SJDR Scandinavian Journal of Disability Research
Established by the Nordic Network on Disability Research

Participation in the Habilitation Process, from the Perspective of Young People

RESEARCH

CHARLOTTE KARLSSON
ANNA KARIN ANDERSSON
LARS-OLOV LUNDQVIST
KARINA HUUS
*Author affiliations can be found in the back matter of this article

STOCKHOLM UNIVERSITY PRESS

ABSTRACT

Young people have the right to participate in their habilitation process. The aim was to describe how young people with disabilities perceive participation in the habilitation process. Data collection was performed at child and youth habilitation centres in Sweden. A total of four interviews were conducted, two individual interviews and two group interviews. The transcribed data was analysed using inductive qualitative content analysis. The analysis reveals two generic categories: 'the right prerequisites must be provided to be able to participate' and 'adults' behaviour and attitudes are important for participation in the habilitation process'. The findings reveal that how young people perceive participation in the habilitation process is based on environmental factors, such as information, and that the professionals strive for the young people's voices to be heard by including them in planning. In conclusion, the important aspects of participation are a young person-friendly environment and individual support from adults. These aspects can provide a source of reference for professionals who want to develop strategies to promote young people's participation.

CORRESPONDING AUTHOR:
?l l_ l_pgl ?l bcpqqm l
Department of Physiotherapy, School of Health, care and Welfare, Mälardalen University, Sweden
anna.karin.andersson@mdu.se

KEYWORDS:
Disabilities; Participation; Rehabilitation; Qualitative research; Young people

TO CITE THIS ARTICLE:
Karlsson, Charlotte, Anna Karin Andersson, Lars-Olov Lundqvist, and Karina Huus. 2025. "Participation in the Habilitation Process, from the Perspective of Young People." *Scandinavian Journal of Disability Research* 27(1): 227–239. DOI: https://doi.org/10.16993/sjdr.1086

DOI: 10.16993/sjdr.1086

INTRODUCTION

Participation is essential for young people with disabilities to develop new abilities, to enhance their physical, emotional, and social well-being, and to improve their overall quality of life (Granlund et al. 2021; Hoogsteen and Woodgate 2010). Participation is not only beneficial but also a fundamental right, as younger people with disabilities have the right to be heard and to influence decisions that affect them (United Nations Committee on the Rights of the Child 2009). However, young people with disabilities are known to experience more restricted participation in daily activities than other young people (King et al. 2010; Woodmansee et al. 2016). As a consequence, their disability has led to less diverse participation, more time spent at home, fewer social relationships, and less active recreation activities (Law 2002).

In the Classification of Functioning, Disability, and Health (ICF), participation is defined as 'engagement in a life situation' (WHO 2007). Imms et al. (2017) regard the concept of participation as a multidimensional framework, and in the Family of Participation-Related Constructs they describe participation as two separate, but interrelated dimensions: a) attendance, defined as 'being there', and b) involvement, defined as the experience of participation while attending. Involvement consists of a complex and subjective 'in-the-moment experience' of participation, incorporating elements of engagement, motivation, persistence, social connection, and emotional affect (Imms et al. 2017). The Family of Participation-Related Constructs framework can be used to identify factors that are important to an individual in the context in which the individual lives together with his or her family and can be used as a starting point for new ways of thinking and talking about participation in the various stages of the process of pediatric rehabilitation (Imms et al. 2017) (King et al. 2018). Research shows that young people have different wishes regarding the degree to which they want to participate in conversations about their care (Gilljam et al. 2016; Jeremic et al. 2016), e.g., some young people express satisfaction with only being involved in decisions that are not so extensive for their care (Andersen and Dolva 2015). Research in child protection services proceedings has shown that involving young people in describing problems from their everyday lives and planning their care can clarify their desires, potentially increasing participation, and improving safety, care arrangements, and well-being (Vis et al. 2011). Identifying personal goals and the individual young people's participation in the goal-setting process have been pointed out as important for achieving the goal (Pritchard-Wiart, Thompson-Hodgetts, and McKillop 2019). Although young people are capable and want to be engaged in identifying goals concerning problems or needs in everyday life (Pritchard et al. 2022), their willingness to participate in the therapy is dependent on the professional's level of engagement in the collaboration (Antoniadou, Granlund, and Andersson 2024).

Additionally, prerequisites that strengthen young people's participation in communication, planning, and decision-making processes in care have been related to young people's preferences to varying degrees such as, the time giving young people the opportunity to ask questions and express their concerns, the family's feelings about staying in the environment, knowledge about care, and having a positive relationship with professionals (Anaby et al. 2013; Coyne and Gallagher 2011). Also, young people are dependent on age-appropriate information and on the attitudes of primary caregivers and professionals (henceforth referred to as adults) when both are implied to make their own well-grounded decisions (Mårtenson and Fägerskiöld 2008). Not having access to the necessary information to participate in decision-making processes can result in feelings of anxiety and vulnerability (Bekken 2017). In pediatric rehabilitation, the primary caregivers have a central role in choosing meaningful goals for young people (Bexelius, Carlberg, and Löwing 2018; Nguyen et al. 2021) and have a predominant role in conversations with professionals when goals are formulated (Kelly et al. 2019). Furthermore, prerequisites for participation are, according to Coyne and Kirwan (2012), that young people feel more involved and can interact in communication if professionals provide clear explanations and adapted information. In a Swedish study, young people stated that they feel safe when there is continuity by meeting the same professional who confirms them and their situation in an adapted care environment (Gilljam et al. 2016). However, this safety is not enough for young people's participation, they also need to feel sufficient support and encouragement from professionals to become involved in matters related to their care (Boland et al. 2019). By listening to the voices of young people during encounters about what they perceive as positive conversations and activities that feel valuable, professionals can gain insight into how they can improve the quality of their practice concerning young people (Bekken 2014).

In Sweden, child and youth habilitation centres (CYHC) are offered to young people with early acquired or congenital disabilities and to young people who receive interventions from the CYHC and have distinct types of disabilities within diagnostic groups, such as intellectual disabilities, neuropsychiatric disabilities, and physical disabilities related to movement. The CYHC provides social, psychological, and medical services to young people with disabilities in the age group 0–21 years and to their families. The professionals at CYHC work in multidisciplinary teams, and include dieticians, doctors, nurses, occupational therapists, physical therapists, psychologists, special educators and speech therapists (Thylefors et al. 2000). The young person, along with their family, are offered services from the appropriate professional based on their needs and challenges, ensuring that the young person develops and maintains their abilities (Thylefors et al. 2000). These encounters can take place either physically during on-site in-person sessions, through digital channels, at school or in the young person's home environment child.

The habilitation process can be seen as a circular process over time with the steps of problem identification/mapping, prioritisation of problems to work on, goal formulation, method design and method implementation, and evaluation (King, Williams, and Hahn Goldberg 2017). Young people have the right to participate in processes that affect their everyday lives, which include habilitation processes. Indeed, as the conditions that emerge from previous research illustrate, is that young people want to be involved and engage in the decisions that affect them through safe relationships with adults and good communication. Participation can theoretically be conceptualised as the dimension of attendance and involvement, and if these dimensions are made possible for young people it can lead to increased independence and well-being but also increase the chance that the measures taken have positive implications for the young people'. However, adults need to consider and take into account individual differences in young people's different wishes and conditions for participation.

The research described above has revealed some aspects that we now know affect young people's participation in planning and decision-making processes in care. Yet, knowledge is limited about how young people perceive their participation in all stages of care (Wangmo et al. 2017). More nuanced knowledge is needed (Antoniadou, Granlund, and Andersson 2024); this study therefore aimed to describe how young people with disabilities perceive their participation in the habilitation process.

METHODS

STUDY DESIGN

This is a study with a qualitative descriptive design using semi-structured interviews. The data collection was part of the ongoing Swedish research programme, Mental health and participation in habilitation interventions for children and youth with disabilities. The transcribed data were analysed guided by Elo and Kyngäs (2008). It has been stated that data can be analysed with a methodological inductive approach if the previous knowledge of the phenomenon is deficient or fragmented (Thomas 2006; Elo and Kyngäs 2008). The current study prioritised that the participants' voices were expressed in an area that needs to be studied.

RECRUITMENT

The recruitment of participants took place in 2020 in four regions of CYHCs in southern Sweden. Young people aged 12 to 21 years from the CYHC were included in the study. Within the CYHC, it is practised that when young people reach the age of 18, care is transferred to adult rehabilitation, but there are regional differences. In some regions, young people transition to adult rehabilitation at the age of 16, while in other regions this transition occurs at 21, when they graduate from upper secondary school. The criteria for inclusion was young people older than twelve years with Swedish as their native language, having ongoing habilitation care, and being able to understand information about what participation in the interview situation entailed. The criteria for exclusion was young people who did not understand the meaning of voluntary participation. Professionals at the CYHC and people within various interest associations (contact persons) provided written information about the study. Information was provided through an easy-to-read Swedish brochure and an information film in simple Swedish, accessed via a QR code that was found in the brochure. In case of interest in more information about the study, the professional and/or contact person provided the primary caregivers' contact details to the first author.

DOI: 10.16993/sjdr.1086

PROCEDURE

Information letters were distributed to primary caregivers of young people with disabilities who had care contact with CYHCs through CHYC professionals or through people involved in interest organisations, for example: FUB – National Association for People with Intellectual Disabilities. The primary caregivers were asked about the young person's participation in the study. Primary caregivers were contacted by the first author by telephone for those young people who were interested in participating, to convey verbal information about the study. In the phone call, primary caregivers were informed about the young people's right to withdraw their participation in the study at any time without giving any specific reason. They were also emailed written information so that the primary caregivers and the young people would be given an additional opportunity to read the information in their home environment. In the case of consent to the study, documents were sent by ordinary post where the primary caregivers and the young person could sign a written consent separately, as well as an attached reply envelope for return. All young people who showed an interest in participating and met the inclusion criteria were allowed to participate in the study.

PARTICIPANTS

A total of seven young people aged 14–21, agreed to participate in the study, six boys and one girl (Table 1). The participants live with disabilities within one or more of the diagnostic groups represented within the CYHC. This data collection was part of a larger project with a limited time frame in which professionals and primary caregivers of young people with disabilities participated. Two individual interviews and two group interviews were conducted. In this research process, it was important to gain access to the voices of these young people and to make them feel comfortable in the interviews, hence the constellation of participants. Participants were allowed to choose which digital application they preferred the interview to be conducted through. In interview numbers 1–3, different types of digital applications for video calls were used through face-to-face encounters, such as Zoom or Microsoft Teams. In Interview 3, the participants were friends and knew each other through shared leisure activities. In Interview 4, the young people knew each other as classmates. All participants were rewarded for their efforts with a small gift as a token of appreciation.

Table 1 Descriptions of participants.

INTERVIEW	NUMBER OF PARTICIPANTS	GENDER (MALE/FEMALE)	STUDY CONTEXT
1	1	1/0	Digital encounter
2	1	1/0	Digital encounter
3	2	2/0	Digital encounter
4	3	2/1	In-person encounter

DATA COLLECTION

The interviews were conducted in March-April 2021. The authors have experience meeting young people with disabilities through their professions but do not have any professional relationship with the young people in this study or at this CYHC. The same interview leader (first author) participated in all four interviews. In Interview 4, the number of participants was the largest and a co-leader was present who was responsible for technical aspects and for the interview being conducted according to the interview guide. The interview questions were based on an interview guide to guide the conversation and ensure objectivity. An example of a question in the middle of the interview was 'When you were at CYHC, did you have the opportunity to say what you think?' The participants were also asked what they thought could be done better at the CYHC, so that they might be more involved and feel more engaged. At the end of each interview session, the interviewer presented a summary of what emerged during the interview, and the participants then had an opportunity to adjust their answers (Krueger and Casey 2015). The interviews lasted between 20 and 60 minutes, were digitally recorded using a dictaphone, and were subsequently transcribed.

DATA ANALYSIS

To ensure the participants' confidentiality, interviews were assigned a code that was then used in the analysis work. The transcribed interviews were analysed in several steps through inductive

qualitative content analysis according to Elo and Kyngäs (2008). Furthermore, the data analyses were supported by the computer-assisted qualitative data analysis software NVivo version 12 Pro, which is a data organisation tool (QSR International Pty Ltd 2018). All the authors read the transcripts of the interviews to get a sense of the content. In the preparatory phase, units of analysis were marked based on the purpose of the study without losing relevant content. In the organised phase, the units of analysis were written out on a coding sheet. Units of analysis from the coding sheet were grouped into subcategories which express the latent content of the units of analysis. By moving back and forth between units of analysis subcategories, generic categories were identified based on their similarities and differences. To ensure credibility, verbatim quotes were used to illuminate the findings and to verify subcategories and generic categories. The analysis was performed by the first author, while the other authors validated the analysis throughout the process. To increase the linguistic certainty and readability of the manuscript, it has been reviewed by a professional language editor.

ETHICAL CONSIDERATIONS

The study followed the guidelines issued by 'World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects' (2014), i.e., the young person consented to participate in the study; they, in consultation with the primary caregivers, were allowed to participate and to influence the type of meeting place to be used, such as telephone or digital channels (e.g., Zoom or Microsoft Teams). During interview 3, it was ensured that both informants individually felt comfortable using the digital platforms. This approach helped to ensure participants felt secure in a familiar and safe environment. In connection with informing primary caregivers and young people about the interviews, the importance of confidentiality was emphasised, and every participant would be treated respectfully, with no risk of feeling insulted or mistreated with no risk of feeling insulted or harmed emotionally or verbally. During the interviews, particular attention was paid to ensuring that the young people did not feel forced to share any information that could potentially compromise their integrity. To ensure this, if any questions or needs for contact arose after the interviews, all participants and primary caregivers were given contact information for either the research leader or the responsible habilitation professional.

FINDINGS

The young people's perceptions of their participation in the habilitation process emerged as two generic categories: 'the right prerequisites must be provided to be able to participate' and 'adults' behaviour and attitudes are important for participation in the habilitation process'. The generic categories and subcategories are presented in Table 2.

Table 2 Overview of the results. Generic categories and subcategories.

(A) GENERIC CATEGORIES	(B) SUBCATEGORIES
The right prerequisites must be provided to be able to participate	• Information about the encounter needs to be developed individually • How and when the encounters take place makes a difference
Adults' behaviour and attitudes are important for participation in the habilitation process	• To be listened to as a young person and to be allowed to give their own opinion • To have trust as a young person in adults and their responsibility • To have individual support for coping with everyday activities independently

THE RIGHT PREREQUISITES MUST BE PROVIDED TO BE ABLE TO PARTICIPATE

This generic category consisted of two subcategories: 'Information about the encounter needs to be developed individually' and 'How and when the encounters take place makes a difference'. This main category focused on the individual young person and their descriptions of, for example, how information was given in relation to the individual young person or how the specific encounters were adapted to the individual.

INFORMATION ABOUT THE ENCOUNTER NEEDS TO BE DEVELOPED INDIVIDUALLY

Some young people expressed a need for the encounter to be predictable, to know what would happen and to be aware of its purpose. Others, however, did not specifically express how they

would like adults to help them understand what the encounter might be like or how far in advance they wished to know what would happen.

> *Well, because I know what I'm going to do and all that and it's not that important to think that I'm going to do this or that in a week, it's not really that important* [what to do in an encounter]. *(Interview 1)*

During the interview, some young people stated that clear signs referring to the lift would be needed to make it easier for young people who have difficulty walking to avoid taking the stairs and becoming very physically tired before the encounters.

> *We were at the habilitation, and we didn't see the lift. We had to run up and down the stairs, so they needed to mark the lift a little more clearly. (Interview 3)*

Some young people reported that they did not always know what activities were to be conducted during the encounter with the CYHC. Some young people suggested a need for the professional to talk about what will happen at the next encounter. In this way, the young people could feel prepared and could have an understanding of which activities would take place. The young people described that they learned how the encounters were planned and designed by the professionals as the content in the encounter was repeated and the same activities were practised.

> *We hadn't understood* [how the interventions were to be conducted] *but you must learn* [the design of the encounters]. *(Interview 4)*
>
> *Sometimes I know because then sometimes we say before we have finished* [what activities are to be conducted at a future encounter]. *(Interview 4)*

The young people stated that inexperienced professionals do not always know that the young people like to know what will happen at the next encounter. Sometimes the young people were told what to do during the encounter, and some were happy with that. Some young people reported that they know about the habilitation plan but do not participate in designing it. Continuity was also important for some young people, such as being allowed to come to the same room every time they went to the CYHC. The young people felt that there was an effort on the part of professionals to involve them in the design of the interventions already determined. It might be that the young people were asked about and had wishes regarding what should be practised next time or in what order things should be done during the encounter.

HOW AND WHEN THE ENCOUNTERS TAKE PLACE MAKES A DIFFERENCE

The young people's attendance at the CYHC differed with regard to how frequently their encounters occurred. They stated that there could sometimes be a long time between the encounters, and sometimes they were more frequent with only a week or so in between. Some young people said they went to the CYHC for an annual encounter, but the number of encounters increased when problems arose, such as somatic complications or technical or communicative aids that needed to be reviewed. Some of the young people preferred the primary caregivers to receive the call for the visiting date as they were afraid of forgetting the visiting time themselves, and the young people felt confident that the primary caregivers would remind them. Some young people expressed good feelings about going to the CYHC, especially during school hours.

> *I think it's quite nice to get there* [at the CYHC]. *(Interview 4)*

Some young people wished that the encounter would include a treatment element during their attendance at the CYHC, but they wanted the encounter to end with a pleasurable activity, such as playing football.

> *We have played football after it is over, so if you think that there is a quarter of an hour left, then that's what we do* [the young people state that they play soccer as a hobby after the professionals have completed their treatment portion of, the encounter]. *(Interview 1)*

DOI: 10.16993/sjdr.1086

ADULTS' BEHAVIOUR AND ATTITUDES ARE IMPORTANT FOR PARTICIPATION IN THE HABILITATION PROCESS

The second generic category describes the importance of interpersonal relationships. This generic category consisted of three subcategories: 'to be listened to as a young person and to be allowed to give their own opinion', 'to have trust as a young person in adults and their responsibility' and 'to have individual support for coping with everyday activities independently'.

TO BE LISTENED TO AS A YOUNG PERSON AND TO BE ALLOWED TO GIVE THEIR OWN OPINION

The young people shared the experience that professionals usually listened to them, and the young people's attitude towards professionals was that they did so in a good and positive way. Some of the young people stated that professionals listened to them and their opinions, for example building a climbing wall to increase motivation during the encounters. Nevertheless, young people have opinions about how the CYHC could be improved. For example, encounters could have been better coordinated and planned to avoid travelling repeatedly to the CYHC.

> *If we say that I'll go in like a week before, before the New Year, we'll just take that as an example, then I can get a month after, you'll come in to arrange things and so on* [the young people has a proposal for encounters that should be coordinated between different professionals so that the young people only needs to go to CHYC as few times as possible]. *(Interview 3).*

The young people said that it was important to be listened to, to be involved, and to influence things that concern them. Their experience of being able to take part in decisions was mostly about deciding the arrangement of the encounters and what they perceived as important aspects of visits.

> *...that it is the same day and the same staff* [the young person would like and suggests that the encounter takes place on the same day of the week and that young people wish to see the same staff each time]. *(Interview 4)*

The young people perceived that the professionals asked them directly about the type of activity or material they preferred to use during the encounters. For instance, the professionals inquired about what materials the young person liked to use for learning new and challenging words or sentences, such as newspapers or comics. Some of the young people stated that when they were younger, the professionals did not give them as much space to make their voices heard, as many meetings included various checks and follow-ups that were done without them having any influence. However, the older and the more mature the young people became, the more they were allowed to influence and decide. The young people describe a feeling of control and responsibility from meetings there but report that they do not remember what was decided or which people decided what during the encounters. The young people also reported difficulties in making their own decisions and stated that it is not always advantageous for the young people to make decisions by themselves.

> *In my opinion, it would have been a bit so if I had decided something, I don't think it would have been particularly good* [that it is difficult to make big decisions as a young person]. *(Interview 1)*

TO HAVE TRUST AS A YOUNG PERSON IN ADULTS AND THEIR RESPONSIBILITY

During the interviews, it emerged that some young people thought about their lives and why their situations required contact with CYHC. The young people expressed the opinion that their encounters with the CYHC were necessary because of their disability and could not be changed, ignored or cancelled. However, the young people felt that the adults wished them well. Young people have strong trust in their primary caregivers, for example by getting guidance in handling everyday situations. Young people also reported trust in the primary caregivers, saying that they made good decisions in the encounter about which the young people themselves had no opinion and that they were satisfied with what was done without having to make their own decisions.

> *Yes, I am satisfied with the path they have taken, as they have shown and led me in a clever way and in a way that has become a way that has meant that I have not been such a determined young person* [the young people give full expression to the trust that the primary caregivers have acted based on their best interests, which has shaped the young person to be less stubborn or assertive in everyday situations]. *(Interview 2)*

Some of the young people felt that their relationship with the professional was important, and when the young people described their contact with the CYHC they referred to the professional by their first name. The young people felt that they wanted to meet the same professional during their encounters and contact with the CYHC. The young people expressed a feeling of discomfort when adults participated in encounters when these people were not known to the young people.

> *They don't even say hello, they just stand in a corner and kind of stare. Yes, it can be a little uncomfortable. (Interview 3)*

TO HAVE INDIVIDUAL SUPPORT FOR COPING WITH EVERYDAY ACTIVITIES INDEPENDENTLY

Some of the young people expressed a desire to be involved in the planning of their everyday activities and to be able to understand why or in what way activities should be carried out because otherwise, it would not be clear to the young people. The everyday activities that the young people talked about were everyday situations or events that happened in their everyday lives, such as not getting off the bus in the morning or not being able to speak clearly so that friends could understand what was being said.

The young people reported different individual types of support they receive from the CYHC, for example, language training, time aids and memory training. Some young people needed answers to existential thoughts and had benefited from conversational contact in their treatment through the CYHC. The individual support the young people received helped them function both in everyday life and at school. The young people stated that the support that CYHC provided to the primary caregivers allowed the primary caregivers to support the young people so that they young people could cope with everyday activities and school without experiencing any pressure or stress.

DISCUSSION

Young people with disabilities receiving services from CYHC in this study state that prerequisites are important, such as adapted information and at what time of day the encounters take place. At the same time, the results show that their perceptions vary. Some young people feel well-prepared and understand the purpose of the encounters, while others state that inexperienced professionals do not know them well enough to understand how they would like encounters to be prepared. By giving the young people clear information in advance about what will happen and whether the same structure is repeated, the young people experience themselves as participating. It is also clear from the current study that individual information is important for young people's participation. Moreover, they are listened to by the professionals when they express their opinions. This indicates the importance of identifying each young person's views and needs to enable the young people to participate in the habilitation process. At the same time, this study shows that the younger the young people were, the fewer opportunities professionals gave them to make their voices heard. This was linked to encounters that often included various checks and follow-ups conducted without their input. These findings are also supported by the UN Convention on the Rights of the Child, which emphasises the implementation of Article 12. This article demands respect for the young person's right to express their views and aims to promote healthy development and well-being for every individual young person. Article 12 also highlights the importance of ensuring that even younger children receive information to be able to participate in their care (United Nations Committee on the Rights of the Child 2009). The importance of being listened to, given space, and respected in their opinions is supported by O'Connor, Lynch, and Boyle (2021), who highlight that even younger individuals value being heard and respected. Similarly, Davis and Watson (2001) emphasise that young people's participation is not only shaped by professionals' preconceptions of their abilities but is also influenced by prevailing workplace values.

Through the multidimensional Family of Participation-Related Constructs framework, the dimensions of attendance and involvement can contribute to an increasing understanding of how young people describe and report their participation in the habilitation process (Imms et al. 2017). When the young people in the present study reported how often they attend CYHC, it can be regarded as the dimension of attendance. The model explains attendance as 'being there', but it can also be seen as a metric to measure the frequency of attending and/or the range or variety of activities. Also, our findings show that young people need to get to know the professionals to understand how the professionals normally structure the encounters and what they should do together when they meet. When young people describe the importance of being able to recognise and meet the same professional, it can also be seen as a dimension of involvement. The findings reveal that the encounters lack the clarity and consistency desired by young people. Additionally, they express a preference for continuity, such as having the encounters take place in the same room each time. One example is a young person with a motor disability who says that CHYCs should put up signs about the lift so that he does not have to take the stairs and become physically tired. A previous study has shown that young people's participation is largely prevented by barriers in the physical environment, but more studies targeting different health conditions and age groups are needed because the focus of research has mainly been on young people with physical disabilities (Anaby et al. 2013). Listening to young people's suggestions about how they would like to make various improvements in the environment (Andersen and Dolva 2015) that could lead to the young people perceiving the visit at CYHC to be positive, which could also lead to an increased willingness to become involved.

In the present study, it emerged that the willingness of young people to be involved in decisions varies depending on how much and in what areas adults make decisions. Decisions that the young people express have an environmentally oriented character, such as how encounters should be arranged and what they consider to be important concerning the encounters. This may seem to be outside the scope of what should be included in the young people's decisions regarding the habilitation process. But during the interviews the young people gave the impression that these aspects are very important to them and that the primary caregivers have a significant role in and around decisions. However, Wangmo et al. (2017) reported that paediatric patients in communication and healthcare decision-making processes emphasise the value of the role of adults in decision-making. Building on this, collaboration between young people and adults, as well as the establishment of strong relationships, can further encourage young people to express their wishes and share their experiences (Lundberg et al. 2022).

This study highlights that young people experienced a feeling of discomfort and reduced security during encounters where there were adults who failed to introduce themselves and were unfamiliar to them. Such situations can directly impact the prerequisites for their participation, as suggested by Anaby et al. (2013), who emphasise that professionals play a crucial role in creating a supportive environment by introducing all participants and fostering a sense of teamwork. In line with the study by Gilljam et al. (2016), it appears that experiencing fear and uncertainty in care situations inhibited young people's willingness to participate, but that the young people's participation was promoted through trusting relationships with healthcare professionals. This result indicate the importance of spending time and resources creating safe relationships that favour young people's willingness to be attentive and engaged. The current study also revealed the young people's willingness to be involved and to have varying degrees of influence and decision-making. However, their engagement was primarily focused on how the encounters were conducted and on the type of activity or material they preferred to use during these interactions. Similarly, it appears from other research studies in the context of care, that young people vary in how and to what degree they want to participate in planning and decision-making (Andersen and Dolva 2015; Gilljam et al. 2016; Jeremic et al. 2016). Professionals can support young people in having influence over their affairs by respecting diversity and recognising each young person as an individual. This includes professionals reflecting on their influence on young people and actively developing their communication skills (Olli, Vehkakoski, and Salanterä 2012). A recent scoping review by Curtis et al. (2022), highlighted a lack of evidence regarding the involvement of young people with disabilities, particularly those who are younger or have communicative or cognitive disabilities, in goal-setting processes. Similarly, Crawford et al. (2022) reported that there are obstacles to applying the oriented goal-setting practice at the individual level within the CYHC. At the same time, the study by Pritchard-Wiart et al. (2022) showed that young people at the CYHC felt valued and heard, in connection with the identification of functional goals done at the CYHC.

DOI: 10.16993/sjdr.1086

Finally, the current study showed that during the interviews, the young people expressed themselves in a practical and everyday manner, describing events and situations related to their participation in the various steps of the habilitation process. The results also show young people's descriptions of their perception of the disability, e.g., 'The young people express the opinion that their appointments with CYHC are necessary due to their disability and cannot be changed, ignored/cancelled'. This raises further questions about how the young people view their disability with the support from CYHC. Is it because they want to be or are expected to be or think they should be more 'normal'? Or, how do young people themselves perceive their disabilities?

The results of the study are in line with previous research in which typically developed young people in healthcare situations describe, in a way similar to that of young people with disabilities, that participation requires conditions such as individual information, clear interpersonal routines, and an adapted environment. More research is needed on young people's perceptions of being involved in all stages of the habilitation process. This can lead to adaptations of the instruments and methods used in interventions so that they better meet the individual needs of young people and families. These are valuable aspects to consider for a better understanding of young people with disabilities and their right to make their voices heard, a point also observed by Carroll and Twomey (2021).

LIMITATIONS OF THE STUDY

When the design of this study was completed, all interviews were planned to take place through face-to-face encounters, but due to the restrictions of the COVID-19 pandemic, this was not possiblbe. Most of the interviews were conducted online, which may have made it difficult for the young people to express themselves. However, the young people were positive and helped each other if there were any problems with, for example, the audio connection. From a geographical perspective, it will be an advantage to digitise the encounters with the young people. Another limitation noted is the absence of participants using alternative, non-verbal communication methods. All participants were able to communicate without the use of communication aids, and those who took part in the interviews had verbal abilities. However, young people who could not express themselves verbally were excluded from this study, which denied them the opportunity to make their opinions heard. This limitation is significant, as it reflects a broader issue: many young people and younger children are likely to face similar exclusion in the habilitation process, contradicting their rights under Article 12 (United Nations Committee on the Rights of the Child 2009). The results regarding young people's satisfaction with being listened to within CYHC cannot therefore be generalised to all individuals with disabilities. It would be valuable for future studies to include both younger children and young people without verbal communication to gain a more comprehensive understanding.

CONCLUSION

This study explored how young people with disabilities perceive participation and identified factors that can enhance their participation in the habilitation process. It highlighted that while young people trust adults to consider their opinions, they need appropriate conditions, such as tailored information and continuity, to feel truly involved. However, they do not see themselves as active participants in goal-setting for greater independence. Instead, they view their involvement as being limited to selecting materials or activities during sessions, which obscures the purpose of evaluations. Key factors for an effective habilitation process include creating a young-people-friendly environment that fosters motivation and provides individualised support to create a sense of security. These insights provide valuable guidance for professionals aiming to develop strategies that empower young people and promote young people's participation in habilitation interventions.

ETHICS AND CONSENT

The research programme, Mental health and participation in habilitation interventions for children and youth with disabilities and the data collection procedure were approved by the Swedish Ethical Review Authority DRN 2019-05028.

ACKNOWLEDGEMENTS

The authors would like to thank all the young people who participated in the study, as well as their primary caregivers. The authors also thank the CYHCs and interest associations for their assistance in recruiting young person participants. Additionally, thanks are due to the funders who made this study possible.

FUNDING INFORMATION

This study was supported by grants from the Swedish Research Council (VR), grant number 2018-05824.

COMPETING INTERESTS

The authors have no competing interests to declare.

AUTHOR CONTRIBUTIONS

Charlotte Karlsson was responsible for data collection and the initial writing of all sections of the article. Anna Karin Andersson analysing data and drafting the manuscript. Lars-Olov Lundqvist analysing data and drafting the manuscript. Karina Huus designing the study, analysing data, and drafting the manuscript.

AUTHOR AFFILIATIONS

Charlotte Karlsson orcid.org/0009-0001-4727-9171
Nursing department, School of Health and Welfare, Jönköping University, Sweden; CHILD Research group, Jönköping University, Jönköping, Sweden

Anna Karin Andersson orcid.org/0000-0001-5701-9085
Department of Physiotherapy, School of Health, care and Welfare, Mälardalen University, Sweden

Lars-Olov Lundqvist orcid.org/0000-0002-6703-7575
University Health Care Research Center, Faculty of Medicine and Health, Örebro University, Sweden

Karina Huus orcid.org/0000-0003-4599-155X
Nursing department, School of Health and Welfare, Jönköping University, Sweden; CHILD Research group, Jönköping University, Jönköping, Sweden; Centre for Augmentative and Alternative Communication, Faculty of Humanities, University of Pretoria, Pretoria, South Africa

REFERENCES

Anaby, D., C. Hand, L. Bradley, B. Direzze, M. Forhan, A. Digiacomo, and **M. Law.** 2013. "The effect of the environment on participation of children and youth with disabilities: A scoping review." *Disability and Rehabilitation* 35(19): 1589–1598. DOI: https://doi.org/10.3109/09638288.2012.748840

Andersen, Christina Strandholdt, and **Anne-Stine Dolva.** 2015. "Children's perspective on their right to participate in decision-making according to the United Nations Convention on the Rights of the Child article 12." *Physical & Occupational Therapy In Pediatrics* 35(3): 218–230. DOI: https://doi.org/10.3109/01942638.2014.918075

Antoniadou, Marianna, Mats Granlund, and **Anna Karin Andersson.** 2024. "Strategies Used by Professionals in Pediatric Rehabilitation to Engage the Child in the Intervention Process: A Scoping Review." *Physical & Occupational Therapy In Pediatrics* 44(4): 461–488. DOI: https://doi.org/10.1080/01942638.2023.2290038

Bekken, Wenche. 2014. "'I want them to see that I feel normal': three children's experiences from attending consultations in paediatric rehabilitation." *Disability & Society* 29(5): 778–791. DOI: https://doi.org/10.1080/09687599.2013.874329

Bekken, Wenche. 2017. "Decision-Making in Paediatric Rehabilitation: Exploring Professionals' and Children's Views on Decision-Making Involvement." *Children & Society* 31(6): 486–496. DOI: https://doi.org10.1111/chso.12218

Bexelius, Annemarie, Eva Brogren Carlberg, and **Kristina Löwing.** 2018. "Quality of goal setting in pediatric rehabilitation—A SMART approach." *Child: Care, Health and Development* 44(6): 850–856. DOI: https://doi.org/10.1111/cch.12609

Boland, Laura, Ian D. Graham, France Légaré, Krystina Lewis, Janet Jull, Allyson Shephard, Margaret L. Lawson, Alexandra Davis, Audrey Yameogo, and **Dawn Stacey.** 2019. "Barriers and facilitators of pediatric shared decision-making: a systematic review." *Implementation Science* 14(1). DOI: https://doi.org/10.1186/s13012-018-0851-5

Carroll, C., and **M. Twomey.** 2021. "Voices of Children with Neurodevelopmental Disorders in Qualitative Research: a Scoping Review." *Journal of Developmental and Physical Disabilities* 33(5): 709–724. DOI: https://doi.org/10.1007/s10882-020-09775-5

Coyne, Imelda, and **Lisa Kirwan.** 2012. "Ascertaining children's wishes and feelings about hospital life." *Journal of Child Health Care* 16(3): 293–304. DOI: https://doi.org/10.1177/1367493512443905

Coyne, Imelda, and **Pamela Gallagher.** 2011. "Participation in communication and decision-making: children and young people's experiences in a hospital setting." *Journal of Clinical Nursing* 20(15–16): 2334–2343. DOI: https://doi.org/10.1111/j.1365-2702.2010.03582.x

Crawford, L., J. Maxwell, H. Colquhoun, S. Kingsnorth, D. Fehlings, S. Zarshenas, S. McFarland, and **N. Fayed.** 2022. "Facilitators and barriers to patient-centred goal-setting in rehabilitation: A scoping review." *Clinical Rehabilitation* 36(12): 1694–1704. DOI: https://doi.org/10.1177/02692155221121006

Curtis, Derek John, Lene Weber, Kristine Berggren Smidt, and **Birgitte Nørgaard.** 2022. "Do We Listen to Children's Voices in Physical and Occupational Therapy? A Scoping Review." *Physical & Occupational Therapy In Pediatrics* 42(3): 275–296. DOI: https://doi.org/10.1080/01942638.2021.2009616

Davis, J. M., and **N. Watson.** 2001. "Where Are the Children's Experiences? Analysing Social and Cultural Exclusion in 'Special' and 'Mainstream' Schools." *Disability & Society* 16(5): 671–687. DOI: https://doi.org/10.1080/09687590120070060

Elo, Satu, and **Helvi Kyngäs.** 2008. "The qualitative content analysis process." *Journal of Advanced Nursing* 62(1): 107–115. DOI: https://doi.org/10.1111/j.1365-2648.2007.04569.x

Gilljam, Britt-Mari, Susann Arvidsson, Jens M. Nygren, and **Petra Svedberg.** 2016. "Promoting participation in healthcare situations for children with JIA: a grounded theory study." *International Journal of Qualitative Studies on Health and Well-being* 11(1): 30518. DOI: https://doi.org/10.3402/qhw.v11.30518

Granlund, M., C. Imms, G. King, A. K. Andersson, L. Augustine, R. Brooks, H. Danielsson, J. Gothilander, M. Ivarsson, L. O. Lundqvist, F. Lygnegård, and **L. Almqvist.** 2021. "Definitions and operationalization of mental health problems, wellbeing and participation constructs in children with ndd: Distinctions and clarifications [Article]." *International Journal of Environmental Research and Public Health* 18(4): 1–19, Article 1656. DOI: https://doi.org/10.3390/ijerph18041656

Hoogsteen, L., and **R. L. Woodgate.** 2010. "Can I Play? A Concept Analysis of Participation in Children with Disabilities." *Physical & Occupational Therapy In Pediatrics* 30(4): 325–339. DOI: https://doi.org/10.3109/01942638.2010.481661

Imms, Christine, Mats Granlund, Peter H Wilson, Bert Steenbergen, Peter L Rosenbaum, and **Andrew M Gordon.** 2017. "Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability." 59(1): 16–25. DOI: https://doi.org/10.1111/dmcn.13237

Jeremic, Vida, Karine Sénécal, Pascal Borry, Davit Chokoshvili, and **Danya F. Vears.** 2016. "Participation of Children in Medical Decision-Making: Challenges and Potential Solutions." *Journal of Bioethical Inquiry* 13(4): 525–534. DOI: https://doi.org/10.1007/s11673-016-9747-8

Kelly, Gemma, Carolyn Dunford, Rob Forsyth, and **Alja Kavčič.** 2019. "Using child- and family-centred goal setting as an outcome measure in residential rehabilitation for children and youth with acquired brain injuries: The challenge of predicting expected levels of achievement." *Child: Care, Health and Development* 45(2): 286–291. DOI: https://doi.org/10.1111/cch.12636

King, Gillian, Christine Imms, Debra Stewart, Matt Freeman, and **Tram Nguyen.** 2018. "A transactional framework for pediatric rehabilitation: shifting the focus to situated contexts, transactional processes, and adaptive developmental outcomes." *Disability and Rehabilitation* 40(15): 1829–1841. DOI: https://doi.org/10.1080/09638288.2017.1309583

King, Gillian, Mary Law, Patricia Hurley, Theresa Petrenchik, and **Heidi Schwellnus.** 2010. "A Developmental Comparison of the Out-of-school Recreation and Leisure Activity Participation of Boys and Girls With and Without Physical Disabilities." *International Journal of Disability, Development and Education* 57(1): 77–107. DOI: https://doi.org/10.1080/10349120903537988

King, G., L. Williams, and **S. Hahn Goldberg.** 2017. "Family-oriented services in pediatric rehabilitation: a scoping review and framework to promote parent and family wellness." *Child: Care, Health and Development* 43(3): 334–347. DOI: https://doi.org/10.1111/cch.12435

Krueger, Richard A., and **Mary Anne Casey.** 2015. "Focus Group Interviewing." 506–534. John Wiley & Sons, Inc. DOI: https://doi.org/10.1002/9781119171386.ch20

Law, Mary. 2002. "Participation in the Occupations of Everyday Life." *The American Journal of Occupational Therapy* 56(6): 640–649. DOI: https://doi.org/10.5014/ajot.56.6.640

Lundberg, V., M. Sandlund, C. Eriksson, R. Janols, T. Lind, and **A. Fjellman-Wiklund.** 2022. "How children and adolescents with juvenile idiopathic arthritis participate in their healthcare: health professionals' views." *Disability and Rehabilitation* 44(10): 1908–1915. DOI: https://doi.org/10.1080/09638288.2020.1811406

Mårtenson, Eva K, and **Astrid M Fägerskiöld.** 2008. "A review of children's decision-making competence in health care." *Journal of Clinical Nursing* 17(23): 3131–3141. DOI: https://doi.org/10.1111/j.1365-2702.2006.01920.x

Nguyen, Linda, Andrea Cross, Peter Rosenbaum, and **Jan Willem Gorter.** 2021. "Use of the International Classification of Functioning, Disability and Health to support goal-setting practices in pediatric rehabilitation: a rapid review of the literature." *Disability and Rehabilitation* 43(6): 884–894. DOI: https://doi.org/10.1080/09638288.2019.1643419

NVivo 12, QSR International Pty Ltd.

O'Connor, Deirdre, Helen Lynch, and **Bryan Boyle.** 2021. "A qualitative study of child participation in decision-making: Exploring rights-based approaches in pediatric occupational therapy." *PLOS ONE* 16(12): e0260975. DOI: https://doi.org/10.1371/journal.pone.0260975

Olli, Johanna, Tanja Vehkakoski, and **Sanna Salanterä.** 2012. "Facilitating and hindering factors in the realization of disabled children's agency in institutional contexts: literature review." *Disability & Society* 27(6): 793–807. DOI: https://doi.org/10.1080/09687599.2012.679023

Pritchard, Lesley, Shanon Phelan, Ashley McKillop, and **John Andersen.** 2022. "Child, parent, and clinician experiences with a child-driven goal setting approach in paediatric rehabilitation." *Disability and Rehabilitation* 44(7): 1042–1049. DOI: https://doi.org/10.1080/09638288.2020.1788178

Pritchard-Wiart, L., S. Thompson-Hodgetts, and **A. B. McKillop.** 2019. "A review of goal setting theories relevant to goal setting in paediatric rehabilitation." *Clinical Rehabilitation* 33(9): 1515–1526. DOI: https://doi.org/10.1177/0269215519846220

Pritchard-Wiart, L., S. Thompson-Hodgetts, A. B. McKillop, R. Rosychuk, K. Mrklas, L. Zwaigenbaum, J. Zwicker, J. Andersen, G. King, and **P. Firouzeh.** 2022. "A multi-center, pragmatic, effectiveness-implementation (hybrid I) cluster randomized controlled trial to evaluate a child-oriented goal-setting approach in paediatric rehabilitation (the ENGAGE approach): a study protocol." *BMC Pediatrics* 22(1). DOI: https://doi.org/10.1186/s12887-022-03381-4

Thomas, David R. 2006. "A General Inductive Approach for Analyzing Qualitative Evaluation Data." *American Journal of Evaluation* 27(2): 237–246. DOI: https://doi.org/10.1177/1098214005283748

Thylefors, I, E Price, O Persson, and **L von Wendt.** 2000. "Teamwork in Swedish neuropaediatric habilitation." *Child: Care, Health and Development* 26(6): 515–532. DOI: https://doi.org10.1046/j.1365-2214.2000.00162.x

United Nations Committee on the Rights of the Child. 2009. "General comment No. 12(2009): The right of the child to be heard (CRC/C/GC/12)." https://digitallibrary.un.org/record/671444/files/CRC_C_GC_12-EN.pdf.

Vis, Svein Arild, Astrid Strandbu, Amy Holtan, and **Nigel Thomas.** 2011. "Participation and health – a research review of child participation in planning and decision-making." *Child & Family Social Work* 16(3): 325–335. DOI: https://doi.org/doi.org/10.1111/j.1365-2206.2010.00743.x

Wangmo, Tenzin, Eva De Clercq, Katharina M. Ruhe, Maja Beck-Popovic, Johannes Rischewski, Regula Angst, Marc Ansari, and **Bernice S. Elger.** 2017. "Better to know than to imagine: Including children in their health care." *AJOB Empirical Bioethics* 8(1): 11–20. DOI: https://doi.org/10.1080/23294515.2016.1207724

WHO. 2007. *International Classification of Functioning, Disability and Health*. ISBN: 978-92-4-154732-1.

Woodmansee, Carmen, Andrew Hahne, Christine Imms, and **Nora Shields.** 2016. "Comparing participation in physical recreation activities between children with disability and children with typical development: A secondary analysis of matched data." *Research in Developmental Disabilities* 49–50: 268–276. DOI: https://doi.org/10.1016/j.ridd.2015.12.004

World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. 2014. *J Am Coll Dent* 81(3): 14–8. https://www.wma.net/policies-post/wma-declaration-of-helsinki/.

TO CITE THIS ARTICLE:
Karlsson, Charlotte, Anna Karin Andersson, Lars-Olov Lundqvist, and Karina Huus. 2025. "Participation in the Habilitation Process, from the Perspective of Young People." *Scandinavian Journal of Disability Research* 27(1): 227–239. DOI: https://doi.org/10.16993/sjdr.1086

Submitted: 29 September 2023
Accepted: 31 January 2025
Published: 14 May 2025