#### COMMISSION OF THE EUROPEAN COMMUNITIES

#### **GREEN PAPER**

## Improving the mental health of the population Towards a strategy on mental health for the European Union

### Consultation Process Contribution by Schizophrenia Ireland

#### March 2006



#### **Mission Statement of Schizophrenia Ireland:**

Schizophrenia Ireland is the national organisation dedicated to upholding the rights and addressing the needs of all those affected by schizophrenia and related illnesses, through the promotion and provision of high quality services and working to ensure the continual enhancement of the quality of life of the people it serves.

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#### Introduction

Schizophrenia Ireland welcomes the production of the Green Paper by the European Commission and sees it as a first step in consolidating good standards of mental healthcare across the European Union member states. We note that the purpose of the Green Paper is to launch a debate within the European institution's governments, health professionals, stakeholders and others, about the relevance of mental health for the EU, the need for a strategy at EU level and it's possible priorities. Specifically we also note that the organization and delivery of mental healthcare services in each member state is a matter for member states only and is not subject to the jurisdiction of the European Union.

#### Response to specific questions posed:

(Question 1) How relevant is the mental health of the population for the EU's strategic policy objectives, as detailed in section 1? EU's strategic policy objectives:

- Put Europe back on the path to long-term prosperity
- Sustain Europe's commitment to solidarity and social justice
- Bring tangible practical benefits to the quality of life for European Citizens

The answer to this question is self-evident. Good mental health of the population is synonymous with good physical health. Both physical and mental health are essential to ordinary social and economic activity in the community. The converse is true - a decrease in physical or mental health will lead to deterioration in participation in society with a consequent reduction in social and economic well being.

This section needs to be expanded clearly outlining why mental health is important, such as:

- It enables people to live fulfilled lives, contribute to society, and citizenship therefore contributing to the EU's strategy policy objectives.
- Mental health is very costly to society in terms of social costs and economic costs (perhaps site WHO research to support this and to provide a clear indication of that cost).
- It might be advisable to include the following: WHO has calculated that 'mental disorders' rank second in the global burden of disease and 5 out of 10 leading causes of disability worldwide are mental health conditions such as depression and schizophrenia.

## (Question 2) Would the development of a comprehensive EU-strategy on mental health add value to the existing and envisaged actions and does section 5 propose adequate priorities?

The development of a comprehensive EU-strategy on mental health would greatly add value to the existing and planned actions in mental health. By creating an EU-strategy, the importance of mental health on Member States' agendas would be highlighted, increasing attention to the issues. Specifically, the development of a comprehensive EU-strategy is essential for the following reasons:

- a. To promote best practice across member states
- b. To co-ordinate and monitor the establishment of best practice across member states
- c. To encourage transfer and dissemination of research.

Critically, an EU-strategy on mental health would open a platform for positive exchange of information and cooperation at all levels. Individual organisations and Member States have a vast wealth of resources that have never been fully catalogued and pooled. By creating a framework for exchange and cooperation, stakeholders across the EU would be better equipped to work together to create positive developments in mental health.

Additional aspects to consider for the EU-strategy's focus:

- Develop a mental health information, research and knowledge system for the EU, which includes facilitating the links between Member States' stakeholders.
- Provide funding for Member States' stakeholders to exchange information and cooperation (including EU conferences and cross national projects specifically relating to mental health).

# (Question 3) Are the initiatives proposed in sections 6 and 7 appropriate to support the coordination between Member States, to promote the integration of mental health into the health and non-health policies and stakeholder action, and to better liaise research and policy on mental health aspects?

We propose additionally that key consideration be given to the relationship between service provision and service policy across Member States, and the various international treaties, which outline the various rights of people to good mental health, to which many Member States are signatories.

However, the following recommendations are as follows:

**6.1** Promoting mental health and addressing mental ill health through preventive action In addition to the actions outlined in this action, SI would propose that there should be discussion on the whole area of preventative strategies, based on principles of early intervention. It is well recognised internationally that the duration of undiagnosed psychosis (DUP) can in many cases be up to eighteen months. It is also clear from research that there is a relationship between the period of DUP and the likelihood of recovery post treatment, in other words where interventions are applied early in the onset of the condition the greater the likelihood of a sustained and full recovery being achieved. Many modern mental healthcare services are now piloting or promoting early

intervention models aimed at identifying early symptoms of psychosis, and putting into place strategies to prevent the onset to a more pathological form of the condition. (See Appendix 1)

#### **6.1.1** Should also include:

- 'Targeting people with severe and enduring mental illness'
- 'Promoting mental health for people with intellectual disability'
- Other areas of consideration:
  - o Forensic mental health
  - o Homeless people
  - o People with co-morbidity
  - o People with eating disorders

#### **6.1.2**. Preventing suicide

- Possible initiatives at Community level should include:
  - o Free access to talking therapies (such as Counselling, Cognitive Behavioural Therapy (CBT), Psychoanalysis, etc)
  - Establish training programmes that equip everyone in the community with skills to respond effectively to someone in crisis, such as ASIST (Applied Suicide Intervention Skills Training) workshops. ASIST is a two-day intensive, interactive and practice-dominated course designed to help recognise and review risk, and intervene to prevent the immediate risk of suicide. It is by far the most widely used, acclaimed and researched suicide intervention training workshop in the world. Currently ASIST is presented around the world in English, French, Norwegian, Spanish and Inuktitut. Accessible formats include Braille, audio and electronic files designed for reader technology. The statutory Irish organisation, the Irish National Office for Suicide Prevention, has overseen the roll out of ASIST throughout Ireland. For further details on ASIST, please see: <a href="http://www.livingworks.net/">http://www.livingworks.net/</a>
  - Promote community-based research to identify specific determinants of suicidal behaviour and to evaluate the effectives of a range of interventions in health, educational and community settings.
  - Ensure appropriate community discharge planning for individuals leaving mental health services (as this is a time of great risk for suicidal behaviour).
- **6.2.** Promoting the social inclusion of mentally ill or disabled people and protecting their fundamental rights and dignity
  - The need for the shift in the attitudes of the media needs to be specifically cited. According to the World Health Organization (WHO), research over the last 30 years has convincingly demonstrated that the mass media are one of the most significant influences on belief systems. Since people with stigmatised mental health problems do not usually announce themselves, people often form their attitudes through the news reports, films and television programmes they see. For

- that reason, the media have a significant role to play in reducing stigma towards people with mental health difficulties.
- In the sentence "Governments: improving public awareness about mental ill health and treatment options....", it is suggested that "treatment options" be changed to "recovery". This is because 'treatment options' might come across as solely medical interventions, whereas recovery is much more a holistic approach. Recovery does not necessarily imply a cure, but suggests that the individual can live a productive and meaningful life despite vulnerabilities that may persist, equipped with the necessary self-understanding and resources to minimise relapse. Also, it is important to highlight that people with mental health problems can—and do—recover.
- In addition to the text under this heading, Schizophrenia Ireland considers it important to have a discussion on two major issues:
  - i. The involvement of users and families in the provision of service at the planning, development, delivery and evaluation stage.

    It is important that models of mental healthcare service are patient and family centred. To achieve this, family members and patient representatives must be involved, at executive level, in the planning and delivery of mental healthcare services. (See Appendix 2)
  - ii. The concept of patients and families as active participants in the process of recovery.

The academic research and anecdotal experience to date, indicates that the process of recovery is more likely to be achieved when the patient is seen as an active partner in the process of recovery, along with family members and health professionals. It is considered by many researchers, that partnership in care and recovery is a positive indicator. It is one factor that separates a recovery-orientated service from other types of services. The achievement of such partnership is based fundamentally on the attitudes and expectations of those involved in that partnership process. (*See Appendix 3*)

#### Possible Initiatives at Community level:

- Facilitating participation in employment through supported employment schemes (in Ireland, the CE scheme)
- Housing is a major cause of stress amongst people with self-experience of mental illness. Many people with severe mental illness find themselves having to remain in the family home beyond a time that is of their choosing. Increased provisions for accommodation is needed, along with greater flexibility to meet the current community needs.
- Given the high level of unemployment amongst people with enduring mental illness, the provision of adequate and appropriate income supports is particularly important. A diagnosis of mental illness should not be a prescription for poverty.
- Community based research on the relationship between social inclusion and mental health needs to be carried out.
- Supports need to include community based life skills training and development (as opposed to centre based training).

#### Section 7

- It is imperative to specifically note the necessity for service user and carer involvement in developing an EU-strategy on mental health.
- It is also important to indicate that EU funding will be available for stakeholder participation in the development of this process.

Additionally, it would be helpful to include that human rights treaties recognise the right of everyone to attain the highest possible standard of mental health. Specific agreements and treaties include:

- European convention and human rights and fundamental freedoms;
- The UN recommendation 2004-10 under protection of the human rights and dignity of persons with mental disorders;
- The UN principles for the protection of persons with mental illness and improvement of mental healthcare;
- The UN International convention of civil and political right and the UN international convention on economic, social and cultural rights, general comment 14.

All mental health policies and strategies should promote the following overarching human rights principles that apply also to service users and carers;

- The right to equality and non discrimination
- The right to privacy and autonomy
- The right to physical and mental integrity
- The right to participation
- The right to reciprocity
- The right to information
- The right to the least restrictive alternative
- The right to freedom of association
- The right to proportionality and all restrictions imposed on rights

There are other international human rights that relate to these overarching principles such as:

- The right to freedom from inhumane and degrading treatment
- The right to respect for family life
- The right to education

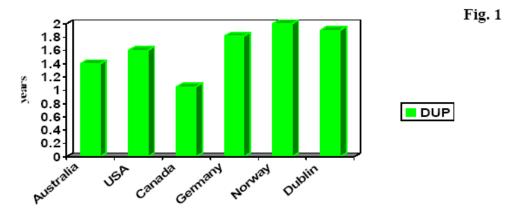
International human rights standards explain that the right to health requires the adequate provision of quality (mental) health and related services. The right to (mental) health should be understood as a right to the enjoyment of a variety of facilities, groups, services and conditions necessary, for the realization of the highest attainable standard of (mental) health.

#### Some general comments (not referring to any specific question posed):

- We note the statistical analysis on page 4, outlining the numbers of people affected by mental illness and suicide. We would make the following comments:
  - o In addition to individuals who are directly affected by the experience of mental illness, we must assume that there are a significant number of family members also affected. On the basis of a ratio of three to one, we can assume that for every one individual directly experiencing a form of mental illness, there are three family members directly affected by the condition.
  - On the issue of the 58,000 citizens who die from suicide, it must be acknowledged that a percentage of these people may have an identifiable severe mental illness. Many of these people are already in receipt of mental healthcare services.
  - o Many mental healthcare services focus only on the mental well being of the person and often overlook or neglect the physical well being of the person. Over the last two years the World Health Organization has designated World Mental Health Day to focusing on the physical well being of people with severe mental illness. This is an issue that should be taken up at EU level.
- Page 5 "The impact on prosperity, solidarity and social justice": the intangible costs on how society treats mentally ill people extend to family members as well.
- Greater emphasis should be given to rehabilitation, education, early intervention and therapeutic activities.
- Clarify diction throughout the document, paying particular attention to the following:
  - O Rather than use the term "patient" throughout the document, the term "service user" may be more appropriate, as it refers to both past and present users of the mental healthcare services. It is important to note that the term "patient" is perceived by many to be a somewhat unfavourable term.
  - "Mental health problem" refers to the full range of mental health difficulties.
  - O "Carers" should refer to family and non-family members who have a supportive and caring role.
  - O "Mental illness" refers to specific conditions such as schizophrenia, bipolar disorder and depression.

#### **APPENDIX 1**

## Duration of Untreated Psychosis—a global problem



Duration of untreated psychosis is one of the only malleable factor that can influence clinical presentation 10 and recovery. 11 The Norwegian Health Service reduced their duration of untreated psychosis in Rogeland County 12 with the result that people were less ill, had fewer symptoms and were functioning at a higher level . In Canada, patients with a DUP of less than 6 months were significantly more likely to remit than those with a delay of 22 weeks or more.

The number of suicides in Ireland is a national concern. People with psychosis and schizophrenia are at ultra high risk of suicide; with a rate 25 times higher than the general population. Between 25% and 50% attempt suicide and between 5% and 13% of people take their own lives. This group provide an ideal opportunity for targeted interventions to reduce suicide. This group was recently invited to present this data to a Joint Oireachtas Sub-Committee on High Suicide Rates. Intervening early and appropriately in psychosis may reduce the risk of suicide since increased risk has been associated with factors such as adolescent onset, co-morbid substance abuse, fewer treatment opportunities, greater deterioration and stigma.

Early intervention does not simply mean reducing delays to treatment. Psychosis is a complex condition that requires "phase specific" interventions i.e. the needs of a person experiencing the problems of schizophrenia after 20 years of treatment is very different to the needs of a young newly diagnosed individual and interventions should take cognisance of this. The first three years following the diagnosis of psychosis is known as the "critical period" 13 and specialised interventions aimed at this early phase have been developing in early intervention services around theworld.14

9 Beautrais A (2000) Risk for suicide and attempted suicide among young people *Australian and New Zealand Journal of Psychiatry*, 34, 420-436

10 Melle I, Larsen TK, Haahr U, Friis S, Johannessen JO, Opjordsmoen S, Simonsen E, Rund BR, Vaglum P, McGlashan T (2004) Reducing

the duration of untreated first episode psychosis: effects on clinical presentation *Arch Gen Psychiatry*;61(2):143-50, 2004

11 Malla, A et al (2003) A Canadian programme for early intervention in non affective psychotic disorders *Australian and New Zealand Journal* 

of Psychiatry 2003; 37: 407 - 4

12 Between 1995 and 1999 a education programme (TIPS Project) to reduce duration of untreated psychosis was rolled out in Rogaland

County, Norway, which had a DUP of 118 weeks. By 1999 duration of untreated psychosis had reduced to 26 weeks (www.tips-info.com)

13 Birchwood, M., Todd, P., & Jackson, C. (1998). Early intervention in psychosis: The critical period hypothesis. *British Journal of Psychiatry*,

172(Suppl 33), 53-59

14 Edwards, J. & McGorry, P. (2002). *Implementing Early Intervention in Psychosis: A guide to establishing early psychosis services*. London:

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#### APPENDIX 2

From 'A Vision for Change" Report of the Irish Expert Group on Mental Health Policy - page 31 section 3.8 -Wider Partnership (February 2006)

#### 3.8 Wider partnership

'The requirements for effective collaboration include, first and foremost, an acceptance by the agencies concerned of the need for collaborative efforts. Mental health agencies and the people involved in the planning and delivery of mental health services have to take a lead in explaining and convincing people in other sectors, especially those outside health, of this need. Some ways of enhancing collaboration include: involving other sectors in policy formulation; delegating responsibility for certain activities to agencies from other sectors; setting up information networks that involve agencies from other sectors; and establishing national advisory committees with representatives of relevant agencies from sectors outside mental health' 27

The vision that guides this policy requires that mental health services be characterised and led by a partnership between all stakeholders. Everybody providing mental health services and engaged in other mental health activities (such as mental health promotion) needs to seek out and work with a variety of partners.

The fundamental partnership is between service users, carers and all those working in mental health services. However, a variety of partners need to be engaged in the wider community. These should include community support groups, voluntary organisations, schools, the local county council, the local chamber of commerce, and other key individuals such as religious leaders of all faiths.

The *Strategic Partnership Guide28* produced by the National Disability Authority (NDA) outlines twelve essential principles for effective partnership with people with experience of mental health difficulties and provides training materials and guidance on getting started in this process.

**RECOMMENDATION 3.10:** Service user involvement should be characterised by a partnership approach which works according to the principles outlined in this chapter and which engages with a wide variety of individuals and organisations in the local community.

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#### APPENDIX 3

From 'A Vision for a Recovery Model in Irish Mental health Services' by the Irish Mental Health Commission – pages 40, 41

#### Core Elements of a Recovery- based Mental Health Service

Developing a recovery-based model of service would involve very significant change in key areas of our present services

**Training in recovery principles**: The adoption of a recovery model primarily represents a radical change in thinking about the process of recovery from mental ill health and about the role of mental health professionals in facilitating recovery. Training in recovery principles would need to be available for all staff and be built into induction programmes and professional training programmes for new health professionals. Contact with mental health service users who have recovered would be part of the training of all mental health professionals.

Individualised self-management plans: Individualised treatment programmes, incorporating self-management plans, developed in collaboration with the individual service user and his or her support persons would replace standard treatment programmes. Health professionals would seek agreement in respect of treatment programmes in a respectful dialogue with their clients rather than operate on the expectation of patient compliance with expert advice. The Quality in Mental Health - Your Views report (MHC 2005) advocates "respectful, empathetic relationships" and "an empowering approach" to service delivery. Services would develop protocols, which ensure that a collaborative approach is facilitated.

**Optimism about recovery**: The recovery perspective fosters optimism about the possibility of recovery from mental illness based on sound research evidence. All mental health staff would be aware of the findings of outcome studies for serious mental illness and be aware of their important role in fostering hope in service users. Personal self-management plans would identify a person's strengths as well as vulnerabilities and would work with these strengths as part of the process of recovery.

## Peer support and use of community resources are integral parts of recovery plans:

The recovery model recognises that help for persons experiencing mental ill-health may involve a range of mental health disciplines but also involves the use of peer supports, formal and informal, and local community resources. Services would identify the peer supports and resources in the local community available to their service users and incorporate the use of these resources as important aspects of individual treatment plans.

A Vision for a Recovery Model in Irish Mental Health Services

**Health professionals would work to reduce clinical distance**: Mental health professionals would be able to establish professional relationships with service users based on a respectful collaboration which acknowledges the expertise which the professional may be able to offer, the unique knowledge the individual has about his

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or her own experience and their common experience as human beings. Professionals would be highly qualified and skilled but would also be able to see themselves as human beings who will experience trauma at different points in their own lives and who can imagine what it is like to be ill.

Service developments would incorporate the expert knowledge of service users: Mental health service users, as important stakeholders, would be involved at all levels in the planning of all service developments. Management structures would be widened to incorporate the involvement of service users. At present our mental health system tends to disregard the valuable knowledge of those who have found a pathway to recovery as somewhat insignificant.

Equality of access to mainstream housing, education, health and social services: Services would work to ensure that service users have proper access to mainstream services in all respects and would develop mechanisms for facilitating this access rather than developing separate and potentially ghettoising services for users of mental health services.

An increased emphasis on psychosocial research and research using qualitative and action research paradigms which can capture more of the complex multilevel data which comprises the experience of mental illness and recovery: Traditional scientific research methods tend to be reductionist in terms of the data which can be gathered and the outcome variables are measured, and would need to be balanced by research which can address a wider range of human variables. The recovery model forces a rethink of some fundamental aspects of our present services and indeed of the whole structure of our interactions with those who consult our mental health services. The Mental Health Commission hopes that this discussion paper will serve to stimulate constructive debate about the recovery-based model of mental health services and its potential application within our services.

This paper represents the views of its author on the subject. These views have not been adopted or in any way approved by the Commission and should not be relied upon as a statement of the Commission's or Health & Consumer Protection DG's views. The European Commission does not guarantee the accuracy of the data included in this paper, nor does it accept responsibility for any use made thereof.