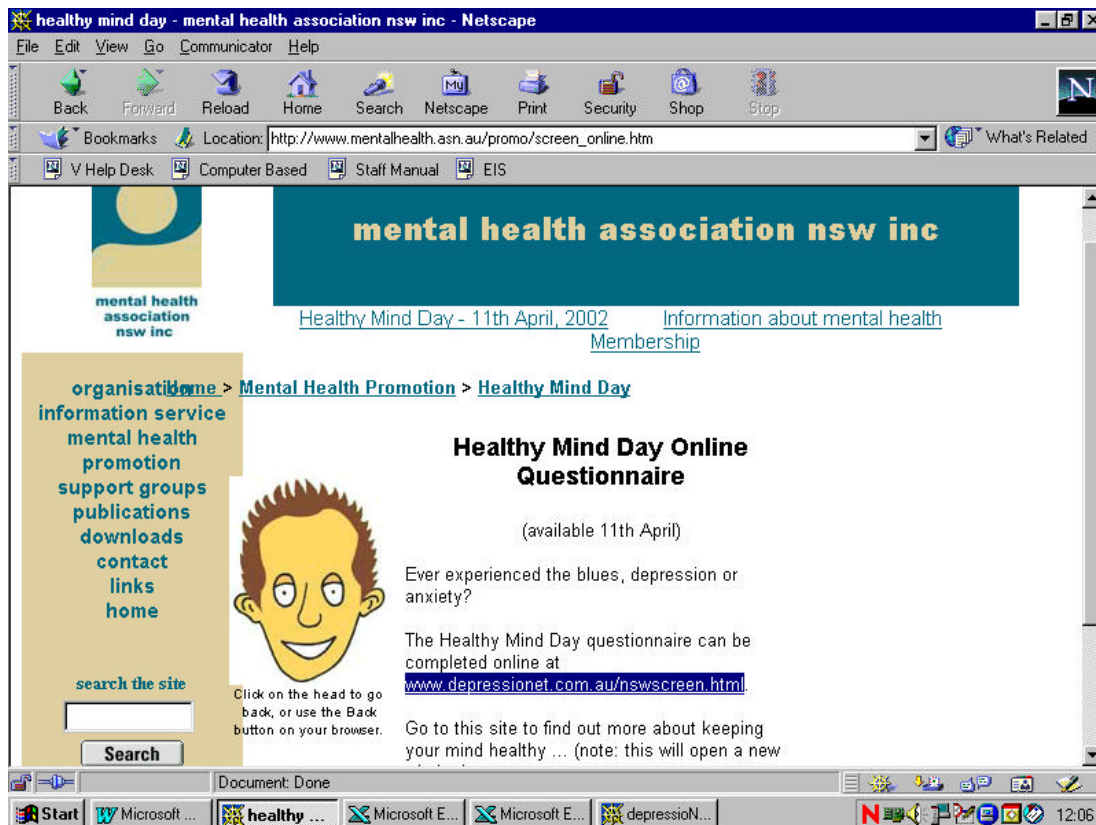
A range of programs, media campaigns, and community resources have been developed at local, state and national levels to promote awareness of mental health issues and access to early support and intervention. The effectiveness of many of these programs has been assessed through focus groups and project committees and in some cases using evaluation pre-post testing.

The programs vary from general promotional campaigns to specific targets or needs. Examples of the more general approach are the activities of the Mental Health Association of NSW, Australian Rotary, Mental Illness Education Association of NSW and the Neuroscience Institute of Schizophrenia and Allied Disorders.

The **Mental Health Association NSW Inc**, funded by the Centre for Mental Health, provides a comprehensive Mental Health Information Service. The Association provides information on local mental health services, self-help and support groups, information brochures and other resources for the general community. It is staffed by mental health professionals, consumers, carers and volunteers and maintains a focus on the needs of individuals and families affected by mental health problems and disorders.

The Association coordinates Mental Health Week held in October each year. Each Mental Health Week highlights a specific aspect of mental health. These have included the promotion of mentally healthy workplaces and confronting stigma and discrimination against people living and recovering from mental illness within the workplace.

The Association organised 'Healthy Mind Day' held on 11 April 2002. Anxiety and Depression screenings were offered at major shopping centres and chemist stores associated with the Pharmacy Guild of NSW. The screening involved a self-administered questionnaire that provided a score indicating if help was required and at what service level. Pamphlets with information on self-management techniques and treatment options were distributed. The project will be evaluated, including a telephone survey and follow-up. A website has been developed to provide further information at: <http://www.nswamh.org./promo/screen.htm>.



The **Australian Rotary Health Research Fund** has pledged \$5 million for research into mental illness over the next five years. Rotary has been conducting community forums across NSW in conjunction with NSW Mental Health Services. One of the aims of the forums is to build an awareness of mental illnesses in the Australian community in an endeavour to remove the stigma currently attached to them. The response to the forums has been overwhelming in many areas, with attendances between of 250 to 400 people.

The **Mental Illness Education Association of NSW** is a non-government organisation founded in 1987 to promote awareness of mental health problems and issues. The Association was initially funded by NSW Health as a pilot program and has been maintained since that time.

It has developed a curriculum for secondary students known as '*INSIGHT – A Mental Health Awareness Program*'. The Program includes:

- an overview of mental health; understanding of mental health problems and disorders;
- awareness of stigma and attitudes about mental health problems and disorders; and
- encouragement of help seeking.

The hour-long session is presented to groups of students by trained volunteers who have had a personal experience of mental illness. The approach has been designed to be flexible and interactive to appeal to young people.

The Association has also developed strong partnerships with NSW Health and area health services. In particular, through the NSW School-Link initiative, it has become part of a wider promotion and prevention approach to mental health in schools. Methods for ongoing

evaluation of school and community presentations have been developed in consultation with Northern Sydney Area Health Service.

The **Neuroscience Institute of Schizophrenia and Allied Disorders** (NISAD) and NSW Health Partnership Project was established to raise awareness of mental illness issues in the workplace. Presentations designed to combat the stigma and prejudice towards mental illness have been made to more than 5,000 people, at workplaces and community clubs, to unions and corporate executives. This has provided a significant opportunity to inform, and change attitudes in the wider community towards mental illness and to reduce stigma.

NISAD supports research to better understand the clinical components of schizophrenia and to improve treatment and services. The research provides hope that causes of schizophrenia can be found and prevention may be possible. Since 1996, NISAD has received major support from charitable foundations and trusts, as well as significant donations from many local organisations, small businesses and national corporations.

Sponsorship awards embody an evolving health strategy of partnership and collaboration between government, research expertise and the business community that is intended to achieve a greater understanding of mental illness, and a maximising of community mental health.

Other community education/integration programs target specific groups or needs. The following examples focus on children, young people and their families, mothers and infants as well as depression and suicide.

The **Family Help Kit** developed by the Centre for Mental Health was first published in 1998. The Kit helps families understand about mental health problems that may affect children and young people and how to recognise the early signs. It also provides information on how and where to get help to assist parents responding to mental illness.

The Kit has been distributed to general practitioners and area health services and has been incorporated in to the Parenting Booklets released by the Department of Community Services.



A Multicultural Family Help Kit

has been developed to assist families and young people from culturally and linguistically diverse backgrounds to recognise the signs of mental health problems for children and young people and to seek help early. The information was used in 1999 for SBS radio programs and was translated into 16 community languages. The Kit is available on audio-tape, printed format and on the Transcultural Mental Health Centre web-site.

The **Integrated Perinatal and Infant Care program** (IPC) incorporates psychosocial factors into the assessment process for maternity and early childhood services. It is intended to assist in the identification of difficulties that may impact on parenting and to enhance the mechanisms needed for appropriate care and support for new mothers and their infants. The Centre for Mental Health has funded and developed the framework to progress the initiative. Primary Health and Community Care Branch will support the implementation through links

with the Families First: Health Home Visiting initiative currently being developed for maternity and early childhood services.

South Western Sydney Area Health Service is the lead agency in development and providing consultation to other area health services about IPC. Training of staff, supervision and facilitation of collaborative care planning processes are also part of the IPC implementation. An IPC Training Manual has been developed and trialled in metropolitan and rural localities.

As well, the IPC Implementation Manual currently under development will support consultation, raise awareness of the initiative, and provide information to services already developing psychosocial assessment and support as part of their maternity services planning.

Adopting a population health approach to the delivery of parenting programs to enhance parenting skills means services can be offered without increasing stigma or increasing the perceived discrimination of targeted communities.

The **NSW Parenting Program for Mental Health** provides infrastructure for a coordinated local approach to assist families in the prevention of mental health problems. Collaboration with the Parenting Centre, established by the Department of Community Services at Bidura House, will help to provide a range of resources to enhance parenting practices across NSW, including Children's Services and non-government organisations.

In 2001, 781 workers from NSW Health and other agencies were trained across all levels of the Positive Parenting Program (Triple P) by the NSW Parenting Program for Mental Health. Approximately 1,500 parents attended Triple P groups across NSW to December 2001. Parents are reporting positive results: significant reductions in child behavioural problems, use of dysfunctional parenting styles and parental stress and depression and significant improvement in their parenting effectiveness, satisfaction with their parenting role, and marked reductions in their use of punitive (including physical) forms of punishment. Of the total participants, 85 per cent felt that their child's behaviour had also improved due to the skills learnt in the program.

The Centre for Mental Health provided funding to the **Family Support Services Association** of NSW in 1999 to develop a training program on mental health issues for family support workers in NSW. The Living on the Edge project ran 15 two-day workshops, delivered to 16 Family Support Services across NSW over 1999 and 2000. The evaluation from these workshops indicates that family support workers found the training to be of value and has led to further training on specific issues and better links between family support workers and mental health services across NSW.

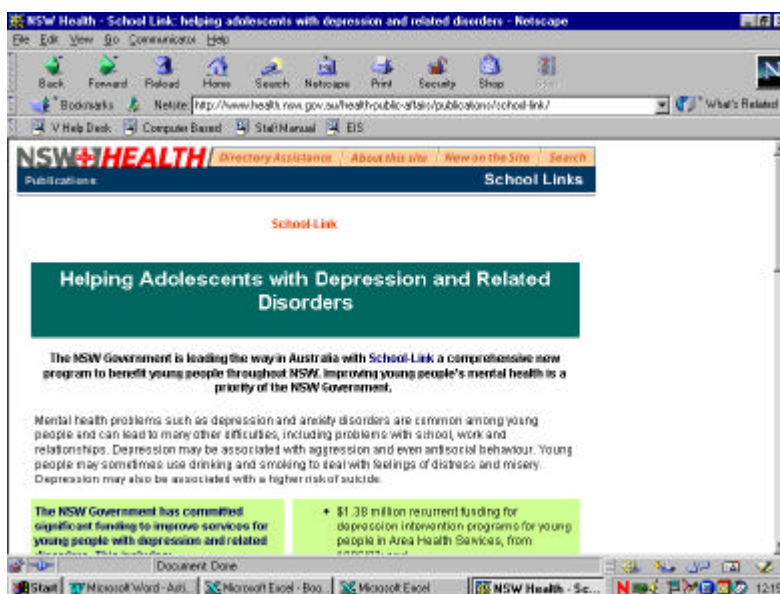
The *School-Link* initiative has helped to foster inter-agency collaboration between health and education to work together to support adolescents with mental health problems, particularly depression and related disorders.

School-Link is managed centrally by the Centre for Mental Health. Local coordination is by Area School-Link Coordinators in each of the 17 area health services.

During 2000-2001, almost 1,800 school and TAFE counsellors and mental health workers participated in the shared School-Link Training Program. The Program focussed on depression and related disorders in adolescents within a framework of collaboration and developing local pathways to care and links between schools and mental health services. Further specialist modules relating to adolescent depression and related disorders are being

developed, including advanced assessment and management, cultural diversity, same-sex attracted young people and Aboriginal young people.

The Area School-Link Coordinators work with schools to enhance their participation in promotion, prevention and early intervention programs in mental health. Such school-based programs help to develop mental health literacy for young people so that they learn to recognise emotions and feelings, develop skills for coping with adversity and become better equipped to negotiate life transitions.



Some local programs include:

- The Resourceful Adolescent Program (RAP), a universal school based program aimed at preventing depression in Year 8-9 students. RAP has been piloted and evaluated by the Griffith Early Intervention Project at Griffith University, Queensland, and is being implemented in many schools throughout NSW.
- Adolescents Coping with Emotions (ACE), a school based depression prevention program, focusing on high school students at high risk. It is being implemented in schools throughout NSW and being piloted in New Zealand.

MindMatters, a national mental health promotion school based initiative, is currently being implemented throughout Australia. *MindMatters* provides a whole of school approach to promoting the mental health of the school community. It includes audits of school policies and initiatives impacting on mental health, as well as curriculum components covering enhancing resilience, preventing bullying, dealing with grief and loss and understanding mental illness. The NSW Area School-Link Coordinators have an integral role in the implementation of *MindMatters*, including participation in two-day professional development, providing briefing sessions on *MindMatters* for schools and assisting with professional development and support for *MindMatters* focus schools.

The *Dumping Depression* project is a collaborative partnership between mental health, youth health and health promotion. The project was established to enhance community perception of young people; to provide information to young people and parents about early recognition of depression; to provide strategies for dealing with symptoms; and to provide information about how to access services.

A number of resources were developed for the project including: four CD-sized pamphlets on Grief and Loss, Feeling Good, Good Communication and Anger, Conflict and Bullying; five postcards and a wallet-sized card providing information and explaining where to get help. The has been well received by young people. The resources have been adapted for each area health service with local service information and distributed throughout NSW.

The *Same Sex Attracted Project* was funded by the Centre for Mental Health and developed by the Central Coast Area Health Service. The project has produced information resources for health professionals, young people and their families that are now available for NSW. Young people participated in the design and development of the resources and were

instrumental in directing the project to focus on relationship issues that affect most young people, of which, same sex attractions is one issue.

Early Psychosis services and initiatives are available in most area health services across NSW. Areas are focussing on providing evidence based services to young people aged 15-24 years who are at risk of or experiencing first episode psychosis. Interventions include early identification and comprehensive assessment, assertive case management, family support and intervention, psychological interventions and groupwork.

These services are assisting in addressing the situation where mental health problems in young people have been poorly recognised, identified and managed and there has often been a considerable delay in young people receiving appropriate care. Links are being strengthened with the many different settings in which young people with mental health problems may attend, such as schools, general practice, youth and community organisations, mental health and juvenile justice services.

Getting in Early – A framework for early intervention and prevention in mental health for young people in New South Wales (2000) is a framework for early intervention and prevention for young people in NSW. The need to foster collaboration between mental health services and other services is critical to increase awareness and pathways to care for mental health problems in young people.

A range of organisations contribute indirectly to preventing suicide through improving the community's well being and its ability to cope with problems.

NSW Health and Transcultural Mental Health Centre suicide prevention initiative, a first in Australia, provided comprehensive research to inform other suicide prevention initiatives for people from culturally diverse backgrounds. Information gathered highlights the importance of improving information on suicide, particularly for health and other workers, enhancing community resilience, increasing awareness and better recognition of 'at risk' situations, and reducing adverse consequences of suicide.

Suicide prevention initiatives established by the NSW Rural and Regional Youth Suicide Prevention Project throughout rural and regional NSW include suicide prevention education and training for the general public, welfare and related agencies and health staff.

A range of publications have been developed for community dissemination to help increase the understanding of the impact of suicide on family and friends and to help people to know where to access support when they need it. These include:

- The *'Care and support pack for families and friends bereaved by suicide'* developed by the Centre for Mental Health, with the substantial contributions by Brian Wilson, Coroner, Central Coast, Dianne and Mal McKissock and Ruth Anderson. The pack is a practical, imaginative and caring resource for families and friends bereaved by suicide. It contains information, advice and shared thoughts for people who have experienced loss, as well as practical information about the role of the police, coroner, the funeral director and where to access support and counselling.
- *'Supporting Children After Suicide'* booklet, developed by South Western Sydney Area Health Service, aims to provide advice to parents and to assist those who may be worried and unsure about providing the best support and care for their children, following a suicide death.

In 1997/98 the Older People Suicide Prevention Network was formed. The Network has been active in generating a diversity of initiatives for this age group and in raising awareness of suicide risk, its identification and treatment in older people.

From the 2000 NSW Elderly Depression and Suicide Conference a video has been produced and features keynote speakers from the Conference. It is used as part of health and non-health staff training about elderly suicide prevention and mental health of older people.

On-line community education is on-line has been used successfully to educate and inform young people. The *Reachout* website is a component of the National Suicide Prevention Strategy. It provides helpful advice concerning problems that young people are experiencing including how to assist their friends during difficult times.

The *Make-a-noise* website is a community initiative to encourage help seeking behaviour with young people. The site is easy for young people to access. The site provides a range of information on health issues for young people, information on local health services, chat rooms and links to other websites.

¹ Thornicroft G & Betts V, *International Mid-Term Review of the Second National Mental Health Plan*, Mental Health and Special Programs Branch, Commonwealth Department of Health and Ageing, Canberra, 2002, page 5.

² World Health Organisation, op cit.