

Client participation in medical rehabilitation for adults with severe disabilities

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The Social Insurance Institution (SII) of Finland arranges medical rehabilitation for people with severe disabilities. The rehabilitation process requires collaboration between the client and several organizations and professionals. The study aimed to find out what kind of experiences persons with disabilities had on their possibilities of participation in the planning and process of rehabilitation, and what factors were associated with the degree of their participation in the rehabilitation process. The study group was chosen using stratified sampling from among rehabilitation clients. The data were gathered using a questionnaire survey. Over half of the clients reported having participated actively in the rehabilitation planning and most found that their opinions had been taken into account at least fairly well during the planning phase. The results indicate that special attention should be paid to developing client-driven approaches in the rehabilitation system and to supporting the participation of clients who have difficulties in expressing their needs because of their illness, disability, or educational and social backgrounds.

Keywords: participation; medical rehabilitation; adults; severe disabilities

This study addresses medical rehabilitation for adults with severe disabilities. In Finland, the public health care system is primarily responsible for arranging medical rehabilitation for persons with disabilities. The Social Insurance Institution (SII) of Finland is a major provider of vocational and medical rehabilitation as well as income security during participation in rehabilitation. It has a statutory liability to provide so-called demanding medical rehabilitation for people with severe disabilities, which aims to maintain or improve the work capacity or functioning and promote the autonomy of individuals who have a long-lasting need for rehabilitation on the basis of chronic illness or injury.

In 2006, the SII started a project that aimed to develop good practices in medical rehabilitation arranged for persons with severe disabilities. The purposes of this project were, among others, to describe the current practices in rehabilitation for severely disabled persons, to highlight the needs for development and to draw up guidelines for good rehabilitation practice, including client-centredness, the holistic approach, optimal timing and long-term follow-up (see Paltamaa et al. 2011). As a part of the project, the research group at the University of Lapland and the Rehabilitation Foundation investigated the experiences that the service users and their proxies had with the rehabilitation planning and

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the rehabilitation process (Järvikoski, Hokkanen, and Härkäpää 2009). The study included both a quantitative and qualitative part.

The aim of this sub-study is to find out how adult clients with severe disabilities perceive themselves in terms of participation and being heard during the medical rehabilitation process, basing on a questionnaire survey of the clients. A special interest is in finding out whether there are differences in participation perceptions based on gender, impairment or disability, and socio-economic situation. All clients should have equal opportunities to be heard and to participate in decision-making in their rehabilitation, in spite of their life situation. The question of what factors – both individual and system based – are associated with better possibilities to participate, has not been a focus in quantitative studies. Hagen-Foley, Rosenthal, and Thomas (2005) found, however, that the extent of informed choice and participatory planning in community-based rehabilitation differed according to the level of difficulties caused by the impairment: persons with more difficulties perceived themselves less informed than others.

The research questions of this study are:

- (1) How do persons with disabilities perceive their possibilities to participate in the planning and process of their rehabilitation and how they experience the correspondence between their needs and the implemented rehabilitation?
- (2) What factors are associated with the service users' experience of their possibilities of participation?

Client-centredness and participation in rehabilitation

Client-centredness

Client-centredness has emerged as an important concept in rehabilitation during the past few decades. It aroused from a critic against the clinical model in rehabilitation, in which persons with disabilities were only reduced to their illnesses and disabilities (see Anderson 1975; Stubbins and Albee 1984; Järvikoski and Härkäpää 1995). This development had clear connections with civil rights movements and independent living movements in the 1960s and 1970s (deJong 1979; Rothman 2001). Safilios-Rothschild (1976) pointed out that the client should be a central agent in rehabilitation planning and decision-making and the professional should be a supporter in this process, acting more as a consult than an authority in goal-setting. She concluded that this would mean transferring some of the decision power from the professional towards the client. A related view was that the clinical model of rehabilitation should be substituted with the ecological model that emphasizes the role of environment in the disability process and environmental change as an important means in rehabilitation (Stubbins and Albee 1984).

Respecting the client's dignity and autonomy, seeing behind the client's disability, is usually regarded as a basic ethical principle in all rehabilitation. According to Leplege et al. (2007) person-centredness represents anti-reductionism in rehabilitation: clients are not only reduced to their disabilities, but their subjectivity and living environments are also taken into account. Client-centredness is, however, a concept that has been used in several meanings. The authors found four different ideas behind this concept: (1) addressing the client's individual, specific and holistic properties; (2) addressing the person's difficulties in everyday life, in his/her social and physical environments; (3) seeing the client as an expert in his/her rehabilitation, and emphasizing participation and empowerment; and (4) respecting the person and his/her capabilities behind the disability. Cott (2004) found similar components for client-centredness in her focus-group study,

using people with disabilities as informants. Emotional support and sharing information and education according to the client's wishes also appeared as its components.

These different views can be interpreted either as the dimensions of one practice or as representing essentially different approaches. The third idea, seeing the client as an expert of his/her rehabilitation, differs from the others in that it requires a radical change in the collaborative relation between the professional and the client. According to Hammell (2006), this approach advocates the client's rights to make and enact choices and thus requires a fundamental realignment of power (p. 155).

A solution for the discordant meanings of the client-centredness has been sought with different terms. Gage (1995) suggested a term 'client-driven practice' for the approach in which decision-making control is placed in the hands of the client. In Finnish, there are two terms that describe two different approaches. The concept *asiakaskeskeinen kuntoutus* (client-centred rehabilitation) was introduced in the 1990s as an antithesis for the clinical model in rehabilitation (see Järvikoski and Härkäpää 1995), but was later on substituted by the concept *asiakaslähtöinen kuntoutus* (client-driven rehabilitation), which more clearly emphasizes the client's active role in planning and decision-making. The client-centred practice is client-driven (*asiakaslähtöinen*) only if it is implemented with the client, not for him: then he/she is no longer an object but participates in the planning and implementation of services together with the professionals (Virtanen et al. 2011).

Kosciulek (2000) uses a similar but more policy-oriented term 'consumer direction' of an approach in rehabilitation which emphasizes disabled persons' possibility not only to participate in planning and making decisions on their own rehabilitation but also to participate in planning services for people with disabilities in general. This approach presupposes the possibility for the client (1) to direct the delivery of services, (2) to choose from several service options, (3) to receive appropriate information and long-term support, and (4) to participate in design and allocation of rehabilitation services. Through having the opportunity to make choices, the clients have the possibility to strengthen their personal control and also to influence social and political systems.

Autonomy and participation

The theoretical concepts behind the client-centred and client-driven approaches are autonomy and participation, respectively. In disability policy, autonomy refers to the right of a person or his/her family to make decisions and exercise control over what happens to him or her, without influence or interference from others (Stowe, Rutherford Turnbull, and Umbarger 2005); it implies independence and self-determination. In rehabilitation as in health and social care in general, there is always a danger that professionals have paternalistic or belittling attitudes towards people with disabilities, which form a barrier to autonomy. In another view (see Schipper, Widdershoven, and Tineke 2011), autonomy means the possibility to direct one's life according to personal convictions and being free to pursue one's own goals. This view does not emphasize independence but collaboration: autonomy often requires interaction with others who may give information, stimulate reflection and give social support. In analysing rehabilitation clients' autonomy, Cardol, de Jong, and Ward (2002) separate decisional autonomy, which refers to a person's ability and possibility to make decisions, and executional autonomy, which refers to his/her ability to act on the basis of these decisions. Rehabilitation professionals may help their clients in providing meaningful information that facilitates the possibility to make decisions and help in achieving the goals.

Participation, in turn, is regarded as the involvement in systems and decisions of the people who are directly affected (Stevens, Bur, and Young 1999) or as the involvement of an individual in life situations (WHO 2001). Participation can thus be seen as referring to social activities and consumption as well as making choices and decisions (Hill et al. 2004). Participation can be seen both as a means towards social inclusion and as a goal as such, and Stevens, Bur, and Young (1999) regard participation 'as the opposite to the process of social exclusion'. One motive behind promoting participation is to enable marginalized or disadvantaged people to exert a greater degree of control over their own lives and the political, economic and social structures which shape their communities (see also Hammel et al. 2008).

Jenkinson (1993) emphasizes that, with persons with intellectual disability, participation in planning and decision-making is in accordance with the principles of human dignity and autonomy but also brings about other benefits, such as increased motivation and task performance. In rehabilitation, client participation refers to the client's possibility to have an active role in planning, make decisions and participate in the evaluation of outcomes during the rehabilitation process. Possibilities of participation and mutual collaboration during the rehabilitation process can strengthen the client's autonomy and his/her sense of mastery. It is believed that it may contribute to removing barriers in the process towards stronger involvement in life situations.

The participation of the rehabilitation client does not, however, guarantee that the client is able to exercise the influence that they have a right as citizens (Normann, Sandvin, and Thommesen 2004, 100). To analyse the client's autonomy and participation is not possible without mentioning power. In the relationship between the client and the professional, there is always an imbalance of power, which is built into the rehabilitation system (Masterson and Owen 2006). The power of rehabilitation professionals is based on expertise and the control of service allocation. Professionals 'have the power to determine who has access to services, what to provide and how much' (Chan 2002). They can act as gatekeepers for particular services and decide if the client's wishes are realistic and valid. They can use their power to control their clients 'in ways ranging from obvious management of resources and decisions to subtle behaviours that highlight and reinforce the power imbalance in the relationship' (Clapton and Kendall 2002). Client-centred practice means sharing power: it requires that the professionals transfer some of their decision power, based on their expert knowledge, to their clients (see Safilios-Rothschild 1976). This transfer is typical especially in the client-driven approach of the client-centred rehabilitation.

Medical rehabilitation of people with severe disabilities

The medical rehabilitation for people with severe disabilities, as provided by the SII, is originally based on the rehabilitation legislation in 1991. As medical rehabilitation otherwise belonged to the responsibilities of municipalities, the goal of the legislation was to create a system that would ensure equal opportunity for demanding and expensive rehabilitation for all citizens having severe disabilities, regardless the economic standing of one's municipality of residence. Legislation aimed to ensure rehabilitation for people in the most disadvantaged positions. One of the problems of the legislation was then and still is, however, that it sets a label of severe disability for rehabilitation clients, and this label may undermine their expectations of the future possibilities (see Autti-Rämö, Faurie, and Sakslin 2011).

According to the act of rehabilitation provided by the SII, medical rehabilitation for people with severe disabilities is aimed at children, adolescents and adults who have a medical certificate about their need for rehabilitation and receive Disability Allowance or Pensioners' Care Allowance at its highest or increased rate. *Disability Allowance* for people aged 16–65 years is aimed at making it easier for disabled persons to manage their everyday activities and to cope with their work and studies. The allowance can be awarded to people who have an illness or injury which will reduce their functional capacity for a period of at least one year. Its purpose is to compensate for the hardship, the need for assistance, the need for guidance or supervision, and/or the costs resulting from an illness or injury. Disability allowance at the highest rate can be awarded to people who need substantial outside assistance on a daily basis or who incur substantial expenses from their disability, and disability allowance at the increased rate can be awarded to people whose hardship is considerable and who need outside assistance or supervision at least weekly or have expenses that are at least equal to the amount of the increased disability allowance per month. *Care Allowance for Pensioners* is intended to help pensioners with a long-term illness or disability with their daily activities, to assist with the maintenance of their functional status, and to support their care and rehabilitation. It provides compensation for some of the costs arising from a decline in functional capacity. A person is eligible for the highest rate if his/her illness or injury results in an around the clock assistance and guidance by another person and for the increased rate if his/her illness or injury results in a daily need of several personal activities (such as eating, getting dressed, washing) or need for regular guidance and supervision.

Receiving disability allowance or pensioners' care allowance at its highest or increased rate is thus a precondition for eligibility for rehabilitation for people with severe disabilities. As the costs arising for a person from the disability form one of the criteria applied in estimating the rate of allowance, the present legislation can lead to a situation where people with higher incomes meet the criteria more easily than others and are, consequently, more easily regarded as eligible for rehabilitation (Virta 2006).

Eligibility for rehabilitation also requires a statement on the need for rehabilitation and a rehabilitation plan. Preparing them is the responsibility of a public health care physician and thus separated from the implementation of rehabilitation, which is the responsibility of the SII. According to the legislation, preparing the rehabilitation plan should always take place in collaboration with the client and/or his or her proxy. It is also recommended that the client's own therapist is heard during the planning process. Nikkanen (2010) describes three practices that are used in the planning. In the physician-centred model, planning is based on earlier documents and the physician's meeting with the client. The cooperation model is based on strictly divided responsibilities, i.e., a rehabilitation counsellor or social worker is responsible for preparing the plan with the client, whereas the physician accepts and signs the plan. The team model is based on multi-professional collaboration, where the team members meet the client together as a part of the planning process. After the preparation of the plan, the application for rehabilitation measures is submitted to the SII which makes the administrative decision regarding the rehabilitation. In decision-making, the plan is viewed as a recommendation that assists the SII in the decision-making, together with other documents – not an obligation (see Nikkanen 2010, 7). Rehabilitation measures can include individual multimodal rehabilitation in rehabilitation centres, rehabilitation courses arranged for groups or individual therapies (e.g., physio- or occupational therapy, neuropsychological rehabilitation, psychotherapy). Rehabilitation is arranged by private service providers that

can be individual therapists or rehabilitation centres and takes place in in- or outpatient settings in rehabilitation centres, on a therapist’s premises, or the client’s home. A thorough assessment of the results is also needed when updating the rehabilitation plan or considering the next measures (Figure 1).

A special characteristic in this form of rehabilitation is the separateness between the organization responsible for rehabilitation planning (public health care), the organization responsible for organizing rehabilitation and covering its costs (the SII), and the private service providers. Medical rehabilitation arranged for adults with severe disabilities thus requires cooperation between several actors and organizations, which makes the process demanding and sometimes difficult for the client.

Method

The study was based on a questionnaire survey. Ethical approval for the study was granted by the ethical committee of the SII. The participants received detailed information about the study and its purpose in the cover letter for the questionnaire; it was also emphasized that answering the questionnaire was voluntary.

The study group was chosen using stratified sampling from among people aged 20–64 years, who had applied for rehabilitation arranged by the SII and whose application was accepted in 2005. The sample ($n = 1443$) was stratified by age, sex and disability benefit. The questionnaires were sent by mail. As poor return rates are typical particularly in people most affected by their disability, the proxies were allowed to answer on the service users’ behalf when needed. Altogether 818 (57%) questionnaires were filled in and returned. Of these questionnaires, 42% were filled in by the service user alone, whereas in 25% of the cases the service user had filled in the questionnaire with the assistance of a family member and in 22% with the assistance of a professional assistant. In the remaining 11% of the cases, the rehabilitation client had not participated in filling in the questionnaire, but it was filled in by the proxy.

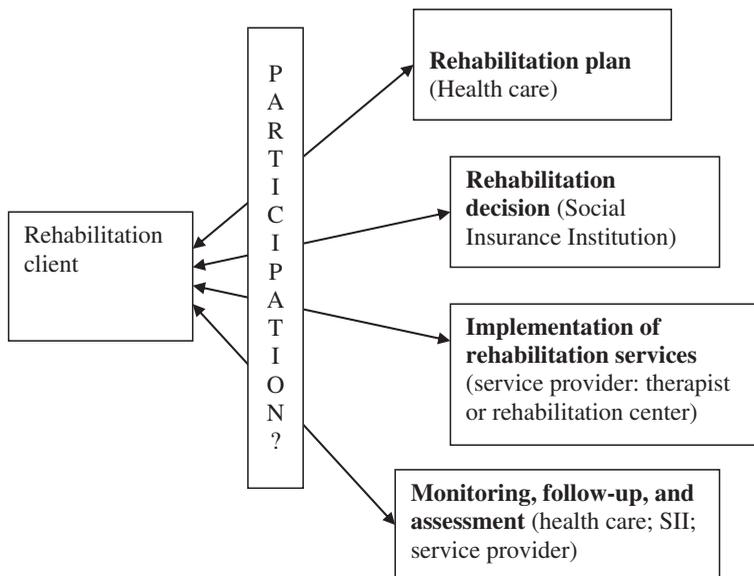


Figure 1. Arenas of participation during the medical rehabilitation process.

For this particular sub-study, we chose to exclude those questionnaires which the service user had not participated in responding to (11%). This solution was chosen because we wished to base this study specifically on the participants' own experiences and perceptions. According to earlier studies (e.g., Ball et al. 2001), the correlations between the responses of the disabled people and the proxies are seldom satisfactory. The solution meant that the share of those with intellectual and learning disabilities, mental disorders, and cerebral palsy was in this study smaller than in the original sample, and the shares of those with rheumatic disorders, multiple sclerosis (MS) and respiratory diseases were respectively greater. This choice must be kept in mind when evaluating the results.

All people eligible for medical rehabilitation arranged by the SII have long-term or permanent disabilities. All the respondents had long-lasting difficulties in coping with everyday life because of severe disability. Many of them had taken part in rehabilitation arranged by the SII earlier. Some background data of the study group are presented in Table 1. Half of the respondents were aged 30–54 years. Almost a third of women and

Table 1. Characteristics of the study group by gender (%).

	Men, <i>n</i> = 321	Women, <i>n</i> = 383	All, <i>n</i> = 704
<i>Age</i>			
20–29 years	12	13	12
30–54 years	48	49	49
55–64 years	40	38	39
<i>Marital status</i>			
Unmarried	38	32	35
Married	48	48	48
Divorced or widowed	14	20	17
<i>Life situation</i>			
In work	9	13	11
On pension	91	87	89
<i>Basic education</i>			
Elementary school or exempt from compulsory education	42	27	34
Comprehensive school	41	42	41
Matriculation examination	17	31	25
<i>Disability benefit</i>			
Disability allowance (highest or middle rate)	9	11	10
Care allowance for pensioners, middle rate	63	65	64
Care allowance for pensioners, highest rate	28	24	26
<i>Main diagnoses given in rehabilitation plans</i>			
Multiple sclerosis	13	23	19
Cerebral palsy	6	8	7
Other diseases of the nervous system	15	14	15
Diseases of the circulatory system	21	9	14
Musculoskeletal disorders (e.g. rheumatoid arthritis)	8	21	15
Congenital malformations or deformations	4	6	5
Injury and poisoning	12	2	6
Intellectual disability	6	2	4
Other diagnostic categories	15	15	15

17% of men had passed a matriculation examination. Nine out of 10 were receiving a disability pension; a tenth was at work or seeking employment. The disability pension was more common with men than with women. The increased rate of care allowance for pensioners was the most common form of disability benefit. Disability caused by MS and musculoskeletal disorders were more common among women, whereas the diseases of the circulatory system, intellectual disability and injuries were more common among men.

The questions depicting the client's possibilities of participation, becoming heard and influencing the rehabilitation process were as follows:

- (1) Did you yourself participate in preparing the rehabilitation plan? (1 = no, 2 = somewhat, 3 = significantly);
- (2) Were your opinions taken into account when preparing the rehabilitation plan? (1 = very poorly to 5 = very well);
- (3) How does the latest rehabilitation plan support your personal goals? (1 = very poorly to 5 = very well);
- (4) Did the service provider listen to your wishes when implementing the rehabilitation process? (1 = very poorly to 5 = very well);
- (5) Were your wishes, concerning, for example, the service provider and the site of rehabilitation, taken adequately into account by the SII when making the rehabilitation decision? (1 = strongly disagree to 5 = strongly agree);
- (6) Has the rehabilitation you received during the past two years corresponded with your wishes and needs? (1 = very poorly to 5 = very well).

On the basis of variables 1–6, a sum index was created. Because of the skewness of distributions, items 2, 3, 4 and 6 were rescored along a scale ranging from 1 to 3. The range of the sum index was 6–20, and the coefficient alpha of the scale was 0.64. The index was named *a sum index of client participation*. The dependent variable of logistic regression analyses was based on this index.

In addition, the questionnaire included items regarding who had initiated the preparation procedures for the rehabilitation plan and how actively, if at all, different actors had participated in preparing the plan.

The questionnaire also included several social and socio-demographic variables that were used as predictor variables in logistic regression analyses, in addition to the variables listed in [Table 1](#): the residence area, age of disablement, self-rated income (1 = very insufficient to 5 = very good), perceived competence (feeling oneself to be successful in realizing planned tasks: 0 = strongly disagree to 5 = strongly agree), and participation in political or community life (1 = active participation, 0 = less active participation, based on participation in associations, voting in public elections and memberships in political parties; see Puumalainen 2011).

The following variables of health and functioning were also used as predictor variables: subjective health (0–10), a sum score of communication and cognitive functioning (nine items; e.g., reading, using a computer, learning, communication with strangers; coefficient alpha = 0.93), a sum score of functioning in daily activities (six items; e.g., mobility at home, dressing, using the toilet; 0.92), and a sum score of functioning in demanding housework or work (six items; e.g., cleaning, cooking, using public transport, employment; 0.86).

Statistical analysis

To decrease the possible non-response bias caused by the low response rate, stratified sample weights were formed on the basis of register data and respondents in each stratum were weighted by the inverse of the response rate in this stratum (Kim and Kim 2007).

Logistic regression analyses were applied to find out which factors predicted the good possibilities of participation. For this purpose, the sum index of client participation was dichotomized: 1 = an index score of 17–20 (26%) and 0 = an index score of 16 or less (74%).

Two separate predictor groups were used, one that included social and psychosocial variables and another that included variables related to health and functioning. In both predictor groups, the association between each predictor variable and dependent variable was first analysed separately; the results of these analyses are presented as Models 1 (independent associations). In the second phase, all of the variables that had statistically significant independent associations with the dependent variable were entered into the regression model simultaneously. The results concerning the simultaneous analyses are presented as Models 2. The Wald test was used in assessing the contribution of the independent variables to the overall model. The goodness-of-fit of the models was tested by the Hosmer–Lemeshow test; all *p*-values were non-significant which shows that the models fit the data adequately.

Results

In response to the question about the people or organizations acting as initiators of the rehabilitation process, 40% of the clients reported that they had initiated the process themselves (Table 2). Women had acted as initiators more often than men. On the other hand, a family member – a spouse or parent – had a more active role in the rehabilitation of male clients than with female clients. A physician in public health care had been an initiator of the process with 26% of the clients and a professional representing the service provider (e.g., a physio- or occupational therapist) with 22%.

Two-thirds of the respondents reported that the physician had a significant role in the rehabilitation planning and 39% that their own therapist had a significant role. Other professionals (e.g., rehabilitation counsellors, nurses and social workers) had a significant role less often. Family members had a significant role in the planning in almost a fifth of the cases, with men more often than with women and with the clients receiving the care

Table 2. Different actors who initiated the preparation procedure for the rehabilitation plan (%).

	Men	Women	Disability allowance	Care allowance for pensioners	All
Client	37	45*	53	40*	41
Physician in public health care	26	26	25	26	26
Service provider	20	24	15	23	22
Family member	17	7**	4	12	11
Other employee in health care	6	5	4	6	5
Employee of the SII	6	5	7	5	6
Physician in private sector	1	4*	7	3*	3
Other	8	11	9	10	10

p* < 0.05; *p* < 0.01.

Table 3. Participation of different actors in preparing the rehabilitation plan^a by gender and disability benefit (%).

	Men	Women	Disability allowance	Care allowance for pensioners	All
Physician	64	66	72	65	65
Therapist	36	42	32	40	39
Family member (e.g., spouse, parents)	22	13***	7	18**	17
Rehabilitation counsellor	11	13	14	12	12
Social worker	6	9	10	7	8
Employee of the SII	5	7	6	6	6
Employee of rehab centre	5	6	4	6	5

** $p < 0.01$; *** $p < 0.001$.

^aTotal number of respondents ($n = 715$) used as a base-number in counting percentages.

allowance for pensioners more often than with those receiving the disability allowance (Table 3).

In Table 4, the respondents' evaluations of their possibilities of participation or becoming heard during the rehabilitation process are presented. Over half of the respondents reported that they themselves had participated in a significant way in the rehabilitation planning. Women had participated actively more often than men and those with a disability allowance had participated more actively than those with a care allowance for pensioners. The client's opinions were taken into account in preparing the rehabilitation plan very well with 43% and fairly well with 42%. The client's rehabilitation plan met his/her personal goals very well with 37% and fairly well with 51%. Over half of the clients reported that the service provider had paid attention to their wishes in rehabilitation very well. With 86%, the rehabilitation received during the past two years had corresponded the client's needs and wishes very or fairly well. In these four items, the proportion of negative answers ('very or fairly weakly') varied from 1% to 5%. Of the respondents, 72% strongly or somewhat agreed with the claim that the SII took the client's wishes into account very well; 14% neither agreed nor disagreed and 14% somewhat or strongly disagreed (Table 4).

Results of the logistic regression analyses where the dependent variable is based on the client participation index are shown in Tables 5 and 6. Being female, being younger, reporting stronger perceived competence, being active in the labour market, having a good income, and actively participating in political and community life had statistically significant independent associations with participation (Model 1). In the model for simultaneous associations (Model 2), gender, perceived competence and participation in community or political life made statistically significant contributions to the model (Table 5).

Subjective health, having cerebral palsy, MS, intellectual disability or cerebrovascular disorders and the sum scores for communication/cognitive functioning and work/housework functioning had statistically significant independent associations with participation (Model 1). Of these, the associations of intellectual disability and cerebrovascular disease to the dependent variable were negative. In the model for simultaneous associations (Model 2), good communication and cognitive functioning as well as having cerebral palsy, MS or intellectual disability made statistically significant contributions to the final model (Table 6).

Table 4. Client participation and becoming heard during the rehabilitation process, by gender and disability benefit (%).

		Gender		Disability benefit		
		Men	Women	Disability allowance	Care allowance for pensioners	All
The client participated in preparing the rehabilitation plan (<i>n</i> = 704)	Actively	46	62**	69	53	55
Client's opinions were taken into account in preparing the rehabilitation plan (<i>n</i> = 645)	Very well	39	47	48	43	43
	Fairly well	44	40	42	42	42
	Uncertain	12	9	8	10	10
	Fairly or very weakly	4	4	3	4	4
The latest rehabilitation plan supported the client's personal goals (<i>n</i> = 656)	Very well	34	40	42	36	37
	Fairly well	52	50	47	52	51
	Uncertain	11	7	9	9	9
	Fairly or very weakly	3	4	3	4	4
Client's wishes were paid attention by the service producer (<i>n</i> = 698)	Very well	52	54	63	50	53
	Fairly well	40	38	30	41	39
	Uncertain	4	6	5	5	5
	Fairly or very weakly	3	2	1	3	3
The rehabilitation received during the last 2 years corresponded the client's wishes and needs (<i>n</i> = 689)	Very well	34	38	44	35	37
	Fairly well	51	48	42	51	49
	Uncertain	10	10	12	9	10
	Very or fairly weakly	5	4	3	5	4
The client's wishes (e.g., concerning the service provider) were taken into account by the SII (<i>n</i> = 669)	Strongly agree	31	32	32	32	32
	Somewhat agree	41	40	47	38	40
	Neither agree or disagree	14	14	14	14	14
	Strongly or somewhat disagree	14	14	8	16	14

***p* < 0.01.

Table 5. Logistic regression analysis: socio-demographic and social variables as predictors of client participation.

Candidate predictors	Model 1: independent associations			Model 2: simultaneous associations (<i>n</i> = 534)	
	%	OR	95% confidence interval	OR	95% confidence interval
<i>Gender</i>					
Female	42	1	0.433–0.905	1	0.448–0.994
Male	58	0.626*		0.667*	
<i>Age</i>					
20–44	34	1		1	
45–54	27	0.633*	0.402–0.999	0.737	0.437–1.242
55–64	39	0.559**	0.367–0.852	0.758	0.445–1.291
<i>Life situation</i>					
Active	19	1		1	
Not active	81	0.522*	0.315–0.866	0.888	0.501–1.575
<i>Age of disablement</i>					
Congenital disability					
0–39 years	50	0.629*	0.407–0.972	0.723	0.448–1.168
Over 39 years	29	0.377***	0.223–0.639	0.536*	0.279–1.031
<i>Perceived competence</i>					
No or uncertain	47	1		1	
Yes	53	1.800**	1.250–2.592	2.572*	1.051–2.370
<i>Self-rated income</i>					
Poor or moderate	87	1		1	
Good	13	1.768*	1.080–2.894	1.628*	0.940–2.818
<i>Participation in political or community life</i>					
No or minor participation	67	1		1	
Active participation	33	1.726**	1.178–2.530	1.572*	1.046–2.364

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Model A (independent associations): statistically significant independent associations.

Model B: simultaneous associations.

Discussion

This study focused on the rehabilitation clients' experiences with their possibility to participate in the planning and process of medical rehabilitation for people with severe disabilities; a special interest was in what factors were associated with good participation possibilities. Quantitative studies on these questions are rare. In examining the results, it is important to keep in mind that the clients with the most severe physical or mental disabilities, who did not collaborate in answering the questionnaire, were left outside this study. Therefore, extra caution must be applied when interpreting the results. As the study was cross-sectional, it is not possible to make inferences about causal connections between different factors.

According to the clients' responses, the physicians of public health care were the professional group that most often had a significant role in rehabilitation planning. The result is not surprising, for they are, according to the legislation, responsible for preparing the plan. Many clients also valued the contribution of their own therapist in planning, but the role of other professionals or officials was regarded rather small. It seems that the physician-centred model, as described by Nikkanen (2010), was in the rehabilitation

Table 6. Logistic regression analysis: health and functional ability variables as predictors of client participation.

Candidate predictors	Model 1: independent associations			Model 2: simultaneous associations ($n = 573$)	
	%	OR	95% confidence interval	OR	95% confidence interval
<i>Subjective health</i>					
Low (0–3)	22	1		1	
Moderate (4–6)	50	1.274	0.768–2.114	1.107	0.651–1.882
High (7–10)	28	2.241**	1.319–3.806	1.596	0.900–2.832
<i>Communication and cognitive functioning</i>					
Have problems	38	1		1	
Good	61.8	2.102***	1.427–3.096	1.605*	1.037–2.485
<i>Work and housework activities</i>					
Have problems	90	1		1	
Good	10	2.244*	1.178–4.273	1.454	0.720–2.936
<i>Diagnoses in rehabilitation plan</i>					
Intellectual disability	5	0.380*	0.155–0.929	0.331*	0.115–0.952
Cerebral palsy	12	2.002**	1.187–3.378	1.988*	1.082–3.652
MS	20	1.707*	1.120–2.601	1.917*	1.189–3.091
Cerebrovascular disease	15	0.375**	0.201–0.700	0.557	0.286–1.088

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$.

Note: Model A (independent associations): variables with statistically significant associations. Model B (simultaneous associations), adjusted for age and gender.

planning of adult clients the most common, whereas the cooperation model and the team model – where the planning is based on collaboration and the role of other professionals is more active – were relatively seldom used.

However, it is important to note that a third of the clients did not regard the role of the physician of public health care as significant. The result suggests that with many clients the plan was prepared on the basis of an ordinary medical examination and documents rather than a thorough discussion on future goals and needed steps between the client and the professionals. This conclusion is supported by the fact that just over half of the clients experienced having themselves been a significant participant in the planning process. If the professionals take the stage as a planner and have no time for discussion, the client is rather an object or an outsider (Puumalainen et al. 2009; Nikkanen 2010) and his/her autonomy in the process is endangered. Using the terms by Alve et al. (2013), rehabilitation planning is then based on restrictive interaction instead of collaboration led by the client or by interaction.

Women reported having acted as the initiators of the process and active participants in planning more often than men while a family member – a spouse or parent – had had a more active role in rehabilitation planning among men than among women. According to some earlier studies (e.g., Kristofferzon, Löfmark, and Carlsson 2003) men with a chronic illness tend to involve their spouses in the recovery process more often than women and also report receiving more support from their spouses. One factor that may explain the gender differences in this study is that the women were active in work life more often when compared with men. They also had a longer education than men did.

A majority of the respondents reported that their opinions had been paid attention to during the planning process, the plan supported their personal goals and the rehabilitation had met their needs very or fairly well. The share of negative answers was low. Edwards, Staniszewska, and Crichton (2004) and Hokkanen (2012) have warned against making too positive interpretations out of satisfaction results. Reported satisfaction may in such situations reflect more the positive value attached to receiving services in general than genuine satisfaction with how the services were implemented. Good satisfaction figures may arise from a client's dependence on the system, when an 'exit' to other services is not possible due to lack of real alternatives (cf. Hirschman 1970).

The assessments concerning the service provider, such as a therapist or a rehabilitation centre, were the most positive and that concerning the SII the most critical. A similar result was found earlier with child rehabilitation (Järvikoski et al. 2013). Results seem to indicate that clients feel more autonomous in collaboration with the therapists during the rehabilitation process than with the professionals or officials that represent the more structural aspects of the service system (see Summers et al. 2007). The SII has probably remained a rather remote organization for many rehabilitation clients even though it has, during the past few years, aimed to shake off the image often associated with bureaucracies (see Heinonen 2009).

All clients should have a possibility to be heard and to participate in planning and decision-making in rehabilitation, in spite of their gender, age, socio-economic status or disability. The second goal of the study was to find out what factors were associated with the clients' perceived possibilities to participate in the rehabilitation process. The measure of client participation consisted of six items, depicting different aspects of participation, being heard, and autonomy and influence. The results show that several factors describing a client's social situation and disability are associated with participation experiences. Older people perceived their participation possibilities weaker than younger ones did. Men also had more negative views of their participation possibilities than women; the gender differences were especially great in assessments on the rehabilitation planning process. This result may be due to a greater share of women in workforce but also the fact that the impairments varied much between the genders or the men's more critical attitude towards rehabilitation systems.

Intellectual disability and cerebrovascular disease predicted a weaker possibility to participate and become heard during the rehabilitation process. Also people with poorer health and more problems in communication and cognitive functioning estimated their possibilities to participate in the rehabilitation process weaker than average. Results are parallel with those by Hagen-Foley, Rosenthal, and Thomas (2005), who found that people with greater difficulties associated with impairments, learning disabilities, intellectual disabilities, or psychiatric disabilities, reported lower perceptions of choice than average. Altogether, the results imply that those who have greater problems or difficulties in communicating their wishes to professionals, on the basis of their disability or other reasons, have weaker possibilities to get attention and diligent treatment during their rehabilitation process than others.

The participation experiences of those with congenital disability were, however, more positive than those whose disability had occurred in late middle age. People who have lived all their lives with disability, more often feel themselves as experts in their disability and rehabilitation; perceived competence also makes it easier for them to use their voice when communicating with professionals.

The usual indicators of socio-economic status are education and income. In this study, education was not associated with the client's views on participation possibilities. Instead,

self-rated income was associated with participation and being heard during the rehabilitation process. A similar but somewhat stronger association was found between the parents' income and their perceptions of becoming heard during child rehabilitation (Järvikoski et al. 2013). The results imply that people in a better social situation tend to have better possibilities to become heard and be active participants in their rehabilitation.

Social exclusion is multidimensional (e.g., Silver 2007), and participation also includes several components, from client participation in rehabilitation (referring to planning and decision-making in the rehabilitation process) to participation in social activities and larger life spheres. According to Puumalainen (2011), disabled persons' participation in different areas of life is cumulative: activity in one area of life is associated with being active in other areas as well. This study shows that participation in social activities is also associated with the client's possibilities to participate in the planning and process of rehabilitation. Those who participated in work life had more positive experiences on their participation in the rehabilitation process than those on pension. It is possible that the strong work orientation, typical for all rehabilitation, is reflected in that it is easier for professionals to accommodate with the goals of clients who pursue to maintain their work ability. On the other hand, a similar association was also found between client participation and activeness in political and community life. Causal relations between different dimensions of participation may run in many directions and there are several possible factors behind these associations. Insufficient income is one of the possible factors behind these associations; according to Puumalainen (2011), self-rated income was strongly associated with participation in political and community life among rehabilitation clients.

The results thus suggest that the clients' communication abilities, their participation in work and community life and being in a good financial position support their possibility of participation in planning their rehabilitation and influencing the implementation of the rehabilitation process. Physical and psychosocial competence together with an awareness of prevailing alternatives give the clients better chances to negotiate about services and be more assertive in requesting those services they consider appropriate for themselves. Respectively, those clients who have – because of their disability or life situation – several risks of exclusion are in danger of becoming also excluded from participation in the rehabilitation process. It should be noticed that those clients who were not able to respond to the questionnaire either themselves or assisted by a proxy or a professional assistant were not included in this study. This group of clients is probably in an even more vulnerable position in terms of their autonomy and participation if they do not have a skilful proxy as their aid.

In conclusion, even if client participation in rehabilitation is included in the rehabilitation laws of Finland, this study shows that there are differences between client groups in their participation possibilities. The different individual and societal mechanisms contributing to discrepancies in access to health services are not easy to overcome (e.g. Keskimäki et al. 1997). The inequalities in participation have received very little attention in the research literature on rehabilitation, even though the securing of client participation in rehabilitation is included in the legislation of many countries. In addition to focusing more research efforts on these issues, it is important to develop the practices of rehabilitation in such a way that rehabilitation professionals are able to pay more attention to the autonomy of those clients who have, because of individual or system-based reasons, difficulties in bringing forth their needs. It is important to use professional power positively, i.e., to create opportunities for all clients, so that they can take active roles in decision-making during rehabilitation (Clapton and Kendall 2002). The client-

driven approach in rehabilitation also means that the professionals have time to listen more carefully to the voice of those clients whose possibilities to control their life conditions are weak.

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