CONSENSUS STATEMENT ON REDUCING STIGMA AND DISCRIMINATION AGAINST OLDER PEOPLE WITH MENTAL DISORDERS

A Technical Consensus Statement

The World Health Organization and World Psychiatric Association have (in collaboration with several other international agencies) produced three Technical Consensus Statements on the scope of psychiatry of the elderly. These describe:

- the specialty of psychiatry of the elderly
- the organization of services in psychiatry of the elderly
- education in psychiatry of the elderly

The aim of this fourth Technical Consensus Statement is to provide all concerned with a practical tool to assist in the reduction of psychiatric stigmatisation and discrimination in old age. Its objectives are to:

- promote debate at all levels on the stigmatisation and discrimination of older persons with mental disorders;
- outline the nature, causes and consequences of stigmatisation and discrimination of older persons with mental disorders;
- promote and suggest policies, programmes and actions to combat the stigmatisation and discrimination of older persons.

1. DEFINITIONS

Stigma is a process whereby certain individuals and groups are unjustifiably rendered shameful, excluded and discriminated against.

Discrimination means any distinction, exclusion or preference that has the effect of nullifying or impairing equal enjoyment of rights. Special measures solely to protect the rights, or secure the advancement, of persons with mental illness shall not be deemed to be discriminatory. Discrimination does not include any distinction, exclusion or preference necessary to protect the human rights of a person with a mental illness, or of other individuals. (UN Resolution 46/119: 17.12.91)

2. GENERAL PRINCIPLES

All persons with a mental illness (or who are being treated as such persons) shall be treated with humanity and respect for the inherent dignity of the human person (ref). Stigmatization of old people with mental illness not only makes them feel shame about themselves and their illness, it reduces the likelihood that they or their family carers will seek treatment or that providers will give adequate treatment resulting in prolonged suffering and unnecessary costs to the system. It therefore follows that the stigmatisation of older persons with mental illness (psychiatric stigma) must be countered wherever it occurs. However, stigmatising is a basic human characteristic, and is difficult to counteract without clear and conscious strategies.

To date, the focus of most thought and action on this topic has been on psychiatric stigma in younger adult populations (e.g. Hayward and Bright 1997; Sartorius 1999). The aim of this document is to apply the concept to older adults. As in previous Consensus Statements, ‘older adults’ are defined here as those over the age of 65 years. However, it should be noted that the

age at which an individual is perceived as 'old' varies across cultures. Since stigma and discrimination against old age – independent from that against mental disorder – also occurs in most societies, there is therefore a 'double jeopardy' for older persons who are mentally ill, and both issues need to be addressed in anti-stigma and anti-discrimination strategies for this age group.

- All forms of stigma and discrimination relating to mental illness in old age are unacceptable and everyone has the right to be protected from it.
- Everyone has the right and duty, individually and collectively, to counteract psychiatric stigma in older people.
- Counteracting psychiatric stigma and discrimination is a duty of governments, Non-governmental organisations (NGOs), services, patients' organisations and the general public. To be effective, they will need to work in partnership.
- Actions against stigma and discrimination of older persons with mental disorders:
  - should be a priority of all, to achieve the state of physical, psychological and social well-being as defined by the Constitution of the WHO (ref);
  - should form part of the promotion of good mental health by professional training and public education, and should be a major component of all levels of a health and social care programme.

3. THE CAUSES AND CONSEQUENCES OF PSYCHIATRIC STIGMA IN OLDER PEOPLE

Psychiatric stigma applied to older people with mental disorders has both cognitive and behavioural components, both of which need to be addressed by any actions designed to counter it.

3.1 **Causes include** the following:

- **Ignorance / misconceptions** of the facts regarding the nature of old age, and of mental illness and its treatments;
- **Fear** of injury, contagion, the unknown, psychological abuse, unpredictability, the burden of care;
- **Drive for social conformity** and the subsequent suppression of difference;
- **Mistaken attributions** of personal responsibility for mental illness and its consequences.

Psychiatric stigma is reinforced by:

- Cultural factors, such as differences in specific beliefs regarding the value of older members of society, of the causation of mental illness, and what it implies about the patient's family, etc.;
- Social instability and crisis (war, migration, the influx of refugees, etc.) encourage the stigmatisation of people with mental illness at all ages;
- The actual or perceived absence or inadequacy of treatments for mental disorders;
- The lack of information systems to educate both professionals and the general public;
- Gender discrimination, which will be greater in elderly populations, where women outnumber men (i.e., there is a 'triple jeopardy' for elderly women with mental illness, so far as stigma is concerned);

- Any rewards for those who stigmatise (financial, denial of problems, enhanced social status etc.)

3.2 The **consequences** of stigma include the following:

3.2.1. *Attitudes*

Psychiatric stigma applied to older people with mental disorders leads to the development of negative attitudes, such as:

- Prejudice: for example, the 'common sense' attitudes that people with mental disorders are dangerous, weak, irresponsible, spongers, tainted, etc and 'ageist prejudices' about older people include ideas that they are weak, ill, peculiar, inflexible, unproductive, etc. Stigma fosters hostility against its victims.
- The creation of popular stereotypes of both the elderly and the mentally ill, often supported and reinforced by the public media.
- Damaging self-beliefs held by those who are (or who might be) stigmatised, e.g. shame, low self-esteem, unwillingness to discuss problems or access services.
- The creation of 'taboo' subjects, and lack of public discussion.
- Negative professional attitudes towards elderly mentally ill.
- Alarmist professional and popular statements about need, burden, cost of care, etc.

3.2.2. *Discrimination*

These negative attitudes lead in turn to discrimination against older people with mental disorders:

Against:

- individuals
- their families
- those who care for them (families, agencies, etc.)

In:

- the home
- the workplace
- the community
- health and social care (communities, institutions)
- research
- legal practice
- financial services

In terms of:

- poor quality treatment and care (access, provision, outcome, relapse)
- lack of empathy and communication
- marginalisation within care systems
- low status of professionals, services providing care
- difficulties in recruiting and retaining staff
- inadequate funding at national and local levels

- inequity in reimbursement for treatment
- impact on families (blame, marriageability, etc.)
- victimization, abuse, neglect
- social distancing of the suffers and lack of familiarity with their experiences
- poor quality of life
- lack of evidence to inform policy
- adverse economic effects (personal, social)
- discriminatory legislation
- financial inequity (insurance, mortgages, etc.)
- Government neglect, and lack of legislative protections

There are some important adverse interactions between the stigmatising attitudes towards mental disorder and towards old age. Examples include:

- The ageist notion that old people are inflexible and unable to change reinforces the therapeutic pessimism that is commonly attributed to mental disorders.
- The damaging effect that a psychiatric history can have on the access to physical health care in old age (e.g. not taking physical complaints seriously).
- The adverse effects of mental disorder on professional and family attitudes towards older persons' autonomy, and their capacity to make life decisions, etc.
- The reluctance of many professionals and services to take responsibility for elderly patients with long-standing mental disorders.
- The fact that psychiatry and psychiatric services are seen as stigmatising by the elderly population, and so are less used by them.
- The fact that diagnostic criteria are often ageist.
- Reluctance to use more expensive 'modern' psychotropic drugs for older patients

4. STIGMATISATION OF PARTICULAR MENTAL DISORDERS IN OLD AGE

This section sets out some of the ways in which persons with specific mental disorders in old age are stigmatised (unless appropriate educational and attitudinal changes are made).

4.1 Depression

- Depression is seen as a natural consequence of ageing, loss and physical illness (by patients, their families and professionals), and is therefore not diagnosed or treated.
- Certain treatments (e.g. ECT, drugs) that are perceived as more stigmatising than others (e.g. psychotherapy) are more likely to be offered to elderly patients.
- Depressive cognitions (e.g. guilt, pessimism, hopelessness) and behaviours (e.g. suicidal acts) have a stigmatising impact on patients and their families.
- Depression and anxiety are seen as marks of moral weakness.

4.2 Dementia

- Dementia is often seen as a natural part of ageing, and therefore is not recognised or managed appropriately.

- In some cultures, the fact that dementia has an organic aetiology may reduce stigma associated with it, i.e. public awareness of this means that patients are not regarded as 'mentally ill'. This reflects ambiguity in how it is classified, and has implications for service organisation and reimbursement.
- However, it is still the case that specific symptoms of dementia are powerfully stigmatising (e.g. disturbed behaviour, poor self care, incontinence), both in the community and in care settings.
- Popular (and some professional) use of the term 'dementia' is still stigmatising.
- The patient's loss of memory often leads to loss of their past, and their conversion from a person into a thing.

4.3 Delirium

- The poor management of delirium in inpatients is a specific example of how mental disorders arising in physical care settings are often stigmatised, resulting in non-recognition, misdiagnosis, and inappropriate treatment.

4.4 Psychosis

- The stigmatising effect of psychosis has been well described in younger adults. The diagnosis of schizophrenia is less used in old age psychiatry, but where it is, the same stigma attaches to it.
- Psychotic elderly people are perceived as less dangerous (and are therefore less stigmatised) than younger patients.
- However, there is a prejudice that all old people are odd, and psychotic patients consequently receive less recognition, treatment, rehabilitation, and engagement in society.

4.5 Anxiety

- There is prejudice that all old people are fearful, therefore there is less recognition and treatment of anxiety disorders.
- With regard to post-traumatic stress disorder, the late consequences of early trauma are often not recognised, and is another example of how older people are often perceived as having no history.

4.6 Substance abuse

- This is often under-diagnosed, since it is assumed to be a problem of younger adults.
- There is inappropriate therapeutic nihilism in this age group.
- There are inappropriate age cut-offs for therapeutic services.

4.7 Personality disorder

- These are often misdiagnosed, due to ageist assumptions that most old people are peculiar.
- Elderly people with personality disorders are often excluded from appropriate care and treatment.

4.8 Learning disability

- Health and social services for this group are ill equipped to provide for elderly people with learning disabilities.
- Elderly people with learning disabilities are often excluded from appropriate care and treatment if they develop a mental disorder.

5. ACTION AGAINST STIGMA AND DISCRIMINATION

The main goal of a campain against stigma and discrmination against older people with mental disorders would be the public acceptance of ageing and of the mental disorders

5.1 A strategic approach

Changing stigma mainly involves education, while changing discrimination has a primarily legal agenda (e.g. changing laws and policies). The main goals of a strategy to reduce stigma and discrimination in the context of mental health problems in old age are to

- Position mental health of older people in the public agenda – mental illness is as important in old age as earlier in life (including encouraging positive notions of ageing)
- Promote a greater understanding and acceptance of older people experiencing mental illness
- Create a supportive environment for older people experiencing mental illness
- Ensure that the health and social care systems can meet the needs of older people with mental illness and their carers

Achieving these goals will involve

- Increasing awareness
- Supporting empowerment
- Stopping exclusion
- Ensuring appropriate treatment and care
- Credible advocacy

Although governments have primary responsibility in reducing stigma/discrimination, other groups and individuals also have major roles to play. The duties, responsibilities and opportunities of a range of groupings are summarised below. It is neither exhaustive nor mutually exclusive, and is intended primarily as a check list of possibilities both for direct action and for lobbying. When considered in the context of specific local needs it should provide a basis for developing a local action plan. Such a plan will involve collaboration between several of the groupings, often led by NGOs and/or professionals, and should be

- Realistic
- Time limited
- Evaluated

It is also useful for the local action plan to contain appropriate ‘key messages’. These might include any or all of the following

- Most elderly people are fit and well
- All elderly people with mental health problems will benefit from treatment and care
- All elderly people with mental health problems can function, and should not be isolated or restricted in old age

- Depression is a treatable illness, not a weakness
- All people with dementia can have a good quality of life
- If you are low or forgetful, go and see your doctor
- Stigma is destructive and obstructive
- Stigma and discrimination hurt - face them, eliminate them

5.2 Roles, responsibilities and opportunities

Policy-makers including government (national/local)

- Specific policies and laws around stigma/discrimination need to be developed at all levels of government
- Mental health problems in old age should be featured in party political agendas
- Necessary resources should be allocated for the development and realisation of information campaigns within education and through the media. In particular, government should ensure that mental health problems in older people are included in school curricula and addressed in a positive way
- Politicians should ensure that professionals, lay carers and patients have a 'voice' – and listen to it
- National and local justice systems should provide explicit effective and accessible protection against stigma and discrimination
- Services should be planned to ensure equity of provision to older people with mental health problems. These include
    - Adequate pensions
    - An appropriate range of community facilities and activities
    - Age sensitive public transport
- Health and social services for older people should be planned, funded and provided as part of general health and social care system and in accordance with the guidelines in previous WHO/WPA consensus statements. This will require
    - adequately trained, compensated staff
    - a safe working environment
    - credible information systems both for needs assessment and to ensure service delivery
    - the development of distinct services for older people with secondary needs
    - financial incentives for primary care workers to carry out regular assessments of older people

NGOs (international/national/local) have a crucial role in

- Developing appropriate relevant policies for their country/locality
- Raising awareness (lobbying)
- Leading collaboration with other stakeholders and coordinating multi-agency working
- Ensuring a 'voice' for health professionals, lay carers and patients
- Selecting and supporting effective spokespersons
- Pointing out to governments what is discriminatory about their laws and policies and lobbying for change
- Developing and maintaining
    - campaigns (inc mass media campaigns)
    - advice lines

    - websites
    - information leaflets
    - educational links with schools and universities
- Maintaining close liaison with journalists
    - Media packs
    - Face to face contact
    - Seminars for journalists
    - Involving journalists directly in NGO activities
    - Media watch (correcting misleading media material)
- Modelling acceptance and understanding through their own employment and supportive care policies

Professionals (including paid care workers) should

- Ensure that training and continuing professional development curricula contain
    - appropriate material on mental health problems in old age
    - training to develop awareness of stigma and discrimination
    - training to ensure that assessments and planned care provision take positive account of aspects of mental health and of ageing
- Ensure that due weight is given to issues of mental illness in old age in the professional research agenda
- Ensure that professional bodies have policies in place to identify and reduce stigma and discrimination
- Ensure that local workplace policies are in place to identify and reduce stigma and discrimination
- Join with government, NGOs and patients and carers to plan services that avoid stigma and discrimination
- Provide information and advice to individual patients carers and families re
    - Diseases
    - Treatments
    - Local community and specialist services
    - The work of relevant NGOs
- Provide accurate information to journalists
- Disseminate good evidence-based practice to ensure early identification and effective treatment of mental disorders in older people
- Assure and regulate the competence of care providers

Carers and families can be effective by

- Joining (or where necessary, forming) associations and support groups
- Providing information regarding their issues and experiences to government, professionals and NGOs
- Going public about their experiences with mental illness and of caring and discrimination
- Participating in the planning of services that avoid stigma and discrimination
- Seeking and using services that combat stigma and discrimination
- Acting as advocates (e.g. calling attention to problems, changing systems) where stigma or discrimination occur

The general public can

- Exert constructive influence on policy and decision makers (e.g. initiating government debate, referenda etc)
- Press for adequate services for older people with mental health problems, including citizenship rights

Patients should, where possible, be encouraged to

- Go public and share their experience of old age, of illness and of discrimination
- Participate in information and education campaigns
- Join (or where necessary forming) associations
- Express their needs to service providers, NGOs and government
- Join in planning services that avoid stigma and discrimination
- Report and denounce any experiences they have of professional malpractice

The Media should

- Recognise their responsibility for promoting truth about mental health problems in old age
- Recognise their potential for creating or sustaining myths about mental health problems in old age – and taking appropriate steps to avoid such myths
- Ensure that journalists are properly informed about mental health problems in old age
- Ensure that policies are in place to avoid the dissemination of stigmatising and discriminatory material
- Take all possible opportunities to report
    - appropriate information/stories about mental health problems in old age
    - malpractices, abuses, and good practices
    - adverse effects of stigma and discrimination
- Raise the need for services
- Provide public information about services, support groups, and associations

The Corporate sector should

- Ensure that non-discriminatory policies are in place (e.g. health insurance, supporting carers in work, policies re mandatory retirement)
- Sponsor educational and media campaigns
- Ensure that employers are sensitive to the mental health needs of their older workers and those taking care of older relatives
- Ensure employees have access to and means to pay for appropriate services for themselves and their older relatives
- Ensure that older people and those with mental health problems have fair access to the goods and services they provide.

Schools, universities and vocational training (e.g. police, fire service) should

- Ensure a range of opportunities for intergenerational contact
- Including aspects of mental health and ageing in their curricula

6. CONCLUSION

Stigma and discrimination against older people with mental health problems are widespread and their consequences are far-reaching. More research is clearly needed both

to identify such stigma and discrimination where they do occur, and to define their effects. Equally important, research is needed to examine the most effective ways of intervening to reduce stigma and discrimination. Meanwhile, this consensus statement attempts to summarise some of the available evidence and to make practical suggestions for action. Such action needs to be developed locally to ensure that it is sensitive to, and specific for, an area's needs and culture. Local multi-agency workshops using this consensus statement as their starting point may be a useful way of developing appropriate national or local action plans.