

User/consumer involvement in mental health service delivery

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SUMMARY. The involvement of mental health service users in service delivery is a new and growing phenomenon. Such involvement is complex, given the history of paternalism in the mental health system, the power differential between service providers and service users, and the very differing views each group holds on multiple issues. Unless such differences are addressed, there can be no meaningful involvement. Service user involvement needs to apply to all aspects of the service delivery system, including professional training, service design, delivery, evaluation, and research. User/survivors, and their organizations, have developed a body of experience and knowledge that needs to be recognized and respected. Unless there are multiple opportunities for ongoing and open dialogue on these many difficult issues, real user involvement will not occur.

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The phrase “involving users and consumers in mental health service delivery” has become widely used in recent years, as the mental health system moves toward a more participatory model. Traditionally, people who were diagnosed with severe mental illness (schizophrenia, bi-polar disorder, or major depression), were considered, by the nature of their illness, unable to appreciate their need for treatment or to make the “correct” decisions about how to conduct their lives. The mental health system, therefore, took a paternalistic stance and controlled the lives of diagnosed people, usually by isolating them in large mental institutions for many years. In this model, the only “involvement” of service system users was as passive recipients of decisions made by others.

Even in this very controlling model, patients¹ tried to assert themselves, although their attempts were usually unsuccessful. Peterson (1982) gathered a series of first-person published accounts going back to 1436 in which people labeled as mad described their experiences and their attempts to make sense of them. These were usually self-published books and pamphlets that fell into obscurity, and a theme that runs through many of them is the

loss of freedom and the suffering inflicted by incarceration in madhouses.

The demise of large institutions in the later half of the twentieth century has resulted largely in the paternalism of the older system being replicated in what are called community programs. The people who live in halfway houses and community residences may have more say in the details of their lives in comparison to the patients in large institutions, but they are still widely viewed as incapable of making the major decisions about their lives.

The development and growth of the user/consumer movement paralleled the transition from institutional to community based care. In the 1970's and 1980's, user organizations began to develop in North America and Western Europe, and by the early years of this century, such organizations were found in many countries of the less-developed world as well². The basic premise of these organizations was that mental illness was a social and political construct and that people needed basic legal and human rights protections (Chamberlin, 1978). As these organizations developed, they called for active participation by people who received services in the decisions that affected their lives.

Numerous forces have led to the current situation in which both users and professionals talk about the need for user involvement, although the term often means very different things to different participants. While users are usually very aware of the power differentials that exist between them and professionals, the whole question of

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power relationships is one that is seldom frankly addressed by professionals. Yet, an understanding of these power differentials is essential if user involvement is to become real and meaningful.

People diagnosed with serious mental illness are defined by psychiatrists to lack insight and to be unable to make decisions by reason of their illness (American Psychiatric Association (1994). Users, on the other hand, contend that it is precisely their attempts to assert themselves and their rights that are often dismissed as “symptoms” or “products of their illness.” Given such basic divergence in worldview, it is not surprising that the concept of “user involvement” is seen very differently. It is important to acknowledge that users see “involvement” as nothing less than full and complete decision making power over such fundamental questions as whether to be engaged in mental health treatment, the type(s) of treatment desired, the duration of treatment, where to live, whom to associate with, whether to go to school or to work, choices about intimate relationships, marriage, and parenting—in short, the basic life decisions that other citizens take for granted.

When compared with many professional views of “involvement,” such as “allowing” patients to sit in on treatment meetings or to decide which of a limited range of day activities to participate in, it is clear that much discussion and negotiation are necessary to even define what “involvement” means or who gets to participate. Underlying these discussions is the necessity to recognize and deal openly with the power differentials that exist between mental health service system users and mental health professionals.

Because of the inherent power differential between psychiatrists and people who have been diagnosed with serious mental illness, it is not at all surprising that users continue to have a very difficult time in getting their voices heard at all, let alone in making real and substantial changes in the conditions of their lives. This power differential has a long and painful history. Involuntary commitment is rarely acknowledged by professionals to be the underlying basis of the operation of mental health services³, yet it forms the backdrop to any discussions of user involvement or any of the other potentially transfor-

mative practices (e.g., user operated services, users as researchers, etc.) currently buffeting the mental health world. So long as users can be subjected to involuntary interventions in supposedly voluntary services, the power differential is a real and overwhelming obstacle to any kind of real equality in decision-making.

Involuntary commitment laws vary from country to country, but, in general, they provide for the detention and treatment of a person in a mental hospital if the person is diagnosed as mentally ill and meets several other criteria. In some jurisdictions, a finding that the person is dangerous to self or others is required, while in others it is only necessary to show that the individual is deteriorating and is likely to benefit from treatment. The looseness and elasticity of these definitions should be immediately obvious. Who, for example, gets to define “mental illness,” “dangerousness,” “treatment,” or “benefit,” for example? It should be clear that in the current climate, it is the psychiatric view which prevails.

Therefore, the question of promoting genuine involvement on the part of users must be viewed in this historical and political context. Merely calling for more involvement, without any recognition of these facts, will not change very much. Only if there are genuine efforts to address power differentials and to recognize the very different contexts in which users and professionals view the operations of the psychiatric system does any real effort toward meaningful user involvement become possible.

User involvement must proceed from ongoing dialogue between the mental health service delivery system, on the one hand, and the organized user/survivor movement, on the other. The user movement in many countries has a long track record of organizing service users, developing position papers, providing self-help services, advocating for legislative change, and numerous other activities representing its constituency⁴. The main concerns of user/survivor organizations include limitations on involuntary commitment (and its eventual elimination), improvement of institutional conditions, the development and support of user-controlled alternative services, combating discrimination, and the promotion of services and supports that promote recovery.

¹ Even the terminology used to refer to people diagnosed with mental illness is problematic. In the era of large institutions, referring to people as “patients” made a certain amount of sense (although the term “inmate” is probably at least as accurate). In the era of deinstitutionalization, on the other hand, although they have largely left the role of “patient,” people with mental health problems are still widely referred to by this term. Organizations comprised of recipients and ex-recipients of mental health services usually prefer the terms “user,” “consumer,” or “survivor.”

² The 2004 conference of the *World Network of Users and Survivors of Psychiatry* included representatives of fifty countries, including ten in Africa, two in Latin America, and three in Asia.

³ See, for example, Edward Shorter, *A History of Psychiatry*, John Wiley & Sons, Inc., 1997, in which the term “involuntary commitment” does not even appear in the index. This omission appears to be typical in mainstream writing about psychiatry.

⁴ See, for example: www.enusp.org and www.whusp.org

Among the major differences between the psychiatric system, on the one hand, and the user/survivor movement, on the other, are divergent views on the definition of what is called mental illness. In general, psychiatry promotes a "medical model" view of mental illness as a brain disease with a genetic or biochemical origin, although it admits that there is as yet no proof for this theory. It must be noted that, despite the widespread acceptance of "mental illness" as "brain disease," *there is no physical test which can distinguish people diagnosed with major mental illnesses from others without such diagnoses.*

While some users and survivors accept a medical model viewpoint, the user/survivor movement recognizes that there are many possible explanations for non-ordinary behavior, which can be collectively defined as a "social model" of mental illness. Among these possible explanatory frameworks are poverty, social status (such as race and gender), and social isolation and lack of support. In fact, the largest cross-cultural studies of schizophrenia, conducted by the World Health Organization, found that outcomes were better in the less developed countries than in the industrialized west, which would certainly not be true if the medical model were correct (World Health Organization, 1979).

However, medical model interventions, such as pharmacology, electro-convulsive therapy, and psychosurgery, are the main treatments used in psychiatry worldwide. The promotion of psychosocial interventions, such as supported housing, supported work, supported education, and the like, are still less common and less available in most of the world. User-run services, such as peer support programs and drop-in centers, are even less available. Once again, it is clear that the power differential is at work, since non-medical interventions are usually poorly funded and seen as less necessary than purely psychiatric services.

Given the reality that mental health professionals and users/survivors have unequal power and very differing views, how, then, can the goal of meaningful user involvement be realized? By meaningful involvement, it is meant that users, through their organizations, will take on meaningful roles in at least the following activities:

- Training of mental health professionals
- Design and operation of mental health service programs
- Evaluation of services
- Mental health research
- Provision of and funding for alternative user-run programs

TRAINING OF MENTAL HEALTH PROFESSIONALS

Students of psychiatry, psychology, social work, nursing, and other mental health disciplines need to have ongoing opportunities to learn from user/survivors, particularly since their textbooks and other course material largely promote a medical model view of mental illness. Students, ideally, should be mentored by users/survivors who have recovered and who can provide real-life experiences which will help future professionals to have a more hopeful view of the capabilities of people diagnosed with mental illness.

Users/survivors who serve as mentors for student-professionals should be viewed as part of the educational team and should receive appropriate payment for their work.

Having a single lecture by a user/survivor is not an adequate substitute for the kind of relationships being proposed. Student-professionals need the opportunity to meet regularly with a user/survivor mentor, to discuss course material and the experiences they are having in clinical practice situations, so as to insure that they receive ongoing exposure to user/survivor views.

DESIGN AND OPERATION OF MENTAL HEALTH SERVICE PROGRAMS

Users/survivors need to be involved in all aspects of service delivery. Users/survivors should be employed in meaningful numbers and in meaningful roles when services are being planned, and the expressed needs of users/survivors must be taken into account in deciding how resources should be expended, so that the services provided most closely meet these needs. Users/survivors should be included in meaningful numbers in governing (not advisory) boards. Users/survivors should be included in meaningful numbers in hiring committees.

There are a growing number of academically-qualified mental health professionals in the various disciplines who are *also* users/survivors, and they bring great value to their work by nature of this dual role.

In all of these roles, users/survivors/survivors should be seen as full members of the service delivery team and should receive appropriate payment for their work.

EVALUATION OF SERVICES

Mental health services should be evaluated on an ongoing basis to ensure that they are performing as designed and that they meet the needs of their clients. Users/survivors should be involved in meaningful num-

bers in the design of evaluation tools, to ensure that the questions being asked are those that are most useful to service recipients. User/survivors make ideal interviewers of service recipients, who often feel more comfortable, and will be more forthcoming, with a peer. Users/survivors must also be involved in interpretation and dissemination of service evaluations, and dissemination should be made directly to clients of the service, in language and formats that are accessible to them.

User/consumer involvement in evaluation is a way of ensuring that it leads to real change. If aspects of a service are found to be unsatisfactory or not meeting clients self-defined needs, there needs to be a commitment to making the changes in practice that these evaluation findings point to. Otherwise, evaluation (with or without user/survivor participation) becomes merely a meaningless exercise.

Users/survivors who participate in evaluation activities should be seen as full members of the evaluation team and should receive appropriate payment for their work.

MENTAL HEALTH RESEARCH

Users/survivors can be more than subjects of research; they can be involved in research design, administration, interpretation, and dissemination. The model is one of participatory action research, which has been used in many social science fields. Research is, in essence, the framing of questions and the process of figuring out ways to find the desired information. When users/survivors are involved, the questions asked can become more meaningful and useful to the people who use services. The practice of participatory action research demystifies research and makes it a part of a developing knowledge base useful to practitioners and service users alike.

There are a growing number of academically-qualified researchers who are *also* users/survivors, and they bring great value to their work by nature of this dual role.

Users/survivors who participate in research should be seen as full members of the research team and should receive appropriate payment for their work.

ALTERNATIVE USER-RUN PROGRAMS

Meaningful user involvement in mental health service delivery must also include the financial and programmatic support by the mental health system of user-run alternative service programs. Because many users are dissatisfied with professionally-run services, user-run services have been developed to fill service gaps, and to provide services based on a peer-support model rather than the

traditional model in which providers are experts and service recipients are in the client role. Users need opportunities to use whatever mix of peer and professionally run services they choose to meet their self-defined needs.

User-run programs, like professionally-run programs, should be subjected to evaluation and performance standards. It is essential, however, that user-run programs not be held to a *higher* standard than other programs, as may happen should an unforeseen event occur. No one would suggest to close a professionally-run program if, for example, a suicide should occur; if the same thing were to happen in a user-run program, it most likely would be shut down. This is still another example of the power differential at work.

Peers who work in user-run alternatives should be seen as professionals doing meaningful work, and should receive appropriate payment for their work.

In this overview of the various modalities of user/survivor involvement, it should be clear that there are many potential pitfalls and difficulties. There needs to be genuine commitment at all levels to addressing these problems and coming up with solutions. In particular, there needs to be recognition that for at least some participants (both users/survivors and professionals) there is a learning curve involved. Users/survivors may be unfamiliar with professional jargon or with the formats of meetings. Professionals, on the other hand, may be uncomfortable with dealing with users on an equal basis. Recognizing that these difficulties exist is the first step toward overcoming them.

Users/survivors may require reasonable accommodation to participate meaningfully in meetings and discussions. Also, the existence of societal discrimination and negative attitudes toward people diagnosed with mental illness cannot be discounted. User/survivors and professionals alike need to openly deal with these difficult issues, among which are "crazy" behavior, differing views on involuntary commitment and treatment, and the problem of provider misconduct. What I will suggest here is not the "solution" to these difficulties, but a framework through which they can be openly confronted and discussed.

A FRAMEWORK FOR DISCUSSING "CRAZY" BEHAVIOR

"Craziness" does not exist in a vacuum. As should be clear from the discussion of power, above, the definition of what is "crazy," and the ability to decide that someone is acting in a "crazy" way are inherent parts of the inequality between service providers and service recipients. What, then, should be done if someone shows up at

a meeting or other activity and appears to be unable to participate meaningfully because of their emotional state?

Protocols need to be in place, in advance, that are the subject of joint decision-making, so that in the event that someone is in an emotional state that presents difficulties, there will be a clear idea of how to proceed. One important aspect would be to develop "advance directives"⁵ so that each situation is approached in an individualized way. Should an individual temporarily have to withdraw from the activity because of a period in which he or she is experiencing a high level of distress, it should be made clear that he or she can resume the activity once the distress has been alleviated. In this way, difficult emotional states can be seen as natural life events rather than as medical crises.

A FRAMEWORK FOR DISCUSSING INVOLUNTARY COMMITMENT AND TREATMENT

It is often easier, in the short run, to avoid discussing difficult subjects, but when these subjects are likely to arise at some point, it is much better to discuss them in advance. Since involuntary commitment and treatment is such a highly contentious issue, it is helpful to have the opportunity for both professionals and users/survivors to get to listen to one another's views and attempt to understand why they may look at things so differently.

Neither professionals nor users/survivors have a single, monolithic view. Among the views that may be held by professionals are that involuntary interventions are a method of last resort, or, conversely, that they are a valuable therapeutic tool that should be utilized to keep a person safe and prevent further harm. Users/survivors often believe that involuntary interventions are a violation of their civil and human rights, and that being involuntarily confined is equivalent to imprisonment. Both professionals and user/survivors sometimes view involuntary interventions as a necessary evil and as an indication of system failure. If all participants have the opportunity to discuss their views and to listen to one another, they may find, if not a meeting of the minds, at least a chance to see things from another vantage point. Without this kind of discussion, it is likely that attempts to foster meaningful participation will break down when a situation arises in which involuntary interventions are involved.

There may never be consensus or agreement on such a difficult issue; often the best is to agree to disagree. But the ability to discuss difficult and contentious issues in an atmosphere of mutual respect is essential.

A FRAMEWORK FOR DISCUSSING PROVIDER MISCONDUCT

Provider misconduct is real, yet the existence of the power differential has led to its being frequently ignored or covered up. A complicating factor is that, in addition to behavior that is almost universally viewed as misconduct (e.g., rape or assault), some behaviors that users/survivors view as misconduct (e.g., involuntarily committing an individual or reporting on his/her behavior to family members) are viewed by many professionals as essential and necessary elements of treatment. Once again, the provision of multiple opportunities for frank discussion of this issue is essential. It is also important that there be agreement that in cases where misconduct reaches the level of criminal behavior, it be reported to the authorities and prosecuted (therefore directly confronting the power differential). When there is agreement that professional misconduct has occurred, but it does not rise to the level of criminal behavior, professionals and user/survivors alike should be able to utilize other penalties, such as reporting the behavior to the appropriate licensing authorities.

In summary, major changes are in the process of occurring in the mental health service delivery system, in which there is real opportunity for meaningful user involvement on multiple levels. There are, at the same time, numerous forces attempting to maintain the status quo. The process of change is difficult and will not occur without genuine efforts by all parties to move things forward, to openly confront and address differences, and to strive to reach commonalities so that people who experience emotional distress can have access to a multiplicity of services and supports which meet their needs and which promote their full participation and integration not just in the mental health service delivery system, but within society at large.

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⁵ An advance directive is a document, drawn up in advance, in which a person, at a time he/she is competent, can outline what he/she wants in the future should a situation arise in which he/she may be deemed incompetent.