

Reflection on Mental Health Policy

INVOLVING ALL STAKEHOLDERS IN MENTAL HEALTH POLICY – A CHALLENGE FOR THE INTERGOVERNMENTAL ORGANISATIONS

PROPOSALS TO IMPROVE SOCIAL INCLUSION BY ENGAGING THE GRASSROOTS IN A MEANINGFUL WAY

THE LIVES AND LIVELIHOODS FOR MANY OF THE worlds population are precarious and fraught with seemingly intractable problems exacerbated by poverty, conflict, exclusion and continued disparities in the distribution of power. Public policy-makers in and around governments have had a chequered history of coping with such problems. International bodies like the UN, the international development banks and the World Health Organisation (WHO) have been hugely influential but not necessarily successful, when considering long-term impact or outcomes for disadvantaged people. The risk is high that the views of powerful agents will be imposed on the poor and marginalised sectors of populations. Discrimination and social exclusion of people with mental health problems is one area where improving the situation will depend substantially on the progress made in combating stigma, negative stereotypes and taboos surrounding people with mental distress.¹ There is growing evidence that mental health policy is failing and that one reason for this may be that the top-down approach of governments and transnational agencies is unable to successfully engage the grassroots, and in particular, with users and ex-users of mental health services.² At the same time, attempts by the grassroots to reach out and engage top-down actors face significant barriers. Failure to work in partnership with the grassroots begets policy failure when translated to the local level.

There is an on-going need to address issues of stigma, discrimination, and social exclusion especially in Central & Eastern Europe ... human rights abuses continue to exist in the outdated psychiatric institutions and social care systems that remain the mainstay of some mental health systems

European Health Forum, Gastein, 2004

The major emphasis of those steering political transition has been at the national or macro level; in establishing or revitalising the rule of law, political parties and parliamentary practices. Less attention has been devoted to building and supporting grassroots, citizen-based initiatives (Siegal, quoted in Hayward & Nica, 2000)³. Top-down approaches reproduce the existing power relations and thus support the status quo and exacerbate socio-economic disparities among different groups, including people with mental health problems.⁴ Similar practices exist in the social welfare arena where government, administrators and the international agencies predominantly centralised and formalised management style threatens to reproduce practices that can be interpreted as patriarchal, insensitive, uninformed and

elitist. Governments are slow at dealing with reforms, particularly if they originate from grassroots organisations. Many react better to large external agencies such as the WHO. This has implications for both the ways in which indigenous and foreign NGOs work and the nature of the tasks they undertake. There is evidence to support this contention in both developing countries and those in transition, like Albania, for example, where the WHO has imposed projects that are biased towards one kind of response to problems at the expense of more local alternatives. In this instance the weight of the WHO solution has both influenced and effected local responses to problems and had arguably a negative impact on local alternatives. Low cost, low-tech public action by local organisations are rejected in favour of (relatively) well funded prestigious pilot projects, which are (naturally) supported by health officials (and government)⁵. It has been frequently commented by Albanian NGOs that the government officials fear exposure by the international community more than electoral retribution from its own citizens.⁶

The WHO are not unique in this pattern of intervention. The European Health Forum in Gastein (2004) (which exists to “provide a platform for discussions for various stakeholders in public health”) proposed that the European Union develop a global health strategy in collaboration with the WHO and international development agencies to guide EU foreign policy. Although at Gastein some efforts were made to involve a wider range of stakeholders (other than just professionals) the relative numbers of what might be termed grassroots community activists were so small as to be simply tokenistic.

THE LIMITATIONS OF TOP-DOWN APPROACHES

Governments and transnational organisations assume the way that policy is made is through rationalistic decision-making. Typically the WHO has a strategy to synthesise evidence by producing mental health country profiles – situational appraisals that focus on medical and specialised services that will provide a blueprint for planning for mental health needs. The problem here is that there is a restricted set of questions addressed by this kind of systemic review which fails to involve the interplay of a range of other social factors. The WHO have not convincingly indicated how they intend to integrate evidence from multiple sources (that may very well conflict) or even that they can identify what those sources might be. In practice they defer to consultation with

prominent government officials and self-selected professional groups. Whilst they acknowledge that “consideration of medicines is only a small component”⁷ they continue to operate at a macro rather than individual level, ideally preferring to subject government policies to randomised controlled evaluations rather than consulting directly with users. Managing the tension between blueprint and process approaches to policy development in which multiple agencies with conflicting interests, goals and values, are involved is not something the WHO seems to want to consider. Similarly, other international agencies have failed to confront the concerns with problems that beset so many mental health programmes – low quality of life, poverty, lack of human rights – despite development efforts. Notwithstanding best intentions, neither governments nor most international agencies have achieved goals or expected results (as evidenced in the Gastein quote, above). In transitional economies and developing countries this presents an additional challenge in promoting and managing alternatives to old orthodoxies of capitalism or socialism and the need to promote culturally acceptable and relevant policies.

“Foreign experts are at the same time clever and stupid. They know a lot about community mental health but next to nothing about the country they come to. They do not know the language, the mores, customs, they do not know the power structures and it is hard for them to tell apart potential allies and enemies. The received knowledge will be of a deductive nature and will unavoidably mean Westernisation of the styles of working, it will not use local resources and the knowledge embedded in the local culture. It may mean making mistakes and be obstructive in the operational part of any co-operation”

Vito Flaker, Ljubljana University⁸

There is evidence that the basis for some of the assumptions upon which policy strategems are made is incomplete or inadequate information.⁹ In many developing countries and certainly those in transition, information and information systems are poor, inadequate and out-dated. “Official” statistics may bear little relation to the reality on the ground, and it may behove the larger organisations to look to different kinds of evidence from grassroots sources and to consider different methods of investigation to provide the basis for mental health policy. Even reputable sources of information can be unreliable. The WHO Atlas¹⁰ fails to properly take into account the impact of the system of social care homes or “internats” that exist alongside formal mental health care in many countries of CEE. The publication is presided over by predominantly western experts and the information it contains is accepted substantially and will be used as a basis for policy decisions.

There is a danger that exclusive WHO contacts at governmental level restricts the quality and type of information possible, particularly when dealing with governments of developing countries or those in transition who may have reasons to present the best possible public face to international organisations. A Lithuanian psychiatrist publicly admitted that if his minister asked him if they used methods disapproved of by the international community, he would deny this. His response would be given on the basis of what he knew the minister wanted to hear rather than based in any sense of reality, thus enabling the minister to relay positive findings to the international community. By devolving to governments the responsibility for provision of information or identification of problems and needs, the WHO

distances itself from sources of information other than that the government officials wish to provide and closes the door on other sorts of information not deemed “scientific”, “rational” or “of relevance”. They also may find it difficult to relate to groups that are rooted in local communities, such as NGOs, or those that are representative of sectional interests (like user groups, see below). They may also be effectively screened from organisations that are critical of government practices or supportive of unpopular causes (such as human rights). A pertinent question might be “why did it take the Budapest-based Mental Disability Advocacy Centre to publicly expose the widespread practice of using caged beds in central European psychiatric hospitals and not the WHO”? The box below illustrates this point with regard to the Ministerial meeting in Helsinki in 2005.

In many countries, Government practice with regard to the provision of mental health services falls foul of Human Rights legislation. Organisations representing users of the services, and which can bring such practices to the attention of the international community, are all too easily silenced. Each of the governments of the 52 countries supporting the WHO is invited to send a delegation to include one representative of civil society as well as government officials and mental health professionals. Consequently, it is easy for a government with something to hide to nominate a ‘safe’ representative of civil society, instead of a credible delegate. There has been serious criticism of psychiatric institutions in the Kyrgyz Republic where there has been denial of human rights, serious abuses and worse¹¹. The General Director of the Republican Mental Health Center is Dr. S. Nazarculov. A report from an IWPR investigation paints a dismal picture of abuse and neglect in the mental healthcare system (Ulugbek Babakulov, Natalia Domagalskaya and Asel Sagynbaeva in Bishkek (RCA No. 212, 28-Jun-03). Mental Health & Society, an NGO based in Bishkek, has been assisting in exposing these abuses. We have information that it is Dr. S. Nazarculov who is nominated as national coordinator for the Ministerial Meeting in Helsinki and meeting in Brussels along with two of his colleagues from the governmental staff. Clarification is being sought from the Ministry about representative of NGOs, but it currently looks as if Mental Health & Society will not be nominated.

The mental health policy arena is dominated by psychiatrists and medical discourse despite an acknowledgement of the need for evidence from multiple sources and the involvement of different actors, but little is done that might challenge established power bases. In Oslo in September 2003 psychiatrists and academics met under the auspices of the European Observatory of Health to plan a book on European Mental Health Policy. The predominance of psychiatry was largely unquestioned and, apart from one chapter on user research, the authentic voice of the endpoint recipients of care remained unheard. This reflects the failure to engage with other stakeholders, not just NGOs – for mental health policy should not be solely the concern of psychiatrists, academics or policy “experts”- it should reflect the concerns of everybody in society. There are, in most countries, organisations of users who would welcome input into the policy process. The European Network of (ex) Users and Survivors of Psychiatry is one such organisation that is seeking to take a place at

the discussion table. ENUSP (motto: “nothing about us without us”) have representatives in 27 countries of Europe, but are a poorly funded and unable to compete on the same terms as the better off organisations. Nonetheless they have been hugely influential and can lay genuine claim to represent a large constituency who normally do not get represented at any level. A strategic response would be to provide ENUSP with the core resources to build an independent user-led infrastructure across the region to enable them to work as equals with the other stakeholders.

For the last three years, the Hamlet Trust has run a programme called *Pathways to Policy*, which has involved a range of different grassroots stakeholders, including service users, through the creation of Local Policy Forums (LPFs) in five countries of CEE. The LPFs have gathered a large amount of evidence¹² including many instances of a lack of meaningful contact with policy-makers and decision-makers and report that grassroots activists and service users feel alienated from externally imposed policies that are based on little evidence, but, more importantly frequently also fail to meet their needs¹³. Furthermore, with training and support, these grassroots activists have been able to shape and influence mental health policies to both better meet their needs and benefit of their wider communities. In two countries, these LPFs have now graduated to become National Policy Forums able to complement traditional top-down approaches¹⁴

“the local impact of the modestly funded Pathways to Policy programme is far greater than the lavishly funded Stability Pact programme”

Bosnian Ministry official to Halida Vejzagic.

The absence of official WHO representatives at the recent *Re-thinking Mental Health Policy* conference, Slovenia, October 2004 spoke volumes about the importance attached to the views of grassroots, users and representatives of users. Participants at the conference were invited to contact the WHO in Geneva and Copenhagen directly with feedback and comments from the event. To date most delegates are still awaiting any form of response or acknowledgement of their attempts to reach out and make contact. The WHO needs to do more to demonstrate their commitment to users and the first step is active dialogue.

Meetings of a new mental health policy think-tank have begun to identify and highlight some of the limitations of adopting a predominantly top-down approach to policy-making. Key actors from across the region are now beginning to unite to promote more democratic, inclusive and pluralistic approaches to policy formation.

MIRROR MIRROR –
new people, new thinking,
new possibilities

The MIRROR think-tank aims to examine, discuss, evaluate and critique current policy-making. Traditionally, thinking in the field of mental health policy has drawn from a limited pool of techniques and a limited range of thinkers. Many with real insights and original ideas to contribute have found the barriers of poverty, stigma, geographical isolation and exclusive networks impossible to overcome. Informed by a policy-as-process model, rather than more traditional, prescriptive approaches that focus on incremental, technologically determined solutions based heavily on

the hegemony of medical discourse, the way decisions are reached is seen as significant as the decisions themselves. By linking creativity from the grassroots with thinking from national and international levels, MIRROR creates a network of ideas, research and personal experience that informs and evaluates the policy process. In addition, MIRROR will propose innovative and more inclusive solutions based on the views of an extended stakeholder group.

ENGAGING WITH THE GRASSROOTS

“A key challenge to European values and objectives in health are democratic accountability, empowerment and participation, dignity equality and exclusion”¹⁵.

Although many agencies talk about these issues, few are prepared to act on them. In some circumstances it could be argued that it has more impact and is more important in its own right to empower members of an organisation or community than “getting the job done”.

A way forward for governments, international agencies and transnational organisations concerned to improve social inclusion and make mental health policies more meaningful would entail:

1. The understanding and development of policy as **process** (as opposed to prescriptive practices) so that public action becomes a part of a number of actions influencing social processes rather than using resources to meet goals directly.
2. There is the recognition of a number of development agents and local institutions, national agencies, NGOs and other players. This requires rather different methods of investigation: stakeholder analysis, network mapping, narrative accounts. Here, intervention in society is viewed as part of the process of change and recognition that process is affected by a multiplicity of interests (not just the State), and that not everyone agrees the social goals – not only the means of achieving them, but also what they are.
3. Instead of hierarchical command, policies must evolve through negotiation and brokering, working alongside other agencies with a variety of actors who need to be brought on board.
4. The basis for the economic and social/political analysis needs to shift. A move from narrow (medical, neo-liberal, organisationally oriented) specialisms to a more holistic approach that integrates the macro with micro, and the public and private domains.
5. Ethical considerations – an acceptance that any agency has the right to intervene on someone’s behalf on the basis of legitimate representation. Greater accountability needs to be built in to the structure and practices of transnational agencies.
6. In turn both project design and management require re-appraisal – to move from strict control and rational technological appliance to adopting more adaptive and flexible systems as a means of intervention that incorporates the process of locally accountable and responsive administration.
7. Research and appraisal has to shift from reliance on long-term, quantitative methods to more qualitative

methods that offer a quick and relevant appraisal of a situation and the likely impact of proposed interventions on the basis of incomplete information. This would utilise for example, PAR, radical participative methods of research and similar systems-based methodologies used in development management.

8. Institution development and capacity building – democratisation as process of building institutions in post soviet countries and the developing world which would involve the development of civil society through an expansion of NGOs and other local bodies. Managers would need to be de-centralised and to know the community to be effective.
9. Empowerment and participation. New radical methods to work with communities and particular groups of the poor and powerless such as people who have used mental health services which would entail explicit consideration of working alongside other powerful agencies, whether in opposition or collaboration. This fits well with what many user groups say they want. Existing values and power structures would need to be re-examined and reformed with a view to being more open, transparent and representative. A rethink of status in mental health needs to be undertaken – is one stakeholder group given precedence over others?

RECOMMENDATIONS

1. The Ministerial conference in Helsinki in 2005 provides a real opportunity to bring delegates and representatives of a wider range of stakeholders to the meeting. More efforts should be directed by both the WHO and governments represented to identify people and organisations working at local community level to bring their views to the table and end an over reliance on medical and technical input. Other complementary and alternative networks already exist and these should be taken up by the WHO. People with mental health problems are willing to engage, it is up to the intergovernmental organisations to find ways of making this happen.
2. The ENUSP and similar organisations should be party to the discussions and be fully funded to enable them to participate on an equal basis with other representatives. This would go part way to decreasing the dependence on a narrow range of opinions and options and increase the basis of stakeholder input.
3. Closer inspection should be paid to the government nominees participating, particularly from those countries with poor records on human rights, openness and transparency. A number of countries could be cited, but in this instance particular attention could begin to focus on the Kyrgyz Republic where certain NGOs and their representatives are being discouraged or blocked from attending. Similar conditions should be attached to some of the countries from the FSU and Caucasus region.
4. Transnational organisations, such as the WHO, need to audit their activities (and invite outsiders who have experience of mental health services to fulfil this role) to examine issues such as accountability, transparency, will, values, privilege and power to see how they reflect and represent the people on whose behalf they are working.

ENDNOTE

How have intergovernmental organisations traditionally responded to challenge? If we consider other fields from outside the mental health agenda there appear to have been two main strategies. One is to ignore criticism and challenge in the hope it will go away. This approach also tends to marginalize those who are prepared to stand up and challenge. The second response is to put up a defensive wall, presenting the agency as the hurt or wronged party and attacking back. Neither of these have resulted in constructive dialogue or the building of long term partnerships (for example, the polarisation of the WTO and anti-capitalists). What is required is for the WHO and other organisations to use their significant assets of credibility, reputation and resources to demonstrate real leadership and learn and reflect on honest feedback and challenge from the grassroots. We call upon the WHO to engage with the grassroots in a more meaningful way. It is beholden to those user-led organisations and the mental health organisations working in CEE, countries in transition and the developing world to work more closely together to promote grassroots participation in the policy process. They need to positively encourage the intergovernmental organisations, like the WHO, to become more socially inclusive and accountable to people in local communities. This first Policy Position Paper is presented as a step on that journey.

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Comments, opinions and contributions to this debate are actively sought and can be submitted to the discussion forum on the website.

References

- 1 Mental Health Europe (2000) Social Inclusion – A Challenge to the European Union
- 2 In this document the terms “users” and “ex-users” are used to describe people with mental health problems and is no reflection on the validity or relevance of other terms.
- 3 Hayward & Nica (2000) *Gaining Ground*, London: Hamlet Press
- 4 Hayward & Nica (2000), *ibid*
- 5 *Mental Health Reforms*, (2002), 3, 8-9
- 6 Private correspondence
- 7 Jenkins (2004), presentation, *Re-thinking Mental Health Policy* conference, Slovenia
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- 10 WHO (2001) *Mental Health, New Understanding, New Hope*. Geneva: WHO
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- 12 Cutler & Hayward *Development in Practice* (in press)
- 13 Cutler & Hayward *Mental Health & International Development: A Public Action Approach* (in press)
- 14 Cutler & Hayward, *ibid*
- 15 Gastein, 2004