

Recent developments in european Mental Health: change, choice, conflict and challenge

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I am pleased to be here today to look with you at European mental health systems.

Perhaps a meaningful way to do so would be to focus on specific themes, while bearing in mind that Europe is diverse. "Europe" includes the UK, but also Central and East Europe, Western Europe, and has a pronounced South and North divide. The diversity is partly due to historical reasons, as well as current cultural, economic, political and social differences.

Yet the similarity exists as well, especially if we look at Europe from the perspective of other continents.

Perhaps I need to establish my credibility before taking the plunge; I am a chartered clinical psychologist and social worker by training, currently professor of interprofessional health and social studies at Anglia Polytechnic University, based at Cambridge.

I have been researching European mental health since 1982, focusing mainly on Italy and the Netherlands, but visiting mental health services in Bosnia, Greece, Finland, Hungary, Ireland, Portugal, Russia, Slovenia, Spain, and Ukraine.

What has attracted me to Europe? I was trained following British and US traditions, but when I came to live and work in the UK in the 1970s, the state of mental health services was so different from what I have envisaged it to be that I was ready to look elsewhere.

Themes

In a one-hour talk it is not possible to cover all themes. I shall not cover Central and East Europe, though will refer to some relevant examples there.

The comparative perspective

In principle Europe is a natural laboratory, enabling a cross-country comparison among societies which share a number of important characteristics in common, thus making the comparison more viable and getting:

- More comprehensive knowledge about common and uncommon features;
- Indicators of what works and what does not on a larger scale;
- Monitor changes over time and different social conditions;
- Pointers to useful policies;
- Verification of experimental schemes, research methodology, and conceptual innovations.

For example, the statistics highlight that there are considerable changes in suicide rates between countries in Europe and within countries over time. Hungary and Finland remain very high on the list, Greece and Malta remain very low. There are some major increases: Portugal and East Ger-

many, and a notable decrease in West Germany. For most of the countries there are modest increases.

The statistics do not explain trends, but establish their existence. How would we explain the trends? Not by psychiatric morbidity, but by social change; not by religion, but by social change, not by deterioration of economic standards, but by cultural and political changes.

Anomie, the classical concept used by Durkheim at the beginning of the 20th century, seems to capture best the relevant explanation - social and personal turmoil due to either "upward" or "downward" change, in addition to population characteristics.

The diversity and similarities are further highlighted by Morant, in her research titled:

Research on the Social Representation of Mental Ill Health in Communities of Mental Health Practitioners in London and Paris (1) This is a study of the views of managers of community mental health services in Paris and in London, in which the bi-lingual researcher was interested in the views and dilemmas these managers have. The data was collected through individual interviews, supplemented by observation of team meetings.

The findings highlighted the shared sense of not having enough knowledge, of uncertainty about the knowledge one has, and nevertheless of continuing to work through practice wisdom and intuition.

This was the case despite the fact that while the London managers came from a medical and behavioural approach, the Paris managers came from a psychodynamic, almost psychoanalytic perspective combined with a medical approach.

From my own observations everywhere in Europe I am aware of the high level of uncertainty concerning mental health knowledge.

The impact of the context

One of the major changes from the 1970s onward in Europe has been the establishment of the EU.

It is in particular an important facet of life in West Europe, symbolised by acts such as the introduction of the European Human

Rights Charter in the UK as from this year, which has legal priority over UK laws.

We need to ask if the development of the EU has made a significant difference to the development of mental health services in each of the member states? In some of them? if so, how?

Mental health is not a recognised arena of action for the EU. Yet the EU has impacted on mental health services, and has contributed to the move to community focused services. This has happened through the various anti-poverty programmes which have been characterised by:

A typical example is provided in the Mistral project. This was a project of four EU countries (Britain, Italy, Portugal and Spain) focused on introducing people with disabilities into training for work, and for a work placement. My role was to evaluate the effectiveness of the transnational collaboration, and that of the British project (2).

Each country has gone about this task differently, and eventually also each country focused on a different group of people:

- Britain (Lincoln) constructed an induction to work course and placed a few people for short periods with small business employers. Although it was to include people with mental illness, the project workers felt uncomfortable with this group and fostered instead their initiative almost exclusively with people with learning difficulties.
- Italy (Savona, a therapeutic community) constructed a theatre course in a real theatre, leading to a number of productions. They worked only with people with mental illness.
- Portugal (Algarve) focused on training the trainers, and through a face to face and CD-ROM course achieved this aim. The course was aimed at trainers for any group of people with disabilities.
- Spain (Seville) trained people with physical and learning disabilities to undertake a variety of unskilled and skilled jobs, by training them in a setting that enabled direct work experience.

This project highlights the richness and diversity within Europe, but also the difficulty to evaluate such a high level of diver-

sity. It also highlights the existence of stigma towards people with mental illness in the UK.

Concerning the process of collaboration, the conclusion from the evaluation was that it had enriched the workers in the different projects, and each could mention at least one element of such a learning. Yet the cultural differences were so great, and could not be offset by the quality and quantity of transnational interaction, which consisted of short, half-week visits to each other sites. This was particularly noticeable in the attitudes to the Italian project, seen as "outlandish" especially by the British workers, who therefore did not even attempt to understand what it was about.

None of the users got to be involved with users from the other projects, a reflection of where the workers were. In other projects which I know this is not the case, and service users too visit projects in other European countries, and loving it.

I have also participated in two educational projects focused on training for community mental health in Slovenia (1991-1996) (Ramon, 1995) and Bosnia (1999-2001) (Magliajlic, 2001). In both we had partners from social work, psychiatry, and psychology as disciplines; from Britain, Italy and Austria as countries in addition to local participants. The participants were all postgraduate, working in the field.

Both projects were supported by the EU under the Tempus-Phare programme.

Aimed at introducing knowledge about community mental health, a lot was about how to introduce change, as well as its content and the implications of the move from hospital based psychiatry to community-based mental health. The participants were eager to learn, and eager to come for a three-six months period of observation and participation in local education in a West European country.

The Slovenians were much more ready for the changes, as many of them were in touch with what was already happening in Italy and have moved rapidly from the mentality of a communist society to a post-communist Central European country.

The situation in Bosnia was very different, because of the savage war that took place there, and because we have been working there with both Bosnian Moslems and Serb

professionals. Although these professionals were exposed to the impact of the many international support organisations, including in the field of mental health, their sense of devastation blocked the capacity to learn, and the local context blocked rapid change too. Paradoxically the war -more correctly the physical destruction of psychiatric facilities- enabled the Bosnians to be ready for new structures, but mentally this seems to be a leap difficult to take. Small-scale innovations are taking place, such as the establishment of a number of user groups. The international organisations focused on responding to post traumatic stress disorder (PTSD), a necessary feature given the circumstances, but this in itself is insufficient to change approaches to mental illness.

Although West European knowledge was delivered, there was a lot the partners from West Europe could learn from the Slovenian and Bosnian experiences. Yet for that to happen, the partners had to come with an attitude which enabled this type of learning.

There are many small scale educational exchange programmes available within the EU, a few of these are focused on mental health.

However, an exception to the rule that the EU does not contribute directly and significantly to mental health services is its contribution to the re-structuring of mental health services in Greece in a significant way. The involvement with Greece has been justified by the dire state of Greek mental health services, but probably has been affected by having a commissioner at the time who had a child with learning disability. Following a public scandal about the state of Greek psychiatric hospitals, especially the one in the island of Leros, in which patients were habitually washed by a hose, eating from one bucket usually bare footed, and did not have drinking water between 5.00p.m. to 7.00 a.m. (the island does not direct access to drinking water, and uses bottled water brought from the mainland). On the basis of human rights the EU has decided to grant the Greek government \$8 million dollars, a large sum in the early 1980s, for the purpose of:

- Establishing psychiatric wards in general

hospitals.

- Improving the physical conditions in existing psychiatric hospitals.
- Constructing rehabilitation programmes for those able to benefit from such initiatives both inside and outside the hospitals.
- Establishing community mental health centres.

An EU experts committee was asked to monitor the implementation of the programme, through regular visits, and professionals from Italy and the Netherlands to volunteer to work in Leros together with the Greek professionals. A higher salary was offered to Greek professionals ready to come and work in Leros. It took the Greek government about five years to master the art of filling in correctly the EU forms. Nearly twenty years later half of the in-patients from Leros have left it and have been resettled in the community, some of them on the island itself and many more in Athens (3).

My visit in 1993 was a mixed blessing. On the one hand I saw the villa just on the hospital perimeter where some of those who did not talk and could not use cutlery started to do both after many years of literal incarceration. I also visited the small group living in a group home in an ordinary house in the island, looking very relaxed and treated respectfully by the local community.

But I also saw someone who choked on his food and died, just three weeks before he was due to leave the hospital, and all other residents turning into statues unable to move, either towards him or away from him, and the International team deciding to resign because the administration was more pre-occupied with bureaucratic coverage than with rehabilitation, people walking without shoes even though there was a cupboard full of shoes, for which no one was ready to take responsibility.

In Athens, where most of the ex-Leros residents came from and where they were resettled, they seem to have blended well into the mental health services, but led the separate life of people in a group home.

On the whole the investment in Greece has had beneficial effects on:

- Reducing the number of in-patients;

- Increasing the number of community mental health centres;
- Introducing psychiatric wards in general hospitals;
- Improving the physical quality of life in the existing hospitals;
- But not leading to changing the regime within the hospitals;
- Not leading to change in stigmatisation by lay people.

Hospital Closures and Resettlement in the Community

If asked to single out one element of change as the most important one since the 1950s, I would opt for hospital closure and resettlement in the community as signalling a radical shift in the direction of mental health services, the way we think about service users, aims, knowledge and skills of professionals.

The two countries which have gone for wholesale closure and nearly wholesale community based services are Britain and Italy.

It is important to pause and ask why only these two countries have opted for such a policy, while the rest of Western Europe is going for what I would describe as "muddling through" - i.e. introducing community based services without phasing out the hospital system.

Reasons for opting for hospital closure:

- Belief in the need to de-segregate and de-stigmatise people suffering from mental illness.
- Disappointment at the quality of refuge hospitals have provided.
- Proven evidence that people with mental illness can live in the community and have a better quality of life than in hospital.
- Government's belief that community care will be cheaper than hospital care.
- Professional satisfaction from rehabilitation and resettlement.

Reasons for not opting for hospital closure:

- Belief that hospitals provide asylum.
- Disappointment which the way communities have responded to the mentally ill.
- Sense of safety in hospitals, which became important as we became more

focused on risk issues.

- Some professions feared loss of power in the move to the community.
- Fear of losing jobs and influence (trade unions).
- Good community services cost too.
- Some people need respite care some of the time.

Why compare Britain and Italy in particular:

- A lot has been written about the American experience, and relatively much less about the European experiences.
- These countries are only two European countries to opt for a wholesale closure of psychiatric hospitals.
- They share the belief in the centrality of community-based solutions and services to mental health issues.
- Are similar in population size (57m. vs. 55m inhabitants).
- The quasi-market dominates the scene in both countries' health and social care services.

There are, however, major differences between the two countries which include:

- Italy's belated post Second World War social reforms took place only in the 60s and 70s, but were more emancipatory and participatory than the British reforms of 1945-1950.
- Attitudes to politics among professionals are different: Most British professionals continue to view politics as outside their domain; not as something they need to get involved with; Italian professionals view involvement in politics and influencing the public as part of everyday work.
- Italy's professionals are less specialised in their training than the British professionals are.
- The Italian psychiatric reform was spearheaded by mental health professionals; the British reform was mainly government-led; there are advantages and disadvantages to each choice.
- The Italian professionals committed to the reform were interested in social, rather than in clinical, solutions.
- Italy has poorer welfare provisions.

In looking at deinstitutionalisation, processes are not less important than outcomes, as the implementation of the values men-

as the implementation of the values mentioned above depends to a large extent on how is deinstitutionalisation being applied (4).

As a consequence of the differences outlined above, there were considerable differences in the processes developed and evolved in the two countries:

- The UK focus has been on preparing individuals for resettlement; placing them in very sheltered accommodation and traditional day centres.
- The Italian focus was on:
 - Changing the hospital regime and using it as a re-socialisation setting.
 - Preparing the various stakeholders' groups for living and working in the community.
 - The Italians moved hospital staff to community services; no one had to re-apply for their jobs, or feared being made redundant.
 - Budgets were moved automatically from a ward which closed to a community service in Italy;
 - Users were not placed in day centres, but mostly in work co-operatives on a part-time basis;
 - Work with the general public continued - e.g. involvement of local youth, local artists, joint events which combine mental health and art.
- The Italians have developed more informal relations with users;
- The British process was more orderly, better planned in advance, and more bureaucratic;
- The British resettlement programme applied only to those who were for more than two years in hospital (the "long long stay") and excluded those who came for shorter periods (the "new long stay"), even though they may have come often, but for short periods only.

Major Outcomes

By and large the resettlement of people with long term mental illness who were institutionalised went well in terms of the following indicators (5):

- Most of those resettled were highly satisfied with their lives outside the hospital; virtually no one wanted to re-enter the hospital even for a visit.

- Less than one percent of the British sample became homeless or committed offences; if any, a minority found itself victims of violence.
- There was a considerable improvement in self care and social skills of the resettled population;
- There was no change in its clinical, symptomatic, state.
- Less than 5% had a relapse episode; no homicide and few suicides within this population.
- The cost of living and being looked after for the majority of the resettled population is less than it was in hospital; it is as expensive as hospital care only for a small minority which has a mixture of high security needs, physical and mental care (6) (7) (8).

Italy

- Fewer people are hospitalised in Italy than in the UK, especially via compulsory admission; the length of stay is shorter too (9).
 - A number of the resettled people - usually the younger ones - are working on a part-time basis in co-operatives (10).
 - The Italian media is less hostile to people with long term mental illness than the British media is (11).
 - There are no calls for re-opening psychiatric hospitals in Italy or for halting their closure.
 - Less specialised interventions are offered in Italy to people who use public mental health services than in the UK.
 - Nurses, social workers, and to an extent psychiatrists too have a more flat career structure and scale in Italy.
 - Having a good service for the large group of people with mild mental health problems is a matter of luck in Italy.
 - There are fewer voluntary sector services in Italy than in the UK; a number of those which belong to the Church are of poor quality and perpetuate institutional mentality.
 - Institutional mentality can be observed in Italian psychiatric wards in the general hospital, as well as in some of the settings set up for the resettled population.
 - There is relatively little by way of formal advocacy in Italy in comparison to the UK.
- The Italian government is taking a back seat in terms of initiating mental health policies.

UK

- The UK government continues to lead reforms in mental health, advised mainly by psychiatrists; but increasingly enabling users and carers to take a formal part in service planning (12).
- The government is now moving to focus on mental health promotion and social inclusion, following a public health model of mental health, re-discovering the connections between poverty and social exclusion and mental illness (see Standard 1 of the National Service Framework for Mental Health).
- Yet the government is also increasing the control element in mental health services (13).
- The government is also pushing the focus on employment and education for all people with a long-term disability, including mental illness (14) a minority of professionals are becoming engaged in these issues, these are left mainly to the voluntary sector and to non-professionals to handle.
- Institutional mentality is visible in many of the settings constructed for the resettled population.
- There is a growing number of user-led and carer-led organisations and services; as well as in advocacy settings, largely poorly funded (15).
- The considerable growth in the voluntary sector has in parallel led to curtailing the campaigning function of this sector.
- There has been a considerable growth in private, for profit, facilities in the hospital and secure units sector, as well as in private psychotherapy; but not in other components of the mental health system.
- The resettlement project is perceived to be a failure among politicians, the general public and many professionals, despite the statistics which shows it to be a success in terms of major indicators stated above (16) (11).
- If there was a failure, it is in being

uninterested in changing attitudes, in being afraid to admit that the hospital regime was a poor option; in not offering a resettlement programme to the "new long stay", and in being over-protective towards the resettled population.

The major lessons for other countries are:

- Deinstitutionalisation can succeed;
- The quality of life of the resettled population has improved with their move to live in the community;
- Integration within the community requires a non-institutionalised mentality by the service providers and policy makers;
- It is both necessary and possible to involve the general public in a positive way in the process of deinstitutionalisation;
- The achievements of deinstitutionalisation do not stand still; they require to be re-fostered within the new context constantly, as attitudinal change towards the resettled population has yet to take hold;
- The over-emphasis on continued care clients is detrimental to the provision of a comprehensive mental health service, to catering for the needs of the growing, vast, majority of people who suffer from mild mental distress, and to a mental health promotion agenda.

Thus the challenge of continuing to be simultaneously committed to deinstitutionalisation yet to a mental health promotion agenda is considerable; it requires a well developed psychosocial approach and a strength-focused perspective; one which takes on board community development approaches and methods, the social model of disability, and social inclusion. The medical model is insufficient to deliver this duality, and its dominance hinders the whole project.

Presently, we have an unexpected outcome of the way hospital closure went in the two countries in terms of public opinion. Although the outcomes of the resettlement in the UK are largely positive, hospital closure and community care are regarded as a failure. The opposite is true of Italy.

Thus we need to understand where is this difference in public opinion coming from.

The Italian services are less well resourced financially; offer less economic benefits to service users, and the professionals there have less specialised training than the British ones are.

There is no reason to assume that the Italian population suffers less from mental illness. Yet we do know that there are far fewer compulsory admissions to the Italian facilities. Of the few studies that look at satisfaction of users, carers and professionals, Italian users and professionals seem to be more satisfied than their British counterpart, but the Italian carers are less happy than the British ones (who are unhappy too, but less so).

Perhaps the difference in the public verdict is due to focusing on working with public opinion, on attempting to involve the community from the very beginning, developing a more informal relationships with clients and emphasising employment and sociability more than medication and psychotherapy. The Italians seem to have accepted that their work is about care rather than cure a long time before the Normalisation approach has introduced this perspective in some professional circles in the UK.

The Netherlands.

The lack of hospital closures in the Netherlands is equally worthy of attention, because the Dutch were the first to establish day care and crisis intervention services in Europe, as early as 1948. They do have a wide network of services in the community, which today includes obligatory groupwork on employment issues, often run by service users employed by the insurance companies which run the 43 psychiatric hospitals, most of which have a patients council. The Dutch have also the most developed user representation in Europe, which began in 1974. They run an advocacy schemes both at a group and individual levels, funded by the government. They have halfway houses, sheltered accommodation, community mental health centres..

And yet not even one psychiatric hospital has closed there since the Second World War, nor is there a move to enforce such a closure. One way to explain this state of affairs is to think that the hospitals - rather

more comfortable than the British ones - provide an asylum, and that the Dutch system has not led to a change in approach on the scale achieved by the Italians. Another is the fact that hospitals are run by insurance companies, and not directly by the government, and it is not in the financial interest of these companies to close their "golden egg". The government seems keen to curtail the power of the insurance companies and that of the hospital sector. Four years ago the government made it mandatory for hospitals to give a slice of their income to innovator community-based projects.

The Impact of the introduction of market economy principles to mental health services

The introduction of such principles is taking place all over Western Europe, even if at a different pace, with the German system having such elements from the very beginning, the UK introducing it ten years ago, and only five years ago in Italy.

The principles include:

- decentralisation;
- greater autonomy over financial and organisational matters given to local units (hospital trusts, primary care trusts);
- enticing private for-profit, and private not-for-profit organisations to enter the service systems;
- fostering competition among the different providers;
- establishing a greater managerial section with greater than ever responsibilities for the financial, organisational, and professional functions.

This introduction is justified on the grounds that competition will reduce costs, improve quality and quantity of available services, and thus improve consumer choice.

Judging from the British experience, the main outcomes of this fundamental change are:

Positive outcomes:

- a much larger and stronger not-for-profit, largely unmedicalised, mainly socially oriented, sector;
- a small specialised private-for-profit

sector catering for the high at risk population;

- competition between the public and the two private sectors at the beginning of this change process;
- enthusiastic managers, keen on positive change and innovation;
- greater legitimisation for user and carer involvement;
- opportunities for re-thinking the existing system of services and reforming it.

Negative outcomes:

- fragmentation of the system;
- demoralised workers in the public sector;
- losing the campaigning element of the not-for-profit sector;
- split between professional and managerial interests;
- the managerial ethos becomes the driving ethos;
- running services for the sake of balancing the books and for the sake of profit rather than to meet identified needs;
- over-emphasis on working with individuals as individual practitioners, and under-emphasis of collective work.

Much greater focus on getting people with mental health problems back to work or at least into education and training than before can be observed in the British system. This is positive in terms of enhancing people's strengths, confidence, and social esteem, and in reducing costs in the long term. However, it also may mean that people are penalised if they are not ready for any type of training or work, and that the fear of losing financial benefits may prevent people from taking up employment opportunities, while if they remain on benefits they can earn relatively little.

Innovation in Intervention Methods

A new approach to working with users and carers has been introduced in the late 80s, and further developed in the 90s. Using educational methods, and self-management techniques, such programmes attempt to provide:

- updated knowledge about a specific mental illness;
- updated knowledge about patterns of

behaviour and emotions to be expected from people suffering from the condition;

- knowledge about early warning signs;
- strategies of handling the warning signs as constructively as possible;
- coping strategies for both users and carers;
- conflict resolution tactics;
- things a person can do for him/herself;
- strategies to enhance self-esteem

The approach focuses on knowing and especially on doing, enables users and carers to be more in control over what is happening to them than before, and treats them as active, capable, learners, rather than as passive patients.

Such an approach has its limitations too. It can be used in a biased way, for example to provide only knowledge the presenter believes in, or to provide knowledge we are unsure about as high in certainty, as users and carers prefer certainty over uncertainty. More often than not educational programmes oversimplify the highly complex issues aimed to be covered. Thus it is tricky to provide accessible cover which does not oversimplify, is not biased in one direction, and admits to areas of uncertainty, as well as to losses and suffering.

User involvement: achievements, failures, and challenges.

- The growing interest in user involvement (UI) at the European level and at the level of each European society is reflected in a number of ways, such as:
- The coming into existence of the European Users Network, based in the Netherlands in the mid 1990s;
- The systematic use of West European user trainers to enhance UI in East Europe;
- The presence of users in planning and auditing groups in countries such as the Netherlands, Sweden, and the UK;
- The involvement of users as trainers on professional courses, mainly for social workers, but increasingly also for nurses in the UK;
- The involvement of users in running user-led projects in a variety of fields.

It would be useful to understand the rea-

sons for this growth, after centuries in which users were told that the professional knows best, in order to ascertain the motives and to then look at whether these developments follow the motives behind them. Likewise, it would be relevant to look at opportunities and barriers for such an involvement

The motivation for involvement differs according to the stakeholder. Thus:

- Users wish to be involved in order to have greater control over their lives and for the purpose of gaining more say in what is happening to them and the type of services on offer than they had up to now;
- Carers wish to have more say for themselves, as they feel largely ignored by professionals and often barred by users from having information as well as from having a say in decisions. They have not demonstrated up to now any interest in developing direct UI, and if they may see it as a threat;
- Professionals as we know do not speak in one voice and do not represent only one position on UI. Psychiatrists -identified by politicians, the public, carers and users, and themselves, as the leaders of this field- have not come forward in favour of user involvement thus far in most European countries, perhaps with the exception of Italy and the Netherlands. Instead, they may tolerate it or oppose it, depending on their individual and small group inclination.
- As a group, psychologists do not have a clear position on UI - some of them have indeed led such initiatives, while others did not
- Social workers have favoured UI in most European countries, including Britain. Their national organisations have openly supported it, as it fits well the value of self-determination, the strength approach to social work clients, and more recently that of empowerment. In many cases social workers initiated, with users, such projects.
- Nurses have not embraced as a collective UI, but have willingly participated and initiated this in many instances.

- Occupational therapists (a profession that does not exist in every European country) have taken a position similar to that of nurses;
- Politicians in North Europe have come forward for UI, whereas those in Southern Europe have not. Politicians in post-communist countries (Central and East Europe) do not seem even to comprehend what it could possibly mean.
- The media, which plays a major role in shaping and reflecting public opinion, has underplayed publicity for UI, but at times interviewed prominent members of the user movement when their personal stories are judged to be of sufficient news value. This is true of a minority of quality papers; most papers have just ignored UI or examples of users' success.

Achievements

UI in its recent, post-modern, incarnation, dates from 1974, when the Dutch user movement succeeded in becoming partners to the planning cycle of policy of the Dutch government and opened the first patients council and the Client Bond (an advocacy service run and managed by service users) in Utrecht.

Thus the Dutch have had three major achievements:

- Involvement in making policy;
- Managing and providing a much needed advocacy service for other users;
- Creating a voice for the much-neglected population of inpatients, which empowered them in the encounter with hospitals managers.

These have become achievements to be emulated throughout Europe, though not all at once and not all at the same time in the same country; some countries are still not there.

For example, (17) was invited to come to Nottingham in the UK in 1986 by Ingrid Barker, then development worker of Mind, to train British workers and users in how to set up patients councils. Yet participation in planning - as distinct from attempting to put pressure on planners from the outside - has happened for the first time in the UK in the early 1990s, when the Mental Health Task Force came to exist for two years only, and

when in parallel members of the Camden Consortium were invited to become members of the management committees of the new facilities established to resettle people leaving Friern Barnet psychiatric hospital, as part of the planned UK hospital closure and resettlement programme.

The recognition that users who participate in planning committees, or any other committee for that matter, require training in becoming effective committee members followed much later. In an interesting scheme based in North Essex the newly established Mental Health Users Network commissioned a training module from my school.

Titled Pathway to Empowerment, it has the following components:

- Update of knowledge of mental health policies and legislation;
- Update of knowledge of structures and content of mental health services;
- Formal and Informal understanding of how mixed membership committees work;
- Skills for effective committee membership, including a short field placement

Southern Europe has less formal participation, and a greater focus on solidarity and support network, often led by professionals (18). Although by definition more paternalistic when led by professionals, these projects do not only reduce isolation and demedicalise user and staff experiences. They also can enable the development of more user-led initiatives, enhance the confidence and competencies of users to imagine what they wish to do and to be able to run it.

The work co-operatives, and the social firms which exist all over Europe but in particular in Southern Europe (19) (10), enable to build another type of confidence and competencies in an area which is so central to our self and social esteem.

Within the social firms users are not only acting as workers, but as:

- members with a say in the decision making of the co-operative or the firm;
- head of work groups;
- representing the project in contacts with external agencies and the community;

- demonstrating the strength approach in practice.

An important further step has been the involvement of users in training, as it marked the acknowledgement that users' experiences are not only valid, but also provide useful new perspective to be understood and taken into account by professionals. Users trainers are operating on a regular basis in Italy, the Netherlands and Britain, and on a less regular basis in most other European countries, including by now the post-communist countries. User trainers need to be trained in how to teach and in particular how to find the right balance between self-exposure and representing more general experiences, and have to be supported at both the preparatory and debriefing stages. Participants' (be they students or workers) comments are usually extremely positive, even if they felt uncomfortable by the critique implied or stated by the user trainer of current practices. Yet another crucial step in the evolving UI is the contribution of users to research as active researchers. While there have been a number of users who became fully qualified researchers through the completion of their academic studies and working as professional researchers, this relatively new initiative entails:

- self-selection of users and selection by professional researchers for the role;
- training within a relatively short period for a general understanding of research and for being able to perform specific research tasks (e.g. interviewing, administering a questionnaire, composing a research tool);
- participation in the process of formulating the research questions and taking methodological decisions;
- participation in the process of getting ethical permission;
- contributing to the recruiting research participants;
- data collection;
- data analysis;
- writing up;
- dissemination

For references see: (20) (21) (22) (23) (24) (25)

While it is clear that only a minority of

users can be researchers, in the same way that only a minority in the general population will be researchers, the importance of taking on research by users is about changing the knowledge and evidence base in mental health. Both knowledge and evidence are central to our understanding of mental health and ill health, of what works and what does not in terms of interventions, desirable and undesirable attitudes. Yet for far too long this important component was left only to professionals to create and verify.

To date in Europe we find user researchers in the UK only, though outside Europe they can be found in the US and Israel.

As one of the relatively few professional researchers engaged in initiating these type of research projects I cannot suggest that they offer "plain sailing". Not surprisingly they entail a number of likely obstacles, which I will detail below, but all of which can be overcome.

To provide one example of how users researchers can contribute new knowledge, I would like to look at the project in which people with personality disorder were trained to research the experience of personality disorder of other people, carried out in Colchester in 1999. (23) (24).

Background to the User Researchers Project on Personality Disorder:

- build upon an 18 months project by local users in a Mind advocacy project focused on local policy recommendations for services for people with personality disorder in the locality, incorporating their experiences into the work of the project and its written recommendations;
- proposed by a university researcher;
- financially supported by the university through RAE (research assessment exercise) funding and by time and facilities donated by the local Mind group, as well as supervision free of charge by two university researchers;
- training programme provided over three months, focused on listening and recording skills, understanding research principles and power relations, ethical base, formulation of research questions and turning them into an interview schedule, role play of interviews in the group, piloting interviews



- with friends, debriefing techniques;
- participation in the process of getting ethical permission, facilitated by the fact that the committee's administrator was an ex-user and a Mind activist.
- ensuring on-going support for the six users researchers, all of whom have gone through crisis periods during the research process, four of whom made it to the interviewing stage;
- none of the user researchers were researchers before; only two had a university degree in unrelated subject areas.

Main findings

- 50 people with personality disorder were interviewed;
- Most of them lived on their own and were unemployed;
- Most women were given the diagnosis of borderline PD, while most men were given that of anti-social PD.
- Nearly all interviewees have had other diagnoses, usually depression;
- More than 80% suffered from child abuse, mainly sexual abuse;
- 80% felt that being attributed the diagnosis led to worsening the attitudes and interventions of professionals towards them, while 20% felt these have improved after being given the diagnosis;
- 90% could identify some strengths in themselves; some could not;
- All wanted to be better heard and their traumas worked with;
- Family support was perceived by half of the group as very helpful, and as harmful by the other half;
- Police and CMHTs (community mental health teams) interventions were rated as the least helpful;
- GPs and psychotherapy were rated as the most helpful interventions;
- With the exception of one person, no difficulties were experienced in interviewing by the user researchers or the interviewees.

Dissemination phase

- Involvement of the user researchers in the dissemination was essential to this project;
- Users researchers have participated in most of the dissemination opportuni-

- ties (more than 10 by now!), including two to the professionals in the teams working with them;
- Responses to the presentations moved from great enthusiasm to utter silence;
- Four (short) articles were written with the users researchers, two (a dissertation, and a long article for publication in an academic journal) without them;
- A national newsletter about PD has been established by the group;
- Two of the users participated in a university research module, one of them has gone back to college since.

I hope that this example has highlighted that such projects are both possible and desirable, even if they come with their own set of difficulties.

Failures

Because UI is "politically correct", morally right and recently developed, we tend not to look at failures in this field. We are pleased with every small project, and rightly so. Yet without taking stock of both success and failure we are not going to progress further.

Thus far, the main failures have been:

- UI is not taking place every where, and is not part of everyday practice;
- UI has not impacted on everyday practice with individual service users;
- UI can be tokenistic at times;
- Users active in UI initiatives are not being paid adequately;
- Users do not seem to have an alternative vision of services against which the current system would be judged;
- The media, and the general public, are blissfully unaware of UI and it has not led to any change in lay perceptions of mental ill health and of people suffering from it.

Again, most of these failures can be explained away by the short time since the introduction of UI, assuming that for such a radical shift to take roots time is necessary. This may be the case in part, but does not tell the full story. Users are perceived by a number of professionals as cheap labour who should be grateful for being asked to participate and do the work. The fact that most of them live on benefits, that even



those who do not live on benefits are free lancers and have only part-time work, is conveniently forgotten. The limitations imposed by the benefits system is another impediment.

Tokenism is hardly surprising if professionals are not convinced of the necessity for UI (26). Such necessity should be part of training for professional practice in any of the helping profession, as there is plenty of evidence that lack of motivation by the client is a major stumbling block to any successful intervention at the individual level. The lack of alternative vision by users reflects in part the heterogeneity of the users group. In part it is derived from the preference for a pragmatic perspective, a focus on the achievable, and the fear of clashing with the more powerful stakeholders, such as managers, professionals and politicians (26).

Yet the lack of vision perpetuates the existence of the aspects users do not like in the current system, and makes it easier for users to be co-opted into that system. For example, relatively few users are against the use of medication, but most of them have difficulties in taking medication for life, with the toll of the side-effects, with lack of good enough explanations and looking for alternative medication with fewer side effects, and with the continuing paucity of use of other interventions once medication has been prescribed. Yet we have not seen sustained work by user groups any where in Europe on this central issue in terms of what they would like to see instead, and how we can get there.

Likewise, no sustained attempts seem to have been made by those professionals keen on UI to work with users on these issues. This aspect relates also to the separatist agenda which is perceived to be the more politically correct approach to go about UI. Based on the lessons from the women's movement and Black people, it is assumed that an oppressed group has to work on its own to gain a liberated identity and to fight its own battles. It seems to me that this is only partially true. Yes, users have to find their own voice and identity and others can only help in facilitating this process.

But the future of European mental health systems affects not only users; it affects all

of us in different ways, and it affects carers and professionals more than most other groups.

Furthermore, as professionals and carers too do not have only one position on most issues of mental distress and health, these groups too have to work out a shared vision. Each group could contribute therefore to the process of arriving at such a vision without having to reinvent the wheel, and share in owning it.

As long as UI is not an inherent feature of the service culture, it is unlikely to make any inroads to lay culture, even if reaching the latter requires the use of different means. The current growing interest in the mental ill health at the workplace could facilitate a greater interest by the lay public in UI.

Challenges

The first, and main, challenge relates to the failure outlined above, namely the fact that UI has not become part of everyday life of service users and everyday professional practice, a benchmark against which we judge a service and a system.

If this will not happen UI will remain the "icing on the cake".

Yet for this cultural change to happen a fundamental shift in the views of professionals of the people they are working for and with, and about their own role and competencies, has to take place.

To get this fundamental shift a re-appraisal of the following is needed:

- the strengths of users as against the current dominance of their problems and weaknesses;
- the limits of professional understanding and of current knowledge;
- the value added by the insight users have about their experiences and the usefulness of different interventions;
- the value added by the insight carers have;
- the necessity for shared work by the different stakeholders in this field.

Conclusions

In conclusion, we are living in an era of considerable changes and innovation in mental health systems. Not all of these

changes turn into innovations which benefit service users, carers, or frontline workers.

Also, innovations once in place require constant attention, or else the system will easily revert to it's the less demanding past, as attitudes take even more time to change than structures and ways of work. It is up to those of us who work in these systems to ensure that innovations are put in place,

and kept there. This most demanding task requires partnerships between professionals, managers, users, carers, and the general public.



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