

An approach to measurement and statistical description of participation in community life for people with psychiatric disabilities

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Participation has emerged as a central concept in defining the goals of disability policy in Sweden as well as internationally. Yet it has rarely been operationalized as a foundation for planning services. As part of an attempt to survey the needs of individuals experiencing psychiatric disabilities, the authors have developed a scale for measuring participation in five areas of community life. The scale uses four distinct categories as levels, specific for each area of life, and a set of statistical descriptive techniques designed to illustrate and communicate information regarding levels, capacities, and wishes related to a participatory life in the community. Based on a pilot study, the article illustrates how the collective needs of a population of individuals experiencing psychiatric disability can be described and presented to practitioners as a support for system planning.

Keywords: participation; psychiatric disability; measurement scale; statistical representation

Introduction and background

Psychiatric disability is often described as a ‘hidden disability’ (Fox and Kim 2004, 328). This has led to the fact that the capacity and potential of this group often disappears within a haze of outdated assumptions as to the effects of psychiatric illness on the person’s ability to participate in community life. Recently, research has been carried out that has studied conditions for recovery for persons experiencing serious mental illness (Drake et al. 2003; Freeman, Fryers, and Henderson 1985; Thornicroft and Szmulker 2001). Longitudinal studies have shown that the possibility of recovery exists, and with much greater frequency than previously described in the literature which presented schizophrenia and other psychotic illnesses as leading to deterioration and probable chronicity (Harding, Zubin, and Strauss 1987; Topor 2001; Spaniol et al. 2002). In an influential study, the authors draw the following conclusion: ‘The possible causes of chronicity may be viewed as having less to do with the disorder and more to do with a myriad of environmental and other social factors interacting with the person and the illness’ (Harding, Zubin, and Strauss 1987, 483).

Opportunities for the individual to participate, or take an active role in community life, are often presented as one of the most essential ingredients in

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recovery from serious mental illness (Anthony and Lieberman 1986; Deegan 2003; Rosen and Barfoot 2001; Topor 2001; Hughs and Weinstein 2000, 41). This environmental turn in the discussion of recovery from serious mental illness is one that is also reflected in the disability literature which describes disability as the consequences of the illness for the life of the individual as they live in the community (Barnes, Mercer, and Shakespeare 1999; Hydén 2005). The following definition of psychiatric disability illustrates this point and is the one that was utilized in the study presented here:

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. (National Committee for Coordination of Psychiatry, SOU 2006)

These hopeful developments in our understanding of serious psychiatric disabilities point to the need for a discussion of opportunities and outcomes related to participation in community life. In addition to the hopefulness which the *recovery* literature has linked to a participatory role in the community (Anthony et al. 2002; Topor 2001), we see a growing research base which shows that with evidence-based methods such as *supported employment* (Anthony et al. 2002; Burns et al. 2007), a large percentage (up to two-thirds) of these individuals can participate, even in regular employment.

Disability – a question of participation in society

Swedish policy in the area of disability is intended to focus on ‘Identifying and removing obstacles to full participation and full equality in society’ (Socialstyrelsen 2006). The Handicap Inquiry of 1989 stated that ‘We will use the concept participation in the sense of active participation in social life. Wishes and interests can change in different periods of life, between different people and places . . . People with disabilities should be in the society together with and on the same conditions as all others’ (Swedish Institute 2000). According to the Social Services Act in Sweden, 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 (Social Services Act, chapter 5, section 7). The responsibility of the municipality, according to this legislation, is not related to treatment or care of the symptoms of the illness. They are directed to strive for the individual’s opportunity to live as others, a promise grounded in participation in community life.

Participation is a concept that may be seen from various perspectives and requires a longer discussion than we have room for here. 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 also due to environmental factors. The language contained in the Social Services Act fits neatly into the handicap perspective expressed in the International Classification of

Functioning, Disability and Health (ICF) 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 (often environmental factors) (WHO 2002). 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.

As a research tool, ICF has been used to measure outcomes, quality of life, and environmental factors (WHO 2002). We studied ICF as well in order to identify concepts that would assist us in measuring and describing participation. 'Activity is the execution of a task or action by an individual', 'Participation is involvement in a life situation' (WHO 2002). In attempting to look at outcomes, participation appears as the more appropriate measure from the standpoint of the social services legislation in Sweden (and many other countries). While helping a person to be active, which we have focused on for many years, may be seen as positive, it has not led to positive outcomes related to a participatory life in the community. People with psychiatric disabilities are not becoming employed (less than 15%), live in social isolation, and have few opportunities to participate in leisure time activities and the educational system (Brunt and Hansson 2005). A lack of supports, methods and societal accommodations, as well as stigmatizing attitudes and even the poverty associated with disability have created barriers which are often presented as accounting for the poor outcomes. 'ICF classifies not the person, but the person in situation' (Hydén 2005, 69).

Purpose

Despite the growing knowledge-base described above, the majority of attempts to describe the needs of this population focus primarily on their impairment or care-related needs. Attempts to explore the community environment, in other words how successful a particular local system has been in supporting the participation of individuals with psychiatric disabilities, would therefore seem extremely relevant. Methods which can help to measure and describe participation and related needs, complicated due to the challenges inherent in defining these disability-related concepts, must however be explored in order to begin developing knowledge of the concept of participation in practice.

The purpose of this article is to describe an approach for measuring participation of persons with psychiatric disabilities in various aspects of community life and for statistically describing data generated by these measurements. A pilot study, involving a survey of persons with psychiatric disabilities, will be presented in order to illustrate the approach. We will additionally explore the idea that such a model has the potential to describe need for the purpose of developing supports by comparing participation, capacity, and the wishes of individuals experiencing these disabilities.

Methods

We conducted a pilot study to test our newly developed measurement scale in a survey of persons suffering from psychiatric disabilities and their needs conducted in

two Swedish municipalities. This study was the statistical portion of a wider survey of needs which also included focus group and individual interviews.

Our aim, when surveying the needs of individuals experiencing psychiatric disabilities, has been to develop relevant knowledge of participation in the community, as well as report it in a way which is relevant for professionals and decision-makers involved with this target group. To accomplish this we needed to compare actual levels of participation in various areas of life with corresponding capacities and wishes for participation. Scales for social measurement are typically operational or representational (Bartholomew 1996, 9). For our purposes, we obviously needed the levels of a scale to represent states of participation interpretable in reality in an area of life, so that operational approaches were discarded. We also needed the levels of the scale to take into account that an individual's participation is restricted not only by that person's disability, but also the situation as mentioned above, referring to aspects of the environment.

For the pilot study we developed five separate scales, each with four levels of ordered categories of participation in the corresponding areas of social life. The levels were specified so that they were interpretable in their context, which means that we suggest a realist approach according to Bartholomew (1996). The scales are presented below.

Several organizations cooperated in the data collection by filling in a questionnaire for each client actively utilizing their services and who belonged to our target group of psychiatrically disabled persons, described above. Informants were persons who had a professional relationship with clients, rather than the clients themselves. This was due to the poor response rates in similar surveys that were directly distributed to clients (Socialstyrelsen 1999).

Clients were identified in such a way that we could recognize if the same individual was reported by two or more organizations. When analyzing the needs of all unique individuals, we utilized the record that was submitted by the organization that had the most relevant contact with the individual, as based on a priority listing determined in advance.

The four-level category scale

Our aim was to obtain data on clients' participation in five areas of life: living, social life, work, education and leisure. For the survey instrument, each area of life had specific descriptions of its categories; we can describe them as context or area specific. For the areas of living and work, the categories were described as follows:

<i>Life area: Work</i>	<i>Participation</i>
No activity or activity without rehabilitation plan ('drop-in')	Less participation
Planned rehabilitation activity	
Internship/subsidized employment	
Regular employment	More participation
<i>Life area: Living</i>	<i>Participation</i>
No residence or in treatment institution or group home	Less participation
Own apartment with intensive support	
Own apartment with limited support	
Independent living, alone or with others	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 exclusionary situations, while the two categories indicating higher levels of participation describe more inclusive situations 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 discusses, participation may be described as performance or as 'involvement in a life situation', a definition that can be difficult to operationalize in the area of living for example. We also want to point out that issues related to the social life of the individual are described in a distinct life area.

For each specific life area, three questions, using the same answer set, were posed to the informants. For example, in the area of work life, the first question referred to the client's present work situation. The second described the highest category of the four that matched the client's capacity for participation in work life, as assessed by the informant. The third question referred to the category which the client aspired to, again according to informant's assessment, in terms of work. The use of the term capacity was borrowed directly from ICF. According to 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 individuals are grounded in their interests, hopefulness, and choices, factors which research in psychiatric rehabilitation have shown to be decisive in promoting recovery (Anthony et al. 2002; Topor 2001).

Data analysis

The three questions within each life area are identical as to the answer set, so the collected data meets requirements for analysis of pairs of data, i.e., pairs of responses about the same client. We analyzed the pairs that coupled answers about the current situation with those about capacity, and with those about wishes. Categories were coded 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) through an opposite dissimilarity (4, 1).

Types of mismatch

We interpreted the measurements as categories and displayed the complete distributions of outcomes in four by four contingency tables. See Figure 1 for an example. Cases in which informants classified current situation and capacity in the same category are referred to as a match. There were two types of mismatch however, depending on whether the current situation was categorized as more or less participation than the assessed capacity.

When thinking about match and mismatch in the context of participation in community life, the mismatch of a client being placed in a higher category in the *current* dimension than in *capacity* is qualitatively different from that of a mismatch that is 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 offers 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.

Furthermore, within the same type of mismatch there can be one, two, or three steps between categories of *current situation* and *capacity* (or client’s wish). Since we do not consider the scale to be interval, we consequently do not consider the steps between categories to be of equal length. Still, with regard to the environmental context in which we describe participation, we have found it relevant to report the magnitude of mismatch in terms of the *number of steps* that differ. There are two reasons for this. One is that the number of steps is restricted to only one, two, or three, which makes interpretation obvious. The other reason is that the meaning of these steps are easily understandable as referring to the levels of participation in the scale, and would not be misinterpreted when information is presented. The number of steps can therefore be a relevant and useful measure of the order of magnitude of a client’s PR or ED mismatch, even without the condition that the steps are of exactly the same length.

A four-level ordered categorical scale may seem coarse as to the measurements, but when used to obtain relevant pair-wise data, both descriptive and inferential statistical methods are available which are quite useful. In addition to the descriptive measures which we use in our analysis of the pilot study data, there are other methods for evaluating the patterns of the pair-wise measurements as displayed by cross tabulation. These include *the rank-transformable pattern of agreement* (Svensson 1993) and measures defined as *relative position* and *relative concentration* (Svensson and Starmark 2001) which can evaluate statistical significance of changes in mismatch over years or differences in mismatch between populations.

Results

Interesting in the context of this article are problems due to non-response in using the scales for participation. Responses related to the clients’ current situation were straight forward, but questions concerning capacities and wishes for participation in areas of life were more difficult to answer for many informants, which led to many individual cases lacking data on these variables. Thus the area of work life as a typical example had 30% missing observations (136 out of 458) due to informants’ non-response as to clients’ capacity for participation in work life. We don’t consider this to be a problem of the scale however, since professionals involved with this target group were in agreement that they ought to have this knowledge. Instead, in the context of our pilot study, the rate of non-response to the questions about capacity and wishes provided important feed-back, as to the lack of knowledge in certain life areas. Non-response therefore becomes a relevant measure for these professionals and the leadership of the organizations within which they worked.

Match and mismatch in work life and in living

In our pilot study, half of the cases had a match between current situation and capacity in work life. In the area of work life clients aged 65 or older were excluded in the data analysis. Those with a mismatch were predominantly of PR (participatory restriction) type. This was 49% of the cases while the ED (excessive demand)

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

Figure 1. Participation in work life, current and capacity.
 Note: We notice for instance that 50 persons had ‘No activity’ as the current work life situation but were assessed to have capacity for the category ‘Planned activity’.

mismatch was as low as 1%. For the complete distribution refer to Figure 1; it is clear from the distances between table cells and the diagonal that a PR mismatch can be up to three steps. The number of steps of mismatch in each direction is displayed in Figure 2, and we can see that as many as 37 of the 322 clients in the analysis had a current situation three steps below their capacity as to participation in work life, 49 had a two-step PR mismatch and 72 had a one-step PR mismatch. Only 3 of the 322 clients had an ED mismatch in work life. A comprehensive table of the results of the survey as related to participation in work life is displayed in Figure 3.

Results can be compared between the life areas as well as between current-capacity and current-wishes pair-wise measurements. The data analysis results for work-life and living are displayed in Figure 4. When comparing results from current-capacity pair-wise analysis with those of current-wishes, we can see that the proportion of PR mismatch is higher in current-wishes measurements in both areas of life. We can also see that *living* has much less PR mismatch than *work life* and much more ED mismatch. As a matter of fact the area of work life has almost no ED mismatch.

Discussion

We have developed and tested a means of measuring participation in the context of community life for people with psychiatric disability, by utilizing a four level

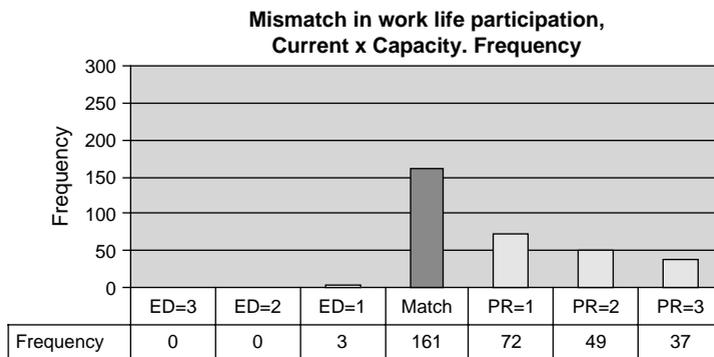


Figure 2. Participation in work life: ED and PR mismatch.
 Note: We see, that 49 of the clients had a two step mismatch of the participation restriction type.

Total match	Total mismatch	Number of steps of mismatch, mean	ED mismatch	Number of steps of ED mismatch, mean	PR mismatch	Number of steps of PR mismatch, mean
50 %	50 %	1.8 steps	1 %	1.0 steps	49 %	1.8 steps

Figure 3. Participation in work life; ED, PR and total mismatch.

Note: PR-mismatch had a large value on the mean for number of steps of mismatch, 1.8 steps per client among those sharing this mismatch.

categorical scale. We have also tested a set of statistical descriptions for analyzing and communicating the results from a survey of the psychiatrically disabled in a municipality in Sweden.

Interpretation

Need may be viewed in the case presented above as reflected in the concept of mismatch. When the individuals' capacity, as judged by personnel, is greater than their current participation, and their wish is at a higher level as well, we have a situation where need is present and may reflect environmental limitations. These may include inadequate opportunities for rehabilitative supports, a lack of appropriate opportunities, and even societal attitudes which may create discriminatory barriers. In such cases, the result must be seen as pointing to a need for additional analysis of obstacles that are reducing the individual's ability to participate at a level that they aspire to and have the capacity to achieve.

Describing need

The results presented allow us, and the recipients of the pilot study report, to analyze a number of factors. We have the ability to look across the five life areas (only two displayed here) and make comparisons of the frequency of mismatches and the magnitude of mismatch (the number of steps). Almost half of the individuals in the

Life area	Total match	Total mismatch	Number of steps of mismatch, mean	ED mismatch	Number of steps of ED mismatch, mean	PR mismatch	Number of steps of PR mismatch, mean
Work life, Current x Capacity	50 %	50 %	1.8 steps	1 %	1.0 steps	49 %	1.8 steps
Work life, Current x Wishes	43 %	57 %	2.2 steps	2 %	1.0 steps	55 %	2.3 steps
Living, Current x Capacity	78 %	22 %	1.1 steps	16 %	1.1 steps	5 %	1.2 steps
Living, Current x Wishes	79 %	21 %	1.2 steps	8 %	1.1 steps	13 %	1.2 steps

Figure 4. Comprehensive result table for more than one life area.

Note: We may notice that the highest rate for match was 79% and was attained in life area *living*, between *current* state and *wishes*.

study had a participation restriction when comparing their current situation and their capacity in the area of *work life*. This may be compared with the *living environment* where we only saw a 5% PR mismatch. The study within which this measure was included, and which used a variety of techniques to gather information regarding the needs of this group, supported this finding with practical examples of satisfied users, as well as quantitatively, since 71% of the population lived independently, many with flexible supports. At the same time up to 62% of the individuals identified had no activity and only 12% were employed part or full time, many dependent on subsidies to maintain their employment situation. The results are consistent with what might be expected based on both evaluations of the Mental Health Reform in Sweden and the international literature on community mental health services (Socialstyrelsen 1999; Socialstyrelsen och Länstyrelserna 2005; Leff and Warner 2006). Generally speaking, while previously institutionalized individuals have begun to successfully live independently in the community with appropriate supports, their opportunities for vocational rehabilitation and participation in work life have not materialized to the same extent. The results therefore strongly corroborate the validity of the measurement scale and the constructs PR and ED mismatch.

Looking at the different rates of mismatch within each life area we found for instance, that while personnel believed that 49% had the *capacity* to participate more fully in *work life* (1.8 steps average more fully), 55% *wished* 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.

These measures have value at both a collective and individual level. At the collective level we may see indications of which areas of life have been most challenging for the target group, as evidenced by the degree of mismatch between participation and capacity and between participation and interest/wish. In our test study, the area which showed the greatest degree of mismatch was in the area of employment, a result which is well grounded in the literature (Brunt and Hansson 2005; Burns et al. 2007). In order to further increase validity related to need, we would need to adapt the method and will likely have the opportunity to do so, by including the assessment by the user themselves. At the individual level those seeking support might be asked to use these measures as a sort of self rating scale, or potentially in conjunction with support personnel who could either complete the measures themselves, or in a third variation, together with their client during a discussion of the measures.

Limitations of the study

The structure of the scale is filled with potentially controversial uses of certain concepts such as 'regular work' and even the idea that participation in community life can be broken up into four mutually exclusive categories that all would agree upon. We are 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. It would therefore seem

reasonable to at least begin to operationalize these concepts and explore the potential of utilizing statistical methods for measuring participation.

A limitation of this pilot study is of course that we only received input from staff and not the individuals themselves. While we plan to test the scale with both staff and clients in the future, we will also reiterate that our primary purpose here has been to present a meta-perspective on the participation of individuals experiencing psychiatric disabilities, as an aid to planning and a focus on societal and system barriers. From this perspective, the input of personnel who work most closely with these individuals has value as well. Future studies however, must of course involve clients, partly to gain access to their own perspective, but also to validate the perceptions of personnel in studies where direct input will not be possible.

Future research

The reliability and validity have not been established for the measurement process in the study. We suggest for future research in connection to our approach, that the definitions or descriptions of categories in our five areas of life are further investigated as to usefulness, but also as to validity and reliability. Other possible partitions of life into life areas would obviously call for other descriptions. Another line of research would be to look into how the professionals involved understand the reports of data analysis using the mismatch construct and the statistical descriptions, especially when it comes to how these interact with their view of their professional mission.

Conclusions

‘Participation is emerging as the gold standard of outcome measurement in disability and rehabilitation’ (Seekins, Ipsen, and Arnold 2007, 319). By integrating the ICF concept of capacity, and the field of *recovery*’s focus on the wishes and interests of the individual in an attempt to concretely measure participation, our intention is to move the focus in describing the needs of these individuals to their potential for development, a direction of interest both to the individual and to the helping system. Seekins and his co-authors (2007) clarify that ‘Whereas disability reflects the limiting dimensions of this interaction (between the individual and their environment), the concept of participation describes the positive aspects to be achieved’. A focus on the possibilities for participating more fully in community life corresponds well with findings in the field of *recovery*, which see a participatory role in the community as an essential factor in recovery from serious psychiatric disabilities. By measuring participation and providing information related to capacities and wishes, organizations planning services may have a more concrete foundation on which to analyze needs and develop appropriate services.

With regard to the lives of persons with psychiatric disabilities living in the community, this study argues that the relevant construct to measure is participation. We suggest that an instrument which addresses various life areas, utilizing a four category ordinal scale can be valuable in research and when communicating aggregate results to professionals working with clients of this target group. Focusing on the simultaneous distribution of pair-wise data – on actual situation versus capacity and actual situation versus wishes – we revealed data patterns that facilitate an understanding of participation, needs for support and environmentally related

restrictions for persons in the target group. On the aggregate level, a quantification of the need for support was made possible by using the measurement scale for data collection and the analysis techniques for description.

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