COMMUNITY SUPPORT SYSTEMS

FOR

PEOPLE WITH SEVERE MENTAL DISABILITIES

A Framework for Definition

John O'Brien

Responsive Systems Associates
1447 Peachtree Street, N. E., Suite 811
Atlanta, Georgia, 30309

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THE PEOPLE

A substantial number of adults experience severe, usually life long disability in social functioning which is labeled as chronic mental illness and results in extended contacts with the mental health service system. These people are impaired in their ability to make and keep mutually satisfying and productive relationships with other people --families, friends, neighbors, employers, and human service workers. Relationships with them are strained by what others experience as extreme dependency and strong, sustained demands for tolerance of odd behavior and idiosyncratic interests and concerns. Their difficulty in maintaining a variety of everyday relationships results in social dysfunction and often in considerable personal suffering. They often experience depressed ability to perform the tasks of everyday living and working and seem to have more difficulty than most of us in acquiring new skills. In particular, people with severe mental disabilities will have difficulty structuring their time around activities which most people in a community would see as worthwhile. They find it extremely hard:

- To maintain regular employment or otherwise fill a role which permits them to be economically self-sufficient and have a reliable source of food, clothing, and shelter;

- To participate in the range of leisure time investments which provide most members of a community with a sense of personal meaning and enjoyment (for instance, church membership, shared hobbies and recreational activities, civic groups, and social action groups); and

- To utilize the services typically provided by helping agencies in a manner that helpers can agree is appropriate.

Their social isolation and marginal economic position results in periodic strain on their ability to adapt to adverse conditions. To compound this, people with severe mental disabilities seem to be characterized by a special vulnerability to stress. As stress increases, so does the likelihood that the person with a severe mental disability will have atypical experiences which are difficult to control and display behavior that is increasingly unacceptable and disturbing to others.

From the point of view of the human service system, people

with severe mental disability are defined by their lack of response to commonly available mental health service processes and by the puzzlement they cause people who want to explain their behavior. A person with a severe mental disability can be reliably identified and labeled --most of them are diagnosed as "schizophrenic." But available diagnoses do not establish a chain of causation for the person's condition nor do they lead clearly to the design of valid interventions. Genetic, biochemical, physiological, psychological, and social levels of explanation each provide useful information. But, taken alone or in combination, available explanations don't adequately explain.

People with severe mental disabilities may be similar in their social functioning and in the generalized social response to their disability, but they are a far from ahomogeneous group in their interests and abilities. In fact, people with severe mental disabilities appear to respond less to community norms than the rest of us. And each person seems to choose his own pattern of non-response resulting in highly individualized patterns of attention, motivation, and concern.

People with severe mental disabilities experience significant problems in living. The level and power of social support with which they are able to maintain contact over time is a critical determinant of the quality of their lives.

THE PROBLEMS

One social consequence of severe mental disability is a heightened risk of devaluation and avoidance by more typical community members.

- Their odd behaviors and unusual preoccupations are disturbing to others. In many of us they create the sense that they are "not right" and we should keep our distance. Coupled with the fact that some people who are also seen as "mentally ill" commit inexplicable acts of violence, this often results in rejection of the person as unpredictable and dangerous.

- The fact that most people with severe mental disabilities do not work can lead to a perception of the person as trivial, worthless, or a burden of community charity.

- In recent history, people with severe mental disability have been managed in mental hospitals under medical

leadership. This contributes to a social perception of them as having a sickness which exempts them from expectations of typical role performance, demands hospital treatment until cured, and, for some of us, raises the threat of contagion.

- People with severe mental disabilities are, as a group, responsive to medical stabilization of periodic crisis situations. However, hospitalization beyond a brief period of time does not seem to improve social functioning and often leads to an actual decline in competence. They are usually uninterested in verbal therapies regardless of setting and often don't comply with a prescribed regimen of activity and medications. Unresponsiveness to traditional mental health interventions can lead others to conclude that the person with a severe mental disability is suffering from a chronic, incurable disease. Many of us --including many people with severe mental disabilities-- are confounded by this failure and confused about whether and when a person should be held responsible for lack of enduring change.

- People with severe mental disabilities have difficulty establishing good relationships with mental heath workers. Their idiosyncratic preferences for the type, timing, and extent of influence they want another person to exercise over them leaves many helpers frustrated and confused. The helper who expects early, steady, significant progress toward wellness and independence will be doubly frustrated. The helper who expects such progress in response to traditional mental health processes will have no refuge but to judge them unmotivated, unsuited, and undeserving of service; avoid any personal engagement with them by declaring them some other agency's responsibility, and sanction their long term segregation in mental hospitals.

Traditional human service patterns have failed people with severe mental disabilities by embodying one or another of these common devaluing social perceptions and providing either too little social support or too much social control and segregation. These failures have become more clear and more perplexing with an increasing concern for the civil rights of people with severe mental disabilities and a declining social consensus on the desirability of isolating people on the basis of differences.

- Traditional mental institutions provided some severely mentally disabled residents with sufficient structure to establish their ability to work and to relate. However, these settings have been extremely difficult to manage in a humane, cost-effective way over long periods of time. The best of them seem to have been gripped by cycles of reform and

deterioration into human abuse. And even in the best of times many people with severe mental disabilities were likely to experience a lower quality of service than other residents who were seen as more able or more responsive to help. In any event, such settings almost certainly provide people with more shelter, control, and segregation from community life than they need all the time.

- Most community placement schemes have achieved physical movement out of hospitals but have seldom provided adequate social, fiscal, or programmatic support to allow people with severe mental disabilities to support more than a very isolated and marginal community role. Many people have found their way only as far as a single room occupancy, an isolated "foster care" placement, or a boarding house with few characteristics to distinguish it from the hospital.

- The shape of program and support available has been determined less by a sense of the needs and capabilities of people with severe mental disabilities than by the interaction of one or more of the common socially devaluing perceptions with a funding pattern. For example, as people with severe mental disabilities became eligible for federal funding in nursing homes, large numbers of people were defined as needing such service. In this context, "movement" reflects a shift in sources of revenue and not necessarily concern for a fuller measure of citizenship.

- Severe mental disability is not "curable", but people with severe mental disabilities can develop their skills and many of them can work productively at least part of the time. Rehabilitation services --such as sheltered workshops, support for employment, and independent living programs-- could make an important contribution to improving people's quality of life. But many rehabilitation agencies judge their success in terms of movement to "independence" within reasonably short time limits. Such agencies frequently select out people who will not realistically be ready to "graduate" soon. Services based on the expectation of rapid transition deny the reality of many people's disability and thus exclude them from realistic opportunities for skill development.

- Many community mental health services define their responsibility for people with severe mental disabilities narrowly. Mental health services which define themselves as primarily concerned with "treatment" in the form of verbal therapies and medications for cooperative people relegate people with severe mental disabilities to unspecified or unwilling community agencies or to institutionalization.

A FRAMEWORK FOR SOLUTION

There are a number of well established interventions which support an improved quality of life for people with severe mental disabilities and decrease the social and fiscal costs of their disabilities. Many of these interventions have been small scale, time limitied experimental and demonstration projects. Seldom have there been opportunities to test the synergy among a variety of these approaches in the same area. So the extent to which it is possible to create a genuine alternative to institutionalization which is based on the best available practice on a large scale over time is unknown.

What is needed is a pattern of human service responsibility based on principles consistent with the state of the art. The notion of a community support system defines such a pattern:

> A community support system is a network of responsible people and coordinated resources within a defined area. This network is committed to assisting people who are vulnerable to personal suffering, social dysfunction, and community exclusion because of severe mental disability. The network measures its success by its increasing ability to improve their capacity to meet their needs for a reasonable quality of life and participate as much as possible as valued members of natural communities.

Such a community support system should insure each person with a severe mental disability access to:

Direct Service Activities

- Someone who is responsible to be concerned with his personal welfare throughout the time he chooses to live in the area regardless of whether or not he uses other services. This person fills the role of adviser, assistant, and broker between the person and the community's organized service and social control agencies as well as between the person and the community's naturally occuring social systems. She sets the high expectations for a reasonable quality of life and community participation which are essential, helps the person establish and maintain some role in the world of work, helps him gain entry into a supporting social system, uses personal influence to get as much cooperation as possible in taking appropriately prescribed drugs and treatments, and is

readily available in times of stress.

- The active opportunity for work to support the person's self image and reputation with others, to maintain and increase competence, to reduce the amount of time the person must structure for himself, and to provide at least some money for self-support.

- Arrangement of choices for investment of leisure time in educational, civic, religious, and recreational activities which will provide a diversity of potential social contacts and opportunities for meaningful activity.

- Housing of good quality which provides the potential for community contacts, privacy, and a setting for a reasonable standard of living.

- An opportunity to develop functional life skills in a structured and well organized program.

- The full range of entitlements to assistance with income support, housing, general health care, etc. which are his by virtue of citizenship, residency, and disability.

- Proper use of psychotropic drugs. While drugs do not, at this stage of development, cure severe mental disabilities they can help a person control many experiences and behaviors which cause him personal suffering and which stigmatize him in his community. Proper drug use includes effort to teach people as much control over their own drug regimen as feasible.

- Reliable, immediately available crisis assistance, oriented to maintaining and improving social linkages. Crisis services should, as much as possible, be delivered in the settings and interpersonal circumstances where problems occur and use sheltered environments -- such as hospital places -- only when less restrictive environments cannot be arranged.

- Provision of opportunities for necessary practical and emotional support to those who live and work with the person with a severe mental disability.

Enabling Activities
(To guarantee availability of adequate support.)

- Means to identify those people within an area who need organized support to maintain community membership because of severe mental disability. This should include people currently institutionalized in state hospitals and nursing

homes who come from the area.

- Ways to form an initial relationship within which a person with a severe mental disability and other people who are concerned with him can decide the pattern of support he needs and the terms on which he will accept it. In the event that a person's choices appear to conflict with legitimately established social control functions of the mental health service system, the community support system must observe due process to protect the person's civil rights. If a person appears legally incompetent to make decisions, guardianship proceedings should be initiated.

- Specification of the resources which will enable the delivery of the required pattern of support -- including organized service programs, entitlements, and volunteer resources-- and the agreements and follow up arrangements which will coordinate support.

RESPONSIBILITY

The public mental health system is the most reasonable focus of responsibility for developing and guaranteeing the community support system for people with severe mental disabilities. However, this responsibility cannot be discharged effectively by providing a total system of services that duplicates services which are more generically available in an area.

Most communities have dealt with people with severe mental disabilities by isolating them in large and small institutions or abandoning them to marginal social roles in urban areas. Most organized community services --including even community mental health agencies-- have mirrored this pattern of abandonment. Thus the mental health system in an area must develop a long term strategy to reverse these patterns of exclusion and organize a network of community support. In the meantime, the mental health system needs the flexibility to provide essential supports --such as housing or access to work-- in ways which meet the dual objectives of providing adequate support and increasing the responsiveness of other community resources.

In building a network of community support, the mental health system will confront two major internal issues:

- The tradition of dual public mental health systems, one

system based in state hospital services to the more severely impaired and the other based on community services to people who are less impaired. This dual system needs to be unified within an area and moved toward a unified system.

- The fact that without very substantial (and very unlikely) increases in funding, service and spending priorities in communities must shift systematically in favor of providing community based services to the most severely disabled and away from services to people with less disabling conditions and services provided in total institutions.

POTENTIAL PROBLEMS & NECESSARY SAFEGUARDS

+ Prof-Fam. Conflict

A community support system for people with severe mental disabilities will be difficult to convene and maintain.

The collaboration across agencies and jurisdictions implied by the definition of a community support system is far easier to think about than it is to achieve. Agencies vary widely in how they define human problems, their sense of who can be helped and how, and their priorities for allocating service. People with severe mental disabilities are likely to fall just outside the definitional boundaries of most human services.

People with severe mental disabilities are seldom seen by their helpers as people who are rewarding to work with. There is little professional status in working directly with them and in providing the kinds of services that structure meaningful social roles. People who arrange for decent housing or provide necessary work supervision or teach functional daily living skills are not as highly regarded among human service workers as people who provide verbal therapies.

The people who make up a community support network are not immune to the devaluing perceptions of people with severe mental disability common to the rest of us. They are the inheritors of buildings, traditions, language, and symbols which support isolation and segregation.

The essential challenge to the people who make up a community support system defines its mission:

The mission of a community support system is to provide people who have major difficulty in making and keeping productive relationships and who are consequently at

risk of being excluded from the life and services of a typical community with a source of reliable personal contact and a coordinated program of services to support as many positive relationships as possible.

Committed leadership, careful management control against clearly stated principles, and carefully considered strategies for self-renewal are critical to maintaining focus on this mission and preventing services from drifting toward service forms which traditionally enjoy higher levels of professional involvement and thus away from contact with people with severe mental disabilities.

At the minimum, the leaders of a community support system need to initiate two types of safeguards. First they must clearly state the network's basic principles and clarify its commitment to them by monitoring and modifying actual practice. Second, they must design, operate, and manage in terms of an information system which will track the pattern of service it provides in terms of the changing needs of people with severe mental disabilities.

PRINCIPLES

The community support system should design, manage, and monitor its activities in terms of these principles.

- The aim of the network should be to increase the level of participation of people with severe mental disabilities in as many spheres of community life as possible. As used here, "as much as possible means that effort on the part of the community support network is not limited by negative expectations but only by the personal choice of a legally competent consumer and by the knowledge limits of the field as a whole, given effort to discover and utilize available knowledge.

- Support should be accessible to those people in an area who have severe mental disabilities and who need it to maintain community membership. This implies:

  - Support will be actively offered in the natural settings and situations where those served live and spend their time.

●● To a far greater degree than has been typical in human services, basic relationship to the community support system accommodates the personal relationship and service preferences of the people it supports.

●● Support will be offered in ways that provide as much as possible for continuity of personal relationships between representatives of the community support system and each person supported.

● Support should be sufficient to offer people with severe mental disabilities a range of options in the programs which structure and support enduring social roles in three major spheres of community life: daytime, particularly full time and part time work opportunities; evening and leisure time opportunities; and housing.

● Services should be provided as economically as possible in as socially integrative a setting as possible. This implies:

●● Each person should be assisted to fully utilize the entitlements of citizenship and residency.

●● No more service should be offered than is sufficient to maintain community membership.

●● Service programs, especially those that structure people's community roles [occupation and housing arrangements], should make as much use as possible of opportunities and organized services utilized by typical community members, with extra help as needed to support participation.

●● When a person is unable to find the support needed from typical community resources, the community support system should:

- Utilize or organize mutual self-help efforts.

- Provide an individualized brokerage and skill training program when there is a reasonable possibility that the barriers to serving a person in a more typical setting can be overcome by influencing the person and the environment he seeks to enter;

- Collaborate with an existing community setting when extra help or resources in that setting will permit people with severe mental disabilities to participate;

- Provide a program of service when the above strategies are carefully considered and found impractical.

- Service structures, methods, and settings should be consciously designed to be familiar to and valued by a significant number of typical community members and should provide settings, activities, routines, and rhythms of the day, week, and year which are appropriate to the age of the person served.

- Service structures, methods, and settings should consciously avoid stigmatizing people by association with locations, practices, and symbols which signal dangerousness, sickness, triviality, pity, or charity.

- Services should assume no more control of a person's life than is necessary consistent with due process protections available to each citizen.

- There should be a functional grievance management process including openness to outside monitoring by citizen groups and access to legal counsel.

- When necessary, people should be provided with guardians.

- It should be unusual for a person to spend more than brief periods of time in a setting which structures and controls all 24 hours of his day. Generally, when a person is in structured programs, his daytime occupation should be in a setting which is separate in location and management from the place he lives.

- Services should promote increasing acceptance of people with severe mental disabilities by typical citizens by:

  - Dispersing service settings across an area rather than concentrating them in one or two places.

  - Avoiding congregation of excessively large number of people with severe mental disabilities in any particular geo-political area.

  - Avoiding groupings of people with severe mental disabilities which are larger than groupings of typical citizens in comparable settings.

  - Locating services in buildings and neighborhoods which are consistent with the function they are intended to serve.

●● Providing and supporting a broad range of well timed challenges to involvement of typical citizens in a variety of interactions with people who have severe mental disabilities.