This article scrutinizes children’s participation concerning the assessment process of respite care in Sweden. It is a qualitative study based on 82 documents of application of respite care and a group interview with social workers. We use the participation model of Shier, which describes extent of participation as well as the mandate of the organization. Social workers try to inform the children and meet them. They also seek approval of respite care. However, children who don’t use spoken language and children who are seen as immature are not given adequate support to enable them to speak their voices. Besides, the participation is often restricted to saying yes to respite care. There are hardly any traces of children’s reasons for being at respite care. This means an absence of knowledge concerning children’s views upon their own needs and problems.

**Keywords:** respite care; child; participation; assessment process; disability

**Competent children?**
Children with disabilities experience asymmetries of power in several ways. Like other children, they are often perceived as part of their family and not as subjects of their own. Moreover, they have been treated as vulnerable, weak and in need of adult care. Likewise, they have often been compared with models of ‘normal development’, where they fail to achieve ‘normal’ standards (Brownlow, Bertilsdotter Rosqvist & O’dell 2015). Due to their difficulties adapting to ‘normal development’, children with disabilities are expected to practise, train and prepare in order to develop (Mietola & Vehmas 2019). In childhood sociology, such a view has been called ‘children as becomings’, as opposed to ‘children as beings’ e.g. perceiving children as a category living here and now, fully capable of being social actors (Prout 2005; Qvortrup 1990).

Children with disabilities’ status as ‘becomings’ has had a great impact on their opportunities of agency. They face challenges in being perceived as ‘competent children’, not least when it comes to being assessed for and obtaining welfare support (Franklin & Sloper 2009). In this article, we study children with disabilities’ opportunities to participate in the assessment processes of respite care.

Children with disabilities’ chances to participate in assessment processes are often conditioned by access to support and adjustments. Concerning welfare support, an active stance is necessary to realize their participatory rights. McNeilly, Macdonald and Kelly (2015) have shown that children’s participation in social services is influenced by the availability of resources, the actions and attitudes of parents, the practices and attitudes of professionals, the provision of information, and adequate preparation for decision-making and ongoing support. For children with disabilities, consideration must also be taken to children who communicate in other ways than spoken language, children who concentrate only for short periods of time and children in need of adjustments to understand information.

This article studies the prerequisites and opportunities to participate that are available to children with disabilities in the assessment process of respite care. We see individual attempts of the social workers to involve the children, but nevertheless the results concerning participation in decision-making processes are insufficient. From the perspective of childhood studies and disability studies, current emphasis is on the child as subject and actor and disability is regarded not as an individual and biomedical anomaly, but as a consequence of society’s failure to adapt to the impairment (Prout 2005; Oliver 1996).

**Aim**
The aim of this article is to critically explore how children’s participation is handled within a disability context exemplified by the administrative assessment process of applying for respite care. In what ways do the children participate in the
assessment process? How do social workers discuss children’s participation? How does participation affect the respite care?

**Respite Care**

Respite care is one of ten support interventions pursuant to the Swedish Disability Act (SDA). The purpose of respite care is to offer children with disabilities ‘environmental change and recreation’ and to provide opportunities for ‘personal development’. In addition, respite care should provide relatives with relief and relaxation. The support can also be ‘...part of breaking an interdependence between children and parents’. Either parents’ need for relief or the children’s need for environmental change is enough for respite care to be granted. Consequently, respite care is not only services for parents but also aiming at the children’s needs. Respite care can be provided by an institution, a support family or a camp. It may be provided on a regular basis or offered as a solution in an emergency situation.

Children’s participation is an explicit goal of the Swedish law concerning respite care. There are formulations such as ‘in the best interests of the child’ (SFS 1993: 387 6a§); it states that the child should receive ‘relevant information and be given the opportunity to express his/her views’ and that a child’s participation should be guided by his/her ‘age and maturity’ (SFS 1993: 387 8§).

The double aim of addressing both parents’ and children’s needs is the reason why we have chosen to study respite care. In Sweden, respite care can be provided both as relief for parents and as change of environment for children with disabilities. Thus, it is possible for children and parents to have different opinions about respite care. The parents might need relief, whereas the child might want to stay at home, which implies a potential dilemma for the social worker making the social needs assessment. Juridically, parents have the right to apply for respite care regardless of their child’s opinion (SOU 2016; National Board of Health and Welfare 2014). Despite this clear juridical position, practical issues remain concerning child participation and respite care. There are at least three different issues concerning participation that social workers need to handle in the assessment process.

First, social workers may face the delicate task of mediating between parents’ and children’s (potentially) different opinions concerning respite care. The problems of handling this situation have been well documented in focus group interviews, where social workers argue that there is a ‘fine line between motivation, persuasion and coercion’ (Hultman et al. 2019). Second, social workers claim that they lack the skills to communicate with children with disabilities if they use other ways of communication than the spoken word. Some are reluctant to use alternative supplemental communication modes (Engwall 2013; Hultman, Pergert & Forinder 2017; Nowak, Broberg & Starke 2018). Third, social workers have difficulties to balance the juridical demands on children’s participation in relation to ‘age and maturity’ and how maturity is supposed to be defined in connection to certain impairments.

This article focuses on respite care in order to scrutinize how children’s rights to participate are handled by the social workers. Their work of assessment including children’s participation is documented in the social documentation of each child applying for respite care.

**Methods**

This is a qualitative study based on social documentation with an analysis of 82 documents and a group interview with social workers specializing in SDA assessment and e.g. respite care. The documentation concerns children aged 7–18 years who had applied for respite care during 2017 and 2018. The request was sent to 10 municipalities in the Stockholm area. Before the documents were sent to the researchers, they were de-identified. All names and personal data were removed, and the documents were only marked with gender and age (Table 1).

Among the 82 de-identified documents providing gender, age and diagnosis, 34 were related to girls and 48 were related to boys. More than half were for teenagers. Of these documents, 60% referred to diagnoses within the autism spectrum, while 20% referred to the diagnosis of intellectual disabilities. The rest were made up of combinations of intellectual disabilities, diagnoses within the autism spectrum and/or other diagnoses. Application can be made by the child if she or he is above 15 years. Applications from children were unusual in our material, only two applications were initiated by young persons.

The form and disposition of the documents differed slightly between the 10 municipalities, but the content was the same. First, it is determined whether the child belongs to the target group for SDA and, if so, there is a social investigation on whether the service can be granted. Next, the child’s diagnosis, consequences of the diagnosis/disability, family relationships, school situation and leisure activities are described. The social investigation concludes with a decision regarding respite care, the number of days that are granted, the goal of the service and a standard text on how the decision can be appealed. The applications mainly involved continued short-term stay, but there were also

| AGE     | 7–9 years | 10–12 years | 13–15 years | 16–19 years |
|---------|-----------|-------------|-------------|-------------|
| girls   | 4         | 10          | 9           | 11          |
| boys    | 7         | 13          | 21          | 7           |

*Table 1: Social documentation divided by age and gender.*
new applications. Most applications resulted in approval. No application was completely rejected, but some did not fully receive the number of days they applied for or were not granted access to a specific camp.

Social documentation is the fundamental material on how and why the child is granted or not granted respite care as well as a documentation of the child's participation. Social documentation serves several purposes; it may be used in juridical processes, it should facilitate control and transparency, it should be a ground for evaluation and follow-up and it is also a documentation which the child and her or his parents have the right to read (National Board of Health and Welfare 2015). The quality varies, e.g. due to skills of the social worker, different opinions what is worth mentioning and different local routines (Billquist & Johnsson 2007).

It is possible that social workers do more things concerning children's participation than are recorded. This is the reason why we also chosen to interview social workers about the assessment process. The social workers who participated in the group interview worked together and consisted of eight women. Five had a degree of social work, one was a social work student and two had a professional background in legal or behavioural sciences. Their experiences in handling and making decisions based on SDA legislation varied from a few months to five years. However, the social worker who had worked the shortest time had experience of working within other areas of social work. The interview started with information about the study, voluntary participation and was concluded by informed consents of all participants of the group. The group interview was based on a question guide, which aimed to stimulate conversations between the participants. The interview took about an hour to complete and was recorded and transcribed verbatim by one researcher. During the group interview, one of the researchers had the main responsibility of moderating the conversation, while the other asked follow-up questions to stimulate the discussion.

**Ethics**

This project has been approved by the regional ethical board of Stockholm: 2018/857-31/5. The documentation was anonymized before it reached the researchers and has been handled with care. Changes concerning places, family background and schools have been made in order to minimize the risk of recognition. The social workers who took part in the group interview were informed that the participation was voluntary and they have all approved to take part. They have also been anonymized in this article.

**Analysis**

All documentation and the transcripts from the interview were analysed by both authors. The material was categorized according to different ways and modes of participating. In a later phase, these ways of participating were related to Shier’s (2001) model of participation. Shier’s model is a way to illustrate the diversity of ways of dealing with children’s participation, in terms of both extent and the mandate of the organization. Compared to the ladder of citizen participation by Arnstein (1969) or Hart’s ladder of participation (1992), Shier’s model focuses the different commitments that individuals and organizations may have to the process of empowerment.

Harry Shier’s model of participation is based on five different levels:

1. Children are listened to.
2. Children are supported in expressing their views.
3. Children’s views are taken into account.
4. Children are involved in decision-making processes.
5. Children share power and responsibility for decision-making.

Since an assessment process results in a decision by an authority, shared power and responsibility is not possible to achieve, which means that level five is not relevant in our study.

Beside the possibility to discuss different steps towards participation, Shier (2001) also discusses different commitments made at the organizational level. He talks about *openings*, such as what the professionals are prepared to do at present to increase children’s participation; in the form of *opportunities*, when the needs are met to enable the social worker or organizations to work at this level; and in the form of *obligations*, which refers to an agreed-upon policy of the organization to work with participation. By doing this, he emphasizes that children’s participation must be grounded in policies and responsibilities of the organization and not be dependent upon the judgement or good will of the individual social worker. His model helps us to describe different aspects of children’s participation and the need of policies necessary to assure children with disabilities their participatory rights.

**Children’s Participation**

**Out-line**

Studying the social documents, it was obvious that most of the social workers attempted to work in accordance with the law’s intentions. This was seen in their ambitions to meet the child, inform the child about respite care and ask for the child’s opinions, and a few times the social workers took their views into account. Nevertheless, there were also too many examples of how children’s participation was missing, not addressed or did not influence the decision.
To meet the child

In most of the documentation, the social worker met the child face to face, often together with his or her parents. Still, in about a fifth of the documents, it was not possible to detect whether a physical meeting with the child occurred. The meetings took place either at the office or in the child’s home. The home seems to be a place where children can say hello to the social worker but are also free to spend their time in another room during the conversation between parents and social workers if they want to. The interviewed social workers also emphasized that they had the opportunity to make use of a special meeting room adapted to children at the office, but that they often chose to make home visits and/or meet children and young people in short-term housing. The interview also revealed that not all social workers were aware of this room specially designed for children.

Even when the child was clearly present in the meetings, according to the documentation, it was difficult to know the extent of the child’s participation. Sometimes the child was present but was not involved in the meeting, and the discussions took place above the child’s understanding: ‘During the meeting, she was worried and looked sad. Sarah stood by the door most of the time and waited to go home’ (Document 12). The meeting between the child and social worker was sometimes just a ‘meet-and-greet’ occasion.

In the group interview, the social workers discussed taking into consideration how the disability affected the opportunities for children and young people to attend meetings.

But sometimes when they have a more profound disability, it is more that they are there; to meet them and to hear what is being said. Sometimes it can only be to meet: to greet [them]. The person may not be able to participate in the context of the meeting. They make noises and cannot cope with the attention, light or sound.
(Veronica, social worker)

To inform the child

Some documents specifically stated that the child had been provided with information, with phrases such as: ‘She has received information about the assessment process’. A few cases also showed that the social workers had sent a specific letter to the child in advance, to prepare the child for who he or she was going to see and the aim of the meeting.

Kevin is very positive about the meeting and has waited for the social worker to come. He shows the letter that the social worker has sent him. He takes active part in the meeting and is very interested in talking to the social worker (Doc 28).

Visiting the future respite care institution was used as another way to inform the child what respite care is, before granting the application (Docs 37, 49, 60). The importance of preparing the child was displayed in a document:

David’s parents have talked at home about respite care and what this service means. They have spoken of respite care as a place where you sleep over and meet other children and adults. David thinks that it sounds a bit scary but nods his head when the social worker asks if he wants to visit (Doc 26).

A few documents also stated that information had not been given to the child. ‘Dan does not have the ability to understand information regarding his support. Consideration has been taken with assistance from his guardians’ (Doc 30).

In the group interview, it became obvious that individual social workers used different strategies to involve children in the assessment process: while some preferred to send out children’s letters with information before the meeting, others chose to tell the child about the purpose of the meeting when they met the child. One of the social workers in the group interview emphasized that it is important to ‘listen to the child’s needs’ and adapt the communication accordingly. She gave an example: Once, when a child seemed unsure whether he wanted to talk to her, she started talking to the child’s siblings, giving the child space to observe her and create an idea of whether she seemed to be a reliable person.

The social workers concluded that children’s involvement in formal meetings require the social workers to both adapt their mode of communication and trust individual children’s ability to communicate their opinions. On the one hand, the social workers aspired to include all children in the assessment process, but on the other hand (in practice), they did not ask the children for in-depth information about their experiences with short-term accommodation, especially if the children used non-verbal communication and/or had an intellectual disability.

To express views

From the documentation, it is generally difficult to determine what questions the social worker posed and what the answers were. For example, one social worker wrote that the child takes part in the meeting and expresses her opinions. She takes part in the conversation and asks questions if she wonders about anything’ (Doc 52). Yet the documentation says nothing about what the child said.
The focus of the documentation seems to be on establishing that the child enjoys respite care. It is principally only the spoken language that is documented. For example: ‘She tells the social worker during the meeting that she thrives well on [the respite care] and that she wants to continue to be there to the same extent’ (Doc 31). A few times, however, bodily expressions are documented: ‘Nods his head when the case worker asks if he enjoys respite care’ (Doc 8). Otherwise, even when children are described as being in need of using alternative supplemental communication modes, there is no reference to the use of this kind of material during the meeting (e.g. Doc 2).

Although the documentation reveals children’s challenges with communication, there is rarely any in-depth reasoning about what would enable the children to express their opinions. At best, it is possible to read a description of the child’s communicative ability: ‘According to the custodian, Muhammed can say a few words, such as “mom” and “yes”. It is basically only the parents who can understand him. At school, he communicates with PEX images. [He] often points to make himself understood’ (Doc 95).

It is possible that the social workers make more use of tools and adaptations than the documentation shows. In the group interview, many participants talked about the need to adapt children’s and young people’s participation to their individual circumstances.

I have experienced that social workers try using graphic support, that children can participate based on their ability and that you ask questions directly to the child. From 6–7 [years of age] you can say what you want and how it feels, actually already before, but it is so dependent on the type of disability... If you have no communication... or if you are normally gifted, then you can show on a scale how it is at the short-term stay accommodation. So, the child participates in the meeting according to his or her ability. It’s this simple: yes, no, happy and sad, most people can do it. (Eva, social worker)

The documentation shows that, if children are not considered to be competent to express an opinion regarding the application or service, the child’s perspective is replaced by those of the parents or other adults. They are judged to have an understanding and knowledge of how the child experiences his or her situation: ‘… cannot express what he thinks of his respite care. But according to his parents, he seems to like it’ (Doc 95). Children’s opinions are sought through the opinions of parents or other adults who are close to the child.

When children are asked for their opinion, it is often about support that has been granted. A common question is whether the child likes the short-term accommodation. Some children answer the question and develop the answer by describing what they do in the respite care:

Expresses that she likes Downhill’s respite care home. She usually plays video games, watches TV, plays with Legos, goes to the kiosk and buys sweets with the staff, and plays with the other children. The most fun thing is to buy sweets. She explains that she sleeps in the respite care home when it is boring at home, but sometimes when she is herself in the short term care, then she thinks it is boring to spend the night there (Doc 52).

Samuel told me that he enjoys being short-term during the two days spent on a weekend per month. He told me that he has not been happy lately during the two days spent in the middle of the week, as there has been a quarrel between Samuel and another child in the group (Doc 27).

Hans says he enjoys the Dalvågen’s short-term home and says he has friends there with whom he plays. Hans himself says that he wants to spend more days in the short-term home (Doc 25).

Most children who comment on short-term housing have a positive opinion of it and want to continue being there. The children mention other children, friends and chances to make new friends (Doc 43, 44, 60, 63). They also tell how they sometimes refuse to sleep at respite care because their friends are not there and it is also possible that they refuse to go at all if they do not like the institution or care.

Participation is conditioned by ‘age and maturity’ according to the law. Assessing children’s maturity is of central importance in determining the degree of participation children receive in practice in assessment processes (National Board of Health and Welfare 2014). Several key legislative texts contain regulations on the importance of children’s opinions and attitudes in relation to age and maturity. These regulations are based on Article 12 of the Convention of the Rights of the Child (CRC). At the same time, it is not clear in the CRC – neither in Swedish law nor in public investigation – how maturity should be defined. However, researchers have argued that all children have a right to express their views regardless of if their opinions are mature or not (Lundy 2007). Hultman et al. (2019) have shown that social workers usually involve children in the assessment process when they reach the age of 15, regardless of impairment or maturity, which means that age is valued more highly than ability in this context.

In the documentation included in this study, the social workers emphasized that the children’s opinions were taken into account because the child was perceived as age-adequate and consequently ‘mature’.
She has told me that she is very happy with her short-term family and that she wants to stay there. Ida is perceived as adequate for her age and therefore her own opinions play a role in the assessment (Doc 34).

There are examples of opposite situations as well. When children were judged to be unable to comment on a proposed service, it was usually explained in brief terms: ‘Hugo cannot express his opinion on the issue on the basis of his maturity and ability’ (Doc 30).

**To take Views into Account**

Even if the children's opinions are mentioned in the social documentation, they are rarely manifested in the outcome of the assessment process. Very seldom, the children's views seem to result in special arrangements. This is seen e.g. in the quote above where Hans wants to spend more nights at respite care which is not granted or commented upon (Doc 25). Nothing of the children's preferences at respite care, like activities or friends, are included in the decisions. There are two exceptions. One youth wants to be on short-term housing on weekends and not weekdays because he has lots of homework during the week which is respected (Doc 44). A girl insisted that she only wants to visit the respite care home when her friends are there; therefore, she has no interest in receiving more nights at the respite care home. Her parents claimed that they need more time by themselves; their daughter was granted one more night if she changed her mind (Doc 24). The last example also shows the compromise between the girl’s and parents’ views.

A formal way to state the importance of children’s participation in the assessment is to use a heading called ‘child perspective’. Such a headline is used by six of the municipalities. Sometimes it helps the social worker to actually consider the child perspective, but many times there are standard phrases and children’s voices are mixed with parents’. One recurrent phrase is: ‘The best of the child has been taken into consideration’ (Doc 56) without further explanation.

**Listening to the Child at Follow-Up**

In order to safeguard children's participation in the execution of services, it is necessary to routinely follow up on children's experiences of ongoing services. Several documents showed that the children who had already been granted short-term stays were satisfied:

Josef says that he enjoys being in short-term homes and camps; Josef thinks it is fun to do excursions and activities with his friends on short-term stays. Josef has made friends with whom he keeps in touch via the Internet (Doc 83).

However, in the conversation with the social workers, it emerged that there was a lack of a structured approach to follow up on meetings and ongoing support. How and to what extent they chose to find out what the children and young people thought about their experiences varied greatly between individual social workers, which was expressed as follows:

You should have a follow-up after three months, to evaluate the service with the child. With this target group, it is not always possible, but I know it was one of the things that we did not do and that we should have done. And it seems that it is difficult to achieve it, because there is no time for it. (Anna, social work student)

Sometimes, which I think is not unusual, the parents get back to you. After a month or two… I do not always get back to them, but I have quite a lot of text message conversations with my clients, and then it is easy to get a response. However, there is so little feedback, so I wish I could have much more, of course. I agree with Anna, that it is a development area – a challenge! (Eva, social worker)

Some social workers, like Eva, had text contact with the children and young people who were granted support. Overall, the social workers felt time-pressured, which made it difficult for them to find time to do follow-ups soon after the children/youths began their respite care stay. Instead, many social workers chose to contact staff at the short-term home and get information from them about how the first weekend or the stay worked out. For the mandatory one-year follow-up, the social workers talked to the child or the youth, usually together with staff from the short-term residence.

In our discussion on children's participation during the follow-up of ongoing support, several of the participants reflected that they had not thought about the consequences of having staff present when they asked the children and young people about how they were doing at the respite care institution. On the other hand, they had considered that the presence of parents could affect the responses of the children and young people.

During the focus group interview, it became clear that in some cases there was a discrepancy between what the social workers did to prepare for children's participation and how these preparations were documented in the social investigation. However, the interview also revealed that there is little child participation within the assessment process. From the studied investigations, it was difficult to understand to what extent children have been involved in the decision-making process. The direct involvement of children and youth with disabilities continues to be poorly reflected in clinical practice. Rather, decisions and goals continue to be determined primarily by parents and/or professionals.
Engwall and Hultman: ‘Meet and Greet’

(Hodgetts, Richards & Parks 2018). The social workers emphasized that they want to see the children face to face, in order to be able to observe the child and say hello. It is also important to gain the child’s approval of the respite care. There are seldom discussions on what will be done, how many nights the child will stay there and so forth. Instead, the focus seems to be to ‘meet and greet’.

**Children’s Participation in Shier’s Model**

Harry Shier’s model (2001), which deals with children’s participation, highlights different steps towards shared decision making. Shier’s model also highlights the importance of formalizing policies concerning children’s participation and not depend upon individual social workers’ benevolent attempts. Shier (2001: 111) represents his model in a diagram replicated and slightly amended below. We have added, ‘yes’, ‘no’, ‘partly’, to the original diagram based on our analysis of the material comprising the group interview with the social workers and the social documentation (Figure 1). Mapping our analysis against his model has allowed us to reach the following conclusions concerning children’s participation and organizational policies.

**Children with Disabilities and Participation**

The first, basic, step of Shier is ‘being listed to’. However, the social workers start on an even more basic level which is absent in Shier’s model. In order to understand what respite care is, the children need information about the services to be able to express their thoughts about it. Receiving information is a prerequisite to enabling children to take a stand and express a view (Archard & Skivenes 2009). However, information is not included in the participation model. Yet it is an important and sometimes time-consuming task for the social workers. It takes creativity and knowledge to adapt information to an understandable level, which may include pictures, easy-to-read text or signs (e.g. Archard & Skivenes

![Figure 1: Children’s involvement in the assessment processes of respite care, based on Shier’s model (Shier 2001: 111).](image-url)
2009). The SDA law also emphasizes children’s rights to receive ‘relevant information and be given the opportunity to express his/her views’ and the requirement to work ‘in the best interests of the child’ (SFS 1993: 387 6a§).

As shown in Level 1 of Shier’s figure (children are listened to), the social workers are motivated and willing to listen to children, although obstacles arise in terms of actual opportunities such as adequate resources in the form of meeting times, time to establish a relationship with the child, access to communication aids and self-confidence in using communication aids. As a result, there are major individual differences, depending on the skills of the individual social workers and the actual and perceived competence of the children. Nevertheless, the Social Services has an obligation to listen to children, according to Swedish policy requirements.

When it comes to Level 2 (supporting children in expressing their opinions), even though there is a high level of ambition, it becomes more difficult for social workers to say that the children receive support in expressing their opinions. Although the children and youth are present at meetings, the main communication takes place between the parents and social workers. Difficulties may be due to the fact that the social worker lacks an established relationship with the child/youth and lacks knowledge of the individual child’s ability to express his or her opinion. As in Level 1, obstacles arise concerning the opportunities of the social workers. They develop methods but lack a systematic and common approach when it comes to how and under what conditions children can/should be involved. However, there are formal obligations to involve children according to policy requirements.

As the demands on children’s and young people’s participation increase, it becomes increasingly difficult for the social workers to live up to these expectations. At Level 3, the social workers agree that children’s opinions should be taken into account, but state that the parents’ need for relief should also be taken into account. When children and parents hold the same opinion, no problems arise. But when children do not want a particular form of support while parents consider it necessary, the situation becomes more difficult. Children with access to verbal communication have more chances to make their voices heard and have their opinions taken into account than children who cannot communicate verbally. Credibility and the opportunity to be heard increases with the child’s ability to verbally tell how they experience the SDA support.

By Level 3 (children’s opinions are taken into account), it becomes clear that there is a difference between being listened to and having real influence. This becomes even more evident at Level 4 (children are involved in decision-making processes), probably because there are no policy requirements for children and young people to be involved in decision-making processes. When there is no formal obligation, the social workers’ ability to set requirements diminishes. This reduces both the openings and the opportunities to increase the participation of children and young people. Our material does not reach Level 4 (involvement in decision-making processes), and Level 5 (children share power and responsibility for decision-making) is not relevant for assessment processes, in which decisions are made by an authority.

As Shier’s model shows, a huge responsibility rests on ‘policy requirements’ to support participation. Moreover, the likelihood of a child’s attendance at a meeting resulting in participation also depends on the level to which they are engaged in the meeting and the value placed on their input (Kennan, Brady & Forkan 2016). Although the social workers’ ambition is to involve children in the entire process (from the initial meetings to follow-ups of ongoing services), their actions display a discrepancy between their aspirations and their actual behaviour. Their actions indicate a lack of a systematic approach with common strategies to enable children’s involvement, which results in the social workers having individual approaches towards the children’s and/or parents’ participation. Thus, it depends on individual social workers’ skills, knowledge base and perceptions of children’s competence. Since there are no guidelines regarding the type of information that should be provided before and after meetings and how many meetings children and parents should be provided, there is a great variety between what individual children are offered in terms of participatory rights. The initiative and work of individual social workers will never be enough to create sustainable social work in which children participate. Children’s participation must be part of the organization’s everyday work and must be underpinned by polices and formal instructions. According to Kennan, Brady and Forkan (2016) the effectiveness of structures and procedures depends on professionals’ willingness to accept the participation principle and having a shared understanding of what it entails, which must include both the management and practitioner level.

The results of this study also show that children with different sorts of impairments do not get access to the support they need to be able to express their views. The need of communication aids might be mentioned but not taken into account. Shier has chosen the description ‘being listened to’ as the first step of his model, and this is literally true since the spoken word is rewarded. According to Wyse (2004), communicating with children involves many and sometimes distinct yet complex interrelated skills that can include: maintaining autonomy or sharing a positive understanding, building trust, sustaining a good rapport, empathy and an ability to work or talk at the child’s level. However, many adults are more likely to limit, control and shape conversations with children, and to misinterpret non-vocal or non-intelligible expressions of meaning (Clarke & Wilkinson 2009).

The SDA, including respite care, is a salient example of the familiarization in which children are seen as part of a family and not as individuals, which has an impact on their opportunities to express agency. The legislators have not considered that parents and children may hold different opinions. This is problematic for the parents, the children as well as the social workers. It is a challenge to act both as a parent requesting respite and as an advocate of the child
who supports the child’s opinion (Nowak, Broberg & Starke 2018). The attitudes of parents and parenting practices can either facilitate or hinder children’s participation (McNeily, Macdonald & Kelly 2015). Other studies have shown that parents want their children to be more included in the assessment process than they are (Nowak, Broberg & Starke 2018). A difference in opinion also presents a challenge for the social workers, who need to balance these different opinions (Hultman et al. 2019). Finally, it is also problematic for the children. Their participation in the assessment process mostly involves being informed and confirming the social worker’s decision by saying that they like the respite care.

Consequences of Poor Participation

Using the material of documentation, we point out that children’s participation is under-developed concerning the assessment process of respite care. Referring to Shier’s ladder of participation, we see deficiencies both concerning extent of participation and organizational mandate, which becomes particularly salient in regard to children’s right to influence the outcome of decisions. This is problematic due to children’s rights perspective as well as the qualitative aspects of the decisions the social workers make. What relevant themes are missed out due to insufficient participation during the assessment process?

The assessment processes miss out on the documentation of children’s perceptions of their own needs and perceptions of problems. The documents are filled with parents’ stories of problematic everyday lives in which siblings’ need for their parents and parents’ own need for recovery. Of course, such stories might be a part of a strategy when arguing for respite care (Stone 1984): without emphasizing the family’s need for respite care, it is difficult to obtain it. Applying for support is similar to a negotiation (Gundersen 2012). By letting the parental perspective dominate there is a risk that the child is perceived as the cause of the problems, which might emphasize the view of children with disabilities as a burden (Ytterhus et al. 2015). The consequences of defining the child in social services as ‘the bearer of the problems’ instead of ‘bearer of rights’ may in worst case lead to the wrong services, since the child’s experiences have been neglected in the assessment process (Heimer, Näsman & Palme 2018).

Children with disabilities are often seen as particularly vulnerable and are therefore not invited to decision-making, which causes a vicious circle in which the children never get the chance to improve their appearance as vulnerable. Pupavac (2001) points out that children’s rights are based on their presumed incapacity, rather than on their self-determination. In effect, this view produces greater paternalism towards children.

The lack of children’s participation also means that the parents define their children’s problems. Very often, parents refer to their children’s loneliness and absence of friends as a reason for getting respite care. Social interaction, leisure activities and friends belong to a ‘normal’ childhood. Parents worry when their child’s reality looks different than the norm. In some cases, it is possible that the parents consider loneliness to be a bigger problem than the children do. In all the studied documents, only two children referred to their lack of friends, but other mention the joy of friends at respite care. The number of children experiencing loneliness in this sample is probably underestimated, because very few children want to identify with lonely people. Nevertheless, we observed a lack of information on children’s experiences concerning whether and how loneliness is a problem.

Within this assessment process, both social workers and parents tend to evaluate social skills with reference to a ‘normal standard’ and ‘normal development’, where many children with disabilities come up short. An alternative is to view social interaction as a double empathy problem, where there it is mutual difficulty in understanding the social motives of the other (Milton 2012). In this case, the inability to ‘read’ the subtext of a social situation is not only perceived as a deficit of the child with an autism diagnosis. In such a case, it would be interesting to see whether a child with an autism diagnosis would request support concerning social skills, in what situations, and what kind of support they would request (Brownlow, Bertilsdotter Rosqvist & O’dell 2015). Such a perspective is lacking when children with disabilities are not asked to give their views on what they find problematic in their everyday lives.

A greater emphasis on the child’s opinions and experiences would also strengthen the view upon children with disabilities as ‘beings’ instead of ‘becomings’ (Qvortrup 1990). The social workers often describe the children with disabilities as ‘becomings’, in need of practice and training (Engwall & Hultman 2020). The purpose of respite care includes breaking interdependence between parents and teenagers in order to prepare for an independent life. Jenny Slater (2013) argues that independence is often illusory for young people, not only for young people with disabilities. She argues for a perspective where we ‘…unhook youth from adult expectation…’ (2013: 192). Such a perspective concerning the assessment process includes more focus upon the child’s abilities and wishes to create a service that actually fits the child. The documentation seldom discusses children as being ‘here-and-now’. The children tell about friends, playing with Lego, buying sweets, doing excursions and having conflicts with other children, which reveals such a focus. Inclusion of a children’s participation in the assessment process would make it easier to describe the child as an actor in need of certain support in order to develop according to her or his own standards. It would give the child a chance to express her or his will without framing it in terms of ‘normal development’, but this demands more than a ‘meet-and-greet-encounter’ with the social worker.

Competing Interests

The authors have no competing interests to declare.
References

Archard, David, and Marit Skivenes. 2009. "Hearing the child." Child & Family Social Work 14: 391–399. DOI: https://doi.org/10.1111/j.1365-2206.2008.00606.x

Arnstein, Sherry R. 1969. “A Ladder Of Citizen Participation.” Journal of the American Planning Association 35(4): 216–224. DOI: https://doi.org/10.1080/01944366908977225

Billquist, Leila and Lisbeth Johansson. 2007. “Sociala akter som empiiri. Om möjligheter och svårigheter med att använda socialarbetares dokumentation i forskningssyfte.” Socialvetenskaplig tidsskrift 14(1): 3–19.

Brownlow, Charlotte, Hanna Bertilsdotter Rosqvist and Lindsay O’Dell. 2015. “Exploring the potential for social networking among people with autism: Challenging dominant ideas of ‘friendship.’” Scandinavian Journal of Disability Research 17(2): 188–193. DOI: https://doi.org/10.1080/15017419.2013.859174

Clarke, Michael T. and Ray Wilkinson. 2009. “The collaborative construction of non-serious episodes of interaction by non-speaking children with cerebral palsy and their peers.” Clinical Linguistics and Phonetics 23(8): 583–97. DOI: https://doi.org/10.1080/02699200802491132

Engwall, Kristina. 2013. Barnperspektiv i LSS-akter. En aktgranskning – hur barnperspektiv och begreppet normalt föräldraansvar används. Tumba: FoU Södertörn.

Engwall, Kristina, and Lill Hultman. 2020. “Constructions of childhood: The assessment of respite care for children with disabilities in Sweden.” European Journal of Social Work. DOI: https://doi.org/10.1080/13691457.2020.1763260

Franklin, Anita, and Patricia Sloper. 2009. “Supporting the participation of disabled children and young people in decision making.” Children & Society 23: 3–15. DOI: https://doi.org/10.1111/j.1099-0860.2007.00131.x

Gundersen, Tonje. 2012. “Human dignity at stake – How parents of disabled children experience the welfare system.” Scandinavian Journal of Disability Research 14(4): 375–390. DOI: https://doi.org/10.1080/15017419.2011.592955

Hart, Roger. 1992. Children’s participation. From tokenism to citizenship. UNICEF: Florence.

Heimer, Maria, Elisabet Näsman, and Joakim Palme. 2018. "Vulnerable children’s rights to participation, protection, and provision: The process of defining the problem in Swedish child and family welfare." Child & Family Social Work 23: 316–323. DOI: https://doi.org/10.1111/cfs.12424

Hodgetts, Sandra, Kathryn Richards, and Elly Park. 2018. "Preparing for the future: Multi-stakeholder perspectives on autonomous goal setting for adolescents with autism spectrum disorders." Disability and Rehabilitation 40(20): 2372–2379. DOI: https://doi.org/10.1080/09638288.2017.1334836

Hultman, Lill, Pernilla Pergert, and Ulla Forinder. 2017. “Reluctant participation – The experiences of adolescent with disabilities of meetings with social workers regarding their right to receive personal assistance.” European Journal of Social Work 20(4): 509–521. DOI: https://doi.org/10.1080/13691457.2016.1201051

Hultman, Lill, Ulla Forinder, Ann-Marie Öhrvall, Pernilla Pergert, and Kerstin Fugl-Meyer. 2019. “Elusive participation. Social workers’ experiences of disabled children’s participation in LSS assessments.” Scandinavian Journal of Disability Research 21(1): 38–48. DOI: https://doi.org/10.16993/sjdr.558

Kennan, Danielle, Bernadine Brady, and Cormac Forkan. 2016. Exploring the Effectiveness of Structures and Procedures Intended to Support Children’s Participation in Child Welfare, Child Protection and Alternative Care Services: A Systematic Literature Review. Galway: The UNESCO Child and Family Research Centre, The National University of Ireland.

Lundy, Laura. 2007. “‘Voice’ is not enough: Conceptualizing Article 12 of the United Nations Convention on the Rights of the Child.” British Educational Research Journal 33(6): 927–942. DOI: https://doi.org/10.1080/01411920701657033

McNeilly, Patricia, Geraldine Macdonald, and Berni Kelly. 2015. "The participation of disabled children and young people: A social justice perspective." Child care in practice 21(3): 266–286. DOI: https://doi.org/10.1080/13575279.2015.1014468

Mietola, Reetta, and Simo Vehmas. 2019. “He is after all, a young man’: Claiming ordinary lives for young adults with profound intellectual disabilities.” Scandinavian Journal of Disability Research 21(1): 120–128. DOI: https://doi.org/10.16993/sjdr.590

Milton, Damian. 2012. “On the ontological status of autism: The ‘double empathy problem’.” Disability & Society 27(6): 883–887. DOI: https://doi.org/10.1080/09687599.2012.710008

National Board of Health and Welfare. 2014. Stöd till barn och unga med funktionsnedsättning. Handbok för rättstillämpning vid handläggning och utförande av LSS-insatser. National Board of Health and Welfare. 2015. Handläggning och dokumentation inom socialtjänsten.

Nowak, Herawati, Malin Broberg, and Mikaela Starke. 2018. “Opportunity to participate in planning and evaluation of support for children with disabilities: Parents’ and professionals’ perspectives.” Journal of intellectual disabilities 24(1): 5–20. DOI: https://doi.org/10.1177/1744629518756227

Oliver, Michel. 1996. Understanding disability: From theory to practice. London: Macmillan. DOI: https://doi.org/10.1007/978-1-349-24269-6

Prout, Alan. 2005. The future of childhood. Towards the interdisciplinary study of children. London: RoutledgeFalmer.
Pupavac, Vanessa. 2001. “Misanthropy Without Borders: The International Children’s Rights Regime.” *Disasters* 25(2): 95–112. DOI: https://doi.org/10.1111/1467-7717.00164

Qvortrup, Jens. 1990. “A voice of children in statistical and social accounting: A plea for children’s rights to be heard.” In *Constructing and Reconstructing Childhood*, edited by Allison James and Alan Prout. London: The Falmer Press. SFS (Svensk författningssamling) 1993:387.

Shier, Harry. 2001. “Pathways to participation: Openings, opportunities and obligations.” *Children & Society* 15: 107–117. DOI: https://doi.org/10.1002/chi.617

Slater, Jenny. 2013. “Research with Dis/abled Youth: Taking a Critical Disability, ‘Critically Young’ Positionality.” In *Disabled Children in Childhood Studies. Critical Approaches in a Global Context*, edited by Tillie Curran and Katherine Runswick-Cole. Basingstoke: Palgrave Macmillan. DOI: https://doi.org/10.1057/9781137008220_14

SOU (Statens offentliga utredningar) 2016:19. 2016. *Barnkonventionen blir svensk lag.*

United Nations. 1989. *Convention of the Rights of the Child.* New York.

Ytterhus, Borgun, Snaefridur Thora Egilson, Rannevig Traustadóttir, and Berit Berg. 2015. “Perspectives on Childhood and Disability.” In *Childhood and Disability in the Nordic Countries. Being, Becoming, Belonging*, edited by Rannevig Traustadottir, Borgun Ytterhus, Snaefridur Thora Egilson, and Berit Berg. Basingstoke: Palgrave Macmillan. DOI: https://doi.org/10.1057/9781137032645_2