

**Psychiatric disability in the community:**

**Surveying the social landscape in the post-  
deinstitutional era**

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## Abstract

This dissertation presents a discussion of life in the community for people experiencing psychiatric disabilities in the post-deinstitutional era, with the goal of developing knowledge that can suggest a focus for planning more relevant services and supports. While evaluations of deinstitutionalization have focused on possibilities for providing community, rather than hospital-based services for these individuals, the intention was to support a participatory life in the community, a life defined by much more than just care and treatment. The Mental Health Care Reform of 1995 in Sweden paved the way for this more community-based view of needs related to psychiatric disabilities, as local social services became responsible for supports to a participatory life, “like all others”. The general aim of this dissertation was to explore and analyze the results of a series of surveys of psychiatric disability, in order to develop knowledge of the social context of the lives which individuals experiencing these disabilities live in the community. More specifically, the aim was to;

- describe contacts/interactions between these individuals and the societal organisations with which they seek services or support.
- describe characteristics and needs of the individuals identified in these studies as expressed by representatives of the helping system and users who participated in the studies.
- develop knowledge of the mechanisms involved in these patterns of seeking support by exploring and analyzing the empirical results within the context of theoretical (social) approaches to understanding psychiatric disability.

The findings of this research are based on an analysis of the quantitative and qualitative results of three studies involving seven municipalities in northern Sweden. Of the 2385 individuals who personnel identified as meeting the criteria for a serious psychiatric disability, approximately half did not have active contact with the formal mental health system. They did however seek services, supports and opportunities that they saw as relevant to their lives and needs as community members. These included health, housing and financial assistance as well as opportunities for education and employment. Various mechanisms operating in the community, including stigmatizing attitudes, exclusionary practices and organizational systems and rules, were seen by respondents as obstacles to these individuals developing meaningful and participatory roles.

Social approaches, when utilized to explore and understand issues regarding psychiatric disability in the community, support a focus on the social landscape

in which individuals experience disability-related needs, as well as the dynamics of the disability experience. While in the deinstitutional era, needs were assessed relative to the individual's relationship to the psychiatric care system, in the post-deinstitutional era, they should be assessed from a participation-relative perspective, where their position as community member, rather than as patient or client, describes the social location of need. Specialized support to general community resources and services in addition to psychiatrically defined supports, would likely reach many, especially younger individuals who might otherwise become seriously disabled.

Key Words; psychiatric disability, social model, community mental health, deinstitutionalization, recovery

## Foreword

I've been working with this project since just a few months after I arrived in Sweden, an experience which has likely contributed to my interest in new geographies and how we struggle to find ourselves in communities. My roles, as FoU researcher and doctoral student, have allowed me to find a place here and opened the door to many wonderful people and meetings. This time has also given me the opportunity to reflect on the extraordinary individuals struggling with these disabilities who I have spent time with during my years working in community mental health, and who I would like to dedicate this work to.

Additionally, I have to start by thanking Birgitta Moen and Ann Lundberg who saw the survey process as a chance to challenge prevailing myths and gave me the freedom to run with their vision. And Annika Bostedt for her continual enthusiasm, and intuitive understanding of the challenge becoming a researcher would pose for my mental health and recovery. Without FoU Västernorrland however, and all the knowledgeable, competent, curious, engaged, confused and supportive characters that make it very special, this would have been not only an impossible journey, but not nearly as fun. And special thanks for the privilege of being fully employed. I especially need to thank Gunhild Nyberg for all her support and guidance, her insights into the social services and her calm as I became overly enthusiastic or overly critical about social psychiatry. And Eva Rönnbäck, in all her various forms; as doctoral student struggling to complete her thesis, while all the time encouraging me to start mine, as a valued colleague and partner in social work and research, as my boss, and as a friend and consultant in my försvenskningsprocess. And Rolf Dalin, my partner in many phases of the project, who has the unique ability to reveal the complicated simplicity of statistics, laugh at the same time, and isn't afraid to correct my English. Special thanks to Eva Forslöf, Marie-Louise Bladh, Eva Westin, Ulla Anderson and all the others in the kommuns who worked together with us to produce the local reports. And thanks to May Andersson and Kommunförbundet Västernorrland who have given me the privilege of being their co-worker. And to Birgitta Edin for lots of help and lots of laughs.

My "community" during these years has in many ways been the social psychiatric community in Sweden. Here, I have to thank Socialpsykiatriskt Forum and the many extraordinary board members I've served with, who always energized me with their intensity and passion and hope. I have to especially thank Olle Östman for his leadership and the many discussions which helped me see the bigger picture. And in what I hope will not be taken as American superficiality, my socialpsykiatriskt foster family, Socialpsykiatriskt Kunskapscentrum, where Maine, Urban, Mikael, Karl-Anton, Egil and Karin have been an indescribable source of inspiration, camaraderie, opportunity and jocularly. Some

other inhabitants of this community who I want to thank for their friendship and support are David Ershammar, whose instincts, knowledge and abilities keep me hopeful that we are on our way somewhere, Marit Grönberg-Eskel who reminds me it's ok to be excited about what I'm doing, Rosemarie Henrikson whose stories remind me why we do this, and Camilla Bogarve and Cheryl Gagne, valued colleagues, inspiring teachers and my "Boston" connection.

Too many years ago to mention, I spent some time at Umeå University, welcomed by Bengt Börjesson and a group of doctoral students, many of whom are now leading the social work department, so in many ways finishing my doctorate here feels like the completion of a very long and winding circle. I'm thankful for all the opportunities I've had at Umeå, but especially now to Rafael Lindqvist and Urban Markström, my advisors. I'm not sure I would have ever really done this without Rafael's support and encouragement. His suggestions, feedback, interest, challenges, as well as his own approach to research have been invaluable. Urban is a "force of nature", whose knowledge and competence is only matched by his interest in and patience with the work I've done during this time. While their direction has been invaluable, the many discussions we've had have been inspiring. The research has been in part supported by FAS DNR 2004-0833 as well.

Finally, I have to thank the Forman family of Umeå (formerly of Brooklyn) who gave me shelter during the many trips to Umeå, and especially Mike who contributed to the quantitative findings. And last but not least my own family, Maria, Ana and Emi, whose love and support should not be measured by the number of pages of my work that they read, but by the fact that they are always there for me when I stop writing. Nothing is more important than them. So, to set expectations at an appropriate level, some words of wisdom...

It is better to know some of the questions than all of the answers. James Thurber

As we acquire more knowledge, things do not become more comprehensible, but more mysterious. Albert Schweitzer

## Chapter one – Dispersal in the community

*“The lives they left behind...Suitcases from a state hospital attic” is the name of a project completed in 2004. When Willard Psychiatric Center closed in 1995, workers discovered hundreds of suitcases in the attic of an abandoned building, many untouched since their owners packed them decades earlier. The suitcases and their contents bear witness to the rich, complex lives their owners lived prior to being committed. From the clothing and personal objects left behind, we can gain some understanding of who these people were before they disappeared behind hospital walls. They speak about aspirations, accomplishments, community connections, but also about loss and isolation. We can picture their jobs and careers, see them driving cars, playing sports, studying, writing, and traveling the world. We can imagine their families and friends. But we can also see their lives coming apart due to unemployment, the death of a loved one, loneliness, poverty, or some other catastrophic event.*

*The people memorialized by the Suitcase Project were basically discarded by society, but each of them has a fascinating and often heartbreaking personal story. Each of their stories provides an opening to consider some of the broader issues that affected these people: poverty, poor health, trauma, displacement, loss of loved ones, voice-bearing and idiosyncratic beliefs, religious guilt and acts of redemption, and the many ways the psychiatric system failed them. And the exhibit raises the question; Is it better today? Do we ask people seeking help for psychiatric disabilities to “leave their lives behind”? (<http://www.suitcaseexhibit.org>)*

The social landscape for providing supports to people experiencing disabilities related to serious mental illness has changed. Attempts to treat a specific group of mentally ill individuals in isolation have given way to an emphasis on community-based services and the vision of a participatory life for those experiencing psychiatric disabilities (Leff 1997; Grunewald 2000; Ralph and Corrigan 2005; Lindqvist 2007). Ever since we began to open the doors of the institutions, where we had assembled the seriously mentally ill, we have struggled with trying to define, find and then treat these “lost souls” in the community. As we have watched them disperse in the “crowd” that is our community today, we have often watched in frustration as those we do find have become homeless, begun to abuse drugs, or returned to our outpatient clinics having experienced nothing but isolation, poverty and continuing illness. While many of the deinstitutionalized, an increasingly historic group, remain in our service systems, new generations have come of age in what may someday be seen as a transitional era. Barnham and Hayward (1995:4) have argued that “...social policies of deinstitutionalization have largely collapsed the structures which in an earlier period appeared to bind the “mentally ill” together as a homogenous group...”.

New organisational structures for providing services in the post-deinstitutional era have been established in the community, and struggle today with engaging and delivering services to individuals who defy these categorizations developed during the institutional era (Bacharach 2002; Leff and Warner 2006).

## **Introduction and problem formulation**

The deinstitutionalization movement, which has dominated the second half of the twentieth century, resulted from a number of causes and had various goals which have been extensively discussed in the literature (Bacharach 1997; Markström 2003; Talbott 2006). The discovery of psychotropic medications, the development of social and psychotherapeutic methods, criticisms of institutionalization, the focus on civil rights, and economic factors are all posited as the impetus for the reform (Markström 2003; Drake et al. 2003). The goals of releasing or relocating patients who had received institutional care over long periods of time to the community and the reduction of beds which would insure that future generations would not become institutionalized in the same manner have, to a large extent, been achieved (Thorncroft 2006; Leff and Warner 2006). The vision forward however, was to develop a network of community-based services which would serve as a platform from which to take steps towards a more integrated and participatory life in the community, and this goal would seem to be more elusive (Sharfstein 2000; Drake et al. 2003; Feldman 2004).

This relocation of the focus of care, from the institution to the community, is most often exemplified in the concept of the Community Mental Health movement, where comprehensive services would be offered to the entire population of a given geographic area or community (Cutler et al. 2003; Drake et al. 2003). Institutions however, provided not only treatment but housing, occupation, social networks and these would also need to be “spatially dispersed” in the community, if the new paradigm was to avoid reproducing the “worst features of the asylums” (Leff and Warner 2006), which included all of these “under one roof”. This focus on the relocation of service structures, carried with it therefore, a vision of integration and participation in community life. In this manner, the connection between the social location of treatment and support and the goal of community living was established to a great extent during the deinstitutionalization era. Put simply, the abolishment of institutional structures and the establishment of community-based care and support would lead to inclusion and participation.

It may be argued that evaluations of deinstitutionalization regularly take their starting point from a position that is relative to the institution. Have we

succeeded in creating a community support system that is as effective in caring for our patients, without the damaging effects of the institution? Questions in effect, are most often related to the success of the mental health system in delivering services to the target group of seriously mentally ill, a group now living in the community, but essentially thought to be the same (Carling 1995; Sharfstein 2000). Many studies have pointed to the fact however, that the changes initiated by the process of deinstitutionalization and the locating of services in the community have also stimulated changes in the way that the population of individuals with serious mental illness experience their lives as psychiatrically disabled. Many individuals, in what may be termed the post-deinstitutionalization era, have never been institutionalized and have only experienced care in the community (Bacharach in Anthony 2002:xvi). Others do not seem to take contact or actively avoid psychiatrically-defined supports.

Many authors have described resistant populations, the young adult chronics described by Pepper already in the 1970's (Pepper et al. 2000) and those "lacking insight" or the "hard to engage" (Carling 1995; Thornicroft 2006). In fact the WHO World Mental Health Survey Consortium (2004) found that up to 50 percent of serious cases in developed countries and up to 85 percent in less developed countries received no treatment in the 12 months before the survey they describe. Thornicroft (2006:88), in a review of a major survey in the US, found that only about a third had contact with the mental health system and concluded that; "It is wrong to think that health services are usually the first port of call when people want help for mental illness". Hatfield (in Carling 1995:14-15) emphasizes that only a "small percentage of people with psychiatric disabilities participate in any formal mental health program....many drop out after their initial experience with services". And Corrigan (2004) argues that many people do not seek help or minimize their contact with services in an attempt to avoid being labelled as mentally ill. The development and success of case management models including ACT (Assertive Community Treatment), which venture out into the community landscape to find these individuals and bring them into treatment, attests to the need for further work in understanding the dynamics and mechanisms of community life for the psychiatrically disabled (Bond et al. 2004; Salyers and Tsemberis 2007).

If we accept the premise that it is important to understand factors which may help to explain why so many remain unknown to the system, then it is a logical step to attempt to understand more about the mechanisms which may help to explain why those we do know come to us and often remain. For these individuals, who we do find in services, the lack of opportunities to participate in rehabilitation oriented services has been of great concern (Carling 1995; Weeghel 2002; Anthony 2002). There is widespread agreement that people with

disabilities resulting from serious mental illness have not achieved the social roles that would point to success in the area of community integration. Impoverished social networks, unemployment and a lack of meaningful activity, poverty, increased mortality and ill health, substance abuse, and poor housing options or homelessness are all factors pointing to the failure of the community vision (Brunt and Hansson 2004; Leff and Warner 2006; Thornicroft 2006). While services in many systems continue to maintain a focus on care rather than participation in the community, there are also social mechanisms operating which create limits for these individuals. The lack of opportunities in societies, who continue to react based on stigmatized attitudes have created what a number of authors have termed social or mental health “ghettos”, where people live in the community, but isolated from the life of the community, and based on a social distance that is difficult to traverse (Ralph and Corrigan 2005; Thornicroft 2006).

There is, as a result of these changes, a lack of knowledge regarding what is estimated to be a large percentage of people experiencing psychiatric disabilities who do not engage with services in the community. There is also a lack of knowledge regarding the mechanisms which hold back many who do engage, and risk what is often referred to as a “transinstitutionalization”, where they may return to “... an unprepared and rejecting society, in a living environment which is just as entrapping as the old fashioned mental hospital (Weeghel 2002:xi; Pilgrim and Rogers 2005:182). These two knowledge gaps may be seen as pointing to specific needs for new research. “Our field does not even have basic information on where and how people with psychiatric disabilities live, work, learn and socialize; we certainly do not have the information about where they want to live and learn and work, and on what they want in their lives” (Wilson 1992 in Carling 1995:15).

### **Problem formulation**

It may be stated that in the second half of the twentieth century, we have been concerned with the relocation of structures of treatment and support, from institutional to community-based contexts. Research questions and service-delivery systems have, despite the new geography, appeared to proceed from a traditional paradigm of the individual as client, receiving services from professionals and within the settings of the formal mental health system. Developments in disability policy, attempts to define and understand disability utilizing social approaches in addition to medical models, and the emerging understanding of recovery, have also led to confusion in attempts to describe and define the target group who are to receive these supports.

A growing awareness of the changing nature of the meeting, or lack of meeting, between the mental health system and individuals experiencing psychiatric disabilities has led to the need for what might be seen as updated information regarding people with psychiatric disabilities living in the community. Given the social dislocation or dispersal stimulated by the move from institutional to community care, questions can be posed as to whether we are capturing a holistic picture of the needs of people with psychiatric disabilities, if we only study those who are already our clients, and only them with regard to the structures or services which we administer (Hasenfield 1992; Bengtsson-Tops 1999; Mulvaney 2000). Rather than comparing community care with institutional care, for a target group of patients or clients, there would seem to be a need to develop new knowledge about the current situation for people experiencing psychiatric disabilities and the desires, obstacles and potential for participatory roles which might inform our vision of a socially inclusive community.

In contrast to the deinstitutionalization movements in many other western countries, the process in Sweden is built on the extremely broad back of the structure of the Swedish social welfare system. Where Community Mental Health in the US for example, was primarily tied to the extension of specialized and hospital-based psychiatry into the community sphere, in Sweden, a primary focus is on the integration of needs related to psychiatric disability into the “normal social services” (available to all) in cooperation with medical psychiatry (Markström 2003; Socialstyrelsen 2006). A more concrete presentation of the welfare system will follow, but the presence of a comprehensive, community-based social welfare system is central to the research questions that will be posed.

This array of authorities in the community, which comprise the system, are charged with helping all citizens, and provide us with an opportunity to see how individuals experiencing psychiatric disability seek and utilize supports. While an oversimplified picture, it is possible to broadly state that whereas individuals who did not have contact with a community mental health center following deinstitutionalization in the US, were lost in the community, in Sweden there exists the possibility of their “popping up on the radar” as they seek primary medical care, employment, housing and income supports, all based on their status as citizens, and not necessarily as mentally ill.

Within this complicated social context or landscape, municipal social services are directed to “maintain an awareness of the living conditions” for people experiencing psychiatric disabilities. These two factors, the availability of a broad network of social services and the municipality’s responsibility to complete surveys in order to describe living conditions in the community, may be seen as providing an opportunity to explore issues of social location in the

post-deinstitutionalization era. This dissertation will build on a series of these studies, completed by the author over a seven year period.

## **Aims of the research**

The general aim of this dissertation is to explore and analyze the results of a series of surveys of psychiatric disability in the community, in order to develop knowledge of the social context of the lives which individuals experiencing these disabilities live in the community, in the post-deinstitutional era.

More specifically, the aim is to;

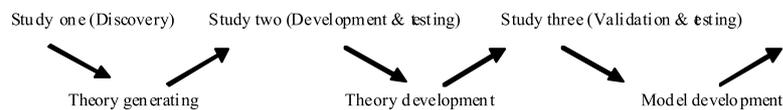
- describe contacts/interactions between these individuals and the societal organisations with which they seek services or support.
- describe characteristics and needs of the individuals identified in these studies as expressed by representatives of the helping system and users who participated in the studies.
- develop knowledge of the mechanisms involved in these patterns of seeking support by exploring and analyzing the empirical results within the context of theoretical (social) approaches to understanding psychiatric disability.

The goal of the research is to contribute to the development of knowledge of the lives of people experiencing psychiatric disabilities in the community, and to suggest a focus for planning relevant services and supports, as well as for further research.

The dissertation is based on three empirical studies, including seven municipalities in northern Sweden, and completed at their request in order to satisfy a legislated responsibility for surveying living conditions in the community for people with psychiatric disabilities. The initial study began during the fall of 2000, was completed in 2001, and involved a municipality in the northern part of Sweden with a population of 93,000. Funds left over from the Mental Health Care Reform (1995) were utilized to finance an inventory of persons with serious psychiatric disabilities and a survey of their needs, which would then serve as a basis for planning and service development. Based on this financing I became employed at that time by the Research and Development Unit for the social services in Västernorrland. As the other municipalities in the county became aware of the initial study, interest grew for completing similar studies. This growing awareness of the need to survey the needs of this group was additionally fuelled by a climate emphasizing evaluation of the implementation of

the 1995 Reform, and an oversight report produced by the County Administrative Boards and the National Board of Health and Welfare which included the finding that 55 percent of Sweden’s municipalities had not completed such a survey in the years following the Reform (Socialstyrelsen and Länstyrelserna 2005).

The studies presented in this dissertation are grounded in what is often seen as a practice-based research model (Karlsson and Drugge 2000; Kirk and Reid 2003) and are also influenced by Action or Participatory Research models (Lundberg and Starrin 2001; Stringer 2007). Questions are drawn in such models from the needs of the practice community, rather than being posed by the academic researcher. From such a structure, questions are often developed with the motivation to directly apply the results in practice, and sometimes without the scientific and theoretical grounding that would be required for the development of new knowledge within a traditional research model. While these three studies, encompassing seven individual reports, may be seen in this light as an investigative assignment, the aim of the dissertation, as described above, is to examine the findings from a theoretical perspective, one that applies theoretical constructs in an attempt to explore the empirical material. What may be somewhat specific to this project, is the fact that the research and investigative projects proceeded simultaneously during the time frame, influencing each other chronologically as illustrated below. Results confirmed theoretical suppositions and in turn created more informed questions, which were in turn integrated into the next study



This interaction between practice-oriented and theory-driven research reflects the structure of my specific doctoral project. My studies were supported by the research and development unit where I was employed, under the condition that these studies would be completed and presented to the municipalities who finance our research. It also reflects the theoretical frame for the studies which developed over time, as I became increasingly aware of social approaches to disability, which assisted me in exploring many of the concepts contained in the Swedish Social Services Act, the legislation which underlies the responsibility to conduct such surveys.

The remainder of chapter one will address the specific background to the studies presented in this dissertation. The social welfare system which comprises the organizational field in which people with psychiatric disabilities are

offered supports in Sweden is presented first, since while many of the underlying changes related to deinstitutionalization reflect international trends, the specifics of the mental health system and community services in a social welfare state such as Sweden need to be understood in order to interpret the results presented in the studies. Policies related to the deinstitutionalization process in Sweden and focus on development of community-based social services will also be presented, followed by a number of national evaluations of this process. The issues raised in these reports describe the context in which both the studies and the results will be interpreted and discussed. The final section addresses the specific task assigned to the social services, related to inventories and surveys of need, a legislated responsibility which as described above, influenced the method developed and described in Chapter four.

## **Swedish welfare and disability policy**

An initial focus on the language and intent of legislation related to the Social Services Act reflects the manner in which the initial study included in this dissertation began. In attempting to understand the aim of an inventory and survey of needs, which the municipality had ordered, it became important to deconstruct the specific paragraphs and see what they might offer in terms of guidance which would help focus the study that would follow. Many of the specific concepts utilized in these paragraphs are especially relevant when examined within the context of social approaches to disability. An exploration of theories regarding disability became a necessary precursor to the development of methods which would attempt to achieve the purpose of these studies. This discussion is presented therefore in this and the following two chapters, prior to presenting the method.

### **Municipalities, county government and responsibilities**

The municipalities of Sweden (kommun) are the local government entities of Sweden. There are currently 290 municipalities organized in 21 counties (län). The municipalities are responsible for a large portion of local services such as schools, emergency services and city planning. Medical care and treatment are regulated by the Health and Medical Services Act and administered at the county level. At the national level, Swedish disability policy strives to guide these government entities to “boost each individual’s prospects of living an independent life and close the gap between disabled and non-disabled people” (Socialstyrelsen 2006:1).

Social assistance (provided by the municipal social services), according to the Social Services Act, is needs-tested and based on maintaining a “reasonable

standard of living”. In most cases the social welfare authority includes departments for individual and family services (IFS), services to the elderly and to the disabled – and social psychiatry units supporting people with psychiatric disabilities. These social psychiatry units may be part of either the individual and family services departments or the handicap care department. While some municipalities may not have specific social psychiatry units, all of the municipalities in the current study did. I will be using the term “municipal social psychiatry” to describe these units since this is the manner in which they are commonly referred to organizationally. Social Psychiatry as a concept or field of knowledge is relevant of course for all branches of psychiatry. Describing these units as providing mental health services would also be misleading since this term implies a much broader mandate than the one assigned to these units in the social services. People with psychiatric disabilities additionally interact with a number of other welfare agencies, of which the county-based specialized psychiatry, the public employment service, the social insurance office and the local health care centre (primary care) are the most significant.

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. The Social Services Act of 1982 begins with the following paragraph;

*Public social services shall, on a basis of democracy and solidarity, promote peoples;*

- *Economic and social security*
- *Equality of living conditions*
- *Active participation in the life of the community*

*With due consideration for the responsibility of the individual for his own social situation and that of others, social services shall be aimed at liberating and developing the innate resources of individuals and groups. Activities shall be based on respect for people’s self-determination and privacy. (Social Services Act, 2001, Chapter one, Section one)*

Already evident, in what is referred to as the ”portal paragraph”, there is a clear emphasis on the right which all community members have, to expect active participation in the life of the community, one grounded in a respect for self-determination and integrity. Paragraph five goes further in defining the municipi-

pal responsibility for people experiencing disabilities utilizing the following language;

*5 Kap 7 § The social welfare committee shall endeavour to ensure that persons who, for physical, mental or other reasons, encounter difficulties in their everyday lives are enabled to participate in the life of the community and to live like others.*

We see here once again an emphasis on the difficulties which may result from psychiatric and other impairments, as well as a promise of participation in community life, despite the effects of these difficulties on their ability to further their own lives. A key point, which will be discussed throughout the dissertation, is that the legislation does not base its responsibility to provide supports to the individual on the assumption that their medical condition has resolved itself. The opposite is actually true. While the legislation acknowledges the medical reasons for a disability, its emphasis in providing supports is clearly related to the difficulties that might restrict the person from participating in community life. In the same chapter, it goes on to specify a responsibility for acquiring knowledge that can serve as the basis for planning and developing services.

*8 § The social welfare committee shall make itself closely acquainted with the living conditions of persons within its boundaries with physical and mental impairments and, in its activation measures, shall disseminate information concerning social service activities in these fields.*

*The municipality shall plan its measures for persons with physical and mental impairments. In this planning the municipality shall cooperate with the county council and with other public bodies and organisations.*

Here again, in its direction to develop a knowledge base, the emphasis is on living conditions and not the illness or symptoms. The information is also to be gathered cooperatively, together with both the county council (specialized psychiatry) and other public actors that might contribute their perspective. The legislation directed us to further clarify the differences between illness and disability, between health and participation, and between satisfaction with services and with living conditions. The following section will describe the public actors in the organizational field within which these surveys took place, before return-

ing to a discussion of the actual task assigned to the municipalities within the legislation.

### **Employment Service**

The Public Employment Service is a national authority which delivers services in 68 labor market regions in Sweden. Their overall aim is to improve the functioning of the labor market, specifically by; matching jobseekers with employers wanting to recruit staff, making an extra effort to service individuals far from the labor market, and contributing in the long term to stable and high employment rates. The employment service offers a number of specialized measures which may be used to support the entry of people with disabilities into the labor market. These include; work internships, subsidized positions, sheltered work in the public sector, job coaches and the ability to purchase places in sheltered workshops. They additionally have access to vocational and psychological evaluations and can offer guidance services. ([www.arbetsformedlingen.se](http://www.arbetsformedlingen.se), SOU 2006:100)

### **Social Insurance**

The Swedish Social Insurance Agency, a national authority regulated by the Insurance Act, provides financial protection for families and children, for persons with a disability and in connection with illness, work injury and old age. Included are sickness benefits, activity benefits (for those 19-29) and sickness allowances, commonly referred to as disability pensions. These may be time-limited or without time limits, and in these cases they are often referred to as early retirement pensions, an earlier term which was used throughout the first years of the project and is still often used to refer to permanent disability pensions. They also have the primary responsibility for rehabilitation to work, a responsibility which includes the coordination of other available social welfare measures, both for those in the labor market and for those who are unemployed and ill (SoU 2006:100).

### **Health Care and Psychiatry**

Sixty hospitals spread around the country provide specialist care and emergency services (Swedish Health Care, [www.sweden.se](http://www.sweden.se)) and are administered by the Swedish health care system which is centrally steered but administered by the locally elected county councils. Included in these specialized services are both inpatient and outpatient psychiatry. Sectorization, an organizational change that attempted to unify all psychiatric services in geographically defined catchment areas, was instituted in the years following this transfer and was completed in the mid-80's. At that time there were 135 such catchment areas, each served by an outpatient clinic which had (and has) responsibility for all outpatient ser-

vices. By 2005, this number was reduced to just over 100 due to efforts to concentrate these into larger units. The vast majority of specialized psychiatric hospitals have been replaced by inpatient care provided in psychiatric units within general hospitals. Primary care centers are the foundation of the health and medical care system. Most health care is provided by these centers where doctors, nurses, midwives, physiotherapists and others provide frontline services. Since the Mental Health Care Reform, representatives of primary care report an increase in patients with mental illness. They also report continuing difficulties in collaborating with specialized psychiatry and the municipal social services, as well as a lack of resources and knowledge which would allow them to more effectively support these individuals (SOU 2006:100, NOMEKO 2007).

In the following chapters I will be referring to the “formal mental health system” by which I mean, in the case of Sweden, specialized psychiatry (within the county-based health care system) and social psychiatry (within the municipal social services). These are the two organizational actors who provide direct services exclusively to people with psychiatric disorders, illnesses and disabilities. I will also refer to the other actors, including primary health care centers, the public employment service, and the social insurance authority as “generic community services” since they are intended for all members of the community and not specialized to one group, in this case people with psychiatric disabilities. The purpose of distinguishing these two structures will become clear below, but they are also based on a model which Carling (1995) has discussed. In describing a framework for support in the community, he suggests that support comes first from family and friends, then from “generic community services (housing, cash assistance, employment training, recreational opportunities, somatic health care, etc.) and only then the formal mental health system. While the formal mental health system in many countries includes hospitals and community mental health centers, in Sweden, based on the Mental Health Care Reform described below, many of these formal mental health services related to community support have been transferred to the social services at the municipal level.

In such a complex welfare system, including authorities with different legislative and administrative mandates, different budgets and staff with different educational backgrounds and professional perspectives, problems of inter-organizational cooperation are one common thread in discussions related to effectively serving people with psychiatric disabilities. Varied perspectives for example, related to medical determinations of disability (social insurance) and employability (employment service) lead to complications for assessing employment-related needs for these individuals (Lindqvist & Grape 1999).

Responsibility for vocational rehabilitation is a particularly pressing issue since the Swedish government introduced, at the end of the 1980's, the new "work line" in social policy. Employers were to improve working environments and take an increased responsibility for rehabilitating their employees, the social insurance authority would facilitate an "active rehabilitation" and coordinate measures to minimize absence due to illness. The work principle includes the idea that employment is always preferable to cash support and so is intended to be applied even for those with disabilities who have never succeeded in entering the work force and do not have a current employer.

### **The Mental Health Care Reform**

The international movement away from institutional and towards community-based care is one that has most visibly manifested itself in Sweden through the Mental Health Care or Psychiatry Reform of 1995. The process of deinstitutionalization began relatively late in Sweden, in the 1970's, following the transference of responsibility in 1967 from the state to the county councils. As of 1967 there were still 4 psychiatric beds for every 1000 inhabitants, a figure which has been reduced to 0.50 as of 2006 (Markström 2003; NOMEKO 2007). While policy began to point in the direction of an increase in outpatient services, the development and implementation of such services lagged until the 1980's. Beginning in 1992 a state sponsored psychiatry investigation was instituted with the goal of surveying the situation for people with mental illness in Sweden.

The results of this investigation confirmed the fact that "provision often fell short of the expectations of users and relatives, with a pronounced hospital bias in all health care, and poor coordination between separated county health and municipal social services" (Carpenter 2000:612). A medical bias, as an explanatory factor for the sluggish implementation of the community-based ideology, may be seen as a theme in the process of reforms in Sweden. Another is the difficulties presented in coordinating services between the two primary actors, the county-based medical treatment services and the municipal social services which should have, based on a series of legislative changes, assumed a greater responsibility for community-based services. Based on prior legislation, most notably the Swedish Social Services act of 1982, "...municipal social services were given greater responsibility for meeting the needs of the long-term mentally ill in various respects, among them for acceptable housing and meaningful employment" (Socialstyrelsen, 1998). According to the Reform, social services were to make it possible for people in the target group (those undergoing long-term treatment in hospitals or nursing homes) to live outside institutions

(Nomesko 2006). Specifically, the municipalities were to be responsible for housing, daily activities and rehabilitation of these individuals, who were deemed to have “completed treatment”, referring to the need for 24 hour inpatient care.

The specific goals of the Mental Health Care Reform (SoU 1992:73) included;

- (Entitlement to)The same rights and responsibilities as all others.
- Services of good quality and developed from the individual’s circumstances and needs.
- Services based on the individual’s own choices and priorities
- Availability of necessary services locally in the community where they live
- Services are formed so that they support independence and integrity
- Services are formed so that they support the individual’s welfare

An emphasis on housing and occupation is the concrete task given to the social services, within the broader goal of helping to create better living conditions for individuals with psychiatric disabilities. Specialized psychiatric care services, within the county councils, were directed to adapt their efforts and develop adequate treatment methods, as well as supporting the work of the municipal social services. Social services and psychiatric care organisations were together challenged to direct their efforts towards “social integration and the best possible life for the mentally ill, on equal terms with the rest of the population” (Socialstyrelsen 1998). At the same time that these legislative developments were progressing however, changes in perspective regarding the mentally ill were beginning to stimulate broader thinking as to the relationship between illness and social or living conditions, and to the language that would guide this process.

Since the beginning of the 90’s in Sweden, official terminology has exchanged the concept of illness for that of psychiatric disturbance, in an effort to “move away from an individually directed medical conception and instead emphasize that these conditions, as well as the need for care of these conditions, is dependent on the environment surrounding the ill or disturbed individual” (Socialstyrelsen 1999b). This exchange of language, which has undergone a further metamorphosis to include the currently used “person with a psychiatric disability” in various forms, reflects the handicap perspective which has developed from the work of the World Health Organization. The National Board of Health and Welfare has decided in a recent (2008) publication ([www.sos.se](http://www.sos.se)) to dispense with the use of the term handicap however. They currently recommend using functional impairment to refer to a reduction in functional capaci-

ties, and disability to refer to the consequences of such impairments in relation to the environment. They state that an “important consequence (of this terminology) is that a disability is not something that a person has, rather it is the environment which is disabling”.

### **After the Reform...**

In addition to a number of other problems which will be addressed below, the Reform was implemented at a time when many municipalities and county councils were faced with demands to reduce expenditures because of a nationwide recession. Uncertain political support, a lack of evidence-based methods and the challenges of coordinating so many actors operating in the welfare system also contributed to a somewhat fragile foundation for implementing this wide-ranging reform (Markström 2003; SOU 2006:100). Specific problems however, in implementing the intentions of the Reform, have been well documented in a series of follow-up studies conducted by government at various levels. Three of these investigations will be briefly presented here, as they may be seen as providing insight into the national discussion during the period of time in which the studies presented here were conducted.

### **Welfare and Freedom of Choice**

The Swedish government commissioned the National Board of Health and Welfare to follow-up and evaluate the Mental Health Reform four years after it took effect. The specific aim of the evaluation was to focus on the manner in which the Reform had impacted people with mental disabilities, with respect to their living conditions and their overall quality of life (Socialstyrelsen 1999c). The final report of the National Board concluded that “the process of reform is in motion, but much remains to be done”. They note that 4000 patients and hundreds of rehabilitation programs have been transferred to the municipal social services. State subsidies, which attempted to stimulate the development of community-based services and models, have additionally promoted interaction and integration between specialized psychiatry and the municipal social services. However, there were still conflicting interests which hamper these efforts and which result from both organisational and cultural (professional) interests.

They note a lack of clarity in distinguishing between responsibilities related to what they call “social welfare” as distinct from “psychiatric care”. In Sweden, these distinctions must be interpreted within the organizational context of the municipal responsibility for social welfare as opposed to the county-based responsibility for health, including psychiatric care. In many other countries, spe-

cifically those that have developed a community mental health philosophy as a model for developing community-based services, these distinctions are much less clear. Case management for example, is most often provided within a community mental health center, while in Sweden, the diverse responsibilities assigned to case managers require coordinated organizational structures, at least between psychiatry and the social services. As a result, an emphasis in the evaluation is on the need for improved cooperation between authorities, a cooperation that should be achieved by creating local agreements to address organizational issues, and the development of a common knowledge base to address cultural and professional issues. Already in this report (1999) they suggest that cooperation must be a “means and not a goal” however if the intentions of the Reform are to be achieved. The goal they state is integration, with the individual as the starting point (p. 293), and they suggest the need for individual care and service plans as a tool for developing relevant services which should then be coordinated. These two aims, the coordination of the organizational actors, and the focus on the needs of the individual, are presented as placing new demands on the organizations involved.

A number of other issues which are taken up in the evaluation are relevant to the discussion that will follow here. Throughout all of the evaluations and oversight reports, there has been a stated emphasis on the importance of including user and family associations in the process of planning and developing services. In this evaluation, the conclusion was that while municipalities have attempted to inventory the needs of individuals with psychiatric disabilities, “users still had no influence over the specific forms of care and social support received”, and that “opportunities for user groups to influence the form and content of activities was inadequate”(p.289). Another conclusion was that especially for the workers in the municipalities, who had only recently inherited community-based responsibilities for this group, there were inadequate opportunities for developing new knowledge and competencies. They suggest that new responsibilities demand new skills and that; “... necessary expertise includes everything from knowledge about living conditions and the social situation of the mentally disabled person to understanding of the disability’s nature and manifestations”. One final issue which is relevant here, is their finding regarding the “unclear borders of responsibility between the state, county councils and municipalities”, with regard to rehabilitation, a situation which they believe has led to the large number of individuals receiving early retirement benefits (p.287).

### **Municipal psychiatric services – a national oversight**

The 1999 evaluation of the Mental Health Care Reform additionally recommended that an “active, clear, and comprehensive oversight process” was needed in order to support programs which would help to achieve the intentions of the Reform. As a result the National Board of Health and Welfare, together with the county-based oversight units, completed an extensive analysis of the services in place in the municipal social services, from 2002-2004 (Socialstyrelsen and Länsstyrelserna 2005). A number of municipalities received a local evaluation, including three of those who were eventually to become involved in the project presented here, and then a final report was completed in 2005. Many of the conclusions pointed directly or indirectly to the need for increasing knowledge of individuals with psychiatric disability in the community, and acted as a stimulus for many municipalities throughout the country to begin completing inventories and surveys of need.

The oversight process however was limited to those between 18 and 65 years of age who were receiving some type of assistance from the municipal social services (most often social psychiatry units), despite the fact that the evaluation of the reform had noted that contact with younger people with serious disabilities had not been particularly successful, and needed improvement. During 2002 only 19,500 people were receiving services from the municipalities for psychiatric disability, out of what was estimated to be 35,000 who had such a need. The problem areas identified in the study included many which were specifically relevant to the project that will be presented here and included the following. They recommended that activities related to inventory and outreach should be intensified, a concern related to the risks that the oversight report noted might occur when people with psychiatric disabilities were not utilizing social services units and therefore not even aware of what the municipalities offer. They also noted that there was a lack of clarity over the definition of who should be included in the target group, and a lack of methods with which to complete an inventory and survey of needs. Other issues included; the lack of comprehensive planning and the fragmented organization of responsibility for this group, a lack of access to knowledge and methods for supporting the potential of people with psychiatric disabilities, a need for developing more variation and flexibility in programs and services, and a lack of a holistic perspective on need from which services might be planned and coordinated, based on the particular needs of the individual.

### **The National Psychiatry Services Coordinator**

The National Psychiatry Services Coordinators office was created and received its mandate to analyze shortcomings in the Swedish psychiatric system and

propose measures and models in the fall of 2003. While many of the concerns related to the implementation and success of the Reform were still being debated, the creation of the NPSC was linked to a period of time where a number of violent crimes were attributed to people who were receiving or had recently received psychiatric care. In an attempt to raise the standard for psychiatric care and support, and develop a long term sustainable strategy that would achieve substantial change for users and their families, the NPSC (SOU2006:10) proposed the following vision, accompanied by four comprehensive goals;

*As a resident of Sweden I shall be able to feel secure that my fellow human beings and I shall:*

- *receive good and safe care and social services if we experience mental health problems and*
- *have the same opportunities for housing, work, a sense of community and participation in society as anyone else, even if we have a psychiatric disability or suffer from a serious mental illness.*

Once again the NSPC vision appears to support the ideology contained in the Social Services Act which promises opportunities for a participatory life in the community despite the continuing effects of a mental illness. The four comprehensive goals supporting this vision include; functional housing alternatives for all, jobs, studies or meaningful occupation (based on their condition) for all, that all participate in a community where they are met with understanding and respect, and that they be offered care and support based on their individual needs (as outlined in individual plans and continual follow-up).

A number of other specific recommendations are worth mentioning here as well. The NPSC considered its target group to be broader in a number of ways, than that targeted in the Reform and subsequent follow-ups. Based on a number of recent reports they were concerned with children and adolescents who were at risk for developing such disorders and disabilities, whereas the Reform had targeted adults who were already known to the system. They proposed a modified definition as well, which was utilized in the third study, and described in Chapter seven.

## **Finding the target group**

In its evaluation of the Psychiatry Reform in 1999, the National Health and Welfare Board (Socialstyrelsen, 1999b:293) states that a more flexible view of disability, “where needs may be modified in the perspective of the course of

life... affects both working methods and the decision-making process". This flexibility in defining disability challenges the notion that a disability is static or that changes in the condition of the psychiatrically disabled are rare or unseen. From a disability perspective, an individual's condition and life circumstances may change dramatically as the result of changes, supports or adaptations in the surrounding environment, not only in their individual condition. The "variation and diversity" that may result from this complex interaction, between the individual's impairment and the adaptability of the surrounding environment, leads to the following conclusion in their report; "The target group for the psychiatric care reform may easily be perceived as homogeneous, but it is extremely heterogeneous (p. 293)". Markström (2003) takes up this issue as well, as he points out that the many terms used to describe these individuals often actually corresponded to different groups with different needs. This created a fundamental uncertainty in the workings of the Reform, generating many questions as to who should and shouldn't be included in the target group.

The attempt of the National Health and Welfare board to integrate a disability perspective into Swedish social welfare policy may have created challenges to local government's ability to clearly plan for a defined group. At the same time however, they had created the expectation that the municipalities would "intensify their activity in seeking out or outreaching clients who lack contact with the social services or psychiatry" (Socialstyrelsen 1998). There is a realization that members of the Reform's target group might "fall between the cracks" in the system as they move further into the natural community and there is a lessened ability to keep track of them. Their concern originates in a number of points regarding the individuals in this group. "Many have difficulties in seeking the services, supports and help they need (ibid.)". There is an appreciation, well grounded in the experience of similar processes in other countries, that many of these clients can easily "disappear" in the community, and are particularly at risk for many social problems including substance abuse, poverty, homelessness, and criminality. In their evaluation of the Reform, the National Health and Welfare Board (Socialstyrelsen 1999b: 41) makes one more attempt to describe characteristics of this group. "Another way to consider the Mental Health Reform's target group is that they operate from the problem areas that effect them as psychiatrically disabled and generate various needs (social, psychiatric, support) that require various services." They go on to note that this "needs perspective" works well with the perspective that the Reform promoted. The direction there is that individuals with psychiatric disabilities should be supported in the community, as others (non-disabled) are supported, with regard to their need, not through specialized services determined by the limitations of their illness. Finally, they note that a characteristic of this group is

that they “wander between the various fields (of need)” over time. This tendency to “wander” reinforces the importance of the municipal social services responsibility to find these individuals and survey their needs, as they may lose contact with the various authorities charged with serving them over time.

### **Inventories and surveys of need**

As stated earlier, there is a clear and legislated responsibility (5a§SoL) for the local social services, as administered by the municipality, to become “familiar with the conditions of life for people who have physical or psychiatric disabilities, and in their outreach activities present information regarding the activities and services of the social services in these areas” (Socialstyrelsen 1999a: 7). As a result of the Mental Health Reform, the municipalities were given an increased and clearer responsibility to “plan and coordinate services to individuals with psychiatric disabilities and to promote outreach/survey activities cooperatively with the county medical councils, and other societal authorities and organisations” (Socialstyrelsen 1999a:7-8). This clearly stated language was an attempt to emphasize the importance of this responsibility and resulted from concerns expressed in the Psychiatry Inquiry as well as in other official reports. The emphasis on seeking out these group members arose from concerns that they can become isolated and difficult to find in the “shadows” of service agencies. A strong commitment to finding these individuals and planning for them is motivated by these concerns as well as the “necessity of local needs assessments in the municipalities – in order to develop activities and services that correspond to the real needs of the target group”(Markström 2003:176).

The background that has been presented here describes a number of themes which provide the context for the studies that will be presented and explored in this work. They include both the international background for deinstitutionalization and the specifics of the implementation of this move from institutional to community-based models for dealing with psychiatric illness and disability in Sweden. The theoretical perspectives which will be presented in the following two chapters both inform and transcend the details of the particular implementation of this shift in Sweden. As stated above, a discussion of theoretical notions of psychiatric illness and disability helped to provide both a context for the particular studies and at the same time influenced the method which was eventually developed and utilized. Chapter two includes therefore a discussion of the concept of disability and an exploration of social approaches to understanding disability. It also explores theories related to organizational structures for service delivery, since the organizations of the social welfare system are central actors in the move to community-based supports. It begins however with what might be considered a meta-theoretical background which provides a

context for the methods, theories and results which will be discussed throughout.

## **Chapter Two – Social approaches and the organizational field**

A number of models which describe the theoretical context for the discussion of surveying psychiatric disability in the community will be described in this chapter and the one that follows. I begin with a broad discussion of social approaches and some of the characteristics of the organisations that are active in the community context for the Mental Health Care Reform. In the following chapter, I present a number of theories and research findings which attempt to see the individual in the community. The chapter finishes with a discussion of theories that underlie many of the visions for the mental health systems interventions.

### **Critical Realism and psychiatric disability**

There are however, a number of broad, meta-theoretical issues that may help to frame the theoretical and empirical discussions to come. I have chosen therefore to borrow a number of notions from Critical Realism in order to lay the groundwork for how I will utilize theory and interpret the results of the surveys presented in the following chapters. This is not to say that Critical Realism is the only meta-theoretical perspective that can inform my work, but that it has been the most effective in helping me to find a frame for my theory analysis. Specifically, there are three broad arguments that relate to the topic of this thesis that I will briefly discuss below. These relate to the open system in which these surveys explored psychiatric disability, attempts to develop a more holistic perspective on need than any one model might provide, and finally a discussion of the relationship between agency and structure, as these concepts relate to the experience of disability.

#### **Institutionalization – a legacy of “closed systems” in research**

Critical Realism sees social research as always occurring within an open system where attempts to describe complex mechanisms can help us to understand, not necessarily predict a result. The movement from hospital/institutional to community-based care may be seen as a move from a “closed-system” where interventions and effects might be effectively isolated and measured, to the “open system” that is the community context for today’s mental health care.

*Any type of social organization, such as the judicial system, the organization of working life, family, the educational system or the health care system, are examples of such pseudo-closed systems – they are the result of a conscious striving to make society (and nature – nature’s mechanisms are inevitably involved) more controllable in relation to people’s different aims. (Danermark, et al. 2002:68)*

One of the most important historical factors in the care of individuals experiencing psychiatric disability has been the era of institutionalization, where due primarily to a medical model of illness, individuals were institutionalized in order to receive treatment and remove them from society “for their own good”. This rational attempt to apply new methods of medical treatment within what might be termed a closed system led to many “side effects” that Goffman (1963) and others have described as having socially damaged the individual as they adapted to an artificial environment that did not prepare them for an eventual return to the society. In the deinstitutionalization era, the primary focus has become community-based care, where the individual receives treatment and support, while living their lives, geographically at least, in the natural community.

It is possible, in my opinion, to draw parallels between this practice within a closed system and the tradition of research within a closed system. If we proceed with the metaphor, it is possible to argue that research traditions which preceded and led to the rationale for institutionalization, that of medically determined care leading to the “cure” of psychiatric illness, have continued despite a paradigm shift in the location of care. Bhaskar (1998) states that; “...it is equally the case that such knowledge as we actually possess always consists in historically specific social forms”. In further discussing knowledge, he states that; “Though the (natural) world does not change with a change of paradigm, the scientist afterward works in a different social (or cognitive) world”. As we look at the majority of research related to the needs of individuals experiencing psychiatric disabilities, we see that the focus remains on the connection between service and result. Do certain types of treatment or support services lead to certain desired results? Yet this type of question may be seen as a remnant of the historical social form that was institutional/medical care. It does not address the mechanisms inherent in community life, of which interaction between the client, now a community member, and the surrounding community play a major role. In practice, a number of researchers (Markström, 2005; Leff and Warner2006; Thornicroft 2006) have described the phenomenon of community institutionalization, where the individual, despite living in the open community, is surrounded and limited in their contacts, to the service providers who sup-

port them. These service system structures have sometimes been described as “mini-institutions”. Archer (1996:691) states that; “When “structural properties” are drawn upon in routinized fashion, an institution becomes “sedimented” as a clustering of the practices constituting it. In turn this means that institutions are never something concrete to which we can point, but are “processual”. The contradiction here has to do with mistaking the end of the material institutional form for the end of the process of institutionalizing people.

What we experienced in the initial phases of our research process was a pressure to complete our survey of need within a “pseudo-closed system”. We were to define the “objects” of our inquiry based on an individual deficit model, based in concepts of illness, and pose questions related to the provision of services, a concept which predetermined the possible expressions of need by the client. Critical realism, by embedding the research process within an open system, provides a platform for analyzing the change that has occurred within the field of psychiatric disabilities, as well as allowing us to expand the focus of research to include the structures and mechanisms that come into play as the individual leaves the institutional world and enters the community.

### **Moving beyond the “model wars”**

Research that proceeds from the assumptions of a medical model of illness, which prioritizes individual impairments, is often viewed in opposition to social models of disability, which prioritize societal and cultural determinants of disability. Social approaches to disability will be discussed in this chapter, and it is therefore important to clearly state my orientation to the issue of these models prior to entering that discussion. Critical Realism seeks to avoid such dualisms, which in this case risk minimizing either the biological and psychological or social aspects, both of which can help to explain the total experience of illness and disability. It allows for a “biopsychosocial” model of the type embraced in the WHO’s International Classification of Functioning, Disability and Health (ICF – to be described below) and that would welcome a broad spectrum of research, multidisciplinary and certainly inclusive of both the medical and the social.

In their article addressing interdisciplinarity and disability research, Bhaskar and Danermark (2006) argue that all three of the models that have dominated the disability field have been essentially reductionist. These include the medical, socio-economic and cultural models and while they do not mean to imply that these have ignored each other, they do tend to “emphasize one type of explanatory mechanism to the detriment, often tantamount to exclusion, of the others”. In my own research, the pressure to develop my analysis on one or another of these models has created a tension that might be said to undermine its

value at the level of practice. Bhaskar (1998) has described a hallmark of Critical Realism as being that of theory/practice consistency. Social workers and other personnel who support individuals with psychiatric disabilities are often intuitively aware of the limitations of one or another of the models. Constructionist models which see disability as a cognitive or cultural idea or belief seem to appeal to them on a humanist level, but do not explain the severe symptoms and behaviors that they recognize as biochemical imbalances. Socio-economic models of disability which see societal structures as determining disability appeal to their sense of equality and justice but do not explain issues such as stigma and difference. And while medical models are supported by the apparent efficacy of medication, they do little to explain the unemployment and societal exclusion that their clients experience on a daily basis. As research attempts a dialogue with practice, as in the case of the local surveys of need to be described here, Critical Realism offers a meta-theoretical context for developing a complex, but intuitively real, attempt to explain the phenomenon which these practitioners witness. Rather than compete with each other, these mechanisms must be looked at empirically and in relation to one another.

### **Agency and structure - The emergence of the individual**

*The reasonable man adapts himself to the world; the unreasonable one persists in trying to adapt the world to himself. Therefore all progress depends on the unreasonable man. (George Bernard Shaw)*

Another dualism rejected by Critical Realist researchers, as unnecessarily promoting an either/or approach (Danermark et al. 2002:2), is that of agency and structure, with one or the other being of paramount importance in explaining social phenomena. Agency is a particularly central question for individuals experiencing psychiatric illness and disability, who are often seen as passive and “unreasonable” (without reason) objects for treatment interventions, or as helpless victims of an oppressive system. People who experience psychiatric disabilities may be said to have particular problems with respect to the issue of agency and structure. The first may be said to exist on a theoretical level, as in constructivist thinking, where the agency of the individual is largely secondary to the issue of disability as it is interpreted by the culture. Psychiatric disability has been defined, in many historical periods and in a variety of ways, as the absence of reason (Hydén 2005). Whether being persecuted or treated, depending on the particular cultural discourse, the individual was transformed into a passive recipient of the predominant social structures’ attempts to deal with their behavior. The second problem may be seen in relation to the medi-

cal/individual materialist model, where the designation as ill, assumes that the individual is not functioning properly, specifically in the area of cognitive/executive functions and emotion. Reasonable action on their part is dismissed as not possible when extreme emotional or cognitive expressions and their accompanying behaviors, are defined as symptoms of a biochemical malfunction. As Beresford (2002) discusses, it is even difficult for the consumer movement as a collective to call into question notions of mental illness, as this may be taken as further evidence of irrationality. “What is called into question about us; the very basis of our collectivity, is the instrument by which we seek to develop our own discourse and critiques – our minds and thoughts”(p. 582). Byrne (2001:281) describes the reaction to a book by Shaw (1998) that described her own depression; “how can we believe this person’s account to be credible when she says herself she was suffering from severe depression at the time”. Chamberlain (in Kramer and Gagne 1990) describes mentalism, as a “set of assumptions that most people seem to hold about mental patients, that they are incompetent, unable to do things for themselves, constantly in need of supervision and assistance, unpredictable, and likely to be violent or irrational”.

Attempts to dismiss the individual/material level attended to within the medical model, have also robbed the individual of their ability to act reasonably, within the complex system that is disability in society. Critical realism, in attending to the interrelationship between agency and structure, can offer a great deal of support to this discussion. “The central problem of theorizing agency”, according to Archer (2002) is “...how to conceptualize the human agent as someone who is both partly formed by their society, but also has the capacity partly to transform their society”. The fact is, as discussed above, that many individuals in the wake of deinstitutionalization have confounded efforts to help, explained often as a lack of insight into their illness, or utilized services inappropriately, defined as resistance, two conditions which are often presented as further proof of their loss of reason. Thornicroft (2006:213) discusses the complexities of the insight issue, stating that while a refusal to accept that their difficulties are a form of mental illness often leads to their stopping contact with health services, there may also be positive effects, such as avoiding the stigmatizing effects of a diagnosis. Gleeson (cited in Parr 2008:15) argues that representations of disabled people as “simply swept up and routinely institutionalized... do not do justice to their resisting of such processes... by clinging to society on the streets, some disabled people resist “the duty” to attend the asylum”. As these various types of resistance and lack of insight have become more of an area of concern, they have become the basis for more aggressive attempts to “capture” and treat such individuals for their own good. Specifically, this chain of reasoning can be seen in recent discussions of ACT, a model

of outreach oriented case management, and legislation regarding involuntary outpatient care.

Bhaskar and Danemark (2006) offer a useful insight into this problem as they discuss the doctor/patient role in which the medical system does not always see the individual as an “epistemological subject”. The loss of their ability to “know” and act may be seen as one mechanism in the process of the individual becoming a passive recipient of “services to the disabled”. Many ex-patients have described the “learned helplessness” (Deegan 1992) that accompanies an acceptance of the role as patient. The move here is from a perspective that sees the individual as a passive object for the helping system, to one which sees them in an active relationship, positive or negative, with the structures of the mental health system. Smith’s argument, 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”, reflects the agency of these individuals as a very real factor in their relationship to the helping system and the community (cited in Fossey & Harvey, 2001:94). That these individuals act in response to and in relationship with community and organisational structures, is a premise that will be explored in this thesis.

## **Social approaches to disability**

The Swedish Social Services Act, which has been described in the previous chapter as an ideological starting point for the research project presented here, does not actually contain a definition of disability. However it does clearly promise that the municipal social services will try to help the individual with a psychiatric disability to participate in community life and live like others (Lindqvist 2007). While there are many definitions of disability, a fact attested to by a recent thesis (Grönvik 2007), the most commonly utilized perspective seems to be that disability describes the consequences of an impairment or illness. As described in the World Health Organisation’s International Classification of Functioning Disability and Health (WHO 2002), the concept of disability is used to describe the “impairments, activity limitations and participation restrictions” that result from health conditions. 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). Grönvik (p.32) concludes in his study that there are several definitions of disability which are in use in contemporary research. Disability may be “relative to” or an interaction with the environment, may be caused by the environment, or may even be seen as an administrative construct based on categorization

processes for distributing support. I will look further into some of these models in this chapter, but will establish here that the term disability is unclear and controversial, and that, as Grönvik concludes (p. 33) “different definitions suit different purposes”. On the other hand, the term is exceptionally clear in its ability to move beyond the purely medical description of an illness, and begin to describe, as stated above, the consequences of the illness or illness-related impairment for the individual’s life. It is this use of the term, which sees the “person-in-environment” as the focus, which comes closest to the intention of the Social Services Act, and therefore the aim of the project that will be described here.

*We have concentrated on individual, psychological problems and processes, leaving social factors as a vague, undefined background or context. (Estroff 1993: 7)*

As I discussed above, the medical model provides a useful point for comparison when exploring social approaches, and the two, as will be discussed in this chapter, “run into each other” organisationally. This does not mean that they necessarily have to be in conflict with one another. While the ideal for understanding psychiatric disability in the community might be seen as a synthesis of the two, it is necessary however to begin with these relative descriptions, in part due to the negative outcomes that may be attributed to an exclusively medical/individual approach. As Estroff points out, medical/individual models of psychiatric disability have received the majority of the attention, and even when social approaches are discussed, there is a lack of concrete focus.

## **Medical and social models - finding a balance**

*During my time as a patient, I learned that my feelings were a part of my mental illness. It was terrible to hear that the most essential part of me was mentally ill. (Judi Chamberlain)*

Quotes such as this one by Judi Chamberlain, author of one of the first books by a “psychiatric survivor”, *On Our Own*, focus on the injury that can result from having an identity that is consumed within the role of patient. Beresford (2002:582), in addressing the manner in which we use the medical model in describing a psychiatric condition as a mental illness, expands on the experience which Chamberlain describes. He sees an exclusive focus on mental illness, as based on a deficit model and leading to a “...medicalized, individualised interpretation of the phenomenon it seeks to explain...”. While there is clearly a

serious critique of psychiatry's tendency to "bundle" the individual's entire life experience within a diagnostic label, he also raises the possibility that mental illness may be seen as a phenomenon, with different components. Cohen (2000:75) sees the exclusively medical/individual model, which is primarily equipped to focus on psychopathology, as contributing to a phenomenon which he terms "decontextualization". He describes three types, all of which may be seen as contributing to a "decontextualization of need", a theme that I will be returning to. Cohen refers to situations where social mechanisms (such as isolation) are attributed solely to the disorder or illness, where social factors are not even considered relevant (as when poverty is ignored), and finally a "propensity to look at biological/individual risk factors and not the social context of such risk factors".

*Psychopathology cannot be divorced from social context. The psychopathology model is also prone towards decontextualizing mental disorders, and a social perspective can correct this tendency. (Cohen 2000, p. 74)*

The dominance of the medical model has also influenced the development of community-based psychiatric services, and this is sometimes seen as an explanation for the fact that so few people with psychiatric disabilities have been offered opportunities for a participatory life in the community. Carling (1995:76) states that 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...". Kramer and Gagne (1997:473) expand on this perspective, pointing to the low expectations which may be created when those who are most often considered experts within psychiatry have limited experience with and knowledge of functioning in the social environment.

*A model that focuses on illness, chronicity, stabilization, and symptom management creates and trains helpers who are often unable to help the people they work with realize their full potential / consequently contributing to the hopelessness and despair of people with psychiatric disabilities.*

The social model in comparison, rather than focusing on the impairments which the person experiences as an "individual attribute" defines disability with reference to the societal context within which the individual lives(Barnes at al.

1999). The social model distinguishes between the impairment (the injury or illness) and the disability, which is a social disadvantage based on societal restrictions (Lindqvist 2007). The application of such an approach to the study of mental disorders would call for an analysis of the complexity of restrictions and social disadvantages faced by people having psychiatric diagnoses (Mulvany 2000). Oliver (1996:33) describes disability as related to “society’s failure to provide appropriate services and adequately ensure that the needs of the disabled are fully taken into account in its social organisation”. The model moves the focus from the individual to the individual in their environment, a move which immediately sheds light on the structure of the society within which the individual becomes disabled as they attempt to actualize their life. Such a widening of the focus should necessarily create a demand for increasing knowledge of the social landscape within which the individual will be active. Oliver begins to inventory the types of restrictions which he sees imposed on disabled people, including; discrimination, inaccessible buildings and segregated work and educational arrangements. While prejudice would seem to be a category that covers all people with disabilities, as we look at some of the more concrete examples including the need for physical accommodations such as wheelchair ramps, it becomes clear that the types of restrictions and social conditions that may be relevant for individuals with psychiatric disabilities may be substantially different. It is therefore worth developing some ideas regarding mental illness and psychiatric disability, before continuing with the discussion of social approaches.

### **Finding a frame - Social construction and psychiatric disability**

Barnes, Mercer and Shakespeare (1999:37) take up the notion of ideas about disease and the body which he states have “hitherto been regarded as stable realities”. Yet functionalism’s influence has begun to diminish according to these authors and a social constructionist approach has begun to gain influence. Pilgrim and Rogers (1997:18) discuss social constructivism as having over the past 20 years, proceeded from the central assumption that “reality is not stable and waiting to be discovered, but instead is a product of human activity”. While there are many versions of social constructivism all, according to these authors, can be seen as a reaction against the positivism that remains central to medical psychiatric attempts to diagnose and treat. Most important here is that a social constructivist viewpoint would at least question the attempt to approach the concept of disability in the same positivistic manner that diagnosis is utilized.

In contrast to a static view of psychiatric illness suggested in the medical model, and grounded in diagnosis and prognosis, the social approach sees psychiatric disability as relative to the social and historical context within which the individual lives and receives care and support. Hydén (1995:25) presents “sickness and illness as continually constructed and reconstructed ...reformulated from new contexts and information, and in this meaning we must see the formulation of illness as related to various social situations”. A clear example of this construction and reconstruction may be seen in the decision of the American Psychiatric Association to completely remove the diagnostic classification of homosexuality as a psychiatric condition in 1986 from the Diagnostic and Statistical Manual, after first modifying it in 1973. Bayer (1987) states that; “...the result was not a conclusion based upon an approximation of the scientific truth as dictated by reason, but was instead action demanded by the ideological temper of the times”. In deconstructing homosexuality as an illness, it is possible to imagine the chain of reactions that would flow towards the experience of the homosexual individual as attitudes, systems and services realigned themselves to reflect this new reality. The diagnostic root of the disability had determined the system’s relationship to the individual as well as the individual’s experience of themselves.

In discussing the phenomenon of mental disorder as a “social construct”, Busfield (2000:546) states that the phrase can mean a number of things. “On the one hand, it can mean little more than that mental disorder is a social category – that is a product of how humans think about and act in the world – a proposition that is likely to be elaborated in terms of claims that what is so categorized, and the meanings attached to the categories, vary across time and place. On the other hand it can be taken to incorporate an ontological claim that mental disorder is only a category and does not refer to any objective reality.” Regardless of how extreme a position one takes on the constructivist continuum with regard to mental illness, the common conclusion is that the experience of illness-related disability is a function to some extent, of the societal conditions in which the individual lives. My own long experience as a practitioner supports a position which, as described above, sees value in developing a broad knowledge base which includes the social constructivist standpoint. At the same time it is very difficult to ignore the concrete and palpably biochemical pathology I have seen firsthand in many individuals. The process of seeking a theoretically enriching and yet practical integration of the various models that have been briefly introduced, has resulted in what a number of authors have begun to describe as a social approach to disability.

Tew (2002), in an article discussing the potential for social work to adapt a more holistic stance towards mental distress, has attempted to argue for a posi-

tion which focuses on the importance of social contexts and factors, without minimizing the reality of the medically defined individual perspective. “Rather than taking the extreme position that “mental illness” does not exist, a social model need not rule out the possibility that some people may have greater innate vulnerabilities to particular experiences due to medical, nutritional, genetic or other factors” (p. 5). Another moderate or integrative position on illness and disability is provided by Busfield (1992) who discusses Rosenberg’s concept of “social framing”, language which she sees as consistent with critical realism. “This conceptualization has advantages, indicating as it does, that the way we understand illness varies across time and place, but does not suggest any denial of the phenomena that come to be constituted as disease or disorder”(p. 547).

I also 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 (Barnes et al. 1999; Corker and Shakespeare 2002; Danermark 2004). By specifying and reinforcing the notion that a social approach must include the material, political and even discursive aspects of the societal environment in which the individual experiencing a psychiatric disability lives their life, it becomes clearer that the community is an open system that cannot be reduced to a specific number of causal relationships.

## **Disability in the community**

From a social approach to disability, the individual may be seen, despite a continuing illness, as a full member of the community with a “life concept”, that might lead to their needs being planned based on their wishes and from the environmentally relative perspective on disability that was the ideological basis of the Reform and other Swedish disability policy (Regeringens Prop. 1999/200:79). There are many implications of beginning to reconceptualise the patient as a community member. Barham and Hayward( 1995:137), in discussing their research conclude that “What they (participants in their study) can be said to ask of us is that we should relocate the discussion of the lives of people with a history of mental illness in the community away from “illness” (the management of an illness and the management of patients) as the dominant frame of reference to the frame of “well-being”, which puts personhood rather than patienthood in the foreground of analysis”. Considering the individual as a

person, as a community member, and even as an “active citizen” (Ware et al. 2008) helps to, as they state, “relocate the discussion”.

There are also practical implications of the social approach regarding methods of supporting the individual. Psychosocial rehabilitation models in particular have focused on the “person-environment fit” (Fossey and Harvey 2000) as more indicative of success in community environments than diagnosis alone which has not shown itself to be an accurate predictor of success in community life (Anthony et al. 2002 ). Psychiatric Rehabilitation principles and methods help individuals with psychiatric disabilities to develop both the skills they need as individuals and the environmental resources which are necessary for them to move towards their goals in the community environment of their choice. As the social context for receiving mental health care in the community as well as living a participatory life become the focus, theories related to making sense of the social landscape became increasingly important. That which first comes clearly into focus as we “zoom out” from an exclusive focus on the individual are the various organisations charged with supporting them.

## **Organisational cultures and paradigms**

In this section I will discuss a number of aspects related to how organisational structures meet individuals experiencing psychiatric disability, as well as the manner in which this meeting may potentially affect outcomes for the eventual relationship with the client. In chapter one I have laid out the specific organisations and their responsibility areas. These are the five organisations (Psychiatry, Social Psychiatry, Primary Care, Employment, Social Insurance) who have a direct responsibility for aspects of the lives of these individuals, and to whom the research project turned as primary informants for the survey process.

Parr (2008:31) describes the “new geography of deinstitutionalization” with its well-documented inefficiencies and failures. Referring to Pilgrim and Rogers (2005) she states that; “care in the community” has replaced the asylum system, and patients and their services have been redistributed over space, supposedly resituated in networks of caring relations held together by a raft of policies and organizations dedicated to monitoring of patients, the programming of care and joint working arrangements between caring agencies”. The extremely “contained” system that was the institution or the psychiatric hospital in later years, has been forced to collaborate with a wide range of actors, in what I have earlier described as a pseudo-closed system. The inefficiencies and failures may in part be attributed to the fact that these collaborative arrangements and strategies do not realistically reflect the broad reality of the community or “open system” that is the post-deinstitutional location for care today.

Lindqvist (2007:166) discusses the “organizational field” which may be seen as occupying a central location in the social landscape for individuals with psychiatric disabilities seeking a life in the community. He states that;

*If the individual model leans towards medically oriented psychiatry as its knowledge base, in the form of diagnosis and various (biomedical) treatments, and the psychiatric care (hospital clinic) as its organisational environment, the social model requires a widened field for analysis, the social environment in which the psychiatrically disabled individual lives. In this environment one finds the various authorities belonging to the social support system and professional helpers, potential employers, and the individual's social network, including user organisations. (Lindqvist 2007:166)*

Powell and DiMaggio (1991:28), in their work on New Institutionalism and Organizational Analysis emphasize that; “... organizational environments are composed of cultural elements, that is, taken for granted beliefs and widely promulgated rules that serve as templates for organizing”. New institutionalism’s focus on the cultural context of organisational development supports a focus on, in the case of this work, the social context of the organisations comprising the social welfare system in Sweden. New Institutionalism sees the organization as a social construction, not as consciously and rationally formed in order to achieve predetermined operative goals (Scott 1995; Lindqvist, 2007). Scott (1995:31) offers a definition of the concept of institution as consisting of “cognitive, normative and regulative structures that provide meaning and stability to social behaviour”. This is a broad definition, and yet one that allows for an “organization-in-environment” notion that in some ways is a helpful reflection of the “person-in-environment” position that I have been building on here. More specifically, it is possible to discuss “institutional sectors” or “organisational fields” where actors having similar tasks do their work within a context based on the cognitive, normative and regulative structures that Scott describes. From the perspective of the social landscape following the Reform, this organisational field, comprised of the five actors named above, may be seen as a central focus for this study.

Meyer and Rowan (1991:44) describe “rationalized myths” that build on “powerful institutional rules”, including ideologies, policies, programs, political systems, professional knowledge and public opinion, in other words, “widespread understandings of social reality” and that these myths “generate formal organizational structures”. They argue that; “Organizations in post-industrial society dramatically reflect the myths of their institutional environments instead

of the demands of their work activities”(p.41). This leads to a perspective on the generative mechanisms in the organizational field, as steered by rational myths which lead them to accommodate to one another within the same organizational field, a process described as “institutional isomorphism”(Powell and DiMaggio 1991). From this position it is possible to view the actors working within the organizational field defined by the Mental Health Reform, as working within, and being formed by, a social context defined by a particular social reality.

The “taken-for-granted beliefs” that have served as the template for the organizational field in the years following the Mental Health Reform, may be seen as still dominated by the medical/individual model. In reviewing the implementation of the Reform in Sweden, but even the community-care movements in other countries, it is possible to argue that the continuing dominance of a medical paradigm has obstructed the development of a socially-defined community-based model. Powell and DiMaggio, discuss the idea of “archetypes” or “elements linked to old institutions (which themselves) become institutionalized” (p.29). It is possible to argue that many “archetypes” from the era of Deinstitutionalization, continue to steer the organizational field where individuals with psychiatric disabilities seek support for a life in the community. For example, day hospitals, which were a support in the community for previously institutionalized patients, have now become day programs, but still maintain the same structure, physically and programmatically, a clue to the enduring nature of archetypes from the era of deinstitutionalization. It is also interesting to consider the “rational myths” that permeate the organizational field today, and how these promote or constrain the possibilities for a participatory life in the community. The notion that organizations meeting individuals with psychiatric disabilities may be more steered by “the myths of the institutional environment” than the actual needs of the individuals they meet, and that these myths reside within a medical/individual model of disability, is a perspective that can shed a great deal of light on the dynamics of these meetings.

### **Classification and categorization – the construction of the client**

New Institutionalism brings culture and the environment firmly into the discussion regarding the organizational field for individuals experiencing psychiatric disabilities. With this background, it is possible to explore the manner in which individuals experiencing mental illness or psychiatric disabilities meet the helping system as they decide to seek help. Hasenfeld (1992:4) states that that “the core activities of the (human service) organization are structured to process,

sustain or change people who come under its jurisdiction”. The use of the term client often confirms that the person is now raw material for the organizational “transformation process”. Within the psychiatric realm, Kirk and Kutchins (1992:169) discuss the process of new groups entering the system, with diagnosis as the “first scientific step in the organizations technical process of transforming a person with an ambiguous complaint into a client who will be a member of the organization with a defined mental disorder to be remedied”. While this construction of the client, or more accurately patient, is appropriate within the medical psychiatric services, the starting point for this research was the Social Services Act and the municipal responsibility to develop knowledge regarding the lives of people with psychiatric disabilities. As a context for the organizational integration of the target group described as the psychiatrically disabled, it is important therefore to examine some trends within the social services. Helsing and Blom (2001) describe a clear tendency in the social service system to specialize or to functionally divide programs within the general social services. In the case of the Reform and the legislative process leading up to it, this tendency may also be seen as a reaction to the acceptance of what had been previously a medically defined problem. Hydén (1998) describes the paradoxical process that occurs as a traditionally defined medical concern is “demedicalized” and moves into the social sphere. The development process that occurs within the social service system is presented as a “re-medicalizing” as there is a tendency to take in the medical knowledge, concepts and the manner in which social work with these new clients experiencing psychiatric disabilities is conducted. Helsing and Blom (2001) discuss this integration of a health-care perspective within the social services as a functional specialization that the leadership sometimes argues is necessary. They argue that the risks include however that social work becomes delineated based on a medical classification of need that is not relevant in the social services. While a heart operation requires a different competence than a hip procedure, the same cannot be said for clients of the social services. They also see functional specialization as leading to a situation where the focus is more on the organisation’s need than the clients. This type of reasoning mirrors that which was presented by New Institutional theory, where institutionalized belief systems come to dominate the generation of the organizational form, and may additionally, increase the “legitimacy and survival prospects of the organization” (Meyer and Rowan 1991:41).

It is also possible to consider how the organizational culture of the social services has developed a “rational myth” regarding individuals with a psychiatric disability. The diagnostic-medical perspective may be seen as contributing to an organizationally constructed paradigm of individuals as “belonging” to a disability group. The conceptualization of individuals experiencing psychiatric

disabilities as being similar enough in their lives and functioning to compose a homogeneous group can be said to be an institutionalized construct which has come to direct planning and practice. It is argued here that this construct can trace its roots more to the inherited tradition of classification predominant in medical psychiatry, than the social perspective which is central to the legislation directing the social services as regards these individuals. Underlying notions of illness and disability, and the implications of these for how we classify the users and potential users of various services, would seem to be a fundamental mechanism that steers the manner in which the organisation develops and delivers services.

*Such difficulties in implementing policies can be traced back to difficulties in altering cognitive structures ie. , the frames through which the nature of psychiatric illness and disability is interpreted. These structures have not changed in any fundamental way. We still tend to regard this group mainly in terms of illness and disease and not in terms of disability (Markström et al.2004:60)*

Attempts to classify individuals by client type, thereby creating categories, may be done so for the purpose of developing specialized services for a group with similar needs. Categorizing individuals as belonging to a certain group may therefore perform a “gate-keeping” function for the organization. There is also however the experience of “being categorized” which might be attended to, as we attempt to see the individual as agent in the meeting with the system. Stone (1985) describes a “crisis around disability” in terms of the categorization that occurs related to societal responses, and which she feels has become more difficult to resolve in the late twentieth century based on the following four factors. Standards for eligibility have become more detailed, groups once accepted into a certain category have difficulty leaving it, people are socialized into the disabled role, and categorization is legitimated by the medical and welfare bureaucracies. Hydén (1995) presents the handicapping process as implying a societal redefinition of psychiatric suffering – a process which points towards normalization and social integration, but presupposes that the client is first categorized as “abnormal” so that they can then access the helping systems supports for normalization. There is a kind of “give and take” in the process of being categorized as a client with a psychiatric disability, one receives services, but also acquires an identity that may be hard to escape. Ingstad and Whyte (p.19), in discussing symbolic interactionism and labelling theory (Scheff 1984), point out that; “One of the points of labelling theory is that the identification of a singularity by social agencies has consequences for the subsequent career

of the impaired person; primary deviance, once labelled, is encompassed by secondary deviance that is socially determined". The immediate effects for the life of the individual as they meet the helping system should therefore be one focus for understanding interaction between the individual and the organizational field. What labelling theory helps us to see is that there may also be implications for the individual within the other spheres of their life in the community. This "secondary deviance" is in many ways the concrete evidence of the organizational categorization process. The stigmatizing effects of such labelling will be discussed in the next chapter, but with regard to the organizational field, there are a number of points to be made. Is the categorization process, and subsequent labelling, a passive process where the individual is unaware of the potential "secondary deviance" as they seek help? Is the organization conscious of the potential for negatively impacting the identity of the individual as they plan and develop services?

## **From categorization to fragmentation**

Before leaving this discussion of the organizational field it is important to look at additional organizational mechanisms which may impact the meeting of the individual and the helping system. It is also clear that within the organizational realm, the structure of the entire social welfare system is a component of the social context for organizational development.

*It must be kept in mind that the Swedish welfare system is highly "sectorized" ie. several players act in the field of care and social services. Since each authority must cope only with categories of clients that clearly fall within it's jurisdiction, clients needs tend to be "compartmentalized". (Markström et al. 2004:54)*

This compartmentalization can also lead to fragmentation and help to explain the lack of a holistic perspective in the needs assessment process. By organisationally "separating" the individual from a holistic context for their lives, needs may be misrepresented and services developed based on organisationally-steered rather than "real" needs. These organisationally defined needs may be more susceptible to influence by traditional medical or individual perspectives on need, which many of the actors in the social psychiatric organizational field have integrated. Compartmentalized perspectives on need may be seen as an additional hinder to the ability of the organization to adapt to the social/environmental turn in understanding disability.

A specific area of concern in the landscape today are the “silos” between health care and social services (McDaid et al. 2007:191). The process of discharge from inpatient care for example, initiated with the concept of “completed medical treatment”, as an organizational marker for the municipality to now begin social work, is one that has often focused primarily on medically determined needs. “To discharge patients into the community without regard to community resources shifts the problem from the health care sector to the family, social welfare and/or criminal justice systems and contributes to fragmentation of services”(Farone 2002). This issue is both more and less acute in Sweden, where the clear municipal responsibility for community-based services reduces the risks of these needs being completely ignored. It may also however allow for them to be reduced to simplistic expectations on the municipality, and without holistic assessments of need that include both medical and social/environmental factors.

### **Approaching the organizational field**

*Clients follow a variety of routes in arriving at a mental health agency, come at times and in numbers that may not conform to the organization's capacities or work flow, present with a bewildering array of personal and interpersonal troubles, and possess all manner of idiosyncratic personal histories (Kirk and Kutchins 1992:164)*

I have discussed a number of features of the organizational field that may influence the manner in which individuals with psychiatric disabilities are received and offered services. In many ways I have continued to refer to them as a group, despite the many sources which have disputed that they may be seen as a homogenous group (Socialstyrelsen 1999; Markström 2003). Kirk and Kutchins (1992) help to clarify the individual perspective with which it would be prudent to analyze the situation today. Not only do they have different problems and needs, it would seem that the nature of mental health issues leads to an especially challenging variety of “meeting points” between the individual and the system. The issue of individuals avoiding or resisting services has been described above to some extent, here I would focus on two additional points regarding how individuals with psychiatric disabilities “present” themselves for services and how they are received. The first involves the organisations difficulty in “meeting” complex cases, and the second has to do with the struggle between the individual and the organization as a result of the dynamics of the situation.

Hasenfeld (1992:15) describes “contingencies”, as arising since neither the” reactions of the clients or the responses of the staff are completely controllable”. Contingencies include clients with multiple problems, complicated social networks, and multiple service providers in the picture. Helsing and Blom (2001:34) discuss the complexities of the life situations of such individuals, and that these complications defy the organizations attempt to categorize and divide responsibility. They state that these “complex cases” who are often the most vulnerable, are therefore seen as “administrative problems”. Diagnosis, or diagnosis-like categorizations (attempts to define disability) attempt to seek the proper category for the client, and therefore create expectations or constraints for the work which may be done. Hasenfeld (1992:15) sees compartmentalization as a “means for controlling the “service trajectory” of the client”. He sees the second issue, of compliance, as related to the organization exercising control by “tracking the client into various service trajectories, which in turn, constrain their options”. What may be seen is the individual presenting the entire complexity of their disability experience, to an organization which is only prepared to direct them into predetermined “service trajectories”, probably grounded in “rational myths” of the job they have been assigned, and not relevant to the actual needs/tasks that the current reality demands. Such a perspective sets a framework for the “meeting” as a relatively understandable clash of organizational and individual needs within a poorly understood context. Such a framework allows for the possibility of an active position by the individual in response to this attempt to categorize them and constrain the possibilities for helping them from a life- or community-based perspective on need. The action/reaction of the individual may therefore reflect insight into a dysfunctional situation, rather than the lack of insight into their illness which is so often raised as an explanation. One of the “myths” maintained within an exclusively medical psychiatric perspective is presented by Pilgrim and Rogers (2005:318) who state that the “psychiatric” assumption is that “services are ... sites of a patient’s right to treatment, rather than seen as potential threats to their well-being and citizenship”. Pescosolido et al. (1998) add another layer of complexity to the meeting between the individual and the system. They describe the importance of developing methodological approaches which include social processes, for example the effect of social networks as “first timers” come into contact with the mental health system. They describe three categories of individuals entering treatment; choice, coercion and “muddling through”. The last, which was frequently described in their study, is especially compelling as it describes individuals who neither resist or actively choose, but end up in care through a complicated interaction between individual action and social influence.

This chapter has presented what may be seen as two widely diverse theoretical starting points, that of social approaches to disability and organizational theory and process. At the same time, they are both necessary starting points for an exploration of the manner in which people with psychiatric disabilities meet the helping system which is now community-based. Has the organizational field developed its services to the psychiatrically disabled based on an accurate and current understanding of these individuals and their situation or based on organizational structures grounded in outdated knowledge? The following chapter explores theories related to the lives of these individuals out in the community, in order to develop a broader context for the analysis of the survey results.

## **Chapter three- Beyond the mental health system**

This chapter will present some ideas about how need may be related to what I will refer to as social location. While many of the concepts presented ideally demand a more thorough presentation, the intention here is to use them as “guideposts” to some of the operative mechanisms that may influence life in the community for these individuals. They may also be seen as tools, which may support the shift in attention from the institutional meeting with the individual, a system perspective, to the individual’s attempt to experience their life in the community. As stated earlier, research in an open system such as the community, demands a variety of perspectives in order to explore issues of need from a person-in environment perspective. The discussion of social location is followed by one which begins to describe mechanisms and dynamics which influence the experience of disability. The chapter ends with a brief discussion of the goals or vision for our work with people experiencing psychiatric disability, specifically normalization and recovery paradigms.

### **Describing the social context – Recontextualizing need**

In the previous chapter, I presented Cohen’s notion of the “decontextualization of need”, a process that occurs when we only employ individual/medical models to understand the lives of people with psychiatric disabilities. Descriptions of the social context of need would allow for more nuanced descriptions of the mechanisms which influence need as the individual interacts with the system and community. I use the term social location here, to specify the location in the social context where a certain phenomena is occurring or existing, as a means of “recontextualizing” the individual with the disability. Location, as I will use it, is quite broad and describes the “social”, that which is not individual, and that which may be described by a place in the physical community, a position in the society, or even a historical or generational location. While sacrificing precision, the aim of utilizing this notion is to begin to concretely describe the social landscape in which people with psychiatric disabilities are living their lives.

The notion of location, a geographic concept, seems appropriate given the geographical changes that the deinstitutionalization movement has implied.

Parr (2008:11) states that; “The spatial shift from asylum to community-based care has clearly not eliminated the relations of difference between the “sane” and “insane” that the asylum both invented and cemented”. She goes on to describe how the “asylum effectively enclosed patients as insane outsiders in ways that have proved difficult to disrupt in contemporary social life, even with the gradual demise of the asylum itself” (p.165). Yanos (2007) refers to the work by Dear and Wolch (1987) with the title “Landscapes of Despair”. Already then, they presented the image of “new geographies” of homelessness, ghettos of mentally ill, reinstitutionalization and “zones of dependence”. (Parr 2008:182). They described people living in their community but not part of the community. Yanos (p.5) concludes that we have not moved on from the study of “post-asylum” settings within the traditional urban “service dependent ghetto”. Gabe and Warner (2004:388) discuss the concept of “transinstitutionalization” and summarize arguments describing community care as simply a “transfer of the main functions of social control from the asylum to a new location”. The result is continued alienation but in an alternative site (the community). These “post-asylum” locations may be seen as the first step out from the institution. The point he makes, which I would like to build on, is that we have not looked beyond those locations defined by the boundaries of the service system, either to see if some individuals have ventured beyond the mental health system or to see if there are opportunities for them to do so in the future.

According to Ingstad and Whyte (1995:4); “Studies of disability require us to move away from the clinic toward the community where individuals and families live with deficits”. The social approach calls for this focus on the social context or location of need, since social environments, whether they enable or obstruct a participatory life, are part of the social landscape which defines disability. They go on to specify the question, asking; How does impairment interact with factors like sex, age and economic standing to create different situations within a social universe?(p.16)”. This is the type of question that may be seen as an inroad into the operationalizing of the social approach for people with psychiatric disabilities. The following sections will briefly address a number of aspects of the social context in which researchers and theorists have begun to develop insights into how people live in the community.

### **“Neighborhood” as a physical, economic and social phenomenon**

While there has not been a great deal of attention to the social universe within which the individuals experiencing their disability live in the post-deinstitutional

era, there are quite a number of studies that have attempted to look at social factors that may interact with mental illness. The “neighborhood” in which a person lives, is a clearly relevant factor in attempting to understand the social landscape for people living with psychiatric disabilities. The concept of neighborhood may be thought of locally, but even on a national and global basis, since our neighbours interact with us on many levels in the globalized world we live in today. The concept becomes even more complicated as the possibility of cyber communities such as Facebook develop. Parr (2008:137) states that “...contemporary technologies are implicated in changing the geographies of social support and cohesion for vulnerable groups like the ill and disabled”. There are clearly implications of such cyber communities for developing support in many areas of life. Just as the concept of neighborhood may be stretched geographically, it can also be seen as a framework for discussing economy and therefore class, as we know that financial resources allow for entry into many of the community resources that are central to quality of life in the community. While poor or marginalized neighborhoods are less common in social welfare states such as Sweden, than in the UK or USA for example, the social landscape of Sweden is changing as well, with greater class differences and housing areas predominantly composed of immigrants, and where unemployment is extremely high. “One of the most consistently replicated findings in the social sciences has been the negative relationship of socioeconomic status with mental illness”(Hudson, 2005:3). While the causal structure of this relationship is unclear, what does seem clear is the importance of focusing on neighborhood as a factor that may impact disability for people with mental illness (Busfield 2000:548).

Such findings are often discussed in relation to geographic drift (Busfield 2000), where in conjunction with the illness, or as a precursor to the stress which may unleash the illness, the life situation of the individual worsens. This is a phenomenon which seems clearly linked to the lives of people with psychiatric disabilities. It may refer specifically to an economy-related crisis which precipitates a move to a “poorer”, often more marginalized neighborhood, but it may be used in a broader fashion as well. Hatfield and Lefley(1993) raise the concept of “downward drift” as they discuss the increasing incidence of dual diagnosis among individuals experiencing psychiatric disabilities. They bring up the consequences of the illness or disability which may impact the individual’s lifestyle. These include poverty and isolation, social consequences not directly related to the impairment, but resulting from the effects of the manner in which society responds to the disabled individual. The low income associated with a dependence on social insurance may lead to the need to live in marginal neighborhoods where drug use and other criminal practices as well as violence

may prevail. Markström (2003:110) takes up the incidence of increasing drug use as well, as a “price” that we must be prepared to pay for ideas of normalization and community integration. As individuals turn away from the care system, they turn more towards a problematic community life. As these individuals come more into contact with the people who populate these community locations, and come more under the influence of these lifestyles, the social consequences of their psychiatric impairments increase.

Another factor often associated with downward drift is unemployment, which is excessively high for these individuals. A 1995 study in Sweden reported 8 percent employment rate among the “target group” for the Mental Health Care Reform (Hansson and Eklund 2005: 233) and Thornicroft (2006:50), in a review of European studies found rates of from 5 percent in the UK to a high of 20-23 percent in Spanish and Italian cities. Bond (2004) describes the chain of results that may be associated with unemployment, including heightened risks of alienation, apathy, substance abuse, physical ill health and isolation. The mechanisms by which unemployment produces such negative effects over time would seem to be the same for people with psychiatric disabilities and those without. The effects of unemployment would in this light, become a central focus in an environmentally-relative model of psychiatric disability, and would seem to lead us into a broader discussion of such “normal” social mechanisms. The confusion related to the “causality” issue with regard to the issue of neighborhood, is further complicated as we look at the community from the standpoint of unemployment, and realize that the long-term unemployed, as they begin to experience downward drift, may begin to experience mental health issues.

Finally, Gabe and Warner (2006:5) describe the poverty that individuals with psychiatric disabilities most often live in, due to restrictive social benefits, and which excludes them from participation in even relatively inexpensive activities such as going to the movies, or attending sporting events. This economic exclusion is compounded of course by the high unemployment rates discussed above. The authors note that (p.50) there are surprisingly few studies of the financial problems of people with psychiatric disabilities living in the community. Thornicroft (2006:71) reports the results of one study which concluded that the “most powerful factor that shaped the identities and everyday opportunities (of people with psychiatric disabilities) was their subsistence income”. While poverty, or subsistence incomes (more common in Sweden), may not always determine physical marginalization, finances are often an extremely concrete barrier to participation in the activities of the community.

### **Social exclusion – Challenges and possibilities for citizenship**

If we follow the downward spiral associated with economic and social drift of the type described above, we see that social networks are intertwined with the neighborhoods in which we live and our opportunities to participate. Byrne (2001:281) states that; “Lack of social networks is, in effect, social exclusion”. From this perspective, it becomes clearer that a lack of resources can create a marginalized social location for the individual. In other words, our social networks may be seen as “locating” us in the society or community, in a similar manner to the geographic function of the neighborhood. Both dimensions are important however and help to orient us towards the possibility of developing knowledge of the mechanisms active in these different locations. “Normal” social stresses such as those related to economy and social networks would also seem to be points of intersection with the community, where both individuals experiencing psychiatric disability and those who are not, are affected by the same social mechanisms. The effects of such common social factors may have particular effects for the individuals we are interested in however. Byrne also describes literature pointing to the fact that social networks, real and perceived, may actually predict the onset and recurrence of mental illness (Corrigan and Phelan 2004). Thornicroft (2006:27) summarizes the research which has been done in the field and concludes that “people with more severe forms of mental illness have smaller social networks than others”. People with larger social networks, on the other hand, are less likely to be admitted to the hospital for mental health issues.

As Parr (2008:28) describes; “Critically exploring these new geographies of community participation throws into relief the limits to social inclusion for people who can only ever partially live out the ideals of “active citizenship” as they are currently configured by the state”. There are two critical points contained in this quotation. The first has to do with the fact that it is only by exploring the landscape within which people experiencing psychiatric disabilities live their lives, that we can become aware of the social barriers which frustrate their attempts at participating. The second point has to do with the individual as “citizen”, a position often discussed in relation to the role as patient. “We define social integration as a process through which individuals with psychiatric disabilities develop and increasingly exercise capacities for interpersonal connectedness and citizenship” (Ware et al. 2008). Meeuwisse (2000:475) sees user and family associations, as well as the clubhouse movement, as having advocated for a move from a perspective that sees the individual as patient to one that sees them as citizens and with possibilities for demanding more participation and influence. Mulvaney (2000:585) links the “examination and identification of the social barriers that deny or restrict access for people with a serious

psychiatric disability to the rights of citizenship”. Inability or disability in this view is often connected to a loss of the right to participate equally. Nancy Fraser raises the notion of “the parity of participation” (Hugemark and Roman 2007) where all, regardless of ability, maintain their right to participate in the community.

*It (the social model) has shifted the emphasis from "individual adjustment and rehabilitation" to challenging discrimination and securing the human rights of disabled people (Beresford 2002:583)*

The move from a patient/client perspective to one that sees the individual as a member of the community can influence the manner in which needs are framed, explored and acted upon. The next section will discuss stigma as a specific example of social exclusion.

### **Stigma and the integration of shame**

One of the most well known examples of stigma and social exclusion is represented by the NIMBY (not in my back yard) phenomenon (Leff and Warner 2006). While essentially positive to the process of deinstitutionalization, when it came time to actually “locate” a group home in a particular neighborhood, there was resistance by local residents, based on their fears of the mentally ill. The NIMBY response helps to place the focus on the manner in which “normal” society attempts to hold people with psychiatric disabilities at a distance. Not only is there a tendency for these individuals to end up in poor and marginalized neighborhoods, there is also an active resistance to their locating in better neighborhoods. One of the most widely discussed, and in some ways least addressed mechanisms which lead to social exclusion is stigma. Thornicroft (2006:180) presents what he believes is the most complete model of stigma, including four key components. These are;

- 1) *Labeling, in which personal characteristics, which are signaled or noticed as conveying an important difference*
- 2) *Stereotyping, which is the linkage of these differences to undesirable characteristics*
- 3) *Separating, the categorical distinction between the mainstream/normal group and the labeled group as in some respects fundamentally different.*
- 4) *Status loss and discrimination: devaluing, rejecting, and excluding the labeled group.*

I present these in their original form, since they provide a useful framework for organizing an analysis of the mechanism of stigma in many aspects of the individual's experience in the community. The social process of becoming stigmatized may be closely linked to the concrete experience of downward drift discussed above. Murphy (cited in Ingstad and Whyte 1995:140) argues that the negative identity and the struggle against this "imposed image" leads to the conclusion that "stigmatization is less a by-product of disability than its substance". In other words, the process or mechanism of stigmatization may be seen as constructing the disability. People become disabled by illness-related impairments when they try to live in communities that stigmatize them. In this case, stigma may be seen as a potential cause, and social exclusion as the effect. Leff and Warner( 2006:3) describe one of the mechanisms which can lead to "social ghettos", as people with psychiatric disorders are rejected by the public, resulting in social isolation and a segregated life together with others experiencing similar problems.

Corrigan (2005:130) presents labeling theory as an explanatory framework to account for the stigmatization associated with "devalued statuses". The lack of status, which may result from both external and internal (internalized) stigma, has been extensively described in the empowerment literature, and may have long-term effects on the individual's ability to express their needs and develop their potential (Chamberlain 1997; Deegan 1998). It is central to the understanding of stigma to see this as a process of social transformation, a "socialisation sequence in the individual biography, and a more or less extensive transformation of the social identity" (Svensson, 1994: 101). Psychiatric disability has historically carried more than its share of stigmatizing themes in society, and therefore life choices associated with the experience, or potential experience of being stigmatized are quite powerful forces in the career of the individual. People experiencing psychiatric disabilities, many of whom express difficulties in maintaining a positive self-image for themselves, react to this spectre of stigmatization and it can inform their choices of how and where they seek help. Svensson (1994) describes Goffman's reasoning as to how the social identity develops and can be understood as the product of the didactic relationship between identifying with an organisation and opposition to it. As has been described in discussions of the "young adult chronic" patient sometimes the only manner in which the individual can express dissatisfaction with the choices and structures offered by the system is to refuse them, to "choose with their feet". By refusing to accept the possibility of becoming integrated into the culture created and defined by the classification system of the organization, they are at the same time attempting to preserve an identity as "normal" community members. While the practical results of these decisions, interpreted as rejections

of help by the system, may often be negative, they might better be understood by analyzing their function within this interactive and dynamic process of establishing and maintaining identity or status as a community member.

While stigma is often construed as an external force which may restrict individuals with psychiatric disabilities from participating in the community, there would also seem to be a systemic stigma which may be more difficult to detect. Björkman and his colleagues (2008:176) found that while nursing staff may have more realistic opinions regarding dangerousness and schizophrenia, that they have similar attitudes to the general population when it comes to the hope of improvement in treatment and recovery. They warn that; “For persons who are known as having a high threshold for help-seeking behaviour, experiences of rejection may lead to them not seeking treatment, even when needed”. Even pessimistic attitudes towards the potential for recovery may be “rejected” by individuals seeking help in order to continue their lives. Corrigan (2004:615) points out two disturbing trends; 1) Many people (30-40%) with mental illness never pursue treatment 2) Others begin treatment but fail to fully adhere to services as prescribed. In attempting to explain the manner in which stigma may be seen as an obstacle to seeking treatment supports, he discusses negative attitudes including shame, or self-stigma, which has shown itself to be a “significant predictor of treatment avoidance”. The interesting result is that the greater the “endorsement” of stigmatizing attitudes, by young people for example in one study, the greater the chances that they will avoid seeking care. The causes and effects of stigma are both complex and widespread, yet it is clearly a mechanism operating within the social landscape and is not limited only to the community to which the individual returns. The social context is always there, with the shame that communities may instill in the individual following them directly into the psychiatrist’s office.

### **Liminality –The social suspension of identity**

In a discussion of the difference and similarities between physical and mental illness, from a disability studies perspective, Parr (2008:20) argues that one similarity is that both “challenge conventional norms and conceptions of minds and bodies in ways that result in states or spaces of exclusion”. The discussion above has focused attention on social exclusion, as embedded in marginalized neighborhoods, where poverty and drug abuse for example, may be mechanisms that impact the disability of the individual. However in reviewing the literature related to the experience of disability, it becomes clear that there are other “spaces of exclusion” which are not as visible as the streets where the homeless for example, cannot be avoided.

Murphy (1987:131) describes the “problematic status” of people with disabilities as outsiders or “symbolic others”. He uses the term “liminality” to describe this problematic status, as a state “of social suspension, where people with disabilities are neither out of society or wholly in it, where old roles and statuses have been lost, and nothing new has replaced them, so that they exist in partial isolation from society as undefined, ambiguous people”. He contrasts the label of disability with that of illness, which he describes as transitional to either death or recovery. “The sick person lives in a state of social suspension until he or she gets better. The disabled spend a lifetime in a similar suspended state” (p.154). While institutions concretized this social suspension, it can be stated that the labelling of the individual as disabled, a process that occurs most often in their categorization within the service system, is the process that concretizes this identity for the individual in the community. In this use of the term, liminality may refer to a state of “ambiguous personhood”. The state of the person may be described as “liminal”. “It is during a transitional phase from isolation to emergence that the person is said to be in a liminal state – literally at the threshold – a kind of social limbo in which he or she is left standing outside the formal social system” (Ingstad and Whyte 1995:10). Using more familiar language from the welfare system, it might be said that the person is not seen as eligible for a participatory role in the community, and waits for an assessment that will allow them to move on from the programs that hold them during this transitional period.

Warner and Gabe (2004:394) use the example of users who were perceived as being “difficult to place”, those who defy categories as I have discussed earlier, who may also be seen as being “in-between” places, another sort of liminal position. So that liminality may be used both to describe the lack of a societal role for the individual, not still patient, but not yet citizen for example, but also to describe a geographic place in the community. They also (p.389) discuss liminality as associated with “place”. The “street” for example is one such place, since people are always on their way somewhere else. They state that there is research which suggests that “place” may be an important consideration at the “intersection of risk, liminal otherness and mental health” (p. 388). I have been using the term social location in this chapter as a concept which encompasses and attempts to describe the social landscape which exists beyond the psychiatric treatment relationship as encapsulated within the mental health system. The concept of liminality is one that may also be applied to the structures within the social psychiatric system, that offer day programs as a transition to real work or studies, group homes as a transitional location on the way to your own home, and supportive staff that often take the place of natural social networks. Topor (2001) describes these as “intermediate care forms”

which attempt to fill the void between the treatment system or “total institution” and community life.

What might exist at the other end of this transition, which is concretized by both place/location and role? Mulvaney, (2000:585 ) argues, as do a number of authors (Oliver 1992; Barnes et al. 1999) for a connection between the social approach to disability and the need for social change. She points to the gap between the “rhetoric of “inclusive citizenship” and the reality of resource delivery. When resources are only directed to individual needs they will not be effective in creating opportunities for social inclusion. The needs perspective in this meaning needs to be supplemented by a rights perspective, as presented above. In an article describing the emphasis in the UK on social inclusion, Ramon (2007:17) describes their social inclusion program which “shares the strengths approach and the social model of disability.... and attempts to reduce stigma”. The practical implications of the social approach to disability, discussed above, would seem to lead to a focus on the efforts of the system to begin to understand the mechanisms which lead to social exclusion, such as stigma, and begin to research what mechanisms might help to pave the way for a socially inclusive landscape.

## **The dynamics of time – Capturing social and generational locations**

In this chapter I have so far presented some concepts that might be useful in beginning to better understand the social context for the needs of people with psychiatric disabilities. The discussion to this point, has focused on location, defined from a geographic perspective, but even with relation to the “place” of the individual in the society. Giddens (1984:17) argues however that; “...excluding time and space from social analysis, or privileging a priori one above the other, seriously distorts our understanding of the way social reality is constructed”. Asplund (1983:190), in describing the importance of the concept of time geography, argues that everything that occurs, occurs in time and place. In some ways, discussions of the social approach to disability, which succeed in “recontextualizing” the individual in their social context, do not always prioritize the dynamics of time as a factor in understanding that context. There are two aspects to the time dynamic that I would like to briefly consider here, that which relates to the life of the individual and that which relates to the historical context of the individual’s life in the community.

Ingstad and Whyte (1995:21) argue that; “... any overview of disability and culture should also consider the historical processes through which the range of possibilities and the nature of practices change”. There is a historical change

occurring, in the case of people with psychiatric disabilities, in the development and provision of services, as we work within a continuing process of deinstitutionalization and are on our way to an era that may be termed the post-deinstitutional. Possibilities for receiving help from the service system are determined in no small measure by this historical process, and will therefore impact the lives of particular individuals coming into contact with the mental health system. Priestley (2001:17) states that what he calls a “life course perspective” can offer a “valuable orientation not only to the dynamics of individual lives in historical and social context but can orient us to elaborating that context”. The life course approach as described by Priestley links the two aspects of time which I presented, by focusing on the links between the “individual lived experience of disability and the macro-social context in which disabled lives are played out” (p. 245). In discussing the life course approach he states that; “From a social model perspective, the value of this approach lies in the opportunity to learn about the differing impact of disabling barriers, and the different social meanings attributed to disability, in different generational locations (ie. childhood, youth, adulthood or old age). This concept of generational locations can be quite useful as attempts are made to study the life course of the individual experiencing the disability. At what point in their life cycle and experience of functional limitations do they interact with the helping system and in what ways?

## **Destinations in the community – Beyond normalization**

Up until this point, the discussion has included the foundation for the mental health system, as concepts of disability interact with organizational structures which attempt to develop relevant services and supports. I have also introduced the idea of seeing need as a socially located phenomenon, and argued that in addition to location there is a dynamic quality to the experience of disability that should be attended to. While these are useful starting points in an exploration of psychiatric disability in the community, there is also the question of direction or vision. Where are they on their way to, and what goals should the helping system support? In this last section, I would like to therefore look at Normalization theory, one of the guiding paradigms of the deinstitutionalization era and introduce Recovery as a body of knowledge that has the potential to provide another way forward.

Discussions of how groups of individuals experiencing disabilities exist in and interact with society have been heavily influenced by normalization theory

since the 1960's when it began to spread from Scandinavia. Historically, it can be stated that normalization came about as a natural reaction to the over-specialization and institutionalization that had characterized service provision until the 1960's. Normalisation theory has evolved over this period as well and has come under increasing critique in recent years (Oliver 1992, Barnes et al. 1999). The positive force with which its arguments were made in these earlier years however has been one of the forces pushing society to socially reform its encounter with disability. Normalization begins with the principle that; "...to the highest degree and in as many areas of life as feasible, a devalued person or group have the opportunity to be personally integrated into the valued life of society" (Brown and Smith 1992). Many concrete suggestions that arise from this principle, especially those that flow from Scandinavian formulations connected to normalized environments as opposed to Wolfensberger's later formulations regarding social roles (Barnes et al. 1999), are related to the geographic and structural placement of individuals experiencing disabilities. Housing should be non-institutional and located in "normal" neighborhoods. The daily schedule, which should include work and vacations for example, should follow normal rhythms of community life. Coming from the institutional world, where the structures of life had been totally displaced from community life, normalization theory served an important function as a "map" for the system of how to get the disabled back to a life in the community. Criticisms of the approach grow out of the idea that while this strategy has helped people begin the journey, it has not offered an equally useful paradigm for community change and integration.

Deegan (1998) describes the normalization model as reinforcing the implicit supposition that there is a world for the normal, and therefore a world for the abnormal. This leads to the task of the staff as to "...somehow get the people in the abnormal world to fit into the normal world". Oliver (1992) takes a similar position regarding normalization as he sees people with disabilities as feeling that they must "come to terms" or "come to normality" if they are to have a successful interaction with the community. Many individuals therefore choose to withdraw from contact with "normal" community members due to the pain they experience when interaction only serves to reinforce their differences. The normalization map, so clear as folks were on their way "home", has perhaps become fuzzy at the gates of community life, where many individuals seem to be living a parallel life, a life considerably more present but not yet in the "real world".

The whole focus of the normalization approach, according to Barnes and his co-authors (1999: 74) is to change disabled people, to make them more like normal people, rather than to challenge ideas of "normality". Davis (1997) de-

scribes the concept of the social construction of normalcy. He argues for analysis not just of the construction of disability, but also its perceived opposite. The question this raises is; How would a “normalcy” that includes the disabled in community life look? Many of the answers to this question would focus on society’s need to adapt and create access to community life and roles in the work place, school, socially, etc. As Normalization was useful as a vision for the first steps out into the community during the era of deinstitutionalization, the emerging field of Recovery may offer some answers to these questions and provide the basis for a new vision.

### **Recovery – Social approaches in practice**

Recently, research has been carried out that has studied conditions for recovery for persons experiencing psychiatric disabilities (Thornicroft & Szmukler 2001; Anthony et al. 2002; Drake et al. 2003). Gabe and Warner (2006:162) state that; “the roots of the recovery model may be found in both the consumer/survivor movement and professional psychiatric rehabilitation initiatives”. Opportunities for the individual to participate, as they experience themselves within a broader life perspective, are presented as some of the most essential ingredients in recovery from serious psychiatric disabilities (Anthony & Lieberman 1994; Hughs and Weinstein 2000; Rosen & Barfoot 2001; Topor 2001, Deegan 2003). Longitudinal studies have shown that the possibility of recovery exists, and with much greater frequency than previously believed, for persons experiencing psychiatric disabilities (Harding 1999; Harding et al.1987:483). Many researchers (Topor 2001; Spaniol et al. 2002) have utilized designs where they have asked people with psychiatric disabilities to describe the factors that contributed most to their own recovery. Kramer and Gagne (2002) present a number of conclusions from a review of such studies; People recover not just from their illness but from the loss of a role in community life. They recover from a loss of possibilities and from a loss of their identity, connection and hope. The factor that they consistently present as having helped most is a hopefulness connected to the possibility of a valued role in the community.

Recovery oriented research may be seen as a link between the theories and ideology presented in social approaches to disability and the principles and methods of Psychiatric Rehabilitation (Anthony, et al. 2002), a field which has developed evidence-based research that focuses on the potential of people experiencing psychiatric disabilities. Hughs and Weinstein (2000:41) describe the rehabilitation model as focusing on the “functioning of the individual in the normal, day to day environment, and looks at the strengths and skills people bring to the rehabilitation process and potential supports in the environment”.

Knowledge of recovery supports the conclusion that the individual's relationship to the social environment is central to their particular experience of a psychiatric disability. A recovery/rehabilitation perspective, more connected to the individual's wishes, resources and social possibilities than to their illness or impairments may therefore be seen as providing direction for understanding the needs of individuals with psychiatric disabilities in the community, and planning relevant supports. The recovery perspective fits neatly with the notion of social inclusion discussed above, and is closely linked to psychosocial rehabilitation models which view functioning in terms of a "person-environment fit" (Fossey and Harvey 2001:94). Pepper and Perkins (2003) suggest that social inclusion is an integral part of recovery, as in their view recovery cannot be sustained without it. Secker (2002:410) stresses the importance of a "socially accepting and acceptable environment". Ridgeway(2001) sees recovery as "moving from withdrawal to engagement and active participation in community life". The notion of Recovery as existing within a socially inclusive community which allows for and offers opportunities for active participation, brings us back, after a long and winding theoretical road, to some of the language of the Social Services legislation in Sweden, which promises "active participation in the life of the community" even for individuals experiencing disabilities related to psychiatric disorders.

As stated earlier, this project is grounded in a practice-related research design, so that there was a consistent need to represent theoretical discussions in a practical form that might inform planning. The following section provides a background for the manner in which this aim will be integrated in the studies which follow.

### **Social mapping – Illustrating the social landscape**

Beginning in chapter five with study one, a series of illustrations will be utilized to graphically represent both the starting point for the surveys and the various stages of development of the model that will be presented in the final chapter. These illustrations may be seen as an attempt to apply the concept of social cartography or "social mapping" in a simplistic, but potentially useful manner. It is therefore appropriate to briefly describe this approach. Paulston and Liebman (1993) define Social Cartography, or Social Mapping, as "the creation of maps addressing questions of location in the social milieu... It (social cartography) suggests not a synthesis, but the further opening of dialogue among diverse social players". This is an important point, since the intention of the illustrations I will present is to provide a structure for the findings and to stimulate dialogue regarding the social landscape for people living in the community with psychiatric disabilities, not to present a finished model. Hägerstrand

(1991:145) argues that time has to be taken into account along with space and discusses the notion of the “time-space path” which a given actor may trace on any given day. He includes concepts of spatial proximity and time, for example a given location may be near an individual, but that will not be good enough if the person does not have the time to travel there on a given day ”In time-space the individual describes a path, starting at the point of birth and ending at the point of death” (p. 145). This path may be displayed graphically in order to illustrate the path that the individual might follow during a day or during a “career” of dealing with a disability. So that in the illustrations which follow, there is both an attempt to locate the individual within the social landscape and to explore the dynamics of disability, as they move through their lives as community members and as disabled.

The previous two chapters have described social approaches to disability, as a platform from which to more holistically explore need within organizational and community contexts. They have also laid a foundation for considering disability as a dynamic process and one that, as with other life experiences, changes over time in relation to individual and environmental factors and opportunities. It is finally suggested that there is an element of direction in this process, and that both individuals experiencing disabilities and the organizations and professionals who attempt to help, strive for a vision of what their mutual goal might be. An attempt to graphically illustrate these processes is also introduced, as a goal for the thesis, related to the aim of developing a focus for planning services. Beginning with the following chapter, the design and results of the three studies that will form the basis for this exploration, will be presented.

## Chapter four – Research design and methods

This chapter will present the design of the surveys which were analyzed within the aim of the research. Specific adaptations which were used in each of the three studies, and in a number of cases in a specific municipality, will be described in the appropriate chapter. While the theories presented in the previous two chapters will be utilized as a structure for interpreting the patterns which emerged in these studies, the survey process itself is the basis for the empirical results which will be presented in the following chapters. A specific responsibility within the social services, as described above in the Social Services Act, is to survey the living conditions of people experiencing physical and psychiatric disabilities. While many local systems completed such inventories and surveys of need prior to and just after the Reform of 1995, the majority had not completed new surveys, an especially critical need in the wake of the many changes stimulated by this new legislation. Already in 1998, in a report of the National Board of Health and Social Welfare reviewing the first thousand days of the Mental Health Care Reform (Socialstyrelsen 1998) they concluded that;

*Inventories don't reach the psychiatrically disabled individuals who lack contact with the social services and/or psychiatry. The municipalities should therefore intensify their outreach activity.*

In a final report from the national oversight process which noted that 55 percent had failed to survey needs for this group, they stated that;

*...outreach activities are decisive so that a greater number can be reached by the municipal services and so that early and preventative services can be provided. (Socialstyrelsen och Länsstyrelserna 2005)*

Particularly interesting for the study that will be described here is the emphasis on “early and preventative services”, an aim which goes directly to the method questions we struggled with. Put briefly, if the inventory process is only to count those we already “know” as seriously psychiatrically disabled, how can we develop knowledge that would help us to understand the mechanisms that would shed light on early and preventative interventions?

The three studies, all completed within the same county, proceeded from a common design with regard to quantitative and qualitative methods, and design differences relate primarily to the description of the target group for the study,

the form for the focus groups and the questions related to need and participation in community life. These adaptations related to prior results are introduced here, but discussed extensively in the following three chapters. Study one, the initial study, involved one municipality, and was completed in 2001. Study two involved four municipalities, the first two completed in 2003 and 2004, and the second two in 2004 and 2005. Study three involved the two remaining municipalities in the county and was completed during 2006 and 2007.

A vast amount of data was produced that was directly applicable to questions which the various municipalities struggled with in their planning and development activities. For the purpose of this thesis, the data contained in these reports is utilized as a secondary source, in order to answer questions related to contact with the system and the community context of need, the aim of the dissertation. The individual surveys may be seen as case studies which were then analyzed based on the research questions posed here. In order to investigate the questions posed in the aim of the study, I have reviewed all seven of the reports which were produced in the municipal studies. Both quantitative and qualitative material related to the research questions have been analyzed and in many cases additional tables have been generated which either reflect the cumulative result for a number of, or all municipalities, or alternatively re-analyze the original data based on a new focus provided by the research questions. In the process of studying the cumulative material based on the research questions posed, I have focused on results related to the aim of the research and therefore the results presented in the following chapters reflect only a portion of the total picture that emerged.

## **Research orientation**

While I have described some of the theoretical starting points for the analysis of the data presented here in chapters two and three, it seems important to say something about the general orientation of the research from a methodological standpoint. These may be seen as starting points for the method development in the actual studies, but are also worthy of reflection as the research questions are layered over the investigative surveys. An obvious starting point for this discussion, but one important to remember, is provided by the WHO in their report *Prevention and Promotion in Mental Health* (2002:14); "To provide evidence on descriptive issues requires different research methods from those used to obtain evidence on causal relationships or from those providing proofs of the effectiveness of an intervention". This is essentially a report that seeks to describe. I would point therefore to three broadly defined research orientations which may be seen as framing the overall direction of the project. These in-

clude social reporting, methodological pluralism as described in the realist literature and finally, themes attributable to participatory or action research.

### **Social reporting**

The National Board of Health and Welfare describes the purpose of social reporting as to; "provide a current overview of how social problems and associated risks have changed over time within various segments of the population, and to analyse the possible causes of any such changes" (Socialstyrelsen 2001). Based on a tradition of social reporting in European countries the function of such reports is to provide a basis for the development of welfare policy. (Johansson 2002) describes social reporting as answering the question of "how it is" and not how it ought to be or what should be done, questions that require discussion and opinions as part of the democratic process. Social reporting provides information on "common concerns" that individuals face within the life cycle. Börjesson describes the Nordic tradition in research on living conditions and human welfare, as describing the "individual's access to resources which, under given circumstances, enable one to control and manage one's own living conditions" (Titmus 1976 cited in Börjesson 2002). He goes on to state that "... the task of social policy is to provide favourable conditions for sustenance, based on citizen's access to the various resources that are necessary for maintaining a reasonable living standard".

This language, and the intention to report on the individual's life in the community, in terms of their access to resources and roles, would seem to underlie the intention of the Social Services Act in requiring the municipalities to report on "living conditions" for people with psychiatric disabilities. While often used in the context of poverty and disadvantage, this more holistic method of reporting can inform the process of researching the needs of this particular disability group, a group who all acknowledge has been marginalized or as Börjesson (2002:13) suggests, socially excluded from a participatory life in the community. An important aspect of the concept of social exclusion is that it describes the "relational character" of the interaction between individuals or groups and societal conditions. An attempt to "see" the individual with a psychiatric disability in relation to the wider community, and not just the service system was a starting point for our method development.

### **Methodological pluralism**

Critical Realism is not a method, but rather an ontological and epistemological base from which to develop strategies for understanding social phenomena. I have already described how some of the ideas from Critical Realism have informed the research but will briefly describe their impact on method questions.

While the realist notion of seeing social systems as open systems, and not open to “closed-system” structures for investigating causal relationships continues to challenge methodology, Pawson (2006:19) among others has attempted to develop realism as an empirical method. “The guiding impulse is that it is still worth trying to adjudicate between alternative explanations, even in the knowledge that further explanatory possibilities remain untapped in the unrelentingly open systems in which we live”. The primary point here, as stated earlier, is that attempts to define a “closed system”, the individual as service recipient, within which to investigate the needs of people described as psychiatrically disabled, may be seen as reductionist and no longer relevant to the task of understanding their lives and needs in the community in the post-deinstitutional era. While sacrificing the ability to determine causality with relation to the effectiveness of particular services, an important focus as well, my hope is to begin to identify some of the generative mechanisms which may help to explain the situations/locations in which we have identified individuals experiencing these disabilities. As Pawson (2006:22-25) describes, we seek “outcome patterns” and search for mechanisms, existing within a social context, that can help us to understand these patterns.

In describing their orientation as critical realists, Miles and Huberman (1994:4) discuss their view of the aim of social research. “Our tests do not use “covering laws” or the deductive logic of classical positivism. Rather, our explanations flow from an account of how differing structures produced the events we observed”. Beginning with the initial study, we began to notice patterns that did not fit the expected relationship between client or patient and the helping system. This event or “contrast” (Lawson 1997), was the precipitant for a broader investigation that sought mechanisms and structures which might help to explain these. The move from empirical event or individual phenomena to new ideas regarding how these are part of the structure and internal relations of social phenomena is referred to as abduction. As described by Critical Realists, abduction may be seen as a means of inference, where we “...recontextualize and reinterpret something as something else, understanding it within the frame of a totally new context”. We interpret individual events in other words, with the help of concepts, theories and models as part of a general, more universal context or structure (Blom and Morén 2009). As will be discussed throughout, the empirical observations we were able to make in these studies, have been interpreted within concepts, theories and models related to the social context of disability. Abduction allows us to gain a perspective from which to pose further questions related to the empirical phenomenon.

Retroduction is the process of inference that asks the question; “How is any phenomenon, like an action or a social organization possible?” We attempt to

focus on what is basically characteristic and constitutive of these structures (Danermark 2002; Blom and Morén 2009).

This move, from empirical events as noticeable social phenomena, to strategies for seeking explanations, is one that realist researchers including Danermark (2002) and his colleagues have described as requiring a broad methodological approach, a “methodological pluralism”. Danermark describes the advantage of using mixed methods as having a number of purposes, including the use of qualitative and quantitative methods “side by side in order to empirically elucidate a phenomenon in as much detail and as thoroughly as possible” (p.153). As will be seen below, the studies which will be presented in these pages utilized many methods, and adapted these at many points, in order to reflect emerging knowledge of the landscape in which people with psychiatric disabilities were living their lives.

### **Action Research**

While not explicitly following a Participatory or Action Research model, these traditions and methods influenced the research in at least two ways. The studies presented here began with a community-based need that was intended to lead to change. “Stakeholders” or interest centers, were able to participate in the research process in a variety of ways. One aspect of PAR research, which was particularly familiar in this project, was the reality that the researchers do not have exclusive control over the process.

*A fundamental premise of community-based action research is that it commences with an interest in the problems of a group, a community or an organisation (Stringer 2007:10)*

The need for knowledge arises from a situation “where a problem has to be resolved or where there is a strong wish for change” (Lundberg and Starrin 2001). The “origin” of the research process may be seen in the impetus to practically impact a given situation. In our case, there were at least three factors which led to the studies, none of which began with an academic or theory-based question. There was the legislated responsibility for the municipalities to survey living conditions, the existence of national inquiries which reminded them of this responsibility, and finally the perception within the municipalities and within the field as a whole, that living conditions had not improved as much as had been hoped, a situation requiring first knowledge and then action.

“By having the opportunity to take part in the various phases of a research project, ordinary people in for instance an organisation become important cogs in the control and interpretation of facts and in the assessment of the construc-

tivity of various proposals for change” (Whyte 1989). In the course of these studies, owned by the municipalities and organized by the research unit, stakeholders had the chance to determine the types of questions asked in the survey forms, participated in the analysis phase, had input on who would be invited to participate in focus groups and were consistently provided with results in order to influence administrative and political processes in their organisation. I therefore looked to PAR (Starrin 1993; Danley and Langer 1999) as a structure which helped us understand and steer a process that may have otherwise seemed chaotic and out of control. The dispersion of the knowledge being generated was intended to have a positive and direct influence on practice, and in many ways validated and informed the research questions at the same time.

## **Project structure and design**

In order to effectively develop and complete the survey in each municipality, when it was impossible for the researchers to have specific knowledge of all the actors, organisations, and individuals involved, it was decided to develop a model which placed substantial responsibility on each municipality at each phase of the project. In order to legitimize and establish a base for the project in each municipality, a leadership group was formed. The core of this group was the two researchers together with the chief for social psychiatry, a representative of the county medical psychiatry system, a representative from the social insurance authority, from the employment service and if possible from primary care. This group dealt with issues of organisation, confidentiality and contact with the political leadership for the social services. Additionally, a reference group was formed to increase our awareness of local issues and needs, and to act as a “sounding board” during the process, reviewing initial results, directing us to additional informants, and actively participating in the development of focus groups. In a number of cases memberships overlapped, but the reference group also included representatives of the user and family associations, as well as representatives of the general social services. Additional representatives from county and municipal psychiatry were also recruited to the reference groups to increase the representativeness of the group. A specific example of the work of these groups is contained in the work they did to develop statements of purpose for the surveys in study two.

*It has become apparent to us that there are potentially two groups we are interested in gaining knowledge of. Partly the group we “know” and which can be offered support, housing and activity but partly, and*

*possibly more interesting, a group which we don't have clear knowledge of and who periodically need services.*

## **Survey form**

The process of "wandering" in the community as a result of varying need, described above, pointed to the fact that the target group to be surveyed was not a stable one. Individuals displayed a movement within and throughout the community, a movement that was not really a factor in the initial target group formulations described in the Reform. It was decided that in order to capture as much information as possible, methods would have to take this movement of individuals throughout the system into account. "When many authorities and organisations report information on the same individual, it can lead to a broader and more nuanced picture of the individual's cumulative needs" (Socialstyrelsen 1999a:30). In order to gather information that could contribute to this holistic picture of individual need it was decided to seek information, utilizing a survey form, from each of the authorities primarily responsible for supporting individuals with psychiatric disabilities. These included county medical psychiatry, social services (including social psychiatry), primary care, employment and social insurance.

One of the primary methodological questions was to determine who should complete the form. Should staff of the various agencies identify individuals who they believed to meet the criteria and then ask them to complete the form? In many ways this would have been our preference since the task of surveying living conditions would seem to point to the individual as the ultimate authority on this question. We could have also asked both staff and users to fill in parallel questionnaires, a method which would have given us the opportunity to compare assessments of need. We decided however, in line with the outreach aims discussed above, to prioritize finding as many individuals as possible who had needs related to a serious psychiatric disability. This focus led to a number of practical decisions. As the National Board had taken up in its guide to the inventory process (Socialstyrelsen 1999a), the response rate in surveys directed to users themselves is most often unacceptably high. Another issue for our study involved the starting point which is basic to any type of outreach activity, not all of the potential "subjects" were aware that they might want to participate or be included in such a study, not having previously received a categorization as psychiatrically ill or disabled. This meant that we would have to rely on the subjective judgements of staff at the various agencies, a limitation of the studies

in one respect, but an advantage in allowing us to gather information regarding as wide a group of individuals as possible.

While we were unable to confirm that the respondents were “experts”, in terms of their competence and reliability in making a judgement of psychiatric disability, we were careful in supporting them to make such judgements from the best available information. The survey form itself had an educational structure, in that relevant texts related to the definition and intent were included, so as to be available to the respondent as needed. In study three, they were actually supplied with the official description and discussion of the target group as provided by the National Psychiatry Coordinator. We also made every attempt to meet staff groups that were to fill out the forms, present the intentions of the survey, and answer questions. Phone numbers of the primary researchers were also printed on the forms, and we received many calls in which we clarified the criteria and acted as a sounding board for their decision. Finally, it may be stated that “expert” knowledge can be judged from a variety of standards. From a participatory research model, it is clear that those individuals who are directly involved in meeting and providing services to these individuals possess a knowledge which is extremely relevant to the aim of the investigations and research. While some might argue that a psychiatrist is in a better position to judge mental illness, we were clear that we were operating from a disability paradigm outlined in the Social Services Act, an orientation which views the consequences of the illness, not the illness itself, as the primary defining criteria for inclusion. It is not clear from this perspective, that a psychiatrist or psychologist trained in diagnosis and treatment are more “expert” than a social worker for example, trained in supporting their client to a participatory life in the community.

The definition utilized in the initial studies was taken from the National Board of Health and Welfare (Socialstyrelsen 1999a:9);

*Individuals 18 years and older 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. (prolonged is when the disability has or is expected to persist for at least six months)*

### **Survey form structure**

Two versions of the survey form were produced for study one and all subsequent surveys. A longer form, which included the demographic data described below as well as the questions related to need, were distributed to the primary

responsible authorities in what I have called the formal mental health system. A shorter form, which included exactly the same demographic questions, but not the questions related to specific needs, was distributed to the other three authorities, employment, social insurance and primary care. This was done in order to maximize their ability to participate in the survey when many respondents had large caseloads and were pressed for time.

### **Demographic information**

- Age, sex, civil status, housing, financial support, immigrant background (language-related needs)
- Services currently received – medical psychiatry and municipal social psychiatry
- Health – psychiatric, physical, substance use
- Occupation/activity, employment, studies, social network

### **Needs**

Questions regarding the needs of the individual were related to various life areas (social, living, work life, studies, and leisure time). This approach was based on the idea of need as an environmentally relative phenomenon, as presented in the Psychiatric Rehabilitation literature (Anthony et al. 1990). The form of questions related to needs evolved over time, and while this question will be addressed at some length in chapter seven which describes study three, it is a wider discussion than can be included within the aim of this dissertation. Briefly, questions related to need (in the survey forms) have successively looked at functional level, satisfaction with services, satisfaction or quality of life in the various life areas, and finally a conceptualizing of need based on participation in community life. There are also of course various perspectives or vantage points from which to approach the issue of need. These include; the judgements of the professional staff, the wishes of the individual (realistic or not?), needs based on the service system and offerings currently available, needs related only to the individual's deficits, and needs related to limitations or obstacles in the community. As described above, we were dependent on staff of the various authorities in order to gain information on as many as possible. However we directed the respondents to reflect the opinions and desires of the individual to the best of their ability, in order to prioritize the perspective of the user.

### **Open comments**

Survey forms also included the opportunity for respondents to record comments. In the initial study they were offered the opportunity to comment broadly in response to three open-ended questions. These addressed additional

needs for services or supports, increased knowledge regarding this group and the issue of collaboration between the authorities involved in providing services. In the other surveys, described in studies two and three, respondents were offered the opportunity to comment on additional needs following the questions related to various life areas. They were also offered an open-ended question at the end of the survey form;

*The aim of the project is to survey needs in order to plan services which can support the individual's ability to participate in community life, "as all others". Which needs for support, even beyond your own program/organization, do you see which could reduce obstacles and create possibilities for the individual you describe?*

### **Quantitative analysis**

Response items were recorded in SPSS data files directly from the survey forms in most cases, and in two of the studies in which we received local assistance, in an Excel file which was then imported into SPSS. The structure of the data base, identification of variables, and analysis design were developed by the two primary researchers. While the statistical analysis itself is quite basic, primarily involving frequency and cross tabulation tables, there were a number of background factors that required careful work. Since we were dealing with a number of different authorities, and many different respondents within each authority, we needed to insure as much as possible, that people were answering the right question and choosing the response they and we intended. When there was a potential for variations in interpretations, we utilized the staff that had been assigned to support the local project, as well as the leadership and reference group members to clarify terms, service structures and other variables that might have led to confusion in reporting.

Our analysis also included many attempts to sort the material based on a variety of relevant questions. Since the data base was extensive we were also able to generate statistics based on specific questions posed by stakeholders in the research process, another aspect of the participatory process described above. For example, if the chief of a particular primary care clinic wanted demographic data regarding individuals living in their catchment area, we were able to produce such a customized table. While only a fraction of these results have been published in the local reports, the various authorities have been offered access to this information. All comments were recorded as text within the SPSS file as well, so that they could be analyzed from a number of perspectives. We were able to examine comments as a whole, categorizing them by the needs and issues described, and then integrating them within the analysis of quantita-

tive material in the survey. In other words comments were used to explain the information presented in the tables. We were also able to look at the comments, based on which authority they came from and even with respect to the age group or other characteristics of the individual's they were describing.

### **Identifying unique individuals**

A number of individuals were reported by multiple agencies independently of each other, as was expected. In order to identify double reporting, respondents provided us with the individual's initials, which we used together with information regarding age, sex, where they resided in the municipality (either thru primary care district or geographic location), to determine if the form corresponded to a unique individual. We even used information regarding the individual's economic support, use of day programs, and living situation as an additional screen. In a number of cases we contacted the staff member who had completed the form in order to establish whether the individual had been reported as a client of another agency or authority.

In order to register the individual as unique, we needed to make a decision as to which form would be used in the analysis, since answers to many subjective questions, and even a number of objective questions, varied due to their assessment or a lack of knowledge of the individual's actual situation. We decided therefore to prioritize survey forms submitted by the formal mental health system, specialized psychiatry and municipal social psychiatry, the two authorities who should have best knowledge of the individual as psychiatrically disabled. The priority order was as follows;

- 1) Municipal Social Psychiatry
- 2) Medical psychiatry
- 3) General Social Services
- 4) Primary Health Care
- 5) Social Insurance
- 6) Employment Authority

We prioritized the general social services over primary care for two primary reasons. Reporting from Primary Health Care was especially unreliable, since their responsibility for this group, and knowledge of their status as psychiatrically disabled, varied greatly by clinic. We also felt that since the survey was being completed based on a responsibility outlined in the Social Services Act, that we should prioritize the knowledge and responsibility of this authority. All forms identified as "doubles" were maintained in a separate database. This allowed for future analysis of differences in reporting by various authorities,

and also allowed us to offer each reporting authority the opportunity to request data related to the forms which they had submitted.

### **Missing cases**

Throughout the project, the aspect of missing cases in the data was of importance. In every study there were a number of factors which led to specific groups of missing cases, as authorities, for a variety of reasons, were unable to participate at the level we would have liked. Over and above the specific organisational obstacles faced in various municipalities, was the general issue of not knowing how many cases we missed due to lack of contact with potential reporting sources, judgements made by respondents where they did not include certain individuals, and the overall subjectivity associated with the definition used in the projects. While we are able to note organisational misses, such as the non-participation of the social insurance office in municipalities two and three, we are unable to provide complete information regarding other missed cases. Another type of missing case or missing information is related to the large numbers of missing answers or “don’t know” answers in the surveys. In these cases we know that the individual exists as a person with a psychiatric disability in the particular community, but other statistics suffer as we are unable to include information related to their needs.

### **Focus groups**

Focus groups, despite the fact that they may be defined in various ways by different authors, have the potential to produce rich data in the participant’s own words (Oates 2000). According to Kitzinger (1994:103) focus groups may be defined as “group discussions organized to explore a specific set of issues...”. He also emphasizes “...the explicit use of the group interaction as research data”. Oates states that a focus group is distinguished from a group interview by this interaction but also by the “community of interest” shared by the group. Despite the individual opinions and perspectives, the particular dialogue between the members of the group leads to a collective picture which emerges from this type of focused group interaction (Wibeck 2000).

While focus groups are sometimes used as a sole method of collecting data, in this case they were used in combination with the survey, with the aim of helping us to interpret “previously obtained quantitative results” (Stewart and Shamdasani 1990). In all cases, we scheduled focus groups after an initial analysis of the quantitative results of the survey had been completed, so that the discussion was informed not only by the experience and knowledge of the group members, but also their reactions to these results, another opportunity

for validation. Our groups served a number of other purposes also outlined by these authors as common uses of this method. We were able to generate research hypotheses which could then be tested in the future and gain perspective on how the various interest centers represented by group members described the issues we were interested in. The particular nature of the focus groups organized in these studies may also be seen as having features associated with participatory research models, as the members have a “concrete relationship with the issue in question” and a common need for knowledge in order to change or effect a particular situation (Lundberg and Starrin 2001). The connection between the knowledge-development aspect of these groups and the actual demand for and possibility of concrete change, may be viewed from two perspectives. It was clear to the participants in the groups that their input would be documented and shared with the “powers that be” in order to improve support for people with psychiatric disabilities. They were also presented with the possibility of more directly effecting concrete change by continuing to meet together, a recommendation in the final reports, and with the potential for developing collaborative projects. Both of these possibilities led to a feeling of “empowerment” most often associated with the experience of participants in such action research models (Lundberg and Starrin 2001; Stringer 2007).

In study one, the particular groups to be interviewed were chosen by the reference group that was responsible for the study. Each group had a particular theme to be focused on within the discussion. These are presented in chapter five. In the studies that followed, these themes were grouped or categorized in order to reduce the number of meetings and streamline the documentation process, due to limits on time and resources. These themes were developed during the planning of the second study and are related to both the organization of services in the welfare system and the community-based and individual needs which emerged in the initial study.

The themes which determined the choice of participants were as follows (with the actors participating in each specific to the particular municipality);

- **Social Services:** Individual and family services, children’s services, financial support, immigrant services, the assessment unit, elder and home care services, other handicap services.
- **Health and medical care:** Primary care, district nurses, medically responsible nurses (from the municipality MAS), Psychiatry – outpatient and inpatient clinics (various diagnostic units when appropriate), adult rehabilitation services (medical)

- **Work Life and Rehabilitation:** The employment service, social insurance authority, municipal vocational services unit, adult education, the local university, sheltered workshops (if involved), day training and rehabilitation programs (psychiatry and social psychiatry), co-operatives (if available)
- **Community Life:** User groups and relatives, case managers (PO), landlords of housing developments (where clients often lived), Red Cross, school social workers, police, church representatives, representatives of the business community, of sporting associations, of the retirement association, etc.
- **User perspective:** Individuals and clients from the user organisations, family associations, clients from psychiatry and municipal social psychiatry, and in one case a general announcement in the local media

### **Focus group interview structure**

In each group we began with a review of the project in order to begin the discussion from a common base, a starting point which was especially important given the often diverse backgrounds and experiences of the participants. The review included;

- Background of the project
- Aim of the Mental Health Care Reform
- Aim of the study
- Definition of persons with psychiatric disabilities – used in the survey forms

Every group was presented with four questions at the beginning of the session, utilizing either a whiteboard or large poster paper. We stated that it was ok to take the questions in order or to jump around as the discussion progressed, but that we would attempt to record their input with reference to the questions and then review it with them before the session ended. We stated that the goal was to come to a comprehensive description of need based on the group's knowledge and experience. The questions were;

- Who? (Describe the individuals who you have contact with based on the definition that was used in the survey form)

- Which needs? (Describe the various needs that you believe these individuals require help with)
- Obstacles? (What obstacles/barriers do you see which can make it difficult for us to satisfy their needs?)
- Possibilities? (How can it be better, what possibilities are there for these individuals to have a better life in the community?)

Groups which included representatives of the five authorities were often comprised of five to ten specifically invited representatives, with priority given to those who could best represent the needs of people with psychiatric disabilities, as encountered by that agency/program. Work load issues, lack of substitutes and scheduling accounted for the many obstacles we encountered in setting up these interviews. Those which involved users and other community representatives were often larger, with ten to twenty participants. Since the focus groups produced a large amount of data, it is impossible to present this result in its entirety. Quotations are presented within the empirical results, as examples of categories that emerged during the analysis or specific viewpoints considered relevant to the quantitative results.

Throughout the chapters which present results of the various studies, citations will be marked in the following manner;

(IN) – Individual interview (All from study one)

(FG – Org) – Focus group, followed by the organisation or theme which the individual represented. (May also indicate user or family member)

(SC) – A Survey Comment or answer to one of the open questions.

In some cases the quote was referred to anonymously in the original report, so as not to risk identifying users or staff in certain municipalities, with the result being that the quote is also presented anonymously in the dissertation. All translations of these quotations are by the author.

## **Analysis**

The focus groups were analyzed from two points of view;

- 1) In relation to the quantitative results of the quantitative study (explanatory)
- 2) On their own, in order to generate knowledge related to the aims of the study (exploratory)

Focus groups were recorded and then transcribed in most cases. Beginning with municipality five, results of the discussion were recorded on a whiteboard, with all participants aware of the points to be included in the final summary. In this manner, we were able to continue until the group agreed that we had reached a “saturation point” in which they were satisfied with the results which would be reported. In surveys one, two, three and four we utilized the notes and transcriptions and first sorted quotes and points in relation to the tables that had been produced. This method of presentation continues in the result chapters presented below, where quotations from focus groups accompany the tables. We then continued, working from a grounded theory model (Glaser and Strauss 1967), created sub categories and categories which would allow us to organize the material in presentations and reports. In surveys five, six and seven these results were published as they were collected, so that participants would recognize their input, and in order to report all needs collected, not only those which fit into categories that we as researchers would create. It also allowed for a specificity which made this documentation useable in planning and evaluation activities, such as the yearly follow-ups recommended in each report.

### **Individual interviews – Study one**

Within the time and resources allowed for the study, it was possible in study one to complete individual interviews with a number of users. We were already limited in this case to known and active users, since we did not have a method by which to reach others who had been described anonymously by staff respondents. Participation also needed to be voluntary and follow guidelines for informed consent. A letter was widely circulated to various services within municipal social psychiatry. Of those that responded, we prioritized varying ages and users of various services, to get the broadest possible representation within a limited sample.

The interview format was structured and questions followed those presented in the survey, as related to need. During the interview however, the two researchers who conducted the interviews allowed for a semi-structured form, where the individual described their experience of the helping system and their needs, and we attempted to insure that all of the questions were addressed at some point in the interview. Interviews were recorded if the individual felt comfortable, but notes were also kept, also with the individual’s consent.

## Research design considerations

In a project such as the one presented here, where the aim and design of the research project is continually exposed to the varied demands of a practice-related need for developing knowledge, it is especially important to attend to issues that may effect the different outcomes. The following discussion considers a number of issues that have influenced the research process and outcomes at both the data collection and analysis phases.

### Ethical issues

The material was collected and organized in all of the municipalities within the framework and routines dictated by their internal procedures for carrying out inventories and assessments of need, based on the responsibility laid out in the Social Services Act. Within their legislative and political responsibilities, the social services have extensive responsibility regarding confidentiality, and are also subject to additional laws regarding individual privacy, including the Health and Illness Act (Socialstyrelsen 1999a). The underlying ethical and legal “red thread” in all these decisions was that it would not be possible to connect information in the reporting of the results, to an individual, a situation which might result in their suffering (Socialstyrelsen 1999a).

Anonymity was the goal with regard to the focus groups as well, especially when there were users participating. There was an increased risk in these more public forums that an opinion, given with the context of an open discussion within a local community, might be “recognized” by those reading the report. This was true for both staff and users, but required a different approach from the researchers. In all cases, focus group participants were informed as to how the results would be analyzed and presented. This was especially clear for all in the last four surveys, where they saw us writing their input on a white paper or board which would then be preserved and reported. Once again, since these focus groups occurred within the framework of a municipal responsibility for developing knowledge of needs in the local community, staff participated within their normal role as representatives of various authorities. Other respondents were citizens who, because of special knowledge regarding the group of individuals we were studying, had decided to participate in the process. Users were of course the participants who might experience the process of offering feedback to the municipality as sensitive and had the least power since they were reliant on these actors for their services and security in life. We were therefore clear in all focus groups where users were involved to describe the manner in which the material might be used and offered them the chance to

contact us if they were concerned at all. When possible, we sent a transcript for them to review prior to publication.

In the individual interviews in study one, a letter was circulated within the municipal social psychiatric services, and was available to any users who might be interested in participating in an individual interview. The purpose of the study was explained, anonymity was guaranteed, and those who wished to participate reviewed the form together with the researcher at the time of the interview to be certain that informed consent was given. It was clarified that their comments, in addition to being anonymous, would also not be identified as coming from a participant in a particular program, information that might make them identifiable within that service.

Finally, with regard to ethical issues involved in the use of the material presented in the dissertation, there is an additional level of confidentiality inherent in the secondary use of the material. Comments for example, still anonymous, are now presented within the context of multiple surveys and therefore may be seen as even farther removed from the possibility of being identifiable within a local community.

### **Reliability, validity and generalizability**

“Reliability refers to the degree of consistency with which instances are assigned to the same category by different observers or by the same observer on different occasions” (Silverman 2001). In this study reliability has been attended to on a number of levels. While the primary researcher has been consistently involved across seven different projects, I have also involved other researchers and practitioners in each study-specific team. The repetition of the study in seven different municipalities and over a period of years may also add to the reliability of the research. The mixed methods of the study, utilizing qualitative methods to explore, confirm and explain quantitative findings supports the overall validity. Triangulation has been a central strategy in developing many of the conclusions that will be presented here. As will be seen in the empirical results, arguments are based on information received from multiple sources, so that conclusions are a synthesis of these various perspectives on an issue. The generalizability of the empirical results is likely greater in Sweden than with populations in other countries where the mental health and social welfare systems are quite different. The conclusions however may be more generalizable internationally, since they are based on theories and research that have been developed internationally, and are therefore less system-dependent.

Some additional questions are of special interest with regard to the validity and reliability of the study. I have already discussed the survey respondents as experts in describing not necessarily psychiatric illness, but disability, the con-

sequences of the illness for the individual's life. I conducted the focus groups, most often accompanied by a local representative assigned to the project. This person was always someone who worked within the municipal social services and had good familiarity with the organisation of services, as well as in many cases substantial practical experience with individuals experiencing these disabilities.

### **Strengths and imitations of the study**

In considering the strengths and limitations of the study, it is of course important to include the role of the researcher. As a practitioner with many years of experience in community mental health it is clear that my experience has influenced my interpretation of the data, but also the focus which I bring to the many interactions with participants in the study. At the same time, it is these interactions and the participatory nature of the studies which form the basis for this work, that has supported my role as an objective observer, since the extremely knowledgeable, engaged and experienced personnel and users who participated held me in that role. They told me how their reality looked and expected me to listen. My intention was also to offer the focus group enough knowledge of the project to allow them to feel that their opinions and observations were relevant and would be included in the result. The following points relate to other aspects of the study which have been and will be considered throughout the text.

#### *Strengths;*

- Triangulation of qualitative and quantitative methods
- Municipalities of varying size, rural and urban
- Direct input at the practice level – ie: focus groups led to information sharing, new relationships, future plans for follow-up and coordinated planning.
- Validation at the practice level – constant feedback from leadership and reference group members, presentation in the community as well.

#### *Limitations;*

- Definitions of psychiatric disability varied over time
- Staff responded, lack of direct input from users, especially from those on the “periphery”
- Inter-rater reliability – with regard to assessing the degree of disability has not been tested

- Varied organisational structures and conditions in the different municipalities
- Uneven participation from community organizations ie. police, landlords, sport associations, schools, voluntary organisations
- Regional study – perhaps not reflective of other regions or municipalities in Sweden. Limited internationally as well, since in other systems, individuals may seek housing for example, from the formal mental health system.

### **Presentation of the material**

All of the studies presented in the dissertation have been previously published as FoU reports and are available at the web site for the Research and Development Unit in Västernorrland county. It should be noted, as has been discussed above, that all of the reports, with the exception of the initial study, have multiple authors. Rolf Dalin, a statistician employed by the R and D unit has been a collaborator in all of the studies and played a central role in designing the survey forms and directing the quantitative analysis with SPSS. This has of course lent a great deal of legitimacy to the quantitative research design and analysis. Other co-authors have been individuals who were assigned by the municipal social services to participate in the local study. Beginning with municipality four, we always had a municipal representative who played a variety of roles, including participation in the gathering, processing and analysis of data. Their roles varied in each study, based on time, knowledge and interest, but all played a valuable part in validating many of the results, as well as insuring the accuracy of our research methods as they were implemented in a particular locality. Their contribution may be seen as resting on their “situational knowledge” (Starrin 2001:15) that was “spatially bound to the context” in which the research occurred.

Reports have also been presented at a number of local, national and international conferences (see attached listing). These also provided opportunities for feedback from a wide variety of practitioners, users, politicians and researchers, and may be seen as a form of external validation for the overall results and conclusions of the studies. Especially important in terms of validity, was the consistent presentation of the material to the participants in the study at each stage of the process. This included periodic updates to and feedback from the local reference and leadership groups. These individuals were experts within their various areas of responsibility and were invested in us not falsely interpreting results, since they were also responsible to some extent for the surveys if not the research. Silverman (2005:254) presents “efforts to falsify initial assumptions about data” as an important means of increasing the credibility of

the findings. Finally, an article describing the results from two of the surveys in study two has been published in the *Scandinavian Journal of Disability Research* (Rosenberg et al. 2009). An additional article which builds on the participation measures utilized in the third study has also been accepted for publication (Dalín and Rosenberg 2009).

The chapters which now follow, five, six and seven, describe some of the specific premises, methods and results of each study. As stated earlier, these three studies may be seen as building upon each other, with each study testing and validating certain questions and mechanisms/factors posed in the previous study and as part of the overall focus of the dissertation. Chapter eight analyses the cumulative results of the three studies and attempts to summarize the conclusions of the individual reports. Each chapter begins with an introduction covering the background for that study and including conclusions drawn from the previous study as they pertain to method adaptations, a results presentation and brief analysis, and then a concluding discussion, which summarizes the preliminary conclusions and implications for the next study.

## **Chapter five –Reconsidering the target group**

This is the first of four chapters in which the results of the three studies will be presented and discussed. The background to this initial study, as well as a number of specific issues regarding the method, is more extensively explained in this initial chapter since it set the stage for the surveys which followed. As stated in the introduction to the thesis, study one may be seen as a “discovery phase” of the entire project. It was here that we first noticed a number of contrasts from that which seemed to be expected when such an inventory was performed in Sweden. Exploring these results within the context of the theoretical perspective on disability contained in the Social Services Act, led us to continue generating theories which might be tested in the studies which followed. There is therefore a more extensive discussion of a number of the results than in the following chapters in order to explain the rationale which guided the following studies. As we did in the original reports, I will present both the quantitative and qualitative results of the study from the integrated perspective with which they were intended to be utilized. In other words, quantitative results raise questions which are explored in the focus group and individual interviews.

### **Introduction and background**

In December of 1999, representatives of the county medical council and municipality one met to discuss methods of improving their ability to provide coordinated services to individuals experiencing psychiatric disability. A number of critical areas were identified that required further development. One of these was the desire for a more thorough inventory and survey of the group of psychiatrically disabled which was believed to have widened since the most recent inventory had been completed in 1997. An even earlier inventory, 1994, had only focused on the group of patients who were still inpatients of psychiatry, who were considered to have completed their treatment, and who would now become the responsibility of the municipal social services after the implementation of the Reform. This “target group” was followed in future years and while in 1998, 41 such patients were reported in the county, only 1 was reported in December of 1999. That this group was an “historic” group, created and dealt with administratively in the wake of the Reform, became clear in these figures.

By 1997, the structure for completing an inventory of the target group in the county had changed again and now included two primary criteria. The individual was to be chronically mentally ill and in need of support and service from the social services for their disability (as well as known to specialized psychiatry). Their need was evidenced by the fact that they were in contact with the social psychiatry unit of the social services. A simple interpretation of these criteria would point to the continued prevalence of a medical/illness perspective in the first criteria, and the definition of need limited to existing contact with the system in the second. Not included were individuals unable, uninterested or unwilling to make or maintain contact with the social services. Need was limited to those needs that fell within the parameters of the services that the municipality offered at that time. The evolution of the target group concept can be viewed within the context of these administrative attempts to inventory individuals and their needs.

### **Finding the target group**

A discussion of the target group that the Mental Health Care Reform was intended to serve is now raised again as a focus of central importance in the study described here. As a background issue in presenting a project whose primary purpose was to find and describe this group, the definition process was fundamental to developing a method. The evolving definition of how to identify these individuals for the purpose of planning services for them has clearly led to an uncertainty as to which individuals or group we are referring to. The changing terminology reflects a changing perspective on psychiatric illness and disability, a change that has impacted legislation and policy, the direction of service development and our perception of the needs that these individuals present.

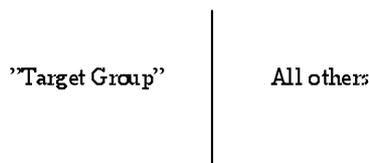
The problem of delineating a group described as psychiatrically disabled from the rest of the population was a difficulty that was recognized early on by the Psychiatry inquiry of 1992. In tracing the roots of this discussion prior to the Reform, Markström (2003:142) sees this uncertainty beginning back in the mid 80's with the National Health and Welfare Board's recommendations on the provision of social services to adults with handicaps. While an environmentally related handicap perspective is clarified and the psychiatrically disabled are included, there is no attempt made to analyze the needs of this group, or to clarify which individuals should belong to this group. Without a great deal of explicit discussion or analysis, the move from a clearly controllable medical/diagnostic categorization of the psychiatrically ill, had given way to a functional and environmentally interactive definition. Since at least a portion of the target group for the Inquiry of 1992 and the Reform of 1995 was still "institu-

tionalized” for shorter or longer periods at this later stage of the deinstitutionalization process, their connection to the “structures” of psychiatry, served to confirm their status as members of a target group. While this group received primary attention at the time of the implementation of the Reform, the National Health and Welfare Board (Socialstyrelsen 1997: 7) emphasized that the Reform was directed at “the whole group with psychiatric disabilities living in the society”. While the one group, those that were still structurally connected to psychiatry was easy to find, describe and plan for, the broader group, now out in the community with no clear or structural ties to psychiatry was much more difficult to develop knowledge of. General estimates of the numbers of individuals who fell into this target group ranged from 40 – 70 000, “after various criteria” according to the Board (Socialstyrelsen, 1999a).

*The whole thing (an investigation that continued during a number of years with the aim of surveying the situation for the psychiatrically disturbed and to clarify the boundaries between various organisations) ends up in a situation characterized by uncertainty, where the question of which people should be included in the venture is still not answered (Markström 2003:187)*

At a time when the National Board of Health and Social Welfare struggled to define and estimate the size of the target group for purposes of planning, and the municipalities and county psychiatric services struggled with limiting their responsibility for intensive supports to a group that was increasingly diverse and difficult to delineate, this initial study attempted to develop a method that built upon these discussions. As described above, a series of illustrations will be presented throughout the thesis which graphically presents the model that developed during the project. Illustration one may be said to represent the initial aim of the first study, as posed by the leadership group. A first priority, before we started to explore the intention of the Social Services Act, was a question of how to define the target group, in order to exclude those who were not part of it.

*Illustration 1; Finding the target Group*



While an overly simplistic picture of the reality that the studies would begin to explore, this illustration does in many ways represent the starting point for the inventory process. The initial challenge posed to the research unit was to define and identify a target group which would then be counted and assessed for need. Some of the organizational and ideological premises for such a picture have been described in the preceding paragraphs, and broadly relate to attempts to categorize a select group of individuals. The implication is that those who are not part of the target group are not of interest.

## Method specifics

During 2001, a survey of persons with psychiatric disabilities was conducted in municipality one, a medium-sized city (93,000) in northern Sweden. The aim was to “increase the possibility of planning services of good quality, according to the intentions in the Reform, the Social Services Act, and the Health Care Act” (Rosenberg 2001). The following authorities participated in the project as partners; the social psychiatry department within the municipal social services, specialized psychiatry from the county system, the social insurance authority, the employment service and primary care. A leadership group was formed with representation from these authorities and I acted as the project coordinator within my capacity as a researcher for the Research and Development Unit in the social services department.

A survey form was sent to staff at each of the five agencies and they were requested to complete one form for each client they had active contact with who they judged to have a serious psychiatric disability, according to the following definition developed by 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. (prolonged is when the disability has or is expected to persist for at least six months)*

In addition to these survey forms, seventeen focus group interviews were completed with staff and users, who worked in or had contact with the various authorities, and eleven individual interviews were completed with users of different ages and with different connections to the system.

## Focus groups and themes

In a number of situations, primarily those involving programs within the municipalities' social psychiatry programs, users were invited to join in the focus group discussion. There were a number of reasons for doing this, including of course an interest in gathering as many viewpoints as possible from the users themselves. A limitation of meeting staff and users together is of course, the fear that users will be leery of criticizing the program for fear of insulting the staff or of reprisals. The advantage of such a form, and this was the priority at the time of the survey, was to create a dialog between program staff and users, and a model for the municipal leadership for collecting opinions and promoting user influence. It should be noted that the following interviews were arranged at the suggestion of the reference group for the project with the aim of collecting a broad and current picture of needs from different perspectives.

1) **National Association for Social and Mental Health (User group) – *User perspective***

Monthly meeting, 8 members in attendance (out of 94), including board members.

2) **Social Insurance Authority – *Rehabilitation needs and collaboration***

Four process officers in a “disabilities unit”, including psychiatric disability.

3) **Printing cooperative - *A Cooperative emphasizing user influence***

Members and staff of a municipally supported cooperative.

4) **Family Association - *Relatives, evaluation of services after the Reform***

Monthly membership meeting. 15 members in attendance, including the board.

5) **Double diagnosis team - *Substance abuse and double diagnosis***

A team with three staff members and responsibility for ten clients, average age 32.

6) **Inpatient treatment unit - *Younger patients and their needs***

Chief and staff of a unit for young adult (18-30) patients with psychotic illnesses

7) **Psychiatric rehabilitation - *Vocational rehabilitation and supported education***

Two staff and four users connected to this program, a collaborative project.

8) **Primary health care center - *Experience with psychiatric disabilities***

One interview during a staff meeting (due to time limitations) and the other with a nurse who had most contact with this group.

9) **Group home - *Needs of residents in a municipal group home***

Staff of a group home that served clients described as needing intensive support.

10) **Supported housing program – *New forms of support***

Four staff and 3 users receiving individualized supports in their own apartments.

11) **Day program - *Activities, social supports and rehabilitation***

Three staff and five users who voluntarily participated in a special meeting.

12) **Inpatient unit (psychiatry) - *Changes in the “target group” for the Reform***

Staff of an inpatient unit serving individuals with serious mental illness.

**13) Employment service - *Rehabilitation opportunities***

Two members of a rehabilitation team with responsibility for disabled individuals.

**14) Integration unit - *Immigrants with psychiatric disabilities***

Two members of the integration unit within the municipal social services.

**15) Hospital-based rehabilitation – *Activities and rehabilitation needs***

Staff of a small in-hospital unit focusing on activities.

**16) Project for long-term unemployed – *contacts with people experiencing psychiatric disabilities***

Four staff, each representing one of the four responsible authorities

**17) Individual and family services - *General social services – Experience of psychiatric disabilities***

Two social workers with long experience were assigned to meet with us.

**Individual interviews**

As described in Chapter four, the individual interviews were intended as a means of collecting additional viewpoints and gaining insight into the experiences of a number of users within the local system. They are by no means intended to convey the majority of user perspectives. The interviews included 10 individuals, 7 men and 3 women. The ages ranged from 21 – 55, with the average age being 41.4.

| <b>Sex</b> | <b>Age</b> | <b>Program affiliation</b>        |
|------------|------------|-----------------------------------|
| 1) Man     | 38         | Day Program                       |
| 2) Man     | 49         | Day Program                       |
| 3) Man     | 38         | Day Program                       |
| 4) Man     | 36         | Day Program                       |
| 5) Woman   | 45         | Group Home                        |
| 6) Man     | 49         | Group Home                        |
| 7) Man     | 53         | Group Home                        |
| 8) Woman   | 21         | Rehabilitation                    |
| 9) Woman   | 55         | Supported Housing                 |
| 10) Man    | 30         | Psychiatric inpatient-young adult |

All users had other affiliations as well as the primary listed, which were discussed during the interviews. For example, all had contact with the social insurance authority, and many living in group homes periodically utilized day programming.

## Results

The inventory resulted in finding 652 individuals who personnel in the various agencies assessed as meeting the criteria, of these 456 had contact either with the municipal social psychiatry or medical psychiatry, considered to be the two primarily responsible authorities. After sorting for clients reported by more than one agency, identifying information was removed to insure anonymity. While the survey questionnaire was quite comprehensive and focused on demographic factors as well as staff assessments of need among their clients, I will only present a sample of results that highlighted the life situation of these individuals in the community, as related to the research questions posed in this thesis.

*Table 1: Survey forms and individuals by organization*

| <b>Organisation</b> | <b>Forms received</b> | <b>Individuals</b> |
|---------------------|-----------------------|--------------------|
| Social Psychiatry   | 337                   | 337                |
| Psychiatry          | 170                   | 119                |
| Primary Care        | 83                    | 51                 |
| Social Insurance    | 202                   | 117                |
| Employment Service  | 32                    | 27                 |
| Total               | 824                   | 651                |

It should be noted that in study one, only the social psychiatry unit was included from the municipal social services. As stated above, all were directed to submit forms for all individuals who met the criteria, regardless of whether they believed that the person had contact with another authority. We received a total of 824 survey forms. After the doubles were sorted by organisation, we were able to arrive at what we reasonably believed were the unique individuals who had been identified in the process. In this table it is possible to determine the number of individuals who were exclusively known to that authority. For example 32 of the 83 persons reported by primary care were known to either psychiatry or social psychiatry, indicating that 51 had exclusive contact with the primary health care system.

While we did not complete an extensive organisational analysis in this first study, we did find a number of significant results which led us to focus on organisational contacts in future studies and raised questions as to the success of the coordination efforts emphasized in the Reform. Members of the leadership and reference groups were surprised on the whole by the number of individuals

who were found to be in contact with only one authority. In fact 79.8 percent or 520 of the 652 identified individuals had contact with only one authority, 17 percent or 111 were active with two authorities and only 3.2 percent or 21 had contact with three simultaneously. There was also a great deal of interest expressed, even at this early stage, in the numbers who had exclusive contact with the social insurance and employment authorities and those only in contact with the primary care clinics. One user described their limited contact with the various authorities.

*As soon as I go out one door, it closes behind me. (IN – user)*

*Table 2: Age groups*

| Age group    | N   | %     |
|--------------|-----|-------|
| 18-29        | 79  | 12.1  |
| 30-39        | 156 | 23.9  |
| 40-49        | 130 | 19.9  |
| 50-59        | 137 | 21.0  |
| 60 and older | 135 | 20.7  |
| Missing data | 15  | 2.3   |
| Total        | 652 | 100.0 |

The interest in focusing on age groupings can be traced back to the concerns of the leadership and reference groups for the study. In these discussions, many had expressed concern about specific sub groupings, particularly young adults who seemed particularly hard to reach. While all agreed that young adults were important, this led to further discussions of other groups, for example older individuals, many of whom had spent long periods of time in institutionalized settings. It was agreed to look at age groupings in as many of the relevant areas of study as seemed appropriate. It should be noted that the age group “60 and older” includes a span of more than 10 years and may not reflect a normal distribution over the life span. Age seemed to reflect, not only aspects of the experience of psychiatric disability, but other societal trends. For example, only 36 percent of those 18-29 were smokers, as compared to 63 and 64 percent of those 30-39 and 40-49. Whether these figures reflect general trends and health awareness in the society or for example a lingering effect of institutionalization (where there was nothing to do but smoke) is open for discussion. Traditional images of the “chain smoking psychiatric patient” may need to be replaced with a more nuanced understanding of young adults in society today. However such

age-related explorations helped to demonstrate the manner in which generational factors may interact with disability-related characteristics. They also reflected the perception among everyone we met, from the leadership group to workers on the ground, that there was a new generation of young adults with needs that were different than the traditional target group.

*Table 3: Mean age by organisation*

| <b>Organization</b> | <b>Mean age</b> |
|---------------------|-----------------|
| Social Psychiatry   | 47.7            |
| Psychiatry          | 49.4            |
| Primary Health Care | 58.0            |
| Social Insurance    | 38.9            |
| Employment Service  | 37.4            |

While not a surprising finding, that the average age for primary health care was significantly older than other groups, due to the increasing physical needs associated with aging, it did help us to further identify the interaction of age and organisational contact. Social psychiatry and psychiatry were close in mean age, but when we looked carefully at the various programs in social psychiatry we found significant differences. For example, of 33 individuals between 18 and 29 years old who were involved in one of the social psychiatry activity programs, 24 had contact with a psychiatric rehabilitation program, and 3 with a double diagnosis unit. The average age for the more traditional day programs was substantially higher, a variable that we looked more closely at in future studies.

These following tables are based on the analysis of social psychiatry and psychiatry (456 individuals), who received the longer survey form.

*Table 4: Marital status*

| <b>Marital status</b>   | <b>N</b> | <b>Percent</b> |
|-------------------------|----------|----------------|
| Married/living together | 43       | 9.4            |
| Married w/children      | 14       | 3.1            |
| Single                  | 353      | 77.4           |
| Single w/ children      | 33       | 7.2            |
| Total                   | 443      | 97.1           |
| Missing data            | 13       | 2.9            |
| Total                   | 456      | 100            |

Representatives for medical psychiatry were especially interested in our gathering information about individuals who were parents, since they were beginning to meet what they described as a new group, young women, sometimes single mothers, who were experiencing serious mental illness. Their condition was exacerbated by their isolation in the community, lack of a positive support network and increasing depression in response to the stress of their situation. These concerns, and the resulting figures, which showed that 10.3 percent of those having contact with the formal mental health system were parents, led to a focus on this information in future studies. Did their role as parent indicate that we should be looking for needs related to their family situation and not just their mental illness? Was it possible that others had primary contact with family and children's services and had avoided the psychiatric system?

*Table 5: Age group and activity*

|              | N (%)       | N (%)         | N     |
|--------------|-------------|---------------|-------|
| Age Group    | No Activity | Some Activity | Total |
| 18-29        | 25 (50.0)   | 25 (50.0)     | 50    |
| 30-39        | 25 (25.3)   | 74 (74.7)     | 99    |
| 40-49        | 31 (36.5)   | 54 (63.5)     | 85    |
| 50-59        | 68 (69.4)   | 30 (30.6)     | 98    |
| 60 and older | 85 (78.0)   | 24 (22.0)     | 109   |
| Total        | 234 (53.1)  | 207 (46.9)    | 441   |

The table indicates that 53.1 percent of the entire group had no activity at all that was reported by staff completing the forms. Of the 46.9 percent who reported some type of daily activity, 37 percent were involved in a day program. This involvement included everything however from 11.8 percent who were actively involved in a rehabilitation oriented program, 25.7 percent who utilized the program for social contacts or "structure" to their day, and even those who only "dropped-in" periodically, perhaps only to eat lunch. It became clear in these figures and in focus group discussions, that the collapsing of all possible activities and involvements into a single category called "occupation" did not accurately describe the diversity of possibilities for these individuals. This coupling of "occupation" with the day program seemed to reflect the low expectations created by the fact that only 3 percent had full time work, 9 percent part time work and only 11 percent were involved in some type of educational activity. These paid work opportunities were often subsidized internships however, and educational activities included both full-time study and study circles, a common form of adult education in Sweden. These figures also include indi-

viduals over 65 years who receive a retirement pension and may not be inclined to any type of activity. The figures for those 50-59 were of particular concern, 69.4 percent had no structured activity. Does the increasing number without any activity reflect an expectation by the various actors that this group is not worth investing in? Or does it reflect hopelessness among these individuals as to their possibilities for recovery? In both cases, the results implied age-related patterns that seemed to demand further exploration.

Figures such as we see above, are quite typical for individuals experiencing psychiatric disabilities (Brunt and Hansson 2005; Thornicroft 2006; 0:10) and are frequently described as the result of low expectations for this group, a phenomenon often tied to poor prognosis for many of the most frequently reported diagnoses. Many personnel reflected this expectation and wrote in on the form that their client was “too sick” to participate in rehabilitation and therefore needed an “expectation-free” activity. At the same time, when asked about the individual’s need for rehabilitation planning, between 63 and 74 percent (depending on age) responded that there was such a need. The results confirmed a picture of these individuals as overwhelmingly isolated from opportunities for education and employment, and supported by personnel who did not feel that they were receiving help to plan in this direction.

*You are “born” as a user, into a system of ignorance, feelings of shame and guilt, prejudice, negative attitudes and pessimism regarding recovery (User association in Rosenberg 2001:91)*

*Table 6: Financial Support*

| Financial support - Type       | Yes |        | No  |        |
|--------------------------------|-----|--------|-----|--------|
|                                | N   | (%)    | N   | (%)    |
| Paid employment                | 14  | (3.3)  | 406 | (96.7) |
| Subsidized employment          | 16  | (3.8)  | 404 | (96.2) |
| Unemployment insurance         | 3   | (0.7)  | 417 | (99.3) |
| Sickness benefit               | 65  | (15.5) | 355 | (84.5) |
| Disability pension - temporary | 57  | (13.6) | 363 | (86.4) |
| Disability pension - permanent | 174 | (41.4) | 246 | (58.6) |
| Social assistance              | 36  | (8.6)  | 384 | (91.4) |
| Retirement pension             | 76  | (18.0) | 344 | (82.0) |
| Family support                 | 6   | (1.4)  | 414 | (98.6) |
| Other support                  | 2   | (0.5)  | 418 | (99.5) |

The results presented above may reflect more than one type of financial support for a particular individual; answers were not mutually exclusive on the survey form. For example we can see that 41.4 percent of the 420 individuals for whom we received information on financial support, were receiving a permanent disability pension. These results also led to a number of questions regarding the various sub-groups who might be reflected in the various types of support. Here again, leadership and reference group members were curious as to why for example, we had identified individuals receiving social assistance, a form of support targeted to poverty not psychiatric disability.

When we looked at permanent disability status and retirement pensions we found an older group, those who had entered the system for the most part during the time when institutionalisation and long hospital stays were frequent. Of more concern were the many “younger” individuals who had received a permanent disability allowance. Almost 34 percent of those 30-39, 54 percent of those 40-49 and 73 percent of those 50-59 had been classified as permanently disabled. While some might consider 50 to be too old to begin a rehabilitation process, one woman who had just turned 50 and received notice of permanent disability status stated that “it was like dying”, she herself still had hopes of returning to a more productive life.

*I tried all possible ways of being rehabilitated but didn't get good support. They pulled the rug out from under me... I could have worked longer... Life ends there (permanent disability pension) (IN)*

The increasing percentages reflected in the figures also pointed to another problem. As individuals became permanently classified as disabled they “disappeared” into an administrative category whereby they were no longer considered candidates for active attempts at rehabilitation. For many, this meant that they had a financial security based on support tied to their continuing status as disabled, and would no longer receive active opportunities for rehabilitation. “It feels secure that its permanent...if I were to begin with something related to work...they would take my pension” (IN).

The “discovery process” in study one preceded in this manner. Some exceptionally concrete findings related to financial support raised a number of questions that led to discussions and attempts to understand mechanisms which might explain these results. These discussions in turn led us to return to the data and search for additional explanatory mechanisms. One primary question concerned the potential for and interest in moving beyond these categories of financial support and towards a more participatory life. How many on social assistance were interested in studying, How many with permanent pensions might be interested in returning to work?

Attitudes towards the potential of these individuals to recover varied greatly for example, among both personnel and users. A high percentage reported a need for opportunities for their clients to receive support for a better quality of life. As many as 58 percent reported that their client had a wish and a need of more help to begin working, 55 percent reported an interest in and need for support to continue their education, and 47 percent described a need for more meaningful activity. At the same time approximately 50 percent of personnel answered that they didn't know if their client had a wish or need for rehabilitation services. Many responded with comments related to the symptoms or illness of their clients, but some saw potential. Describing younger clients she had worked with, one respondent stated; "There's a lot of drive in these young people". When asked about their wishes for daily activity, one user replied; "I want a career".

An exploration of the financial support structure and the quantitative results related to the numbers receiving various types of support led to a series of questions related to rehabilitation potential, the wishes of the individual and even the barriers created by the financial support system. Authorities had rules and time lines for assessing needs, most often tied to administrative categories and routines, and not to the recovery "schedule" of the individual. In order to understand the large number of individuals receiving a permanent disability pension, it became important to explore how they had ended up in that category and what mechanisms might be holding them there. This perspective, while somewhat intuitive, is in stark contrast to one that assumes or accepts that the majority of individuals with serious psychiatric disabilities will always be dependent on disability insurance for their financial support. The relationship between financial support and participation in community life was therefore targeted in this study as an area that would be further explored.

*They (the authorities) should be more flexible...it might take a few years but then they can earn something back on me (when I begin working) (IN)*

## **Discussion and implications for the next study**

One of the primary conclusions of this initial study, in relation to the overall aim of the thesis, was the evidence that pointed to the limitations of seeing individuals with psychiatric disability as belonging to a somewhat homogeneous "target group" that could be planned for, based on some common experience of psychiatric disability. That homogeneity is also most often tied to social locations defined by the formal mental health system, in other words an expectation

of contact with either specialized or social psychiatry. The following discussion of young adults is presented as an example of the types of explorations conducted in interviews and in the local reports, in order to distinguish both sub-groups and unique individuals whose diverse needs should be considered in planning.

### **Young adults – Struggling with a disability or a life?**

During the analysis of results, which increasingly focused on age group differences, special focus was placed on younger individuals, 18-29, who had been identified in the survey process. This group consisted of 79 individuals, 58 percent of whom had no contact with municipal social psychiatry, and 73 percent who had no contact with specialized psychiatry. These figures reflected the reality described by personnel as well as users during the interview process, that these were individuals who had an extremely ambivalent relationship to the helping system, and were difficult to find and “catch”.

*It's very hard to find a general model (for making contact)... so many are isolated or just lie in bed. (FG-Psychiatry)*

*These folks don't work that way (like the organisations that are set up to support them)(FG-social services)*

Other statistics described a group that was beginning to distinguish itself from prior generations in a number of ways. They were more educated than the whole population of individuals in the survey, 47 percent having completed high school, compared with 30 percent for the entire sample. At the same time, they used/abused more alcohol and drugs, 24.5 percent for this group compared with 18.2 percent for the whole municipality. Their abuse also tended to include drugs as well as alcohol, with 67 percent using multiple substances, while alcohol was more pervasive among the broader group. These positive and negative changes reflect trends seen internationally. Various estimates of dual diagnosis among individuals with psychiatric disabilities are typically reported to be in the vicinity of between one and two thirds of the population experiencing serious mental illness (Drake et al. 2001; Thornicroft 2006:135). They also however reflect trends among youth in general. Questions that presented themselves regarding the needs of this group were difficult if not impossible to answer from a psychiatric perspective, as they appeared as individuals with many of the same social advantages and ills experienced by their peers, and not exclusively assignable to their disability. They had become more integrated into both the mainstream of social possibilities and problems in the community. This is a

conclusion that would support a more dynamic view of these individuals as they interact with both the helping system and the community.

Two other descriptive factors regarding this group of younger individuals were considered especially central to a better understanding of who they were or were not. While only 9 percent of the total sample was dependent on social assistance based on economic need, 47percent of this younger group of individuals used this form of subsidy to survive. The others in the survey group, as well as the vast majority of older members of the entire sample, were eligible for and receiving shorter or longer-term forms of disability insurance based on their psychiatric diagnosis. Two conclusions that arose from this unexpected result formed the basis for further focus group interviews that helped to confirm and describe the situation. Many younger individuals avoided contact with psychiatry and therefore the diagnostic labelling process that was the first step to eligibility for disability benefits. Receiving economic assistance in the social services system requires no “registration” process, and social service personnel expressed frustration over the growing number of younger people with psychiatric problems but no diagnosis.

*We don't register our clients as disabled (FG-IFS)*

*They see the problem as being that they don't have a job. (FG-IFS)*

The second conclusion from this analysis was that it was likely that the general social services were in fact encountering individuals who met the functional criteria outlined in the “target group” definition. Since a decision had been made to not include the general social services in the survey process, we were unable to confirm these individuals in the quantitative data. Social workers employed in specialized psychiatry emphasized at all stages of the project (reference and focus groups) that there were individuals meeting the criteria who had exclusive contact with the general social services. More familiar with what might be seen as the traditional target group for the Mental Health Reform, they wanted to instead focus on these young adults.

*With psychosis, we can gather them and help so that they come into the day programs and other services...(FG-Psychiatry)*

They described both young men and women who live “outside” of the adult world, encountering stressful and complicated social situations which lead to extreme stress and often even trauma or abuse. This was particularly true in the case of young women who in seeking a social network might end up in abusive situations. Substance abuse and criminality were also raised as features of these marginal social locations where individuals struggling with both psychiatric impairments and social stress lived their lives.

*A group which is large... lost girls, young women who don't enter the society (FG-Psychiatry)*

Our survey had likely missed many of these individuals as we did not send forms to the social workers in the individual and family services, to the adult substance abuse system, or to other non-profit and charitable agencies. Members of the leadership group for the project might argue that such an outreach process would have cast too wide a net, and that this was not the target group that the Reform had intended to serve. The workers who described many of these young individuals however, as extremely ill and becoming more at risk as their fragility made them targets for drug use, criminality, and even sexual abuse, would debate this attempt to limit the scope of the survey.

*There are many (who we meet) who have psychiatric problems but no diagnosis... Many have absolutely no insight into their illness... It can sometimes take many years... Many are so sick and have no money... and can be subjected to all kinds of abuse out in the community. We are the ones who meet them at their lowest level... It has to go very far, and then it becomes a question of involuntary care (FG – IFS)*

This younger generation of individuals were experienced in this survey as having “broken free” of the traditional “locations” in the system where prior generations were supported and monitored. We became aware of them due to the input of psychiatric staff and social workers in the general social services concerned about their health and safety, as they became increasingly ill in a system which did not seem to understand their needs.

### **A place in the community - Positioning the target group**

Patterns of service use, the individuals’ experience of themselves as disabled, and the complex relationship of social and psychiatric problems were found to be factors that emerged from the survey data and further challenged notions of a definable target group. The characteristics of the individuals found, as described by personnel and experienced by the users, pressed at the “edges” of the target group definition. As noted earlier, the needs perspective outlined by the National Health and Welfare Board (1999b: 41) describes individuals who “wander” over the field of available services, as various needs arise. One of the personnel described many of the individuals she met as “leaves in the wind”, falling to the ground in various parts of the community. Whether we accept the first, more active notion of individuals seeking help when they choose to, or the second notion of individuals helplessly wandering, there is a common sense of unpredictability as they disperse in the community. The survey project experi-

enced this phenomenon directly, as it became necessary to step back further and further from the formal mental health system in order to gain perspective on this process. As respondents shared their perspectives on the individual's place in the system and society we began to expand our picture of the context or landscape within which the survey was occurring.

*You don't belong (feel at home) anywhere (FG- Rehabilitation-user)*

Of the 652 individuals identified as meeting the criteria for a serious psychiatric disability, 456 had contact with the formal mental health system, defined as specialized psychiatry and municipal social psychiatry. The 196 who had contact with one of the other authorities in the study, employment, social insurance and primary care comprised 30 percent of the total population. The majority of the attention in this study was paid to the 456 who were currently "known" to the mental health system, primarily due to the fact that we had received more information (from the long form) on system-related needs such as psychiatric care, housing and occupation. Another factor which influenced this focus however was the initial expectation, advanced in earlier surveys, that this was the group from whom we would learn the most about the needs that the system would then attempt to meet. Put simply, there was an assumption that the target group, defined historically as those receiving services, were the group that needed services, and that these needs would fall within the structures of formal mental health services. In many discussions, staff referred to individuals not receiving social psychiatric or psychiatric services as having "fallen between the chairs". The implication was that these individuals either lacked insight into their illness or the lack of coordinated services had allowed for gaps into which they had fallen. In focus group interviews and other discussions with the leadership and reference groups, participants began to speak of a "grey zone", by which they often meant the "grey areas" of organisational responsibility that lay between the "chairs" or organisational contacts.

A particularly rich source for exploring psychiatric disability in the community, and one that broadened our perspective was the social insurance authority. The special group, which handled all cases related to psychiatric disability, reported 550 cases at the time of the study who they had contact with and responsibility for. Of these individuals they determined that 200 (190 forms were useable) met the criteria outlined in the study and they raised a number of issues that became particularly relevant for this and future studies. They worried for example about the process of awarding permanent pensions, based in part, on the willingness of doctors who thought they were helping, and without considering the long term possibilities related to psychiatric disability.

*We are beginning to wonder if we award a permanent pension too early... there are very young people who have gotten a permanent pension. (FG-Social Insurance)*

Another perspective was that it was difficult to determine the extent of psychiatric disability in many cases. They explained this as being the result of not being able to predict who might succeed with a rehabilitation intervention, who had the best chance of recovery for example. Was it a young man with schizophrenia who had never finished high school, a “burnt-out” and anxious teacher with 25 years behind them or a man who had become increasingly depressed and phobic after a long period of unemployment?

*(We meet )many with social phobia who can't get themselves out through the door... others with psychotic illnesses who function quite well anyway (FG-Social Insurance)*

*It is impossible to say who will succeed (with rehabilitation)...if they end up in the right place, they can succeed (FG-Social Insurance)*

We began to see many of these individuals, or at least those who were more difficult to assess as seriously psychiatrically disabled, as existing in the “grey zone” that had become a metaphor for a social location where individuals moving towards rehabilitation and recovery crossed paths with individuals who were drifting further from their functional roles in the normal community as their life situations worsened. This worsening, which may be seen as a reduction in their ability to participate in community life, was most often accompanied by increased psychiatric symptoms and impairments. Another perspective which confirmed this type of movement towards or away from a serious psychiatric disability was provided in an interview with a project supporting the long-term unemployed, suggested by the reference group.

*Many have for example a difficult life situation over many years. They develop psychiatric problems... for example, over 5-10 years they become more mentally ill. (FG-unemployment project)*

The staff of this project, representing the four major players in the field of vocational rehabilitation, estimated that 50 percent of their clients met the criteria for serious psychiatric disability. This project did not receive the survey so we have no way of saying whether some of these were also receiving formal mental health services, but based on the interview, they were not perceived by others

in the system as typical “psychiatric patients”. These interviews reinforced an emerging picture of what we began to describe as life in the grey zone. For those who “fell out” of a participatory life in the community, for a variety of reasons including mental health problems, there seemed to be an experience of what Hatfield (1993) described as “downward drift”.

*If they had landed right in their lives... it could have worked... if they had support from the beginning. (FG-unemployment project)*

This picture, of social location and timing, as two crucial factors in describing how some of the individuals in our study might fall into the “target group” led to some of the sub-groupings which will be introduced in the next chapter. At this point we were aware that there were a number of groupings, representing various positions at various points in time (or the career of a person with a disability) that were of interest to us. We had heard about many individuals who seemed to be at risk for deteriorating to the point that they would require support for a serious psychiatric disability. We found them with the social insurance authority and with the general social services (IFS). There were also individuals who were attempting to participate in rehabilitation or employment services, despite a serious psychiatric disability and attempting to recover to a participatory life in the community. We found these with both the social insurance and employment authorities, but even in the municipalities’ rehabilitation and supported housing program.

In surveys conducted prior to and during the Reform process, the vast majority of individuals identified as target group members lived a life that was tied primarily to the psychiatric care system. Housing, treatment, support and social life were all connected in a more or less institutionalized fashion to their role as disabled clients within the system. Even in the current survey it was clear that many individuals, especially those who were included as target group members, had the majority of their social contact and support in the community provided by staff within the system. Many other individuals, such as the younger women described by personnel in psychiatry, had resisted a system-dependency and still maintained connections in the community. However, as discussed by these workers, their primary community contact was with other marginalized individuals who lived outside the mainstream for a variety of reasons, including alcoholism, criminality, long-term unemployment, etc.. Many of the “traditional” target group members experiencing serious disabilities had begun to move towards community life as well, but had only succeeded in “climbing up” to the grey zone where they met others with more or less serious disabilities or others living a marginalized existence in the community. The result was that

even those who had begun to move towards independence remained isolated from work and social life, and had not achieved a real integration into community life.

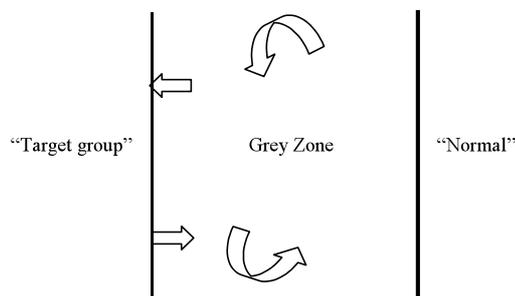
*There is a gap between psychiatry and community life...(FG-employment service)*

*... possibilities(must be developed) for attempting work in a real environment with reasonable work tasks during a long and continuous period (FG-employment service)*

From information received in this initial stage of data collection, it became clear that surveys would need to be sent to the general social services, and that other generic community supports services had extensive contact with individuals who might fit the target group definition. This process of seeking individuals in the community could have continued as well, as information pointed to members of this group in the criminal justice system, on the streets and using drugs or alcohol, and into homes in the surrounding, more rural areas of the municipality, where individuals lived an isolated existence, perhaps only in contact with aging parents. There was a clear sense that the individuals sought as potential members of a “target” group, had broken free of the assumptions inherent in the very process of grouping them.

*I don't like (the name) “the psychiatrically disabled” ... I don't want to be part of a target group (IN)*

*Illustration 2; A community perspective on psychiatric disability*



As described above, a number of tendencies or mechanisms emerged during the analysis of the data in Study one. Both quantitative and qualitative results pointed to the existence of a “grey zone” where people with psychiatric disabilities, who in the assessment of personnel met the criteria for the target group definition, lived their lives while avoiding or attempting to move beyond contact with the formal mental health system. The arrows represent these individuals who were described as either at risk for becoming dependent on the formal mental health system as well as those who had begun to recover and were now trying to establish goals for participating more actively in the community. The following study builds on this picture, attempting to include these individuals who were challenging the system-based target group concept.

# Chapter six – Risk and recovery

## Introduction and background

This chapter will present the results of study two, the largest of the three studies, since it included four municipalities. The surveys are presented together here since we utilized a method which in all relevant aspects remained the same throughout the four surveys. The first two projects, in municipalities two and three proceeded simultaneously since they were part of the same health care district and utilized the same offices for employment and social insurance. These were both smaller rural cities but comprising large geographic areas and a number of smaller towns. Municipality two has a population of 20, 139 and municipality three, 21,000, so that they were close in size as well. Municipality four was a smaller city on the coast, bordering the considerably larger city described in study one and with a population of 17, 143. The final municipality in this study, municipality five, is a larger city, situated on the coast and the administrative center for the county. There are 25,243 residents.

The oversight report (Socialstyrelsen och Länstyrelserna2005) summarized in chapter one and made public during the period of time in which we completed study two, supported a number of the conclusions that had emerged from the initial study in 2001, and many of the adaptations we were planning for study two. The study described in this chapter may in this regard be described as a “development and testing” phase of the overall research study. Conclusions from study one, supported by external reports, were operationalized in the method and analysis contained in this study. Before presenting the method adaptations, a brief summary of the initial findings pertinent to these changes is presented.

An important conclusion of the first study was that the “target group”, people with psychiatric disabilities, was actually a broad collection of individuals with various psychiatric issues, differing relations to the welfare state and a variety of roles in community life. These individuals appeared to belong to different generations as well. Many of those who had lived through the Reform were portrayed as “institutionally damaged” and confirmed as target group members based on their continued dependence on services. Younger individuals, many of whom had come in contact with psychiatry or social psychiatry after the Reform, had an ambivalent relation to the support system, seeking and then rejecting services that did not meet their perceived needs. Many attempted to meet their needs for a life in the community, concretely those related to

work, studies and social contacts, in what was often described as the “grey zone” of society. Without access to positive social networks and meaningful roles, an increasing number had also turned to substance abuse and contact with others on the “fringes”.

Users described an experience confirmed in the recovery literature, that they can recover, worsen and even function at a normal level despite continuing symptoms of an illness. Theirs is not an experience of a static condition. We encountered individuals who were in the process of developing a serious and prolonged psychiatric disability which we began to refer to as a “risk group” and others who were struggling to recover to a life in the community, a “recovery group”. The “target group” concept has its place as well in that it refers to both the traditional group to whom the Reform promised a life in the community and those who become trapped in a primary dependence on the support system. The definition of psychiatric disability, which had been utilized in the first study, was therefore modified to include “risk” and “recovery” groups, an attempt to identify individuals described in the initial study, who had often been excluded due to assumptions regarding the location and service use patterns of the traditional “target group”. The survey form, and subsequent analysis, was also more clearly geared to eliciting information related to the contact points in the system where individuals described as psychiatrically disabled sought service and support. These changes are described below.

## Method specifics

In addition to the target group definition used in the earlier study, staff of the various authorities participating in the survey were asked to include individuals who met either of the two following conditions, as well as to motivate their thinking on their criteria for including these individuals.

***Risk Group:*** *Individuals 18 and older who risk ending up in the target group*

***Recovery Group:*** *Individuals 18 and older who have belonged to the target group and have partially recovered, in other words function better in community life, but continue to exhibit needs due to a psychiatric disability.*

The additional categories of risk and recovery groups were not included with the aim of establishing permanent categories for developing and providing services. Rather, the aim was to broaden the target group 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 specialized psychiatry and municipal social psychiatry. These two additional groupings served the additional function of “locating” the individual within a relationship to the natural community. Risk group members were those who were still functioning in the community but with serious enough psychiatric impairments and functional deficits that they risked losing that ability to maintain their participation. Recovering individuals were those who had begun to participate more actively in community life, despite a continuing psychiatric need.

### **Organisational analysis**

We did not complete an organisational analysis in the initial study to the extent that we did in this study. This allowed us to provide data as to the number of persons considered to be seriously psychiatrically disabled who had contact with each authority, as well as the number of discrete individuals who only had contact with specific authorities. An additional modification was based on the results from the focus group meetings with personnel from the individual and family services department (IFS) of the general social services, who confirmed for us that they indeed encountered individuals meeting the criteria. In this study, survey forms were therefore sent to these workers, as well as those providing housing and income support, and the department for elder and home care services.

### **Focus groups**

Data collected in focus groups was analyzed with regard to documenting the “grey zones” which had been alluded to in study one. In study two, we began to organize the theme-oriented focus groups presented in chapter four. Initially, we took this step due to a need for making the process more effective. We also found that in our analysis of the initial studies, a number of themes had emerged that related to various sectors of society and aspects of community life. Finally, it became increasingly clear at the practice level that the focus groups served as a form of dialogue for the various actors, a dialogue focused on the particular needs of individuals with psychiatric disabilities. This process was one that was also especially applicable to the gathering and spreading of information regarding resources. In the final reports it was therefore recommended that these focus groups would be repeated at least yearly, as a follow-up to the initial report, and in keeping with the conclusion from the oversight report (Socialstyrelsen & Länsstyrelserna 2005) which recommended a “system for continual follow-up” so that services would be relevant to current needs.

## Results

The following results are a small sample of those generated in the original reports. Whenever possible, results from all four surveys have been included in order to examine the factors addressed from the broadest possible sample, and at the same time to allow the reader to compare results from the individual municipalities. When we were able to account for variance in certain responses, we have clarified these in the text following each table.

### Individuals, in the community...

The following tables address results related to age, gender, civil status and financial support. These may all be seen as characteristics of the individuals who were identified in the study, characteristics however that go beyond their identity as psychiatrically disabled or simply “target group” members, and can contribute to an understanding of who these individuals are.

*Table 7: Number and percent by age group and municipality*

| <b>Mun.</b>  | <b>18-29</b> | <b>30-39</b> | <b>40-49</b> | <b>50-59</b> | <b>60 -</b>  | <b>Total</b>    |
|--------------|--------------|--------------|--------------|--------------|--------------|-----------------|
|              | <b>N (%)</b> | <b>N (pop.)</b> |
| M2           | 13 (6.7)     | 36 (18.6)    | 34 (17.5)    | 53 (27.3)    | 58 (29.9)    | 194 (20,139)    |
| M3           | 19 (10.4)    | 25 (13.7)    | 38 (20.8)    | 48 (26.2)    | 53 (28.9)    | 183 (21,000)    |
| M4           | 27 (17.3)    | 25 (16.1)    | 23 (14.7)    | 37 (23.7)    | 44 (28.2)    | 156 (17,743)    |
| M5           | 43 (20.7)    | 37 (17.8)    | 47 (22.6)    | 40 (19.2)    | 41 (19.7)    | 208 (25,243)    |
|              |              |              |              |              |              |                 |
| <b>Total</b> | 102          | 123          | 142          | 178          | 196          | 741             |

Some of the municipalities had more success than others in establishing contact with young adults. The operative mechanisms which may help to explain this are complex, and may have as much to do with the lack of alternative opportunities for young adults in that municipality as with the specific offerings of the formal mental health system. Findings from the focus groups, as well as the predominance of young adults who turn to the employment service and to the general social services for economic support, point to the relevance of investigating need as related to age group differences. The large percentage of individuals 50 and over also points to age related or generational issues which were expressed by participants. As discussed in study one, many of these have “been

in the system” since the Reform in 1995, and for many, there is a prior history of institutionalization.

*Table 8: Marital status and children - Number and percent by municipality*

| <b>M</b> | <b>Married/<br/>living<br/>together</b> | <b>Married/<br/>living<br/>together<br/>w/ children</b> | <b>Single</b> | <b>Single<br/>w/<br/>children</b> | <b>Don't<br/>know</b> | <b>N</b> | <b>All<br/>w/<br/>children</b> |
|----------|---|---|---------------|-----------------------------------|-----------------------|----------|--------------------------------|
|          | N (%)                                   | N (%)   | N (%)         | N (%)                             | N (%)                 |          | N (%)                          |
| M2       | 17(8.2)                                 | 9 (4.3)   | 155(74.5)     | 22 (10.6)                         | 5 (2.4)               | 208      | 31 ( 14.9)                     |
| M3       | 17 (8.9)                                | 4 (2.1)   | 124(64.9)     | 11 (5.8)                          | 35(18.3)              | 191      | 15 ( 7.9)                      |
| M4       | 18 (11.5)                               | 11 (7.0)  | 100(63.7)     | 11 (7.0)                          | 17(10.8)              | 157      | 22 ( 14.0)                     |
| M5       | 24 (11.2)                               | 7 (3.3)   | 155(72.1)     | 19 (8.8)                          | 10 (4.7)              | 215      | 26 ( 12.1)                     |
| Total    | 76 (9.6)                                | 31 (4.0)  | 534(69.3)     | 63 (8.2)                          | 67 (8.7)              | 771      | 94 ( 12.2)                     |

The figures above reflect contact with children but do not specify the relationship or whether the individual has full or partial custody. The consistency of the findings in these four municipalities however, with a cumulative result pointing to at least 94 individuals (12.2%) known to have a significant relationship with a child, would point to the relevance of including family issues in surveys of need. Focus group discussions were able to shed further light on the issue of parenthood. One staff member who worked at the young adult unit within specialized psychiatry felt that there were those who “...built a family early instead of qualifying themselves (for a role in society) by finishing high school, instead they “qualified” themselves by building a family”. While there are clearly many reasons as to why we see so many individuals who are parents there is also a clear need that arises from this role and one that is best expressed by users themselves.

*A support group for the whole family is needed. (FG-user)*

*It's very bad with support services for the children when the parent feels bad. (FG-user)*

A particularly striking account was provided by a user who attended a focus group and related how she had been repeatedly hospitalized over the years for self-destructive behaviour. Despite the fact that her young child had even witnessed a suicide attempt on one occasion, she was never offered help regarding her children, or her responsibilities as a parent. Her perspective on her needs as

psychiatrically disabled, but also as an effective and loving parent, was one that was exceptionally informative, and raised important questions about the categorizing of services within the social services. It was also a challenge to an exclusively individual/medical perspective on psychiatric disability, which seemed unprepared to focus on her abilities and responsibilities as a woman in the community.

*Table 9: Gender and parenthood – all four municipalities*

|       |  | Civil Status            |                                      |        |                    |            | Total |
|-------|--|-------------------------|--------------------------------------|--------|--------------------|------------|-------|
|       |  | Married/Living together | Married/ Living together w/ children | Single | Single w/ children | Don't know |       |
| Men   |  | 24                      | 6                                    | 281    | 17                 | 24         | 352   |
| Women |  | 46                      | 24                                   | 216    | 41                 | 28         | 355   |
| Total |  | 70                      | 30                                   | 497    | 58                 | 52         | 707   |

This table presents a gender perspective on the issue of psychiatric disability and a role as parent. The spread of men and women is fairly even across municipalities in this study (49.6% men and 50.4% women for all four municipalities). It is clear however that the role of parent is one that more frequently enters into the picture for women, when 80 percent of those in a marital or cohabitation situation with children are women. Of those who are single with children, 71 percent are women. Since we did not ask respondents to describe the specific situation regarding the children we are unable to state explicitly the number that may be parents without custody. This is clearly an area that would require further research, and then with a focus on the wide range of roles that parenting can entail. For example, as one respondent pointed out, there may be individuals with psychiatric disabilities who have lost their children to foster care during a crisis, and we don't know if these were reported. Thornicroft (2006) has pointed out that a diagnosis of schizophrenia is often associated with social services involvement in the parenting situation.

*Table 10: Parenthood by organisation*

|    | <b>Ind. &amp; Family</b> | <b>Social psych.</b> | <b>Psych.</b> | <b>Employment &amp; Insurance</b> | <b>Primary Care</b> | <b>Other</b> | <b>Total</b> |
|----|--------------------------|----------------------|---------------|-----------------------------------|---------------------|--------------|--------------|
| M2 | 5                        | 15                   | 9             | 0                                 | 0                   | 2            | 31           |
| M3 | 9                        | 0                    | 2             | 0                                 | 1                   | 3            | 15           |
| M4 | 6                        | 5                    | 8             | 2                                 | 1                   | 0            | 22           |
| M5 | 10                       | 0                    | 7             | 6                                 | 2                   | 1            | 26           |

The issue of parenthood which arose during the study, motivated both by the unexpectedly large number who had children but also by the focus groups involving users, raised questions of need across organisational boundaries.. Where were the parents we found, all with psychiatric disabilities, receiving services? The differences in municipalities confirm that there is no one pattern, but support the idea that there is a need to understand the manner in which local systems respond to the various roles which these individuals have in the community, roles that demand supports beyond purely psychiatric care. In municipality two for instance, there appear to be many who have contact with specialized psychiatry, either municipal or medical. This might lead to questions regarding the types of supports they offer for these individuals and the types of relationships they have created with the family services units as a reflection of this need.

*Table 11: Financial support type by age group*

|                                | <b>18-29</b> | <b>30-39</b> | <b>40-49</b> | <b>50-59</b> | <b>60 -</b> | <b>Total</b> |
|--------------------------------|--------------|--------------|--------------|--------------|-------------|--------------|
| Paid employment                | 7            | 12           | 4            | 4            | 3           | 30           |
| Subsidized employment          | 1            | 8            | 8            | 12           | 4           | 33           |
| Unemployment insurance         | 8            | 4            | 10           | 5            | 4           | 31           |
| Sickness benefits              | 13           | 18           | 9            | 12           | 1           | 53           |
| Disability pension - temporary | 12           | 33           | 35           | 21           | 3           | 104          |
| Disability pension - permanent | 2            | 21           | 43           | 91           | 47          | 204          |
| Social assistance              | 32           | 17           | 15           | 4            | 4           | 72           |
| Retirement pension             | 0            | 0            | 0            | 0            | 99          | 99           |
| Family support                 | 3            | 1            | 1            | 0            | 2           | 7            |
| Rehabilitation support         | 5            | 6            | 3            | 4            | 0           | 18           |
| Activity support               | 8            | 0            | 0            | 2            | 0           | 10           |
| Education support              | 1            | 0            | 2            | 0            | 0           | 3            |

These are the combined results for all four municipalities. No percentages are given since some individuals have reported more than one income source, however we can still make a number of observations regarding patterns in the results, patterns which may provide clues to operative mechanisms. Of those receiving social assistance, 32 of 72 or 44 percent were between 18 and 29, 49 or 68 percent were under 40 years old. The total number of individuals in the age group 18-29 for these studies was 92, 32 of these, or 34.8 percent were dependent on social assistance for their primary support (46% in Study one). As the individuals in the study “age”, if we are to assume that the notion of a “career” as disabled is relevant here, the numbers of those receiving social assistance lessens and the numbers for those receiving permanent disability pension increases.

It is also significant to examine the relationship between temporary and permanent disability pensions where a similar effect may be observed. While it is natural in some ways for this to occur, it is also significant since these forms of support have implications at the early stages, for how the individual is categorized and supported by the system, and at later stages, for the opportunities for the individual to engage in rehabilitation. We see for example 66 individuals all under 50 years old, who are receiving a permanent disability pension. While some changes are under consideration by the current government in Sweden, it meant that if a person was classified as permanently disabled at 30 years old for example, and a new rehabilitation program was developed when they were 40, they would not be contacted, and would likely remain outside the employment market for the rest of their lives. In this manner, interactions with the helping system have clear implications for the life of the individual in the community, in this case creating a financially-determined marginalization or “institutionalization”.

### **Risk and recovery – Dynamics and the target group**

The following tables analyze the results of the four surveys with regard to the expanded group definition which has been described above.

Table 12: Individuals with psychiatric disability by sub-group

|          | <b>Subgroup</b> | <b>N</b> | <b>%</b> |
|----------|-----------------|----------|----------|
| M2       | Target          | 101      | 49.0     |
|          | Risk            | 50       | 24.3     |
|          | Recovery        | 55       | 26.7     |
|          | Total           | 206      | 100      |
| M3       | Target          | 61       | 34.3     |
|          | Risk            | 30       | 16.9     |
|          | Recovery        | 87       | 48.9     |
|          | Total           | 178      | 100      |
| M4       | Target          | 122      | 78.7     |
|          | Risk            | 9        | 5.8      |
|          | Recovery        | 24       | 15.5     |
|          | Total           | 155      | 100      |
| M5       | Target          | 134      | 63.2     |
|          | Risk            | 43       | 20.3     |
|          | Recovery        | 35       | 16.5     |
|          | Total           | 212      | 100      |
| Combined | Target          | 418      | 55.6     |
|          | Risk            | 132      | 17.6     |
|          | Recovery        | 201      | 26.8     |
|          | Total           | 751      | 100      |

The ranges for the various groupings were;

Target group: From 34.3% to 78.7% of the total reported.

Risk group: From 5.8% to 20.3% of the total reported

Recovery group: From 15.5% to 48.9% of the total reported

While the variance in the reporting may reflect subjectivity in the assessment process, as well as probable weakness in the precision of the definitions, there is also a confirmation of the existence of these dynamics as expressed in the numbers reported in the additional group categories. It should also be noted that part of the process of distributing the survey involved presenting this adaptation to the leadership and reference groups, as well as the majority of staff who would be completing the form. In these presentations, the additional categories were accepted as representative of the reality that they experienced with regard to these individuals. Responding personnel were also asked to justify their choices of each group by motivating their choice of group in writing. Their answers were compared across the four municipalities and resulted in the

following descriptive categories (language reflects actual comments in the responses which were reflective of the majority);

#### **Target Group**

- Comprehensive needs – in all areas of life – require support to get through the day
- Serious economic problems
- Severe illness – diagnosis specified included psychosis, severe depression, social phobias and severe anxiety
- Fear of participation/venturing out in community life
- Services they receive confirmed group membership. (*She's been with us for decades; He lives in a group home*)

#### **Risk Group**

- Would belong to the target group if supports were gone
- Little insight into their illness / Have stopped using support services
- 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; Many sink deeper and deeper into isolation and psychiatric illness*)
- Receiving disability benefits and without options for rehabilitation (more and more marginalised and isolated over time)
- Periodic needs for support
- Drug/alcohol abuse in the picture

#### **Recovery Group**

- *Functions well now and can get through daily life, but still needs support*
- Has developed a social network
- Recovery due to continuing support with personnel who they trust
- 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*)
- Periodic need for support due to recurrent symptoms

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 loca-

tions 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 (M2 and M3 figures only) of being without any meaningful activity, 63 percent as compared to the risk group, 37 percent and the recovery group, 44 percent. Unexpected was the fact that 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 percent were considered to meet the criteria for the target group in municipality 2 and 47 percent in municipality 3. Recovery group members were surprisingly found as well with municipal social psychiatry, where 35 percent in municipality 2 and 29 percent in municipality 3 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.

*Table 13: Individuals with psychiatric disability by age and sub-group*

| Age Group | "Target Group" |      | Risk Group |      | Recovery Group |      | Total N |
|-----------|----------------|------|------------|------|----------------|------|---------|
|           | N              | %    | N          | %    | N              | %    |         |
| 18-29     | 52             | (53) | 33         | (33) | 14             | (14) | 99      |
| 30-39     | 70             | (57) | 23         | (19) | 30             | (24) | 123     |
| 40-49     | 79             | (56) | 26         | (19) | 35             | (25) | 140     |
| 50-59     | 99             | (59) | 21         | (12) | 49             | (29) | 169     |
| 60 -      | 107            | (57) | 18         | (9)  | 65             | (34) | 190     |
| Total     | 407            | (56) | 121        | (17) | 193            | (27) | 721     |

These results for the groups varied by age, but varied also by municipality. They are perhaps most useful on a local basis in order to understand how the particular organisational structure and environment for organisational cooperation may have influenced the “location” of individuals at different stages of their lives and therefore needs of their disability experience (or interaction with the system). A number of interesting mechanisms may also be observed here, as supported by many comments in the focus groups. We see a greater percentage of younger individuals categorized as “at risk”, a finding confirmed by many

workers in the Individual and Family Services unit. Interesting also was that 34 percent of those over 60 were considered as being “in recovery”. Looking back to an interview with a primary care nurse in study one, we heard that from her perspective, many of her older patients, still labelled as psychiatrically disabled and dependent on the formal mental health system, were actually at least as mentally healthy as many of her “normal” elderly patients who had the advantage of living in integrated elder housing.

*We shouldn't “psychiatricatize (their word)” a normal aging (FG-psychiatry)*

This information may also be used to target specific sub groupings of individuals, such as the 49 individuals between 50 and 59, who according to many other indicators, are not being offered rehabilitation services, but who according to these judgements could potentially lead more participatory lives, as they are described as “in recovery”. Finally, we see an increasing number who are seen as being in a recovery phase as they age, a positive and somewhat expected outcome. We also see however an increasing number who seem to “fasten” in the target group description, a result which may point to a “deteriorating course of illness” or confirm “institutionalizing” mechanisms which have been described in the literature. In other words, individuals may become trapped in a dependence on psychiatrically defined services, due to a lack of alternatives, rules related to economic support and social insurance, and an impoverished access to social networks in the community.

### **Contacts in the organisational field**

One of the questions posed in the aims of the dissertation related to the patterns of contact between the individuals identified in the studies and the organisations we were able to involve in the process. Focus groups in study one confirmed that many of those experiencing psychiatric disabilities were in contact with a variety of actors in the helping system, and this led to the a careful analysis of the organisational contacts in this study.

Table 14: Individuals with psychiatric disabilities by organization.

| Organization                        | M2  |      | M3  |      | M4  |      | M5  |      | Combined |      |
|-------------------------------------|-----|------|-----|------|-----|------|-----|------|----------|------|
|                                     | N   | %    | N   | %    | N   | %    | N   | %    | N        | %    |
| Social Psychiatry (Social services) | 104 | 50   | 18  | 19.4 | 67  | 42.7 | 29  | 13.7 | 218      | 28.3 |
| Medical Psychiatry                  | 40  | 19.2 | 62  | 32.5 | 23  | 14.6 | 58  | 27.4 | 183      | 23.8 |
| General Social Services (IFO)       | 36  | 17.3 | 34  | 17.7 | 35  | 22.3 | 16  | 7.5  | 121      | 15.6 |
| Elder & home care services          | 28  | 13.5 | 30  | 15.8 | 1   | 0.6  | 16  | 7.5  | 75       | 9.8  |
| Primary Health Care                 | --- | ---  | 13  | 6.8  | 10  | 6.4  | 30  | 14.2 | 53       | 6.9  |
| Employment Service                  | --- | ---  | 34  | 17.8 | 21  | 13.4 | 39  | 18.4 | 94       | 12.2 |
| Social Insurance                    |     |      |     |      |     |      | 20  | 5.4  | 20       | 2.9  |
| Case Manager                        |     |      |     |      |     |      | 4   | 1.1  | 4        | 0.5  |
| Total                               | 208 | 100  | 191 | 100  | 157 | 100  | 212 | 100  | 768      | 100  |

Note: The social insurance authority was unable to participate in M2, M3 or M4. Case managers did not report any unique clients in M2 and M4 and there were no case managers in M3.

As discussed above, the “formal” or “traditional” mental health system refers to the municipal social psychiatry units and specialized psychiatry. The generic community services, which are described as non-traditional locations, refer to social welfare services which are available to all and not particular to people with psychiatric disabilities. Of the individuals identified in the study as meeting the criteria, 52 percent had contact with the formal MH system, 48 percent were only receiving generic community services. By municipality we can see that: M2; 69.2 percent were in contact, M3; 51.9 percent in contact, M4; 57.3 percent and M5; 41.1 percent. There was therefore a range of from 30.8 to 58.9 percent who did not have contact with the formal mental health system. It is also clear that the study did not reach many who either did not have contact with the authorities included in the survey or were missed by reporting personal. An additional group, receiving permanent disability allowances, was also missed if they did not have contact with one of the other authorities, since their cases were administratively “archived” and they had no active contact with staff in the local social insurance office.

The results presented here are based on the actual individuals identified and based on the prioritization outlined in the method discussion. Individuals reported by other authorities than the formal mental health system were only

known to those respondents. We can use the cases of the employment service and primary health care as an example. Results varied for each municipality and conclusions must be drawn locally but the point to be made here is that these results may provide valuable information regarding need, based on the active attempts of the individual to seek support services from actors who they believed were best suited to respond to their needs.

*Table 15: Reported and discrete Individuals*

| Mun. | Employment service |             | Primary health care |             |
|------|--------------------|-------------|---------------------|-------------|
|      | Reported           | Individuals | Reported            | Individuals |
| M3   | 34                 | 34          | 14                  | 13          |
| M4   | 24                 | 21          | 20                  | 10          |
| M5   | 42                 | 39          | 33                  | 30          |

The numbers here reveal that the large majority of individuals reported by the employment service for example, were not reported by the formal mental health system. This would indicate that these individuals have sought help related to their desire to enter the job market. Whether or not they consider themselves to have a psychiatric disability, their priority for seeking support is clearly in the direction of a working life. Many psychiatric professionals would and have explained this as a lack of insight into their illness, and there were focus group participants who agreed.

*These young people place themselves at the employment office... but it's often the case that they are too ill. (FG-social insurance)*

*They come to us when they don't get a response (to their desire to work) anywhere else (FG – employment)*

The primary medical care system comprises local care centres that are the first stop for illness-related needs. While only reporting 6.9 percent of the total population, we see here that they have exclusive contact with many individuals. It should be noted that they have a clear responsibility for those in the first stages of a psychiatric illness, but even for medical psychiatric care to those with long term disabilities now living in the community. Focus group interviews indicated that they do have substantial contact, but that psychiatric needs may be hidden behind a somatic complaint. These centers are also to act as a filter for problems that might then need to be referred to specialist psychiatry. Many individuals who do not meet the criteria for an acute need get no further than these outposts for care in the community. Another explanation for why certain

individuals turn to the primary care centers rather than psychiatry was given by a district nurse in one of the focus groups;

*The positive thing about turning to primary care instead of psychiatry is that the care center is for all people, regardless of what problem they have. You don't separate problems, you are treated like anyone in the community. (FG- Health care)*

Table 16: Organisation by age group – municipalities four and five

|    |                    | Age category |           |           |           |           |
|----|--------------------|--------------|-----------|-----------|-----------|-----------|
|    |                    | 18-29        | 30-39     | 40-49     | 50-59     | 60 -      |
| M5 | Ind. & Family      | 5            | 4         | 5         | 1         | 0         |
|    | Social Psychiatry  | 5            | 6         | 7         | 9         | 1         |
|    | Home help          | 0            | 3         | 4         | 4         | 5         |
|    | Psychiatry         | 12           | 14        | 13        | 9         | 8         |
|    | Case Management    | 3            | 0         | 0         | 0         | 1         |
|    | Employment service | 13           | 5         | 9         | 7         | 5         |
|    | Primary Care       | 0            | 0         | 1         | 7         | 21        |
|    | Social Insurance   | 5            | 5         | 7         | 3         | 0         |
|    | <i>Total</i>       | <i>43</i>    | <i>37</i> | <i>46</i> | <i>40</i> | <i>41</i> |
| M4 | Ind. & Family      | 13           | 6         | 5         | 9         | 2         |
|    | Social Psychiatry  | 7            | 7         | 7         | 19        | 26        |
|    | Home help          | 0            | 0         | 1         | 0         | 0         |
|    | Psychiatry         | 4            | 6         | 4         | 2         | 7         |
|    | Employment service | 3            | 4         | 6         | 7         | 1         |
|    | Primary Care       | 0            | 2         | 0         | 1         | 7         |
|    | <i>Total</i>       | <i>27</i>    | <i>25</i> | <i>23</i> | <i>38</i> | <i>43</i> |

It should be noted that due to either poor reporting or missed cases this particular information was difficult to present across all four surveys, so I have chosen the two with the most comprehensive information in order to illustrate the point. While different for every municipality, it is possible to raise questions regarding tendencies, which in many cases have been confirmed in focus group discussions. For example the tendency for social psychiatry to be dominated by somewhat older individuals many of whom remain after a transfer from psychiatry following the Reform. We also see a tendency for younger individuals to

appear at the employment service, in numbers often greater than for social psychiatry. In Study one, the average age for social psychiatry clients was 48 and for those in touch with the employment service, 37.

As described in chapter five, we became aware that various organizations seemed to attract individuals of different ages or generations, as a general phenomenon. Again, I am not suggesting regular causal relationships, but describing a phenomenon which may be useful in planning. It is fairly obvious that older individuals would seek health care services as part of the normal aging process as we see in M5. One reason for the lower numbers in M4, in contact with primary care, may be that the municipal social services have integrated health care issues within the supported housing system in order to avoid, as we heard from focus group members, having to deal with stigmatizing attitudes and a lack of knowledge at the primary care center.

### **The Silo Effect – The categorization of need**

In analyzing the data we were struck by how many "don't know" choices were checked off. It is possible that these at times reflected the respondent's attitude regarding the completion of the form, or a general lack of knowledge regarding the client's life. We decided however to complete an analysis of these answers with regard to the organization within which the respondent was employed. We did this for each of the questions related to need and satisfaction with services, and found some interesting results, an example of which is presented here.

*Table 17: Knowledge by organization – Satisfaction with work life*

|                     |                              | <b>Know</b> | <b>Don't Know</b> | <b>Total</b> |
|---------------------|------------------------------|-------------|-------------------|--------------|
| <b>Organisation</b> | Individual & Family Services | 21.2%       | 78.8%             | 100.0%       |
|                     | Social Psychiatry            | 85.7%       | 14.3%             | 100.0%       |
|                     | Care services – Home help    | 16.7%       | 83.3%             | 100.0%       |
|                     | Specialized Psychiatry       | 75.0%       | 25.0%             | 100.0%       |

For example, 78.8 percent of respondents from the individual and family services did not know if the individual was satisfied with regard to support for their vocational/work goals. For the home help services, 83.3 percent did not know. Within the formal mental health system we see a much higher percentage of knowledge regarding the individual's needs in this area. What we believe the data shows is a relationship between knowledge of certain life needs of the

client and organisationally-defined responsibility, a phenomenon often described as a “silo effect”. As discussed in chapter three, organisations tend to categorize clients in order to respond to needs which lie within their organisational responsibility and resources. The data allowed us to concretize the effect of this categorization of need in direct relation to knowledge of the client’s needs. The implication is that individuals who have exclusive contact with one organisation may not receive a holistic assessment of their needs. Further analysis of these types of organisationally determined knowledge gaps may be useful in understanding why many individuals fall between the cracks.

*Too much “talk” about who should own the case... Lose the “talk” ...  
All should focus on rehabilitation. (FG-employment)*

*The system steers how they express their needs (FG- employment)*

It is understandable for example, that workers charged with supporting the individual in their home, with cleaning and shopping, would be unaware of their vocational needs. It is still a concern however, if they are the primary contact between the system and the individual. Of greater concern is the lack of knowledge among social service workers, who while primarily charged in the majority of these cases with giving economic aid, should be working under what is described as the “work line”, attempting to support all to a working life in the community. What isn’t clear from this data is whether they have less knowledge of these particular individuals due to pessimistic expectations regarding the ability of people with psychiatric disabilities to work.

*It’s (rehabilitation) more complicated with psychiatric diagnoses...  
we don’t have the knowledge...we definitely need education. (FG-  
social insurance)*

The silo effect that we became aware of as we analyzed the organisational contacts with individuals we found was considered to be one mechanism behind the resultant fragmentation of needs. The employment service couldn’t help with what they perceived to be needs related to a psychiatric illness, and so they sent the individual back to psychiatry, which had no ability to help the person work towards their employment goals. The fact that individuals don’t get their needs met is often rationalized by stating that they “fell between the chairs”, the chairs being the organizational structures within the helping system, the five authorities. This assumption seemed to lead to a passivity in planning, while waiting for the client to arrive, rather than an effort to understand the mecha-

nisms which produced this outcome. As we examined the organisational contacts, the patterns of contacts, and the information we were able to gather regarding the needs which these individuals presented, the metaphor seemed to “collapse”. Our hypothesis at this point was that the individuals were not somehow getting lost in the community but that the “chairs” were not being placed correctly. The results seemed to concretize the locations “between the chairs”, the room within which individuals struggled when the existing structures did not accurately assess and then meet their needs, due to this fragmentation. This will be discussed further in chapter nine, but at this stage of the research supported the notion of describing these “grey zones”. In this case we describe the grey zones as the places where the individuals we found were, when they were not where the system expected them to be.

*Such grey zones (such as those between psychiatric clinics and social service supports) will probably continue as long as there is a tendency to carve up people’s complex needs between various organisations remains. The important part in the practical work will be to make every grey zone, the responsibility of one or both, and not let them become a “no mans land (Markstöm 2005: 55)*

## **Grey zones**

In table fourteen, we saw that only fifty two percent of all individuals identified as meeting the criteria had contact with the formal mental health system. The remainder were found in what I have referred to as non-traditional locations, having sought help from generic community services. Many attempts to explain the lack of contact, as described in the introduction to this dissertation, have revolved around the inability of the mental health system to find and treat these “lost souls”, while portraying them as having no “insight into their illness”. That is not the whole picture that emerged in these studies, a picture made possible by the availability of general social services in the Swedish system. What we do see is individuals who seem to be “choosing with their feet”, as the expression goes. We have found them in contact with financial and housing supports, seeking opportunities for employment and receiving health care, all potential expressions of the needs that they see as most relevant to their lives at the moment. Rather than passively “falling” between the chairs, what we often see is an active rejection of illness-related services and an equally decisive seeking of natural supports that might satisfy their real needs. The focus group interviews allowed us to build on the data that has been presented above, in order to try to understand the mechanisms which might help explain why indi-

viduals end up in these non-traditional locations. As participants described how individuals move between different authorities, sometimes described as a “ping pong match”, they were also able to explain why this happened, an explanation that revolved around a mismatch between the individuals wishes and abilities and the limits on responsibility and knowledge gaps of the various authorities. The result was that the individual ended up in what we have referred to as a grey zone, a describable location in the community, which could be explored as a basis for understanding the actual situation.

The following discussion of grey zones is not intended to imply that we have exhaustively defined all possible “grey zones”, only to exemplify and establish the value of describing such locations for the purpose of understanding the mechanisms that lead to individuals ending up “between the chairs”.

*Many live in a borderland (FG – Social services)*

### **Between psychiatry and work life**

Some comments from the survey forms regarding vocational interest include; ... wants a regular job, a real job, is doubtful regarding the day program, wants to work from their qualifications, wants to study, learn computers, begin an education. Varied opinions as to when a person is “work ready” can become an obstacle to the individual’s desire to work, according to focus group participants. Not having the ability to work fifty percent or more is a standard utilized by the employment service in Sweden to determine readiness, and has the effect of excluding many with a psychiatric disability from work or studies. At the same time, their symptoms may have decreased to the point that their illness is under control and psychiatry has judged them ready for rehabilitation, from a medical perspective.

*You don’t only need help when you are acutely ill or need a new prescription (as we do now). People who are on their way to a new life can even need help in integrating a new identity. (FG-psychiatry)*

The distance between the psychiatric medical judgement and the disability or ability-based judgement regarding work may leave the person without a clear support. The situation is complicated by the lack of knowledge in both systems as to accommodations that might be made to support the individual in the work place or educational situation in order to overcome the participation restrictions in the environment. We have also seen a very similar zone between

those utilizing the general social services and wanting to work, but never having been in contact with medical psychiatry.

*We meet people who have economic problems and can't enter the employment market and haven't been in contact with psychiatry so that there is no given diagnosis. (FG-IFS)*

This mechanism, where specialized rehabilitative supports require a medical diagnosis first, despite the legislated intention of supporting those with disabilities into the work force, may be seen as presenting special challenges to the helping system as a whole. The need to “herd” the person towards psychiatry in order to receive a diagnosis, may actually work against many principles of psychiatric disability and rehabilitation (Anthony et al. 2002). The grey zone here may be seen as built on conflicting assessments of readiness for participation in the community, resulting in this space between treatment and vocational rehabilitation services.

### **Between social insurance and psychiatry**

*One can sometimes begin with a depression... and eventually end up with psychiatry (FG-social insurance)*

*Employers lack knowledge about psychiatric illness and rehabilitation... (FG-social insurance)*

The social insurance authority is often the primary contact for those receiving economic support for a psychiatric disturbance (after an assessment by primary care). At an early stage of a course of illness, there is often no contact with either social services or psychiatry. Even when there is an employer still in the picture there are few options for rehabilitation services which have expertise regarding psychiatric disabilities. Long waiting periods to come in to psychiatry often, according to these workers, lead to deteriorating health, increasingly marginalized lives and increased functional impairments, before they finally become eligible for specialized services. This period of time, between initial contact, and eventual support, was not only seen as a grey zone where nothing positive was happening, but a time and “place” when the person became more seriously disabled than they might have without such obstacles. The grey zone here also represents the distance between primary care, which has the power to assess disability for the purposes of receiving illness-related social insurance

benefits, but is quite distant from specialized psychiatric services which might address these issues.

### **Between general social services and the formal mental health system**

*Between too healthy and too sick, until they become sick enough to come in (FG – social services)*

A very similar location was described by staff of the general social services. This would seem to be an important one to analyze further as we found so many (22% in M4), often younger, who had exclusive contact with these services around economic and housing needs. Both social workers, and the psychiatry personnel who eventually meet them, have described many young adults who in the absence or avoidance of psychiatric support, live in the grey zones of the community, where those using drugs and engaging in criminality may become their most significant support network. Focus group participants in M1 were most worried about young women, who in this space between initial distress and eventual illness, ended up in abusive relationships which caused or at least hastened what they believed, was a potentially unnecessary deterioration and serious disability. Social workers were often, by their own account, without the tools or knowledge to intervene in these complicated social and psychiatric situations.

*If they don't get the support in time, the risk is that they flee reality in the form of drug use. (FG – social services)*

The avoidance of contact with psychiatry and social psychiatry has also been discussed from the aspect of stigma and the fear of being labelled as psychiatrically ill that many users and staff have expressed. So that we have seen both what has been negatively portrayed as the individual's lack of insight into the fact that they are or are becoming ill, but also what seems to be a fairly reasonable decision to utilize normal social services rather than those requiring a categorization as psychiatrically disabled. The grey zone here describes the space between the right to substantial supports from the social services as a community member and psychiatric categorization as a prerequisite for mental health supports.

## **Between psychiatry and social psychiatry**

*The problem is that we (medical psychiatry) can “think that” this one or that one would be right for a certain activity program... but it isn’t certain that this one or that one agrees that they want it. (FG – Psychiatry)*

The quote above points to the varied perspectives on need that may occur between the individual and the helping system, with both specialized and social psychiatry working within a professional and bureaucratic structure that will often interpret the individual need from an expert perspective. An overreliance on group homes to provide a stable life for the individual has been seen as an example of the remains of institutional attitudes among psychiatry personnel. The reliance on day program models to satisfy the individual’s desire for a work life has been a frustration for psychiatry personnel who try to support their patient’s rehabilitation goals. The systemic conflict in values, strategies and structures for helping, described in nearly all focus groups as a lack of cooperation and coordination, leaves the individuals without a holistic assessment of their needs, and faced with ending up as the “ball” in a ping pong match. They may make the choice to avoid both players, again ending up in a marginalized situation and without the expected supports. The grey zone here represents the varied cultures, knowledge bases and expectations between the two major players in the mental health system.

## **Between programs and services and community life**

*It’s important that people in this group get a chance for a fellowship at work, to have a social connection, to have colleagues at work and a coffee table to sit around... (FG-employment)*

*To have work... it means... especially to have a job in your work area... it means for me a place to belong to, to be a part of something and to be in a context. That what its about... It’s important. (FG-user)*

This last comment reflects the interaction of role and social location in a manner that we will explore further in the final discussion. As a worker, with a workplace, they would be located in the community in a way that a day program can never offer, and as such, participating in community life. As described in the background this zone is also one contributed to by the mechanisms which stigma can contribute to. The “NIMBY” syndrome, attitudes among

employers, and a lack of opportunities to participate in community associations and activities, have all contributed to an overreliance on psychiatric programs to provide natural activities. An example from the first study was a group home who struggled to find staff who would have time to organize a bingo activity, since the retirement association, which sponsored such activities (utilizing municipal financing) was according to the staff, “more prejudiced than anyone else” regarding this group. The lack of access to the natural community creates needs within the mental health “community”, and the most often good hearted attempt to meet these needs, may be a mechanism which contributes to the creation of “mini- institutions” in the community. The grey zone here is one that reflects the distance between participation in psychiatric activities and participation in community activities. This may be also be seen as a modern manifestation of the physical distance between the institution and the community, and the community’s continuing attempts to keep these individuals at a distance.

*There is no place for them in the “square life”... they don’t fit in. (FG  
– community life)*

## **Discussion and implications**

### **Generation, age and dynamics**

The results related to age group differences may be seen as supporting attempts to understand the needs of people experiencing psychiatric disabilities from a life course approach (Priestley 2003:2). The results of the surveys presented have raised the issue of generational mechanisms which help to explain the diversity of sub-groups within the community today. Broadly speaking, we have identified an older group, often remaining in contact with the formal mental health system, and limited in their lives by “institutional damage”, an overdependence on psychiatrically defined services, the rigidity of the social insurance system, their advancing age, and negative attitudes towards their potential and “desirability” in the community. At the “other end” of the spectrum we find a new generation who seem to play by their own rules, avoid psychiatric labelling, have never experienced institutional forms of care and have “bought into” the post-deinstitutional eras promise of a life in the community, regardless of illness.

*I can see the difference, the patients we have today are “healthier”  
than before. That means that the goal and expectation for these*

*younger, I think is different.... They want to return to the community, they have a goal. (FG-psychiatry)*  
*The younger ones want to go their own way... no group programs (FG – RSMH)*

We also heard from medical psychiatry staff about young adults who presented with "social complications", not classically meeting a specific diagnosis category, but needing support and structure in their daily life "... so that they don't end up in a destructive context just to avoid being alone"(FG-psychiatry). Such statements have helped us to see that there is a relation between generation and location, in that there appears to be an interaction between time dynamics (age and period) and structure. Put simply, when you meet the system seems to influence what you are offered and where you end up. Given the choice of a psychiatrically defined life, involving day programs and stability, many of the young adults have chosen a life in the community, keeping their distance from the mental health system, and often involuntarily distant from jobs, studies and positive social networks. Many other sub-groups have been described as well, the majority experiencing a complicated interplay between age, opportunity, time and choices. Individuals have explained that they experience their disability, illness and the functional limitations which may limit them at times, as a dynamic experience, changing over time, and in relation to the opportunities and supports they are offered.

*The term disabled... it has such a disparaging sound to it about a person... a person can feel better and worse... what says that a person is forever disabled?(FG – user)*

### **A place in the community**

A number of issues have arisen regarding the individual's "place" in the community. A theory-based discussion of social location was begun in chapter three and will continue in the concluding chapters. No longer located at the hospital, it has been interesting to see where "they" are. Many results have raised the issue of the mental health system's attempt to continue collecting clients or patients in identifiable locations in the community. Activity is connected to a particular day program, housing is connected to the apartments where support staff can visit. The user's association has especially attempted to reject this type of geographic packaging. Other participants have discussed the individual's desire to find a "real" job, to have a "real" workplace. What they are referring to is most often a non-psychiatric location, a normal workplace in the natural

community. The “quality” of the activity, or we might use the term participation here, would seem to be directly related to the location of the activity.

*Don't collect groups in programs (FG-User association)*

Another interesting finding arose when we asked about needs related to housing, an area where many were satisfied with regard to support services. Comments on the forms related to the persons needs were instead often connected to characteristics of the physical housing and not the person's psychiatric needs. They wanted; a balcony to sit out on, to move nearer to their families/relatives, their own contract for the apartment (rather than one owned by the social services), or to move to the country. These needs seemed to point to a desire for a more natural ownership of their living situation reflecting choice and community, rather than system-oriented solutions. For example, despite living independently, many had ended up in certain neighborhoods where apartments were available and cheaper, and where supported housing staff had offices. Many had also moved into the downtown areas of cities, rather than the smaller towns where they might have grown up and had connections. The geographical and physical locations of their living situations seemed to play an important role in their sense of themselves as community member. One further example is offered, related to the issue of the increasing substance abuse connected with individuals experiencing psychiatric disabilities.

*They can end up in a bad situation... with the A-team (FG-IFS)*

The “A-team” refers to chronic alcoholics who can often be found in many cities and towns, literally inhabiting a certain location in close proximity to the state-run liquor store. Regardless of the problems, this is a social location immediately available to many individuals with psychiatric disabilities, and as many staff express, sometimes the only alternative to loneliness and rejection by other community members. A lack of opportunity to participate, living in apartment complexes that are known to rent to social assistance “cases”, and being excluded from positive social networks may all be seen as examples of social exclusion.

*We see attitudes in society as an obstacle. (FG – psychiatry)*

*(We work within) A society which isn't prepared to accept them... (FG-IFS)*

### **A “role” in the community**

Another mechanism which would seem to underlie many of the results is the struggle between activity and role. A role, or functional identity in the community, as confirmed by the persons own network, is a concept from the recovery literature that can help to shed light on these results. We have seen on the one hand, a desire to work or study, as evidenced by the numbers who turn to the employment service for help, and by the many comments in the focus groups related to the individual’s wishes. We have also seen the rationale behind why so many seem to reject activity programs, which “group” people with psychiatric disabilities and do not offer “real work”. These may be viewed not as bad programs, but as failing to offer the person an identifiable and participatory role in community life.

*(We most often offer ) “finished package” solutions... instead of listening to the unique need with the individual. (FG – social services)*

Roles in community life also include marriage and parenthood, roles that were often unavailable during the era of institutionalization. Especially among women, as we have seen, these roles are quite prevalent and might be a focus for further research, since they also serve to “place” the individual within the community. Thornicroft discusses a Finnish study that showed that for those who were married, despite the strains from a spouse with a mental illness, positive effects were the most common (2006:36). The positive effects that familial roles may have on the individual’s ability to participate in community life may also, as we have seen be offset by challenges that the helping system is not prepared to support. Referring to another study completed in Denmark, Thornicroft (2006:38) reports that “... 40 percent had never received professional help related to their children, and a third said their requests for help had not been responded to”.

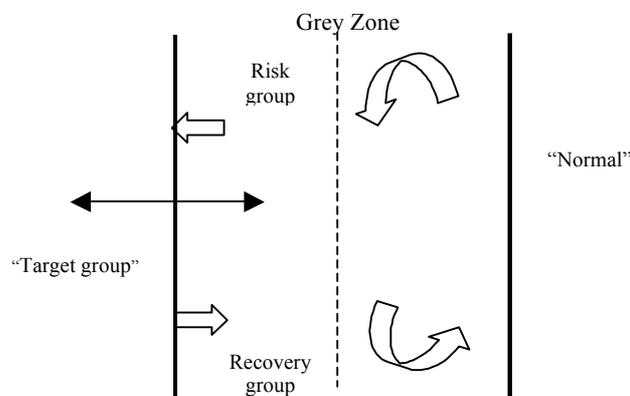
### **Implications for the next study**

Method adaptations based on the results and preliminary conclusions of this study revolve around three primary areas. The first revolves around the criteria and the implications of the risk and recovery groups for the definition of people with serious psychiatric disabilities. The intention of testing these categories was not, as described earlier, to create additional categories, but to explore the community, through its helping system, in order to determine if there were individuals who should be included in such surveys, based on the intentions of the legislation. We believe that the results indicate that there are such individu-

als and that they are of concern to the system representatives and users who we have participated in the study.

The second change results from the discussion of social location, social exclusion and the relevance of these mechanisms to the goal of a participatory life in the community, specifically with relation to the concept of need. While I have not explored the responses related to need here to the extent that we did in the original reports, we were unsatisfied with definitions of need related exclusively to services and the third study includes an attempt to measure participation. The final implication relates not to a change but to the confirmation of the importance of the organisational environment as a context for surveying need. The individuals in the study, as described by study participants, seem to make choices and act in response to the helping system's structure, responsibility areas and meeting with them. Social insurance regulations have helped to explain why many are not seeking work and the institutional features of social psychiatry programs are an obstacle for young adults seeking a natural role in the community. While extensive attention to mechanisms which may relate to interaction with the organisational field was an exploratory direction in study two, it became an accepted and important focus in study three.

*Illustration 3; Dynamics of risk and recovery related to psychiatric disability*



In illustration three we see that the risk and recovery groups have been included and that the “line” has been moved, at least as a hypothesis at this point to the right and out into the “grey zone”. By including the additional categories of risk and recovery in this study, we have been able to gather information

about the social locations of individuals described by these groupings. At the same time, these additional individuals, described with these more dynamic concepts, also seem to defy categories that might capture them organisationally. People described as “in recovery” are caught in the formal mental health system, and individuals “at risk” primarily in contact with general social services, remain so for long periods of time without getting the help they need. The broken line which has now appeared in the middle of the grey zone may be seen as a questioning of whether the actual population which meets the criteria are more diverse and spread in the community than “target group” concepts based on contact with the mental health system would lead us to believe.

## **Chapter seven – Consequences and participation**

In this chapter I present the results of the third and final study which covered the two remaining municipalities in the county. As described earlier, this third study gave us the opportunity to build on the results explored in the second and largest study, but especially to validate and test a number of the results. We did this in part by clearly repeating a number of methodological strategies, which would allow us to see if we attained similar results. However, we were also able to take a strategically different look at a number of phenomena which were of interest in the previous study. In this way we were able to expand our understanding of these phenomena by seeing if the results were consistent when we gathered similar information from a different perspective. I refer specifically to the definition of the target group which was further developed in this study, and a revised strategy for looking at need based on concepts of social location and participation.

The study involves two survey projects carried out in two municipalities in the same county in northern Sweden. One of them, municipality six is a middle sized city on the coast with a population of 54,969. The other, municipality seven is a small, rural city with a population of 10,639 but covering a large geographic area and reliant for many services on municipality one which is approximately 90 km away.

### **Introduction and background**

One of the advantages or complications, depending on perspective, of carrying out a research project over a long period of time is that things change. As presented in chapter one, a national oversight of psychiatry had led to recommendations related to the responsibility of the municipal social services to complete surveys of need, develop outreach activities and spread information in order to reach a wider group of individuals experiencing serious psychiatric disabilities. In the fall of 2003, the National Psychiatry Coordinator described above, was convened in order to review practice, resources and coordination questions in the field of psychiatry. While an extremely ambitious and wide-ranging project, the Coordinator's office decided to focus on clarifying the concept of psychiatric disability, as utilized for the purpose of surveying need and planning services. It is this focus and the resulting report, a preliminary version of which

was released as this study was beginning, that directly impacted the definition which was utilized in this study.

## Method specifics

While in many aspects fundamentally similar to the definition suggested by the National Board of Health and Social Welfare and used in the first two studies, there are a number of adaptations which were specifically interesting for our study, as well as relevant for the municipalities with whom we were conducting these surveys.

### Definition;

*A person has a psychiatric disability if he or she has fundamental difficulties in carrying out activities in important life areas and that these limitations have continued or can be expected to continue during a longer period of time. The difficulties are a consequence of a psychiatric disturbance. (SOU 2006:100, p. 5)*

The following specifics were those that we utilized, and suggested by the Coordinator's accompanying documentation. The only difference is the age limit which was maintained as 18 and over. The report discusses the possibility of including all over 16, the age at which they feel that adult life consequences make the definition relevant.

- Ages – 18 and older
- Duration – At least one year or can be at least one year. (Risk group)
- Including people with "compensated psychiatric disabilities" – fundamental difficulties if support was removed (Recovery group)
- Without developmental disabilities

It is clear from the definition that one of the central factors in determining whether someone experiencing the consequences of a psychiatric disturbance meets the criteria for inclusion in the survey process is the degree of difficulty in carrying out life activities. In attempting to further define the concept of difficulty, they utilize the standard of participation in a life area. Both the definition and the focus on participation became important factors in the structure of the current study.

*A difficulty can be substantial when it affects the individuals participation in a life area that is meaningful for them, even if this difficulty, can appear externally as relatively mild (National psykiatriskamordning 2006:5.p. 7)*

In discussing questions related to recovery, the report describes its thinking as regards the category; “person with a compensated psychiatric disability”. A decision regarding psychiatric disability is not a life-long label or assessment of functioning for a given individual. People, despite continuing symptoms, can have a life with supports where they “can handle meaningful activities and not encounter limitations in their ability to participate”. They go on to state that “in order to support inventories and epidemiologic observation – it is important that those individuals who could be assumed to experience critical problems in their daily life if support was ended or their life situation changed should continue to be included in the group of people with psychiatric disabilities”. In our opinion at the time, this description of those in recovery paralleled the subgroup which we had tested in Study two.

As regards the risk group which we had hypothesized based on the findings of study one, and more clearly identified in study two, we found the following guidance in the new definition. They concur with our starting point in the Social Services Act, that disability is not determined by diagnosis and that; “Many psychiatric disturbances can lead to consequences described as psychiatric disability”. They note that the group is often dominated by those with a psychotic illness, personality disorders and affective disorders, but other disturbances or diagnosis may also lead to disability. Psychiatric illness is not however the only determinant of disability, it is a “necessary but not sufficient” factor. “In addition to the consequences of the psychiatric disturbance, other illnesses and personal as well as environmental factors can contribute to the psychiatric disability.” In this statement it is possible to see many of the individuals identified as belonging to the risk group in study two. While not yet diagnosed, they had a psychiatric disturbance that, together with a challenging environment (i.e. unemployment) and/or personal challenges (i.e. lack of a social network) indicated that they needed support for a psychiatric disability. These aspects of the definition may also be seen as grounded in social approaches to disability, specifically in relation to the further integration of the environmentally relative notion of consequences. The environment is one ingredient in a disability “formula” that examines the relationship between impairment, environment and participation. Finally, the duration criteria helped us to understand that assessment did not have to be exclusively based on past

history, but could reasonably attempt to predict the likelihood of a long term need for support and service.

*The criteria regarding duration are formulated instead as either a year long history of evident activity limitations (ICF definition) or as a prognostic assessment of a continuing limitation during a considerable, at least one year period*

Based on these recommendations, as well as discussions with the leadership group (and even the primary authors of the national report), we decided to utilize the definition as written and even include a copy of the report for all who received the survey form, since it presented examples of individuals who might or might not be included according to the definition and its intention. By utilizing this nationally reviewed document as an anchor for making decisions, the validity of the judgements by the individual respondents may be seen as having improved.

### **A reflection of need – measuring participation in community life**

Up until this point I have not said much about the specific survey questions which attempted to measure need, focusing rather on the implications of the results related to organisational location. This is in part due to the fact that these questions were not specifically connected to the current aim of the research and in part due to the fact that we were not satisfied with the structure of these questions and their ability to provide useful data for planning.

Attempts in the previous studies to measure the needs of people with psychiatric disabilities, proceeded from what might be termed a traditional individual/medical perspective, where the needs of patients or clients were defined by their satisfaction with the services they received. This attempt was based on two perspectives. Both social psychiatry and specialized psychiatry posed the question in this manner. What services were needed by the target group? The satisfaction aspect was our attempt to proceed from what is often termed a user perspective. As described earlier, confidentiality and poor response rates in such inventories made it impossible for us to go directly to the users. We therefore directed personnel to attempt to reflect their client's perspective on what services were needed. In our second attempt (study two), we asked personnel again to answer as to the satisfaction of their client, but this time with reference to a number of areas of life, rather than with reference to services. These included various environments described in the psychiatric rehabilitation literature and including work, living, social, education and leisure time (Anthony et al. 2002). In both cases, we encountered a number of problems. Personnel had

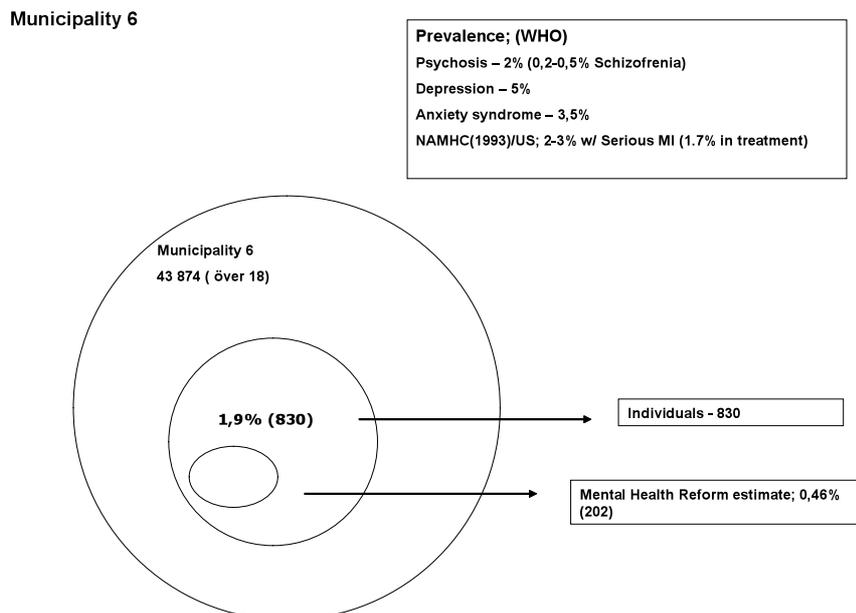
a difficult time in rating satisfaction, always a particularly subjective measure, and more so when attempting to reflect the perspective of their client. Another issue is that satisfaction is a concept which is limited in its usefulness, especially when many of these individuals don't have access to information regarding their possibilities for recovering and participating in community life. As we became progressively more aware of the significance of participation as an outcome, we became increasingly dissatisfied with the idea of satisfaction as a useful measure. Participation in community life also appeared to function well as a way to describe some of the earlier results which reflected the individual's "place" or location in the community. We had identified many who were marginalized and had no chance to participate in normal community activities, others who strived to by seeking support from the employment service, and others who had fallen out of a participatory life and would need rehabilitation supports to make their way back.

As discussed in chapter three, participation is a concept that is used frequently but often poorly defined in practice. For purposes of presenting the measurement model which we utilized in this study, it is important to point out that I use participation based on the theories underlying Sweden's disability policy and especially the intentions of the Social Services Act presented in chapter one. Gustavsson (2004:20) states that the concept of inclusion "lives side by side" with that of participation. As opposed to the concept of integration, which would seem to focus attention on adapting the individual and placing them in the society, the concepts of inclusion and exclusion move the focus to the environment or community in which the individual attempts to participate. Participation can be restricted due to functional impairments but even due to environmental factors. The language contained in the Social Services Act fits neatly into the perspective expressed in ICF (WHO) and can help to further differentiate between a purely medical perspective, where the individual's need is described as related to a reduction in symptoms based on a diagnosis/treatment paradigm, and a social perspective where the individual's need is also related to the reduction of restrictions to participation in community life (environmental factors). The task of identifying and measuring need must necessarily, from such an environmentally relative model, move from only assessing satisfaction with care related services, to a model of need that defines factors related to participation in community life. The discussion of how successful a particular local system has been in supporting the participation of individuals with psychiatric disabilities would therefore seem quite relevant.

## Results

The introduction of the new definition, one that many perceived as even more inclusive, allowed for an exploration of the number of individuals that would be identified utilizing these criteria. We therefore began to explore ideas for validating the result. How might we estimate the potential number of individuals with psychiatric disabilities meeting these functionally defined criteria? With few studies available, other than those restricted to the historical target group described earlier, we decided to use prevalence of mental illness as a comparison. The idea was not to draw a parallel but to find a comparative phenomenon which is clearly linked to psychiatric disability. There is no formula for defining the number of individuals with serious mental illness who will become disabled as a result of the illness and in combination with environmental factors. Yet it is interesting to compare the rates for serious mental illness and for psychiatric disability as identified in the survey.

*Figure 1. Prevalence of psychiatric illness and disability*



The figures presented above are for municipality six where we had the highest level of participation from the various authorities. This was due to a well established cooperation at the administrative level which resulted in access to the key

players who could help us with implementing the study. At the time of the Mental Health Reform, 1995, a number of inventories were completed and focused on those individuals who had contact with the formal mental health system and would be affected by the transference of responsibility from the medical psychiatric system to the municipal social services. This figure (0.46%) is included to provide some historic perspective on estimates of prevalence, but also due to the fact that many recent studies continue to use these estimates to validate their findings.

In order to include what we believe may be a more relevant statistic when looking for the total incidence of severe psychiatric disability in an adult population, we include prevalence estimates from a number of studies looking at mental illness. Some of the figures are estimates for specific diagnose grouping, all of which have appeared in our sample. The final figure is one that describes the incidence of serious mental illness, a term that attempts to describe a range of diagnostic categories but that also prioritizes severity. According to Goldman and Grob (2006), at least 5.4 percent of the adult population in the US suffers form a mental disorder that affects at least one area of social functioning and 2.6 percent experience a “severe and persistent mental illness.” It seems reasonable to assume that estimates of severe mental illness would reflect prevalence of serious psychiatric disabilities. By this measure, the 1.9 percent figure would indicate that the numbers identified in municipality six fall well within what might be seen as a reasonable figure for psychiatric disability in the community. The NAMHC study (1993) presents figures related both to the prevalence of illness and the numbers active in treatment, an interesting manner of more accurately describing and distinguishing the population of interest in planning. While it is likely that a number of appropriate individuals have been missed, and others inappropriately included, the results on the whole fall within what would seem to be reasonable estimates for the number of individuals with psychiatric disabilities in the municipality.

Our interest in generational factors, described in the earlier studies, was further developed in this study. We were able to compare the mean age for individuals having contact with the various organisations. These figures confirm that many of the younger individuals have contact with the general social services, at an early stage in their “career” as disabled due to a mental illness.

Table 18: Mean age by reporting authorities

| Reporting Authorities         | Mean Age – M6 | Mean Age- M7 |
|-------------------------------|---------------|--------------|
| Psychiatry                    | 44.2          | 54.3         |
| Social Psychiatry             | 47.5          | 56.2         |
| Elder Care                    | 73.3          | 73.6         |
| General Social Services (IFS) | 32.4          | 33.7         |
| Social Insurance              | 42.5          | NA           |
| Employment Authority          | 43.4          | 42.4         |
| Primary Care                  | 59.7          | 52.5         |

Social psychiatry units may, as we see in M7 have contact with an older group, many of whom remain from the time of the Mental Health Care Reform. Within social psychiatry it would also be possible to look at age as related to specific types of programs. The average age for example, in M6 was brought down by their success in attracting younger clients to a newly started rehabilitation program. The older group in M7 reflected the fact that the only program was a traditional drop-in type day program.

Table 19: Financial support by age grouping – M6

| Financial Support Type          | Age Group |       |       |       |      | Total |
|---------------------------------|-----------|-------|-------|-------|------|-------|
|                                 | 18-29     | 30-39 | 40-49 | 50-59 | 60 & |       |
| Social Assistance               | 35        | 19    | 9     | 6     | 1    | 70    |
| Disability Pension - Permanent  | 3         | 11    | 30    | 54    | 29   | 127   |
| Disability Insurance – Activity | 29        | 1     | 3     | 3     | 1    | 37    |

Here again, as in Chapter six, we see a pattern of increasing numbers receiving a permanent disability pension over time, including 84 individuals between 40 and 60 years old. It is also clear that a large number, 54 between 18 and 39 years old, were receiving social assistance. A particular group here that requires attention are the 29 receiving Activity Insurance, a newly developed form of pension for those under 30 years old. The individual must have a reduced work ability that is chronic or long term (at least one year) and entirely or partly reduced due to a physical or psychiatric impairment. The insurance in this case is limited to a maximum of three years when the case must be reviewed. Intended to avoid a permanent pension for those who the team in study one felt were receiving a pension when they were too young, there was little evidence how-

ever at this point to indicate that a higher percentage of these young individuals were receiving improved access to rehabilitation services.

*Table 20: Marital and family status – municipalities 6 and 7*

| Family Status                         | M6  |       | M7  |       | Mean% |
|---------------------------------------|-----|-------|-----|-------|-------|
|                                       | N   | %     | N   | %     |       |
| Married/Living together w/o children  | 89  | 10.7  | 12  | 9.1   | 9.9   |
| Married/Living together with children | 163 | 19.6  | 21  | 15.9  | 17.75 |
| Single w/o children                   | 383 | 46.1  | 61  | 46.2  | 46.15 |
| Single with children                  | 113 | 13.6  | 22  | 16.7  | 15.15 |
| Don't Know                            | 74  | 8.9   | 15  | 11.4  | 10.15 |
| No answer                             | 8   | 1.0   | 1   | 0.8   | 0.9   |
| Total                                 | 830 | 100.0 | 132 | 100.0 |       |

33.2% have a role as parent in some capacity in M6 and 32.6% in M7

In both municipalities in this study, the number of individuals having a role as parent was quite high, approximately a third of all identified individuals. Östman och Eideval (2005) found that in a survey of inpatient and outpatient psychiatric patients, 36 percent were parents of minor children and three quarters were living with them. Some of the comments accompanying the responses pointed to other questions that might be raised in planning for this group. One woman couldn't attend a day program because she was "home with the kids", another had no time for leisure time interests since they were "engaged in the children's activities" (driving them to training and helping out). Some of them had a wish to "have more regular contact with their children", while another wanted to "move home to where the children live with their father". While understanding who these parents are and how their individual situations look will require much more research, the move here is to a perspective on the issues that a role as parent may involve for people with serious psychiatric disabilities and the children who share their lives.

Table 21: Activity/Occupation – level and municipality

| Activity/Occupation - Level | M6  |         | M7  |         | Mean % |
|-----------------------------|-----|---------|-----|---------|--------|
|                             | N   | Percent | N   | Percent |        |
| Full time                   | 124 | 14.9    | 15  | 11.4    | 13.1   |
| Part time – Schedule        | 158 | 19.0    | 10  | 7.6     | 13.3   |
| Part time – Drop-in         | 34  | 4.1     | 14  | 10.6    | 7.3    |
| No Activity                 | 395 | 47.6    | 64  | 48.5    | 48.1   |
| Don't know                  | 86  | 10.4    | 23  | 17.4    | 13.9   |
| No answer                   | 33  | 4.0     | 6   | 4.5     | 4.3    |
| Total                       | 830 | 100.0   | 132 | 100.0   | 100.0  |

In municipality 6, 38% (14.9 & 19.0 & 4.1) have a known activity. This means that up to 62% can be without any activity. In municipality 7, 29.6% have a known activity (11.4 & 7.6 & 10.6) Up to 70.4% can be without any activity. Included are both those active with the mental health system and those in touch with other organisations, yet the poor result reflects general trends in Sweden. Of those who do have some type of activity we were able to explore the types of involvement in the following table.

Table 22: Activity/Occupation – Type (multiple answers were possible)

| Activity/Occupation – Type   | M6  |      | M7 |      | Mean % |
|------------------------------|-----|------|----|------|--------|
|                              | N   | %    | N  | %    |        |
| Regular Employment           | 113 | 26.5 | 15 | 23.4 | 24.9   |
| Day Program – Rehabilitation | 25  | 5.9  | 1  | 1.6  | 3.8    |
| Day Program –Social          | 36  | 8.4  | 18 | 28.1 | 18.2   |
| Education/Studies            | 70  | 16.4 | 1  | 1.6  | 9.0    |
| Vocational Rehabilitation    | 60  | 14.1 | 4  | 6.3  | 10.2   |
| Internship/Training          | 34  | 8.0  | 2  | 3.1  | 5.6    |
| Other                        | 38  | 8.9  | 2  | 3.1  | 6.0    |
| Don't Know                   | 51  | 11.9 | 21 | 32.8 | 22.3   |

The categories describing the types of Activity/Occupation were determined by the members of the leadership and reference groups. Various municipalities had different offerings of course, but our intention was to describe categories of activities for analysis and comparison purposes. The figure is quite high for the number out in the regular employment market, a positive result, but it is likely

that it includes individuals working part time and those in subsidized jobs which are time-limited and controlled by the employment service. We also see a significant difference in the number of individuals involved in vocational rehabilitation and educational activities, a result which was supported by the focus group interviews. Municipality seven had only one socially oriented day program, while municipality six had developed a number of collaborative efforts to help especially younger adults with rehabilitation supports.

As we looked more closely at rehabilitation oriented activities, we found that under 10 percent of all individuals identified were participating in such activities. Age did not seem to be a factor, except in the case of those over 60, a result which is of course expected. Conclusions as to whether this is more of a tragedy for those 18-29 for example, who will be an economic drain on the community for a longer period of time, may be considered along with quality of life issues in exploring these needs. While we saw only a slight decrease for those 50-59 there is reason to believe, based on results related to permanent pensions and activity levels among this age group, that they are in some cases less of a priority for such rehabilitation-oriented services.

The Silo effect described in Chapter six pointed to the manner in which knowledge of individual needs might be limited by the responsibility structures of the particular authority. This discussion led to an interest in looking at how organisational contacts might be connected to involvement in specific types of support services.

*Table 23: Number involved in vocational rehabilitation activities by organisation*

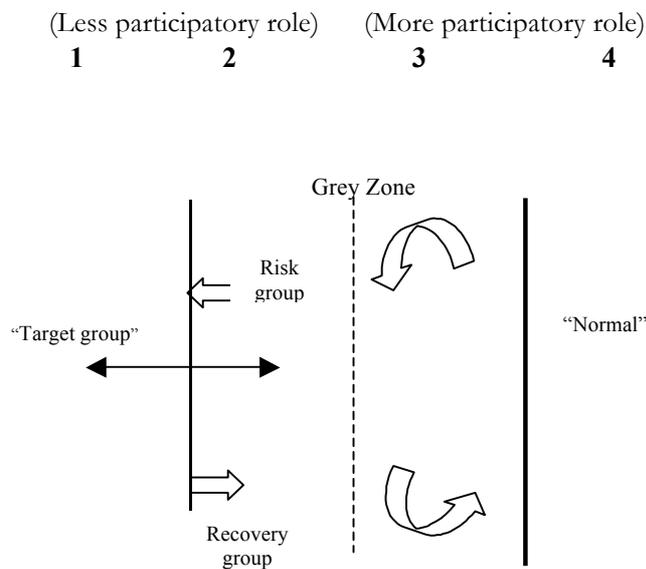
| Organisation        | Vocational Rehabilitation |                   | Total      |
|---------------------|---------------------------|-------------------|------------|
|                     | Yes<br>N (%)              | No<br>N (%)       |            |
| Psychiatry          | 20 (9.6)                  | 188 (90.4)        | 208        |
| Handicap Care       | 4 (25.0)                  | 12 (75.0)         | 16         |
| Elder Services      | 0 (0.0)                   | 73 (100.0)        | 73         |
| Social Services     | 7 (9.6)                   | 66 (90.4)         | 73         |
| Social Insurance    | 8 (7.8)                   | 95 (92.2)         | 103        |
| Employment          | 24 (26.4)                 | 67 (73.6)         | 91         |
| Social Psychiatry   | 4 (5.3)                   | 72 (94.7)         | 76         |
| Case Management     | 1 (5.3)                   | 18 (94.7)         | 19         |
| Primary Health      | 0 (0.0)                   | 94 (100.0)        | 94         |
| Integration         | 0 (0.0)                   | 47 (100.0)        | 47         |
| Financial oversight | 0 (0.0)                   | 15 (100.0)        | 15         |
| <b>Total</b>        | <b>68 (8.3)</b>           | <b>747 (91.7)</b> | <b>815</b> |

The fact that only 7 (9.6%) of the 73 who have contact with the general social services, primarily for financial support, are involved in a rehabilitation activity tells us something about how the “work line” discussed earlier is being implemented. The number for social psychiatry (5.4%) is also noteworthy. While the social insurance authority and the employment service have, as would be expected, a higher percentage of individuals in such activities, there are a number of questions that may be discussed based on this result. One interpretation that we have heard, and that may be objectively argued as well, is that people are where they belong. Those who are more ready to work are in contact with the employment service, and those seeking financial aid do not want to work, or can't. The results regarding the recovery group members in chapter six do not support this conclusion however. An alternative explanation may be related to the silo effect and low expectations for individuals labelled or perceived as psychiatrically disabled. Results indicated a lack of knowledge regarding the desire and ability of these individuals to work, as well as gaps in knowledge of methods for supporting them. The following results and discussion may be seen as an attempt to explore the current situation of people with psychiatric disabilities relative to their potential and desire for a participatory life in the community.

## Participation – A question of capacity and desire

The aim of the scale introduced here was to obtain data on clients' participation in five areas of life: living, social life, work, education and leisure. For the survey instrument, we constructed separate four-level categories for each of the five areas of life. The categories were ordinal in all five areas, but each area of life had specific descriptions of its categories; we can call them context or area specific. The four categories of participation grew out of the earlier work, summarized in illustration three. We were attempting to integrate the individual's position or place in the community with the concept of participation, the intention of disability policy being a participatory life in the community, "like all others". We developed a scale with four categories since we had begun to "map" participation in the community in this manner, as seen in the illustrations, and since it was a statistically feasible number (Dalín and Rosenberg 2009).

### Positions describing participation in community life



For the areas of living and work, the categories were described as follows:

**Life area: Work**

- 1) No activity or unplanned activity ("drop-in")
- 2) Planned rehabilitation activity
- 3) Internship/subsidized employment
- 4) Regular employment

**Participation**

Less participation

More participation

**Life area: Living**

- 1) No residence or in treatment institution or Group home
- 2) Own apartment with intensive support
- 3) Own apartment with limited support
- 4) Independent living, alone or with others

**Participation**

Less participation

More participation

Although the categories were constructed to be area specific for all life areas, they were similar in that the first two categories, signifying low participation, described more or less socially marginal or exclusionary positions, while the two categories indicating higher levels of participation, describe more inclusive situations in the community. The four-level categorization is not meant to imply that one is better than the other for a given person, it is rather to establish a relative position with regard to the intention of a participatory life in the community. The concepts describing these four categories require further thought, since in various life situations, concepts of participation, inclusion/exclusion may differ qualitatively. As ICF (WHO 2002) discusses, participation may be described as performance or "involvement in a life situation", a definition that can be difficult to operationalize in the area of living for example. We were well aware of the problem with jumping into such a controversial and indistinct conceptual structure. At the same time, it is these concepts that form the basis of disability policy and the social services legislation in Sweden and many other countries. Even the UN standard rules on disability (United Nations 1993) place participation in community life as a goal for every society.

The question was presented in the following manner for each life area. The example for working life follows;

|  | No activity or<br>Unstructured activity<br>(no rehabilitation plan) | Program<br>Planned rehabilitation<br>Structure | Internship/<br>Subsidized<br>Employment | Regular<br>Employment |
|--|---|--|---|-----------------------|
| Current<br>Capacity<br>(Staff<br>assessment) | ( )   | ( )  | ( )                                     | ( )                   |
| Wishes of<br>the person                      | ( )   | ( )  | ( )                                     | ( )                   |

The respondents were asked to report, for each life area, as to the individual's current situation, assess their capacity (professional judgement) and present the individual's wishes (based on their relationship with and knowledge of the person). The use of the term capacity was borrowed directly from ICF; "The capacity qualifier describes an individual's ability to execute a task or an action. This construct aims to indicate the highest probable level of functioning that a person may reach in a given domain at a given moment" (WHO 2002). The wishes or aspirations of the individual are grounded in their interests, hopefulness and choice, factors which research in psychiatric rehabilitation have shown to be decisive in promoting recovery (Anthony et al. 2002, Topor 2001).

*Table 24: Participation in work life, current and capacity*

| Current, Work                 | Capacity, Work |                  |                          |                               |
|-------------------------------|----------------|------------------|--------------------------|-------------------------------|
|                               | No activity    | Planned activity | Internship/ wage support | Work, with or without support |
| No activity                   | 76             | 50               | 32                       | 37                            |
| Planned activity              | 2              | 42               | 18                       | 17                            |
| Internship/ wage support      | 0              | 1                | 11                       | 4                             |
| Work, with or without support | 0              | 0                | 0                        | 32                            |

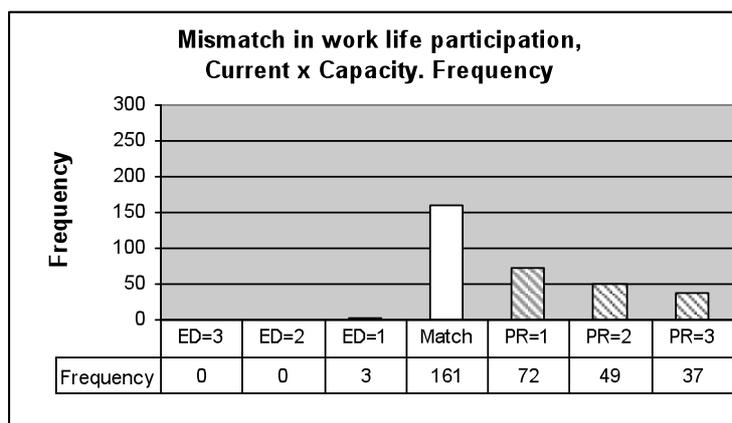
We see that 50 persons (N=322) had "No activity" as their current situation but were assessed to have capacity for the category "Planned activity". (Individuals over 60 not included)

The three questions within the same life area were identical as to the answer set, so the collected data opened up for an analysis of pairs of data, i.e. pairs of responses about the same client. We focused on the pairs that coupled answers about the current situation with those about capacity, and those that coupled the present situation with the clients' wishes, since the intention of the local survey was to say something about the current situation and the potential for change. We coded the categories 1 through 4, so one client could have a data pair varying from (1, 4) to more similar ratings like (2, 2) or (4, 3) or an opposite dissimilarity (4, 1). The dissimilarities cannot correctly be measured on a scale from - 3 through 3 by taking differences, since the scale is ordinal and may be far from interval. Instead as a first step, we interpreted all the dissimilarities as categories and displayed the complete distribution of outcomes in a four by four contingency table. Similarly, we displayed the simultaneous distribution of data received on the Current/Capacity and Current/Wishes questions

in all five life areas in the survey, and decided that a case with the same category in both items should be called a match, whereas one that had a dissimilarity would be called a mismatch. We see here that 37 individuals were judged by staff to have the capacity to work in regular employment but currently had no activity, a situation termed as a mismatch. An example of a match is the 42 who have a planned activity, but are seen as participating at their capacity, not under and not over. The estimate of capacity in this case may be seen as quite conservative since staff tend to underestimate, rather than overestimate the abilities of psychiatrically disabled individuals

When thinking about match and mismatch in the context of participation in community life, we realized that the mismatch of a client being placed in a higher category in the Current dimension than in Capacity, was qualitatively different from that of a mismatch that was the other way around. Therefore we created different names for these different mismatch types and called them Participation Restriction mismatch (PR) and Excessive Demand mismatch (ED) respectively. When the Capacity category is higher than that given by the present situation, we consider the mismatch to be of Participation Restriction type, indicating that the person's potential is beyond their current situation. And when it is the other way around there is an Excessive Demand mismatch. The concept of "excessive demand" is interesting in that it became a description for a situation where the individual is participating beyond their capacity, a situation which might be seen as unsustainable, and therefore a focus for concern. Now, within the same type of mismatch, there are also differences, since it can differ by one, two or three steps between categories of Current situation and Capacity (or Client's wish).

Table 25: Participation in work life: ED and PR mismatch.



We see, that 49 of the clients had a two step mismatch of the participation restriction type.

Essentially the same data is presented in the following table in a summarized form that was developed in order to create comparisons with the other conditions (current vs.wishes) and life areas. The amount of “excessive demand” mismatch is relatively small in this life area, and we can see here that 49 percent of the individuals reported had a mismatch of the “participation restriction” type. In other words they had the capacity, in the eyes of reporting staff to function at a higher level and therefore be more participatory in community life.

*Table 26: Participation in work life; mismatch –current vs. capacity*

| <b>Total match</b> | <b>Total mismatch</b> | <b>Number of steps of mismatch, mean</b> | <b>ED mismatch</b> | <b>Number of steps of ED mismatch, mean</b> | <b>PR mismatch</b> | <b>Number of steps of PR mismatch, mean</b> |
|--------------------|-----------------------|--|--------------------|---|--------------------|---|
| 50 %               | 50 %                  | 1.8 steps                                | 1 %                | 1.0 steps                                   | 49 %               | 1.8 steps                                   |

In the following table we have summarized the contingency tables by placing them next to each other, with two pairings within each life area. This allows us, and the recipients of the report, to analyze a number of factors. We have the ability to look across the five life areas and make comparisons of the frequency of mismatches and the magnitude of mismatch (the number of steps).

Table 27: Comprehensive result table for all life areas (municipality 6)

| Life area          | Total match | Total mismatch | Mismatch (mean) | ED mismatch | ED mismatch (mean) | PR mismatch | PR mismatch, mean |
|--------------------|-------------|----------------|-----------------|-------------|--------------------|-------------|-------------------|
| <b>Work life</b>   | 50 %        | 50%            | 1.8 steps       | 1 %         | 1,0 step           | 49 %        | 1,8 steps         |
| Current x Capacity |             |                |                 |             |                    |             |                   |
| Current x Wishes   | 43 %        | 57%            | 2.2 steps       | 2%          | 1.0 step           | 55%         | 2,3 steps         |
| <b>Living</b>      | 78 %        | 22 %           | 1,1 steps       | 16 %        | 1,1 steps          | 5 %         | 1,2 steps         |
| Current x Capacity |             |                |                 |             |                    |             |                   |
| Current x Wishes   | 79 %        | 21 %           | 1,2 steps       | 8 %         | 1,1 steps          | 13 %        | 1,2 steps         |
| <b>Social life</b> | 66 %        | 34 %           | 1,3 steps       | 3 %         | 1,2 steps          | 31 %        | 1,3 steps         |
| Current x Capacity |             |                |                 |             |                    |             |                   |
| Current x Wishes   | 44 %        | 56 %           | 1,4 steps       | 2 %         | 1,0 steps          | 54 %        | 1,4 steps         |
| <b>Studies</b>     | 58 %        | 42 %           | 1,5 steps       | 2 %         | 1,2 steps          | 40 %        | 1,5 steps         |
| Current x Capacity |             |                |                 |             |                    |             |                   |
| Current x Wishes   | 58 %        | 42 %           | 1,7 steps       | 0 %         | 1,0 steps          | 42 %        | 1,7 steps         |
| <b>Free Time</b>   | 65 %        | 35 %           | 1,6 steps       | 2 %         | 1,1 steps          | 33 %        | 1,6 steps         |
| Current x Capacity |             |                |                 |             |                    |             |                   |
| Current x Wishes   | 67 %        | 34 %           | 2,0 steps       | 0 %         | 3,0 steps          | 34 %        | 2,0 steps         |

We see here for example that in the living environment we saw a much lower frequency, 5 percent, of mismatch related to capacity. The study supported this finding with practical examples of satisfied users, as well as quantitatively since 71 percent of the population lived independently, many with flexible supports. We can also compare within each life area for the purpose of examining capacity and wishes, both in relation to their current situation. In the area of working life, we see that while personnel believe that 49 percent could partici-

pate more fully (1.8 steps average more fully), 55 percent wish to participate more fully (2.3 steps more fully). Many are therefore, in other words, too far from where they, according to the personnel, both want to and could be, if we were to develop support services and reduce restrictions in the environment.

The scale utilized here is not presented as a workable tool at this point, it needs a great deal more development, testing and validation. We have however included these results in two reports, presented them at conferences and received feedback indicating that the results are understandable and applicable in practice when the focus is on improving participation levels in community life for individuals with psychiatric disabilities. A politician in municipality seven for example, was able to immediately seize on the fact that in their town, fifty five percent of the individuals identified had a capacity and a desire to participate more in community life in the area of work than they currently were. This information was completely new to her, as it is not reflected in individual assessments of need that only attend to functional deficits, psychiatric symptoms and needs or satisfaction with currently available services. From the perspective of the research questions the results helped to support the development of knowledge of where the individuals identified found themselves in the community from a participation perspective.

### **Focus groups – Dialogues and perspectives on needs**

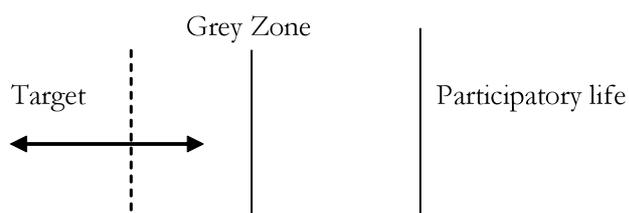
While the aim in the first two studies was to utilize focus group results to explain and develop theories related to the quantitative results, the third study involved a more rigorous analysis of the material produced in these groups. An analysis of the results of all groups in municipality six was conducted using Nvivo7, a text analysis program which allowed us to import the actual text and then sort responses as subcategories and finally into more inclusive categories. This process continued until the categories and sub-categories had described the entirety of data presented. Municipality six was chosen since it had, as described above, the highest levels of participation in all of the various theme-related groups. The complete results of this analysis are attached as an example of the type of material which was utilized throughout the three studies. It should be noted that this analysis is not weighted by the frequency of similar responses, rather it is intended to be exhaustive. While the quantitative results help to clarify the numbers of individuals in a specific situation, the purpose of the qualitative research was to illuminate the factors and mechanisms which clarified need. Even quantitatively limited results in other words, would need to be attended to in planning services. In order to maintain the authenticity of the results, I report the actual language utilized in the recording of comments, ra-

ther than creating an additional distance to the specific information by rewording the result.

It was also often interesting however, to know where a particular comment or focus developed, and which perspective was represented. Throughout the studies it was in fact the exceptions or contrasts to the expected picture of psychiatric disability in the community, often represented by a single respondent, which led to us expanding the scope of the survey and gaining new and valuable information. A number of examples can help to illustrate perspective-related needs. It was staff from the individual and family services in municipality seven for example, who were the only respondents to really focus on children to parents with psychiatric disabilities and the relevance of supporting the family in these situations. Interestingly, it was staff from medical psychiatry who focused on the importance of accessibility to treatment and support services and emphasized the importance of the primary health care sector in a rural area such as this. I emphasize that their response was interesting since the feedback from primary care in this municipality was that they wanted to do more, but received little support from specialized psychiatry, who had also centralized their activities at the hospital 90 km away. From the participants in the group discussing work life we were also able to gain perspective from their vantage point in the community. Having met many individuals who wanted to work despite not having been assessed as having a “work ability” that would allow them to directly enter the job market, they posed the question; “How can we meet those who don’t have a “normal” work ability but want to work their way to health?” And from a local police chief who participated in the discussion on community life, we heard about women who she met on calls regarding abuse in the home. She felt that many of the women she found in these situations had serious psychiatric disabilities, and chose remaining in these abusive but “normal” relationships rather than seeking help from psychiatry. Another example of the unique information that can be seen from other social locations than those that the actors within the formal mental health system occupy was discussed in municipality six. After a discussion that often touched on issues of isolation and prejudice and how social activities run by social psychiatry were often considered “stigmatizing”, the “community life” group directed our attention to a number of evening and weekend activities sponsored by the church that are open to all. The conclusion was that these activities were a resource where anyone could “pass in” and without shame.

## Discussion and implications

*Illustration 4; Effects of the new definition on the social locations*



In Study three we have employed the new definition of psychiatric disability suggested by the National Psychiatry Coordination in Sweden. As discussed above, the number of individuals identified, while greater in one municipality than any other we have surveyed, was still well within what might be predicted by prevalence statistics regarding serious mental illnesses. My conclusion is that many of the risk and recovery group members from Study two are now included within these new criteria, and without requiring special categories (risk and recovery), and therefore the solid line has been moved to the right. The broken line remains to indicate the existence of a “target group” which still meets many of the historic parameters based on contact with the mental health system. Those to the right of the broken line are the individuals we found in non-traditional locations, but still meeting the criteria for psychiatric disability outlined in the new definition. A final change involves the location previously referred to as “normal” life. A participatory life in the community would seem to be a more useful term to describe the goal of community mental health, since “normal” is such a relative and problematic description of the life that we others, “those not dealing with a psychiatric disability”, live.

This chapter has also focused on confirming and replicating findings related to the roles that these individuals may or may not have. Many are pursuing their lives as community members, living in the community and starting and raising families for example. At the same time, many others, who are clearly interested and capable of participating more actively both socially and vocationally, are not being offered the types of rehabilitation supports that might help them develop such roles. Respondents describe a lack of knowledge and obstacles which exist in the community and the welfare system, as contributing factors.

## Chapter eight – Cumulative results

This chapter presents a number of findings utilizing cumulative data from the three studies. While noting the variation in the method and context for the three studies, it became important to look back and see if there was a degree of consistency in the results over the seven surveys. In some instances the data is presented as a summary table and in others by municipality, in order to allow the reader to observe the variation. I also revisit the data regarding reporting by organisation, results which were central in exploring some of the conclusions that will be presented in the final chapters. Results related to the descriptions and organisational locations of the sub-groups described in the second study are also explored. Having now had the experience of conducting two surveys utilizing the new criteria, based on the conclusion that these groups were actually included in the focus for the survey process, the descriptions of risk, recovery and target group members took on a new and central relevance for understanding the social location and dynamics of individuals living with psychiatric disabilities in the community.

### Results

The following table summarizes the actual numbers of individuals identified in each municipality, and as a percentage of the adult population of each.

*Table 28: Incidence by municipality*

|             | <b>M1</b> | <b>M2</b> | <b>M3</b> | <b>M4</b> | <b>M5</b> | <b>M6</b> | <b>M7</b> | <b>Total</b> |
|-------------|-----------|-----------|-----------|-----------|-----------|-----------|-----------|--------------|
| <b>N</b>    | 652       | 208       | 191       | 157       | 215       | 830       | 132       | <b>2385</b>  |
| <b>Pop.</b> | 74,000    | 16,330    | 17,051    | 13,759    | 20,109    | 43,874    | 8951      | 194,074      |
| <b>%</b>    | 0.88      | 1.3       | 1.12      | 1.14      | 1.06      | 1.9       | 1.47      | 1.2          |

Some of the variance may be accounted for by the fact that various actors were unable to participate in certain municipalities and in municipality one, the general social services were not included. These figures may be viewed however with reference to the illustration regarding prevalence at the beginning of chapter seven. In all of the municipalities, despite the large number of missing cases, the number of individuals identified as meeting the criteria for serious psychiatric disabilities exceeds estimates based on studies which restrict themselves to clients of the formal mental health system. Such results would seem to support

the perspective presented here, that attempts to survey the needs of individuals with serious psychiatric disabilities living in the community, must attend to the social locations beyond the system of psychiatrically defined services.

The following table provides a foundation for such an exploration as it summarizes the organizational contacts for the unique individuals who were identified in the three studies. The first figure in each cell represents the number of survey forms received. Each authority was instructed to submit survey forms for all individuals they had contact with in order to gather data on the number of individuals having multiple and unique contacts with the various authorities and organisations. The second figure represents the number of unique individuals, in other words those having exclusive contact with the particular organisation. Five of the seven municipalities are presented here. Municipalities one and six were not included in this table since the data collection by organization varied significantly from that in the other municipalities.

*Table 29: Reported vs. unique individuals by organization*

|                  | <b>Reported<br/>(Inds.)</b> |           |           |           |           |              |                                 |
|------------------|-----------------------------|-----------|-----------|-----------|-----------|--------------|---------------------------------|
|                  | <b>M2</b>                   | <b>M3</b> | <b>M4</b> | <b>M5</b> | <b>M7</b> | <b>Total</b> | <b>% Unique<br/>Individuals</b> |
| Social Psych.    | 108 (104)                   | 19 (18)   | 69 (67)   | 29 (29)   | 40 (39)   | 265 (257)    | 97%                             |
| Psychiatry       | 51 (40)                     | 72 (62)   | 44 (23)   | 96 (58)   | 28 (21)   | 291 (204)    | 70%                             |
| Social Services  | 40 (36)                     | 40 (34)   | 47 (35)   | 22 (16)   | 35 (29)   | 184 (150)    | 82%                             |
| Elder Care       | 34 (28)                     |           | 1 (1)     | 18 (16)   | 26 (16)   | 45 (33)      | 73%                             |
| Case Mgmt        |                             |           | 8 (0)     | 8 (4)     |           | 8 (4)        | 50%                             |
| Primary Care     |                             | 14 (13)   | 20 (10)   | 33 (30)   | 26 (12)   | 93 (65)      | 70%                             |
| Social Insurance |                             |           |           | 32 (20)   |           | 32 (20)      | 62%                             |
| Employment       |                             | 34 (34)   | 24 (21)   | 42 (39)   | 17 (15)   | 117 (109)    | 93%                             |

We can see here for example that on average, 93 percent of the individuals reported by the employment service were unique individuals, in other words not in current contact with the formal mental health system. Employment would seem to be a primary aim of many, especially younger individuals in the study, but even other sub-groupings who view employment or studies as their primary goal and means of participating in community life.

While we were surprised by the numbers we found who had exclusive contact with the employment service, it is clear that all responding organisations had a large percentage of contacts with individuals who were only in active

contact with them at the time of the study. There is a time dimension here as well. For example, it may be that of the 70 percent of individuals reported exclusively by primary care, many had a previous contact with specialized psychiatry. While this points to multiple contacts on the one hand, it also reinforces the “silo effect” where individuals are in contact with one or another at any given time. The problem which was raised repeatedly in focus groups was that there was no shared responsibility for the holistic needs of the individual. While primary care could address their physical needs and even monitor medication over long periods of time, there was a question of accessibility to psychiatry if the individual was to experience a crisis. Primary care staff expressed a clear preference for “sharing cases” rather than taking sole responsibility for these individuals. The concept of shared responsibility and multiple contacts as a necessary condition for a comprehensive support system led us to re-examine the frequency of multiple reporting of individuals, as presented in the following table.

*Table 30: Doubles reported*

| Reported by;    | Total |        |
|-----------------|-------|--------|
|                 | N     | %      |
| One authority   | 1908  | (80.2) |
| Two authorities | 352   | (14.8) |
| Three or more   | 120   | (5.0)  |
| Total           | 2380  | (100)  |

Despite an emphasis in legislation and policy on coordination of services to this group across authorities, approximately 80 percent of the individuals identified in the studies were reported as currently active by only one authority. This figure even includes various units within the municipal social services, where we might have expected an increased frequency of multiple reporting, for example between the individual and family services units and social psychiatry. Multiple reporting may be thought of as a concrete expression of the coordination emphasized in service delivery in Sweden. A need for rehabilitation services provided by the municipal social services does not rule out for example a need for active contact with psychiatric treatment services. The potential for losing track of the needs and life of the individual in the community was magnified as well by the limited “mapping” of responsibility by each authority. While aware of the “edge” of the picture, the point on their map where the individual began to disappear if the other authority did not pick up the case, they were less aware of

the experience of the individual who was attempting to meet their needs within this fragmented system.

The following table presents the results for all seven municipal surveys. As discussed throughout, the two traditional locations for contact and support to persons with psychiatric disabilities are specialized and municipal social psychiatry. These have been referred to as the formal mental health system. While analyzing organisational contacts was initially intended as an ancillary attempt to seek clients that may have fallen outside the view of these primarily responsible actors, this focus became a central element of the remaining studies.

*Table 31: Traditional (formal mental health system) and other contacts*

| <b>Mun. (n)</b> | <b>Psychiatry (%)</b> | <b>Social psychiatry (%)</b> | <b>Total (%)</b> | <b>Other Contacts (%)</b> |
|-----------------|-----------------------|------------------------------|------------------|---------------------------|
| M1 (652)        | 18.3                  | 51.7                         | 70.0             | 30.0                      |
| M2 (208)        | 19.2                  | 50.0                         | 69.2             | 30.8                      |
| M3 (191)        | 32.5                  | 9.4                          | 41.9             | 58.1                      |
| M4 (157)        | 14.6                  | 42.7                         | 57.3             | 42.7                      |
| M5 (215)        | 27.4                  | 13.7                         | 41.1             | 58.9                      |
| M6 (830)        | 26.6                  | 9.2                          | 35.8             | 64.2                      |
| M7 (132)        | 15.9                  | 29.5                         | 45.4             | 54.6                      |

While the subjective nature of the assessment process, as staff made judgments about each individual they reported who met the criteria for a serious psychiatric disability clearly needs to be considered, there is a consistency to the results across the seven municipalities. Between 35.8 and 69.2 percent of the individuals identified do not have contact with the formal mental health system. In studies which restrict themselves to currently active clients of psychiatry and social psychiatry, these individuals are missed and their needs are not taken into account in the planning of services.

Before moving on to summarize the results presented in this chapter, I would like to briefly return to the discussion of groups in chapter six. While I have stated that we considered the definition utilized in the third study to encompass all of the groups which we had described in earlier surveys, it is still possible to use this data to further our understanding of how staff of the various authorities view the individuals that they come into contact with.

*Table 32: Target, risk and recovery groups by organisation*

| <b>Organisation</b>  | <b>Target group</b> | <b>Risk Group</b> | <b>Recovery Group</b> |
|----------------------|---------------------|-------------------|-----------------------|
| Social Psychiatry    | 130                 | 36                | 51                    |
| Psychiatry           | 90                  | 33                | 51                    |
| Social Services(IFS) | 80                  | 24                | 16                    |
| Primary Health       | 22                  | 11                | 7                     |
| Employment Service   | 33                  | 15                | 44                    |
| Social Insurance     | 23                  | 1                 | 3                     |
| Elder Care           | 38                  | 8                 | 25                    |
| Total                | 416                 | 128               | 223                   |

One of the first observations that can be made regarding the data presented here is that individuals believed by reporting staff to belong to the various groups are found with each organisation. All reported having contact with members of all groups. While perhaps an intuitive result, it contradicts some basic assumptions that we began the first study with, primarily that all those with a serious psychiatric disability could be found within the formal mental health system, psychiatry and social psychiatry. Some other assumptions that grew out of this are also challenged. As described in chapter six, we see that there are many (51) who have exclusive contact with social psychiatry who are considered to be in recovery, despite the fact that these programs traditionally serve those who are most disabled and most in need. This leads to many questions regarding the mission of these programs with regard to those considered to be in recovery, especially in light of the poor results regarding rehabilitation activities. We also see that psychiatry, an acute service, while in touch as they would be expected to be, with many in the “target group” (90) also have contact with a substantial number of those in recovery (51). This will be discussed further but clients of the rehabilitation program interviewed in study one emphasized the importance of psychiatry remaining in the picture as they began to take on new roles as part of their recovery process. While the employment service’s contact with individuals in recovery makes perfect sense as they seek work and education, we see a surprising number (33) who are considered to be the most disabled. Based on some of the results presented earlier, it may be reasonable to explore whether these are some of the younger individuals we heard described that have avoided contact with the formal mental health system. Another result that was not expected in the initial stages of the survey project was that the general social services (IFS) would have contact with so many individuals considered to be seriously disabled. It was with this organisa-

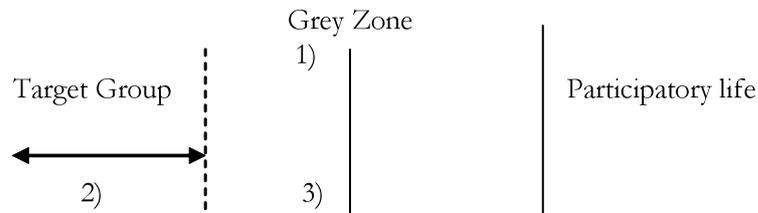
tion that we first began to discuss a risk group, but even in their descriptions of many of the younger adults they met, it became clear that they were dealing with individuals experiencing serious psychiatric issues. Finally, it is interesting to observe the number (25) who staff of the elder care department considered to be in recovery. In study one, a number of participants described the stabilizing effects of aging, and a primary health care nurse stated that she had a difficult time in differentiating between older individuals from a psychiatric group home and those from an elder services home populated with “normal” elders, many of whom had normal age-related functional impairments. She wondered why they remained in a psychiatric residence and therefore had no access to many of the activities and social opportunities that were available in an elder services home.

## **Discussion and implications**

In illustration five the intent is to begin to “locate” some of the subgroups which we have identified in the empirical study. This may be seen as a first move to integrating the theory-based research findings with the potential for practical applications in the planning process. By locating sub groupings of actual individuals identified in the various municipalities, within a representation of the community spectrum related to participation, there is the possibility of posing questions related to the timing and location of services.

The solid line continues to represent the border of the landscape within which we identified individuals experiencing serious psychiatric disability in the community. It is a border suggested by the criteria utilized, which described serious difficulties that limited participation in community life due to psychiatric disturbance. Individuals functioning or participating at a higher level, those to the right of the solid line, despite the possible presence of a psychiatric illness would not be included under these criteria. The dotted line, located at the traditional “border” which defined the historic target group for the Mental Health Reform remains in order to describe the concept of such a target group, defined historically as those who had been receiving institutional care or met certain diagnostic criteria. It remains also, as will be described below, to describe those individuals we targeted in study two and identified in all three studies. Some of these were described as target group members requiring intensive support within the mental health system and others were described by respondents as those who might be ready to move towards a more participatory life in the community if rehabilitative supports were offered and some of the risks involved in such a move were reduced.

*Illustration 5; Characteristics and needs by social location*



The following examples are taken from the three studies. Whenever possible they reflect an integration of quantitative and qualitative results.

Location 1 – Individuals described as a risk group who despite serious or developing psychiatric disabilities have avoided contact with the formal mental health system and function in some capacity in the community.

- 46 percent of those 18-29 in study one whose only support was financial assistance from the general social services (IFS) and were assessed as having serious psychiatric issues which led to consequences in their ability to function.
- 29 individuals, 18-29 years old, receiving an Activity Pension, which would likely lead to a permanent pension if they were not offered active rehabilitation supports
- 78.8 percent of individuals in exclusive contact with the general social services (IFS) in study two, where their primary contact wasn't aware of their interest in working

Location 2 – Individuals who had exclusive contact with the formal mental health system and were not participating in community life ( No activity or activities within social psychiatry).

- 91 individuals in study 2, 50-59 years old with a permanent disability pension, many of these without access to rehabilitation services and others who were fearful, according to both user and staff accounts, of losing the economic security that these pensions provided.

- 94.7 percent of those in exclusive contact with social psychiatry in study three who were not involved in any type of vocational rehabilitation
- Individuals over 60 years old who had exclusive contact with social psychiatry, were considered in recovery, and still had no opportunities to participate in activities for elders

Location 3 – Those individuals who were described by participants as in recovery, as having made substantial gains in their functioning and working towards a more participatory life in the community.

- 24.9 percent of those in study three who were in some type of paid employment and 9 percent in some type of educational activity, who may need continued support to maintain their participation. (Individuals with “compensated psychiatric disabilities”)
- 94 individuals in study two who had exclusive contact with the employment service. This group may also include individuals described as risk group members. While occupying the same “location” in the community, some had avoided contact with the formal mental health system and were struggling to work, while others were seeking support for a recovery process that had begun within the formal mental health system.
- 50 percent of those identified in municipality six who staff assessed as having a greater capacity than that required by their current situation.

This last example raises the issue of potential as measured in this case by the capacity and the desire to do more. It became clear in study two that not all individuals assessed by staff to be in a recovery process were actually moving towards a more participatory life in the community. The sub-groupings suggested here refer to the locations where we found people with serious psychiatric disabilities and are not meant to be seen as static categories. These are locations in the community that people pass through, but can even fasten in, as they experience the consequences of psychiatric disturbance or mental illness. These social locations appear to suggest that mechanisms are in play which can help to explain what individuals found in these locations at various times in their life may need help with.

Another point is that there are likely people experiencing mental illness in the locations to the right of the solid line, an area of the grey zone that social insurance officers and the employment project staff were able to describe in

study one. These were the long-term unemployed for example, who while marginalized due to their unemployment were not so impaired that they had entered into the level of disability described in the criteria. There may also however be people with mental illness who function, despite the symptoms they experience. Many exceptionally productive individuals including artists (Nina Simone), scientists (Charles Darwin), politicians (Winston Churchill), writers (Leo Tolstoy), and others have lived the majority of their lives in the normal or participatory location in the illustration, despite the effects of a mental illness. ([www.time-to-change.org.uk/](http://www.time-to-change.org.uk/); [www.nami.org](http://www.nami.org))

The illustration attempts therefore to reflect two aspects of the experience of psychiatric disability in the community. There is what will be discussed as a geographic aspect, which sees the location of the individuals in the community as a relative position to a participatory life in the community, rather than relative to the institution. There is also a time aspect, which reflects the dynamics of a psychiatric disability. Over shorter and longer periods of time, individuals move towards or away from a life determined by their disability, a movement not always directly related to the severity of their symptoms. And finally, we see an interaction between these two aspects of the experience as people may become stuck in a particular location due not to their functional capacity but to the limitations of the system as embodied in its organisational structure for providing supports and rule systems which may not support recovery. The following chapters will consider these findings within the theoretical frame that was presented earlier.

## **Chapter nine – The social location of need**

This chapter and the next will focus on a discussion of the results presented, as they may be explored within the theories presented in chapters two and three. It begins with a brief presentation of the limitations of what might be seen as an institutional/medical use of the notion of a “target group” that is identifiable and can be cared for within the mental health service system. I instead describe, with my starting point in the empirical results, three essential aspects of the process of surveying need for these individuals in the community. I begin with a discussion of the social locations they occupy in the community. These include what might be seen as their “neighborhood” or physical presence in the community. The broad notion of social location however, also describes their position in the society, a reflection of the roles they have and the opportunities available to them. The second aspect, presented in chapter ten, is based on the many focus group discussions and interviews involving a wide variety of actors and users, who attempted to describe the processes and issues relevant to understanding the situation today. Their insights and experience directed the research to a better understanding of some of the generative mechanisms which might help to explain the locations and positions occupied by these individuals in the community, in other words why they were where they were. Finally, I look at the dynamics of the individual experience of disability, as it was clear that their needs were not static but changed over time in relation to their impairments, but also to choices regarding the manner in which they live their lives.

### **Transcending the target group paradigm**

The Mental Health Care Reform is often considered as a reform of the psychiatry or mental health system in Sweden, an organizational transfer of responsibility designed to correct flaws in providing services to individuals experiencing psychiatric illness. According to the Handicap ombudsman however, this standpoint misses the fact that this was a social reform as well. (Handikappombudsman 1999). After decades of institutional patterns of providing services in which the life needs of individuals were addressed within the context of their illness, it was now legislatively directed that they would resume their role as citizens and their right to a participatory life in the community. While adaptations to the service system have been extensively discussed and described, it is

less clear that the social implications of the reform for individuals now living in the community have been adequately studied. The studies presented in this report began with what seemed to be the fairly clear cut aim of identifying and describing the needs of the “target group”, individuals with serious psychiatric disability. Right from the start however it became clear that there were many factors which had complicated this task in the years following the Reform, factors which were recognizable within the broader historical experience of deinstitutionalization and community care. While the challenge of completing these surveys was complicated by the many changes that had occurred and the lack of clarity as to the current situation, it was also an entry point into an exploratory process that led to the discussion that will be presented here.

The concept of a target group, as it has been utilized within the mental health system, may be seen as a relic of the “binding structure” of institutionalization. Barham and Hayward (1995:4) have stated that the process of deinstitutionalization collapsed the “structures” which had created the idea of the mentally ill as a homogenous group. There is nothing intrinsically wrong with the notion of a target group, as a means of targeting resources to individuals who have the needs the resources were intended to address. This was certainly the case as the process of deinstitutionalization began in earnest and was stimulated by the 1995 Reform. At these points in time, there was a specific group of individuals who were to be followed and supported as they moved into the community. They may not have been homogenous, but within the structural change that the process of deinstitutionalization motivated, they had a homogenous need. The studies presented here have, as they have struggled with the issue of describing community members living with serious psychiatric disability, continually run into the “crumbling structure” of the deinstitutionalization paradigm, which posits a group whose needs are defined by the structures of the mental health system.

The first of these structures which we encountered, were attempts by various actors to describe the target group based on diagnostic, rather than disability-related criteria. The influence of the medical model on the culture and organization of community-based services such as municipal social psychiatry, as discussed in chapter three, may be seen as steering these attempts to define and delineate. Already apparent in the early results, the “behavior” of the individuals we did identify, did not in many ways conform to the organisational culture for providing services, which seemed to be based on expectations connected to illness-related needs. They did not necessarily have or accept a medical diagnosis, they acted in the community and sought support for roles such as worker or student despite their medical conditions, and they experienced their functional abilities in relation to the opportunities and supports which they

were presented with in the community. They appeared to transcend medical model descriptions which continued to bind them together based on illness-related rather than community-based needs. The medical model has been described by Topor (2001), Gagne (2001) and others as contributing to an either/or, us/them paradigm. People are either sick and waiting to get better, or well and therefore without a need for treatment. The notion of a target group membership has been one manner of reflecting this sick/well paradigm in the area of planning services, and has been described earlier, as reinforcing the notion of the disabled as “not able”. The individuals who have been identified in these studies seem to defy these either/or categorizations, as they move within the community and service system.

Leff and Warner (2006:41) assert that there are two populations of users when looking at the social lives of individuals with severe psychiatric disorders in the community. They describe those who have spent a considerable time in hospitals and then been “resettled” in the community. The other population, while they may have received psychiatric inpatient care, have never spent years in institutions and have therefore escaped the “deleterious effects of institutional life” on prospects for a successful life in the community. The target group designation is often used to describe the historic group.

*Many who have previously lived institutions are “institutionally damaged” ... When this generation dies out these problems won't be seen as frequently (FG-group home)*

They remain however as a sub-group which utilizes community-based social psychiatry. In municipality four for example, 70 percent of those who had contact with social psychiatry were over 50 years old. I would like to add a further layer of complexity to Leff and Warner's groupings however, by looking more closely at those who have escaped “institutionalization”, since our results point to a more nuanced picture. There would seem to be a large number, a figure approaching on the average 50 percent (range from 30-65%) who at a given point in time do not have active contact with the mental health system. While receiving other social services and financial supports (in a social welfare state such as Sweden), they constitute a group who in the opinion of our respondents, had or risked a serious psychiatric disability, a population clearly of concern.

*We are speaking of different groups in the target group, it's become quite broad, the difficulties aren't these who are easy to see, that they have been chronically ill and they have a functional impairment...*

*But this risk group, whose members are in different places (in the system and community) and who within a few years have perhaps “tipped over” completely and can’t handle their situations. It is here we have to improve (FG-employment)*

Finally, we have seen another group which has fastened within the “historic” location of the target group concept, in other words, younger individuals who have not been hospitalized for long periods of time, but who have become “institutionalized” within what may be seen as a historic structure for providing services. These younger, non-institutionalized individuals are most clearly seen in the numbers who were considered to be in recovery, and yet had no activity or meaningful work, their primary community connection being the mental health system. This group may be thought of, based on the earlier discussion, as experiencing the process referred to as “transinstitutionalization”, or an institutionally defined life in the community.

*With the younger generation, who haven’t lived in institutions we can place other expectations, more after their individual abilities of course (FG-housing)*

The inclusion of the risk and recovery groups in study two was a response to the challenge of the results in study one, to the expected target group, the one that was located within the realm of the mental health system, specialized and social psychiatry. It was these two additional groupings of individuals, those who had not yet come into contact with the mental health system, and those who were trying to leave, which directed our first attempts to transcend the traditional target group concept. The addition of these two groupings was initially an attempt to recognize that many of the individuals we had identified or been directed to by respondents, defied traditional “service locations”, which in many studies had been assumed to “contain” the target group. So it is essentially this move, from medically-based and individually-defined attempts to categorize individuals, to one which focuses on the social context of disability which has directed the analysis of the results. It may also be said that the early findings indicated that the target group concept as it was being utilized, as a description of the patients and clients of the mental health system, was reductionist in its attempt to “enclose” or presuppose a “pseudo-closed” system consisting of the psychiatrically disabled and the services that had been designed to serve them.

A focus on the social location of individuals experiencing serious psychiatric impairments, as they interact with the service system and the community, has

provided a perspective that can be extremely useful in research and system planning. The social locations, including the “grey zones” described in the study, may be seen as providing a map of where these individuals find themselves in the community, specifically with reference to where and when they seek support for the needs that they experience. We were unable to direct questions for the most part to the individuals themselves, since the very nature of the study was an attempt to develop knowledge of individuals who we have not “found” within the mental health system. At the same time it is possible to see the locations where we found them, as bearers of information. Those who turned to the employment authority were likely interested in working, those who turned to primary care, experienced their disability as a health issue.

## **Contacts in the community**

Whereas a purely medical model of mental illness, that focuses exclusively on individual pathology “decontextualizes” the needs of the individual, a social approach to disability by definition, brings the social context into the formulation of need. The expanding search for individuals that members of the reference and leadership groups requested in study one, directed us to what I have referred to as “non-traditional” locations for finding individuals with serious psychiatric disabilities, who it was assumed would have found their way to the mental health system. There was therefore a direct relationship between our need to “cast a wider net” to achieve the outreach aim of the survey process, and the need to develop knowledge of the social locations in the community where we might find these individuals. At the same time, the perspective that was gained by “zooming out” to the wider community, gave us the opportunity to make some observations regarding the traditional service locations of the mental health system.

Before moving on to a more in-depth discussion of the types of social locations where we found the individuals in the study, it may be helpful to begin with two examples that help to illustrate the relevance of social location as a factor in understanding need. The first has to do with the alternative locations where we found a significant number of individuals experiencing serious psychiatric disability. While there was always an awareness on the part of the leadership and reference groups in every municipality, that a number of clients had “fallen between the chairs” and might be in contact with one of the other three authorities involved in the study, there was less awareness of the large numbers who were in contact with these, and the exclusivity of that contact.

### **Alternative locations – organizational**

Over fifty percent of the individuals identified in the combined studies had exclusive contact at the time with one of the generic community services, primary care, social insurance or employment. The fact that so many had avoided the mental health system, or had needs that they perceived as being better served by these organizations, is a significant result and one that should have serious implications for planning at both the county medical and municipal social services levels. These will be addressed in the final chapter. At the same time, it became clear to us that individuals were not only avoiding psychiatry, they were seeking something. Many of the initial assumptions were that those we found with these collateral services would also have contact with the mental health system. Throughout the three studies however, we repeatedly found that a significant number of individuals had exclusive contact with each of these organizations, and that each group was likely expressing a need based on their seeking the particular services offered by that organization.

These results were unexpected in that they defy the notion that a smaller number of “lost” individuals, often presented as lacking insight into their illness, have inappropriately wandered into the wrong organizational provider. While arriving as individuals, it is reasonable to assume that there is a shared and reasonable motivation, based in their desire to work and participate in the community that has drawn them to the employment service, a pattern of “behavior” that might be explored. Of those in contact with primary care, 70 percent were unique individuals. Their motivation for primarily seeking such a contact is of course very different, but also relevant to understanding need and developing supports. We heard from both psychiatric and primary care staff that some sought attention, preferring to present with “normal” somatic complaints rather than stigmatizing psychiatric symptoms. Others had a legitimate need for physical health interventions due to age or illness, which they had prioritized at that point in their lives. And finally, others who had left an acute phase of their illness utilized primary care for monitoring and prescribing their medicines. In all examples, there is the potential to develop knowledge regarding the individual’s life in the community, based on their connection to these organizational locations, a knowledge that is lost if we restrict our search to the meeting with mental health services. Organizational location in these cases may also provide clues as to the perspective on need that may become the focus, due to the “silo effect” which has been discussed.

### **Alternative locations – community-based**

Another category of alternative locations, in contrast to those in the organizational field, are the community locations with which we came into contact, as

we took a step further out beyond the helping system. For example many staff in the focus groups, especially those working in the area of supported housing, directed our attention to the landlords (and service personnel) of the housing complexes where many of the individuals lived, both those whom they were aware of, and others who they stated that the landlords and possibly police were aware of (often due to disturbing behaviors). While we were unable to distribute survey forms to these individuals, we were able to invite them in to a number of focus groups, and became convinced that they have a perspective on the “person-in-environment” that few others have. They also began to be seen as a resource in outreach and prevention activities, based on their location-based knowledge.

Results related to living situation showed that nine percent of the total population lived with relatives, most often parents, and that approximately sixty percent of these were under forty years old. Living at home was often a position connected with isolation from the helping system, especially in rural areas, and might be seen as linked with the risk of an eventual crisis if the parents were to become ill or unable to provide continuing support. It may also reflect the fact that for young adults in Sweden, the average age at which they are able to move from home has risen from nineteen to twenty seven during the past decade (SOU 2003:92). This example can also help to illustrate the relevance of gathering qualitative information from alternative community-based sources in order to understand such results. We were put into contact by our reference group members, with priests and especially deacons, who had information regarding the aging parents of psychiatrically disabled adults, who sought support in the church. They were in turn able to provide examples of individuals experiencing psychiatric disability who felt more comfortable seeking spiritual than psychiatric guidance. The recovery literature supports the importance of spirituality in the recovery process and reinforces this search for support as reasonable, rather than reflecting a lack of insight into the need for professional services. An example of the potential of such contact was that I was invited to deliver a talk to a regional group of deacons, which paved the way for a continuing dialogue about the various knowledge and roles that may be involved in supporting people with a psychiatric disability in the community.

## **Location and environmental effects**

There were a number of ways in which we came to see the location as a bearer of information, especially in terms of the person-in-environment aspect of the social approach to disability. The studies presented here took place during a time of great interest in the development of supported housing approaches as

an alternative to an over-reliance on group homes. The effect of the change from the individual as “resident” within a psychiatrically labelled group home, where staff had the keys, to one where the individual had their own home, and staff had to knock on the door to come in to their home, was frequently discussed in focus groups.

*We work from the principle that we are guest with the individual and must show respect as well as build relationships based on mutuality.”  
(FG-Supported housing)*

*Even she (the client) regards psychiatry as having a view of the individual as sick and when the support is given in the home, you are met as a healthy person. (FG-Supported housing)*

Both citations reflect the influence of location on relationship, meeting and the social role of the client. There are power dynamics at play, but also a context which offers valuable information regarding role and position to both the staff and the individual. While treatment-oriented relationships are appropriate within a medical setting, information regarding the individual, necessary for treatment decisions, may be more appropriately gathered in a “natural” location such as the home. We also became aware of the learning that occurred for staff that had previously worked in institutional settings and were now working in the client’s home. The process of being “deinstitutionalized” seemed a more accurate description for their journey in these cases than the individuals.

A final example comes from a staff member of a group home who wanted to discuss the effects of institutionalization on many of her very ill clients. “On one occasion we travelled to the mountains on a vacation for a month and rented a house together with the clients, and this was a kind of “turning point” in their/our lives.” Of those who had lived in institutions for many years and had characteristic institutional behaviors, many changed during this trip, and these behaviors disappeared to an extent. We heard many stories such as this from staff in the various focus groups, primarily those who had daily contact with clients, either in residential or day treatment situations. What was striking, as these stories were considered within the theoretical paradigms on disability presented earlier, was not that these alternative locations in natural settings could produce positive changes, but that they continued to work primarily within structures, day and residential programs, which seemed to maintain the institutional behaviors. These examples reinforced the importance of “recontextualizing need” or attempting to understand need within the context of the environment in which the individual found themselves. The following discus-

sion will connect some of the concrete results more clearly to the theoretical perspectives presented in chapters two and three.

## **Neighborhoods in the social landscape**

As we leave the psychiatrically-defined structures of the mental health system and begin to explore beyond the organizational field that is the social welfare system, we encounter the community and the physical/cultural environments in which the individuals we are trying to understand actually live their lives. I am using the term neighborhood here primarily to define these social contexts in the community, naturally occurring and subject to the economic, class, gender, race, and other forces present in our communities. Some of the research I presented earlier was related to the marginal neighborhoods where many individuals with serious psychiatric disability end up due to poverty and what has been described as downward drift. In Sweden, where actual poverty of the type frequently encountered in the US and other countries is still fairly rare, neighborhood may have more to do with “in-between places”, where there is a “poverty” of quality of life, rather than impoverished physical locations. The extensiveness of the Swedish social welfare system, which allowed us to find many of the individuals, may also be seen as an attempt to create an “organizational neighborhood of support”. This organizational neighborhood can, in the best of cases replace that of the natural community for shorter periods of time, but may also run the risk of becoming an institutional neighborhood, with many of the same effects as those seen when people were living in institutions.

## **Liminal locations in the community**

The example of the group home residents who “blossomed” in a new environment, and yet maintained their institutional behaviours in the program, should challenge us to identify the mechanisms behind these contrasts. Striker (cited in Ingstad and Whyte 1995) described liminality as a state of “ambiguous personhood” in which a person, in a transition from “isolation to emergence” is in a state of “social limbo”. It is possible to utilize this image in beginning to understand the social location of community-based mental health services, as they were initially intended to support the individual in the transition from a life within an institutional system to one that was community-based. The promise was that these community-based structures were only intended to “hold” the individual during a period of time until they “emerged” as a participatory mem-

ber of the community. The results presented in the previous chapters may be said to describe an either/or situation where we found approximately half of the individuals firmly within the mental health system and the other half struggling to find supports and opportunities that might accommodate their community-based needs. What we saw very little of was rehabilitation-oriented services which were actively working with the transition from illness-related programs to a participatory life in the community.

Striker uses the term liminal to describe a state of being, Warner and Gabe (2004) use it to describe a place, at the intersection of “risk, liminal otherness and mental health”. For purposes of reflecting on the studies here, the “intersection” that Warner and Gabe describe, is one that we encountered quite graphically in the illustrations related to the risk, target and recovery groups. In illustration five, it is possible to map this phenomenon, as locations one and three may be seen as examples of these intersections, where the individual is attempting (recovery) or maintaining (risk) a life in the community, but due to their psychiatric disability and environmental obstacles have not yet emerged in a participatory role. Location two, that of the traditional target group, is the social location that I begin with here, as results contributed to a picture of this location as indeed liminal.

### **Programs – Transitions from or to?**

*Many stay a long time.... It can be hard to leave. (FG-day program)*

Already in the initial study it became clear that the majority of individuals we identified had few opportunities for a participatory life in the community. Of the 652 we found in study one, 53 percent were without any type of activity and in municipality seven up to 70 percent of the individuals had no activity/occupation. Even in municipality six, where we had the highest levels of participation, and there was an extremely active attempt to coordinate and develop services for the “target group”, only 11,6 percent of those 18-29 had any type of rehabilitation-oriented activity. In study one, it became apparent that the numbers who had some type of meaningful involvement in the community, outside of the mental health system, was also very low, with only three percent working full time, and nine percent part time. The picture which held throughout the project was one where “day programs” had become the primary occupation for the majority of the individuals who had any activity at all. We saw throughout the studies a pattern of success with residential options, where the individual had their own apartment, a fairly stable economy and even support from staff which the majority were satisfied with. On the other hand, we saw

consistent dissatisfaction in the areas of social and work life. While it may be understandable that it is important to begin with a comfortable home and workable economy, the “housing” of these system-connected individuals does not seem to have been accompanied by opportunities to “emerge” or participate in community life. This perspective was often shared by users and staff who echoed the concerns expressed regarding the lack of opportunities for rehabilitation.

*They , the social insurance authority are the ones who get to take the initiative... they decide which resources you get information about.... You have to poke around if you want to find out something (what is available)” (IN, 31yo)*

Lack of information as to options for a more participatory life in the community may reinforce the liminal nature of a life based on a dependent relationship with the mental health system. One of the women receiving supported housing services, interviewed in study one, when asked about her interest in working, stated she was wasn't able to. When I told her about another man who I had spoken with, who was working part time in a subsidized and supported job, and spending every other day at a day program where he could relax and recover, her comment was that she could absolutely do something like that. Her answer regarding her interests, needs and abilities was clearly related to the information she received about possibilities for participating with support, assuming these are available. Her answer when taken only as a reflection of her own ability and health in other words, did not accurately portray the level of participation she might have the potential and desire to achieve. By beginning to look at the mechanisms which may reinforce the liminal nature of programs as they operate today, as I will below, it is also possible to imagine how they might begin to develop in the direction of supporting participation.

*The staff are connected to the house... it's not possible to go out with the residents (and do things in the community) (FG-group home)*

*There are lots of activities downtown... the staff say they can't.... that it's not their job.... Theres a lot that you can find to do, for example in the events calendar (printed weekly) (FG-Family association)*

Many comments reinforced the notion that staff, despite working in community-based programs, were still working within an organizational culture that

had integrated many “taken for granted beliefs” as to how psychiatric staff work, including the focus on behaviour and needs within the home.

*Many new residential programs have become like a mini-hospital.  
(FG- Users association)*

The negative aspects of institutionalization may not be specific to the physical structure of the hospital. It became clear that physical location in the community did not correspond with social integration in the community. A day program which stood for almost all of the municipal social psychiatric services in municipality seven had just moved into the center of town from a location that was quite isolated. Despite the expectation by program planners that this would lead to a more integrated life for the clients, the users reported during the focus group that while there is “more to do in the neighborhood”, they can’t afford to take advantage of these, there is a stigma associated with being connected to this “place” (a prominent yellow house), and the staff lack the time and resources to help them make connections to opportunities for work and study. The discussion turned to one of purchasing equipment and developing activities in the building, a ping pong table, a carpentry workshop, etc, since we “can’t just stamp around here all day”. One younger member suggested that the municipality could subsidize the cost of his becoming a member of a local health and fitness club. Everyone laughed at the idea that the bureaucracy might actually do something like this, but as we continued to discuss the idea all seemed to think it sounded better and better. The suggestion led to a number of key questions. Why was it ok to buy a ping pong table, so that all could play together in the basement of the house, but not to spend money in ways that might actually increase participation in community activities?

The geographic change which stood at the center of the deinstitutionalization movement would still seem to be operative as programs are planned for these individuals. The notion of social location, implied in social approaches to understanding disability, is a much more nuanced attempt to describe a “place” in the community. In this example, it is clear that the physical integration of the day program in the community, had not addressed the exclusionary mechanisms which were obstacles for the individuals dependent on these services.

*He doesn’t have any activity/occupation today and doesn’t want to go to a day program and describes these as a form of adult child care.(FG-supported housing)*

*They want to have more contact with the public (FG-day program)*

As the focus group interview with users in the last survey confirmed, users are well aware, as are staff, of the marginalized lives that individuals with psychiatric disabilities continue to live. Not all the users we spoke with, or the staff that presented their situations were ready or willing to work, but there was almost always an interest in some type of contact with “real life” or “real people”. The feeling that came through was that although many community-based programs offered stability and support for the individuals who chose to use them, that they were still continually aware of their outsider status, and longed for contact with friends, family and a place in the community. Leff and Warner (2006) state that; “Although a minority of users were able to break out of the circle of mental health users and providers, most were trapped within it”.

Originally developed as transitions from hospital to community life, group residences, day programs and other “grouped” activities risk becoming parallel societies. Their transitional function is lost and they become dead ends instead. Hansson (1990) uses the term “arenas of organized normality”, to describe these locations in the community. In the discussion of normalization theory it was stated that this focus for developing services had run into a wall at the gates of a real community life and it is these so-called transitional programs that form the concrete expression of this phenomenon. Murphy’s (1987) concept of liminality or “social suspension” may be used to describe this social location in society, an ambiguous place where the “categorized disabled” reside, while waiting to get better or to die. Topor (2001) has referred to these programs as intermediate care forms which attempt to fill the void between the treatment system or “total institution” and community life.

### **Grey zones as “in-between” places**

Service users who were perceived by their worker as being “high risk” were often identified as also being in in-between places, in particular between the community and the hospital. Frequently, difficulties stemmed from the fact that there were no appropriate services for those in the “no man’s-land” between hospital and community” (Warner and Gabe 2004:394). The “grey zones” which have been presented and discussed may be seen as representing a “no-mans land” of responsibility as well as risk (Markström 2005), and another type of liminal place in the social landscape of the community. During the project we heard many respondents describe socially complicated cases, where the persons’ social needs confounded attempts to define psychiatric needs and appropriate treatment options. Individuals with “complex” or multiple needs were also seen as “difficult to place” and therefore difficult to categorize/place in the correct compartment. In many ways, the risk and recovery group members who we identified fell into this place in the community. While “moving” in

different directions, struggling towards or drifting from a participatory life in the community, they inhabited the same social space. The complexity of their social and psychiatric needs did not fit neatly into the category-based service system, leading to a liminal existence “in between” the chairs of the social welfare and psychiatric systems. Within these grey zones there was an inability, expressed by all of the “chairs”, or actors within the organizational field, to support the individual’s ability to “emerge” positively. The concept of grey zones in the community, while an intriguing theoretical notion, entered the project based on practitioner’s descriptions in the initial study, of the very real failures of providing coordinated and comprehensive services in the wake of the Reform.

*The gap between psychiatry and community life... there’s a need for something in-between (psychiatry and employment authority)... Psychiatry has great expectations for us... but totally unrealistic...They don’t understand how we work... they(the patients they send) aren’t ready for regular work... It becomes a “ping-pong match (between organizations) (FG- employment)*

This was one of the first examples in the initial study, which helped us focus on the gaps between organizations, that space that we began to refer to as the grey zones. The individual, or responsibility for helping the individual in this quote is of course, the ball. It also became clear, as grey zones were confirmed in each of the following studies, that this was not simply a question of a few complex individuals, often presented as lacking insight, “falling between the chairs”. The conclusion, as presented in study two was that the “chairs were wrongly placed”. There seemed to be a structural issue, which was based, as has been discussed within New Institutional theory, in the myths of the organizational environment. In other words, the organizational structures operating within the social welfare system are arguably operating under myths related to the deinstitutional era and medical/individual notions of disability, rather than the actual demands of the work today.

*All the different perspectives on need leave the client nowhere. (FG-IFS)*

The initial attempt to concretize the grey zones involved a triangulation process, they could only be seen clearly by developing knowledge of the various organizational perspectives, since the essential aspect of their social location was their “in-betweenness”. The limited “mapping” of these zones by each

authority is explained by the limits of their responsibility within the social landscape. Individuals who become too ill disappear into psychiatry and away from vocational rehabilitation services. Individuals not judged to be “work ready” by the employment service are supposed to disappear into day programs administered by municipal social psychiatry, where they will remain until they someday emerge, now with the skills and stability assumed as a prerequisite for a participatory life in the community. The concept of liminality is helpful here as well, as a basis for understanding these grey zones. Liminal places are not accidents or mistakes of a system that needs to coordinate better, they are a societal “holding” mechanism, where individuals not seen as ready for inclusion may remain until they “get better”. Day programs and group homes, as remnants of an institutional liminality, fit easily into this picture. The grey zones between organizational actors, and between the welfare system and community life, may also be considered within this theoretical framework. Such a perspective would lead to a need to reconsider the social reality on which the role of these actors both within the organizational field and in relation to community life has been based. Many of the examples presented in this project point to a result more reminiscent of the institutional era, than the promise of community integration.

### **Marginalization and social location**

Markowitz (2005:87) suggests that recent research using multilevel modelling has; “revived the interest that neighborhood context plays in mental disorder”. Marginalized neighborhoods may be economically disadvantaged, disorganized, culturally segregated, etc. While the concept of a marginalized neighborhood may not have the same strong association in Swedish society, due to the strong social welfare system, the relationship between psychiatric disability and disadvantage, disorganized contexts and weak social ties, is clearly present in the picture of life for individuals with psychiatric disabilities. Marginalized neighborhoods, as social locations, are often specific geographic locations in the community landscape, locations which share certain features. Social location may therefore also refer to the places where people sharing a common position in society might congregate. The dual diagnosis program described their clients who often “hung out” with members of the “A-team”, alcoholics and substance abusers who congregated in close proximity to the state run liquor store. This was a marginal location in the community where many individuals with serious psychiatric disabilities found acceptance, regardless of whether or not they had a prior history of substance abuse. The bus station was reported as another social location where people with deviant behaviours might find acceptance and “fellowship”. The economics of these friendships was also commented upon, as the psychiatric patients were known to be receiving a pension.

Aspects of these locations which in turn might contribute to the downward drift phenomenon that I will be discussing at greater length, were criminality as would be expected, but also another feature that was discussed a number of times.

*In certain cases we don't know what the seed is that starts the mental illness or substance abuse for people with double diagnosis. What can be considered are the reasons why one abuses substances, they are perhaps feeling so bad that they use drugs in order to self-medicate. If it is easier and less loaded with taboo to be a substance abuser, then attitudes in the society need to change so that they can get the right help for their needs. (FG-IFS)*

It seemed that being labelled as a drug user was in many ways less stigmatizing than being seen as mentally ill, especially from the perspective of community members, a factor that opened up possibilities for developing a social network, however negative it might be.

Impoverished social networks have long been associated with individuals experiencing psychiatric disability (Brunt and Hansson 2004; Leff and Warner 2006; Thornicroft 2006). While a lack of social skills is often posited as one explanation for the social isolation of these individuals, social exclusion leading to a marginalized position in the community may be another. "Rejection by the public of people with psychiatric disorders leads to social isolation of the patient and results in their segregation with other people with similar mental health problems. It becomes very difficult for an individual to break out of this social ghetto" (Leff and Warner 1997:3). Tew (2002) describes the social isolation that occurs over time as people lose their social and family networks. The result is that they end up as socially isolated or "ghettoized" within mental health services. While there is a process that leads to isolation, it is also important to see a socially isolated life as representing a location in the community, which while not physically "separate" may be a structure that should be considered in the determination of need. Many comments in individual and focus group interviews pointed to the need for supports to establishing social contacts in the community, and confirmed a desire and capacity for participating in such relationships if these supports were developed.

*I want to meet others who are experiencing something similar, or other young people... its important to build up a social network... otherwise you are very isolated... I need help to find people with similar interests, for example at a community college (IN, 21 yo)*

While there is much more to be learned regarding the notion of social location within the social context of disability, it is clear that there is a relationship between location and the experience of disability that can be tracked to particularly concrete aspects of community life. While the examples presented here are somewhat specific to Swedish society, there are parallels in every country that has experienced deinstitutionalization. In my own experience in New York City during the 1980s, it was the subways, single occupancy hotels and even the streets (homeless) which were the community locations that had replaced the institution.

*They (isolated individuals with psychiatric disability) don't disappear just because you don't see them. (FG-social services)*

One final aspect of the discussion of social location is that related to the relationship between location and time. Even when opportunities are provided by the helping system, they may not, as Hägerstrand (1991) has suggested, meet the person in their "time-space path". So that, for example, a Christmas feast offered at a time when the program is open before the holidays, may not satisfy the need of the individual for a social contact on the holiday itself.

*There is a need for satisfying their leisure time interests evenings and weekends, since there aren't resources at these times today. (FG-social services)*

*There are so many who are lonely and Sundays are boring for many, nothing is open. In the old days, the library was open on Sundays and it was a fine social meeting point. (FG-user association)*

Before moving on it is important to reinforce that social location, as a feature of the social landscape, is not a concept that should only be associated with marginalization and deprivation. Many comments throughout the project also reflected a longing for social locations which were seen as positive opportunities for developing a participatory role, like all others, in community life. Adult education centers, offering courses and study circles, and voluntary associations offering structures for pursuing hobbies and sports, were often described as desired locations where individuals could begin to re-enter society.

*I'd like to join an association, maybe connected to computers if there is one, where people could help each other." (IN, 49 yo)*

## Positions and role

*Here, (in the waiting room at the psychiatric hospital) nobody cares who I am. It doesn't matter if I'm a PhD in ethics or an alcoholic. I am well received here (Heberlein 2008)*

The author intends to describe the humane meeting she experienced with psychiatry, one that is equal for all regardless of their role or position in society. At the same time, she may be describing the “decontextualizing” which occurs as the person becomes a patient or client within the mental health system, and is met, in the name of equality, without regard to the social context of their lives in the community. While extremely positive from an equality perspective, there may be, over the long term, implications for the individual as they become a member of an “equal” but marginalized group.

Priestley (2004) reminds us that it is not only the collective experience of disabled people that should be studied, it is important to remember that “disabling societies” affect different people in different ways. The experience of disability may be different for women and men, for people of different ethnic and cultural backgrounds, and as the life course approach suggests, for people of different ages and at different stages of life. I want to use the concept of position to describe the manner in which different people (unique individuals) interact with society from both the various generational locations of people with disabilities (youth, middle-aged, old age for example) and the various roles they may assume at different points. This is also another way of shifting the focus from that of the individual as exclusively defined by their status as psychiatrically ill or disabled to one that places them, or “positions” them in relation to the entire society or community. Giddens (1984) distinguishes between the notion of “role”, which is “specific to a certain location or type of location” and “position” or as he prefers, “positioning”, which situates the person in space and time. With reference to Hägerstrand, Giddens (p. 86) states that “Positioning, in the time-space paths of day-to-day life, is also positioning within the “life-cycle” or life path”. So that a role such as patient, which might describe the individual's relationship to the health care system, does not adequately define the position of the individual within the broader society and within the individual's life. Markowitz (2005:88) suggests that as a result of mental illness people may be “selected into certain social positions”. Reflecting the agency/structure debate presented earlier, I will suggest that people are positioned and position themselves. What is interesting and important for developing knowledge of the lives of people with psychiatric disabilities is the study of the various roles and positions that influence need. I use three examples of how

the individuals we identified are positioned/position themselves in the social landscape, in order to illustrate the information that can be gained from such an exploration of need.

## **Parenthood and gender**

A role as parent is important to understand on a variety of levels of reality, as an identity for the individual of course, but also as reflecting the manner in which she/he is positioned with respect to the expectations/opportunities of the community and even to the categories and resources of the organizational field. Beginning with study one, when psychiatry personnel directed us to the young women they were meeting, many of whom were young parents with mental illness, there was a consistent finding of a significant number of individuals who had a role as parent. Thornicroft (2006) and others have reviewed the literature on mentally ill parents, which most often refers to mothers, and presents a number of findings, including the frequent involvement of the social services as the parent experiencing a psychiatric disability may not be seen as a suitable or able parent. On the other hand there is a paucity of studies which pay attention to the childcare problems of people who are being treated for a mental illness. And finally, there is even evidence that there are many who actively choose to have children, finding satisfaction and success in their role as parent, despite the challenges of a mental illness.

The organizational cultures within which people receive support for psychiatric disabilities did not seem able to meet the individuals in the study as both psychiatrically disabled and parents. As the mother in study two described, the organizational field did not meet her as both a functioning mother and a severely depressed, periodically suicidal young woman. The individuals who were described were either in touch with individual and family services or with social psychiatry. They had support from specialized psychiatry during a crisis, but were then often on their own when they were able to resume their role as parent. Within the theoretical frame presented here it might be stated that the needs related to their role as parents, disappeared within their role as psychiatric patient. Their role as parent within the community on the other hand, one that involved relationships and support as well as needs, became invisible within the psychiatric medical paradigm which was not prepared to include their social role, in their diagnostic and treatment formulations. The significant number who had a role as parent presents a challenge to the municipal social psychiatric services as well, since we were unable to find available supports for families within the array of programs and support services offered. The implication was that individuals needing supports for a serious psychiatric disability were “not

parents”, an assumption that may have been more relevant during the transition from institution to community, than was now the case.

Within the discussion of parenthood we began to focus on gender and role. While this subject might consume an entire dissertation, I present it here since we found that of the individuals identified as having a role as parent in study two, 71 percent of the single parents were women and 80 percent of those in relationships with children were women. In discussing the “right to build a family” Lindqvist (2007:50) states that when people with disabilities build a family there are usually “others” who have an opinion, and may see the act of building a family as a “risk behaviour”. Opinions by professionals as to the suitability of a woman with a psychiatric disability building a family, may also influence their interest in planning supports, when the behaviour is judged as a mistake, and not a right requiring the same types of supports as all others. The appearance of this issue within the frame of parenthood and family may reflect stereotypes which steer the development of knowledge within the field.

*Disabled women are perceived to be needy, dependent and passive-stereotypical feminine qualities. At the same time they are deemed incapable of aspiring to other “feminine” roles, especially those relating to appearance, partnering and motherhood.” (Goodman et al, 1997: 71)*

The “double disability” which the authors argue women with disabilities experience may help to explain the lack of attention to the role of parent within the development of community-based psychiatric services. Studies regarding the numbers of women with psychiatric disabilities who have been abused, and suffer from trauma which goes untreated in the shadow of their psychiatric diagnosis (ibid.), support a perspective on some of the unique experiences of women that should be attended to in planning services. The police chief in study two who was able to describe the position of women she met as partners in abusive relationships, was one not attended to by social service and psychiatry personnel. In this case, the importance of attending to the position of disabled women in the community would help to create a focus on the risks of abuse, rather than in many cases, the need for treatment of the patient after the abuse has occurred.

We become increasingly aware in these examples of what Busfield (1996) has described as the “gendered landscape”. This is an important aspect of the social landscape in the post-deinstitutional era as individuals, as seen in these examples, are constructed relative to their gender, as they attempt to emerge as community members. Shön (2009:94) has stated that; “Men and women in

recovery from mental illness strive towards a gendered normality. In this process social relationships, psychiatric interventions and the society in general have gendered implications”. Such a focus is especially relevant as we attempt to interpret the manner in which individuals emerging from a role as patient may be positioned by gender.

### **Transitions to adulthood – young adults and psychiatric disability**

The concept of “position” as presented by Giddens, seems particularly well suited to capturing the time and space aspects of age in relation to society. While I will focus on young adults, the importance of age and generation as describing positions within the life path of people as they live their lives in the community, is relevant for many groups. We were particularly concerned for example about those 50-59 who seemed to have much higher levels of inactivity and were not offered rehabilitation services. These concerns led to questions regarding the manner in which the system regarded this age grouping, perhaps as nearing retirement and not worth an investment of resources, or as one woman experienced it as she received a permanent disability pension, at the end of a participatory life. Or it might have reflected attitudes among the individuals themselves, as they felt they needed to prioritize their health as they aged, as we heard from a number of the older members of a day program in municipality seven who expressed their satisfaction with a meeting place and support. The opportunity to be seen as an individual experiencing the normal challenges and transitions of various generational locations in a life, may be seen as another aspect of the “recontextualizing” process offered within a social approach to disability. Normal, age-related life transitions were largely ignored within the liminality of the institutional world, but do not seem to have come up yet on the agenda within community-based psychiatry.

Interest in young adults with psychiatric disabilities can be traced back to the discussion of the “young adult chronics” (Pepper et al. 2000) who avoided the newly formed community-based mental health centers in the wake of deinstitutionalization. Leadership and reference group members in the project similarly described their encounters with young adults as; challenging diagnostic categorizations, “socially complicated” due to their involvement in often problematic social networks, and challenging in that they had “higher expectations” for a life in the community and rejected traditional psychiatric solutions such as day programs. In focusing on this group, defined as 18-29 years old, there were two conclusions that are interesting from the life course perspective. The first

relates to the fact that the young people in the study reflected young people in general, and many of the characteristics of these patients we were asked to look at said more about their age than about their disability. In study one, we noted that the young adults seemed to follow many trends in society for people of their generation. They smoked less, used more drugs, and were more educated than the older individuals with psychiatric disabilities, members of the historic target group. While it is clear that some amount of this variance is due to the lack of institutionalizing mechanisms, it is also quite clear that young adults with psychiatric disabilities are more integrated into the “mainstream” of both social problems and possibilities in the post-deinstitutional era.

*I think we are, in part, pathologizing the turmoils and struggles of a cohort of young people who find that when it is their turn to take a positive place in society, there is no room....Inadvertently, by transforming these people into mental health clients, you relieve society of the obligation to examine the terrible human costs of our culture (Estroff 1983:9)*

There was a concern that many of the fragile young women at risk for abuse discussed by psychiatry, the guys lost in a “computer world” who were isolated to a point of social phobia, and those dropping out of high school and facing unemployment and substance use as a social networking tool were not “really” the seriously psychiatrically disabled that we were looking for. At the same time, it was clear to respondents that it was these young adults who, if they did not find a positive direction and support, would end up as “target group” members, seriously disabled and requiring extensive psychiatric and rehabilitation supports. Estroff, in discussing the particular challenge for young people who may have their problems pathologized, raises the issue of social location as well. The lack of a “place” in the community for people who may be experiencing difficult transitions can lead to a marginalized life, a place filled with risks such as hopelessness, substance use and risky relationships. While not one of cause and effect, the relationship between the position of young people in general in the community, the social locations that they inhabit, and the risk for psychiatric impairments to become disabling should be of interest in planning supports and services.

The second conclusion related to the concept of life transitions, the transition to adulthood being the example that will be discussed here. In the project however, there were a number of transitions related to the life path that were of interest. The transition from the possibility of a work life to retirement, age or disability-related, was one that has been discussed. When is someone ready to

“retire” if they have had a career as psychiatrically disabled? What changes, related to a participatory life in the community, would such a transition entail? Many such transitions were involuntary and complicated, such as those for middle-aged men who had an active work life, and who in conjunction with long-term unemployment were dealing with increasingly serious depressions.

It is also possible to look at the results related to age and organizational contact, within the frame of people seeking supports to complete a particular “life project”. For example, in study one, 24 of the 33 individuals 18-29 who the municipal social services had managed to establish contact with, were using a community-based rehabilitation program employing a Supported Education and Employment model. Municipalities without such services would likely be describing these 24 individuals as “complicated” or “resistant”. The language of “deinstitutionalization”, comparing the young adults met in the community to those long term patients who had been institutionalized, referred to them as “young, adult chronics”. A recent report from the US government entitled “Young Adults with Serious Mental Illness” (GAO 2008), was focused on the “transition challenges” of those moving from adolescence to young adulthood. Sometimes referred to as Transition Age Youth, this focus takes a step back from the institutional language which presented these young adults as having “broken away” from the system, and sees them instead as living within the youth culture that exists within the natural community. They begin by describing this as a critical period in human development, with transitions and challenges related to school, employment, housing, relationships, and even parenthood. Young adults with serious mental illness face particular challenges in accessing services, according to the report, “navigating multiple programs and delivery systems”, in order to find services tailored to their needs as they live through these transitions. Tew (2002) describes life transitions as typically involving; “... the renegotiation of personal relationships and social identities”, a task which is particularly difficult for this already vulnerable group.

## **Unemployment, poverty and social isolation**

It is potentially useful to consider unemployment and poverty as societal positions, similar to a poor neighborhood, and where many individuals with serious psychiatric disabilities find themselves. Unemployment, especially as it relates to the finding that so many individuals identified in the project were found at the employment service seeking work, is useful in identifying the relationship between role and position as they help to describe a participatory life in the community. It may be argued that the individuals we found in exclusive contact with the employment service were seeking a role, which would position them in

the community as participating members, a role which the mental health system was unable to provide. A role as worker brings with it not only financial advantages which can lift a person from poverty or subsistence living, restricted social and material opportunities, etc. but also an identity which can lead to respect and social acceptance, even inclusion.

*Having work... it means... especially to have a job in your field... it means for me to have a place to belong to, to be part of something and to be in a connection/context. That's what its about... Its important.  
(FG – user)*

Unemployment, difficult to describe as a role, brings with it, due to the position which the person finds themselves in the society, a number of negatively charged “occupations” which do not seem to qualify as “real” or participatory in the community. Client, patient, resident, member, trainee, client, “retired” (by disability) etc. are some of the roles available when a person is unemployed, not studying, and directed to seek supports within the mental health system. Roles such as these may be seen as obstacles to inclusion in the wider community, and may in fact reinforce aspects of the “mental health ghetto” which has been referred to earlier. Unemployment itself however seems to be related to a number of other effects and factors.

*Looked at another way, unemployment for both mentally healthy people and mentally ill people, brings heightened risks of alienation, apathy, substance abuse, physical ill-health and isolation” (Leff and Warner 2006:102)*

While the lack of a participatory role can lead to a marginalized life for people with psychiatric disabilities, a position in the society as unemployed may be seen as risky for all. Focus group participants reported the loss of social networks and worsening mental health that long-term unemployment could bring. The project serving the long-term unemployed in study one, considered that fifty percent of its participants were seriously psychiatrically disabled, describing a “downward spiral” of mental health problems and disenfranchisement which reinforced each other. A similar phenomenon was noted throughout the project regarding young adults who fell out of a role as student.

*But I believe that in some way, those that fail to finish high school end up in the "backwater" and attract psychiatric symptoms like phobia..  
(FG-psychiatry young adult)*

Archer (2002:17) discusses downward drift as “the absence of a personal identity and the accumulation of circumstances which make it harder to form one”. She sees these downward spirals, based on changes of circumstance as “condemning people” to first-order needs, in extreme circumstances for a place to sleep when homeless for example. Even in the cases we saw, of unemployment, dropping out of school, or being “condemned” to a role as patient, there was an inability to plan for the future since they were focused on first-order or survival needs; feeling better, having enough money, finding social acceptance, challenges that disrupted the normal life cycle. Being without a positive identity may be seen as a marginalized position within the society and a risk factor for individuals with psychiatric disabilities.

Poverty, a particularly concrete result of a downward spiral, may be tied to a number of forms of social exclusion, including an inability to participate in social activities (Thornicroft 2006; Leff and Warner 2006). Parr (2008) notes a strong association between poverty and poor mental health, increased suicidality in poorer areas of cities, and an increased likelihood of being in debt and risking eviction for tenants with a mental health problem. In Sweden, while not living in extreme forms of poverty as in many countries, there is a relative poverty when they are not able to buy in to the same aspects of a “reasonable life” in the community, as all others. Membership fees to sport clubs which may provide socially inclusive experiences, as well as the costs for a study circle where a role as student and contact with community members may be available, are out of their reach.

*My income is lousy, I get by, but nothing more. (IN, 49 yo)*

In these examples, a marginalized life might be seen as being the lack of a positive relationship to the neighborhood in which one lives. Socially excluded or marginalized locations in the community reflect a liminal existence, one in which the individual is waiting for an opportunity to participate. In cases where the lack of a participatory relationship to the community leads to an overreliance on the welfare system and its various programs, this liminal existence may become a somewhat permanent structure in which the individual may experience a life not unlike the institutional. These locations in the community are presented in this chapter quite simply, as bearers of essential information relating to the social context of need.

Active attempts by these individuals to position themselves in society may be seen as an attempt to “negotiate” a role within the community, a role that the mental health system cannot, in its current structure, offer. The question at this

point is, based on the social locations where individuals were identified in the project, what can be understood about how and why they end up in these locations and positions. The “dynamics” of psychiatric disability, as disability is seen as a consequence of the interplay between social context and individual impairment, becomes apparent in the examples presented above and will be taken up in the following chapter. There were also many examples of obstacles to these attempts, provided by both individuals and their support staff, to develop a more participatory role in the community. Social exclusion, stigmatization and categorization and fragmentation are all structural processes which the individual as agent comes into contact with. These interactions are discussed as mechanisms which may help to explain the marginalized position or social location in the community where the majority of individuals with psychiatric disabilities find themselves.

## Chapter ten – Mechanisms and dynamics in the social landscape

As discussed earlier, the aim of this work is not to define a cause and effect sequence based on the isolation of specific variables within what has been referred to by Danermark as a pseudo-closed system, in this case the mental health system. With a starting point in many of the ontological and epistemological precepts of Critical Realism, the aim is to study and develop knowledge or an account of, “the makeup, behaviour and interrelationship of those processes which are responsible for the regularity. (events and situations that we notice in reality)” (Pawson and Tilley 1997:67). The “regularities” that have been seen throughout the three studies may be said to be those described within the discussion of social location. It is in these locations, i.e.: day programs and grey zones, and positions, i.e; unemployed or socially isolated, that we have found individuals considered by a wide variety of organizational actors, to be seriously disabled due to psychiatric impairments. The simple, yet enormously complex question is; how did they get here? This chapter will discuss two more processual aspects of the social landscape, grounded in social approaches to understanding disability, the mechanisms which influence the location of the individual and the dynamics of psychiatric disability.

### **The mechanics of location – Generative mechanisms**

In order to develop knowledge of why they have ended up in, or chosen these various situations, in the open system that is the community, we must consider notions of causality. Realists see causality as referring to the mechanisms that are involved in particular events and situations or as Danermark (2002) concisely defines the concept of generative mechanisms; “What makes something happen in the world”. According to Blom and Moren (2006:112) we move “backwards” from the empirical concrete phenomenon towards the generative mechanisms. Since we are dealing with open systems, there are a great number of possible mechanisms operating and yet not all are equally plausible. By looking at the results across all three studies and by comparing these with theoretical descriptions of disability and literature describing these individuals, my intention is to suggest a number of mechanisms which are more plausible. Generative mechanisms which really exist in the social reality, are also considered to be potential or “tendential” (Blom and Moren 2006). They don’t always lead to observable results, but are “contextually conditional”. Studying the observable

can only give us hints as to what causes an event, we don't see the whole mechanism. This is the case in this research project, where the "whole picture" may only be hinted at by the perspectives presented by the respondents here. There has been however, an attempt to describe various aspects of the social landscape for people with psychiatric disabilities, in order to gain perspective on mechanisms which may be missed within the frame of the traditional mental health system. The patterns that emerged in the analysis of the data, while requiring further research and validation, point to a number of mechanisms which may help to explain the behaviour and needs of individuals experiencing psychiatric disabilities and living in the community. The first two are related to mechanisms which operate within community and organizational cultures. The section on participation restrictions describes those which impact the ability of individuals with psychiatric disabilities to pursue a life in the community.

## **Social exclusion and stigma**

The attitudes and obstacles that may be discovered in an exploration of phenomena such as social exclusion and stigma are not easily measured, nor are their effects. This may be one reason that few studies attempt to include these in surveying need among people experiencing psychiatric disabilities. The challenges of operationalizing such mechanisms should not however exclude them from discussions related to surveying need and planning supports, since as many of the practitioners we talked with expressed, such exclusionary processes may be one of the greatest barriers to their work aimed at supporting integration and participation.

In her work on mental health and social spaces, Parr (2008) uses two different terms which can help to illustrate the move from social location to social exclusion that is presented here. She describes "spaces of exclusion" which may be said to include the marginalized and liminal social locations which were described above. She also uses the term "exclusionary spatial practices" to describe the mechanisms by which people with differences are geographically separated from others in the community. Social exclusion is a mechanism which may be said to encompass both the spatial exclusion of individuals experiencing disabilities as well as exclusion from a participatory life, a position which may not be geographically discernible. Meeuwisse (2000:479) describes the general tendency, a "constant dynamic" (of exclusion) where groups of people are defined as different and are only included when they meet the criteria for "normality". She describes the striving for community inclusiveness underlying the Clubhouse Model (Meuwisse 1997), where members seek solidarity with other members and personnel, perhaps as an alternative to the social exclusion which has characterized their experience in the community.

The first type of spatial exclusion is exemplified in the notion of “mental health ghettos”, where whether in segregated housing programs or day programs which only include other clients and have no physical connection to a neighborhood, the individual is not “seen” by the community. The second type, which is more common in the results presented here, and in Sweden in general since it is a more integrated society, has to do with social exclusion from participatory roles in the community. Why are the social networks of so many limited to contacts with others in the mental health system? Why do we find them in liminal locations such as day programs, when there are many who would seem to prefer relationships and activities based in the community? Are there mechanisms which push people into liminal locations despite their potential to do more? Thornicroft (2006:67) poses a similar question as he discusses exclusionary processes and asks whether civil society, composed of social venues, leisure time and recreation activities, travel and transport, economic and political opportunities, is fully open to individuals with mental illness. Do they have a “full membership” in the community?

In a report by the European Foundation for the Improvement of Living and Working Conditions (2003) an attempt to define social exclusion is presented;

*Social exclusion is characterised by five key factors:*

- *it is multidimensional: it includes not only income but a wide range of indicators of living standards;*
- *it is dynamic: specific factors determine entry or exit from it;*
- *it has a neighborhood dimension: deprivation is caused not only by lack of personal resources but also by unsatisfactory community resources;*
- *it is relational: it implies inadequate social participation and lack of power;*
- *it implies a major discontinuity in the relationship of the individual with the rest of the society.*

*Exclusion includes processes by which social groups or individuals are excluded from full participation in any aspect or activity (social, economic, political, economic, cultural, etc.) (p.30)*

The report goes on to list risk factors for social exclusion and these include the majority of characteristics which have been reported in the project here, including unemployment and dependence on economic assistance at low levels, growing up in a vulnerable family, poor physical health, difficult housing conditions

and as they state, the “cumulative disadvantage” experienced by people with disabilities who share many of these. If it is reasonable to assume that the majority of individuals with psychiatric disabilities experience social exclusion, then it would also seem reasonable to consider factors related to social exclusion in assessing need and developing supports. The factors listed above may be seen as a step forward from the theoretical notions contained in social approaches to disability and towards the concrete implications of the social context for the lives of these individuals in the community.

The deprivation seen in this population, described by the lack of activity, the poverty of social relations and the few opportunities for rehabilitation, if considered within the concept of social exclusion would ask such questions related to the inadequacy of community resources and the lack of opportunities for social participation, rather than look exclusively at needs stemming from the impairment of the individual. Mechanisms related to socially exclusionary processes operate on many levels, individual, system and societal, and can contribute to a variety of results that effect the lives of these individuals. Based on the focus group discussions throughout the project, since socially exclusionary processes are largely invisible in quantitative estimates related to individual need, it became clear that a specific discussion regarding stigma would be called for.

### **Stigma – Avoiding and being avoided**

*Mental illness is nothing to be ashamed of, but stigma and bias shame us all. - Bill Clinton*

Attitudes regarding the process of being labelled as mentally ill or psychiatrically disabled, the differences are likely irrelevant from the perspective of the non-professional community, have been discussed by both users and professionals participating in the project. Negative attitudes towards people experiencing mental illness are posited as one of the major obstacles to their ability to support the person to an inclusive life in the community. At the same time, users who struggle in the community without engaging with the mental health system, are often seen as lacking insight into their illness. Workers from the general social services seemed particularly aware of this paradox, that the stigmatizing attitudes towards psychiatric services, those which frustrated their attempts to help their clients accept their illness, were also those that would marginalize their clients as they became labelled as mentally ill. Beginning with the interview of social workers from the individual and family services in study one, this complicated situation began to become a central focus for the discus-

sions that followed. An awareness of the stigma of mental illness contributed to many individuals avoiding psychiatrically-defined services and instead utilizing the general social services, for economic assistance, housing, health care and employment support. Corrigan (2004:616) sees what he calls “label avoidance”, the act of avoiding “stigma altogether by denying their group status and not seeking the institutions that mark them (i.e. mental health care), as the most significant impediment to care seeking”.

*The last ten years it's become important that you have a diagnosis. People who feel badly have always been there, and there used to be more acceptance for differences. If there is too much focus on diagnosis it can be more difficult to take it back. People experience that they have received a label which becomes a self-fulfilling prophecy. (FG-IFS)*

Individuals with a double diagnosis of mental illness and substance abuse experienced stigma as a socially excluding mechanism, as they met prejudice according to the staff, when trying to utilize 12 step programs in their recovery. The older residents of a group home were not welcome to participate in the activities of the Retired Persons Association, who personnel said, had the “worst prejudices” towards this group. Corrigan (2004) distinguishes between what he calls “public stigma, when prejudice towards a group is endorsed by the public, and “self-stigma”, when the members of the stigmatized group have internalized the public stigma. Link and his co-authors (1989), in a review of Scheff's labelling theory, discuss the steps involved in the process of being labelled as mentally ill. They begin with Scheff's notion that people internalize societal conceptions of mental illness, similar to Corrigan's notion of “self-stigma”. They go on however to note a number of steps which include being labelled by official contact, responses by the patient, consequences of the stigmatizing process on the person's life, and the “vulnerability” to continuing disability that may result. Many of the examples related to the responses of the individual are related to withdrawal, shame, secrecy and attempts to protect oneself from discrimination or devaluation. These “details” of the labelling process that may result from stigma, create concrete effects in the behavior of the individual, behaviors that within a medical perspective were often interpreted as reflecting individual impairments. Many needs might be more effectively described in relation to stigma and the labelling process.

Questions regarding how the structures of the mental health system might contribute to these forms of avoidance or withdrawal would be a natural outcome of an analysis of stigma as a generative mechanism. A number of discus-

sions focused for example, on the reaction of clients to the “shame-laden” programs connected with municipal social psychiatry in the community. Structures which reinforce labels may remind us of the most concrete forms of institutionalization, where the building was the location of mental illness in the community. Corrigan’s “public stigma” is in this example, given a concrete focus for the prejudicial attitudes towards this group, a focus which can, based on labelling theory reinforce either self-stigma or avoidance.

*It would be good if people in general could get more information about mental illnesses so that they don't live with prejudices... many have wrong ideas... for example that people with mental illnesses are violent and such. (FG-user)*

In the focus group interviews, stigma, described as negative attitudes and a lack of information, was reported “across the board”, in similar ways by social service personnel, by representatives of the employment services, psychiatry and health care, community representatives and users themselves. Stigma was often tied to a lack of information among actors outside the mental health system. Social service personnel stated that “teachers and parents needed more information”, employment service representatives said that their personnel “lacked knowledge regarding the groups need and potential”, user groups discussed the “stigmatizing attitudes that resulted from being labelled as mentally ill”, community representatives felt that “politicians needed to prioritize this group and take a greater societal responsibility”, and psychiatry saw obstacles for the individual they were treating created by attitudes in the community. It might be said that stigma, and the stigmatizing effects of poorly informed and negative attitudes, transcended any one perspective.

There would also seem to be a wider effect of stigma on the organization of services for these individuals. In a recent report by the National Council on Disability (2008:12) they point out; “The attitudinal barrier is exemplified by policies, programs and beliefs about people with psychiatric disabilities as needing to receive all services within segregated settings in which mental health providers deliver housing, work, education, health care, and support services entirely within the mental health system. Abolishing this attitudinal barrier is necessary to ensure that people with psychiatric disabilities have access to the wider community and all that it may offer”. The negative attitude in evidence here is the belief that segregated services necessarily precede integrated or community-based efforts. This is an attitude which may be seen as a relic of institutional thinking, still operative today, especially since there is a great deal of research within the field of psychiatric rehabilitation which disputes this

assumption (Anthony et al. 2002). Mechanisms related to stigma would appear to generate effects at many levels and support therefore the inclusion of community attitudes as a factor in understanding disability. As discussed above, stigma may be seen as the “substance” of disability, rather than just a by-product.

Thornicroft (2006) cites the lack of connection between research into stigma models and public disability policy or clinical practice. The description of mechanisms which might be discovered within the social landscape of disability, such as stigma, is only a first step. An example which might illustrate the knowledge that can be gained from an awareness of the concrete effects generated by stigmatizing attitudes is provided by Corrigan (2004:619) who noted that in a neighborhood dominated by African Americans, the church was a better alternative for making contacts related to mental health needs than the clinic. Our contacts in this project with the Red Cross, church deacons, family and user associations and even the police and landlords reinforced the possibilities provided by these non-traditional community-based meeting points. It is interesting to consider that even contact with the police may be less stigmatizing than contact with a psychiatrist. Discussions of stigma as a generative mechanism in the community landscape have the potential not only to explain withdrawal and avoidance, but may point the way to the development of viable alternatives to the structures which dominate today.

### **Organizational mechanisms – Categorization and fragmentation**

I have suggested above that the organizational tendency to categorize the individual as part of a particular target group as they become a client, may be seen as remaining rooted in an institutional/medical perspective on psychiatric disability and can lead to a number of negative effects. These include the aspects of labelling discussed above, which reinforce stigma as the individual is labelled as “abnormal” by the surrounding community and as they themselves may begin to integrate a damaged self-perception.

*The disability experiences of people with a mental disorder are closely related to the conceptualization of their problems as essentially medical. Even in the post-deinstitutional era mental health policies still emanate predominantly from health departments and focus primarily on the way clinical services should be provided. The impact of a policy focus, located within a medical framework, on the lives of people living with a chronic illness in the community must be assessed. ...*

*Detailed analysis of the social barriers and constraints faced by people with serious mental disorders in their negotiation of these government sectors must be undertaken (Mulvaney2000:594)*

Both users and personnel rejected “package” solutions which were more connected to the institutional myths of the mental health system, than to the actual work of meeting the unique needs of the individuals that presented themselves for support. There is a relationship between the notion of a somewhat homogenous and diagnostically definable target group and the delivery of “package” solutions within the organizational field. Once categorized as part of the target group, the service package becomes the starting point for the meeting with the client, rather than the individual’s life or community-based needs. Supported housing programs to support independent living and day programs to develop job readiness, these are the primary packages offered to these individuals.

Markström (2003) describes some of the background to the specializing of services in the municipalities after the Mental Health Care Reform. Specialized services or programs, focused exclusively on the psychiatrically disabled, were only to be utilized during a transition from institutional/medical structures to a community-based model, where these individuals would receive the same services “as all others” within the general social services. The continued influence of this specialized response to a historically defined target group, identifiable as “the psychiatrically disabled”, was clear as the survey process in every municipality was initiated by the municipality’s social psychiatry unit. The socially complicated cases which we heard about, help to illustrate this flawed categorization. When family services don’t see mental health as their territory and when psychiatry doesn’t see substance abuse or family support as a core focus, than it is possible to raise questions as to the template for the organizational field that is the mental health system. It is possible to see all of the “cases” that were found outside of the mental health system as complicated since they were clearly attempting to participate in the community. Those with exclusive contact with the mental health system on the other hand, may be seen as having been categorized within a system that is still operating within many of the institutional myths left over from deinstitutionalization, and as Stone (1999) described, a categorization (as disabled) that is very difficult to leave. This was particularly clear for those who had received a permanent disability pension, and regardless of their age or potential over time, would not be made aware of opportunities for rehabilitation.

The organisations within the formal mental health system also seemed to share a “cognitive inheritance” from the institutional era, which many described as influencing current practice.

*The personnel moved out with them to the group homes when the institutional residences were taken away, but they had the same education, attitudes, etc... (FG-IFS)*

As Scott (1995) and others have pointed out, organisations or institutions use cognitive, normative and regulative structures to give meaning and stability to social behaviour. These derive from the cultural context or environment within which the organization develops. Based on the manner in which the individuals we identified defied the organizational locations where we should have found them, and the manner in which their needs seemed to transcend the limits of each organizations attempts to delineate them, it is possible to draw the conclusion that the current organizational field is operating based on outdated conceptions of the individuals who they are intended to serve. The “myths of the institutional environment” can be seen as the “archetypes” (DiMaggio and Powell1991) of the deinstitutional era, and may be steering these organizations to a greater extent than the individual needs of the individuals now living in the community. The Clubhouse model, which has co-existed with the more traditional system since the 1950’s, may be seen as an example of an alternative rehabilitation model trying to protect itself from what it perceives as the “irrelevant or misconceived institutional demands” of the formal mental health system. With roots in the self-help movement the Clubhouse Model provides not only support for individuals experiencing mental illness, but prioritizes real work and private housing for their members who they believe have a right to participate in society on an equal basis (Meeuwisse 1997).

*They ( programs serving the psychiatrically disabled) work from the program structure, not from need. (FG-IFS)*

### **Fragmentation**

As each authority operating in the organizational field limits its responsibility area based on the categories of clients that fall within their jurisdiction, the needs of individuals tend to be “compartmentalized” as they become clients within one or another system (Markström et al., 2004). The compartmentalization of need undermines the ability of any one actor to see the client as community member and assess their holistic needs. If there were true coordination of services, with the individual in the center, and with few gaps in services, this

might not be a problem. However the results of the studies presented here do not support this picture. Of the individuals identified in the three studies, eighty percent were only actively engaged with one of the five actors at the point in time that the survey was performed. As described in chapter eight, the low frequency of individuals reported by multiple agencies was interpreted as a concrete sign of poor coordination in service delivery. Authorities which responded only to one or another “fragment” of the individual’s need for support to a life in the community, had a number of detrimental effects.

In discussing the organizational field that is social psychiatry today, Lindqvist (2007:167) suggests that the field is sparsely populated, in other words there are few domain conflicts as various actors compete to expand their area of influence. Instead it is quite common that they work to limit the difficult tasks that might otherwise strain their resources. The sparsely populated (organizational) field is therefore filled with quite large gaps between services, within which these individuals may easily disappear. The grey zones that were identified in these studies were often the result of the distances between the actors in the organizational landscape or field, with many individuals and sets of needs that “fell between the chairs”.

Another effect of the fragmentation of services, and the resulting fragmentation of the individual’s needs, was a step-by-step perspective on rehabilitation and recovery. This led to a “linear” philosophy of service delivery, in which the individual was to complete a “phase” with one agency before moving on to the next. The National Board of Health and Welfare (Socialstyrelsen 1999c:291) made reference to this tendency regarding rehabilitation in its follow-up of the Mental Health Reform;

*Rehabilitation should begin early in treatment and function in a coordinated and integrated process. The earlier metaphor of a chain of rehabilitation chain or steps, where each and every agency defines and completes its rehabilitation service, can instead be replaced by a wheel. The spokes symbolize the various efforts which are in themselves insufficient, but which together give enough support and strength so that the process can move forward*

The earlier metaphor seemed to be a more accurate depiction of the current situation, despite the stated emphasis on coordinated and simultaneous services. The limitations on responsibility and the fragmented view of need also reinforced the development of grey zones where individuals having left one phase of the chain, were not deemed ready for the next.

Leff (1997:28) also raises the issue of “service fragmentation” as a serious issue, as patients need to now (with the advent of the community-based system) be “aggressive in navigating through a cumbersome series of disjointed program sites”. Throughout the three studies both personnel and users repeatedly stated the axiom that; “You have to be healthy to be sick”, referring to the demands of finding services and supports in today’s system. The burden to “find your way” in the organizational field is placed on the shoulders of the individual, who in a vacuum of coordinated services and comprehensive information, is often unaware of their possibilities. One young man interviewed in study one expressed his need in the following manner;

*I need help to understand how I can move forward. (Ind, 38 yo)*

As described in chapter six, the large numbers of personnel who answered “don’t know” to many of the questions related to need, led us to an analysis of the “organizational locations” of knowledge related to need. For example, seventy nine percent of the respondents from the individual and family Services unit didn’t know if the person had needs related to their vocational goals. Another type of fragmented knowledge had to do with the competencies of the various authorities and units when it came to psychiatric disability. Supervisors from the social insurance authority complained that they had little knowledge of psychiatric rehabilitation principles and methods despite their responsibility for rehabilitation. Workers from primary care complained of mixed messages regarding their responsibility for these individuals, on the one hand being asked to take a primary role, and on the other hand to defer to psychiatry when decisions related to an individual’s mental illness came into question. Assessments of need were also often related to the organizational culture in which the person found themselves. Workers from the employment service for example described the differences in organizational cultures, where they determined readiness for work from a community employment perspective while psychiatry proceeded from a treatment/illness perspective. Assessments are completed within the responsibility area for that organization, and without a holistic perspective.

*There (at the hospital psychiatric clinic) they concentrate on the illness and not on the healthy and then it is hard to get healthy. (FG-supported housing – user)*

*They forget to see the whole person. (FG-employment)*

## Participation restrictions

While the examples presented here might be described in a variety of ways, my motivation for taking up the subject of restrictions on participation is twofold. The first is that many of the mechanisms described here, and that might be investigated in future studies, have the character or effect of restricting participation. Individuals who have the capacity and the desire to, as presented in study three, participate more actively in the community in a variety of areas of life, meet obstacles in their attempts. The fact that in municipality six, forty two percent of the individuals were judged to have a capacity to participate significantly more in work life, and that fifty percent were presented as having this wish, undermines many of the arguments related to lack of individual ability and desire. Both users and reporting personnel agree on this point, that there are environmental restrictions which frustrate the individual's attempts. Many of the mechanisms that might be explored as active within the social landscape for individuals living with psychiatric disabilities in the community generate participation restrictions. The second reason to develop this concept is that it is one of the primary indicators related to the environment in the WHO's ICF. Are factors in the environment facilitating or restricting the participation of the individual? According to ICF (2002), environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. Participation restrictions are problems an individual may experience in involvement in life situations. So that many of the mechanisms described here, may be said to reflect the environment/participation interaction, which can lead to restrictions on the individual's ability to participate in the society. A further reason to focus on these mechanisms is, as implied in ICF, the possibility of exploring mechanisms that can facilitate participation, a possibility I will return to.

*People with psychiatric disabilities are taught that the problem exists inside of us, particularly inside of our heads. ... The focus must be to change us. However, if we begin to think about it, having a psychiatric disability is for most of us, simply a given. The problem comes when we seek treatment and either cannot afford it or it is not relevant to our needs as we see them. The problem comes when we wish to live in the community and find that there is no housing that we can afford. The problem comes when we seek rehabilitation programs but there are no options or programs that are relevant to our needs. The problem comes when we try to get into school but are denied admission because we are known to have been diagnosed with mental illness.*

*The problem comes when we want to work and are ready to work but encounter discrimination in the work place*

Deegan (1992:11) expresses the philosophy and existential challenge that may be said to lie behind ICF and directs us not only to the environmental barriers to participation, but to the agency of the individual as they attempt to participate. “Consequences presuppose action” as I argued earlier, restrictions wouldn’t be a problem if there was no desire to participate. She goes on in this article to describe the “cycle of disempowerment and despair” which can lead to what she describes as “learned helplessness”, as individuals wish, attempt and are continually frustrated by obstacles in the environment or a lack of resources to help them achieve their goals. The passivity and lack of focus on rehabilitation, despite evidence of substantial numbers of individuals who were considered to be in a recovery phase, may be seen as a symptom of community-based institutionalization. Both users and staff expressed frustration with a system limited by environmental obstacles and a lack of resources to impact these, leading to what might be seen as an “institutionalized” learned helplessness.

Many of the focus group discussions described obstacles related to the environment. They described for example what they referred to as an “achievement society” in which expectations had become so high that their clients had no chance. Other participation restrictions pointed to the lack of accommodations and supports related to psychiatric disability. Time limitations on internships and rehabilitation services were not adjusted for the particular needs of individuals with psychiatric impairments. While a person with a bad back could make a decision regarding the appropriateness of a particular job within a few weeks, it might take six months for a person with a psychiatric disability to adjust to the point where an accurate assessment of the job could be completed. If not given adequate time the person might never have the chance to prove that they could be successful in that environment.

### **Rules and systems**

Kramer and Gagne (1997) describe “barriers to recovery” both internal and external, including stigma, low expectations and medical models, many of which we have described above. Another external barrier may be seen as the rule systems which create “institutionalizing structures” and that hold people in a life where dependency is a trade-off for security. The institutional world may be said to have taken over the life world in these cases. It was this assessment of need as related to the individual’s current situation, as opposed to their potential, that led to the participation focus in study three.

*If you do something, ... they take your pension.... It's tough. (IN, 31yo)*

*I'm afraid of losing my financial support... you have to notify the social insurance authority if you want to try something." (IN, 38 yo)*

This is a man who also believed he could enter the work force, at least with a subsidized job, but currently had no work at all. These statements are especially worrisome, even if only based on fears, when there were so many younger individuals who had received a permanent disability pension. Thornicroft (2006:53) finds that in many countries financial support systems act as “powerful deterrents” to entering the workforce, as the rule systems create powerful incentives not to look for work.

*I was working with a woman the other day... the best economic decision she could make was to remain on a disability pension. (FG- rehabilitation program)*

The final report of the National Psychiatry Coordinator (SOU 2006:100, p. 24) summarizes the situation regarding vocational rehabilitation.

- *The rehabilitation perspective and work line have ended up in the background to the advantage of a treatment and caring perspective.*
- *The community's services to support people with psychiatric disabilities in the area of vocational rehabilitation has been wanting and divided (disorganized).*
- *Some of the regulations within the social insurance tend to create effects which lock in people with psychiatric disabilities in the system of allowances, as the regulations are not well adapted for the course of psychiatric illness and the rehabilitation process.*
- *The employment market is not accessible to people with psychiatric disabilities.*

All of the factors presented above relate to the environment or social context in which people with psychiatric disabilities attempt to participate in the community. Topor (2001) describes the work of several researchers (Corin 1992 and Estroff 1989) who point out the risks associated with the social insurance system and intermediate care forms which may tend to create permanent conditions of economic dependency. He presents these as a recovery to a “position of marginality”. Assessments of need which do not make reference to these

participation restrictions may tend to describe need within such a marginalized position and without an awareness of the individual's potential if the mechanisms which produce these restrictions were not operating. Up until this point I have described aspects of the social locations in the community where the individuals described in the project were found, and suggested a number of mechanisms which may help to explain how they got there. The next section will address dynamics related to the individual who after all, is the central actor in the search for a life in the community.

## Dynamics

*It isn't where you come from that counts; it's where you're going. (Ella Fitzgerald)*

Attempts to utilize an "historic" concept of the target group, as defined by both illness and contact with the mental health system, appropriate during the period of deinstitutionalization, do not accurately describe the situation in the community today. Another implication of the target group paradigm is that the person is a member, until they are no longer a member. This is also a reductionist view and may be tied to the concept of patient in an institution, you are in until you are out. The reality that was described during the project was much more complex and dynamic. There was evidence of conditions that improved and worsened based on a complex interaction with the community, individuals who strived to make changes or establish participatory roles, and even those who actively chose to remain within the system, as their options often implied a loss of security.

*Some days you can be with the "healthy", some days you need to pull yourself back. (FG-user)*

To say that disability is dynamic, an interactive process that cannot be described by exclusively looking at the impairment of the individual, is a natural upshot of exploring social approaches to disability. The remainder of this chapter will focus on exploring two aspects of this dynamic experience, beginning first with a discussion of the individual as agent, actively seeking some type of life in the community. The second aspect has to do with the path and direction of movement within the social landscape.

## **The socially positioned agent**

As Archer (2002) states, we need to understand and model the human being as both “child and parent” of society. Such a frame for a discussion of the relationship between agency and structure has been a support in exploring the results of the project. System representatives struggled to adapt to the behavior of the clients as they did not follow expected patterns related to their “condition” and needs. And the individuals we became aware of struggled with their relationship to a helping system that did not often seem structured with relation to their needs for a life in the community. In some ways, an unconscious “dance”, where the partners seem to stumble as they run into each other, unaware of the expectations and needs which each has for the other.

“It is only through analyzing the processes by which structure and agency shape and re-shape one another over time that we can account for variable social outcomes at different times” (Archer 1996:693). This is a central point in my analysis since what I am describing, at its core, is a historical change in the social landscape for mental illness and psychiatric disability. Thornicroft and his co-authors (2008) present an excellent example of the interplay described above. In discussing the development of community mental health services their experience has been that the expectations of the people being treated rise faster than the pace at which service quality may improve, leading to “a paradoxical decrease in satisfaction”. While the structural changes, from institutional to community care provide a stimulus or opening for the clients to develop expectations, the structures are then challenged by these “ex-patients”, now community members. The advice of the authors is not however to accept the slow pace of system change but instead to realize that “the service users are the best experts”, and follow their very clear signals regarding the direction for improving the system.

The individuals we “met” in our survey of need were in part “born” as patients or clients in their meeting with the helping system, and as their needs were defined as being related to psychiatric issues. The fact that they often confounded efforts to help, defined often as a lack of insight into their illness, or utilized services inappropriately, defined as “resistance”, was often presented as further proof of their loss of reason. As increasingly large numbers of individuals exhibit similar behaviors, the concepts of resistance and lack of insight have become the basis for more aggressive attempts to “capture” and treat them for their own good. Specifically, this chain of reasoning can be seen in recent discussions of “Assertive Community Treatment” and involuntary community care, where the structures are adapting to the actions of the individual.

Giddens (1984:281) sees all human beings as knowledgeable agents, “social actors” who “know a great deal about conditions and consequences of what they do in their day-to-day lives”. Within this project, we have attempted to explore the idea that, as Giddens implies, their actions are likely guided by knowledge and reason. Their attempts to fulfill their life goals by making active choices are however often frustrated by the continuing presence of organizational structures still based on the culture of deinstitutionalization and not yet focused on social inclusion and participation. Their efforts to find a place for themselves in the community are often frustrated by a lack of opportunity and accommodation. As these individuals, now free to live in the community, come in contact with the organizational and community structures, they “shape and reshape one another”.

The many personnel who described their client as lacking insight into their illness implied that; “If they would only realize how sick they are, they would accept treatment and things would get better”. Leff and Warner (2006:4) however, describe research which suggests that “patients who resist the diagnosis of mental illness and who are therefore deemed to lack insight have higher self-esteem than those who accept the diagnosis”. The notion that those individuals who resist categorization as psychiatrically disabled may have, at least in terms of their identity, a better chance of recovering, is one that has implications for both the structure and location of services. Carling (1995) reminds us, as an explanation for the many who avoid community psychiatric programs, that many services are “unattractive” and that “we simply haven’t made people a good enough offer”. As described above, where one explanation for the many who avoid or fall from the helping system is that they are too sick, the alternative presented here is that their lack of presence is an active choice, based on a knowledgeable (their own experience) assessment of what is being offered.

An example of the individual as actively seeking a role beyond that of client or patient and with a desire to participate in community life, is provided by the many who expressed a desire to work. One study in Britain found that people with psychiatric disability had the highest rate of wanting to work among the disabled people interviewed, fifty two percent (Thornicroft 2006:51). Another US study found that two thirds wanted to work in competitive employment and studies repeatedly show the majority want to work and desire support (Cook 2002).

*I want to get an education so that I don't have to be in debt to the society (IN, 31yo)*

Even those who decide not to work out of fear of losing benefits, should not be viewed as passive, but making a positive choice to seek security over risking their financial security. As Leff and Warner (2006:115) point out, when the available economic choices are made clear, “the financial decisions of people with mental illness can be readily understood”. Actively choosing to remain in a day program for example, may be a quite rational decision, despite a desire and capacity to do more, if the financial risks are too great given the current rules. While many of the results presented here are clearly complicated, my primary argument relates to the importance of including the reason and knowledge in their actions as a factor in understanding their situation. The process of deinstitutionalization and development of community mental health was a structural attempt to position the individual as community member, one which has by the majority of measures failed. At the same time, these individuals need to be seen as “socially positioned agents”, with reference to the fact that they will act and pursue goals, not necessarily live their lives within the structures and rule systems that we have created for them.

Having established that psychiatric disability is not a static phenomenon, neither in the personal experience of users or even in the perceptions of personnel, it is possible to consider the various factors which influence the dynamics of this disability. People feel better and worse, and in relation to the opportunities and obstacles they encounter in the community, they may choose to act in certain ways, or they may choose not to act when the obstacles seem too great. The dynamics of disability were also noticed in the movement that was described between the organizational actors and as individuals either maintained themselves in the community or began drifting into an interaction with the helping system. This movement, when explored over time, can be said to indicate pathways or trajectories, within the social landscape, that people with disabilities may follow or fall into as they move through their lives in the community.

### **Finding direction – Journeys in the system and community**

*Somewhere there had to be a more accommodating existence. The search for that existence became the journey of my life, a search for islands of hope in a sea of despair (Deegan 2003)*

The image of pathways in the social landscape, that describe the life path of an individual with a disability, can reflect movement over time. Asplund (1983:197) helps to develop the concepts of agency and movement as he describes the “projects” that we attempt to realize in our lives; “... trajectories

represent active existence. The individuals complete or attempt to complete projects.... In one aspect, a project is defined as the goal the person strives for or has the intention of trying to realize. From another aspect, the project can be defined as a sequence of actions and events, which are necessary in order to reach the goal or realize their intention.” He also uses the concept of “stations” to describe the places where the individual finds themselves when they are not moving or pursuing projects, a metaphor that can be helpful in describing liminal locations within the mental health system. While not specifically written with regard to this population, these ideas can be seen as an entry point to exploring the lives of individuals with psychiatric disabilities, as they pursue various life projects over time in the community. Priestley, (2004:98) also talks about ”individually negotiated life projects and risks”, a similar manner of defining the individual as agent in what they experience as the unfolding of their lives. This is an extremely different image than that of the individual as client within the mental health system, a perspective which is only relevant at discrete points in time and only with reference to one aspect of their life world.

### **Pathways into and within the mental health system**

The concept of “pathways into treatment” has relevance for many of the findings in the research project. Busfield (2000:549) discusses the relationship of social class and mental disorder, and suggests that the social position of the individual influences their pathway into treatment and the type of treatment received. Her example is based on the fact that people of a lower social class often came into treatment through the courts or official agencies, in contrast to referrals by health professionals or families. While class may not play as significant a role in a social welfare state such as Sweden, the notion of a pathway into treatment as a significant concept in exploring the social context of need is relevant.

A number of examples can help to illustrate the manner in which a study of “pathways” can illustrate the dynamics of life in the community as individuals experiencing psychiatric impairments enter the mental health system. Social workers from the individual and family services were able to illustrate one such pathway into treatment, as they described young adults receiving social assistance and attempting to maintain themselves in the community, despite exceedingly negative social networks. They “watched” as these individuals deteriorated to the point where they came into psychiatry in an acute crisis, only then becoming eligible for illness-related assistance from the social insurance authority and referrals to the services of social psychiatry. Those who “accepted” the support now tied to a label as psychiatrically disabled often continued on until they eventually became eligible for a disability-related pension and additional

services. This was one pathway into treatment, a complex, but rich source of information when considering when and how to direct resources and supports. Explorations of other pathways might reveal additional data, including mechanisms which influence such pathways. Other young adults returned to their life in the community, ending up in a “grey zone” between the general social services, psychiatry and community life. While not a pathway into treatment, their movement in the community does follow a pattern that, while unique for each individual, offers information useful in understanding the social context of their disabilities.

*Sometimes you get the feeling that they are passed (like a ball) between in some way... there are certain individuals who go between the various programs and then they are receiving sick pay for a time. There is no beginning and no end... (FG- employment)*

*The lost ones come here when there is a lack of something else on their way (FG- psychiatry, inpatient unit)*

Another pathway into treatment was exemplified in our contact with a program for the long-term unemployed in study one. It is interesting to note from a method perspective, that information regarding pathways into treatment was often solicited from organizations and individuals who were not included in the quantitative survey, since they were meeting people at a point in their lives prior to their labelling as a psychiatrically disabled person. This was the case with the focus group involving the project for the long-term unemployed, a location where no one in the reference group had expected initially to find individuals meeting the criteria for inclusion in the study. The personnel working within that project, after having the criteria explained to them, estimated that fifty percent of their clients fit the description.

*Many have a long-term difficult life situation... and they develop psychiatric problems... for example over 5-10 years, they become more mentally ill. (FG-unemployment project)*

One client described in an earlier report on the same project (Rönnbäck 2003), who had serious psychiatric problems, received support from this program which focused on employment, but was then “motivated” by their social worker to get in contact with psychiatry, a contact that led to a confirmation of their illness and soon after an early permanent disability pension. While the individual may have needed and benefited from the contact with psychiatry, the

pathway from being in an “employment trajectory” with support, to being in a “treatment trajectory” and permanent disability status, is one worth exploring.

*If they had come in the right way/gotten on the right track in their life,  
it could have worked... with the right support from the beginning.  
(FG-unemployment project)*

The points at which the individual is experienced by the helping system as having a psychiatric impairment which may become a long-term disability, may be seen as important indicators for the timing and structure of services. Explorations and descriptions of the pathways into treatment can therefore generate critical knowledge. Once the individual has entered the helping system in some manner, knowledge of the pathways within the system can serve a similar function. McDaid et al. (2007:190) suggest the importance of attending to the “mental health needs of individuals at varying stages of the care pathway”. Their interest is in achieving “allocative efficiency” with regard to the coordination of resources, as these individuals present with needs as we have seen, that transcend the mental health system. The particular needs of the older clients identified in the study for example, often require a complex mix of physical and mental health supports, leading to questions regarding the care pathway as people age within the helping system. Priestley (2001:246) states that; “We need to consider the intersecting life course pathways of disabled people who “become older” and older people who “become disabled”. Issues of age and the care path have implications for younger adults and those I have referred to as “transition age youth” as well, especially with respect to the possibilities of prevention.

*Many have been in and out (of psychiatry when in crisis)... it becomes  
a life style, a career. (FG-dual diagnosis)*

O’Dwyer (1997) discusses “pathways to homelessness” for people with schizophrenia and the “residential histories” which might be explored in order to better understand this phenomenon. The concept of “downward drift”, as discussed in chapter three, is useful in analyzing the various pathways into treatment as well, as issues of economy, marginalization and neighborhood are known to impact mental health. While in many countries, drifting into poverty and socially exclusionary locations may be an individual journey, in Sweden, downward drift might be explored within the organizational field. Social assistance and unemployment for example may be associated with particular organizational locations, which in turn may be risk points for the development of a

psychiatric disability and an eventual long-term dependency within the mental health system.

### **Pathways to the community – breaking out of a carer as disabled**

Barnes, Mercer and Shakespeare (1999: 34) suggest, as a basis for changing the paradigm, that disability might be explored “not as a permanent position but as a “career” which is affected by changing personal and social circumstances and contexts, and interactions with others, including most significantly, professional experts.” The concept of a career with psychiatric disability should not be meant to take the place of a career within work or school, but perhaps as a replacement for reductionist views of the individual as disabled at one point in time. As individuals described their lives in the survey process, they saw themselves within a life perspective (their life world), with psychiatric impairment as a factor along with others, including prior work and relationships, and when in a hopeful context, the possibility of future life in the community. What made for a hopeful context was often their perception of a possible path towards “real life”. This path might include services of a rehabilitative nature, but also the possibility of friends, family, jobs and studies as a central part of their lives in the community.

There are a number of moves being described here as deriving from the notion of a dynamic path when describing individuals experiencing disability. The first is a move from the “permanent position” as disabled, that Barnes and his co-authors note is often the case, to one which sees the individual as moving over time through a care pathway with various needs for services and supports being relevant at different points along the way. The second move is from seeing the person in a dynamic relation with the helping system to one in which the helping system becomes aware of the relationship between the care pathway and a participatory life in the community. Beginning with study one, it became clear that users were interested in goals beyond those of “getting better”, a perspective reinforced when medical models are prioritized exclusively in community care.

*I want to take a course.... in order to break the isolation.... To be together with normal people (IN, 55 yo)*

*It feels good to meet other people and not just speak “psychiatry” the whole day... It feels like I’m part of the machinery again. (A woman working half-time on a subsidized job) (FG-rehabilitation - user)*

While the notion of pathways can be used to describe a journey into disability that may help to develop knowledge of when to intervene in a preventative manner, it also raises questions regarding the potential for supporting paths that lead out of the system and into community life.

*The concept of recovery differs from that of rehabilitation in as much as it emphasizes that people are responsible for their own lives and that we can take a stand toward our disability and what is distressing to us. We need not be passive victims. We need not be afflicted. We can become responsible agents in our own recovery process" (Deegan 2004).*

## **Pathways to recovery**

Recognizing that the majority of individuals with psychiatric disabilities are subject to mechanisms which increase the possibility of social exclusion, Parr (2008) discusses the concept of "pathways to social inclusion". With reference to the idea of "service trajectories" (Hasenfeld 1992), it is possible to consider pathways that might lead in the direction of community life, that might be thought of as "recovery trajectories". What mechanisms might facilitate recovery, and at what points in the career of the disabled individual would different mechanisms support participation, leading to the possibility of landing in more inclusive locations?

A primary feature of recovery is that it develops knowledge from the perspective of individuals with serious mental illness who are participating in community life, "beyond" the disabling aspects of their impairment. It poses questions to those who are now participating from a more inclusive position in the community and asks what helped them to get where they are. Repper and Perkins (2003 in Ramon et al. 2007:117) suggest that social inclusion is an integral part of recovery, as in their view, recovery cannot be sustained without it. Social inclusion may be characterized as engagement and active participation and as the "destination" of pathways leading to recovery. Social inclusion as a measure of recovery, distinguishes itself from medical models which see the absence of symptoms and reduction of impairment as the goal, and therefore do not concern themselves with the social context in which the person struggles with their attempts to live their life.

Antonovsky's work (1987) introduces two concepts which are relevant for this discussion. He describes health and illness as a continuum, a perspective that requires us to view illness in relation to health. "The question is no longer

whether one is healthy or ill, but how far or close one is to one end of the poles of health and disease". This salutogenic model, as opposed to the pathological model which can be argued is the foundation for medical psychiatry, "refers to the fact that all people are to be considered more or less healthy while at the same time being more or less ill" (Bengel et al. 1999:22). He also sees the individual as an agent, striving for health even as they live with the disabling effects of an illness. While Antonovsky was discussing medical illness, it may be said that he comes very close to the dynamics of psychiatric impairment and disability encountered in the surveys. All members of the community might be seen as more or less mentally healthy in such a model.

*... my fundamental philosophical assumption is that the river is the stream of life... 'Wherever one is in the stream— whose nature is determined by historical, social-cultural, and physical environmental conditions – what shapes one's ability to swim well?(ibid.p. 90)*

In Antonovsky's metaphor, we are all fish in the same river, subject to the same currents or forces, and all attempting to swim towards health. This "commonality" within mental health may be seen in the example of individuals experiencing widely differing forms of mental illness who "swim" together during a period of time. By including all community members within the same "river", it becomes possible to pose other questions. What can the helping system do to support those that have begun to swim towards an integrated self-sustaining life in the community? What supports are needed by those who are at risk of falling behind to help them swim better before they become, to a greater or lesser extent, disabled? Hägerstrand(1991:46), who introduced the concept of the time-space path, which people travel on any given day or throughout their lives, presents the dynamics of the life path as fluid and vulnerable to obstacles. "It seems to be more promising (vs. simply sampling various life paths) to try to define the time-space mechanics of constraints which determine how the paths are channelled or dammed up" (Hägerstrand 1991:146). The channels and dams which may facilitate or obstruct the disabled individuals' path through life offer an elegant metaphor for the mechanisms which may facilitate or obstruct participation.

Services designed based on a static, target group paradigm, which only expects to see the individual within the service system and not within the "river of life", have tended to neglect the "currents" of society within a context of normality. The emerging field of recovery (Deegan 1998; Topor 2001; Anthony 2002), breaks out of a reductionist view of the individual as primarily ill and in contact with the mental health system, as the research is rooted in a shift from a

short term and institutional focus to one that is long term and community-based. Rather than primarily focus on the alleviation of symptoms and reduction of pathological patterns, the focus is on learning from the individuals who have begun to “swim well”, despite a continuing psychiatric impairment. Topor (2001: 46) states that the concept of recovery “...places the individual in a broader life perspective, where their own and their social networks exertions are included”. Deegan (1998) describes recovery as a process, not a condition, a process that is the same as that which occurs within normality, not separate from it. Knowledge of recovery, as described by these authors, therefore helps to transcend the distance between the medical and social models. Without denying that the individual has an illness-related impairment, the recovery model helps to describe the path from treatment to participation in community life, a path that can only be detected by including and describing the social context in which the person experiences their disability.

Parr (2008:27) states that attention must be paid to “...potential movements from an “enclosed identity” as mental patients – where this label dignifies negative and static connotations, as traced above – to “disclosive identities” whereby embodied participation in particular spaces is seen to enable multiple disclosures of the skills, abilities, strategies, tactics, personalities and achievements of the people who participate”. As the discussion here has pointed to, there is a relationship between location and identity. Certain locations, including the day programs and group homes in which the individuals in the study resided, do not offer roles that confirm community membership. Opportunities to participate in what were often described as “real” environments, such as work places or schools, allowed for, as Parr suggests, the person to emerge as a community member, not a patient or client or resident. None of the perspectives presented here necessarily imply an abandonment of the medical model, “just a process of reclaiming the whole person from the partiality of purely medical definition” (Tew 2002).

I have presented three themes in chapters nine and ten, which developed based on an analysis of the studies presented here, within a theoretical perspective that focuses on social approaches to understanding disability. The individuals identified as having psychiatric disabilities were found in a variety of locations within the organizational field and often in marginalized locations within the community. A number of mechanisms were identified which appear to facilitate or restrict the ability of these individuals to move within the community. And finally, the dynamics as they move or attempt to move within the social landscape of the community were discussed with reference to the concept of pathways over time, which might illustrate the characteristics of that movement. In some ways, the pathways that characterized the era of deinstitu-

tionalization led from the hospital to the newly developed community-based system of care. Pathways in the post-deinstitutional era need to extend out into the community if we are to succeed with the goals of community integration and a participatory life in the community. In the following chapter, many of the aspects of the social landscape which have been described here, will be explored with regard to their relevance for developing supports and services and for future research.

## Chapter eleven – Models for service planning and research implications

Realist criticisms of research that enclose a societal issue, such as psychiatric disability in the community, within an organisational or systemic frame point to the fact that such models are reductionist and miss the complexities of the mechanisms operating in the societal context. In chapter two, I compared institutional care within the medical psychiatric model as a closed system, to the current emphasis on community-based care within the open system that is the community. Anthony (2003), in an article emphasizing the place of the person in the recovery process, discusses the “walls” that continue to divide us. His point is that while it is clear that we have left the era of deinstitutionalization, with the solid walls of the actual institutions dividing us from each other, that there remain walls, built of attitudes towards those with psychiatric disabilities, which continue to keep them out of the community. Attempts to “wall-in” (or wall out) people with psychiatric disabilities, either concretely, or by not breaking through the attitudinal walls that isolate them as patients or clients within a care system, can lead to what many have described as community-based institutionalization. And for those who have chosen to struggle with their illnesses while maintaining themselves as community members, there is a risk that our interventions and supports do not match their needs, of which we may only become knowledgeable by looking beyond the “wall”. Anthony goes on to quote a poem by Robert Frost addressing the walls that divide us; “Before I built a wall, I’d ask to know what I was walling in or walling out”. The aim of describing the social landscape for individuals with psychiatric disabilities in the community today is just this, an attempt to look at the landscape, and by venturing out, to develop an awareness of the limitations of the “walls” which contain the mental health system.

The previous two chapters have focused on three primary concepts which become noticeable when applying a social approach to psychiatric disability. The studies explored in the research have challenged a simplistic “target group paradigm” which may be understood as a relic of the deinstitutionalization era and based on a medical/individual model that focuses exclusively on patients or clients in treatment or care. Instead we have seen that the social locations and positions in the community which the individual occupies are tremendously rich sources for exploring their needs within the community. As stated earlier, the purpose of exploring social context is not to deny the importance of medical models which must address the individual’s illness and needs for treatment. It is rather to reflect the position of the individual as community member, and

no longer exclusively a patient, as they often were when receiving institutional care. An exploration of the social landscape also reveals mechanisms which help to explain the interactions between the individual, the helping system and the community, and may create obstacles for recovery. And finally, the dynamics of psychiatric disability, often investigated within the helping systems “service trajectories” that emphasize organizational coordination, seem to miss the fact that for community members, notions regarding careers or life paths, may be more helpful in understanding when to set in support.

This chapter will discuss the implications of the knowledge developed in the studies for the development of services and supports to individuals with psychiatric disabilities. The aspects of the social context described above need to be translated into concrete tasks which planners and policy makers can attend to, and not remain as a theoretical background to a historical process of change. The aim of each survey was from the beginning, to develop knowledge of the actual situation in each municipality in order to plan services for this population. The exploration of the cumulative results and the unfolding of the project, analyzed within a number of theoretical frameworks, was the aim of the research project. In this chapter however, my hope is that the two can meet, with the research results pointing to practical directions. At the same time, the methods and analysis utilized here were fairly primitive due to the mixed methods necessitated by the aim, and the collaborative work with each municipality. The last section will therefore take up implications for future research which arise from both the successes and failures in the project presented here.

## **The social landscape in the post-deinstitutional era**

Only four years after the implementation of the Mental Health Care Reform in Sweden, the National Board of Health and Social Welfare (Socialstyrelsen 1999b) stated in their review that;

*We are missing descriptions today of psychiatrically disabled individuals in the community that build on the characteristics of disability and the difficulties that are brought about in attempting to “live like others”*

A continuing emphasis on exclusively medical models that focus on psychiatric impairments, rather than one that addresses the environmental or social context for describing disability, has been presented as an obstacle to developing the descriptions aimed for in this statement. One consequence of the medical model has been that it focuses primarily, and quite appropriately within its

framework, on the meeting between the mental health system and the individual as client or patient. While the meeting has moved, from the institution or hospital, to the community, I have argued that a great deal more has happened, as individuals experiencing psychiatric disability have not continued to lead their lives within this institutional paradigm. Bacharach (1997) states that; "Deinstitutionalization involves more than changing the locus of care; it is a social process with secondary consequences". Consequences not only for the lives of those who have been deinstitutionalized but for those who have never used psychiatric hospitals to the same extent, despite having many of the same needs. Pilgrim and Rogers (2005:180) raise the continuing confusion regarding the term "community care" and the lack of clarity over the ultimate goals of such a policy direction. In practice, according to them, community care currently refers to the fact that "mentally disordered people are receiving care in "non-asylum settings".

Deinstitutionalization, despite many of the more ambitious intentions which were presented in chapter one, has primarily led to a focus on care in the community, and while the location has changed, the focus would seem to be the same. The model, attitudes and organizational structure of the mental health system are most often defined, I would argue, relative to institutional psychiatry. As Bacharach (1997) states, in the days before deinstitutionalization, "service planners had a strong tendency to group all mentally ill people together and to ask in effect, "What ought we to do with the mentally ill?". The institutional answer was to collect them in one physical location. The answer within the era of deinstitutionalization was to still "collect them", in clinics and programs in the community, but still with an expectation that we could "do something" with them. What I am suggesting, in both the title of this thesis and the discussion throughout, is that the geography has changed. The evidence for this change is seen in the locations and positions which individuals with psychiatric disability have occupied in the community. What began as a gradual dispersal, with attempts to capture the few "chronics" who fell between the chairs or cracks, has become a challenge to the entire structure of the mental health system. This is not however a chaotic escape from the community-care model, but would seem to be based on choice in many cases and have positive aspects as well. Individuals experiencing serious mental illness are striving to live in the natural community, minimize the disabling effects of their impairments and participate in work, school and social life. Whether or not they succeed at this point in time, this is where they are, and where the literature seems to indicate they are on their way, based both on their own agency as community members and in fact on the original intentions of the community mental health model. It is this situation, this geography, which I am choosing to refer to as the social

landscape in the post-deinstitutional era. By post-deinstitutional I mean a paradigm where support to individuals with serious mental illness is discussed, not relative to the institution, but relative to a participatory life in the community. In other words, the era of deinstitutionalization was evaluated by our ability to create a support system for the mentally ill in the community, relative to the institution. The post-deinstitutional era should be evaluated based on our ability to minimize the disabling effects of mental illness, by definition specific for each individual, and support participation, relative to the community life that should be available to all.

While broadly declaring the end of an era, and the need for a new paradigm, may be seen as overstated, the change has been in process for many years and has been discussed by many authors (Leff 1997; Sharfstein 2000; Drake et al. 2004). The patterns that emerged in the data in this project however, when viewed within the framework of theories related to disability and social approaches, may be used to illustrate the potential applications of such knowledge. Specifically, by charting the locations and dynamics that emerged throughout the studies, a picture or map may be created that can be useful in suggesting targets for planning and delivering supports.

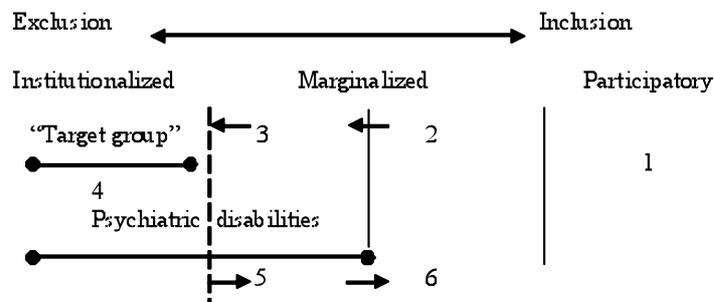
## **Mapping the landscape**

In this final illustration, there is a move to the implications for service development and planning based on a model which socially locates the individual within the whole community, and which can position them with respect to a participatory life in the community. It is also intended to reflect the time dynamics which represent both the career of the individual as disabled and the potential pathways that may indicate life-span related needs. A number of the ingredients in the illustration have developed during the various studies, and specific terms and structures have changed in accordance with my own interpretation of the findings over time. All of the concepts utilized have been discussed either from a theoretical or empirical standpoint in previous chapters.

Based on discussions of social exclusion and social inclusion, a continuum is suggested which relates to the breadth of possible locations in the community. Three broad areas are more specifically described below this continuum. While not included in illustration five, these have been added based on the theories presented in chapters nine and ten, which provided a structure for describing the empirical findings. Grey zones, while having additional characteristics, exist for the most part in what might be seen as a marginalized location in the community. Those found in what respondents described as grey zones, were often “in-between” services that might have helped them to either move towards a

more participatory life, or led to comprehensive care within the mental health system. The “target group” is presented here as a description of those who have primary support within the mental health system, a “liminal” position which has been described, due to the lack of opportunities for recovery, as likely leading to a life that might be described as institutional. The line labelled psychiatric disability, while not objectively measurable, as in diagnostic models, represents those individuals who were identified as meeting the criteria utilized in the studies and based on national guidelines.

*Illustration 6; Mapping social locations in order to target supports*



The numbers in the illustration each relate to the focus of supports in a specific location that would seem to show potential for being useful in developing services, and are described below. The “zones” which are described as marginal or institutional are intended as relative to the first, a participatory life in the community. Participating in community life, as the goal, is not meant to imply that the person is free of psychiatric impairments, rather that they have recovered to a participatory role, despite the possible presence, or periodic presence, of symptoms. This definition is based both on the recovery literature and the concept of “compensated psychiatric disability” as described by the National Psychiatry Coordination (SOU 2006:100). There is some “distance” between these two definitions however that I will not attempt to resolve here. Recovery, as described by many of the authors presented above, would be used to describe even those who are fully participating, while the intent of the commission’s description was focused on those who continue to need mental health supports in order to maintain their functioning, and would likely experience a more serious disability if specialized supports were removed. The zones also relate to the

levels of participation utilized for assessing need in the third study, described in chapter seven. While further work is required in order to more accurately describe these levels of participation, the primary intent here is to provide a graphic description of positions and locations that are relative to community life, and not solely to the mental health system. In other words, in comparison with the initial illustration which failed to account for the complexities which emerged in the studies. It is also possible that in an open system such as the community, evolving descriptions of mechanisms and dynamics that describe tendencies related to psychiatric impairments and disabilities will have to suffice. The suggested categories of interventions based on social location include;

- 1) Social inclusion – “Inclusive communities”
- 2) Generic community services with links to specialized supports
- 3) Preventative services and measures – general social and mental health services with specialized supports available.
- 4) Rehabilitation readiness services – Exploring opportunities for supporting recovery (planning and information) and maintaining support/security
- 5) Development of opportunities for recovery & provision of rehabilitation supports
- 6) Specialized supports which focus on maintaining and developing roles and generic community services

While the numbers are not intended to indicate priorities, it is possible to see position one, which may be seen as a participatory position, as the last focus that we often think about, and at the same time the first that we should attend to. It is in many ways the aspect of community life which mental health professionals are least familiar with, since individuals who are participating have never been focused on as a target group. At the same time, from a disability perspective, that sees the efforts of the community as a crucial component of the interaction between individual impairment and environmental conditions, it is one that should be prioritized in the post-deinstitutional era. In contrast to mechanisms which promote social exclusion, the focus here, as suggested above, might be to define and develop mechanisms which promote social inclusion. An “inclusive community” that actively promotes social inclusion has the following characteristics, as outlined by the National Council on Disability (2008:11);

1. *Provides affordable, appropriate, accessible housing*
2. *Ensures accessible, affordable, reliable, safe transportation*

3. *Adjusts the physical environment for inclusiveness and accessibility*
4. *Provides, work, volunteer and education opportunities*
5. *Ensures access to key health and support services*
6. *Encourages participation in civic, cultural, social and recreational activities.*

The second two potential focus points, positions two and six, both indicate the supports that might be necessary within the initial stages of downward drift (position two) or later stages of recovery (position six). The results of the studies do not directly address these positions in the community, since these individuals were not a focus of the project. At the same time we became aware of them as either in the initial stages of struggling with a psychiatric impairment or having come far enough in their rehabilitation and recovery to leave behind an identity/position as psychiatrically disabled. Examples include the long term unemployed who, as they became more marginalized and their psychiatric impairments worsened over time, might end up risking serious disability. Clients of the rehabilitation services in study one, who described the loss of specialized mental health supports as they recovered to a more participatory life (subsidized work for example), are the individuals who might also require support at this location (position six). Descriptions of these groups indicated that while they might be actively receiving supports from generic community services such as the employment service, there was a need for specialized support, either to prevent a worsening of their condition or to help maintain fragile connections to a participatory role in the community.

In a similar manner, positions three and five, exist in the same location in the community, at the “border” of the mental health system, but indicate different directions or dynamics. Position three may be described as the “risk group” in study two, while position five represents the “recovery group”. These are both sub-groups or populations that were described as being disabled by their psychiatric impairments, and either moving towards or away from a life within the mental health system. Both have been described in Chapter six, and clearly require further study. At the same time, it is possible to suggest that both of these groups, and the many who do not clearly fit either description, yet find themselves in a marginalized location and struggling with a psychiatric disability, require more support than they currently receive. For the risk group, these may be broadly defined as preventative services, and for the recovery group, as rehabilitation or recovery oriented. While some specifics will be offered below, it is important to note that both of these groups may be seen as at risk in that in the “borderland” between mental health and generic community

services, their needs as we have seen, are particularly susceptible to fragmentation by the organizational actors in this field. It is also possible to clearly focus on their position as one in which they risk labelling if they drift into the mental health system, and abandonment, despite their psychiatric disability, if they avoid or leave, the specialized service system.

Finally, position four is the traditional location for the target group, those who are psychiatrically disabled, and clients or patients within the mental health system. While receiving a great deal of treatment, care and support in this location, they have been described as excluded from community life, often participating exclusively in activities determined by their disability label. The risk for them, as described in the discussion of liminality, is that without real opportunities for recovery, supported by active rehabilitation services, they can easily end up living an institutional life, despite their physical location in the community. It should be noted that the intention here is not to imply that all should move on, just that they have a clear opportunity to, one that they are aware of, and is continually available over time. Parr (2008:182) has described this location as potentially a “zone of dependence”, if more participatory positions are not actively explored and supported.

While the locations indicated in the illustration might be used to discuss sub-groups of individuals that have particular needs based on their position in the community, the intent is not to suggest a static picture. As described in chapter ten, the results of the studies pointed to disability as a dynamic experience, subject to the organizational structures of the helping system, but also to the environmental attitudes and opportunities or restrictions, and the will of the individual. While these characteristics of the social landscape must be explored, it is equally important, as Hägerstrand (1991) has argued, to look at the time-space paths of that the individual life may follow. The model is intended to describe a landscape, encompassing the entire community, and within which the individual travels throughout their life as a community member, at various points experiencing a psychiatric disability. Strauss and his co-authors (1997:5) have described, after following the course of twenty eight patients with a psychotic disorder over time, a set of longitudinal principles. They conclude that these individuals follow unique, non-linear paths, with various phases that are influenced by their meeting with the environment. The implication of such knowledge is that while the actual time-space path for each individual would be unique, by understanding the landscape within which they live or “travel”, we might more effectively develop relevant supports.

Barnes, Mercer and Shakespeare (1999: 33) present a similar concept to that suggested here as they describe three levels of analysis which might contribute to a “sociological map” for investigating disability. These include, the individ-

ual, where the individual experience of disability can be explored, the social, which would explore the social labeling and categorization of disability as well as the culture that this process creates, and the societal, where the development of social welfare systems and the politics of disability might be explored. While the map presented above might be seen as “horizontal”, following the life path of individuals and groups over time, the sociological map suggested by these authors, might be seen as a “vertical” description of the various levels of reality that must be understood in order to understand the patterns that we have seen “on the ground”. Many of these levels of analysis confirm the mechanisms which were discussed in the previous chapter and can potentially contribute to an expanded understanding of disability in the community. In such a complex system, graphic attempts to describe the dynamics will always fall short, and yet it seems clear that increased knowledge of the social landscape is a prerequisite for change. The concrete application of the final illustration, with regard to the municipal responsibility for planning services based on the living conditions for people with psychiatric disabilities is as follows. 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 question becomes; where and when can the individual make best 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 (Rosenberg et al. 2008:16). The following discussion will address a number of more concrete implications of this theoretical model.

## **Community-based needs – Participation-relative positions**

*When mentally ill people are asked about their needs, the answers are usually no different from others; they want a decent place to live, a job or productive way to spend their time, and adequate income and friends. Judy Chamberlain (cited in Carling 1995:58)*

As has been stated throughout this work, the focus for the deinstitutionalization era was the organizational field comprising the hospital or institution and the system of community-based care that developed in its aftermath. The needs of the individual, despite this change, have continued to be defined by this impairment-related relationship to the mental health system. In the post-deinstitutionalization era, there is a demand that we understand the disability-related needs of individuals with psychiatric impairments, relative to their lives

in the community. Such a framework for defining need might be described as participation-relative, as described in chapter seven and seen in the illustration above. It was suggested, based on the results of study three, that where there are a significant number of individuals with psychiatric disabilities, who have a capacity and desire to participate more actively in community life, there is a clear need to attend to the obstacles to that participation. Even however, in cases where the person may need further individual support for their impairments, we have seen that many, as in the quotes presented here, define their needs in relation to the roles that they desire in the community.

*I need support to be out there with normal people (IN,55 yo)*

The need is relative to the opportunity to participate socially in the community. While they may also need to take medicine or receive supports to maintain a budget, it would be very difficult for us to prioritize one over the other. Recovery and rehabilitation literature (Anthony et al. 2002) even suggest that for example, a more satisfying social life could reduce the need for other individual supports. In another example of participation-related need, even personnel from medical psychiatry made the point that in one municipality where there was a clearly defined rehabilitation program, the individuals saw using the program as a means to an end, which was a chance to participate as a student in adult education. Again, a need defined by a wish to participate, rather than one based on individual impairment-related need.

*They choose the rehabilitation program because they get to go to Komvux (the adult education center) (FG – psychiatry)*

In these simple examples, it is also possible to raise the following point. Some of the results suggest that if mental health programs, such as the one above, would be more attentive to and active in satisfying the community-based or participation-relative needs of these individuals, they might be more willing to align themselves with these services which would also support their individual impairments. By concentrating on one aspect, the individual/linear that has been described above, we may have missed the opportunity for contact with many individuals who also need specialized mental health services in order to reach their community-related goals. A move from assessing need based exclusively on individual, illness-related impairments to one which includes the social context, has implications for the individual's identity within the helping system as well. Barham and Hayward (1995:137) suggested that we should prioritize "personhood rather than patienthood". Many of the results have shown that

the avoidance of mental health services may be related to the exclusive attention to “patienthood”, and that it is this loss of identity, rather than the help itself, that is being rejected.

The notion of “personhood”, a term which reinforces the person’s community membership can be related to the user movement’s demands for the right to participate in community life and to ideas of citizenship, equality and human rights for disabled people (Ingstad and Whyte 1995; Beresford 2002). Leff and Warner (2006) challenge us to see people with psychiatric disabilities as “fully human community members”. Parr (2008:165) stressed the importance of supporting individuals in “disclosive geographies” where they might be experienced by other community members as able. Workers from Supported Employment programs are aware of the potential of these meetings with community members, as they often witness the positive reactions of employers to the abilities and motivation of their clients in the work setting (Rosenberg 2005). Even though many of the personnel working in day and housing programs appreciated the abilities of their clients, the individuals themselves remained invisible from the natural community.

As will be suggested below, the advantages of an expanded perspective on need, one that prioritizes the participation-related needs of individuals with psychiatric disabilities, extend to the formal helping system as well. Carling (1995:22) makes the point that with “shrinking public resources” we cannot afford a system that fosters dependency. When the natural community and its public resources ignore or exclude the needs of these community members, they are not only doing an injustice to the individual, but to the helping system which becomes overburdened in attempting to satisfy community-related needs. Should we be paying municipal psychiatric staff to play Bingo with elderly individuals, who would have an improved quality of life if they were participating in normal activities with their peers? Promoting social inclusion, as a focus for the mental health system has in fact many advantages and is one that has deep roots in the Social Services Act and disability policy. A disability model, which should attend not only to the impairment related needs of the individual, but to the environments in which they live and want to live their lives, would however, place many new demands on the mental health system as well as all actors involved in the general welfare of the community.

## **Surveying the landscape**

Since it is in many ways a practice we are not familiar with, metaphors related to the notion of “surveying the landscape” are difficult to avoid. It is necessary however at this point, to bring in the concept of mechanisms operating in the

social landscape, and either restricting or facilitating the individual's ability to participate, that were discussed in the previous chapter. The image that comes to mind is a pinball machine (flipperspel), filled with "mechanisms" that may impede the motion of your ball, send it to a "black hole" that will be hard to leave without the right knowledge, or even put you "out of the game". On the other hand, with some knowledge and/or helpful assistance, many of the mechanisms can reward you or facilitate your collection of points, the further you advance, the greater the return on a successful hit. When not hitting the right mechanisms, the game can be very slow and unrewarding, and yet if you find the right ones it can move fast and be very satisfying. I choose pinball rather than sport metaphors, since many of the processes which respondents described were activated "automatically", perhaps bureaucratically, but without a conscious intent of creating obstacles for these individuals. The majority of the actors we met in the project sincerely wanted to help, were distressed over the poor results, and yet were often part of the apparatus that stifled progress. All metaphors have their limits, and this one falls short in the question of agency (who shoots the ball?), but for those who have played pinball, there is a certain "scanning" function that is critical, the ability to see the whole surface in order to anticipate obstacles and target opportunities. Back in the landscape that is the social context for psychiatric disability, an expert group in Scotland produced a document describing comprehensive needs assessment in mental health services (MH Reference Group 2001). In addition to the clear need for individual assessments such as CAN (The Camberwell Assessment of Need), they suggest that in order to anticipate emerging needs we need to engage in "horizon scanning" and "community profiling". It isn't enough to see the individual, we need to "look upstream" to tackle the causes of mental ill health. I would expand on this notion, and suggest that we also need to "scout" for possible paths to recovery. Developing knowledge of the social landscape may be seen, in its applied form, as a survey of the obstacles to and possibilities for social inclusion. While it is important to be aware of mechanisms which exclude people, it is equally important to be aware of those that might facilitate social inclusion.

Some of the results which led to a discussion of mechanisms that might restrict participation in the community have included for example, the rule systems which forced individuals to decide between financial security or attempts to work. Other mechanisms were traced to the organizational field, where categorization reinforced labelling and fragmentation of the clients needs and was evidenced by the silo effect. Finally, one of the most powerful mechanisms operating in the landscape was stigma, encompassing a wide variety of attitudes, beliefs and actions which might limit opportunities for recovery. When these

were initially presented however, in the focus groups and survey responses, the specific issues were often presented as what might be termed, in a closed-system research paradigm, as “confounding variables”. In other words, institutionally created dependency, the fragmentation of need, and fears of attempting to engage in community life, were seen as confounding the aim of the mental health services, which was to support the individual. Now, having taken the specific obstacles and presented them within a theoretical framework that sees the environment as a focus for developing supports, it is time to revisit them as essential aspects of the community in which these individuals live. In the open system that is the social context for psychiatric disability, these confounding variables now become targets for intervention.

*Interventions that focus on the actual performance context of an individual may address either capacity-improvement or else seek environmental modification, either by eliminating environmental barriers or creating environmental facilitators for expanded performance of actions and tasks in daily living. (WHO 2002)*

The WHO’s ICF illustrates the move from a theoretical appreciation of the social context to one that is intervention oriented. By targeting the person in their environment it is possible to focus on specific interventions that would impact their lives as community members. The question of individual need is also influenced by this perspective since the individual’s capacity is relative to the specific environment in which they are attempting to function. One of the criticisms of impairment related assessments of ability is that they do not include an awareness of the environmental barriers or facilitators that may impact the individual’s ability to function in a specific environment. One example which emerged in the studies concerned the incongruity between the administrative routines which steered the timing of rehabilitation interventions by the social insurance and employment authorities and the “recovery schedule” of the individual. Despite a serious illness such as schizophrenia, there was a belief by these workers that individuals could become comfortable in a given work environment given adequate opportunity to do so. Sufficient time to adapt to a specific work environment, with appropriate support in the environment, directed towards both increasing the individual capacity and accommodating the work place, were the interventions which they identified as crucial to success. Individual assessments that focused exclusively on impairments, and rules that were not adapted to the specific needs of people with psychiatric disabilities, were obstacles that would need to be targeted. Natural supports in the specific workplace which might emerge over time, as co-workers for example came to

know the individual or their particular abilities were matched to needed tasks, were potential environmental facilitators.

Another obstacle in the social landscape may be illustrated by the earlier discussion of neighborhood. The frequency of substance use and abuse by individuals with psychiatric disabilities has been discussed as a significant issue. Staff of the dual diagnosis program in study one pointed out the risks to their clients who often found “social inclusion” only in the company of drug users, many of whom had violent or criminal behaviors as well. Housing areas where the majority of the residents are either immigrants or “social cases” are other locations where individuals who are particularly fragile due to their impairments may be at risk. While the actors of the mental health system may have little ability to directly impact these situations, an awareness of the individual’s position in the community can point the way to alliances with community services and the development of alternatives. Focus group members in the third study described the necessity of working more closely with the police and voluntary sector for example, in order to develop alternatives for young adults who rejected psychiatric programs. Case managers, both those we met and in many descriptions of ACT (Weeghel 2002; Salyers and Tsemberis 2007), describe the importance of contact with landlords and other local actors, in order to support a stable housing situation and possibilities for early intervention.

While many in these studies have described stigmatizing attitudes as an obstacle to a participatory life in the community, recommendations as to what to do have been fairly general and primarily focused on education. Thornicroft (2006), one of the foremost researchers in this area, argues that a core focus on stigma, rather than on discrimination and prejudice, has kept us focused on attitudes and not actual behaviour. The National Council on Disability supports this clarification; “While stigma focuses on attitudes, there is a strong argument to be made that more attention should be paid toward discrimination—the way in which stigma is operationalized”. Operationalized stigma, or concrete examples of discriminatory behaviour, may clearly be seen as an obstacle to a participatory life, and potential target for planning interventions. For example, the seniors who might have had the opportunity to participate in the retirement activities of the community but were not welcome, were experiencing discrimination based on stigmatizing attitudes. A politician who was present at one of the survey presentations reacted angrily and publically to this information. He stated that voluntary organizations in the community who received public funding, should lose that funding if they systematically discriminate against people with psychiatric disabilities. While some interventions may require political measures, there may also be instances of individual discrimination where the

support system can directly intervene by developing contacts with community members outside the mental health system.

As seen in the empirical results, obstacles to participation are fairly easy to find, with the primary challenge being to describe them concretely and target them in planning. Surveying obstacles, in order to describe the social context in the post-deinstitutional era, would seem to be a logical addition to inventories of individuals and their illness-related needs. The social landscape includes however not only obstacles but mechanisms that may facilitate a participatory life in the community. The challenge and opportunity to develop and support these paths is taken up in the next discussion.

### **Developing natural resources in the community**

By socially locating the individual within their community, generationally, and in relation to their role (or desired role) as community member, we can more effectively develop and target individual supports. We may also, based on their position in the community, explore and develop environmental supports, where and when they are needed. Developing strategies to break through or navigate obstacles in the community for the individual is a natural outcome of a person-in-environment perspective on disability.

For personnel within the mental health system however, opportunities for exploring the community with their clients were often limited by the structures within which they worked. Some staff working in specialized psychiatry stressed the need to “work out in the community” in the context of the “social complications” that frustrated their efforts to treat their clients. They were trapped however within specialized psychiatric structures, both physically and professionally, despite an awareness of community-based needs. While hospital and clinic-based locations for delivering psychiatric services are somewhat expected, there was a similar expression of structural entrapment among the personnel within municipal psychiatry, who often complained that they had no time to leave the group home or day program in order to explore opportunities for their clients in the community. “Coverage” of the house or program was a priority over the community-based needs of their clients. Another issue, especially for supported housing personnel, was the individual model of care that the municipalities had seemingly inherited from specialized psychiatry. Services were granted to individuals, based on individual assessments of need and delivered individually. Personnel complained that there was no time allocated to the general development of community resources, a development process not necessarily tied to any one individual. While they could follow a client to the store to shop, they had no time for example, to schedule a meeting with the director

of an adult education center to discuss options that might be accommodated to the needs of many of their clients. And finally, there was often little knowledge or competence as to how to develop community resources, as the vast majority of personnel are trained in direct care, and may not have the skills or interest to advocate for this population in the community.

This last point speaks to another aspect of the focus on the social context, resources may be developed, not only for the individual, but in order to contribute to the social inclusiveness of the community by modifying resources and providing supports. Parr (2008) describes the importance of the “inventive uses of mainstream social spaces”, where the individual can be understood outside of the “institutional spaces” where we usually conduct our assessments. These spaces or locations also present an opportunity for the individual to “reclaim a lost or institutionalized civil self”. Group home personnel, who marvelled at the change in their clients when on their one week vacation together in the mountains, provide a clue as to the potential of mainstream or natural social locations for growth and recovery. Leff and Warner (2006:84-86) point to the importance of contact and education in order to increase the accessibility of alternative (to the mental health system) community locations. They include accessible workplaces, social associations, and other natural locations which would reduce the systems tendency to “herd” all with psychiatric disabilities into categorized activities where they can then be occupied. The concrete implication can be illustrated with a simple example reflecting many principles of rehabilitation and recovery. A group home worker might regularly follow along to an activity organized by a local church group, a supported housing worker might be given responsibility for creating a working relationship with a sport club or a cultural association.

The Future Vision Coalition (2008), a multi-organizational network in Great Britain, argues that the mental health system must support people who use services to participate in mainstream leisure activities, occupations and social networks, which are not part of “mental health services”. Leff and Warner (2006) see a focus on preserving and developing natural supports in the community as a cornerstone of recovery and inclusion. The preservation of natural support networks may be seen as an antidote to downward drift. How can we concretely help individuals at risk of a long term psychiatric disability, to preserve natural supports, so that they maintain their position in the community, and we (the helping system) do not become responsible for rebuilding these aspects of their lives, after these have disappeared? It may be equally important to inventory and develop supports for the resources available to an individual, as it is to inventory and develop supports for their individual impairment-related needs. The National Council on Disability (2008) has also used the

term “natural supports” to refer to those non-institutional supports, existing in the community, not provided by the helping system, and available to the person based on community membership and not psychiatric impairment.

*The authorities don't allow the user organizations or other voluntary organizations to be involved and don't let them participate to the extent that is needed. They would win so much if they let us come along in some corner, in some way. (FG-community)*

As the focus on the social context led us farther out into the community, we began to involve representatives of various community groups and associations. As the quote above reflects, there was a feeling among many, including even the user and family associations, that they were not really welcome in to the process of planning and developing services. Many commented that the chance to sit down together, users, social and sports associations, church personnel, police, the Red Cross, etc. was unusual and that the energy and potential in the room was quite extraordinary. While our purpose was to gather information, the participants were much more action oriented and wondered why the municipality did not take the lead in organizing and coordinating these potential resources.

Once again, the mental health system seemed to be missing the potential to tap the resources available in the community, resources tied to the individual's community membership, rather than their psychiatric “patienthood”. These are not just resources that might supplement those offered by the system, but natural supports which may be more relevant to the needs we have seen than many of the mental health systems attempts. In municipality six, a church group invited the municipality to make young adults aware of an evening social activity, as they understood from the conversation that these young adults did not want to be associated with psychiatric services, and that their need for social opportunities was evenings and weekends, not nine to five programs. Scanning the community horizon for such opportunities might be seen as an essential focus for the mental health system, as many of the needs they have complained they cannot meet, might be more appropriately addressed by the creation of new opportunities. One additional example was provided by a cooperative project in study one, whose personnel, a mixture of users and professionals described the advantage of this model.

*We have built respect through the products.... The meeting with the customer... is a natural meeting with the community (FG-cooperative)*

A cooperative such as this, may be seen as operating in another type of grey zone, but acting as a facilitating mechanism for participation. While many customers knew that this was a business that had some connection to mental health, they didn't know who was playing what role, "patients" were running the business and personnel were selling fabrics. Based on the location of the project, they were able to adapt roles which were experienced as participatory, based on the response of the customer.

Before leaving this discussion regarding the importance of focusing on the development of community resources, it is relevant to briefly describe some program models which build on this direction. In addition to case management models which focus on supporting the individual in the community, there are also models which focus on community resource development. Rapp (1998) has described a strengths-based model of case management which views the community "as an oasis of natural resources, where social connections are critical". Closely related to this approach are rehabilitation models which have been available but not implemented to the extent that might be expected given the intentions of these reforms. Two are presented here, as examples of how many of the concepts that have been presented may be integrated within a vision for providing services. The first is Community-based rehabilitation, a strategy described by the World Health Organization, and often discussed in connection with undeveloped countries who do not have the resources to build a comprehensive mental health system, and therefore must rely on community resources (Rosenberg 2002).

*Community-based rehabilitation is characterized by the active role of people with disabilities, their families, and the community in the rehabilitation process... CBR enlarges the concept of rehabilitation to include all of the services that assist disabled people to develop their abilities. It seeks the integration of the interventions of all relevant sectors – education, health, legislative, social and vocational- and aims at the full representation and empowerment of disabled people, promotes interventions in the general systems of society, and adaptations of the physical and psychological environment that will facilitate the inclusion and the self-actualization of disabled people. (WHO 1994, available from; <http://www.who.int/disabilities/cbr/en/>)*

The integration of specialized knowledge into general health and social welfare services and the utilization of non-specialist personnel, would require that specialists spend more time developing simple interventions that can help, and saving more time for supervision and support of non-specialists (Murthy and

Kumar 2008:101). While these authors are again referring to the situation in developing countries, their ideas resonate with many of those expressed in models of community-based care. In Sweden, which has one of the strongest publically funded primary care sectors in the developed world, the lack of success in developing and investing in a primary care model for supporting mental illness in the community is particularly striking.

The next model, described as psychiatric rehabilitation, and most closely associated with Boston University, is closely related to the field of recovery. While I have suggested that we may help make individuals with psychiatric disabilities aware of possible pathways to recovery, there remains a question as to the role of the mental health system and its workers, in supporting people on these paths. Recovery is not something we can do for the person or to the person, it is the task and experience of the individual. Rehabilitation services on the other hand, are what mental health programs and service providers do (Deegan 1988; Anthony 1993; Davidson 2001).

*Psychiatric rehabilitation promotes recovery, full community integration and improved quality of life for persons who have been diagnosed with any mental health condition that seriously impairs functioning. Psychiatric rehabilitation services are collaborative, person directed, and individualized, and an essential element of the human services spectrum. They focus on helping individuals re-discover skills and access resources needed to increase their capacity to be successful and satisfied in the living, working, learning and social environments of their choice. (USPRA 2008, available from [www.uspra.org](http://www.uspra.org))*

A specific model which has developed directly from the principles presented here is that of Supported Employment, a model which has shown itself to be more effective than traditional vocational models (Secker 2001; Burns et al. 2007). There has been a counterintuitive shift in the evidence, from “traditional” models, which focused on training the person in a segregated environment before helping to develop opportunities in the communities, to one that directly supports the individual’s wish to be employed, regardless of impairment. This shift, from “train-then-place” to “place-then-train” reflects the need to move from the institutional remains of the era of deinstitutionalization, to a post-deinstitutional emphasis on the community as the location for supporting participation. Program models such as these emphasize the relevance of the social location for providing services. They take a significant step away from the traditional locations for providing mental health services and out into the neighborhoods and workplaces where these individuals are and want to be.

Parr (2008) reminds us that these “geographies”, those beyond the mental health system, while providing spaces where people can develop as community members, are not magic and also require that the support follows. As case managers and job coaches know, leaving the familiar structures of the clinic, group home or day program, demands new skills and a belief in the rights and potential of these individuals to participate actively in the community.

## **Implications for policy and service planning**

*Mental health policy should be driven not by existing organizational forms but by the goal of meeting individual needs. (The Future Vision Coalition 2008)*

This statement mirrors the points made in chapter two by the New Institutional theorists who argued that organizations reflect the “myths of their institutional environments instead of the demands of their work activities.” (Meyer and Rowan 1991:41). I have argued that the fact that the locations and needs of the individuals we identified did not match the structures of the mental health system can be attributed to this organizational dissonance. I have also suggested that the actors within the mental health system are still operating in what might be termed as the institutional environment of the deinstitutionalization era, when the geography in focus was that between the hospital or institution and the new structures for care in the community. The demands however, of people experiencing psychiatric disabilities in the post-deinstitutionalization era have shifted, and they are operating in a new geography, one that exists in the space between the community care system and the natural community. Their needs are participation-relative, and not properly assessed within an exclusively medical/individual model. What then are the implications of this contrast for social policy and service planning?

Carling (1995:57) describes the tendency of formal services, such as the mental health system, to take on the responsibilities of other sectors of support, including generic community services, self-help, and even family and friends. There is a corresponding tendency for individuals experiencing these disabilities to lose contact with their natural support systems and disappear into the formal mental health service system. This is clearly a resource question as well as one of quality of life, since the mental health system is always challenged to prioritize resources for those most in need, and these needs are often related to either the acute phases of a mental illness or the long term disabilities that may result. Goldman and Grob (2006), based on an extensive review of policies related to allocating resources within the mental health system draw the follow-

ing conclusion. “Programs have used diagnosis (or in the case of the municipalities, diagnosis-like categorization mechanisms) to allocate scarce resources on the basis of severity and need, but this approach has not been satisfactory. Newer methods of managing scarce resources hold the promise of dealing with an enduring tension in mental health policy – how to provide the right services to those “most in need”, to improve their quality of life and to support full participation in the community.” The question of resource allocation is closely connected to the manner in which services are planned and developed. Paradigms which prioritize illness or impairment will likely not be able to “afford” to invest in developing supports to community participation, a result which is confirmed in the studies presented here. Group home personnel did not have the time to assist clients in developing participatory roles, and rehabilitation oriented programs were clearly secondary to those supporting individual needs in the home and program-based activities. In order to liberate resources in the form of personnel for example, it may be necessary to focus on utilizing the services and supports connected to their community membership as well.

While coordination between psychiatric and social psychiatric services has been a primary focus in Sweden, the discussion is usually framed within the context of organizational boundaries rather than the pathways which individuals requiring differing levels of care and social services might need as the focus shifts from the health care system (with social psychiatry as a municipal partner) to generic community services. McDaid and his co-authors (2007), in an article entitled “Moving beyond the mental health care system”, focus on questions of allocating resources at a time when new patterns of need, resulting from changes in policy and societal values, challenge current structures for delivering services within the health care sector. Allocative efficiency, according to these authors, is best achieved when funding and resources follow the individual over the borders between health and non-health sectors. Looking specifically at the example of Sweden, the results presented here suggest that, municipal social psychiatry operates within, if not the administrative province of the health care sector, in many ways a health care culture just as disconnected from generic community services.

*We believe a more realistic and helpful approach is to position mental health along a continuum where everyone has varying levels of mental health need at different times in their life, and where some people will need formal intervention and support to help them regain a good quality of life. (The Future Vision Coalition 2008)*

At points in the continuum, represented by points two and six in the illustration presented above, they suggest focusing on “generic community-based services which include some specialist mental health elements”. The results presented here, which pointed to the fact that we found individuals with psychiatric disability at various locations in the helping system and community, with different needs at different points in their lives and careers, support such perspectives on planning, developing and funding services. While the situation in a social welfare state such as Sweden may be complicated by the number of authorities, each with legislated responsibility areas, there is also an availability of support for all citizens which might be taken advantage of by reframing the person with a psychiatric disability as a community member. For example, the single mothers we encountered have a right to family services, the obstacle being primarily attitudinal and related to categorization and the fragmentation of need. In fact it might be argued that there are a wealth of social welfare services, including the general social services, schools, adult education and employment, immigrant services and others, that must either work cooperatively with the formal mental health system or begin to develop expertise in prevention and support related to psychiatric disability. Such a shift in policy and practice would support a focus on developing supports, offered at the right time and place, and therefore more relevant to the community-based needs that these individuals experience.

## **Research Implications**

Theoretical perspectives on disability, including the social approaches applied in this project, can contribute to an understanding of the situation for people with psychiatric disabilities in the community today. They can also point to directions for further research which can inform the development of policy and services. In commenting on the potential for developing new knowledge in the field, Parr (2008:63) states that; “Some of the more exciting developments arguably lie in fostering new understandings about how social and physical environments beyond health services might be utilized creatively to engage all people with mental health difficulties (diagnosed or not) in the pursuit of psychological health”. The disability paradigm, which focuses on the person in their environment, demands a greater understanding of the environment. The social and physical environment which comprises the social landscape in the post-deinstitutional era, and the mechanisms operating in this landscape, provide a challenging field for researchers to focus on. Describing the social context, as has been suggested here, is essential for understanding the help-seeking behaviors of people with psychiatric impairments as well.

*People's management of their lives will vary depending partly on the nature of their impairment, their self perceptions, their immediate social and physical context and the broader social, cultural, economic and political environment (Butler and Bowlby 1997:421 in Mulvaney 2000).*

Broadly speaking, it is possible to summarize the research suggested here as focusing on three areas related to the experience of disability. These include explorations of the helping and natural communities in which these individuals live their lives, of the dynamics of the individual experience as they age and pursue life goals as well as become disabled and recover, and finally the mechanisms which describe the meeting or interaction between these individuals and the structures/actors within the particular environment. With regard to the community environment, Fox and Kim (2004:324) suggest looking at disability in terms of healthier communities rather than healthier individuals. This reflects the ideas presented earlier regarding inclusive communities, and points to the need for research which focuses on mechanisms that promote social inclusion. Leff and Warner (2006:165) suggest that the task of integrating people with mental illness into society demands a partnership, "It involves all of us". While a compelling thought, such perspectives on inclusive communities providing support in partnership with the formal helping system, are a challenge for research methods. In this project the challenge was experienced directly, as methods needed to be adapted to a broader group of informants, as each step out into the community led to suggestions for new sources of relevant information. Supported housing personnel suggested contact with landlords who suggested contact with the police. New contacts suggested new perspectives on the core issue, psychiatric disability. Group home personnel focused on chronicity and institutional behaviors, psychiatry personnel focused on young adults with social complications and school personnel focused on the transition to adulthood. It becomes understandable that focusing on a specific aspect of the broader issue, such as the care-related needs of the mentally ill individual, allows for clarity in design. Cohen (2000:77) states that "Incorporating social elements into analyses (which rely on statistical significance testing) increase unpredictability and complexity and, consequently the social sphere may be cast aside as noise or "unexplained variance"...". Many municipalities are aware of the importance of many of the factors and mechanisms which I have described, and yet their reliance on familiar methods for researching needs often lead to their restricting their formal investigations to individuals within the mental health system. The limitations of research methodologies in other words, have direct implications for the knowledge base upon which services are planned.

Fossey and Harvey (2001:95) maintain that; “Greater knowledge of the everyday life experiences of persons with mental illness could enhance the face validity of tools since it would allow the assumptions, upon which existing tools have been based, to be evaluated against lived experience”. Cohen (2000:74) suggests that detailed descriptions of the environment in which people experience their disabilities might produce “complementary variables”, which would lead to more sophisticated social research when discussing the needs of these individuals. In study three we attempted, based on many of the initial results, to concretize participation variables, so that they might be utilized in conjunction with individual measures related to need. If the mental health system is providing relevant individual services and supports, than these might be measured against increasing levels of participation in community life for those who have such a desire. Validation of these types of variables will require a great deal of further research before they can be used with any degree of reliability, but if we are to take the social policy focus on participation with any degree of seriousness, than this is the direction we need to go.

Since there is a time aspect, as well as a geographic and social setting for the interactions that individuals experience, research must also focus, as described earlier, on the life or career of the individual experiencing a psychiatric disability. The Social Department (SOU 2001:56) recommends “longitudinal analysis of how people with disabilities travel through life”. Ingstad and Whyte (1995: 20) suggest the use of life histories as a method in order to capture a “processual view of disability”. Long term studies would seem to be indicated in order to follow individuals over time and within the particular social landscape in which they live their lives. At the same time, by exploring the community broadly, and involving a wide variety of actors who might meet the individual at various points in their life path, we were able to draw conclusions regarding needs throughout the life cycle. Future research might more formally include school social workers for example, since many actors in this project pointed to the last years of high school and the transition to adult roles or the lack of an adult role, as a particularly sensitive time requiring a variety of supports. We know that young adults are often struggling to develop careers and that people nearing retirement may have less access to rehabilitation programs since resources may be prioritized for others. A variety of methods is of course indicated, and research needs to address dynamic life issues as well as community environments.

Finally, Marksström (2003), Carling (1995) and others have described the importance of society’s willingness to “invite” individuals with psychiatric disabilities in to community life, as a prerequisite for a true integration. Carling describes the “Community Framework Model”, where services are directed to-

wards supporting community resources, rather than relying solely on professional supports. This conceptual approach he argues, can be a more effective way to think about integration as it “more closely approximates the manner in which all citizens, regardless of any special needs or circumstances, live in and expect to receive support in their communities.” Recovery principles point as well, to the effectiveness of inclusiveness and maintenance of roles in the community as central to the individual’s ability to achieve a better quality of life (Gagne, 2001; Topor 2001; Anthony et al., 2002). As suggested above, there is also a need to explore community abilities and attitudes, on behalf of people with psychiatric disabilities and in cooperation with researchers outside the field of mental health. As I suggested in chapter two, it may be that mental health research related to describing the needs of individuals with psychiatric disabilities in the community is still “trapped” within a legacy of institutional care structures. While we have released the patients to a confusing and challenging reality, we have not taken the same step ourselves.

## **An invitation to participate**

The aim of this work has been to explore psychiatric disability in the community in what has been described as the post-deinstitutional era. Building on a practice-related research project, in which those responsible for developing social psychiatric services set out to systematically describe a population which they experienced as in transition, the aim has been to make some sense of disparities that arose in describing the situation today. Descriptions of disability contained in the legislation directing them to complete these surveys, provided a theoretical entry point into social approaches to understanding disability, approaches which point to the social context as an essential element of the relationship between impairment and disability. The results of seven such surveys have been explored with a focus on the context within which we identified individuals experiencing such disabilities and suggested dynamics and mechanisms which influenced the manner in which impairments became disabilities and frustrated opportunities to participate in community life. While the vast amount of data, and variations in variables related to the specifics of various communities and organizational fields challenged precise conclusions across the various studies, patterns did emerge which could be explored within theoretical descriptions of disability and in relation to the international literature.

Social locations, initially defined by the organizational contacts with which we found these individuals, suggested other locations in the community that were relevant to the aim of describing the social context. Quantitative results helped to describe characteristics of the individuals and draw conclusions as to

sub-groups who established contacts with various organizational actors, including those providing supports outside the formal mental health system. Qualitative results, based on extensive focus group discussions, described the needs which the various individuals presented with, and helped to establish the relationship between organizational location and need. By further exploring these needs-based relationships it became clear that mechanisms operating in the organizational field and the community impacted the manner in which individuals experienced disabilities. It also became clear that individual issues related to the desire for a participatory life in the community, were reflected in active choices and that these were not “just” patients or clients, but struggling community members. The move from “target group member” historically defined as those receiving mental health services, to community member, with a right to participate, shifted the focus from a geography limited by the service system to one that necessitated scanning the entire community. The final illustration represents an attempt to graphically depict the geography in the post-deinstitutional era, one where need should be defined as relative to a participatory life and not limited by the borders of the mental health system.

A focus on recovery that is rooted in the individual’s place in their natural community, a place defined both by physical presence and valued roles, and driven by the individuals desire to participate within that community, is one that can help to summarize the work presented here. This is also a dream of those described as living with serious mental illness, the “...opportunity to participate in the natural and ongoing rhythms of community life “(Davidson et al. 2001). This is an especially challenging vision for those of us who attempt to support these individuals in their journey. Can we help to create services and develop opportunities, based on their right to full membership in the community, so that they don’t need to pack away the “contents” of their lives?

*We are all changing, possible, and potential life stories (Bassman 2000)*

# Svensk sammanfattning

## Psykiska funktionshinder i samhället – Att kartlägga det sociala landskapet efter avinstitutionaliseringen.

Avinstitutionaliseringen inom psykiatrin har pågått i flera decennier nu, med framgångsrika försök att minska vården på institutioner och mindre framgångsrika försök att utveckla samhällsbaserade stödsystem som bildar en övergång till ett liv i samhället ”som alla andra”. Parallellt med nya organisatoriska former för att ge vård, behandling och stöd har individer som upplever allvarliga psykiska sjukdomar mötts av ett samhälle som i många avseenden inte är berett att ta emot dem. Samtidigt upplever dessa personer konsekvenserna av sina sjukdomar och funktionsnedsättningar i samhällslivet - inte bara i kontakt med psykiatrins (inklusive den kommunala socialapsykiatrins) olika specialiserade vård- och stödformer. Under de år som gått sedan de stora institutionerna lagts ner och samhällsbaserade stödformer byggts upp, har målgruppen förändrats. Den består av personer med nya behov och är inte alltid lätt att etablera kontakt med. Syftet med avhandlingen, som bygger på tre studier i sju kommuner i Sverige, har varit att undersöka den sociala kontext som personer med psykiska funktionshinder lever i. Vilka kontakter har de med de olika myndigheter som har till uppgift att erbjuda dem stöd i samhällslivet? Vilka egenskaper och behov har individerna enligt personalens uppfattning och enligt brukarna själva? Syftet har också varit att utveckla kunskap om de olika mönster som framträder i studierna med hjälp av teorier som betraktar funktionshinder utifrån en social modell. Målsättningen med denna avhandling är att bidra med ny kunskap som kan användas för att bättre förstå deras livsvillkor och behov - en kunskap som kan vara värdefull med hänsyn till verksamhetsplanering och fortsatt forskning.

Psykiatrireformen, som byggde vidare på Socialtjänstlagens intentioner, pekade på delaktighet i samhällslivet för personer som tidigare hade vårdats inom den landstingsdrivna psykiatrin. Utmaningen för kommunerna handlade i psykiatrireformens spår konkret om boende och sysselsättning, men den kunde också tolkas som ett löfte om förändringar i samhället som helhet. Kommunernas lagreglerade ansvar att genomföra regelbundna inventeringar för att skaffa kunskap om målgruppens levnadsförhållanden är utgångspunkten för studierna som beskrivs i denna avhandling. Samtidigt har många utredningar ifrågasatt idén att det finns en homogen målgrupp som kan identifieras och som har likartade behov. Dessa försök att inventera målgruppen och kartlägga deras behov försvåras av den definition som används och som bygger på begreppet

funktionshinder och inte på sjukdomsdiagnoser. Den teoretiska diskussionen i kapitlen 2 och 3, är ett försök att undersöka betydelsen av begreppet funktionshinder, som det används i den sociala modellen. Den betydelse begreppet har enligt den modellen är utgångspunkt för de metoder som används i de olika delstudierna.

Efter att i kapitel 1 redovisat syfte och bakgrund redogörs i kapitel 2 för två olika teoretiska utgångspunkter som fokuserar på individens möte med välfärdsystemet. För att vidga analysen presenteras kritisk realism som en metateoretisk ram som inrymmer ett synsätt där hela samhället och inte bara vårdssystemets begränsade perspektiv undersöks. Det finns många processer och mekanismer i samhällslivet som bör ingå i en sådan undersökning. Psykiskt funktionshindrades sociala villkor innebär att de har kapacitet att handla (agency) samtidigt som de är påverkade av och själva påverkar de organisationer som de kommer i kontakt med. Utan att ifrågasätta den medicinska modellens centrala roll i alla diskussioner om psykisk ohälsa, presenterar jag olika sociala synsätt (social approach) som beskriver individen i dennes sociala kontext. Utifrån begreppet funktionshinder är det konsekvenserna av individens psykiska ohälsa som måste ingå i beskrivningen av behoven. Efter avinstitutionaliseringen är det inte bara den medicinskt orienterade psykiatrin som måste ta hänsyn till målgruppens behov, utan också andra myndigheter inom välfärdsystemet. Nyinstitutionell teori tas upp i avhandlingen som ett teoretiskt verktyg för att undersöka det organisatoriska fält där dessa individer kommer i kontakt med välfärdsystemet. Nyinstitutionalismens fokus på den kulturella kontexten, som grund för organisationens utformning, diskuteras då det kan fördjupa förståelsen av villkoren för aktörerna på det aktuella verksamhetsområdet.

I Kapitel 3 vidgar jag synfältet utanför välfärdsystemet och betraktar de olika sociala kontexter, eller "social locations", som har diskuterats i litteraturen om personer med funktionshinder. Social location eller plats, är ett begrepp som fokuserar geografiska (spatiala) förhållanden, dvs. sociala förändringar i rummet, vilka skett eller som borde ha skett efter avinstitutionaliseringen. Begreppet kan indirekt säga något om målgruppens samhällsbaserade behov. Avinstitutionaliseringen, som är en mångfacetterad process, har inneburit en förändrad "geografi" för individer med psykiska funktionshinder. Var folk bor, var deras "kvarter" eller "grannskap" är beläget kan i bred mening handla om ett bostadsområde, men det ger också uttryck för ekonomiska eller klassrelaterade skillnader, och målgruppens position i ett socialt sammanhang. Alla dessa "social locations" skiljer sig markant från de vårdstrukturer som institutionerna baserades på, och samtidigt finns det en brist på kunskap om hur dessa platser samspelar med individens funktionshinder. Det finns faktorer i dessa miljöer som kan påverka individens upplevelse av psykisk ohälsa och behov av stöd.

Man kan också betrakta dessa faktorer som beroende av vårdsystemets olika stödåtgärder. Platsbundna dagverksamheter och gruppboenden kan ses som "liminala", dvs de existerar i ett gränsland som innebär att individen finns utanför både den institutionella psykiatrin och ett normalt samhällsliv. Individen betraktas varken som sjuk eller som delaktig i samhällslivet. Dessa sociala positioner är inte statiska och fixerade; många individer med psykiska funktionshinder erfar en neråtgående social rörelse (downward drift) till följd av livskriser, ekonomiska omständigheter och sjukdomsrelaterade behov som driver dem mot en mer utsatt situation. Motsatsen kan ses som återhämtning, en dynamisk process där individens egen resa mot ett delaktigt liv utgör målet för det socialpsykiatriska arbetet.

Avhandlingen och dess syfte baseras på tre studier genomförda i sammanlagt sju kommuner i Västernorrland, vilka presenteras i kapitel 4. Enligt 5a § SoL ska socialnämnden "göra sig väl förtrogen med levnadsförhållandena i kommunen för människor med fysiska och psykiska funktionshinder samt i sin uppsökande verksamhet upplysa om socialtjänstens verksamhet inom dessa områden. I planeringen ska kommunen samverka med landstinget samt andra samhällsorgan och organisationer". Kommunens ansvar relaterat till kartlägningsprocessen är, enligt lagen, inte begränsad till dem som har en diagnos eller som redan har kommit i kontakt med psykiatrin. De kommuner som deltog i studierna föreställde sig att det kunde vara fler personer som tillhörde målgruppen än de som för tillfället fick del av psykiatrin och den kommunala socialpsykiatrins stöd. Metoden gick därför ut på att försöka hitta även dem som inte hade aktuell kontakt, genom att inkludera hela socialtjänsten men även primärvården, arbetsförmedlingen och försäkringskassan. Studien har haft både ett kvantitativt och kvalitativt angreppssätt. Eftersom vi bedömde att en enkätundersökning riktad till personer med psykiska funktionsnedsättningar skulle ha gett alltför låg svarsfrekvens valde vi att rikta enkäten till personal vid de nämnda organisationerna - personal som arbetar med målgruppen. Vi använde oss i enkäten av socialstyrelsens definition av personer med allvarliga funktionshinder. Genom fokusgruppintervjuer med både personal och brukare, fick vi en bild av både brukares och personals åsikter om personernas behov och hur deras möte med både välfärdssystemet och samhället i bredare mening gestaltades.

I kapiteln, 5 – 8, presenteras resultat från respektive studier. Sammanfattningsvis identifierade vi 2385 individer som respondenterna bedömde uppfyllde Socialstyrelsens kriterier för personer med psykiskt funktionshinder. Siffran representerade 1,2 procent av den vuxna befolkningen i de sju kommunerna (194, 074). Andelen var betydligt högre jämfört med flera tidigare uppskattningar. Denna andel är högre än den som framräknades inför psykiatrireformen

(vilken var 0,46 procent); denna begränsades emellertid till att omfatta de som hade aktiv kontakt med psykiatrin eller socialpsykiatrin. Studierna bekräftade många välkända resultat, som t.ex. att mer än hälften av de inventerade personerna inte har någon sysselsättning alls och att mindre än 15 procent hade reguljärt arbete. Man kan betrakta dessa och andra resultat som att de återspeglar olösta sociala behov och att gruppen fortfarande befinner sig i utanförskap. Vi noterade också några tendenser som pekade på nya behov som behövde tillgodoses för att delaktighet i samhällslivet skulle förverkligas.

Av alla som identifierades i studierna, hade endast 52 procent aktiv kontakt (blev rapporterade av) med de traditionellt ansvariga organisationerna, dvs. landstingets psykiatri och kommunens socialpsykiatri. Vi reste därför frågan om de var aktuella hos andra delar av välfärdssystemet och varför de sökt sig dit. Det visade sig att 93 procent av dem som var aktuella hos arbetsförmedlingen inte hade någon aktiv kontakt med vare sig psykiatrin eller den kommunala socialpsykiatrin. Vi kunde också se att de som sökte arbete ofta var betydligt yngre än de som hade hamnat på kommunala dagverksamheter. Många unga vuxna hade enbart kontakt med IFO där de sökte försörjningsstöd, vilket kan betraktas som en särskilt kritiskt kontakt då socialsekreterarna beskrev dessa som en riskgrupp. En annan grupp som hade komplicerade sociala behov och inte entydigt hade en identitet som patient eller klient, var de 10- 30 procent (beroende på vilken kommun det gäller) som var föräldrar. Helhetssynen på deras behov försvann i kontakten med psykiatrin eller med IFO, eftersom välfärdssystemet tenderade att kategorisera personer med psykiska funktionshinder som om de i första hand hade behov av vård. Av dem som vi fann hos socialpsykiatrin fanns många som personalen beskrev som personer i en återhämtningsfas, där de med rätt stöd skulle kunna bli mer delaktiga i samhällslivet. Här fann vi dock mekanismer eller delaktighetsbegränsningar, t.ex. stigmatiserande attityder från omgivningen och rigida regelsystem, som ledde till ett liv utanför samhället - ett liv som i flera avseenden kunde betraktas som "institutionaliserat".

Fokusgrupperna kompletterade de resultat vi fann i våra kvantitativa studier; de bidrog till att konkretisera det fenomen som oftast beskrivits som "gråzoner". Här hamnade många som försökte tillgodose behov som låg mittemellan de olika organisatoriska ansvarsgränserna eller mellan välfärdssystemet och samhället i övrigt. Många beskrev dessa individer som att de föll mellan stolarna. Vår tolkning var dock att stolarna var felplacerade sett till de samhällsbaserade behov som personer med psykiska funktionshinder upplever idag. Många som sökte hjälp av arbetsförmedlingen var medicinskt färdigbehandlade, men de bedömdes inte ha tillräcklig arbetsförmåga. Dessa personer framförde önskemål om att delta i samhällslivet och ansåg att de hade förmåga till detta. De

ville inte att deras villkor skulle begränsas till deltagande i en socialpsykiatrisk verksamhet.

### **Slutsatser**

Att inventera målgruppen psykiskt funktionshindrade genom att kartlägga behov bland dem som har kontakt med den formella psykiatrin, kan ses som ett paradigm som lever kvar från avinstitutionaliseringens tid. Ett sådant medicinsk synsätt på behov blir problematiskt i ett socialpolitiskt sammanhang där ett delaktigt liv i samhället utgör målsättningen. I avhandlingen används en social modell som fokuserar den sociala kontexten, i vilken konsekvenserna av psykisk ohälsa samspejar med underlättande och hindrande faktorer i samhället. Med hjälp av detta synsätt kartläggs det sociala landskap i vilket välfärdssystemet ingår tillsammans med de övriga samhällsaktörer som målgruppen har kontakt med. De olika samhällskontakter och miljöer där dessa individer befinner sig inrymmer individernas roller som samhällsmedlemmar och tar inte bara hänsyn till deras roll som patienter eller klienter.

I kapitel 9 tittar jag närmare på den sociala kontexten av behov (the social location of need) och försöker analysera var dessa behov är lokaliserade. Spridda i samhället söker dessa individer stöd och möjligheter kopplade till roller som de vill ha, inte nödvändigtvis till det psykiatriska stöd som vi tror de behöver. Det som inte fastnar i det psykiatriska stödsystemet som patienter eller klienter kan finna sig i andra roller eller positioner i samhället, t.ex som föräldrar, missbrukare eller som arbetslösa unga vuxna. Dessa roller och positioner också kan ses som bärare av viktig information, då vi vet att fattigdom och utanförskap är starka faktorer relaterade till psykisk ohälsa och funktionshinder.

För dem som fick insatser via psykiatrin och socialpsykiatrins bostäder och dagverksamheter, identifierades en risk för ”transinstitutionalisering” där, trots ett geografiskt liv i samhället, möjligheterna och stöd till delaktighet är stark begränsad. Dessa ”liminala” verksamheter kan lätt bli ”mini-institutioner” i samhället om de inte erbjuder rehabiliteringsinriktade insatser, kopplade till kunskap om möjligheterna till återhämtning.

I kapitel 10 diskuteras generativa mekanismer och dynamiken i begreppet funktionshinder. En position som funktionshindrad i samhället är inte statisk. Perspektiv som bara tar hänsyn till individens sjukdom riskerar att missa den dynamik som finns i samspelet med samhällets olika aktörer. I den sociala kontexten hittar man olika mekanismer som kan bidra till antingen funktionshindret eller möjligheten att återhämta sig till ett mer delaktigt liv. Fördomar bland myndigheternas representanter men även allmänheten kan komma att begränsa individens möjligheter och leda till att förstärka en marginaliserad position i samhället. Regelsystem och organisatoriska kulturer som ”ramar in” individen i

en psykiatrisk kategori kan också bidra till en fragmentiserat bild av behoven och begränsa tillgången till rehabiliterande insatser. Sådana mekanismer påverkar dynamiken, och kan även bidra till att individen införlivar en föreställning om sig själv som inkompetent och svag. Vägarna in till stödsystemet styrs ofta av förutbestämda "trajektorier" eller banor, där åtgärderna som behövs för att nå ett mer delaktigt liv kopplas till kategorier och åtgärder som själva skapar utanförskap. Vägarna ut till ett mer delaktigt liv, är oftast opreciserade och återhämtningsbanorna vagt definierade.

I det sista kapitlet föreslår jag en modell för att börja kartlägga det sociala landskapet i eran efter avinstitutionaliseringen. Nedläggningen av institutionerna följdes av en fokus på insatser i öppnare former, men dessa insatser utförades utifrån jämförelser med det gamla och utifrån den enskildes position som patient och vårdtagare. Idag behöver utvecklingen tas ett steg vidare för att kunna understödja återhämtning och ett delaktigt liv även utanför vård- och stödsystemet. Sådana modeller kommer att kräva kunskap om det sociala landskapet och de sammanhang där individerna kämpar med roller och positioner i samhället. Utan denna kunskap kommer bilden av behoven att fortsatt bli begränsad och missvisande. Forskning måste också ta hänsyn till individen som aktiv samhällsmedlem, och börja utveckla metoder för att samla kunskap som kan fungera som underlag för verksamhetsplanering. Att ta hänsyn till individens sammansatta behov kräver också att vi analyserar samhällets förmåga att anpassa sig till individen, ett perspektiv som betonar inklusion och som uppmärksammar och utvecklar de naturliga stödresurserna i samhället. Ett sådant synsätt kan också reducera riskerna att individer som lider av psykisk ohälsa hamnar i ett långvarigt utanförskap. Kunskap om samhällsbaserade rehabiliteringsmetoder kan ses som ett sätt att stödja individen och bana väg för en återhämtning.

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**Presentations;** Socialstyrelsen (National conferences, Expert group on inventory and outreach), lectures for local practitioners and politicians, CEPI national research conference (Center for evidence-based research on psychosocial services), Enmesh (European Network for Mental Health Service Evaluation, conference in Poland), FoU Welfare national conference.

## **Appendix A**

### **Focus Group Analysis;**

The specific theme groups and actors who attended (in municipality six) included the following;

- **Social and other municipal services;** 17 participants representing Young adult services; Social psychiatry, school social workers, staff from the financial support division, Integration staff, Rehabilitation staff and the office which supplies “good men” ( economic advisors in crisis situations)
- **Health and medical care:** 17 participants representing Inpatient and outpatient psychiatry (county medical), Occupational therapists, rehabilitation/Habilitation staff, and workers from the primary care sector.
- **Work Life and Rehabilitation:** 27 participants representing Adult education, Psychiatric rehabilitation programs, day programs, the individual and family services, other social services providing work rehabilitation, study associations, the employment authority and the social insurance authority.
- **Community Life:** 16 participants representing the family and user associations, the police, the “debt” authority, a church-based community group and three churches, and case managers.
- **User perspective:** 18 participants and additional observers who did not sign in (according to local staff primarily users). They represented the family and user associations, a cooperative café activity, and a number of clients from supported housing. The announcement of the meeting had been circulated widely in the mental health community.

The categories and sub-categories are presented as they were in the original reports, following after each of the questions which were posed to the group.

#### **Who**

- ❖ Young Adults –
  - Young people (18-30) who have tried everything (work, studies, activities) and have on the whole failed with everything.

- Those who drop out of high school.
- Those who have had challenging and complicated environments as children.
- Challenges in transitioning to adulthood – as a "breaking point" for many, including "students at risk".
- Difficulties in distinguishing normal teenage problems from mental illness, which can delay supports being offered.
- Girls who may have children at an early age.
- "Young people who don't want to be sick."
- ❖ Adults with complex problems – "social complications"
  - Double diagnosis – substance abuse, developmental disabilities and neuropsychiatric problems
  - Economic difficulties – debt, unable to afford housing. "People who have hit bottom."
  - Family situation – parents may have psychiatric disabilities, substance and physical abuse in family
  - Long-term unemployment – deterioration, loss of social network, worsening mental health
  - Those with criminal contacts or history – may have contact with forensic psychiatry
  - Permanent disability pension – No active support and no rehabilitation possibilities
  - Women who are socially isolated and may be dependent on abusive men.
  - Elderly (over 60) – who have complex needs related both to age and disability, but also have normal aging issues.
  - "Odd people" – who exist "outside" of the society, and risk a crisis without support. "Social dropouts" "Those who don't fit in anywhere".
- ❖ Others
  - Isolated individuals – who may live in rural areas or are dependent on older parents or relatives
  - Children of parents with psychiatric disabilities.
  - Those who avoid contact with psychiatry since they consider it "shameful" and others who are afraid of being "classified" as mentally ill.
  - Refugees and immigrants.
  - Those without "insight into their illness".

## Needs

- ❖ Preventive efforts
  - Outreach activities
  - Early supports during the school years (especially for those who drop-out)

- Prevent becoming an outsider /marginalisation – cooperate with other actors in the society.
- Dysfunctional families, support to parents, ”support for the whole family”.
- ❖ Health and medical care
  - Crisis support -Intensive support as needed – and ”following hospital stays”.
  - Community-based support - ”Support for non-acute needs”, in-between periods of intensive need” ”in-between crisis”. “Support in work life”
  - Follow-up regarding use of medicine.
  - Regular physical health check-ups – including dental care
  - Access and continuity in health care – somatic and psychiatric.
- ❖ Work life and studies - rehabilitation
  - Support to employers – staff who can follow along to the work place (Coaches)
  - The public sector needs to take part (offer jobs, internships, etc.) – there are structures for this(OSA)
  - Accommodations in work places and in education environments.
  - Varied opportunities for occupational activities, based on the individual’s ability and interests.
  - Education and training geared towards work life and employment.
  - Adult Education, Study circles
  - ”Real work, not just occupation/activity”.
- ❖ Holistic and individually focused assessments of need
  - Individual need, not the system – ”see the individual, not the category
  - Individual planning – rehabilitation focus
  - The authorities shouldn’t coordinate (services) ”over the head of the person”.
  - Holistic needs – the social and the “everyday must function if we are to help the person (with their psychiatric disability).
- ❖ Coordination of services and supports
  - One entry /”doorway in” to the support system.
  - Limit the number of contacts.
  - Work together with the person, regardless of which organisation you belong to.
- ❖ Program Development
  - Create a variety of alternatives and freedom of choice – in living and activity forms.
  - A way of working which can capture young adults.
  - Recovery-oriented programs.
  - Access and flexibility in supports – including evenings and weekends, telephone times, etc.

- A "good meeting"(reception) – language, culture, empathy, respect. (Staff with social competence".
- ❖ Community life and society
  - Develop opportunities to "spend time with healthy people".
  - Fight against stereotypes/attitudes which limit possibilities
  - Break the isolation, dare to utilize that which is in the community.
  - Invest in the development of social networks and social support.
  - Create alliances with community/societal actors including employers, educators, voluntary organisations, even churches, police, libraries, etc.
- ❖ Knowledge and competence development
  - Clarify roles, develop competence and models. (for delivering services)
  - Improved investigations and descriptions of need.
  - Increase knowledge among all the players of current efforts (by each other)
  - Work cooperatively with the individual –who is the expert on their own rehabilitation
- ❖ Political interest
  - Politicians must take these individuals seriously, meet them, become aware of their needs, create a dialogue, etc.
  - Change in legislation, earmark monies, create long-term solutions, not just projects.

#### **Obstacles/Barriers to having their needs met**

- ❖ Lack of availability/offering of services
  - Access to medical psychiatry – "The problem can become acute before you can activate the system".
  - Relay/substitute doctors – general lacks in continuity.
  - Scarcity of rehabilitation services/efforts – "Sheltered programs as avstjälpningsplatser"
  - "No routines for developing/completing individual plans".
  - A lack of resources in the school system.
- ❖ Lack of coordination of services/supports
  - Coordination is not connected to the individuals needs – "the authorities have their own goals that don't correspond to the individuals."
  - "Messy, confusing system" – many services but no overall direction.
  - Silo effect – categories and organisations dividing responsibility – many can "fall between the chairs".
  - Specialization and centralization – not adapted for general services, and especially not to rural areas .

- Difficult to reach the individual – Hard for those who don't themselves demand supports to get help.
- ❖ Lack of knowledge and competence
  - General lack of information provided to the individual, about the system, economic possibilities, rights, where you should turn for help, etc.
  - Lack of knowledge and information regarding community resources – for example church activities, folk high schools, voluntary organisations, etc.
  - Different organisational cultures – between programs, authorities, but even with reference to immigrant cultures.
  - Professionals and politicians don't listen to users and relatives – they don't see the user as an expert on their own rehabilitation.
  - A lack of knowledge regarding the potential of these individuals.
- ❖ Employment market
  - "Achievement society" – increased demands from the labor market, less tolerance.
  - Time limitations in internships and other rehabilitation forms, which aren't adjusted for this disability.
  - A lack of work places with knowledge regarding mental illness and psychiatric impairments.
  - Difficulties related to the local employment market. (industry moving out, small businesses that can't hire, etc.)
- ❖ Stereotypes/attitudes
  - Attitudes in work life – "The public sector is not a good role model".
  - Stereotypes lead to them remaining outsiders (marginalized)
  - "Shame-laden programs" – many avoid these or hide their need of psychiatric supports.
  - Expectations vary – differing perspectives on diagnosis/illness and functioning/participation.
  - "Low priority" (for this group).
  - Genus perspective – for example, men who don't seek this type of support
- ❖ Rules and organisational factors
  - "Rule systems which counteract each other"
  - The "authority culture".
  - Confidentiality as an obstacle, instead of asking the individual for permission.
  - Stereotyped and rigid organisations.
  - Economic and organisational structures which create obstacles to rehabilitation.
  - Fragmentized financing.
  - Persons who are "sorted away" due to a judgement regarding their work ability for example, at a particular point in time.

- ❖ Politik
  - "Contact and dialogue with the politicians isn't working"
  - Politicians are afraid of making contact – leads to ignorance and unfair treatment for people with psychiatric disabilities.
- ❖ Individual issues
  - Fear of seeking support, difficulties in staying in contact, with making appointments. Timing is also a problem, if they get into treatment too late, it can be hard for the programs to meet them in a positive manner.