



## Supporting User Led Advocacy in Mental Health

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### Summary

Mental health advocacy provides a fascinating test case for the wider role of advocacy in civil society. Often perceived as a specialism, mental health issues are likely to affect up to 1 in 4 people in Europe<sup>i</sup> in the course of their lives. This fact demonstrates the likelihood that many European citizens will access mental health services and probably experience some of the stigma that continues to be associated with mental health. At the same time, there is a little known but vibrant network of service user led mental health projects<sup>ii</sup>, initiatives and self-help groups across Europe that have for years grappled with the concept and ideas of advocacy in practice. The lessons their experiences have yielded are not just applicable to mental health development but have importance for all forms of civil society advocacy.

This paper approaches these lessons from several perspectives. It explores the interrelationship of self-advocacy, peer advocacy and systemic advocacy, and the different sets of challenges and strategies that advocates have to tackle when working in hospitals or doing community advocacy. It provides a concise overview of the most important of those lessons for CSO's, advocates and professionals, and for governments and international organisations. Throughout these reflections, it uses the experience of user group work in Campulung-Moldovenesc, in northern Romania, to illustrate the practical implementation of the lessons.

### Forms of Advocacy

Like many concepts, advocacy is contested and has many different definitions. At its simplest advocacy enables individuals to have a say in their life and the dimensions that affect their livelihood, whether that be their care, their family, their housing or their work. This is particularly important in mental health, as people experiencing crises may have many of their fundamental rights taken away when they are treated or compulsorily admitted to hospital.

However, mental health advocacy can take place on a wider scale than that of individual action. Forms of group and peer advocacy exist alongside simple self-advocacy. Also important is a consideration of the underlying causes of why an individual or group is not having its voice heard, or is having its rights ignored. Strategic or systemic advocacy in mental health looks at the systems and organisations that provide care and intervention as well as the barriers to individuals having a voice in their lives. Power relationships underpin this conception of advocacy, which focuses on the inequalities between people who use services and those that deliver them. An example of this kind of advocacy is the work the Estonian Patients Advocacy Association (EPE) has done in the last ten years with users in hospitals and social care homes, to highlight their needs to policy makers and officials within the Ministries of Health and Social Affairs.

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<sup>1</sup> Over the last eight years the authors have worked together on a number of grassroots mental health advocacy projects in the UK, Central and Eastern Europe. As part of international civil society projects undertaken by organisations like InterAction they have provided training, support and small grants for local groups to develop their own projects. One of the authors is a user of mental health services and has managed a local advocacy project in Campulung-Moldovenesc in northern Romania. The authors have undertaken several pieces of participatory action research to evaluate the impact of advocacy.

In each of these forms of advocacy, it is essential that the life stories and journeys of service users are highlighted and shared amongst advocacy organisations and governments. It is only through recognising this valuable resource that a new knowledge base can be developed. It will then be possible to deploy this to overcome disadvantage and discrimination experienced by many users of mental health services.

## **Effective Advocacy in Mental Health - Lessons for CSO's, advocates and professionals**

The research findings of InterAction<sup>iii</sup> consistently demonstrate that service users want other users or ex-users as their advocates. There is something in the experience of using mental health services that cannot be fully appreciated or understood by the professional. At the same time the professional is inevitably in a position of power due to his status and role. Also, professionals are likely to have divided accountabilities to both the user and their own organisation. Therefore it is essential that mental health advocacy organisations and activists focus on the training and support of service users as self-advocates.

Governments, in their turn, need to recognise that the service user is also an expert in the experience of mental health and using services. The appearance of self-advocates serves to trigger governments and professionals to reevaluate their approach mental health service users.

This is not to say that professionals and governments do not have clear roles in advocacy. Rather, their function is to provide access to networks, resources and support to enable service users to develop their own advocacy organisations and projects. Professionals are also useful in enabling advocates to gain access to specialist advice and tools in areas such as legislation, human rights and treatment options. If advocacy moves to a court situation, legal professionals will be invaluable to work alongside the person and their advocate.

In many countries capacity building for local mental health advocacy initially requires the long-term support of international partners. Their contribution is needed to enable local user groups and civil society organisations to develop the skills, knowledge and networks to deliver effective advocacy. This applies both to the skills of doing advocacy and the organisational development skills to manage advocacy programmes and groups of advocates. Vice versa, direct work with users across Europe has enabled organisations such as InterAction to develop a comprehensive package of advocacy development, which includes training<sup>iv</sup>, grants, on-site support and international networking. Over the last five years groups in the Czech Republic, Hungary and Slovenia have received such support and gone on to develop their advocacy services and access local funds.

Diversity is a key factor in providing effective advocacy, and grassroots groups are often well placed to recognise the diverse local needs and access local resources to meet them. Issues such as gender, ethnicity and religion are key across Europe and advocacy projects must be flexible to adapt their services to adequately respond to the diversity of their target groups. For example, in Tallinn in Estonia the grassroots groups recognised that although Russian speakers constituted nearly half the population, they were practically absent in mental health projects and forums. They were able to recruit local users and family members who could speak both Estonian and Russian to work at a local level with both communities.

The most effective advocacy is that which leads to public action to deliver change on a community level. Advocacy does not end with the assertion of any one right in a specific case. It is the way the community builds new services and relationships that ensures the sustainability of the rights achieved by individual instances of effective advocacy. For example, in Tuzla in Bosnia the local user led group Fenix were able to build on their advocacy activities by developing a local forum of stakeholders, which discusses rights issues and plans joint action on a more long term basis.

## Advocacy in hospitals

Advocacy for patients in psychiatric hospitals is an important function of any mental health advocacy service and it is important that patients are supported by advocates from their own local community, where they lived before admission and to where they will return once they are discharged. This level of continuity is essential to support people through the process of hospitalisation, which is highly traumatic and disorientating for individuals. Research indicates that, in Central and Eastern Europe<sup>v</sup>, psychiatric hospitals are one of the most likely places where a person will experience human rights abuses and physical abuse.

In Romania, some real-world examples of problems for people living in psychiatric hospital and requiring advocacy have included:

- Inadequate treatment for health problems (physical and psychiatric) due to lack of funds and general poverty amongst the population.
- Lack of vocational rehabilitation activities that provide the opportunity for people to regain their capacity for independent living
- Poor physical conditions in the hospital that pose health hazards, including issues of TB and HIV / Aids, and a lack of heating and windows that means hospitals are cold.
- Lack of protection for human rights including privacy, choice, access to information and social relationships

One way to undertake effective advocacy on behalf of patients in psychiatric hospitals was piloted in Campulung-Moldovenesc in Romania. In the hospital there, where service users acquired their own representatives on the hospital board. Representatives from the local civil society organisation Orizonturi Foundation now ensure that advocacy and rights are on the management agenda at the governance and strategic level of the institution.

The Campulung hospital has also supported user-led advocacy at a systemic level by agreeing to a formal written partnership with Orizonturi. This enables the local group to monitor and evaluate psychiatric services in a systematic and coordinated way. Users ask patients to fill in an advocacy questionnaire at the time of their admission and track their needs and rights during their journey through the mental health system. This tool enables the local group to understand peoples needs and put in place a proper advocacy plan.

## Advocacy in the community

Effective advocacy has to overcome a number of social and community based barriers that disempower people who use mental health services. The experiences of stigma, discrimination and social marginalisation reported by many families prevent them from approaching services and support.

Advocacy projects therefore need to reach out to potential users in ways that promote positive images of mental health and that demonstrate the benefits of using local advocacy services. Case studies, life stories and vignettes can be particularly powerful in illustrating positive local experiences. This also links to the wider need to improve awareness and education about the topic of mental health in the community amongst employers, local officials, health professionals and the general population. Advocacy can be a particularly powerful way to share the human dimension of mental health as real people speak and tell their stories in direct and personal ways. This contrasts with the more abstract and technical approaches of mental health promotion that focuses on the diseases and the incidence statistics.

Working as an advocate in northern Romania has presented a variety of challenges to user activists as they promote peoples views and needs. The limited legal framework that currently exists in Romania to protect jobs, pensions and housing of vulnerable people means advocates often do not have recourse to legal principles and standards. Increasingly advocates and users have to refer to international treaties and declarations to make their points.

The lack of real alternative community services in northern Romania also means that even if users and professionals agree on the desirability of non-institutionalised care, the provisions that need to be in place to make this a practical reality are lacking. Here, the link between personal and systemic advocacy is essential to ensure that information about unmet needs and demands of service users is channelled to policy makers and people in power.

In Campulung-Moldovenesc activists have established new lines of communication with ministry officials to ensure that local experiences are recorded and delivered to officials in Bucharest. For example, in March 2005 the Iasi Declaration<sup>vi</sup> collected the views, opinions and signatures of over 80 stakeholders concerning a range of advocacy issues. It was delivered in person to the Minister of Health during a visit to northern Romania. Copies have also been distributed to officials and stakeholders across Romania and a version is available on the Internet.

The Orizonturi Foundation has also systematically kept weekly, reflective diaries about the activities of its advocates, and it uses these as a local evidence base for their work. Periodic research reports and summaries are published to share and disseminate learning and local advocacy case studies<sup>vii</sup>.

Generally, however, the weak relationships and coordination between state institutions, mental health NGOs, professionals and wider society continue to affect the quality of care. Local groups are also concerned that umbrella organisations and networking forums have yet to get the balance right between the interests of the state and the community.

Practical problems can also constrain the effectiveness of advocacy. Northern Romania has a significant rural population. Transport and communication links are poor and many small villages and communities are isolated from services and initiatives.

The Orizonturi Foundation has worked to systemically highlight the different needs of rural populations and has provided information and research to policy makers. At the local level the NGO has introduced several practical measures such as outreach work in rural areas and roadshows that provide educational material to different villages on a rolling basis. They have also subsidised the travel expenses of vulnerable users and families who need to travel to the local population centre to access services.

The most effective measures have linked advocacy activities to local practices and customs. Advocacy consultations and workshops, for example, have been timed to coincide with local market days when the rural populations naturally travel to market towns. These adaptations of the advocacy service have arisen from listening to the experiences of local people and being prepared to provide a practical and flexible service, and demonstrate to professional led services that there are alternative ways to organise community based activities. In this way advocacy becomes a self-reflexive activity that applies its own learning and lessons to the way it develops.

It is also important to recognise that many users continue to live in social care homes. These institutions are more common to Central and Eastern Europe, and are often overlooked on the policy agendas of reformers and governments. Part of the reason for this is that social care homes are not classified as hospitals and so are not included in the numbers of psychiatric beds per country. This can give a misleading perception of how institutionalised the mental health services of a particular country are. As the social care system is managed separately it is subject to different levels of scrutiny to formal psychiatric institutions.

Working as an advocate can be a challenging experience. Research by InterAction<sup>viii</sup> highlights many personal risks and threats experienced by advocates as they undertake their role. Often advocates will be expected to challenge people in power and authority to assert their rights or gain access to withheld information. Advocacy can also be isolating and lonely. It is important that they feel supported by their own organisation, but also by international organisations, which are in a position to scrutinise mental health systems from a wider perspective.

## **Some Barriers to Effective Grassroots Advocacy – Lessons for Governments and International Organisations**

The most successful and effective advocacy projects in Europe are often those that are small scale and localised. This is where local people have designed a project to meet their specific needs and where service users are central to the planning, delivery and evaluation of advocacy services. This is best achieved through localised funding that is small scale and focused. In the author's experiences, the most successful funding strategy of international organisations is to provide small amounts of money on a consistent basis backed up by long-term support and mentoring. This builds sustainability and embeds the advocacy project locally.

Where advocacy fails is when large international projects are developed that are portrayed as set piece interventions or blueprints. Often these deploy large amounts of up-front money for capital and material items such as offices. EC practice has favoured delivery of such projects by complex consortia rather than local leadership. In the end these projects risk failure when local communities are unbalanced, jealousies aroused amongst those excluded and outsiders have too much influence. Governments and international organisations need to commit more to bottom-up development of advocacy and avoid the pitfalls of top-down interventions and policy prescriptions.

Effective advocacy is about creating positive outcomes for the individual and the local community. It is about achieving real changes to a person's life, such as improved housing, work, better social relationships and higher income. It is not simply about the protection of human rights in the abstract. It is important that international donors focus on supporting local advocacy projects to deliver these real-world outcomes, rather than focus on advocacy as an abstract or theoretical activity. Funding programmes and strategies must focus on capturing the real world changes in communities through participatory research, life stories, case studies and personal experiences. It is this local knowledge which is often more available to the local evaluator than to the outside organisation.

Whilst there is much information available on websites and conferences, grassroots actors are often excluded from this through the technology divide, language differences and a lack of direct personal relations with international actors. To really develop effective advocacy at a local level, international agencies need to form and maintain direct relations with service users and local civil society groups rather than via proxies such as regional and national level organisations and umbrella groups. The terrain of mental health is contested and there are different degrees of co-operation and competition between different actors in all countries. Investment in grassroots advocacy requires direct relations with the grassroots. The powerful need to listen more and talk less when it comes to promoting local advocacy.

### **The future of advocacy**

It is important to see advocacy as part of a wider project of development and empowerment, in which service users and their families are at the centre. Advocacy enables them to have a voice, but it is also important to build other forms of civil society capacity, such as bottom-up policy development, organisational development and networking. Through this combination of local initiatives people will be able to run their own projects and deliver community level change.

It is also important that mental health advocacy is not seen as an isolated specialism and the lessons that it provides are taken into account in action on wider agendas such as social development, the disability movement and poverty reduction as well. Given the prevalence of mental health problems in populations, it is important to acknowledge that mental health will permeate all forms of community life and civil society activity.

Effective advocacy requires the combination of technical and practical experience with a wider vision of empowerment and community development. Services need to be flexible and person centred with a strong identification of the barriers and power relationships that stop people having a voice. One way to secure this is to place people with direct experience at the

centre of advocacy initiatives, enabling them to have the power to lead, design, monitor and evaluate projects. The assets of personal experience and local knowledge held by users and their families are the most essential (and indeed sustainable and low-cost) resource and it is time for this to be properly recognised and acknowledged.

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<sup>i</sup> World Health Organisation (2001). The World Health Report 2001: Mental Health, New Understanding, New Hope. Geneva: World Health Organisation. pp. 23

<sup>ii</sup> Cutler, P. and Hayward, R. (2003) Grass-roots initiatives in mental health policy in Eastern Europe, EuroHealth Journal, 8, 5, winter 2002/2003.

<sup>iii</sup> InterAction, a mental health and international development organisation, strives to ensure positive changes to the lives of people affected by serious mental disability, and greater democracy in the societies in which they live. See <http://www.interaction.uk.net>

<sup>iv</sup> Cutler, P., Hayward, R. and Shears, J. (2001) Building for the Future: Making Organisations Stronger and More Effective. London: Hamlet Press

<sup>v</sup> Mental Disability Advocacy Centre (MDAC) (2003) Cage Beds: Inhumane and Degrading Treatment in Four EU Accession Countries. Budapest: MDAC

<sup>vi</sup> Orizonturi Foundation (2005) Iasi Declaration: Rethinking Together Mental Health Policy. Campulung-Moldovenesc. Orizonturi Press

<sup>vii</sup> Orizonturi Foundation (2005) Rethinking Mental Health Policy: People, Participation and Power. Campulung-Moldovenesc. Orizonturi Press

<sup>viii</sup> CRMHP Research Paper (2005) 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