CENTRE FOR REFLECTION ON MENTAL HEALTH POLICY

Official Response to European Union Green Paper on Mental Health titled *Promoting the Mental Health of the Population. Towards a Strategy on Mental health for the European Union*

This document outlines the collective response of international mental health NGO InterAction to the proposals contained in the European Union Green Paper on Mental Health.

In the first section we outline what we did to facilitate grassroots and service user participation in analysis and critical thinking regarding the Green Paper and associated mental health policy issues. This forms the evidence-base for the responses covered by this document and demonstrates the active participation of women and men across Europe from grassroots communities. Secondly, we outline key responses to aspects of the Green Paper and the specific policy prescriptions contained in it. Thirdly, we present some responses to the way the consultation and development process of the Green Paper has been managed and conclude with a series of references and source material.

In the first instance this document has been prepared to contribute to the wider EU consultation process managed by Mental Health Europe. However, the document will also be used to share the learning and opinions captured by the participatory processes to a wider audience through various grassroots dissemination networks.

InterAction remains willing, as always, to engage openly, creatively and critically in the ongoing development of mental health policy across the European Union.

Participatory Processes Managed by InterAction

InterAction has been engaged in a 6-month participation process with a number of users, community groups, activists and representatives of user groups in the UK and parts of Central & Eastern Europe. This consultation has been conducted through a range of devices aimed at informing concerned actors about the World Health Organisation Action Plan for Europe, the EU Green Paper and the response by various international NGOs to the wider policy process and has included:

- Face-to-face discussions with people who use mental health services in Britain and parts of Central & Eastern Europe

- Communication by email, phone and letter with service users from a range of European countries, the Caucasus region and parts of central Asia (falling under the WHO definition of European Region)

- The MIRROR think tank has met twice to explore and critically evaluate mental health policy contained in the Green Paper and associated policy processes. The think tank has involved a variety of service users and grassroots activists from across Europe including those from the Netherlands, Hungary, the UK, Czech Republic,

Slovenia and Romania. InterAction facilitated a series of participatory exercises and mapping activities.

- A follow-up research and evaluation questionnaire was completed by MIRROR participants and responses analyzed.

- InterAction made on-site visits to a number of countries including Hungary and Romania to work alongside user and community groups and consult with local and national policy forums.

- Two pieces of participatory research were completed by InterAction, which have relevance for the Green Paper. In the first piece of research a questionnaire was sent out to community groups across Europe to look at their views and opinions on mental health policy. In the second piece of research, a longitudinal study was conducted looking at the experiences of mental health activists in the community and the policy barriers that currently exist that prevent empowerment and public action.

- Through InterAction's network of partners across Europe we have facilitated a series of ad-hoc discussions and exchanges to consider the Green Paper.

- Publication and dissemination of *Policy Position Papers* to users and mental health providers across the region

- Access to a web-based forum

Response to the Contents of the Green Paper

The staff of the InterAction, working for the Grassroots Mental Health Observatory project, collated the information and data. The output from the various consultations is summarized in the key points below:

- The Green Paper states that "…there is agreement that a first priority is to provide effective and high-quality mental health care and treatment services, accessible to those with mental ill health…" (page 5). Whilst there is no dispute as to the desirability of better mental health services, it is the *primacy* given to this priority that must be questioned. An alternative vision would place the empowerment of people and their families with a personal experience of mental health as a first principle. In any case, there is ample evidence that the terrain of mental health is far more contested and diverse than assumed in the Green Paper and that treatments and services are not universally agreed, or accepted. For example, the continual investment and use of electro-convulsive therapy in the UK is one highly contested and controversial issue.

- The Green Paper is written from too much of a medical perspective and ignores the competing social model. This may reflect more the concerns of the authors rather than the needs of the end point recipients. It is alarming to note that, despite the evidence of recent years in social care and social psychiatry, coupled with the articulated concerns of people who use mental health services, the focus remains heavily skewed towards traditional approaches to mental health care.

- The focus on **community** as the key location for mental health services is welcomed. However, the EU needs to address the limitations and failing of current community care in European states over the last ten years and make explicit the lessons and learning to ensure that these are not repeated over the expanding European Union. There is a danger that community is used as a key word without any critical analysis of the different meanings and understandings of such a complex term.

- The development of a mental health information, research and knowledge system (page 8) is important but service users must be at the centre of this work. The life stories, personal experiences and journeys of people that use mental health services are the biggest asset to the development of effective mental health systems. InterAction proposes that the Green Paper formally recognize the expertise and essential contribution that users and carers can make to mental health development. Grassroots communities should be enabled (via resources, networks and access to training) to take control of the research processes that provide the core of the knowledge system. There already exists in Europe excellent examples of rigorous and effective user led research. These should be highlighted and replicated. The wider concept of evidence based practice must also include the experiences of service users – this is the best source of evidence to demonstrate the success or otherwise of mental health systems. These stories and journeys are the assets of citizens across Europe and should not be owned or turned in to commodities by professionals and academics. Citizens should be empowered through grassroots participatory action research tools to own and use their experiences creatively within the mental health system.

- The Green Paper states "…people with mental ill health or disability meet fear and prejudice from others, often based on misconceptions about mental ill health…" (section 6.2). This is **too weak** a statement and incorrectly associates the cause of mental health discrimination with the attitudes and behaviour of individuals. This statement ignores the role of **power** and **power relationships** at the root of citizens' experiences of mental health. It is essential to recognize and make explicit the institutional and organisational patterns that underpin the way mental health is managed in modern societies. The Green Paper must recognise the fundamental concerns and experiences of people with mental health problems – poverty, human rights abuses, unemployment, lack of voice and lack of choice.

- Large-scale institutions such as psychiatric hospitals, social care homes and large residential establishments are unacceptable in the modern Europe. Evidence, including patients life stories, indicate that large institutions are abusive (physically, psychologically and often sexually as well), deny basic human rights and ineffective. The Green Paper must advocate the closure of these institutions and set time limits and penalties for governments to achieve this. Independent monitoring (involving ex-patients and service users) must be put in place to track the progress to this objective. The EU (and partners such as WHO) must direct their efforts to facilitating the **political will** in the respective European countries to achieve this goal.

- InterAction welcomes the Green Paper's identification of the community level as the key location for change. But the approach of the Green Paper is top-down rather than bottom-up (sections 7.1, 7.2 and 7.3). Experience and evidence collected by InterAction suggests that despite whatever good intentions the EU may have, initiatives that aim at local change but that are organized from the top are liable to failure. It is essential to get

citizens, local communities and users involved at the **start** of the process and not at a later date, once the major boundaries of the initiative have been erected and the powerful international actors have secured their positions in the process.

- InterAction wishes to respectfully remind the EU that one of the guiding principles for all EU policy is 'subsidiarity' - that is the principle that matters ought to be handled by the smallest (or, the lowest) competent authority. In the field of mental health there is increasing evidence that the local community level and partnerships of local stakeholders are able to manage services, advocacy and governance of mental health in effective and creative ways. The Green Paper is an opportunity therefore to realise this principle and it should be built in to the vision of the document.

- The Green Paper lacks reference to the user led networks and initiatives across Europe including NGOs, user groups and local participatory forums.

- The Green Paper ignores the social dimension of gender and the position and experience of women. This is a major omission and needs to be addressed. Research indicates that the experiences of women in the mental health system differ from men and it is essential to recognise these differences. Women are especially vulnerable to discrimination and abuse within the current provision of mental health care. Women's issues such as domestic violence, childcare and specific health needs must be recognized. Also, women make up a significant percentage of community level mental health service provision (as care workers, nurses, family members and carers etc) and yet are underpaid, more vulnerable to arbitrary dismissal and unrecognized. A recent trend in the care systems of western European countries (hostels, homes, day centres) is to replace local women carers with women from central and eastern Europe who can be paid less and who are less aware of their employment rights. There are important issues here for human rights, welfare and quality in mental health services.

- The rights and experiences of other minority groups need to be recognized and incorporated by the Green Paper – ethnicity, culture and sexuality are key issues as well as age and disability. It is also important that the Green Paper gives a lead on issues of religion and population migration (asylum seekers, refugees) as well as how mental health services can recognise and engage Muslim populations, Roma and others. The EU citizen is not homogenous and written policy must explicitly address issues of diversity.

- The section on social inclusion and fundamental rights (section 6.2) is too short and ignores the very issues it seeks to promote. This section is essential to the value base of the Green Paper and must be developed further to include empowerment, advocacy and human rights in the widest context. For example, instead of stating that *"people with mental health problems **could** be included in the activities of the Fundamental Rights Agency..."* it should be a **condition** of the FRA that users participate.

- The Green Paper's recommendation to improve "…public awareness about mental ill health and treatment options, and encouraging the integration of mentally ill and disabled people into work life, can create greater acceptance and understanding across society…" (section 6.2) is dangerous and in the view of InterAction **likely to increase prejudice** and **stigma**. It is important for the Green Paper to consider the evidence and experience of anti-stigma campaigns and apply the learning from the grassroots. It is the view of InterAction that doctors and medical services are in the weakest position to address

stigma as this simply reinforces public perceptions of mental health as an illness and makes the individual either invisible or perceived as a victim. Furthermore, evidence shows that it is often mental health professionals who unwittingly reinforce stigma and negative stereotypes. Experience indicates that health professionals are not trained or experienced in the specialisms of public relations, media work and communication necessary to overcome these disadvantages. As a consequence InterAction believes that many public awareness campaigns have not been effective. Instead what is needed are **positive images** of people with mental health problems as citizens, activists, workers, mothers and sons (i.e. as real human beings with contributions to the community). Mental health systems need to demonstrate greater sophistication in their approaches to public awareness and to clearly identify the underlying causes of prejudice and stigma before intervening. And of course, users should be central to this process.

- The Green Paper needs to identify the **re-allocation** of resources from centralized organisations and initiatives to the community and user level. To realize the aspirations in the Green Paper to effect change at the community level, the initiatives must be properly resourced – and this means not just money but access to networks, information, participatory events and materials. Evidence is starting to emerge that local level mental health initiatives can be both cost effective **and** more economic. They are better able to access assets and resources that are freely available in the local community and which many not be recognized by more centralized organisations – for example, support in kind that local stakeholders can offer such as faith groups, local employers, community groups and libraries. It is the experience of InterAction that, at a local level, small amounts of money can go a long way to leverage community level action and change. The EU needs to ask itself and its partners if the **opportunity cost** of expensive international conferences, hotels and meals are the loss of extra resources for more localised action.

- The pharmaceutical industry is a significant and powerful stakeholder in the mental health policy process. The involvement of pharma must be made transparent in all aspects of mental health and the policy making process. Grassroots systems must be developed and supported by the EU to monitor the ethics and activities of pharma, to work with the pharma industry to promote effective codes of conduct and for problems to be addressed in a transparent way. Evidence indicates that problems usually manifest themselves at the local level first, rather than at the higher levels where more sophisticated corporate presentation is either unaware or counter-balances local realities. Some recent concerns identified by service users include the testing a new drugs in secretive ways with users from poorer countries in Europe, the lack of blood testing to manage the risks of specific drugs, and the unrestricted access of pharma representatives to patient records and notes. InterAction believes a sophisticated approach to pharma is the way forward – an approach that recognises their role while also being mindful of the economics, competitiveness and bureaucratic dimensions of the industry. It is only through the explicit focus on the role of pharma that trust can be established in the system. The Green Paper must have the courage to face this issue directly and there already exists examples of good practice that can be drawn on.

Response to the Process by which the Green Paper consultation has been managed

- It must be recognized that amongst grassroots communities and local level professionals there is an almost total **lack of awareness** about the Green Paper and the consultation processes. This is indicated in the UK as much as in the central European countries.

Information and support has not trickled down to the local level and there has been a lack of engagement by the international organisations participating in the European level consultation process with their local stakeholders in their respective countries. This has maintained the assumption that European level mental health is not for local people but is the specialist preserve of those who portray an international perspective. To make the consultation process real and to engage local people (service users, local professionals and the voluntary sector) the coordinating organisations in the various working parties need to **engage directly** with local communities across their countries.

- The consultation processes are very centralized and the key participating organisations are typically based in the capital cities of their respective countries or in Brussels. To ensure citizens in the wider regions of states and in rural areas are involved there needs to be greater outreach work.

- The Green Paper cites the WHO 2005 Ministerial Conference on Mental Health in Helsinki as providing the fundamental framework for the EU paper. This is a mistake and ignores the failures and barriers established by this particular event. InterAction and partners have already documented concerns and limitations of the WHO approach to policy making that risks disempowering citizens and activists – the very people the Green Paper wishes to support.

- Whilst InterAction passionately welcomes the involvement of civil society organisations in the development of EU policy, it is important to ensure that this participation is truly grassroots based. InterAction urges caution to the assumption that engaging international level non-governmental organisations is a sufficient step in working with civil society and the grassroots. Whilst it is often easier for European and governmental policy makers to engage with umbrella groups and international organisations, this does not necessarily guarantee local citizen involvement. It is an important but not sufficient step. International organisations do not necessarily have a wide grassroots constituency. They are not necessarily organized in ways that are truly representative of or accountable to the grassroots. Like any organisations in the real world they operate under pressures of funding, institutional relationships and the need to self-sustain. A cadre of specialists and professionals often manages international NGOs. Projects in real world often have to be as accountable to the funder than to the service user. InterAction is also concerned that sometimes organisations may not feel able to say what they really think through fear of losing institutional position or access to policy makers. The non-governmental sphere is therefore as complex and contested as any other aspect of human endeavor with multiple levels of cooperation and competition between different actors. InterAction feels able to make these comments as we are ourselves an international NGO and our staff and trustees have considerable international experience. As such we are very aware of both the huge potential **and** the limitations of international civil society organisations.

Key Questions that the Green Paper Needs to Ask

1. What are the failings of current mental health systems across Europe and why has this occurred? The Green Paper will need to directly address the failings and put in place policy action to effect change.

2. What are the satisfactions and dissatisfactions of the various stakeholder groups in the mental health system? This will include service users, carers, family members, doctors, social services, employers, faith groups and a far wider cross-section of stakeholders

3. What is the vision for the future of mental health? Is this a shared vision or are there competing alternatives?

4. How will the EU manage dissonance and disagreement between the views and interests of different stakeholder groups as mental health policy is developed? How can the EU ensure the less powerful and the less privileged have as strong and clear a voice as the powerful?

5. How can mental health agendas engage and inter-relate to wider developmental agendas and pressures in European countries including economics, democratization, participation and transparency?

Targeted Outcomes from a credible 21st Century Mental Health Policy – A Proposed Vision from EU Citizens

The development of new European level mental health law should take a specific outcomes based approach that can demonstrate real changes to peoples' lives at the community level as well as systemic improvements to the mental health system:

1. An EU citizen with mental health problems in any of the EU states should be able to have direct access to:

   - A choice of community services
   - Self help groups
   - Clear and empowering information
   - Independent, user controlled advocacy
   - Support for their carers and family members

2. Barriers or abuses in the mental health system should have clear and transparent mechanisms for investigation and intervention. When abuses are discovered, systemic action should be initiated across the Union.

3. People with mental health problems who want to work should have access to real jobs that pay credible wages

4. Mental health should be closely linked to wider development (social, housing, economic) and visible in a wider range of policy documents beyond the specialism of mental health. Democratic processes (voting, scrutiny, questioning, campaigning) should increasingly address the issue of mental health and the needs of democratic citizens with mental health problems

5. Services should be more diverse, creative and local. Service users should have both a choice of alternatives and real power in their delivery, management and evaluation. Users should be employed by these services and represented in the governance and strategic planning of the work.

References

Policy Position Paper One - *Involving All Stakeholders in Mental Health Policy – A Challenge for the Intergovernmental Organisations*. InterAction Press.

Policy Position Paper Two - *Acta Non Verba - What Contribution Can Ordinary People Make To The Development Of National Mental Health Policies?* InterAction Press.

Policy Position Paper Three – *The Mental Health Action Plan for Europe: Is It Too Late For The Grassroots To Re-Shape The Agenda To Empower Women And Men With Mental Health Problems And Their Communities?* InterAction Press.

Rethinking Mental Health Policy: People, Participation and Power Conference Outcomes Book. Orizonturi Press.

CRMHP Research Paper - *Exploring the Usefulness of the Policy-as-Process Model to NGOs Working in Mental Health in Central and Eastern Europe and Central Asia*. InterAction Press.

CRMHP Research Paper - *Public Action and Mental Health – Development Practice from the Grassroots*. InterAction Press.

European Union (2005) *Promoting the Mental Health of the Population. Towards a Strategy on Mental health for the European Union*

World Health Organisation (2005) *Helsinki 2005 Mental Health Action Plan for Europe*

World Health Organisation (2005) *Helsinki 2005 Mental Health Declaration for Europe: Facing the Challenges, Building Solutions*

All material is available for free from the InterAction website or via the Secretariat.

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