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Elusive Participation – Social Workers' Experience of the Participation of Children with Disabilities in LSS Assessments

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The aim of this study was to gain a deeper understanding of Swedish social workers' experience of disabled children's participation, to discover in what ways their knowledge about impairment and disability, combined with legal literacy and local context influence children's participation in formal meetings and decision making. Seven focus-group interviews were conducted with 35 municipal social workers from communities in different parts of Sweden. The phenomenological analysis resulted in the overarching theme of elusive participation, in which participation was described as difficult to grasp both in relation to what was supposed to be achieved and what it was meant to result in. Elusive participation entailed a discrepancy between policy and practice, norms and perception of normality, conflicting perspectives and needs, judgment of children's abilities. These findings underline the importance of creating safe spaces in which social workers have the opportunity for critical reflections and shared discussions about social work practice.

Keywords: children; disabilities; social workers; participation; decision-making; disability legislation

Background

Since the 1990s, there has been growing support for participation in the context of children's rights (Hart 1992). Sweden was one of the first countries to ratify the United Nations Convention on the Rights of the Child (UNCRC) (United Nations 1989) and is now preparing to incorporate it into national legislation. Article 12 of the UNCRC, which concerns the child's right to be involved and taken seriously in decision making, is central to children's legal right to participate. While children do not have the final say in the decision-making process, their views should be 'given due weight in accordance with [their] age and maturity'.

Although the concept of participation is widely used, it remains unclear what exactly it means (Imms et al. 2016). The level and nature of participation can vary, from being informed to exercising influence over decisions (Hart 1992). In meetings with social workers, children are seldom acknowledged as participating actors (Sinclair 2004). Adults in general often underestimate children's capacities or fail to appreciate the value of their perspectives (Lansdown 2010). Hence children and young people with disabilities are often discriminated against and oppressed on the grounds of both age and disability. Further, a view of disabled children as vulnerable seems to reinforce the tendency to disregard their capacity (Priestley 2000) and also to force such children to emphasise their vulnerability by displaying their disability (Priestley 2000) and stressing the negative consequences of their impairment (Hultman, Pergert & Forinder 2017).

Recurrent contact with authorities and health-care providers, who control and provide access to support, is a typical feature of disabled children's lives (Skitteral 2013). Sinclair (2004) draws attention to the difficulties of achieving meaningful participatory practices within bureaucratic organisations. Although in general participation is increasing, disabled children are less likely to be involved than non-disabled children (Franklin & Sloper 2006). Participation of disabled children is affected by professionals' attitudes toward diversity, by the children's and the adults' communication skills and by institutional factors (Olli, Vehkakoski & Salanterä 2012).

Good practice includes a listening culture among staff, which is created through clarity, flexibility, adequate resources, skills development and training for staff and participating children and young people, feedback and evaluation (Cavet & Sloper 2004). Furthermore, key factors for participatory practices include acknowledging the importance of good relationships and providing information and support to enable participation (Gallagher et al. 2012). Issues identified as barriers included adult attitudes, lack of training for key adults, lack of clarity leading to tokenism, the nature of organizations (i.e., their formality, complexity, bureaucracy and internal politics) (Cavet & Sloper 2004).

Although there is much known about facilitators and barriers for disabled children's participation in public decision-making, this knowledge needs to be further nuanced and adapted to a local context. The aim of this study was to gain a deeper understanding of Swedish social workers' experiences of disabled children's participation and to discover in what ways their knowledge about impairment and disability, combined with legal literacy and local context, influence children's participation in formal meetings and decision-making.

The Swedish context

The Swedish Parliament sets national goals for disability policy, but welfare services are provided mainly by the country's 290 municipalities (local authorities), which allocate resources, determine the organisation of the bureaucracy and issue policy guidelines (Lewin, Westin & Lewin 2008). The municipalities' responsibilities include child care, primary and secondary education, social services and care for the elderly (SKL 2017). Responsibility for welfare services used to rest with the central government but was decentralised to municipalities. The process was concluded in the 1990s. In 1994, disability-rights legislation was strengthened through the enactment of the Support and Service for Persons with Certain Functional Impairments Act (SFS 1993:387; Swedish acronym: LSS) (Tøssebro 2015). The LSS Act, which aims to ensure that people with severe impairments have good living conditions and an opportunity to 'live like others', provides for ten specified interventions, including relief (for parents), personal assistance, short-term housing and a contact person. It lays down that when measures concern children, their best interests must be considered.

Swedish disability policy is based partly on general welfare policy, including universal child benefit, and partly on interventions aimed specifically at people with disabilities (Engwall et al. 2018). The emergence of the Scandinavian welfare-state ideology saw the development of ideals of 'normalisation' (Kristiansen 1999), which implied an aim to integrate disabled people into society by allowing disabled children to grow up at home and by providing them with education and medical care within the mainstream systems (SOU 1964:43). However, in line with a strengthened disability-rights perspective, normalisation has been replaced by concepts such as participation, gender equality and self-determination (Lindqvist 2012).

In practice, however, the extent of interventions under the LSS Act, such as relief, short-term accommodation and escort granted to children and young people, has been in decline since 2007 (Socialstyrelsen 2018). As a result of directives issued by the national government in 2014, there was a change to the interpretation and application of case-law, resulting in severe cut-backs to grants of personal assistance provided by the state (Altermark 2017). As a result, there has been an increase in the number of applications for all interventions under the LSS Act, including personal assistance, provided by municipalities (Socialstyrelsen 2018).

Parents of disabled children can apply to the social services for support for their child (and for relief for themselves). At the age of fifteen, children are entitled to make a formal application by themselves if they are considered mature enough to make an informed decision. A social worker then carries out an investigation to assess the child's needs, writes a formal report and communicates the decision to the applicant. If the parents and children are not satisfied with the decision, they may appeal it before the Administrative Court.

Method

The present study used a qualitative design where data were collected in focus-group interviews and analysed using a descriptive phenomenological approach. Focus-group interviews (Giorgi 1975) were chosen to exploit interaction in order to generate deep and multifaceted data about the phenomenon under study (Morgan 1998). In sharing their experiences with each other, the social workers were prompted to further develop their own motives and to reflect on their experiences. Hence, the joint discussions helped them make sense of their actions. Wilkinson (1998) supports the use of focus groups within the framework of phenomenology, emphasising that they provide an opportunity to facilitate participants' own understanding of the issues under discussion and that they make it possible to include not only people's experiences and understandings, but also their attitudes, opinions, knowledge and beliefs, as subsets of phenomenology. This may make it easier to discern each participant's understanding of the issues in question. The researchers' preunderstanding was bracketed ('epoche') (Giorgi 1985) to ensure that the participants' own voices about children's participation will be reflected.

Participants

The participants in the focus groups were social workers whose duties involved making decisions about support for children and young people under the LSS Act. They were recruited from municipal social services in three Swedish regions, including both rural and urban areas to ensure variation in experiences. The social workers gave informed consent to participate, and their superior managers' permission was also obtained. The recruitment process was time-consuming, and several contacts had to be made to obtain a sufficient number of social workers for each focus group. Some social workers were recruited from natural groups, characterised by a common project and a collective memory (Bauer & Gaskell 1999). Social workers forming natural groups were allocated to the same focus group, while a few focus groups consisted of social workers who were sole representatives of a municipality. Seven focus groups were formed, with 4–7 participants in each, giving a total of 35 participants (**Table 1**). Eight social workers from three municipalities who were interested in participating had to decline owing to high staff turnover and time pressure.

Table 1: Demographics of participants.

Participants	Total (N = 35)
Age (range)	
20–40	9
41–60	22
Above 60	4
Gender	
Female	34
Male	1
Working hours	
Full time	31
Part time	3
No data	1
Experience of the LSS Act as a social worker	
<1 year	2
1–2 years	6
3–5 years	5
6–10 years	8
>10 years	14
Previous experience of working with people with disabilities	
Yes	27
No	8
Type of education	
University degree in social work	16
Other university degree	13
No data	6

The sample is dominated by female graduates, which is in line with the social-worker profession in Sweden. According to the national register of professionals, 18,813 women (86%) and 3,161 men (14%) were employed as social workers in 2016 (SCB 2018). No questions were asked about personal experience of disability, and no participant claimed to have such experience.

Data collection

The focus-group interviews took place from February 2016 to June 2016 and lasted between two and three hours. Each interview was performed by a team of two researchers (two out of three of the authors: L.H., A.M.Ö. and U.F.). One researcher had the main responsibility for acting as a moderator and initiating group discussion, while the other wrote down the social workers' initial statements according to their place at the table to ensure that their voices could be recognised on the audio recording. The researchers shared responsibility for asking probing questions to clarify statements and engaging all participants in the ongoing conversation. Because the emphasis was on discovery and exploration, the group approach was not strictly structured (Morgan 1998). The interviews began with open questions, such as, 'In what ways are children involved in meetings?', 'How do you make contact with the children?', 'How do you plan for children's participation?' and 'What does participation mean to you?' Those questions were asked in each group to promote conversation among the participants, who also reflected on ongoing cases. The participants were encouraged to speak freely and reflectively. The social workers were strongly engaged in the discussions; many of them had travelled far to participate. There were in-depth discussions among the social workers about children's participation in the decision-making process. In some groups, discussions became intense when they touched upon the actual assessment of fundamental needs to be carried out before decisions are made about support and when they touched upon the interpretation of 'fundamental needs' according to case-law. There were also intense discussions in some groups about the use of case-law and the extent to which case-law must always be followed.

The interviews were transcribed verbatim from the recorded audio files. Four of the seven interviews were transcribed by the first and second authors and the remaining ones by a private company, in accordance with established guidelines. Ethical approval was obtained from the Regional Ethical Review Board of Stockholm, Sweden (2012/671/315).

Analysis

A descriptive phenomenological approach was applied to the interview transcripts, using thematic analysis steps in line with Giorgi (1985). During the analysis, the researchers tried to assume a phenomenological attitude by bracketing preconceptions and everyday knowledge regarding the phenomenon of children's participation and allowing the phenomenon to be based on the participants' naïve descriptions (i.e., their experiences of children's participation as they remembered them).

Step 1

The interviews were listened to and read through several times to acquire an in-depth understanding where the content was understood as a whole. The transcripts were read carefully by three of the authors (L.H., A.M.Ö. and U.F.). After reading through the entire interviews separately, the authors discussed their initial thoughts and reflections about them; good consistency was found between their perceptions about the whole material.

Step 2

The text was searched for meaning units from the perspective of the phenomenon studied: children's participation. The text was sorted into meaning units reflecting different aspects of the phenomenon. Those units were extracted as individual statements within an ongoing dialogue between social workers in different group interviews.

Step 3

The meaning units (statements) were transformed into descriptions of how the phenomenon presented itself in the data. The social workers' descriptions were refined until they came as close as possible to the essential meaning (i.e., to describing what the meaning unit expressed without interpreting why it was experienced as it was). This transformation was the result of reflection, intuition and reduction on the part of one of the authors (L.H.), with no interpretation to the meaning-forming level. It was discussed with the other authors.

Step 4

The final step involved the production of a synthesis of the transformed meaning units into coherent descriptive themes. Explicit and implicit meanings were deduced from the experiences described by the informants, with the phenomena emerging from different backgrounds and in varying structures. In addition, the themes so identified are linked to relevant theoretical and/or empirical work in the Discussion.

Findings

The present section first describes the overall theme identified—elusive participation—and goes on to describe the four sub-themes that contribute to the whole. The descriptions are illustrated with quotations from the interviews, translated from Swedish into English (and edited to some extent) by the authors and identified with regard to focus-group (G) and social-worker (SW) numbers. The interviews revealed that the social workers' lived experience boiled down to elusive participation, which was composed of a discrepancy among policy, practice and legislation; judgement of children's abilities; conflicting perspectives and needs; and norms and perception of normality (see **Figure 1**).

Elusive participation

The participants conceptualised participation as self-evident at a rhetorical level but pointed out that it is difficult to achieve in practice because its meaning becomes blurred and ambiguous. In its elusive nature, participation could be likened to a bar of soap, which was constantly slipping from the social workers' hands.

Elusive participation occurred when the social workers performed the investigation in which they were told to promote children's participation. They perceived participation as difficult to accomplish, both in relation to the bureaucratic and legal aspects of the investigation and in relation to the individual child or proxy representing the child.

The social workers tried to grasp what children's participation meant, what it should result in, how it should be accomplished and when it was accomplished. Many of them made a distinction between children's participation in meetings regarding possible access to support and their ability to influence the support interventions provided in their everyday life. The meaning of children's participation in decision-making was questioned by some of the social workers:

We make the decision and it looks great on paper, it says the child was involved, but what participation was there in our investigation? None, really! (G1SW2)

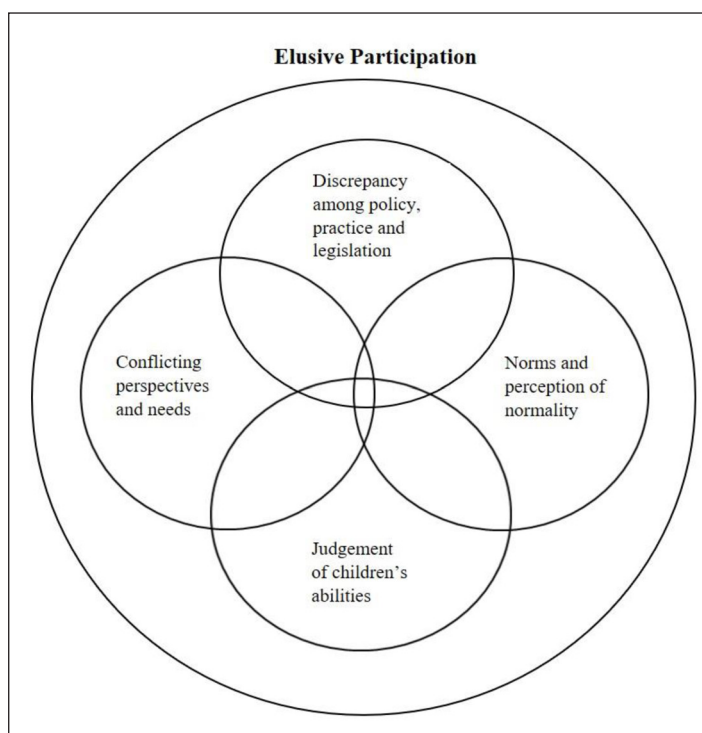


Figure 1: The essence of elusive participation. The figure shows the general structure of the phenomenon of elusive participation. The overlapping circles indicate that different parts of this experience intersect with each other and that, taken together, they create an experience of elusive participation.

In the next step after us, it's very important that [the children] are involved in the 'how', in the actual implementation, because the child perspective extends all the way. (G7SW1)

The meaning of participation varied; sometimes it was enough for a child to be present at the meetings, sometimes the child would be involved in discussions and decision-making. Being present could sometimes mean doing something other than taking part in the actual conversation about the need for support. Some social workers saw the child's presence as beneficial for the future in that having a positive experience would encourage children to become more involved in later meetings:

I think it's more to make [the children] feel it's been a good meeting, that they were part of it. In our small meeting room, we've got some books, they may pick a book and show something, or draw a little, we've got one of those whiteboards. To get them more involved. (G4SW3)

Discrepancy among policy, practice and legislation

In theory, children's participation was supported by local politicians and by the social workers' immediate superiors. In practice, the social workers had to handle the challenge of balancing children's rights to participate against their judgements of children's abilities, and against norms and perceptions of normality, as well as dealing with conflicting perspectives and needs.

The social workers experienced a discrepancy between policy and practice, considering that the expectations about what they should achieve within the framework of assessment and decision-making were unreasonable. While policy directives and local guidelines instructed them to prioritise children's participation, this had less priority in practice. The discrepancy between abstract policy goals and everyday practice made the social workers feel inadequate in their professional role and unsure how to handle children's participation:

Sometimes it's supposed to be in a certain way but there's a discrepancy between reality and theory, and there we are in a little box and have to somehow wave a magic wand, and then sometimes we feel bad because we don't speak to the children. (G1SW3)

The legal requirement for documentation of the child perspective in the investigation further reinforced the social workers' ambiguity about the meaning of children's participation. Some municipalities had introduced a specific heading in the investigation template ('Child Perspective' or 'Child's Participation'), but they felt unsure what to write under it:

'And then you're usually left with that heading at the very end and wonder, "How should I put it? What should I write?"' (G7SW4). There were clear differences among the social workers in the level of detail at which they documented children's participation: some simply made a note about the presence of the child, while others described the child's opinions.

Judgement of children's abilities

The social workers explained that their ambition was to make sure that the child understood the purpose of the meeting: 'To the extent that each child understands, they should gain an understanding that there's an application and what it's about' (G6SW). However, they found it difficult to decide whether, when and to what extent the children should be involved in the meetings. As a point of reference, they relied on their knowledge of nondisabled children's development. While they were supposed to judge children's abilities based on their individual level of maturity, they found it difficult to know how to do this and instead tended to equate maturity and age, in practice using age as the yardstick for assessing children's ability to participate. Children's involvement in meetings increased as they grew older, although the social workers tried to have a flexible meeting structure so that children could participate in part of the meetings:

I think it's rare for children to attend whole meetings, precisely because they have such large and extensive [disabilities] and a lot of questions, so I usually try to see them before [meetings], and talk to them [separately] before or after I speak to the parents. Depending on their age, of course, if they're in their late teens and have the ability to join in, they do so. (G2SW7)

During meetings in the framework of the investigation, children were encouraged to become involved to the extent that the social workers perceived that they were able to: 'Paying attention to [the children] and not overwhelming them with questions all the time, so that they are also at the centre of attention but don't have to answer all the questions' (G4SW1). Even when children were not actively involved in the conversation, their participation was considered to be achieved simply by their attending the meeting:

I still think it's good for the child to be part of the conversation. Even though the parents are speaking on behalf of the child, the child's still part of it and understands why I'm there and what I'm investigating. But then it's up to the parents to decide if they think it's reasonable for the child to attend or not, because they're the ones who know the child best. (G1SW4)

When it came to children without access to oral speech, insecurity about their own competence in interpreting and using alternative and augmentative communication (AAC) was perceived by the social workers as a barrier to communication: 'Some of them use graphic language, but we have to understand it, and they all use it differently' (G6SW6).

The criticism levelled at the quality of the communicative devices included a lack of precision, depriving children of the opportunity to give nuanced answers:

Then there are some symbols for various activities, you know? 'How do you feel about this?' And then there's a happy smiley, an in-between smiley and a sad smiley, and that gets very ... Then it's usually somewhere in the middle, maybe [laughter]. So they're not that subtle, they aren't. (G2SW5)

The social workers did find it easier to provide, ask for and understand information if it was communicated orally, but they did not believe that elusive participation was actually caused by the use of inadequate communicative devices. Rather, they interpreted the children's lack of participation in the light of their previous experiences of participation: 'But it's also that they're not accustomed to having opinions about things' (G3SW4). From that perspective, elusive participation could in fact be seen as a pedagogical challenge capable of being met:

It'll be an educational task for us: 'I'm here to listen to what you think.' In that way, the talking mat is so good, because it's so clear about 'don't like' and 'like'. Then, maybe because it's the first time, they'll like everything you suggest, but eventually they'll learn to have opinions. (G3SW4)

Although many of the social workers saw the value of direct communication with children, they questioned the trustworthiness of the opinions the children expressed. They had less confidence in a child's ability to make an informed decision if the child was perceived as having an intellectual or cognitive impairment, had a severe physical disability or expressed his or her opinions using AAC:

Well, there's this person on short-term stay who's quite severely functionally impaired, but she kind of 'gets' things cognitively ... even with those who don't get things, you can always ask, but you can't attach much importance to the answer. It might be just anything, and then you have a medical certificate saying what it's really like. (G1SW1)

If children were considered to have an intellectual disability *and* needed to use graphic sign language, the social workers became even more insecure about the trustworthiness of the children's opinions. At the same time, they found it hard to trust proxies, especially if the proxies' opinions differed from their own:

It's quite OK to aim for this, but then there are those who are at a very low intellectual level, who have very little communication ... perhaps they can choose pictures to some extent. 'Yes' and 'no', pictures of food, drinks and meals. When it's at that level, what should you do? (G5SW5)

I get a little worried sometimes when [children] can't speak and don't 'get' things. Who's going to interpret their world to them? But then it's good that there's so many people—at school, in short-term homes, at after-school activities, personal assistants, parents. If they all say the same, then surely that must be the way it is? (G1SW1)

For infants and toddlers, as well as for children without access to oral speech, observation was used as a main strategy for gaining access to information about the child's needs and wishes. Observation was also considered a necessary complement to written and/or oral descriptions by parents and other professionals:

Visual impressions are so extremely important. I remember this disabled boy who was turning into an adult. I had a lot of medical certificates, and I had imagined what he would be like, you know. But then seeing him many times added to that picture in that I got a lot more information that the certificates didn't mention: his way of sitting and lifting his eyes, if his arm was co-operative or not, so to speak. And that information can't be conveyed by someone else. (G2SW1)

Conflicting perspectives and needs

The social workers thought it was difficult for children to participate in the decision-making process if there were conflicting perspectives about needs and/or interventions as between the disabled children and their parents. One recurrent situation involved the ethical dilemma that arose when exhausted parents asked for relief by applying for their child to be accepted into short-term accommodation and the child did not wish to go there. Even where the social workers actually believed that it was in the best interest of the child to grant its parents relief, it became a problem when the child did not accept the intervention suggested. If the child was below fifteen, the social workers were more inclined to decide in line with the parents' wishes:

There's a dilemma when children don't want relief, and they don't want to go to a short-term home, and they don't want anything else. At the same time, they don't realise ... they don't have the maturity [to understand] that if they don't ... unless the parents get relief, it'll be a disaster for them. They don't understand that. But right there around the age of 11 or 12, I think it's so difficult ... I often grant it, even though it feels quite wrong, because the child doesn't want it. You try to find other solutions, maybe there's another short-term home, but they don't want to go, they just say, 'I want to be home, I want to sit in my room'. And why shouldn't they be allowed to have it their way? (G3SW2)

If the social workers were worried that a child was socially isolated or at risk of becoming socially isolated, they were more inclined to make a decision in line with the parents' request for social support rather than listening to a child who was rejecting all kinds of support. Many of them thought there was a fine line between motivating, persuading and coercing, but some of them considered it their duty to explain the purpose of the interventions to the children and to give them the opportunity to understand as well as to experience the kinds of support interventions that were on offer:

I had someone very autistic ... and we were discussing short-term accommodation after school. She was really reluctant to do this, but her mother wanted relief. During our conversation, the girl finally agreed to try it over a three-month period. And in the end, at a follow-up [meeting] after three weeks, it turned out that this girl thought it was quite good. That it was a positive experience. Sometimes they say 'no' because it can be a way for them to be in control. But if they get to try it out, they may change their minds and the intervention will be implemented anyway. (G5SW1)

However, the social workers all agreed that, from the age of fifteen, children's own perspectives should take precedence over their parents' perspectives, provided that the child was deemed to have the intellectual capacity to make an informed decision:

I think it's got a lot to do with age, because when they become 16 or 17 or even 15 and say 'But I don't want to go to a short-term home' while mummy and daddy want them to, then what decides the case may be that the child has said this in so many words. Then that's part of what you take into account [in the investigation], a really important part of it. (G4SW2)

According to the social workers, there was a difference in how disabled children could participate depending on whether a meeting concerned personal assistance (PA) or other interventions under the LSS Act. Where children had applied for PA, the focus of the whole meeting was on the assessment of care needs, and all the children could do was to answer questions about care. Given that decisions relating to PA must be in line with the case-law of the Supreme Administrative Court, the child's own perspective did not have any impact on the final decision: '[I don't really think the fact that the children participate, or that we hear them, changes our decisions], but it might give us a more nuanced understanding and strengthen our perspective as outsiders' (G1SW3).

Further, the social workers made a distinction between children's opportunities to exercise influence over decisions depending on whether they concerned the granting of new support or support they had already been granted. When it came to the follow-up and evaluation of ongoing support interventions, the social workers considered it important to hear the children's opinions so as to make sure that they felt they had the ability to influence the provision and use of the support.

Norms and perceptions of normality

Elusive participation was exacerbated by the social workers' difficulties in translating the intention underpinning the LSS Act (i.e., the exact meaning of 'being able to live like others') into concrete support interventions. They tried to find methods to ensure equality before the law in their investigations. Many of them described situations where they appeared to reason as though the LSS Act could be applied with reference to an imagined norm or a standard population, talking about disabled children's access to participation and comparing their opportunities to obtain support (to enable spare-time activities and holiday travel) with the opportunities available to an imagined population of non-disabled peers:

Well, it's so subjective: 'living like others'. Should I kind of judge it based on the social class I think this child belongs to? Is that 'living like others'? Should a child living in this culture get to go on both summer and winter holidays, while the child living in that [culture] doesn't, because there it's not the norm to go on those trips? What's the norm? It's so subjective... (G3SW2)

Perceptions of normality played a decisive part in the assessment of children. To be able to judge what should be considered a reasonable amount of support to compensate for a disability, the social workers compared the development of disabled children with that of their non-disabled peers:

Three-year-olds actually need supervision even at night; they may wake up several times and it's quite usual that you need to get up and make them go back to sleep if they're having nightmares. But if you're awake for five hours every night, maybe that's not normal for a three-year-old. (G4SW1)

Sometimes the social workers felt that parents wanted to 'normalise' their children, and this made the social workers less inclined to grant the support interventions requested. Some of the social workers even thought that the parents of children with autism had difficulties in accepting their child's disability and asked for support interventions that would *make* their child normal: 'So, when I listen to [the child], he says that he's got quite a rich [social life] ... and he's quite happy. The parents are the ones who want the children to be normal and hang out with their friends.' (G1SW1).

Discussion

Our findings show that children's opportunities to participate are vague and context dependent as a result of the ambiguities that we have chosen to refer to as elusive participation. In elusive participation, the dimensions of power asymmetries between and discrepancy among policy, practice and legislation; norms and perceptions of normality; judgement of children's abilities; and conflicting perspectives and needs interact with each other. Combined, these dimensions contribute to positioning disabled children in subordinate positions. Difficulties in involving children who utilize ACC is confirmed by previous studies (Franklin & Sloper, 2006); however, our findings indicate that even when these children are listened to, the social workers' do not consider them as reliable informants. This lack of trust increased if the children had an intellectual disability. The social workers' views on and interpretation of children's participation also depended on the children's age. For young children and children who were considered to lack the capacity for involvement in meetings, participation meant attendance. For children considered to have the ability to express their opinions, participation implied answering questions about everyday-life situations and/or providing descriptions of their perceived need for support. Hence it can be difficult to discern whether what children do is seen as involvement or as a manifestation of activity competence, described by Maxwell (2012) as children's ability to undertake an activity and perform it to an expected standard. In the present study, children who were over fifteen years old, communicated their opinions orally and had only mobility impairments were considered as more capable of making informed decisions than children who were younger and/or needed AAC and/or had an intellectual disability.

The concept of normality, along with those of competence and independence, has been criticised by both childhood studies and disability studies (Tisdall 2012). The findings from the present study indicate that when a child has an

intellectual disability, there is no guarantee that the child will be able to influence decisions more as it grows older. Although the social workers say that they want to involve children, in practice they exclude them from participation in decision-making on the ground that their impairment makes it impossible for them to make informed decisions. The descriptions given by the social workers of their interaction during meetings indicate an implicit ideal of able functioning (McRuer 2006), where children's agency depends on their ability to respond in a way deemed adequate by the non-disabled adults who are in charge of the meetings. Hence the difficulties encountered in implementing children's participation could be understood to some extent in the light of existing social structures, which give adults an authority position in relation to children (Archard & Skivenes 2009). This is particularly prominent in invited spaces, such as formal assessment meetings, which are governed by an adult-driven agenda concerning children's perceived needs (Shier 2010). In this regard, it becomes relevant to discuss the possibility of shared decision-making in which children are given a genuine opportunity to share power with adults (Hart 1992). From the perspective of the 'child's best interests', this could be seen to suggest the importance of both shared and supported decision-making. The aim of supported decision-making is to ensure that people with intellectual disabilities are given the freedom and tools they need to participate in society as equal citizens (United Nations 2006). However, supported decision-making places heavy demands on those adults who are appointed to support the child, because it requires reflection on how to offer clear advice and on how issues can be framed in order not to improperly change the child's mind. In other words, those adults will need to ask themselves when motivating turns into coercing. Generally speaking, motivation tends to increase the range of choices and opportunities available, while coercion tends to restrict it (Miller 2016).

When the child's best interests are discussed, it is customary to distinguish between the child's perspective (i.e., the views, understanding and experiences of the individual child) (Sommer, Pramling Samuelsson & Hundeide 2010) and a child perspective, a broader term that also includes how adults interpret the child's perspective and its best interests (Halldén 2003). The implementation of a child perspective based on the UNCRC can draw upon Articles 3 and 12, where the latter provision embodies a competence-based approach in which the child is regarded as a subject and an actor, while the former provision (which provides that the best interests of a child are to be a primary consideration in all actions concerning him or her) reflects a needs-based approach (United Nations 1989).

One central finding of the present study concerns the elusiveness of participation as reflecting the social workers' struggle to implement the ideal of children's participation in practice and to deal with the fact that certain services have a dual purpose (i.e., enriching the child's life and relieving the parents). In such situations where parents and children had conflicting needs and wishes, the social workers took a needs-based approach to justifying young children's lack of influence, based on the assumption that young children lack the ability to make decisions on personal matters (Singer 2012). Such a justification is intrinsically linked to deficit-centred discourses frequently found in discussions about disabled children, where attention is paid mainly to the impact of the impairment (Oliver & Sapey 1999). In this context, the assessment of children's abilities will interact with perceived norms and perceptions of normality to further reinforce disregard for disabled children's competence. From a cultural point of view, the welfare state can thus be claimed to play a role in shaping normality (Lindqvist 2012).

Our findings show that, although the concept of normalisation is not mentioned in current legislation, norms and perceptions of normality seem to prevail in practice because normality is used as a yardstick when judging what it means to 'live like others'. Hence the current interpretation of the LSS Act can be criticised on the same grounds as the normalisation principle (i.e., for generalising the identities of dominant groups) (Hugemark & Roman 2007) by making disabled children conform to a norm based on, for example, the extent to which the majority of non-disabled children participate in spare-time activities and are able to go on holiday.

The sample in this study did not include social workers with personal experience of disability. This suggests that the values and norms reflected in the social workers' discussions are representative of a group that lacks an inside perspective, making their assumptions about normality and norms more vulnerable to prejudices about disabled children. In cases where the social workers' assessment of children's needs did not match the needs perceived by the parents, some of the social workers blamed parents for wanting to normalise their children, explaining this by reference to the parents' inability to adapt to and accept their child's impairment (Curran & Runswick-Cole 2014). It is in fact common for professionals' knowledge of syndromes and impairment to be privileged over parents' expert knowledge about their own child (Hodge & Runswick-Cole 2018).

On an abstract level, children's participation is frequently framed with positive associations and presented as something that should be promoted (Melin 2013). However, if children's opinions are not given due weight in the decision-making process, their participation runs the risk of being reduced to tokenism (i.e., symbolic representation without any power to influence decision-making).

Conclusions

To prevent children's participation from being reduced to tokenism, social workers need greater awareness of disabling processes that prevent children from influencing decisions that will have a profound impact on their lives. Social workers would benefit from professional supervision in safe spaces where they can reflect upon and critically analyse personal values and societal norms that affect their understanding of disabled children. There is also a need for clearer guidance from national government agencies on how the concept of children's participation should be interpreted

in the exercise of authority. In order to develop an appropriate framework for children's participation, social workers need to shift their focus from assessing whether disabled children can participate to considering how best to enable their participation and how to evaluate the impact of their participation. In the end, this raises the question of whether social workers are prepared to shift the balance of power and increase their recognition of diversity and children's own perspectives.

Study limitations

The focus-group interviews contain rich material, and many aspects of this material could have been analysed and interpreted in different ways. In addition, it was difficult to exploit the full potential of the discussions among social workers. The intersection between disability and childhood in fact represents only one of many possible angles that could be explored. Moreover, this study did not examine personal assistance in depth; that issue is further explored in a separate study.

Competing Interests

The authors have no competing interests to declare.

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