Routledge
Taylor & Francis Group

Working with Individual Plans: users' perspectives on the challenges and conflicts of users' needs in health and social services

Birgitta Langhammer[a,b]*, Vigdis Helen Madsen[c], Elisabet Hellem[a], Kari Anette Bruusgaard[a], Grete Alve[a] and Åshild Slettebø[a,d]

[a]Faculty of Health Sciences, Oslo and Akershus University College, Postbox 4, St. Olavs pl., N-0130 Oslo, Norway; [b]Sunnaas Rehabilitation Hospital, N-1450 Nesoddtangen, Norway; [c]Faculty of Social Sciences, Oslo and Akershus University College, Postbox 4, St. Olavs pl., N-0130 Oslo, Norway; [d]Faculty of Health and Sport Sciences, University of Agder, Postbox 509, N-4898 Grimstad, Norway

In Norway, an Individual Plan (IP) is a statutory right and a tool for cooperation between the client in need of long-term, coordinated services and the public services. This study analyses the explicit needs of users, how the various actors in the IP process met these needs, as seen from the users' perspective, and, finally, how disability influenced the outcomes. Participants expressed physical, psychological and social needs. These needs were similar for persons with physical or psychiatric health conditions, or for persons with an innate or acquired disability. However, time elapsed since a disability had been acquired did make a difference. The municipality or district of residence, the administrative and legislative boundaries, the interpretation of those and the coordinators' position within the hierarchy of the system all affected how well users' needs were met, indicating the existence of tension. This tension between the external conditions or framework of services and user participation may be an explanatory factor for the slow implementation of IPs.

Keywords: disability; users' experience; health care; communication

Introduction

Both specialist institutions and the municipal authorities provide health services in Norway (see Norwegian Board of Health Supervision Act 2010). The Norwegian Labour and Welfare Service (NAV) participates widely in the world of work and society, and contributes to the financial security of both able and disabled people (see Norwegian Labour and Welfare Services Act 2012).

According to the principle of using the lowest effective level of care, all preventive, emergency and long-term health services should be planned to take place as close to the user's home as possible. The concept of 'close care', where a community-based health service caters for those living in its immediate neighbourhood, is linked with the desire to exploit the opportunities and resources found in the local authority (or council) and in social networks close to the patient's home.

The Coordination Reform presented by the Norwegian Government in 2009 (Ministry of Health and Care Services, St. meld. 47: 2008–2009) aims to improve

---

*Corresponding author. Email: Birgitta.Langhammer@hioa.no

coordination across government agencies so as to increase their usefulness and value both to the client and to society (Solli-Sæther 2009). The gains expected and hoped for are shared knowledge and the shared creation of value, and the strategies to produce these benefits are coordinated by liaison between the various health and social agencies of the Ministry of Health and Care Services (St. meld. 47: 2008–2009).

An Individual Plan (IP) is given by right to patients/users in need of long-term, coordinated services (Ministry of Health and Care Services, FOR 2004-12-23, nr 1837). It is regulated by the Health Care Act of 1999, and was approved by the Norwegian Parliament as a statutory right in 2001 and included in the Social Work Act of 2003 (Kjellevold 2005). Furthermore, the IP is personal to the individual patient and contains an outline of the patient's objectives, his/her resources and the services required. As such, it was introduced to take precedence over all pre-existing plans. An IP is a tool for cooperation between the patient and the public services and between the different service providers, and sometimes the patient's relatives. An IP should be voluntary and based on informed consent. Its users have the right to any ethically acceptable treatment offered to them (Kjellevold 2005). Patients have the right to participate throughout the planning process. Other plans, such as an Individual Educational Plan or a Treatment Plan, must be coordinated with the IP.

Essentially an IP seeks to contribute to a comprehensive, individually adapted service for the user. The object is to identify the patient's goals, resources and needs in different areas, and to coordinate measures that will help to meet the recipients' needs for assistance in the long term. It also entails strengthening the interaction between contributors and recipients, between agencies within the administration and between administrative levels. This approach is in line with the goals of Coordination Reform, and the IP as such is expected to be an important instrument in implementing it. User involvement and human rights are both central elements in IP processes, but legal and administrative considerations are equally important, which means that the IP is a tool for quality assurance.

However, the implementation of IPs has been slow, and there remains scope for improvement (Bakke 2009). The Norwegian Board of Health Supervision reported in 2007 that the use of IPs was only documented in 3% of all psychiatric medical records concerning children and young people, and that 33% of all the municipalities and community health services in Norway had not fulfilled the statutory requirements for working with IPs in 2006. Another report showed that only 25% of 400 drug addicts had an IP (Grut 2008). Furthermore, most patients/potential users knew little of the concept of an IP and of the rights accompanying it (Bakke 2009). Only a small fraction of elderly persons receiving community services and people with complex physical problems had IPs (Sørbye, Grue, and Vetvik 2009; Norwegian Directorate of Health 2011). There are indications that in specialist health services for adults, IPs are implemented to a greater extent than within medical rehabilitation and geriatric health services (Sørbye, Grue, and Vetvik 2009; Norwegian Directorate of Health 2011). The health services most involved with IPs are the psychiatric health services and health services for children (Norwegian Directorate of Health 2011).

The Norwegian Directorate of Health had focused on the implementation of IPs in 2008, and arranged six regional conferences. Feedback from these conferences and from professionals practising in the field has identified important success factors in the work with IPs (Bakke 2009).

First, the importance of making it possible for users to be seen, heard and valued was emphasized: to encourage users to come forward with their dreams, hopes and thoughts on what would improve their quality of life would be better than focusing on timing or practicalities.

Another factor that was emphasized in the conference summaries was a hope that the coordinator would function as a 'dream catcher', that is one who would help the user to articulate dreams and hopes for the future (Bakke 2009, 21). The summaries emphasize that to fulfil this function, the coordinator role needs to be empowered and prioritized.

Working with an IP is a time-consuming process; building a relationship/alliance with a user takes time. This process calls for coordinators to be appointed, trained and guided, and for interaction between and across different levels, departments and sectors to be organized. This interaction is meant to ensure that users' needs for assistance are met, whether those needs involve assistance from the health services, the social services, the Norwegian Labour and Welfare Organization (NAV) or educational services.

The principal intention of the introduction of IPs was to strengthen user rights and user involvement after what can be described as years of paternalism and management by experts within the health and social welfare sector. User organizations have been especially interested in finding a strategy to counteract this culture of management by experts (Hansen 2007). However, the introduction of IPs could also be perceived as an attempt to remedy the ineffectiveness of the public health services and to minimise the cost of the same services influenced by the New Public Management (NPM) strategy (Hansen 2007). These different agendas highlight the possible appearance of tensions and conflicts between different actors and within the services when implementing IPs, some of which have been addressed in earlier publications (Slettebø et al. 2011; Alve et al. 2012).

So, how are the dreams and hopes caught by the 'dream catcher'? There may be different perceptions of need between users and those assessing and addressing the needs. The urgency of the demand for effectiveness may threaten the idea of users' participation. The processes may also be influenced by the visibly physical or the cognitive, social or psychological/psychiatric disabilities of the individual, which are less visible or invisible. Furthermore, the time perspective related to living with the condition may play a role in what the authorities perceive as important, that is, acute/chronic, congenital/acquired disability. The access to and eligibility for services may be different with respect to statutory, financial or physical features or the interpretation of them (Smith 1980; Bradshaw 2008). This article focuses on what needs the IP holders expressed, how the different actors in the IP processes met those needs and how the type of disability influenced the outcome of these processes.

Theoretical framework

Some models for working with functionally disabled individuals

Disability can be viewed from different perspectives, and therefore several models have been developed for working with disabled individuals.

First, the medical model views disability as a problem of the person, directly caused by illness, trauma or some other health condition. Consequently, disabled people require sustained medical care provided in the form of individual treatment

by professionals. In the medical model, management of the disability seeks a 'cure', or the adjustment and behavioural change of the individual, which would lead to a 'near-cure' or to an effective cure. Medical care is viewed as the main issue, and at the political level, the principal response is that of modifying or reforming health care policy (Engel 1977).

The social model of disability, secondly, views disability as a socially created problem. In this model, disability is not an attribute of an individual, but rather a complex collection of conditions, many of which the social environment has itself created. Hence, management of the problem requires social action, and it is the collective responsibility of society to make the environmental modifications necessary for the full participation of disabled people in all areas of social life. The issue is both cultural and ideological, requiring change at both individual and community levels, and large-scale social change. From this perspective, equal access for someone with an impairment/disability is a human rights issue of major concern (Shakespeare and Watson 2001).

Thirdly, the bio-psycho-social model seeks to understand how the cause of the illness stems from the functioning of the individual's body and from potential psychological causes, such as lack of self-control, emotional turmoil and negative thinking, causing health problems. This model also integrates and recognizes different social factors such as socioeconomic status, culture, poverty, technology and religion, which may influence health and disability. It presumes the importance of recognizing and handling biological, psychological and social aspects. A growing body of empirical literature suggests that patients' perceptions of health and illness, as well as patients' social or cultural environment, appear to influence health-promoting or treatment behaviours (Pilgrim 2002; DiMatteo, Haskard, and Williams 2007).

The International Classification of Functioning, Disability and Health (ICF) is a model of health and health-related domains (WHO 2011), which classifies according to physical, individual and societal perspectives. It is a framework for health and disability at both individual and population levels. The classification of functioning, disability and health acknowledges that every human being can experience a decline in health and thereby experience some degree of disability. The ICF thus 'mainstreams' the experience of disability and recognizes it as a universal human experience. It takes into account the social aspects of disability and does not see disability only as a medical or biological dysfunction. By including contextual factors, amongst which environmental factors are listed, ICF allows the recording of the environment's influence on the person's performance (WHO 2011). The various models of disability explain how different actors view and identify their work in relation to users and the IP process.

New public management

NPM aims to modernize the public sector and render it more efficient. The basic hypothesis holds that market-oriented management of the public sector will lead to greater cost-efficiency for governments, without having negative side effects on other objectives and considerations. NPM reforms shift the emphasis from traditional public administration to public management. Key elements include various forms of decentralizing management within the public services, increasing the use of markets and competition in the provision of public services and increasing emphasis on

performance, outputs and customer orientation. A combination of economic, social, political and technological factors has driven the NPM reforms. A common feature has been the experience of economic and fiscal crises, which triggered the quest for efficiency and for ways to cut the cost of delivering public services (Harding and Preker 1999; Levi 2010).

User involvementluser participation

User participation is based on the notion of human rights per se 'that all men are created equal' (Jeffersson 1776). Human rights are 'basic rights and freedoms that all people are entitled to regardless of nationality, sex, national or ethnic origin, race, religion, language, or other status' (UN 1948). They are conceived as universal and egalitarian, with all people having equal rights by virtue of being human. They may exist as natural rights or as legal rights, in both national and international law (Nickel 2006). User participation and empowerment are instruments that may enhance the client's human rights in the rehabilitation process and in the contact with health and social services (Webb 2008). User participation has two forms: user participation at the individual level (individual user), or user participation at the administrative and political levels (organized users) (Bradshaw 2008; Fudge, Wolfe, and McKevitt 2008). In this study, the focus is on the individual level.

User participation is a statutory right in Norway (Ministry of Labour, St. meld. nr. 34: 1996–1997). Involving users gives them a voice and allows them to speak out and act for themselves. Such participation may also mean that users are directly involved in decision-making. If users have a better chance of influencing the environment through their own choices and resources, their self-image may be affirmed, thereby enhancing their motivation. User participation will contribute positively to the user's recovery process, and thus have a therapeutic effect. Conversely, when user participation is lacking, many users experience an increased feeling of helplessness (Breeding 2008). So, user participation has an obvious intrinsic value in that people seeking help, like others, would like to manage the important parts of life, receive help on their own terms, and be seen and respected by virtue of their basic dignity (Norwegian Directorate of Health 2010).

Empowerment

Empowerment entails support and strength to influence one's own life situation. Within an empowerment framework, the service providers´ responsibility is to re-cognize the users' challenges and needs, to identify their strengths, and to perform in an advisory capacity so that users can develop participatory competence (Walseth and Malterud 2004). Empowerment refers to increasing the physical, spiritual, political, social or economic strength of individuals, singly or in various combinations, by developing their self-confidence in their overall capacities. And, by developing the service providers' confidence in the users' capacities – such as the ability to make decisions about personal circumstances, the ability to consider a range of options from which to choose or the ability to exercise assertiveness in collective decision-making (Slettebø 2000). The empowerment process should encourage people to gain the skills and knowledge that will allow them to overcome obstacles in life or the work environment, and that will ultimately help them to grow as individuals or in society (Walseth and Malterud 2004; Thomas and Velthouse 1990).

Sense of coherence (SOC)

Reactions to adversity and illness are individual. People have different notions, based on their individual life experiences, about whether new situations seem predictable and manageable. These individual experiences and differences will significantly affect how they cope with the development of their situation. The individual's 'generalized resistance resources' may give an indication of his or her fundamental attitude, which Antonovsky (1979, 1987) calls a 'sense of coherence' (SOC). The SOC consists of three components. The three components are (1) comprehensibility, meaning the degree to which individuals understand their illness/situation and grasp the consequences of living with the condition, (2) manageability, which refers to whether individuals possess the resources needed to cope with the illness/situation and (3) meaningfulness, which relates to individuals' ability to ascribe meaning to and be actively involved in situations (Antonovsky 1979, 1987). Antonovsky (1987) proposes that the level of an individual's SOC is related to his or her strength of character and capacity for successful adjustment.

Material and methods

Design

We have based the design of this descriptive multi-case study on a triangulation of qualitative and quantitative data (Andersen 1997; Yin 2003). We followed the process of establishing and completing 13 selected IPs from the patients' expressed needs to their final assessment by their coordinators within the framework of health and social services.

Ethical considerations

The Regional Ethical Committee approved the study, and the Data Protection Office of Research on Norwegian Social Science Data authorized it. The recruitment process was approved by the local hospital and community service offices involved.

Sample

The focus of this study is the users' experiences and perspectives on IP processes. The two criteria for inclusion in the study were that users had to be at least 18 years old and be eligible for an IP for their rehabilitation processes. The clients volunteered to have an IP.

The sample size was planned to include 12 participants, a convenient number. However, due to varied and slow inclusion in some municipalities, one extra was included in an area with eligible informants early in the process, which resulted eventually in 13 participants. The IPs were initiated by health professionals for 10 of the participants, by close relatives for two participants, and one participant initiated her own plan (Table 1). The users themselves selected the professionals who were included in this study.

The participants and holders of the IPs were eight men and five women. They came from different municipalities and represented a variety of conditions (Table 1). Their disabilities were visible in seven and less visible/invisible in six persons. When

Table 1.   Descriptive information about holders of Individual Plans (IPs) and time perspectives, the perceived purpose and the initiator of the plan.

	Gender	Age	Diagnosis	Participant's purpose concerning IP	Experience of IP	In need of services/ rehabilitation	Initiator of IP
1	Male	47	Bipolar condition	Organize services and life	4 years	8 years	Health services
2	Female	48	Bipolar condition	Structure life	New	1.5 years	Health services
3	Female	33	Burn out syndrome/anxiety	Structure the work of the helpers	6 months	2 years	Social services
4	Female	24	Anxiety/heart condition	Follow-up services	1 year	5 years	Health services
5	Male	72	Parkinson's, stroke	Training and assistance	3 years	3 years	Health services
6	Male	22	Inherited syndrome, visual impairment	Meaningful job; independent living	2 years	15 years	Family and himself
7	Male	47	Inherited syndrome, visual impairment	Social integration, part-time work	New	40 years	Health services
8	Male	20	CP	Plan adult life; education/work; independent living	19 years	20 years	Health services
9	Female	37	Tetraplegia	Coordinating services; predictability	2 years	2 years	Health services
10	Female	48	Encephalitis	Administration of all services involved	6 years	9 years	Patient
11	Male	72	Tetraplegia	Practical administration of help services	6 months	2 months	Health services
12	Male	49	Stroke	Practical administration of help services	1 year	3 months	Health services
13	Female	31	Bipolar condition	Framework for the future and how to avoid becoming ill	1.5 years	15 years	Health services

interviewed regarding the IP, 12 persons were living at home and one was still in a rehabilitation institution.

The time that had elapsed since diagnosis of the condition or trauma differed slightly: one participant was newly diagnosed, two had had their diagnoses for two months, and 10 had lived several years with their diagnoses or conditions and were so-called chronic users, meaning they had complex and long-term need of health and social services (Table 1).

However, as holders of an IP, they were more or less novices. Four participants had recently been introduced to their plan; seven participants had had their plan from three to six months, and two participants were 'skilled users' in that they had had their plans for 2–4 years. In many ways, this was representative of the difficulty in recruiting participants for the study. The IP was introduced as a concept in 2001, but was difficult to launch because it is based on the principle that its management should override administrative boundaries. So, its implementation has not been as streamlined as hoped for, which might explain the difficulties experienced in the recruitment of participants for this study (Grut 2008; Bakke 2009).

Method

The case study is a form of qualitative descriptive research, drawing conclusions only about that participant or group and only in that specific context (Yin 2003). This case study presents detailed information about informants, so that the data can be searched for patterns that give meaning to the interplay of all the variables to provide as complete an understanding of an event or situation as possible. Making a case study is the preferred method when the researcher has little control over the events and when there is a contemporary focus within a real life context. The approach was, therefore, considered useful in this study, where the aim was to look at how users, whose progress needs to be followed up over the long term, expressed their needs during the IP process. Data were collected through semi-structured interviews of users, coordinators and the user's family. The researchers developed the semi-structured questionnaire. In this paper, the focus will be on the users' interviews; how the users expressed their needs and how they believed the coordinators had met those needs. The expressed needs were defined as those measures the client deemed necessary to maintain their independence and/or well-being.

A multidisciplinary group of six health and social researchers collected the data from the 13 participants. The interviewers were a variety of health professionals: nurses, social workers, physiotherapists and occupational therapists. The semi-structured interviews were performed and recorded in the participants' homes ($n = 6$), in health institutions ($n = 4$), at the professionals' offices ($n = 2$) and at the participants' work ($n = 1$). The interviews lasted for 1–2 hours and each participant ($n = 13$) was interviewed on one occasion. We obtained demographic and quantitative data from a questionnaire focusing on the personal and instrumental activities of daily living (ADL).

Analysis

Quantitative data were analysed using descriptive statistics in SPSS programme 18. The interviews were transcribed verbatim, and the texts were analysed using

interpretive text analysis (Malterud 2003). Each of the co-authors performed the analyses in several stages, in small groups and alone as follows:

(1) reading through the interviews as a whole on their own;
(2) discussing with the whole group of authors, structuring the material according to three themes and in relation to the patient's condition:
   • what needs were expressed by the participants?
   • how were these needs met?
   • what was perceived as influencing the process: positively or negatively?
(3) reading through the whole material again, but now divided into three subgroups of co-authors focusing on the three themes in II above, and extracting the essence of the statements in the interviews;
(4) searching for similarities and differences in the interviews with the clients and categorizing such similarities and differences into themes;
(5) interpreting the expressed needs and how they had seemed to be met with reference to the intentions of the IP and the theoretical framework.

Results

The users expressed their dreams and frustrations with respect to their needs. The expressed needs were many, but could be summarized in three categories: medical/physical needs, psychological needs and social needs (Berg and DeJong 1996). We did not find any major differences between the expressed needs of persons with physical conditions and those with psychiatric health conditions. However, persons with a newly acquired condition were more prone to express direct and substantial needs regarding their standard of living, assistance, aids and adaptations primarily related to practical issues in the personal activities of daily living (PADL), and the instrumental activities of daily living (IADL). Persons with a psychiatric health condition, on the other hand, were prone to talk about needs related to coping and to social interaction. Persons born with a physical condition spoke of needs similar to those of persons with a psychiatric health condition: a place to call their own, a social setting where they could act independently and as individuals, relating to the quality of life they would like to have.

Health, activity and participation

Most participants reported that they were in good or reasonably good health; only a minority reported poor health (Table 2).

Table 2.   Participants' self-evaluated health status.

	Very good	Good	Reasonably good	Poor	No answer
How would you describe your physical health at this moment?	1	6	4	2	
How would you describe your psychiatric health at this moment?	1	10		1	1

In general, participants were satisfied with their life and health (Table 3). However, nine of out of the 13 participants reported that they had anxieties. They worried about the following: pain conditions; progress of the disability; economic insecurity; families and friends; low activity levels; the need for more help and more supervision; and help with administering the taking of medication (Table 3).

The majority of participants, 70–75%, were independent in the PADL, and similar proportions were independent/dependent in the IADL (Table 4). As for occupational status, most participants had been working, but when interviewed, only 50% were still employed. Participants felt that their activity levels were adversely affected by their psychiatric or physical condition.

Expressed needs in the IP process

The type of services needed varied across the following range: contact with the supporting team ($n = 5$); psychiatric help ($n = 1$); help with housekeeping and with transport ($n = 2$); combined services from nurse, physiotherapist and home assistant ($n = 4$); or combined services ($n = 1$). These services were provided on weekly ($n = 4$) and daily ($n = 5$) basis for some participants, and for the rest ($n = 4$), the help was provided only when needed.

We analysed the expressed needs according to the protocol and to the theoretical framework; models, NPM, user involvement, empowerment and SOC. Three main categories were identified: medical/physical, psychological and social needs. Regarding medical/physical needs, 12 out of 13 participants expressed a need for help with medication; nine out of 13 participants expressed psychological needs and 11 of 13 mentioned social needs (Table 5).

Physical condition, expressed needs and how these were met

Medical/physical needs

The two persons with stroke had severe disabilities and were dependent for PADL and IADL. They expressed the need for physical exercise and training in order to return to activities and roles they had before their strokes. They had had their stroke just a couple of months earlier, had completed their rehabilitation in the hospital and were now living at home.

Their needs had been met regarding PADL and exercise, and both expressed confidence in their coordinators, helpers and IPs. However, there were some indications of slow processing regarding IADL, transport and financial support, and they thought that the legislation and administrative boundaries had hindered solutions. One of the users said:

> ...and so my house has been adapted to my condition, and it is an on-going process. It is time consuming.... You know, I forgot to specify to the workers, in which Easter holiday I thought the work was going to be done...It thought it would be Easter of 2008, but it is more likely they will finish the work sometime around Easter 2009... (Male, stroke patient)

Another client, dependent for PADL and IADL, who ended up having to move, experienced considerable difficulties in the local community's ability to meet her needs:

Table 3.   A survey of the capacity to perform instrumental activities of daily life among the participants.

	Yes	No	No answer	
Does your physical health influence your activity level?	9	4		
In your opinion, are you in need of more help or assistance than you receive now?	3	9	1	
Are you happy with your housing conditions?	12	1		
Do you have someone to talk to and be confident with?	13			
Are you lonely?	Almost never 5	Sometimes 4	Pretty often 4	
Is there someone who can help you if you are ill or in need of help?	11	2		
Do you meet relatives and/or friends as often as you like?	As often 7	Not as often as I would like 6		
Are you in need of more contacts than you have per day?		11	1	
Are you in need of assistance with your medication?	5	6	2	
Do you need any assistive devices?	7	6		
What?	Physical devices 4	Others 2	Security alarm 1	
Are you working?	6	7		
Were you working before?	11	1	1	
Do you feel comfortable with your financial situation?	8	4	1	
When you think of life now, are you satisfied with life in general?	8	Reasonably 5		
Are you worried about something in your situation?	Yes often 3	Yes pretty often 6	Almost never 4	
What is it that worries you?	Pain 2	The progress of the illness 1	Safety and care for family and friends 2	Money 2

Table 4. Participants' evaluation of their capacity to perform the personal activities of daily living.

	Independent	With some help	Dependent	No answer
Can you use the telephone?	10	1	1	1
Can you get to places out of walking distance (on public transport)?	7	6		
Can you shop for groceries and clothes?	8	3	2	
Can you prepare meals for yourself?	7	3	3	
Do you do house work?	5	4	4	
Do you feed yourself?	11	1		1
Do you dress yourself?	9	3	1	
Can you care for your personal hygiene?	9	3	1	
Can you walk?	10	1	2	
Do you need help getting in and out of bed?	10	3		
Do you need help to shower/bathe?	9	3	1	
Do you need help to use the toilet?	9	3	1	
Can you reach the toilet in time?	9	4		

> I got no help; it is shocking when you think of it, and I have since complained to the Health Ombudsman. So, people from the rehabilitation unit recommended that I should move to another community, because they knew there were differences between the two communities in the services they could offer. (Female, tetraplegic)

A woman, also dependent for PADL and IADL, had a similar experience. Likewise, she had chosen to move to another community to get adequate services.

Another elderly man, with tetraplegia, dependent for PADL and IADL, expressed a need for help in the PADL activities and the need for a personal assistant. The physical needs expressed were met with understanding and action. He stated:

> Basically it is they who control and manage this, and I just give them input when it does not work out properly. I cannot tell experienced people what to do. (Male, Tetraplegic)

Psychological needs

A middle-aged woman with an acquired condition, independent for PADL and IADL, expressed needs related to her medical condition, such as help to maintain

Table 5. The expressed needs reported by the participants divided into three categories and analyzed according to diagnosis, age and time perspective.

				Time perspective	
	Diagnosis ($n=13$)	Age <50 years ($n=11$)	Age >51 years ($n=2$)	New ($n=3$)	Long-standing ($n=10$)
Physical needs	12	10	2	3	9
Psychological needs	9	8	1	2	7
Social needs	11	11	0	2	9

dental health because of severe dentophobia, help to live independently at home and to receive services from the community.

Unlike other users, she felt that both her expressed physical and social needs were met satisfactorily. She felt respected and listened to, and that her psychological needs had been met with understanding and practical solutions. She stated:

> Well, I have chronic pain, and so I get two rehabilitation periods per year. It is recognized as one of the strategies for living and coping with pain'. (Female, Encephalitis)

Social needs

A young man with a lifelong experience of disability had a progressive syndrome slowly making him more in need of help mainly for IADL. He said he needed help to get a job, transport to work, a place to live independently of his parents and a meaningful life. He mentioned other needs related to more technical assistance to maintain his independence in his activities of daily living.

His expressed needs had been met with suspicion regarding the need for technical assistance. The process did not empower him or enable his independence. His social needs had not been met at all, and he felt he had to struggle with the system. He had found the process tiresome and exhausting and it had left him feeling resigned and disillusioned. His frustration was expressed verbally thus:

> I have had some bad experiences with the representatives of the Norwegian Labour and Welfare administration; they have not done a good job. As for example, when I was offered a position, I needed some assistive aids in order to 'get going' and the representative from NAV did not send a requisition order to the technical aid centre for 10 weeks. (Male, progressive syndrome)

The same client also felt that the promised services had not been fulfilled:

> you are not always met with respect and trust . . . . . . I have had a hard time communicating with them (NAV). And they have promised things and then broken their promises. So I am getting more and more disillusioned with the whole system. (Male, progressive syndrome)

This experience was in contrast to that of another young man with cerebral palsy and a lifelong contact with health and social services. He felt his expressed needs had been met and that the coordinator had 'opened doors' for him. He felt he had support and that he was involved in the process.

A middle-aged man with a severe progressive disability also mentioned his need of assistance in maintaining his independence, such as a support person and help to do the paperwork for applications. He also expressed a need for suitable work and organized social inclusion.

His expressed needs for physical assistance had been met very satisfactorily, but regarding social needs, he felt resigned, but accepted the limitations of his condition, as he said: 'it works . . . It could perhaps have been better . . . but, on the other hand, so can everything'.

To sum up, the following factors influence outcomes related to needs expressed by users with physical disabilities:

- municipality or district of residence; personal competence of the coordinator;
- interpretation of legislation and structural conditions.

Some of the needs of persons with visible physical disabilities seemed to be easier to meet than others. Needs such as practical caring services, rehabilitation and assistance were met, but the social and personal needs (like finding suitable work, financial support or support for re-education) were not so easily negotiable.

Psychiatric health condition, expressed needs and how these were met

Medical/physical, psychological and social needs

A young female with a psychiatric condition said she needed help to stay 'healthy'; that is, help with medication, help with maintaining daily routines, thereby stopping outbreaks of the illness. She also expressed needs with health advocacy, like help to structure her life, for a motivator and support person, but also said she needed to be independent, free and unrestricted by other people. She needed suitable work and a support contact/personal assistant to help her with social interaction and activities.

Her expressed physical and psychological needs had been greeted with understanding and flexibility after she moved to a new municipality. The social needs she had mentioned were also met with practical assistance and support. She perceived the coordinator as a 'door-opener':

> Well, she has shown me the way, and she has been a door-opener for me to get back to work again. It has been very important to me'. (Female, Bipolar condition)

A middle-aged man, with the same psychiatric condition, expressed a need for help with medication, help with the organization of practical issues, contact with the social services, the organization of his financial affairs and help to structure and organize life. He also said he needed help to find a place to live, a resource person 'on call', and he also had worries about his immediate family. The medical needs he had stated had not been met, because of perceived administrative boundaries in that the doctors in the hospital and in the community had different views on his medication and this led to poor communication between medical service institutions. His psychological needs had been met; however, the psychological support for and communication with his family were lacking. The system had no routines for handling the stress experienced by the close family:

> The mother of my children is frustrated over the fact that the children's needs have not been taken care of and that she has received little or no information regarding my unstable condition. It has been hard for her to plan things and she gets reactions from the children when they experience serious incidents because of my condition. She feels alone and has no one to share with . . . (Male, bipolar condition)

His social needs, on the other hand, were 'balanced' and in constant process thanks to the attention of experienced helpers within the system.

A woman with a psychiatric condition said she needed help with financial matters, the structure of her daily life, meals, doctor's appointments and exercise. And she also said she needed help with staying 'healthy', which was related to her awareness of the consequences of her condition. She wanted to 'be normal', that

is, to live without the negative consequences of her condition. She asked to be respected as a person and to be able to envisage having an occupation or work in the future:

> Hmm . . . I don't always enjoy meeting the coordinator. I suppose it has something to do with the fact that I am . . . well, it is hard for me to relate to the fact . . . that I am ill and need help. (Female, bipolar condition)

Her stated physical and psychological needs were met through communication, cooperation and teamwork between her, the coordinator and the IP group. Her social needs had been met within the legislative possibilities, with a suitable job, and she had been allocated a personal assistant:

> I have this job, an adapted assignment. I do have the experience of working, of having responsibility and so forth. It is not paid, but it has been valuable . . . it means a lot to me, to use myself and my experience and that I can contribute something to the community. It comes down to being seen and listened to. (Female, Bipolar condition)

A younger female with an acquired psychiatric condition expressed a need for help to manage a better balance between rest and activity: to re-learn and recognize the limitations of her own bodily capacities. She wanted people to understand that it takes time to recover; she also said she needed financial support, guaranteed planned services and a retraining programme.

The needs she had expressed regarding her medical condition had not been met with understanding at first, mainly because of structural boundaries. However, through the coordinator's sympathy and knowledge of the system, the participant's medical, social and psychological needs had now been met. She had expressed her needs in a letter to the coordinator:

> So, when I came back to the Norwegian Labour and Welfare administration, my contact person said he had received my letter and supported my wishes. He said it was a good plan and that he honestly could not come up with a better solution or alternative. 'It seems the right thing for you', he said. (Female, anxiety condition)

To sum up, the factors influencing outcomes related to needs expressed by users with psychiatric health issues were the following:

- The coordinators and the IP meetings were in many ways reported as stabilizing pillars/good support, but were sometimes a reminder of a failure to live independently.
- The coordinators were viewed as 'door-openers' to services and as providers of solutions for the users. The notion was often related to the coordinator's status, knowledge of the system or personal qualities.
- There were also examples of dissatisfaction with the processes and of feeling stripped of integrity and pride.

Some users accepted the ambivalence between desiring independence and recognizing their need for professional help as an existential crusade; that is to say, they needed psychological acceptance, to distance themselves from the helper and the 'system', or a 'time-out'.

Discussion

This study focuses on the users ' perspectives on the IP process, from the client's expressed needs to services that had been granted, and on analyses of how the type of disability had influenced the outcomes of the process.

On one hand, age and the reason for the disability, diagnosis or performance seemed to have little or no influence on participants' expressed needs. Participants displayed a mixture of medical, psychological and social needs unrelated to age or diagnosis. They were disabled in the context of ICF′s activities and participation, and the underlying physical or psychological conditions resulted in similar problems regarding their participation in daily life. This finding is in line with disability as a function of the body, the person and the environment (WHO 2011). To solve these problems, it is not enough to cure the condition or change the environmental context, as suggested in a medical or social model. The following must be explored: the possibilities that lie within the 'user'/patient, the empowerment process and the possibility of optimizing performance through enabling processes and rehabilitation goals (Hammell 2006; WHO 2011).

The time from the onset of the disability, on the other hand, influenced both the expressed needs and the processes. Participants with newly acquired conditions had direct and substantial needs, in contrast to persons born with a physical disability or persons with a psychiatric health condition. The direct and substantial needs they had mentioned concerned adapted housing, assistance primarily related to the performance of PADL and rehabilitation. All their expressed needs were closely related to the immediate needs presented by a changed life situation. Persons born with a physical disability and persons with a psychiatric health condition, by contrast, expressed more psycho-social needs, such as a place to call their own and a social setting where they could be independent and be viewed as individuals. Their variously expressed needs might indicate a certain maturation and development regarding psychological acceptance of a condition that one must live with, acceptance of the psycho-social consequences and a high level of SOC (Hayes et al. 2006; Breeding 2008; Ruiz 2010). It could be seen as empowerment of the individual with expectations of mutual collaboration between themselves and health and social workers (Webb 2008).

Participants with a newly acquired disability may be in a period requiring them to understand and manage a new situation. Their expressed needs are part of their strategy to cope and find new meaning in a changed life situation, related to their sense of coherence (Antonovsky 1979, 1987).

A recently acquired medical condition seemed to be experienced and handled as something that would be curable, and the expectation of returning to 'normal life' was strong. This expectation may reflect either a pre-understanding of a medical model or a poorly processed psychological adjustment to the new situation (Engel 1977; Hayes et al. 2006). In a bio-social psychological model/perspective, a process of adaption, both physically and psychologically, is expected as a prerequisite part of rehabilitation (Pilgrim 2002). People with chronic or progressive medical and psychological conditions, and professionals, should ideally not focus on 'cure' only, but rather on acceptance and coping in a wider perspective (Engel 1977; Hayes et al. 2006; WHO 2011). In this study, the people who had lived several years with a condition wanted to be part of and accepted by society as they appeared and were as individuals. This finding is in line with WHO's ICF, which considers the experience

of disability as a universal human experience, including medical, biological, social, contextual and personal factors. From this perspective, it follows that disability is not something that happens to a minority of humanity, but rather that every human being can experience a decline in health and thereby experience some degree of disability (Pilgrim 2002; WHO 2011).

How people´s dreams were met by the 'dream catchers' depended on administrative and legislative frameworks and on the coordinators' position within the system hierarchy. Furthermore, it was dependent on the coordinators' knowledge and experience, and their skills in communicating with other professionals and users. Last, but not least, it was also dependent on their skill in manoeuvring, in the sense of knowing their way around in the system. This supports the notion of IPs as effective tools in multidisciplinary and inter-agency collaboration (Hansen 2007).

The competence of helpers and how they perform their role are important. Informants reported that helpers and the rehabilitation process were facilitators in this process, and that the IP seems to fill this function to a certain degree (Kjellevold 2005; Bakke 2009). User involvement regarding the IP seemed to have an empowering effect on the users; they became aware of their own rights and strengths, and aware that they have a 'voice' in their own process (Ministry of Labour, St. meld. Nr. 34: 1996–1997; Walseth and Malterud 2004; Elstad and Eide 2009). Nevertheless, the process could also be experienced as intimidating and as exposing the client's weaknesses or failures. This feeling of poor esteem might have the opposite influence, and adversely affect coping and empowerment in the IP process, leading to a low level of SOC (Breeding 2008).

The IP process also exposed difficulties related to manoeuvring within the health and social systems, focusing on various pieces of legislation, different interpretations, different management levels and different levels of attention to cooperation, thus encapsulating the tension between the individual and the framework of health and social services (Hansen 2007; Slettebø et al. 2011). The participants created different solutions; however, difficulties remained unsolved. These different solutions and the remaining difficulties are probably representative for many persons with disabilities, and need to be discussed and met to sustain the credibility and use of the IP (Ministry of Health and Care Services, St. meld. 47: 2008–2009; Slettebø et al. 2011). Furthermore, the establishment of NPM as an ideal led to the prioritization of clients with fewer problems, so that the number of cases in which IPs were successfully delivered increased.

Earlier findings revealed that the power to define what was important in the IP process depended on the knowledge possessed by both client and coordinator, and on how this knowledge was expressed through language and communication (Kjellevold 2005; Ministry of Health and Care Services, St. meld. 47: 2008–2009; Solli-Sæther 2009; Slettebø, et al. 2011). Such findings support the argument for empowering the coordinator's right to implement the IP as a working tool in accordance with the legislation (Bakke 2009). However, it also puts into focus different interpretations within the different municipalities or districts' health and social services, and the consequences these have for the individual when it comes to receiving services and help. The accessibility of services in response to needs has been met differently in different municipalities or districts. This difference in accessibility of services may be perceived as a social injustice, and therefore the need to work for equal accessibility to services throughout the country appears to be warranted (Ministry of Health and Care Services, St. meld. 47: 2008–2009).

This study, however, has some limitations. It has focused on analysing the IP process. Informants were invited and volunteered to participate, which makes the data selective material and, therefore, perhaps not representative of a general population. The sample did not include drug addicts or children with disabilities. However, participants had different medical, psychological, congenital and acquired conditions and disabilities. The variety and the small sample represent a hetero-geneous sample, which does give insight into the experience of different individuals with IPs. On the one hand, there were more cases of chronic than acute conditions, so that the picture of the acute situation may be incomplete. On the other hand, the focus on chronic conditions may be more in line with the intentions for IPs, where the target group consists of persons with complex and long-standing conditions. This study highlights the tensions of the service providers′ commitment to providing quality services and the target of cost saving and coordinated care, and also the tensions between individuals′ needs and the system limitations. It also shows how elapsed time after an acquired disability seems to affect the needs that the client feels, shifting from physical to social needs, and so this paper has made a contribution to the disability literature.

Conclusion

Expressed needs/'dreams' are related to physical, psychological and social needs. The dreams expressed do not differ between persons with physical or psychiatric health conditions, or between persons born with a disability or those who acquire one. However, the time elapsed after a disability has been diagnosed seems to show how needs shift from the physical towards social needs. Persons with a newly acquired physical disability are more prone to have substantial worries about their standard of living, assistance, aids and adaptations. People with a psychiatric health condition relate their dreams to coping and to social interactions. Those born with a physical disability express needs more closely related to those with a psychiatric health condition, that is, needs more closely related to their quality of life: a place to call their own and a social setting where they can act independently and as individuals.

How expressed needs are met or how dreams are caught depends on adminis-trative and legislative boundaries, on the interpretation of the same and on the coordinators' position within the hierarchy of the administrative system. Both processes also depend on the coordinators' knowledge and experience, on their skills in communicating with other professionals and with users, and, last but not the least, on their ability to manoeuvre within the systems.

References

Alve, G., V. Madsen, Å. Slettebø, E. Hellem, K. A. Bruusgaard, and B. Langhammer. 2012. "The Individual Plan in Rehabilitation Processes: A Tool for Flexible Collaboration." *Scandinavian Journal of Disability Research*. doi:10.1080/15017419.2012.676568.

Andersen, S. S. 1997. *Case-studier og generalisering: Forskningsstrategi og design* [Case Studies and Generalization. Research Strategy and Design]. Bergen: Fagbokforlaget.

Antonovsky, A. 1979. *Health, Stress and Coping*. San Francisco: Jossey-Bass.

Antonovsky, A. 1987. *Unravelling the Mystery of Health: How People Manage Stress and Stay Well*. San Francisco: Jossey-Bass.

Bakke, T. 2009. *I have a Plan*. Report 15-1672. Oslo: Norwegian Directorate of Health.

Berg, K., and P. DeJong. 1996. "Solution Building Conversations: Co-constructing a Sense of Competence with Clients." *Families in Society* 77: 376–391. http://www.familiesinsociety.org/Show.asp?docid=934.

Bradshaw, P. L. 2008. "Service User Involvement in the NHS in England: Genuine User Participation or a Dogma-Driven Folly? *Journal of Nursing Management* 16 (6): 673–681. doi:10.1111/j.1365-2834.2008.00910.x.

Breeding, R. R. 2008. "Empowerment as a Function of Contextual Self-Understanding: The Effect of Work Interest Profiling on Career Decision Self-Efficacy and Work Locus of Control." *Rehabilitation Counseling Bulletin* 51 (2): 96–106. doi:10.1177/0034355207311346.

DiMatteo, M. R., K. B. Haskard, and S. L. Williams. 2007. "Health Beliefs, Disease Severity, and Patient Adherence: A Meta-Analysis." *Medical Care* 45 (6): 521–528. doi:10.1097/MLR.0b013e318032937e.

Elstad, T. A., and A. H. Eide. 2009. "User Participation in Community Mental Health Services: Exploring the Experiences of Users and Professionals." *Scandinavian Journal of Caring Sciences* 23 (4): 674–681. doi:10.1111/j.1471-6712.2008.00660.x.

Engel, G. L. 1977. "The Need for a New Medical Model: A Challenge for Biomedicine." *Science* 196 (4286): 129–136. doi:10.1126/science.847460.

Fudge, N., C. D. Wolfe, and C. McKevitt. 2008. "Assessing the Promise of User Involvement in Health Service Development: Ethnographic Study." *British Medical Journal* 336 (7639): 313–317. doi:10.1136/bmj.39456.552257.BE.

Grut, L. 2008. *Erfaringer med bruk av individuell plan. En litteraturoversikt* [Experiences with the Use of Individual Plans. A Review of the Literature]. Oslo: SINTEF. Rapport A6178.

Hammell, K. W. 2006. *Perspectives on Disability & Rehabilitation: Contesting Assumptions; Challenging Practice*. Edinburgh: Churchill Livingstone/Elsevier.

Hansen, G. V. 2007. "Samarbeid uten fellesskap. 0m individuelle planer i kommunalt psykisk helsearbeid [Collaboration and No Community. Individual Plans in Community Based Psychiatric Health Care]." PhD thesis. Karlstad: University studies.

Harding, A., and A. Preker. 1999. *Innovations in Health Service Delivery: Corporatization in the Hospital Sector*. New York: Oxford University Press.

Hayes, S. C., J. Luoma, F. Bond, A. Masuda, and J. Lillis. 2006. "Acceptance and Commitment Therapy: Model, Processes, and Outcomes." *Behaviour Research and Therapy* 44 (1): 1–25. doi:10.1016/j.brat.2005.06.006.

Jeffersson, T. 1776. *US Declaration of Independence*. Accessed April 26, 2013. http://www.archives.gov/exhibits/charters/declaration_transcript.html.

Kjellevold, A. 2005. *Retten til individuell plan* [The Right to an Individual Plan]. Bergen: Fagbokforlaget.

Levi, R. 2010. "New Public Management. End of an era? *Public Policy and Administration* 25: 234–239. doi:10.1177/0952076709357152.

Malterud, K. 2003. *Kvalitative metoder i medisinsk forskning- en innføring* [Qualitative Methods in Medical Research – an Introduction]. Oslo: Universitetsforlaget.

Ministry of Health and Care Services. 2004. Forskrift om individuell plan etter helselovgivningen og sosialtjenesteloven [Regulations on Individual Plans for Health Care Legislation and Social Services]. (FOR 2004-12-23 nr 1837). Oslo: Sosialtjenesteavdelingen.

Ministry of Health and Care Services. 2009. "The Coordination Reform: Proper Treatment – At the Place and Right Time." (Samhandlingsreformen: Rett behandling – på rett sted – til rett tid. Oslo: St.meld. nr. 47; 2008–2009). Accessed August 16, 2012. http://www.regjeringen.no/upload/HOD/Dokumenter%20INFO/Samhandling%20engelsk_PDFS.pdf.

Ministry of Labour. 1997. *Resultater og erfaringer fra Regjeringens handlingsplaner for funksjonshemmede og veien videre* [Results and Experiences from the Government's Plans for Disabled and the Way Forward] (34: 1996–1997). Oslo: Stortingsmelding.

Nickel, J. 2006. *Human Rights*. Stanford: Encyclopedia of Philosophy, Stanford University.

Pilgrim, D. 2002. "The Bio Psychosocial Model in Anglo-American Psychiatry: Past, Present and Future." *Journal of Mental Health* 11 (6): 585–594. doi:10.1080/09638230020023930.

Norwegian Board of Health Supervision. 2010. Rettigheter til helsetjenester [Rights to Health Care]. Accessed January 2, 2012. http://www.helsetilsynet.no/no/Rettigheter-klagemuligheter/Rettigheter-helsetjenester/.

Norwegian Directorate of Health. 2011. "Kartlegging av individuelle planer i landets kommuner 2011 [Mapping of Individual Plans in the Country Municipalities in 2011]." Accessed March 15, 2013. http://helsedirektoratet.no/helse-og-omsorgstjenester/habilitering-rehabilitering/individuell-plan/Documents/kartlegging-av-individuelle-planer-i-landets-komm uner.pdf.

Norwegian Directorate of Health. 2010. "*Brukermedvirkning – psykisk helsefeltet. Mål, anbefalinger og tiltak i Opptrappingsplanen for psykisk helse* [User Participation – Psychiatric Health Care. Goals, Recommendations and Actions in the Plan for Psychiatric Health]. (IS-1315)." Oslo: Norwegian Directorate of Health.

Norwegian Labour and Welfare Service Health. 2012. Accessed January 2, 2012. http://www.nav.no/Helse/, http://www.nav.no/English.

Ruiz, F. J. 2010. "A Review of Acceptance and Commitment Therapy (ACT) Empirical Evidence: Correlational, Experimental Psychopathology, Component and Outcome Studies." *International Journal of Psychology and Psychological Therapy* 10: 125–162. Accessed April 26, 2013. http://xa.yimg.com/kq/groups/8446968/1695767363/name/A+reveiw+of+ACT+evidence+2010.pdf.

Shakespeare, T., and N. Watson. 2001. "The Social Model of Disability: An Outdated Ideology? *Research in Social Science and Disability* 2: 9–28.

Slettebø, T. 2000. "Empowerment som tilnærming i sosialt arbeid [Empowerment as Approach in Social Work]." *Nordisk sosialt arbeid* 2: 75–85.

Slettebø, Å., E. Hellem, K. A. Bruusgaard, V. Madsen, G. Alve, and B. Langhammer. 2011. "Between Power and Powerlessness: Discourses in the Individual Plan Processes, A Norwegian Dilemma." *Scandinavian Journal of Disability Research*. http://dx.doi.org/10.1080/15017419.2011.574846.

Smith, G. 1980. *Social Need. Policy, Practice and Research*. London: Routledge & Kegan.

Solli-Sæther, H. 2009. Organisatorisk modenhet og nytten av samhandling [Organizational Maturity and Utility of Interaction]. Stat & Styring nr. 4. Oslo: Universitetsforlaget.

Sørbye, L. W., E. V. Grue, and E. Vetvik. 2009. "Kunnskap om svikt i tjenester til skrøpelige eldre. Nyere norsk forskning relatert til helse – og sosialtjenesten." Oslo: Diakonhjemmet. rapport 2009/5. Accessed March 15, 2013. http://www.helsetilsynet.no/upload/Publikasj-oner/andrepublikasjoner/kunnskap_svikt_jenester_skroepeligeeldre2009.pdf.

Thomas, K. W., and B. A. Velthouse. 1990. "Cognitive Elements of Empowerment: An 'Interpretive' Model of Intrinsic Task Motivation." *Academy of Management Review* 15 (4): 666–681. Accessed April 26, 2013. http://amr.aom.org/content/15/4/666.abstract.

United Nations Document. 1948. "The Universal Declaration of Human Rights." Accessed December 12, 2011. http://www.un.org/en/documents/udhr/.

Walseth, L. T., and K. Malterud. 2004. "Salutogenesis and Empowerment in the Perspective of General Practice." *Tidsskrift For Den Norske Lægeforening* 124: 65–66. Accessed April 26, 2013. http://tidsskriftet.no/article/953695/.

Webb, S. A. 2008. "Modeling Service User Participation in Social Care." *Journal of Social Work* 8 (3): 269–290. doi:10.1177/1468017808091040.

World Health Organisation. 2011. "The International Classification of Functioning, Disability and Health." Accessed December 11, 2011. http://www.who.int/classifications/icf/en/.

Yin, R. K. 2003. *Case Study Research: Design and Methods*. California: Sage Publications.