Policy Position Paper 2

Centre for Reflection on Mental Health Policy

ACTA NON VERBA*

WHAT CONTRIBUTION CAN ORDINARY PEOPLE MAKE TO THE DEVELOPMENT OF NATIONAL MENTAL HEALTH POLICIES?

" At least a third *of all families today are effected by mental illness – because of shame these people will not agitate. But they would certainly appreciate any political party which took their problems seriously"* [1]

Advisor to British Government

IT MAY SURPRISE MANY COMMENTATORS THAT there are people prepared to agitate and that examples of innovative practice are coming from Central & Eastern Europe, rather than from the West. Generally ordinary people are not realistically implicated in developing national mental health policy and are only rarely involved in local policy. In many countries national mental health policy is the exclusive preserve of government – a top-down affair, usually the domain of civil servants and administrators with some recourse to international agencies, medical professionals and "experts" who implement, monitor and evaluate these policies on behalf of the recipients of mental health care services. Policy-making in this fashion is characterised by few actors, prescribed debate and only limited efforts to encourage real involvement and participation at a local level. Ironically, at the local level there is lots of *action,* but fewer *words* in the public domain highlighting the lessons and learning from participatory mental health and the consequent benefits that accrue from public action within local communities. Innovation and development at the grassroots are often instigated by ordinary people from local stakeholder groups that includes local health workers, but also users (that is, people with a personal experience of mental distress), family members, NGOs, media, the business community and local activists etc. who all have an important part to play in modern democratic health care. Many of the innovations in social psychiatry and social care, such as advocacy, crisis cards, self-help, for example, have originated, not as one might expect, from the professionals, but from ordinary people (often those on the receiving end of psychiatric treatment)[2]. Similarly, the critique of care, demands for "talking therapies" and questioning of the efficacy and side effects of various medications has largely emanated from users of mental health services. Recent development practice has begun to demonstrate the possibilities of local communities engaging in local mental health policy and has been the subject of much research by the *Centre for Reflection on Mental Health Policy* (CRMHP)[3]. The challenge now is to apply this grassroots learning to the development of national mental health policy and thus address the gap between the top-down and bottom-up styles of policy-making. This debate is timely and crucial given a recent judgement on the feasibility of this analysis:

> *"The aim of all mental health services is to empower all they serve … clearly such empowerment is not feasible …"*[4]

It may be unsurprising that a senior government advisor holds such views in private, but it is remarkable to find such pessimistic and limited stereotypes of the potential of citizens committed to paper. It raises the question of the underlying assumptions being adopted by policy-makers and their real commitment to any social change that involves the user of mental health services. Acceptance of this statement reveals as much about government positions as the culture of exclusion and marginalisation that prevails in mental health policy-making disguised under the thin veneer of empowerment. The future necessitates more action by governments in listening and responding to the voice of people at a local level and developing actions that are responsive, empowering and socially inclusive. People with mental distress have a weak voice in the decision-making process that has always tended to be led by powerful practitioners and interests. In practice people who use mental health services are more likely to be the passive recipients of care[5]. This situation certainly prevails in the post-transition countries of Central & Eastern Europe and the Former Soviet Union where resources are scarcer and social inequalities growing. Users are all but invisible in the policy debate or consigned to the sidelines, especially when their views do not correspond to those of the powerful élites. Wider social policy's relative lack of interest in mental health issues, and in particular user involvement and concomitant issues of empowerment, justice, equity and human rights is reflected in mental health policy texts where user-involvement is only viewed as a desirable (usually unattainable) ideal or the co-incidental spin-off of successful policies. Traditional mental health policy texts (e.g. Brown[6], Rogers & Pilgrim[7], Jones[8]) rarely refer to people at the grassroots or to communities that actively involve themselves in some aspect of mental health policy. Even the more recent texts such as Knapp et al[9] focus more on a medical orientation and technological approach that ignores the key actors and has disproportionately very little to say about the input of the people on the receiving end. Even the language of mental health policy is essentially a negative and pejorative one where key issues are identified such as the *burden* of ill health or *disability adjusted life years* (DALYS). The emphasis is on clinical treatment (specialist services, community teams, differentiated care etc.), co-ordinated multi-sectoral approaches and consultation with all stakeholders "where NGOs have a role"[10] – but little is said about what that role might be or which stakeholders might be involved and how this might be achieved, nor the long term work required to build trust and open partnerships.

The case study from Romania in this position paper is used to illustrate the possibilities of involving a wider range of stakeholders in policy-making and draws on the foundation of nearly four years of local policy work led by mental health service users, which is now being applied to the whole of Romania through a grassroots led National Policy Forum (NPF).

*Action not words (Romanian NPF, March 2005)

POLICY FORUMS IN CENTRAL & EASTERN EUROPE – THE EXPERIENCE OF ROMANIA: POLICY & PUBLIC ACTION

Background

Acţiune şi nu vorbe (action not words) was the clarion call of the third Romanian National Policy Forum held in Iaşi in March 2005. This forum brought together over 70 stakeholders, of which a significant third were service users and representatives of user groups and other community-based NGOs in mental health and related fields. Words *were* produced in the form of a **Declaration on Re-thinking Policy on Mental Health**[11], and presented to the Health Minister in Iaşi on 18 March. The NPF is the culmination of over 10 years of development work begun in Bucovina, a part of rural northern Romania, centred on the small town of Câmpulung-Moldovenesc where there is a mental hospital serving the local community. This paper summarises the journey from modest beginnings along the pathway from individual advocacy through capacity-building and organisational development to public action at a national level (for more details see Tanasan et al[12]), which provides evidence of the contribution that ordinary people working to develop their own communities, can make to mental health policy-making.

Pathways to policy and public action

Advocacy and self-help

In 1993, representatives of a UK-based mental health charity made contact with two young Romanian psychiatrists who had recently taken responsibility for running the psychiatric hospital in Câmpulung-Moldovenesc. Following the political changes in Romania, the medics had been exposed to ideas from western Europe and had become convinced that traditional forms of mental health care failed to provide for both the health and social care needs of their patients. In 1994, they made a study visit to Britain as part of a larger group that contained, at the insistence of the UK organisation, representatives of patients from the hospital. During this study visit they met with user groups such as Survivors Speak Out and Lambeth Link. Inspired by their experiences, the Romanians held a conference in Câmpulung-Moldovenesc in 1995 where they invited a prominent user-activist from the UK to speak. One of the outcomes from this conference was the establishment of the first Romanian user group, *Orizonturi*, which was set up in the hospital to provide support and assistance to the patients housed within.

Organisational development

By 1996 Orizonturi, with the support of the psychiatrists, had quickly grown to over 70 members. It produced a newsletter, *A Fi* ("To be"), and engaged in mental health advocacy in individual and group forms, initially within the hospital, but then in Câmpulung-Moldovenesc and the small towns and villages in the region. With the assistance of the UK partner, it ran regular training programmes for service users in aspects of mental health, advocacy and self-help.

Institution-building

Part-time paid workers began to be employed in 1998 as the organisation continued to grow. Until this time, modest funding had been obtained through donations, sales of the newsletter and from small grants from international organisations, but financial viability and sustainability had become an issue as activities and expenditures increased. During this period the organisation participated in a three-year organisational development programme to secure the long-term sustainability of the organisation (see Cutler, Hayward & Shears)[13].

Public action and campaigning

1. At a local level: Local Policy Forums (LPF)

For three years between 2002-2004, Orizonturi were involved in a second programme, *Pathways to Policy,* a six country pilot project to develop the capacities of NGOs to influence mental health policy at a local level in their respective countries. A key component of this was the employment of a local policy co-ordinator (LPC), which in Romania was a job share between a service user and her daughter, who were hosted by Orizonturi. The LPCs were trained and supported by the UK organisation which assisted them to establish a Local Policy Forum (LPF) consisting of approximately 30 stakeholders with an investment in mental health. A key feature of this LPF was that at least one third of the places were taken by (ex) service users as well as health workers, local authority representatives (including the town Mayor), businesspersons, a lawyer and a priest. The LPF identified salient local issues through public consultation and other processes that provided a voice to ordinary people. Rural mental health is a key issue for the Câmpulung LPF (as it subsequently became for the National Policy Forum) and resources were targeted to enable people from rural areas to travel and attend LPFs. Forums had been arranged on market days in local centres to enable rural workers who would normally travel for the markets to also participate. Training and experiential learning enabled local activists to develop new skills in policy and public action. Training trainers supported the wider growth of networks with the capacity to share knowledge and information whilst ensuring sustainability as local people took responsibility for their training needs. The reliance on outside facilitators (either from urban centres or international agencies) gradually reduced. InterAction staff designed and provided packs of materials on policy topics such as lobbying, participation and campaigning which were adapted to local needs with case studies and examples of local experience incorporated into the finished materials. A major focus of the policy training has been on research skills and evaluation to promote grassroots learning. Tools such as reflective journals, participatory action research methods (PAR) and consultations have enabled local people to capture their experiences and learning, analyse key lessons and disseminate outcomes to wider populations in Romania and international audiences.

> *"… the users started to have a louder voice through an active and visible participation on the LPFs and local action plans (campaigns, media work, meetings with people and teenagers in rural and urban area, training workshops). As a natural consequence our image for the families and the communities in which we live changed in a positive way. At the same time the communities became more understanding and open with regard to everything related to persons with mental health problems and mental health issues generally …"*
>
> Gabriela Tanasan[14]

2. At a national level: Developing a National Policy Forum (NPF)

By the third year, the challenge for the Romanians was to extend their work to a national level and involve stakeholders from a wider range of local communities throughout the country. Already activists and users from other cities such as Bucharest, Cluj and Braşov were indicating an interest in the learning and outcomes of the LPF in Câmpulung-Moldovenesc. Using the fundamentals of the local model, a nascent National Policy Forum was set up and local stakeholders from across Romania were

invited to participate and contribute to the design of the new institution.

Orizonturi provided the basic infrastructure for the NPF development including user activists trained in participatory policy, organisational and logistical elements, and some limited funds to enable grassroots participants to travel from all over Romania to take part. Study visits were organised between local members of different communities throughout Romania to enable users and activists to travel to meet each other, learn about local policy and practice and plan joint activities. The study visits were low cost, involved grassroots activists and users who never normally have the opportunity to participate and created longer-term relationships within the country. One participant remarked:

> *"… before the study visit I knew less about what was happening in other parts of Romania than in other countries. Now I understand my neighbours better …"*
>
> Study visit participant[15]

Given the size of Romania, NPF meetings were held in different venues each time. This ensured that more local communities had the opportunity to host events and widened the participation of local people. At the same time a decision was made to avoid locating the first few meetings of the NPF in the capital city of Bucharest to reinforce the notion that the NPF is a grassroots initiative and to avoid centrist tendencies. Indeed, experience has indicated that Bucharest-based organisations (both governmental and civil society umbrella organisations) were the least willing to participate in such events and maybe felt threatened by a true grassroots initiative. Whilst disappointing, this reinforces the analysis that the powerful and privileged are the least willing to give up their positions and listen to local people. Competition and lack of trust at the level of national NGOs is a significant barrier to genuine grassroots civil society gaining a voice as national level organisations try to mediate and control the aspirations of users and their families rather than involving them as real and equal partners.

> *"… mental health policy must have at its centre of attention the people who use mental health services and their interests and must be made through consultations between all decision makers at local and central level, stakeholders, representatives of the civil society such as users' organisations, human rights' organisations, professional associations, clergy and the mass media …"*
>
> Iaşi Declaration, Romanian National Policy Forum, March 2005

Priorities for Romanian mental health policy

Based on the discussions and activities of the NPFs, several priorities have been identified that need to be addressed by Romanian mental health policy:

- Promoting a model of mental health that places the voice and rights of the user at the core of mental health practice and promote meaningful partnerships with professionals.
- Raising awareness of mental health in the local communities, challenging stigma and recognising the talents and contributions of people with mental health problems as members of those communities with fundamental democratic and social rights.
- Comparing variations in professional and government practice in different communities with regard to protecting users rights, providing adequate information to families and working in the least intrusive ways in the community.
- Assessing the practical implications of Romanian mental health legislation at the grassroots (the "… establishment of legislative norms …") and the way local practice interprets and implements policy and procedure.
- Holding the Romanian national government to account for the commitments and promises made at the Helsinki meeting of ministers in January 2005. Monitoring and evaluating the implementation of the Helsinki action plan.

So the NPF chose "Acta Non Verba" to be their motto as they demand action from government and international agencies such as the WHO. The user involvement mooted by the WHO and other reformist agencies have, to date, been shallow and meaningless, co-opting isolated users but retaining power and control hidden behind platitudes, excuses and diplomatic language. Ordinary people in Romania frequently express a lack of faith in their ministries and officials ability to adapt and take on new ways of working when trans-national organisations advising their government on mental health are perceived as non-participatory, lacking in accountability and foisting inappropriate, prescriptive models upon them.

The contribution of ordinary people

- Stakeholders from all over Romania have had the opportunity to work together, network and create strategic relationships for change by building grassroots coalitions across the country.
- The NPF has influenced ministers and officials to visit psychiatric hospitals and express commitments to reform and the development of community services
- The Iaşi Declaration has been signed by representatives of over 80 organisations across the country and has been used to lobby and campaign for change
- Stakeholders have worked together to create a participatory model for the NPF that involves people who do not normally have a voice. The structure of the forum has come from the members rather than being imposed from outside or from national level organisations.
- One concrete proposal generated by the NPF has been the idea of including user advocates in the development of community mental health teams. These teams are very new and experimental within the context of Romania but it has been essential to establish the principle of user involvement at such an early stage. A further example is the adoption of user representatives on the management boards of psychiatric hospitals.

The case study of Romanian national mental health highlights the possibilities and potential for grassroots engagement in policy and public action. Through wider programmes, the model and learning from Romania has been tested in other countries including Bosnia and Hercegovina, Estonia, Armenia, Kyrgyz Republic and Kerala, India. Lessons from Romania provide a potential model for other European countries to explore the feasibility of involving people who are traditionally disempowered and marginalized and bringing them into the centre of the policy arena. Testing has begun in the UK to provide a comparative study of participation in a western European context. Early indications are that the approach has validity in these varied settings whilst acknowledging the diversity and individuality of each cultural context.

Observations

1. Ordinary people welcome the opportunity to participate in the decisions that affect them and, given the right kind of support, are fully able to arrive at policies that meet local needs which are both effective and equitable. More importantly, these policies carry a resonance and are meaningful to the local context. Involving ordinary people is not only feasible, but also desirable in terms of reducing stigma and improving the self-esteem and confidence of people normally at the bottom of the social order

2. Despite fierce stigma, widespread ignorance and prevalence of corrupt practices, the programme in Romania transcended many obstacles to place ordinary people at the centre of policy-making. It might be argued that Romania is a relatively easy place to instigate these processes, given the lack of local infrastructure and vacuum in public policy-making. Events in Romania demonstrate the advantages and benefits of a bottom-up approach to complement that which is predominantly top-down and may provide an example from which more developed countries may learn.

3. The policy-as-process model[16] provides opportunities for people who are normally excluded to be involved and provides an alternative model for decision-making to the traditional prescriptive model of policy making. The model is not easy to implement and local stakeholders require continued support and quality training to enable them to be properly involved.

4. The policy programme in Romania was a low cost enterprise realised with minimal resources. People and NGOs gave freely of their time and energies to achieve the outcomes described. There is a case to be made for a transfer of resources away from biomedicine and high-cost international interventions to more local, user-led interventions.

Recommendations

Governments and international agencies must:

1. Recognise that effective national policy can emerge from the grassroots (as well as from elected policy-makers and administrators) and therefore they should demonstrate a willingness to give up power, be challenged, be criticized and scrutinised – to put the last first and themselves last for a change.

2. Provide funds direct to local organisations to enable them to engage in mental health policy using a more inclusive and participative model. This should include a review and redistribution in funding to interim agencies such as WHO that tends to work at ministerial level and have failed to demonstrate real user involvement to NGOs and self-help groups at community level. Involving users in the governance of all mental health services and institutions should be a pre-requisite of mental health development and the WHO should lead all international agencies to assert this as a fundamental principle of their own organisations and those that they support and work alongside in all countries.

3. Develop new and better models for resource allocation. Medical professionals and the associated medical model is not the basis for resource allocation. A wider range of stakeholders need to be involved and that will require different perspectives and modes of analysis, not least there has to be a concomitant shift from quantitative to qualitative research that gives an authentic voice to the user and recognises the needs of the disenfranchised and excluded rather than the expediencies and priorities of politicians and administrators.

Endnote

Discussions of national mental health policy easily descend in to abstraction and coldness unless real issues are introduced from real world situations. It is important to remind ourselves that the purpose of policy should be to empower and support people with mental health problems and their families who spend much of their lives facing stigma, human rights abuses, poverty and isolation. At the same time national health policies face very real and urgent problems to resolve such as the continuance of abusive psychiatric hospitals and social care homes in eastern Europe and the entrenched poverty of service users throughout the world. What is less clear is the willingness of governments to be prompted, lead or challenged by ordinary people. Power remains in the hands of people at the top and many are not willing to give it up. Whether they will do so willingly is unlikely – grassroots public action may be one method of re-balancing power relations and of ensuring that democratic rights are at the heart of public health in the 21st century.

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