

The social location of need – surveying psychiatric disability in the community

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The majority of studies related to the needs of individuals with psychiatric disabilities focus on their meeting with, and use of, the traditional mental health system. Environmentally relative conceptions of disability have only shown limited success in expanding the views of the field of community psychiatry to include social and organizational contexts. Swedish disability policy emphasizes the individual's ability to participate in community life and may therefore be said to reflect a social approach to disability, in contrast to an exclusively medical perspective that focuses on deficits and the individual's need for psychiatrically defined services. In this study, inventories of need for people with psychiatric disabilities, a legislated responsibility of the social service system in Sweden, were completed for three municipalities. Results indicated that these individuals resist psychiatrically defined categories as they seek supports based on their own experience of need in the community.

Introduction

The 'playing field' for individuals experiencing psychiatric illness and disability has radically changed in recent decades as the focus of treatment and support has moved from institutional to community-based forms. Changes in the physical structures and locations for providing care and support have led to organizational attempts to categorize and define areas of responsibility, which have in turn influenced the manner in which individuals living with these conditions act, experience their disabilities and live their lives in the community (Drake et al. 2003; Hydén 1998; Markström 2003; Sayce 2000). A number of models have emerged during this period attempting to clarify the importance of the social context in which individuals experiencing disabilities become identified as disabled due to the consequences of their impairments (Barnes, Mercer, and Shakespeare 1999). While often applied to other groups experiencing disabilities, the implications of such environmentally interactive models have only received limited attention when surveying the needs of people with psychiatric disabilities (Beresford 2002; Mulvany 2000).

Attempts to describe a 'target group' as disabled due to psychiatric illness, in order to survey their needs for support and services, may be seen as remaining rooted in many of the medical/individual traditions representing the building blocks of the

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institutional care paradigm. As notions of chronicity give way in the literature (Anthony et al. 2002; Harding, Zubin, and Strauss 1987; Topor 2001) to research results which describe a dynamic group of individuals who deteriorate and recover in their functioning as the result of a complex interplay between their illnesses, the societal and organizational structures that attempt to support them, and community resources and attitudes, the question of ‘need’ must be examined within a much broader paradigm than has traditionally been the case.

Aim

Needs for services and supports are most often discussed in the literature with reference to surveys involving individuals already identified as clients of a specialized system for psychiatric care, including medical and community psychiatry. This focus on the individual as a client or target group member is understandable, as methods for measuring and defining need tend to focus on the meeting with the psychiatric care system or the individual’s quality of life as measured by such tools as the CAN (Camberwell Assessment of Need) and the WHO’s Quality of Life Measure (Arvidsson 2004; Jansson, Sonnander, and Wiesel 2005; Mulvany 2000). Such measures may be seen as ‘normative’ in that they take account of the individual’s needs with reference to companionship, work, control over their lives, etc. (Joska and Flisher 2005). While these tools offer many advantages, especially in their potential for making comparative studies possible, they lack a focus on the experience of need as it occurs in ‘interactions between persons and their physical, social and cultural environments’ (Bengtsson-Tops 2005; Fossey and Harvey 2001, 94).

We will argue in this article that surveys of need must include descriptions of the ‘social locations’ of the lives which individuals wrestling with the disabling consequences of a psychiatric illness attempt to create and pursue in the broader community. This broader context of our study includes the local providers and agencies of the Swedish welfare state. The aim of the study presented here is:

- (1) To explore if and to what extent individuals with serious psychiatric disabilities had contact with traditional (psychiatric) as well as non-traditional (social welfare) services in three Swedish municipalities.
- (2) To identify and describe characteristics of those individuals who had contact with the various agencies in the system, including those who were at serious risk for or had begun to recover from a period of psychiatric disability.
- (3) To describe aspects of the social/organizational context within which the identified individuals attempted to express their needs for support.

The Swedish context – on equal terms . . .

Sweden, often described as a model of the modern social welfare state, organizes its municipal social services, which support economic and social security, under the Social Services Act. An ideologically forceful document, it primarily offers a framework legislation which allows every municipality leeway in developing services based on local conditions. Medical care and treatment are regulated by the Health and Medical Services Act and administered at the county level. Grounded in a belief in equal rights for all, Swedish disability policy strives to ‘boost each individual’s prospects of living an independent life and close the gap between disabled and

non-disabled people' (Socialstyrelsen 2006). Like many societies turning away from institutional forms of care for those experiencing mental illness, Sweden began in the 1970s to move towards alternative forms for providing treatment, which would emphasize community-based and open forms of care. The Social Service Act of 1982 directed local governments to take responsibility for the 'psychiatrically handicapped', with specific reference to residential and social needs and an active life in the community (Markström 2003). A lack of clarity as to the actual definition of the target group covered in the legislation, as well as to the manner in which local governments would provide support services (especially shortcomings in terms of employment, rehabilitation, housing, leisure activities) led to the establishment of a Psychiatry Commission in 1989 and a series of reports and recommendations which attempted to steer the development of both medical and community psychiatry (SOU 1992:73).

The Psychiatry Reform, which was introduced in Sweden in 1995 (Regeringens proposition 1993/94:218; see also Markström, Sandlund, and Lindqvist 2004) had as its overall goal to improve the life situation for people with serious mental illnesses and increase the possibilities for this group to participate in community life. The Reform directed that the municipal social service system would develop new forms for providing residential, occupational and rehabilitation services as well as improve inter-organizational cooperation. The county medical authority (specialized psychiatry) would limit itself to treatment.

As prescribed in the Social Services Act in Sweden (5 Kap 8 §), the local social welfare authority must maintain an awareness of living conditions in the municipality for people with psychiatric disabilities. They are obliged to work cooperatively with the county-based medical care system as well as other public authorities (Socialstyrelsen 1999a, 8) and to identify suitable methods with which to survey living conditions based on the Psychiatry Reform's promises of 'fellowship' and participation in community life (Socialstyrelsen 1999b).

Social assistance, according to this law, is needs-tested and based on a 'reasonable standard of living'. In most cases the social welfare authority includes departments for individual and family services, services to the elderly and to the disabled – and social psychiatry units supporting people with psychiatric disabilities. People with psychiatric disabilities additionally interact with a number of other welfare agencies, of which the public employment authority, the social insurance office and the local health care centre (primary care) are the most significant. Given the fact that these welfare agencies have different legislative mandates, different budgets and administrative areas and staff with different educational backgrounds and professional perspectives, problems of inter-organizational cooperation do occur. Varied perspectives related to medical determinations of disability (social insurance) and employability (employment authority) additionally lead to complications for assessing employment-related needs of people experiencing psychiatric disabilities (Lindqvist and Grape 1999). It is within this organizational structure that individuals experiencing psychiatric disabilities come into contact with the helping system.

In a follow-up study by the National Board of Health and Welfare, after the 'Reform's First Thousand Days', it was concluded that supports needed to be more individual and flexible than was often the case (Socialstyrelsen 1998a, 10–14). Community-based services had not 'freed themselves' from the medical model: 'The dominating culture in programmes is often closely allied with medical psychiatry, and rehabilitation programmes work together more often with medical psychiatry than

with other actors working with rehabilitation', according to the findings in an review report (Socialstyrelsen 1998b, 9) Many of the critiques of the Reform may be seen as reflecting a lack of ability to reformulate the concept of need, as individuals experiencing these disabilities were now subject not only to a variety of organizational structures and legislated responsibilities, but to additional actors and forces in the natural (non-psychiatric) community.

Towards a social approach to psychiatric disability

The influence of the medical model on social psychiatry has contributed to persons with psychiatric disabilities not having been offered opportunities for integration in community life. According to Carling (1995, 76) the medical model 'has as its basis a concept of mental illness as a disease rather than a disability... with a focus on incapacity and medical or care-giving supports that should be provided, leading to a primary need for professionally delivered services over the lifespan'.

The medical model also focuses on the impairments (which the person experiences) as 'individual attributes' (deficit model) in contrast to the social model which defines disability with reference to the societal context within which the individual lives (Barnes, Mercer, and Shakespeare 1999). Estroff (1983, 7) contends that 'we have concentrated on individual, psychological problems and processes, leaving social factors as a vague, undefined background or context'. As described in the World Health Organization's International Classification of Functioning, Disability and Health (ICF), the concept of disability is used to describe the 'impairments, activity limitations and participation restrictions' that result from health conditions (WHO 2002). It concretely brings the environment into the descriptive process, emphasizing its ability to either 'facilitate or obstruct' the activities and participation of the individual (Sandlund 2005, 67)

In contrast to a view of psychiatric illness suggested in the medical model, and grounded in diagnosis and prognosis, the social approach sees psychiatric disability as continually constructed and reconstructed depending on a changing reality (Hydén 1995). A social approach to disability contends that disability cannot be abstracted from the social world which produces it, 'it is society which disables people with impairments, and therefore any meaningful solution must be directed at societal change rather than individual adjustment and rehabilitation' (Barnes, Mercer, and Shakespeare 1999, 27; see also Oliver 1992, 101). The application of such an approach to the study of mental disorders calls for an analysis of the complexity of restrictions and social disadvantages faced by people having psychiatric diagnoses (Mulvany 2000, 41).

We will use the term 'social approach to disability' here, in order to be inclusive of what has been described as the social model of disability, which emphasizes the socio-economic structures of society, and the post-modern or cultural model, which emphasizes the 'complexity of disabled people's lives' as they interact with the totality of socio-political arrangements in society (Corker and Shakespeare 2002; Danermark and Gellerstedt 2004). From such an approach, the individual might be seen, despite a continuing illness, as a community member and from the environmentally relative perspective on disability that is the ideological basis of the Reform and Swedish disability policy (Regeringens proposition 1999/2000, 79).

Surveying need – social locations and directions

The majority of studies attempting to assess needs of individuals experiencing mental illness and psychiatric disability proceed from a perspective on need that is restricted to the population currently receiving services, either community care or psychiatric treatment (Arvidsson 2004; Jansson, Sonnander, and Wiesel 2005; Joska and Flisher 2005). While making some mention of the complicated nature of need, it may be argued that the studies miss at least two central perspectives. We know that many individuals in the community who experience serious psychiatric disabilities do not initiate or maintain active contact with the responsible authorities. Others ‘wander’ within the community, accessing services, but based on their own perceptions of need at different points in time (Socialstyrelsen 1999b).

An additional limitation on studies which attempt to assess need within what may be termed a ‘closed system’, where the focus is on psychiatric providers and service provision, is that the reporting authority, and even the individual, will often express need from the limited perspective of the specific services being delivered and for the particular impairment to be addressed (c.f. Hasenfeld 1992). The individual is not seen within the context of his/her life in the system and community. The need to search beyond the boundaries of psychiatrically defined services, increasingly apparent to the service providers in our region, led to the studies that will now be presented.

Data, methods and research design – mapping need in the community

The study, consisting of parallel projects in two local communities, and completed during 2003, builds on the findings from an earlier study. In that study, an inventory/survey of 652 persons with psychiatric disabilities was completed in a medium-sized city (93,000) in northern Sweden (Rosenberg 2001). The following actors participated in the project: social psychiatry within the municipal social services, medical psychiatry, the social insurance authority, the employment authority and primary health care. A survey questionnaire was sent to staff at each of the five agencies and they were requested to complete one questionnaire for each client they had active contact with and who they judged to have a serious psychiatric disability, according to the following definition from the National Board of Health and Welfare (Socialstyrelsen 1999a):

Individuals 18 years and older, residing in the municipality and with severe/difficult psychiatric disturbances/illnesses which have caused a reduction in function with a loss of ability (disability) to such an extent that it influences their daily life (social consequences) and that this disability is considered to be of prolonged duration (has or is expected to persist for at least six months).

The survey questionnaire focused on the staff’s assessment of the psychiatrically disabled person’s situation, needs and satisfaction in areas of life related to health, employment, social network, personal development (education and training), planning and their ability to influence services. While needs and satisfaction are of course best expressed by users themselves, the decision was made to direct the survey to staff since response rates in surveys distributed directly to clients most often result in unacceptably low response rates (Socialstyrelsen 1999a). In addition to these survey forms, focus group interviews were completed with staff from the participating authorities and agencies, user and family associations and individuals (participants in

social psychiatry programmes). These discussions raised questions regarding many individuals and subgroups who met the criteria but demonstrated patterns of service use not predicted in the original design, a result which led to method adaptations in the following study.

Since the two communities in the present study were similar in size and both reliant on regional services related to employment, social insurance and medical psychiatry, it was decided that these surveys would be completed simultaneously. In addition to a planning group which included the heads of municipal social psychiatry and a regional director for medical psychiatry, a reference group consisting of representatives of the participating authorities as well as the user and family associations was formed. These provided a support for the researchers in establishing local contacts and in considering the findings at various stages of the study. In addition to the distribution of survey forms to participating actors, as described above, 12 focus group interviews were completed with personnel from participating authorities and programmes. In addition to 1–2 staff members from each of the employment and social insurance authorities, interviews with psychiatric and municipal social psychiatry programs included multiple staff and even users at day and residential programmes. Additional interviews included representatives for Individual and Family Services, case management and even the Red Cross in a rural town where other services were not present. All received a copy of the survey criteria, which defined the individuals we were seeking and were then asked to discuss their experiences of the needs of this group. Interviews were recorded and analysed by the two researchers employed in the study and both planning and reference group members were given the opportunity to corroborate the accuracy of the findings. While responsible directors were included in the planning and reference groups, personnel who had extensive contact at the direct service level were recruited for the focus groups.

Building on the results of the earlier study, three significant changes related to the discussion in this article were included in this process. In addition to the target group definition used in the earlier study, staff of the various authorities participating in the survey were asked to take account of individuals who met either of two additional conditions and to motivate their thinking on their criteria for including these individuals.

- *Risk group*: persons age 18 and older who *are at risk of* ending up in the target group.
- *Recovery group*: persons aged 18 and older who have met the criteria for the target group, but have partially recovered, i.e. display improved functioning in community life, yet continue to have needs based on their psychiatric functional impairment.

These additional categories, and indeed the language describing them, were based on descriptions of individuals who respondents felt we had missed in the previous study. The aim was to broaden the target group perspective to include individuals whose needs were in a developmental stage and therefore involved with supports not included in the traditional locations for the target group, namely medical psychiatry and municipal social psychiatry. These additional groupings additionally served to ‘locate’ the individual within a relationship to the natural community. Risk group members were those who were still functioning in the community but whose

psychiatric impairments and functional deficits were serious enough to threaten their ability to maintain participation. Recovering individuals were those who had begun to participate more actively in community life, despite a continuing psychiatric need. The use of additional categories may be seen as a limitation of the study, potentially distancing us from a more inclusive perspective as additional labels are created.

Another modification was to send survey forms to additional departments in the social services, locations where we had heard from personnel in the earlier study that they encountered individuals who had avoided an illness-based classification, but met the inclusion criteria. These included the department for Individual and Family Services, offering social work, housing and income supports, and the department for elder and home care services, offering support in the home. Finally, we emphasized in addition to the primary question of need, a discussion of the ‘grey zones’ that had been alluded to in the earlier study in focus group interviews. Why did clients ‘fall between the chairs’ (of various service systems)? Why were they rejected for certain services and why did they choose to leave others?

Results – surveying need in the community

Our intention in the study was to see what we would discover if we moved beyond the traditional ‘target group’ classification, which has limited many surveys, and which sees the ‘individual in care’ as the primary unit. A social approach to disability sees the individual in a dynamic interaction with their environment, and attempts to understand need from such a perspective.

As summarized in Table 1, the total number of individuals reported by the various services was 208 for municipality 1 and 191 for municipality 2. The total population over 18 in municipality 1 is 16,330 indicating that the percentage of residents identified was 1.3%. For municipality 2 with 17,051 residents, the percentage of those over 18 is 1.12%. While assuring anonymity in the final report, the issue of double reporting was addressed by using a number of identifying variables prior to coding the forms, and then creating a priority list of service providers (with the formal mental health system coming first). Although the definition asked respondents to focus on the extent of disability, it is reasonable to assume that there would be a connection between prevalence rates for serious psychiatric illnesses and the incidence of persons experiencing serious psychiatric disabilities. Epidemiological studies in the US, for example, identify between 2 and

Table 1. Numbers of persons with psychiatric disabilities by organization.

Organization	Municipality 1		Municipality 2		Combined	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Social Psychiatry (social services)	104	50.0	18	19.4	122	30.5
Medical Psychiatry	40	19.2	62	32.5	102	25.5
General Social Services (Individual & Family)	36	17.3	34	17.7	70	17.5
Elder & home care services	28	13.5	30	15.8	58	14.5
Primary care – medical	—	—	13	6.8	13	3.5
Employment Authority	—	—	34	17.8	34	8.5
Total	208	100.0	191	100.0	399	100.0

3% of the population as affected by a severe mental illness (Barker et al. 1992; NAMHC 1993). International studies present the incidence of serious mental illness as between 1 and 5% depending on which diagnostic groupings are included and the particular country (WHO 2004).

It is clear from these figures that the number of individuals we identified as suffering from severe psychiatric disabilities was probably low, rather than high. Studies in Sweden that have only focused on those receiving traditional psychiatric services have reported between 0.46% (Socialstyrelsen 1999a) and 0.57% (Jansson, Sonnander, and Wiesel 2004) but both state that these figures were probably low due to missing individuals. It might be safe to say that 0.5–1% might reflect the number of individuals who are active as clients at any given point in time (the figure was 1.7% in NAMHC [1993]), but that based on prevalence statistics of 2–3%, it is likely that a much greater number are living in the community but lack contact with traditional psychiatric services. We can now look at the issue of where these individuals turn for support from a further analysis of Table 1.

As discussed above, many surveys have only focused on the needs of individuals receiving services from one or both of the traditional providers, medical psychiatry or municipal social psychiatry. In this study we see a range from 69.2% in municipality 1 to 51.9% in municipality 2 who are receiving services in these traditional locations. This indicates that from 30.8% to 48.1% are receiving services from an alternative provider. The totals for the two studies indicate that 56% were receiving services from psychiatry and social psychiatry and 44% from an alternative provider. Reference group members clarified that individuals were not reported by primary care in municipality 1 due to workload issues. Employment authority representatives explained the lack of reporting in the same municipality as reflecting a cooperative project focused on rehabilitation, their clients had been reported by other actors. A potentially large number of those receiving social insurance (disability benefits), and without active contact with municipal or medical psychiatric services were missed, since the social insurance authority was unable to participate in the survey.

The specific services used by those individuals we found can provide valuable information about the needs that they themselves experience. The numbers here reflect those clients who had contact only with these authorities, in other words those not reported by psychiatry or social psychiatry as active clients. Social workers in the Individual and Family Services units reported many of their clients as meeting the criteria. The combined result for the two municipalities was 17.5% of the total reported. The majority of these were seeking financial support or a housing allowance, due to financial need. Others likely sought help in their role as parents (10.5% of the total reported), a significant group that few had predicted. Individuals reported only by the employment authority comprised 8.5% of the total population. Since these personnel have extremely large caseloads, and since documentation of disability is not reliable as concerns psychiatric disability, these numbers are almost certainly low. These individuals were of course seeking employment or training opportunities but had most likely been assessed as not being fit for work at this time. (Many of these may also have been seeking unemployment benefits, indicating a prior work history.) At the same time, they were often unwilling to accept a referral to 'psychiatric' programs, not considering them relevant to their desire for employment.

Two other locations worth noting are the primary health care system and elder/home care. The response rate for both was extremely poor since neither sees this disability group as their primary responsibility. While only reporting 3.5% of the total

population, the primary health care centres have a clear responsibility for those in the first stages of a psychiatric illness, and also for psychiatric care to those with long term disabilities now living in the community. Group interviews indicated that they do have substantial contact, but that psychiatric needs may be hidden behind a somatic complaint. These centres are also to act as a filter for problems that might then need to be referred to specialist psychiatry. Those who do not meet the criteria for specialized services get no further with their needs than these 'outposts' for care in the community.

Elder and home care services deliver concrete supports related to maintaining a reasonable standard of living in the community. These services reported 14.5% of the total population identified in the study. From interviews with social service personnel, these individuals were described as isolated, sometimes living outside of city centres and often with elderly parents. While these limited services supported the family or individual to maintain themselves at home, they had no knowledge of or access to rehabilitation or recovery-oriented services. They were often described as a hidden group, and without opportunities to develop their lives, at risk for serious crisis if their support system were to fail.

Life in the 'grey zone'

A total of 44% of the total population identified was found to have contact with what we have described as non-traditional social and health care services. If we proceed from the assumption that there is a reason that they are pursuing support as they do, then the locations where they turn for this support become significant. Smith's conclusion that 'people with mental illness make their own sense of what is happening to them, develop expertise about those activities that are important in their lives, and about their experiences of doing, or trying to do, these activities', seems very much to the point (Smith cited in Fossey and Harvey 2001, 94). From such a standpoint, their expression of needs related to economic, housing and health care and employment supports may be seen both as a rejection of traditional illness-related services, and a reflection of their real needs. By 'choosing with their feet', they may be telling us more about what they are ready and willing to participate in than we can learn when we limit our focus to interactions with traditional psychiatric services. The 'grey zones' became quite clear as we viewed the 'playing field' from these alternative locations. From the group interviews that built on the survey data, we were able to identify a number of these grey zones that were of interest and could lead to recommendations for service development.

- Many younger clients who were in contact with Individual and Family Services (29% of those aged 18–39) in order to receive economic supports, avoided contact with psychiatric services which they perceived as stigmatizing and controlling. Despite poor quality of life and extreme distress, they preferred, according to social workers, to maintain their identities and social networks, however negative they might be, rather than enter into a psychiatrically defined and limiting or 'liminal' (marginalized) world.
- Those who turned directly to the employment authority for support in studying or finding work (34 in municipality 2), often after receiving acute psychiatric care, rejected recommendations that they contact the municipal social psychiatry and participate in day training programs to increase their

work functioning. Unable to function at a level acceptable to the employment authorities, they became more and more isolated in the community and often relapsed into illness.

- Many who did participate in sheltered types of work and learning environments expressed fear of taking a step into regular work or studies in the community. They feared failure, economic sanctions (as their disability status was threatened), and they feared losing the intensive support available to them within municipal social psychiatry.
- Even positive stories regarding individuals who had been extremely disabled, and who were now living independently in the community, thanks to supported housing interventions, reflected the limitations of social psychiatry, as these individuals often had no natural contacts with ‘real’ community members. Their social network consisted exclusively of personnel and other clients.

These ‘grey zones’ were described by respondents as ‘social locations’ where individuals were difficult to reach and support to a more participatory life. The fact that 88% of the individuals in the study had contact with only one of the responsible authorities, despite an emphasis on coordinated services, also increased the likelihood that any one lapsed contact would leave them totally without support. Without a joint responsibility for meeting the needs of the individual, the potential for that person to become lost between two services, or between those services and a marginalized life in the community increases. ‘When I go out through one door, it closes behind me.’ The predominant Swedish figure of speech, that this group ‘falls between the chairs’ seemed misleading based on these results. A more realistic one may be that the chairs have not been placed correctly. Many variables come into play in such an analysis of patterns of service use and avoidance. The reality for the municipalities where these studies were completed is that many individuals with serious psychiatric disabilities, and those at risk of developing such, are not living their lives within the closed system of psychiatric services that would allow us to easily measure their number and service-based needs.

Dynamics of psychiatric disability

Tables 2 and 3 summarize the results related to the three groupings that we asked personnel to refer to in their assessment of the psychiatric disability of the individuals they came in contact with. While there was a good deal of variation in the number of individuals that the two municipalities perceived as belonging to the various groups, there was wide-ranging agreement in their descriptions of the types of individuals and needs that belonged to each grouping. These motivations for their choices are therefore presented (with a representative summary of comments) in the following.

Target group

The target group is characterized by:

- comprehensive needs – in all areas of life – require support to get through the day;
- serious financial difficulty;

- severe illness – diagnosis specified included psychosis, severe depression, social phobias and severe anxiety;
- fear of participation/venturing out in community life; and
- the services they receive confirmed group membership (“She’s been with us for decades”).

Risk group

The risk group is characterized by:

- members would belong to the target group if supports were gone;
- little insight into their illness/have stopped using support services;
- a fragile life in the community – a crisis could lead to a serious deterioration (‘Always living on the edge – finances or social structure could collapse at any time’);
- members are receiving disability benefits and without options for rehabilitation (more and more marginalized and isolated over time);
- members have periodic needs for support; and
- drug/alcohol abuse.

Recovery group

The recovery group is characterized by:

- ‘functions well now and can get through daily life, but still needs support’;
- development of a social network;
- recovery due to continuing support with personnel who they trust;
- members have taken steps in their recovery and can continue (‘Due to meaningful activity has begun to recover, otherwise would have remained in the target group’); and
- a periodic need for support due to recurrent symptoms.

Table 2. Persons with psychiatric disability by sub-group.

		<i>N</i>	%
Municipality 1	Target group	101	49.0
	Risk group	50	24.3
	Recovery group	55	26.7
	Total	206	100.0
Municipality 2	Target group	61	34.3
	Risk group	30	16.9
	Recovery group	87	48.9
	Total	178	100.0
Combined	Target group	162	42.0
	Risk group	80	21.0
	Recovery group	142	37.0
	Total	384	100.0

Table 3. Persons with psychiatric disability by age and sub-group – total sample.

Age group	'Target group'		Risk group		Recovery group		Total	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
18–29	12	(39)	15	(48)	4	(13)	31	(100)
30–39	27	(44)	14	(23)	20	(33)	61	(100)
40–49	26	(37)	20	(28)	25	(35)	71	(100)
50–59	42	(45)	12	(13)	39	(42)	93	(100)
60+	48	(45)	10	(9)	48	(45)	106	(100)
Total	155	(43)	71	(20)	136	(37)	362	(100)

The motivating factors that personnel of various authorities and departments included as they chose a grouping that best described their client may be seen as confirming that at the individual level, there is rather clear agreement as to the dynamics of a psychiatric disability. Both recovery and risk group factors confirm a movement towards or away from a serious and dependency-producing disability. That there is some overlap between the needs of these two groups may be seen as reflecting the fact that despite the varied directions of their disability 'careers', they find themselves in similarly marginalized locations in the community. Target group descriptions confirm an illness-related and comprehensive need, but also point to the fact that those in the target group risk becoming chronic members of that group, since their need for services rather than their potential can become the primary focus. Members of this group also had a greater incidence (63%) of being without any meaningful activity, as compared to the risk group (37%) and the recovery group (44%). Unexpectedly these target group members, despite the severity of their illnesses and needs, were also found in non-traditional locations. Of the individuals reported by the Individual and Family Services, 72% were considered to meet the criteria for the target group in municipality 1 and 47% in municipality 2. Recovery group members were surprisingly found as well with municipal social psychiatry, where 35% in municipality 1 and 29% in municipality 2 were considered to be in a recovery phase despite still receiving services within what might be described as a system designed for the most chronic and needy clients. Focus group participants validated these survey results as they described individuals meeting these conditions in response to our questions regarding need.

Factors related to age were also investigated in these studies and led to a number of tendencies regarding what might be termed 'generational locations' (Priestley 2003), a temporal aspect of their social location. Older clients were described as 'historic' in that there would never be another generation that had experienced the debilitating effects of long-term institutionalization. Younger clients were described as a generation characterized by 'social complications' as they attempted to live their lives in the community despite the disabling effects of various psychiatric illnesses. Middle-aged individuals seemed to reflect the changing nature of the system during the post-deinstitutionalization era, where many seemed to have become trapped in a life limited by the programs offered within social psychiatry, and others struggled with frustrating attempts to develop a participatory life in the community.

While there is some indication that younger individuals dominate the risk group category, a factor confirmed by many comments in the focus groups, the spread of target group and recovery group members is fairly even over middle age. As regards a

permanent disability status, where the individual could receive lifelong benefits, 17% of those aged 30–39, 31% of those aged 40–49, and 49% of those aged 50–59 were receiving these benefits. Such a status meant in practice that the individual would no longer receive active offers of rehabilitation support. (People aged 18–29 and over 65 are not in the same system.) This type of ‘system-determined chronicity’ does not seem to take into account the high percentages of individuals who are in recovery in these age groups or the many described by personnel as still hoping to work or study.

The results related to age group differences can be seen as supporting attempts to understand need in the sense that Priestly (2003, 2) has discussed as a life course approach that offers ‘the opportunity to learn about the differing impact of disabling barriers and the different social meanings attributed to disability in different generational locations’.

Conclusions – towards a social approach to surveying need

Several studies indicate that we plan services from an extremely simplistic picture of psychiatric disability in the community (Deegan 1998; Kramer and Gagne 1997). The notion is that people are sick or healthy, disabled or functional, and therefore members of a target group or not. The idea of a target group that can be defined, identified and then worked with within the confines of the traditional mental health system, may be seen as a ‘relic’ of the medical model in community-based services. In Mulvany’s (2000, 587–588) terms:

While this focus (the interface between medical services and the users of these services) is understandable, given the importance of medical treatment in the lives of people suffering from serious psychiatric disorders, the social location of the individual and their perceptions of the significance of their mental health problems in terms of their wider life experiences is not unfortunately addressed.

Many of the individuals in this study appear to have asserted their status as community members by breaking free of the illness-based categories of service that had been developed for them and that they experience as limiting their life possibilities. Our results describe a collection of individuals with various psychiatric issues, differing relations to the ‘welfare state’, distinctive ambitions and belonging to different generations as well. Both users and staff described disability as dynamic and related to the environment in which they found themselves. Psychiatric impairments were seen as one phenomenon among others operating in what might be termed a ‘social landscape’ of agencies and actors.

If the medical/individual model sees diagnosis and psychiatric treatment as its knowledge base and the hospital or clinic as its organizational environment, then the social approach demands a wider field for analysis, specifically the social environment in which the individual acts. In this study, we begin with the support system comprised of various organizations and professionals that come into contact with individuals experiencing serious psychiatric disabilities. Human service organizations however primarily address the needs of clients that are located within their purview and have difficulty in responding to the holistic needs of the individual (Hasenfeld 1992; Lindqvist and Grape 1999). The lack of a response perceived as relevant to their personal goals, as well as the fragmentation of the system, seems to precipitate the tendency for these individuals to land in ‘grey zones’ within the community. Another ‘mechanism’ which we see as operative (Bhaskar and Danemark 2006), as

we incorporate the ‘open system’ that is the community, is the striving of the individual towards a participatory life. Results pointed to attempts to either avoid or escape a life limited by categorically-defined psychiatric services. Our study demonstrates that there is much to be learned from studying the manner in which these individuals interact with the helping system as they pursue their life goals. Studies which address the broader social environment must be developed however in order to more fully understand the context in which these individuals act. The perspective of the individual must also be further explored, although the Recovery literature has taken a huge step in this direction (Anthony et al. 2002; Topor 2001)

Approached as a ‘community member’ rather than a target group member, individuals experiencing psychiatric disabilities might have the opportunity to express their needs, abilities and wishes from the expectation that they have a right to seek support for a participatory life in the community, regardless of their illness. New paradigms regarding disability direct the discussion to healthier communities, not only healthier individuals, and move the ‘locus of control’ from individuals to society (Fox and Kim 2004). An understanding of the dynamics of a psychiatric disability, as they develop over time, and in relation to various organizational systems and actors, can lead to the planning of more appropriate services.

If we accept that individuals with psychiatric disabilities move within a social landscape in which they express their needs for support as they pursue life goals, the questions become: where and when can the individual best make use of supports and services, and how should these be developed and coordinated so that they match the needs of the individual at various points in their life? Social approaches must necessarily be seen as a complement to, rather than replacement for, a medical/treatment focus. However by locating and describing need within the social contexts and communities in which these individuals live, we can add many layers of perspective to the complex and intertwined issues that they present us with. By analysing the whole playing field, we can quite simply increase our chances of reaching the goal.

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References

- Anthony, W.A., M. Cohen, M. Farkas, and C. Gagne. 2002. *Psychiatric rehabilitation*. Boston, MA: Center for Psychiatric Rehabilitation, Boston University.
- Arvidsson, H. 2004. *After the 1995 Swedish Mental Health Care Reform – a follow-up study of a group of severely mentally ill*. Gothenburg, Sweden: Department of Psychology, Gothenburg University.
- Barker, P R., R.W. Manderscheid, G.E. Hendershot, S. Jack, and C.A. Schoenbon. 1992. *Serious mental illness and disability in the adult household population: United States 1989, Advance Data, 218*. Atlanta, GA: Center for Disease Control, National Center for Health Statistics.
- Barnes, C., G. Mercer, and T. Shakespeare. 1999. *Exploring disability: A sociological introduction*. Oxford, UK: Polity Press.
- Bengtsson-Tops, A. 2005. Behov av vård och stöd. In *Att Leva med Psykiska Funktionshinder – Livssituation och Effektiva Vård- och Stödsatser* [Living with psychiatric disability – life situation and effective care and support; not available in English], ed. D. Brunt and L. Hansson. Lund: Studentlitteratur.

- Beresford, P. 2002. Editorial. Thinking about 'mental health': Towards a social model. *Journal of Mental Health* 11, no. 6: 581–4.
- Bhaskar, R., and B. Danermark. 2006. Metatheory, interdisciplinarity and disability research: A critical realist perspective. *Scandinavian Journal of Disability Research* 8, no. 4: 278–97.
- Carling, P. 1995. *Return to community: Building support systems for people with psychiatric disabilities*. New York, NY: The Guilford Press.
- Corker, M., and T. Shakespeare. 2002. Mapping the terrain. In *Disability/postmodernity: Embodying disability theory*, ed. M. Corker and T. Shakespeare. New York, NY: Continuum.
- Danermark, B., and L.C. Gellerstedt. 2004. Social justice: Redistribution and recognition – a nonreductionist perspective on disability. *Disability and Society* 19, no. 4: 340.
- Deegan, P. 1998. Recovery: The lived experience of rehabilitation. *Psychosocial Rehabilitation Journal* 11, no. 4: 11–9.
- Drake, R.E., A.I. Green, K.T. Meuser, and H.H. Goldman. 2003. The history of community mental health treatment and rehabilitation for persons with severe mental illness. *Community Mental Health Journal* 39, no. 5: 427–40.
- Estroff. 1983. How social is psychosocial rehabilitation? *Psychosocial Rehabilitation Journal* VII, no. 2: 7.
- Fossey, E., and C. Harvey. 2001. A conceptual review of functioning; implications for the development of consumer outcome measures. *Australian and New Zealand Journal of Psychiatry* 35: 91–8.
- Fox, M.H., and K. Kim. 2004. Understanding emerging disabilities, *Disability and Society* 19, no. 4: 324.
- Harding, C.M., J. Zubin, and J.S. Strauss. 1987. Chronicity in schizophrenia: Fact, partial fact, or artifact? *Hospital and Community Psychiatry* 38, no. 5: 477–86.
- Hasenfeld, Y. 1992. The nature of human service organizations. In *Human services as complex organizations*, ed. Y. Hasenfeld, Newbury Park: Sage.
- Hydén, L-C. 1995. *Psykiatri, Samhälle, Patient – Psykisk sjukdom i socialt och kulturellt perspektiv* [Psychiatry, society, patient – psychiatric illness in a social and cultural perspective; not available in English]. Stockholm, Sweden: Natur och Kultur.
- Hydén, L-C. 1998. Den 'nya' psykiatrin – från sjukdom till handikapp [The 'new' psychiatry – from illness to handicap]. In *Nya Kulturer i Psykiatrin* [New cultures in psychiatry; not available in English], ed. S. Sjöström. Lund, Sweden: Studentlitteratur.
- Jansson, L., K. Sonnander, and F. Wiesel. 2005. Need assessed by psychiatric health care and social services in a defined cohort of clients with mental disabilities. *European Archives of Psychiatry and Clinical Neuroscience* 255: 57–64.
- Joska, J., and A.J. Flisher. 2005. The assessment of need for mental health services. *Social Psychiatry and Psychiatric Epidemiology* 40: 529–39.
- Kramer, P.J., and C. Gagne. 1997. Barriers to recovery and empowerment for people with psychiatric disabilities. In *Psychological and social aspects of psychiatric disability*, ed. L. Spaniol, C. Gagne and M. Koehler. Boston, MA: Center for Psychiatric Rehabilitation.
- Lindqvist, R., and Ö. Grape. 1999. Vocational rehabilitation of the socially disadvantaged long-term sick – interorganizational co-operation between welfare agencies. *Scandinavian Journal of Public Health* 1: 5–10.
- Markström, U. 2003. *Den Svenska Psykiatireformen. Bland brukare, eldsjälur och byråkrater* [The Swedish psychiatry reform. Among users, pioneers and bureaucrats; not available in English]. Umeå: Boréa Bokförlag.
- Markström, U., M. Sandlund, and R. Lindqvist. 2004. Who is responsible for supporting 'long-term mentally ill' persons? Reforming mental health practices in Sweden. *Canadian Journal of Community Mental Health* 23, no. 2: 51–63.
- Mulvany, J. 2000. Disability, impairment or illness? The relevance of the social model of disability to the study of mental disorder. In *Rethinking the sociology of mental health*, ed. J. Busfield. Oxford, UK: Blackwell press.
- NAMHC, National Advisory Mental Health Council. 1993. *Health care reform for Americans with severe mental illnesses: Report of the National Advisory Mental Health Council*. Rockville, MD: National Institute of Mental Health.
- Oliver, M. 1992. Changing the social relations of research production? Disability. *Handicap & Society* 7, no. 2: 101–14.

- Priestley, M. 2003. Symposium on disability and the life course. *Disability Studies Quarterly* 23, no. 2: 3.
- Regeringens proposition. 1993/94:218. *Psykiskt Stördas Villkor* [Government proposition: Conditions for the psychiatrically disturbed; not available in English].
- Regeringens proposition. 1999/2000:79. *Från Patient till Medborgare – en Nationell Handlingsplan* [Government proposition: From patient to citizen – a National Action Plan; not available in English].
- Rosenberg, D. 2001. *Att Planera en Framtid utan Gränser. Psykiatrireformens Uppföljning I Sundsvalls Kommun* [Planning a future without limits – a follow-up of the psychiatry reform in Sundsvall; not available in English]. Härnösand: FoU Västernorrland Rapportserie nr 3/01.
- Sandlund, M. 2005. Vad är psykiska funktionshinder? In *Från Psykiskt Sjuk till Psykiskt Funktionshindrad* [From psychiatrically ill to psychiatrically disabled; not available in English], ed. L. Hydén. Lund, Sweden: Studentlitteratur.
- Sayce, L. 2000. *From psychiatric patient to citizen, overcoming discrimination and social exclusion*. New York, NY: Palgrave.
- Socialstyrelsen. 1998a. *Reformens första tusen dagar. Årsrapport från psykiatrireformen* [The first thousand days of the Reform. Annual report from the National Board of Health and Welfare; not available in English]. Stockholm, Sweden: Socialstyrelsen följer upp och utvärderar, 1998:4.
- Socialstyrelsen. 1998b. *Gränsöverskridande rehabilitering. En studie av 111 verksamheter för personer med psykisk störning* [Rehabilitation over borders. A study of 111 programs for people with psychiatric disabilities; not available in English]. Stockholm, Sweden: Psykiatriuppföljningen, 1998:3.
- Socialstyrelsen. 1999a. *Att inventera psykiskt funktionshindrade personers behov* [To inventory the needs of the psychiatrically disabled; not available in English]. Stockholm, Sweden: SoS-Rapport, 1999: 8.
- Socialstyrelsen. 1999b. *Välfärd och Valfrihet? – Slutrapport från utvärderingen av 1995 års psykiatrireform* [Welfare and freedom of choice – Final report from the evaluation of the psychiatry reform in 1995; not available in English]. Stockholm, Sweden: Socialstyrelsen följer upp och utvärderar, 1991:1.
- Socialstyrelsen. 2006. *An introduction to the Swedish system. The National Board of Health and Welfare*. Stockholm, Sweden: Socialstyrelsen, Art. Nr. 2006-114-11.
- SOU. 1992:73. *Valfrihet och Välfärd* [Freedom of choice and welfare; not available in English]. Stockholm, Sweden: Allmänna förlaget.
- Topor, A., 2001. *Managing the contradictions: Recovery from severe mental disorders*. Stockholm, Sweden: Stockholm University Studies in Social Work 18.
- WHO. 2002. *Towards a common language for functioning, disability and health – ICF*. Geneva, Switzerland: World Health Organization.
- WHO. 2004. World Mental Health Survey Consortium. Prevalence, severity and unmet need for treatment of mental disorders in the World Health Organization World Mental Health Surveys. *Journal of the American Medical Association* 291: 2581–90.