Pathways To Policy – Developing Inclusive Mental Health Policy In Eastern Europe

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'I have used mental health services for many years, but I've never before had an opportunity to stand up and give my opinion of how those services should be run.'

These are the words of Orieta Kallushi, a service user speaking at the launch of Hamlet Trust's *Pathways to Policy* programme in Tirana, Albania, a project that is enabling those who are most affected by mental health policy – service users – to have a powerful voice in how services are developed.

People with mental health problems have long been discriminated against, marginalised and excluded from the process of developing policies that actually respond to their needs. It was with the aim of developing inclusive, alternative mental health initiatives that the Hamlet Trust, a UK-based charity, was established in the early days of care in the community in the 1980s. Since the early 1990s, the main focus of Hamlet's work has been in its development of a network of grassroots, user-led partner organisations in central and eastern Europe and central Asia – communities still coping with the social and economic upheavals that followed the collapse of communism.

During Hamlet Trust's *Developing Network Partners* project, 2000-2002, service users repeatedly stated that, though their organisations were becoming stronger and more effective, they still felt excluded from the decision-making processes. Too many decisions about their lives were being made by municipalities, governments, professionals and business people with their own agendas and without consulting service users.

This led to the Hamlet Trust's *Pathways to Policy* programme which, since its launch in 2002, has demonstrated that it is possible to improve mental health policies and outcomes for service users by inclusive, open means. As a result, service users are beginning to perceive the influence they can wield in the policy environment. To date local policy forums have been established in eight countries. These forums are independent bodies featuring a broad range of stakeholders (including – vitally – a minimum of 33% service users) who come together on equal terms to influence and contribute to local mental health policy. Forums were developed in the first year in Estonia and Poland, followed in the second by Bosnia, Romania, Armenia and Kyrgyzstan, while in 2004 and 2005 new forums were launched in India and Albania. A major international policy conference was held in 2004 in Slovenia where stakeholders, including many service users, shared experience and good practice with representatives from international policymaking bodies and national and international NGOs.

Funding for the programme initially came from the Big Lottery Fund (formerly the Community Fund), with more recent support coming from the Open Society Mental Health Initiative, and lately from local authorities and other local funders in the countries themselves. The *Pathways to Policy* project was evaluated using a combination of quantitative and qualitative methods including semi-structured interviews, focus groups and questionnaires, along with reflective diaries. Quotes used in this article are taken from that evaluation. The programme has

proven to be extremely transferable across vastly contrasting local circumstances, precisely because it is not an imposed 'model', but is rather a framework within which local people can determine methods of action, according to local priorities and local needs. A toolkit to facilitate grassroots involvement in mental health policy development will be published shortly (Bureau & Shears, in press).
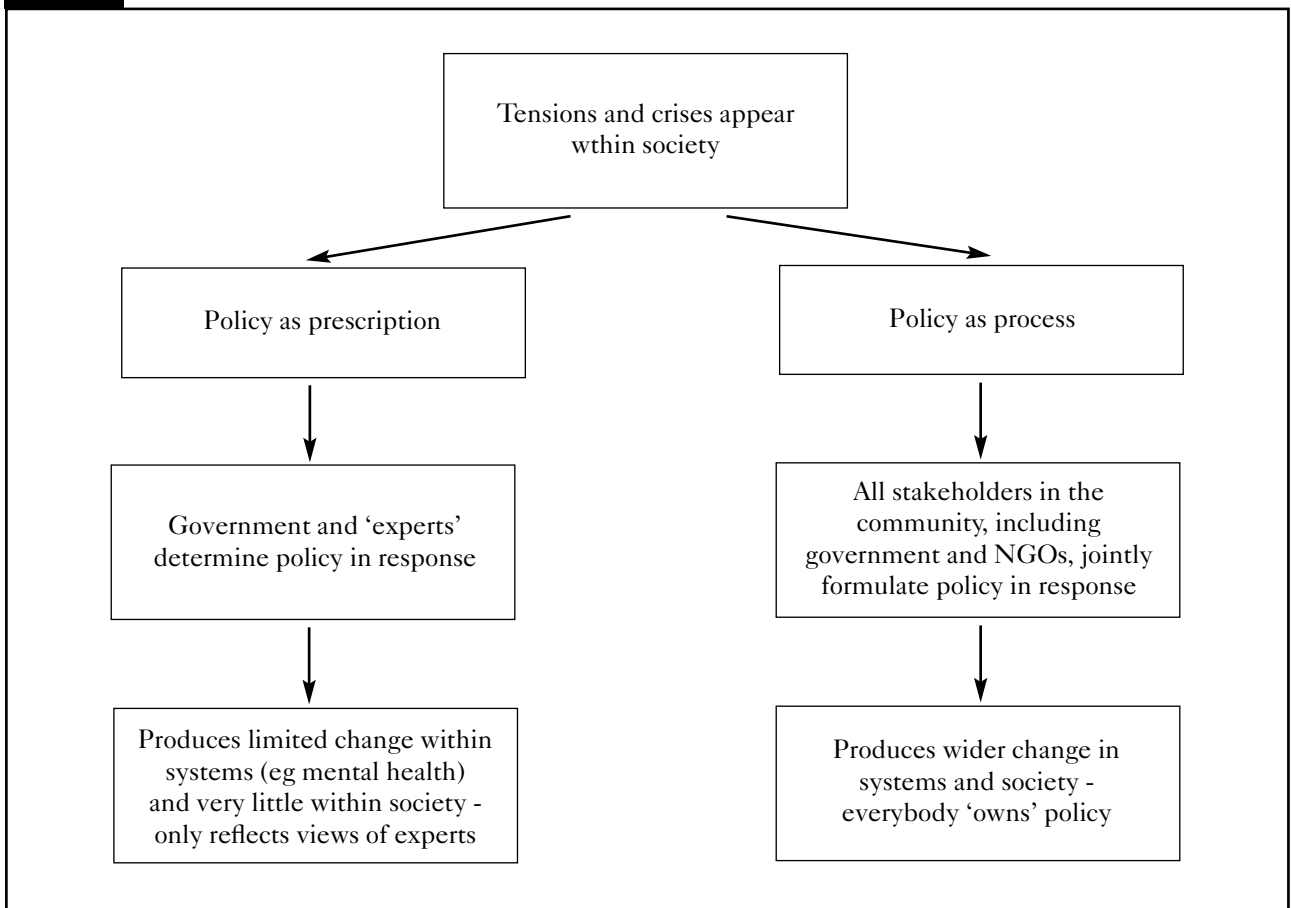
Mental health and policy

More traditional top-down views may hold that mental health is primarily a medical or psychiatric issue and that the public objectives of policy are to treat illness as effectively as possible while ensuring protection of the public. This has focused mental health service delivery on a system of institutionalisation. The decision-makers in these cases inevitably tend to be those who manage the systems and decisions are made in a prescriptive way.

The *Pathways to Policy* programme has played a part in broadening this interpretation of mental health policy so that the perspective of those with experience of

using mental health services is an integral component of policy development. This contribution sees mental health primarily as a social experience, with policy objectives being to empower users and their families to take control of their lives in societies where stigma and discrimination are significant barriers. Inclusive decision-making, arrived at by consensus rather than imposed, is likely to be deeper, more effective and longer-lasting – the decision-making process is owned by the many, not by the few, and hence will result in a wider change in systems and society (**Figure 1**).

Developing policy in Albania – a case study

Orieta Kallushi's home town of Tirana, Albania, provides a good example of the process of the *Pathways to Policy* programme. The social and economic dislocation experienced in Albania has been as profound as anywhere in the post-communist era. Soviet period health-care and education infrastructures have been neglected; mental health has not been given sufficient resources or publicity, with a lack of creative responses and initiatives. This has left

Figure 1 Policy as prescription versus policy as process

Tensions and crises appear wthin society

Policy as prescription

Policy as process

Government and 'experts' determine policy in response

All stakeholders in the community, including government and NGOs, jointly formulate policy in response

Produces limited change within systems (eg mental health) and very little within society - only reflects views of experts

Produces wider change in systems and society - everybody 'owns' policy

a policy vacuum as few systems have risen so far to fill the void. As in other *Pathways to Policy* countries, people have said 'there is no policy here – things just happen as they always have, with no leadership or overall plan'. Yet in this situation there have been opportunities for users and grassroots organisations to show leadership.

Through Alternativa Association, a local NGO with whom Hamlet has worked in partnership for many years, two local policy co-ordinators were employed in a job-share in August 2005. Charged with the development of the Tirana Local Policy Forum, the first tasks of these co-ordinators, Adri Bicaku and Alkent Birko (a service user), were to carry out some preliminary surveys and research to gain some understanding of mental health issues from the views of different stakeholders. As throughout the world, they found that stigma, poverty, unemployment, lack of community services and awareness of human rights were key local issues.

By building confidence and trust through personal contacts, the co-ordinators laid the foundations on which to hold an 'Open Forum'. Over 60 stakeholders from a variety of backgrounds attended, from service users and carers to media people, lawyers, mental health professionals, municipal representatives and other NGOs. Through exercises specifically designed to develop a consensus from disparate views, participants discussed ways in which they could be involved in developing mental health policy – which previously had been almost exclusively the reserve of traditional 'experts' in Albania. Stakeholders agreed on a list of local policy priorities for mental health and made suggestions regarding the design of the local policy forum.

Twenty of the participants of the Open Forum then participated in a two-day policy skills workshop, the members forming the nucleus of the fledgling Tirana Local Policy Forum. This workshop was co-facilitated by a Hamlet Trust consultant and Gabriela Tanasan, a service user and the co-ordinator of the Local Policy Forum in Romania. The exchange of experience and ideas across borders was a significant aspect of the training – as it has been throughout the five years of the programme. Participants analysed the processes by which policy is made both at a local and national level, using mapping techniques to create a visual map of networks and stakeholders in the locality. They identified hierarchies and power dynamics in local mental health structures and examined ways in which services could be improved and developed.

Following the policy workshop, the Tirana Forum began meeting on a bi-monthly basis in an independent location, providing a focus for action and reflection and developing a number of sub-committees to promote ways of structuring and sustaining grassroots policy initiatives in the longer term.

Achievements

The long-term aim of the programme is for users and NGOs to influence mental health policy at a local level but even in its first year the Tirana Forum made significant progress:

- the forum conducted a successful campaign to raise awareness of mental health issues in Tirana including press conferences and TV broadcasts of the work of the forum alongside 'real-life' stories of members of Alternativa. The raised visibility has had an extremely powerful effect on service users
- the building of trust during partnership working with those in government has greatly facilitated the lobbying process. Government commitments have been made to increase the resources allocated for mental health
- a new multidisciplinary community centre is being established, working alongside a local polyclinic, to provide structured support and follow-up for people discharged from psychiatric hospital. Further centres outside the capital are planned. Previously, the only community provision in Tirana had been Alternativa's day centre, providing activities and a place to meet for 30 to 40 service users every day
- concerns over the lack of information about mental health led the forum to lobby successfully for the Ministry of Health to fund an information centre – a central referral point for mental health queries
- government officials have agreed to re-examine mental health legislation, thus helping to tackle the twin problems of corruption and lack of implementation
- the forum has helped promote dialogue between government departments; a number of ministries are starting to work in a more joined-up way (a lesson here for the UK!). For example, the forum has highlighted the need for representatives of the departments of health and of social security, along with insurance companies, to co-operate more and take responsibility for people with

mental health problems, to prevent them falling through the net of state support

- forum members have developed skills in presentation, training, research and evaluation, and team working, and have participated in training nursing and social work students on mental health issues from a user perspective

- human rights campaigning – for example, the case of a service user who was taken away by police following complaints by neighbours. He remained in an ordinary prison for five months until lobbying by forum members resulted in him being taken to a hospital.

Future plans include holding a national policy forum which will provide a space to share issues and approaches from across the country, helping to highlight problems in more isolated communities and developing a stronger voice at the national level.

The above is just an example of the progress made in one country – positive outcomes have been manifold in all the *Pathways to Policy* countries, ranging from successful lobbying for employment rights in Bosnia to working in partnership with a local radio station in Romania to broadcast regular programmes on mental health. On the international stage, delegates to the international policy conference in 2004 helped raise recognition of the voices of users as an integral element in the shaping of mental health policy. As a result, just such a priority was inserted into the World Health Organisation Mental Health Declaration and Action Plan for Europe adopted at a meeting in Helsinki in 2005 attended by 52 health ministers from across the WHO European region and expected to drive policy on mental health for at least the next five years.

Conclusions

Local NGOs and service users often have access to resources and networks that are unavailable to government policy makers, having developed local knowledge, relationships and trust within their communities. These are all used by the local forums and NGOs to steer the policy agenda, engaging officials in reflection and new thinking on mental health policy. This in turn will have an effect on new ways of working collaboratively.

Through the *Pathways to Policy* programme, the bringing together of a variety of stakeholders to form an independent, structured body, collectively deciding priorities and strategies has proved highly effective and empowering. The requirement that service users comprise 33% of the forum membership has in some cases been treated with scepticism, but without such a quota it is too easy for users to continue to be marginalised. In Tirana, as in the other *Pathways to Policy* countries, it is this very overt inclusiveness that has gained respect. The forum is being increasingly recognised as a credible player in the policy arena – with the user voice at the forefront.

The programme has shown that barriers can be brought down and real differences made to people's lives by providing a simple framework to promote joint action, without having to expend huge resources. As one official from the World Health Organisation and Stability Pact for South East Europe said in a meeting with a local policy co-ordinator: 'Your work on the *Pathways to Policy* programme has achieved more to engage communities in mental health policy than we international agencies ever thought possible, and you have far fewer resources than us.'

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