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# Constructions of childhood: the assessment of respite care for children with disabilities in Sweden

## Barndomskonstruktioner: handlägningsprocessen för korttidsvistelse enligt LSS i Sverige

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### ABSTRACT

This study examines how childhoods are constructed within the assessment process concerning respite care for children with disabilities in Sweden. The social workers need to take into consideration the needs of the child with disabilities as well as those of the parents and siblings. The application for respite care compels the social worker to prioritise needs, evaluate children's development and define what constitutes a good childhood. One of the results of such a process is a construction of childhood for children with disabilities which contains a strong focus on practising and developing, whereas their siblings are perceived as needing relaxation and quality time with their parents. It matches the childhood sociological concepts of 'becomings' and 'beings', where children with disabilities are stressed as 'becoming' and continually needing to develop their skills.

### ABSTRAKT

Studien undersöker barndomskonstruktioner inom handlägningsprocessen för korttidsvistelse enligt LSS. I denna process behöver socialarbetarna väga samman behoven avseende barnet med funktionsnedsättning, föräldrar och syskon. Socialarbetaren måste prioritera behov, utvärdera barns utveckling och definiera vad som utgör en god barndom. Ett av resultaten är att barndomskonstruktioner för barn med funktionsnedsättning fokuserar på att öva och utvecklas till skillnad från syskonen som uppfattas vara i behov av avkoppling och kvalitetstid med sina föräldrar. Konstruktionerna överensstämmer med de barndomssociologiska begrepp "beings" och "becomings" där barn med funktionsnedsättningar är "becomings" i ständigt behov av att utveckla sina färdigheter.

### KEYWORDS

Child welfare; disability; childhood studies; social investigation

### HUVUDORD

social barnavård; funktionshinder; barndomsstudier; social utredning

## Introduction

Swedish disability policy for children is based partly on a general welfare policy of universalism, such as subsidised childcare and free education, and partly on special measures aimed specifically at children with disabilities. Yet, there is a special law, the Swedish Disability Act (SDA) (SFS, 1993, p. 387), that focuses on people with comprehensive disabilities. It has been regarded as an example of

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targeted social policy aimed at strengthening social citizenship for individuals with comprehensive disabilities (Lindqvist, 2000). An overarching goal is to provide the individual with 'good living conditions' and ensure full participation in society.

The SDA confers ten specified interventions, some of which are aimed at children and their families. Examples include after-school supervision at youth recreation centres, residence care outside the family and respite care. These interventions have a strong family focus, offering children with disabilities new experiences and offering their parents and siblings support and relief. All municipalities must offer these interventions. This article focuses on respite care for children with disabilities and on the assessment process used when families apply for this support. Respite care can be provided by an institution, a support family or a camp. The organisers might be the municipality or private organisations. It may be provided on a regular basis or offered as a solution in an emergency situation. Respite care is free of charge, except for food costs.

The SDA has a strong family focus, even though the law has been complemented with a child perspective with formulations such as 'in the best interests of the child' (SFS 1993: 387 6a§) and stipulations 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 child perspective is applicable not only to children with disabilities but also to their siblings. In making their assessments, social workers have to take into account the interests of the children with disabilities as well as those of the siblings. The argumentation for applying child perspectives for all children in the family is examined in this article.

Historically, children with disabilities have been studied mainly based on diagnosis, vulnerability and burden to the family (Ytterhus et al., 2015). There is an obvious risk that such a view will be reinforced in the assessment process for respite care, since the parents feel that they have to argue for their need for relief and that the social workers are looking for arguments to approve or disapprove the application for respite care. On the other hand, it may be argued that children with disabilities should be able to apply for respite care themselves with a view to achieving personal development and gaining new experiences.

As representatives of the state, the social workers are at the intersection of responsibilities to both care and discipline (Weinberg, 2016). In the bureaucratic context, social workers contribute to moral regulation, that is, processes that encourage individuals to accept certain practices, conditions and discourses as normative, taken for granted, or obvious, when in fact these are socially constructed (Rousmaniere et al., 1997).

## Aim

In this study, the social documentation on respite care is scrutinised. In particular, the arguments for granting respite care are studied in order to detect constructions of childhood. The intersection of childhood and disability becomes evident since children with disabilities are often given a special position within the social documentation compared to their siblings without disabilities. Different constructions of childhood appear in the assessment process. The social documentation also reveals normative discourses on age, development and life courses. It raises questions about the relation between individual children with disabilities and 'normal development' and how the comparisons are made and used.

The aim of the study is to explore how childhoods are constructed in the documentation of assessment and how children's needs are exposed in relation to 'normal development' and 'age-appropriate' behaviour.

## Theoretical context

This study takes its departure in childhood and disability studies, which are aligned in their criticism of normality, competency and independence (Tisdall, 2012). Other similarities can be distilled in a

rejection of what is lacking in the individual. Children have previously been regarded as missing adult rationality, and people with disabilities have been judged as lacking a normal body or other abilities (Tisdall, 2012; Watson, 2012; Ytterhus et al., 2015). They have been denied civil rights as well as attributions of agency and competence (Boggis, 2018).

Childhood is not a natural state but is filled with content by its contemporary environments. Instead of perceiving childhood as a transport route towards adulthood by way of a period of immaturity, ignorance and inability, childhood studies try to go beyond such linear thinking about development (McLaughlin et al., 2016; Prout, 2005). The denial of childhood as a fixed state is aligned with the denial of disability as a lack of normal body and mind. Disability is perceived as the product of barriers in society and not an individual characteristic (Oliver, 1996).

Beyond the context of childhood and disability studies, we also use social constructions of age, normal development and age-appropriate behaviour. Age is connected to a serial following life phases which are connected to rights, obligations and expected activities. This order of age constitutes a power structure that affects resources, possibilities and norms (Närvänen & Näsman, 2004). Our society is characterised by contradictory tendencies in views on age and ability, where it is sometimes important to connect ability and age, but at other times chronological age may be considered more important than competence (Priestly, 2001; Forster, 2010). Age limits, for example, focus on number of years regardless of performance. For example, in Sweden everyone has the right to vote at the age of 18 no matter how intelligent, mature or capable they are. For children with disabilities, who are not capable of carrying out certain things, references to age limits might be positive. For example, there seems to be an unwritten standard that requires social workers to ask children above 15 years about their opinions regardless of the assessment of their maturity (Hultman et al., 2019).

Otherwise these ways of discussing age in connection to abilities often have more negative implications for individuals with disabilities. For example, people with intellectual disabilities are often evaluated in accordance with their abilities, whereas chronological age is ascribed less importance. Accordingly, the fewer tasks an individual can perform, the more childlike he or she is considered to be. Consequently, there is an overlap between childhood studies and disability studies in these matters, which is also seen in the construction of adults with intellectual disabilities being called 'eternal children' (Baron et al., 1999).

In the assessment process for respite care, the social workers often compare the applicant children's needs and competences to those of children without disabilities. Linear development of children has been enforced by the possibilities to measure, register and compare children to each other. Such a medical gaze has led to an acceptance of 'normal' development of children – physically, psychologically and intellectually (Kelle, 2010). Child developmental discourses use age-based stages and thereby fail to account for the 'normal' development of children with disabilities (Oliver & Sapey, 1999). Consequently, focusing on 'normality' also reveals the 'unnatural', the 'deviant' and the 'abnormal', which affect many children with disabilities. Developmental psychology therefore both contributes to and reflects dominant assumptions and debates about families in informing practice. Usually, the normative role of developmental psychology is tacit, yet it becomes much more explicit where it informs legal discussions about children's rights, needs and 'best interests' (Burman, 2007).

Children with disabilities experience asymmetries of power in several ways. They are often compared to models of 'normal development' where they fail to achieve 'normal' standards and, like all children, they are compared to adults with respect to competence. Children with disabilities therefore face challenges to being perceived as 'competent children', not least when it comes to being assessed for and getting welfare support (Franklin & Sloper, 2009).

The most common way to handle some children's failure to adapt to 'normal development' by professionals is to suggest practising. Practising becomes a way for children to learn age-appropriate behaviour. In the social documentation concerning respite care there are teenagers with social challenges who are encouraged to practise social interactions, children who need to practise being in groups and children who must learn to control their impulses. Children with disabilities are expected

to practise, train and prepare in order to develop and 'act their age' (Laz, 1998; Mietola & Vehmas, 2019).

The focus on practising and training for children with disabilities makes the childhood sociological concepts of children as 'beings' or 'becomings' relevant in this study (Qvortrup, 1990). Viewing children as 'becomings' focuses on childhood mainly as a transport route to adult life. It takes a futuristic view of children and emphasises what they might achieve as adults (Hockey & James, 1993). The opposite way to look at children and childhood is to perceive them as a category living here and now – children are 'beings' and they are perceived as social actors (Prout, 2005). Children as 'beings' '... interact with the norms of being that surround them, creating opportunities for both playing out of those norms and the challenging of them' (Hardman, 2001).

'Beings' and 'becomings' have been useful in many studies; however, there are also critical opinions on the distinction between them. The concepts have been criticised for characterising adulthood as stable and fixed and as a life stage featured by independence and autonomy. In our contemporary society, adults also have to be flexible and ready to change (Lee, 2001). Likewise, the need for relationships and everyone's (not only children's) dependence on other people has been highlighted (Prout, 2005). Moreover, the disability movement has questioned the definition of adulthood as equated with independence. The critique of the concept of independence within disability studies overlaps with the ongoing discussion in childhood studies. Children need to be seen both as 'beings' and as people in need of care and social interactions (Halldén, 2007). This article uses the assessment process for respite care as an illuminating example of the 'normative role of development psychology' as well as an example of constructions of childhood.

Respite care is available in more than half of the European countries for individuals with intellectual disabilities according to WHO (2007). It is defined as a support providing periodic relief to families taking care of a relative with disabilities. Reviews conclude that in relation to carers' well-being, respite care reduces stress, it gives siblings the opportunity to spend more time with their parents, the children with disabilities are given support to be more independent from their parents, and eventually that it is important with good quality of respite care (Health and Social Care Board, 2017; Robertson et al., 2011). Despite national differences, many of the advantages and challenges with respite care seem to be relevant for many European countries (Collins et al., 2014; McConkey et al., 2011; Welsh et al., 2014).

## Material and analysis

This is a qualitative study based on social documentation for 88 applications for respite care concerning children 7–18 years old. The ambition was to obtain ten sets of social documentation from ten different municipalities that collaborate within a research and development unit in Stockholm County. The ten municipalities vary in size, political governance and exposure to social problems. Some of the small municipalities, however, did not have access to ten applications but sent the ones they had. The selection of documents was made by the municipalities in accordance with the instruction to choose ten documents concerning respite care for children 7–18 years old during the years 2017 and 2018. The free way of selecting documents within the communities was guided by an ambition of not disturbing the social workers too much in their daily work. The documents were deidentified before they were sent to the researchers. All names and personal data were removed, and the documents were only marked with gender and age (Table 1).

**Table 1.** Social documentation divided by age and gender.

Age	7–9 Years	10–12 Years	13–15 Years	16–19 Years
<b>GIRLS</b>	4	10	9	11
<b>BOYS</b>	7	13	21	7
<b>INTERNAL MISSING</b>	6 <sup>a</sup>			

<sup>a</sup>The applications concerned adults.

Thirty-four sets of documentation concerned girls and 48 concerned boys (6 sets of documentation concerned adults). More than half concerned teenagers. Concerning diagnoses, 60 percent referred to diagnoses within the autism spectrum. A fifth concerned the diagnosis of intellectual disabilities. The rest were made up of combinations of intellectual disabilities, diagnoses within the autism spectrum or other diagnoses. The families applying for respite care constitute a cross section of Swedish families. There are native Swedes as well as immigrants, married couples as well as divorced, high income earners, low-income earners and unemployed individuals of whom had different numbers of children.

The form as well as the disposition of the investigations differ slightly between the municipalities, but the content is the same. First, it is determined by the social worker whether the child belongs to the target group for the SDA and, if so, has a right to apply for respite care. Secondly, if the child belongs to the target group for the SDA, there is a social investigation into whether the sought intervention can be granted. In such an investigation, the social worker scrutinises the needs of respite care and if these needs cannot be accessed in any other ways. The child's diagnosis, consequences of the diagnosis/impairment, family relationships, school situation and leisure activities are described. There is a lot of 'cut and paste' from previous social investigation documentation. The social documents conclude with a decision about respite care, how many days are granted, the goal of the intervention and an informative text on how the decision can be appealed.

Most of the applications concern continued use of short-term stay, but there are also 17 new applications. The majority of applications resulted in approval. No application was completely rejected, but 7 applications did not receive the total number of days applied for. Many applications concern 2–4 nights/month, but there are also examples of a week/month or more. It is not possible to detect from the documentation how the social workers reason to grant a specific amount of nights. We see similarities within the municipalities, but not between municipalities (Engwall & Hultman, 2019). A couple of years ago, the National Board of Health and Welfare (2015) studied local routines concerning SDA and pointed out that respite care is one of the interventions which is most affected by local routines. Such routines can recommend numbers of nights and restrictions of respite care in combinations with other SDA interventions. There are substantial variations between different municipalities.

The social documentation and the assessment process are governed by the law and local routines. The social workers' actions are therefore circumscribed, for example, by local routines and medical perspectives on disabilities of the law. However, respite care is a popular intervention among the social workers since it is appreciated by the parents and access to respite care might be the difference between the child's possibility to live at home or being permanently placed in an institution which is more expensive and cause suffering for parents who due to lack of adequate support are not able to care for the child with a disability (Engwall & Hultman, 2019). An alternative to respite care is relief service in the home which is preferred concerning younger children.

Methodologically, a conventional, qualitative content analysis was used (Hsieh & Shannon, 2005). Initially, we read the social documentation several times looking for descriptions of childhood. These descriptions were divided into several categories. In the later phase of the analysis, theoretical concepts were taken from childhood and disability studies, such as 'beings', 'becomings' and 'age-appropriate behaviour', to help us analyse the material.

## **Ethics**

This project has been approved by the Ethical Board of Stockholm: 2018/857-31/5. The documents were anonymised before they reached the researchers. However, other personal information has been removed or changed in order to minimise the chances of recognition in the article.

## Respite care – a cure for the family?

According to the preparatory works for the SDA, the purpose of respite care is to offer children with disabilities ‘environmental change and recreation’ and provide opportunities for ‘personal development’. Likewise, respite care should also provide relatives with relief and relaxation. The intervention 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.

The SDA has been characterised as taking a family perspective, and this is salient concerning respite care. The social documentation describes the family situation and the need for respite care. There are examples of parents’ interrupted sleep, constant monitoring, and concerns about their children’s loneliness and lack of friends. The children with disabilities are often described as having difficulties in school concerning establishing and maintaining social relationships with peers.

The family life is also affected by some children’s challenges concerning social interaction and impulsiveness. It is especially seen in relation to the siblings. In some families, the relations between siblings are tough and tense, and descriptions of violence among the siblings appear. ‘His mood goes up and down, it shifts very quickly. According to Mum, there are many conflicts at home. Hits his brother every day, hard blows’ (Doc 6). A mother describes how a little brother, 1½ years old, fears his 12-year-old sister with disabilities due to her aggressive outbursts. The mother says she is unable to leave the siblings together in the same room without surveillance (Doc 82). Respite care becomes a way to handle these problems by referring to parents’ need for recovery, siblings’ need for their parents, and the child with disabilities’ need for development and a change of environment.

The descriptions of family life bear witness to the demands of everyday life in these families. Yet, it is important to keep in mind that these narratives are part of the disability assessment process in which granted interventions depend on family members’ ability to convince SDA officers that the child’s need for support provides a rationale for granting respite care. Disability evaluation is thus an instrument the state uses to determine who is entitled to support (Stone, 1984). In such contexts:

Applicants learn through both community knowledge and personal experience the characteristics, code words, phrases, and behavior necessary to a successful application for benefits. To a large extent, the interactions of the agency personally with its clients actually serve to teach the clients what behavior or characteristics the agency will reward (Stone, 1984, p. 145).

Nevertheless, it is important to bear in mind that these types of strategic behaviour are not necessarily deceptive since many applicants consider themselves to have legitimate disability claims (Stone, 1984). Previous studies indicate that in order to gain access to personal assistance Swedish adolescents felt it necessary to reinforce their identity as disabled teenagers and underline the negative consequences of their physical impairment (Hultman et al., 2017). At the same time, the social workers responsible for making the assessments maintain their professionalism by conducting objective assessments, where discovering distorted claims is part of their professional conduct (Hultman et al., 2018). Other studies found that parents disliked the feeling that, to improve their chances of being granted support, they needed to play up their children’s disabilities rather than focusing on their strengths and progress (Gundersen, 2012).

## Reasoning about respite care

The law that regulates respite care discusses the needs of the children with disabilities as well as the needs of their parents and siblings. In the investigations we have read, it is most common to grant respite care both to relieve the parents and to give the children with disabilities opportunities to create their own relationships and stay in another environment. Common reasons are described as follows:

With a short-term stay, he is given the opportunity to have a change of environment and to enjoy recreation together with others and given the opportunity to pursue personal development in a safe environment. With respite care, the custodians are given the opportunity to remove their burden of care and to engage in activities that Dan cannot participate in. (Doc 3)

Kevin's need for an environmental change and his parents' need for relief are met with two weekends per month. (Doc 75)

Another common reason for granting respite is to address the siblings' need for their parents. There is an understanding that siblings might be affected by their family situation and often must stand back because the child/youth with disabilities requires their parents' attention. The siblings might need to show consideration in a way that would not be necessary if they had a sibling without disabilities (see, for example, Doc 89, 33).

Also, siblings have a need for their parents' time and attention ... However, from a child's perspective, the undersigned makes the assessment that the siblings need to have their own time with their parents since Saga occupies much of their time and attention. (Doc 21)

In a third of the investigations there are clear references to the siblings' need to have time alone with their parents while the child with disabilities is in respite care.

Mazoud's parents also receive relief from the care and nursing work and time to devote to the little sister and their own leisure activities. (Doc 10)

The efforts should also be able to help Kim talk to someone who is not a mother or father, which contributes to a calmness at home that makes everyone, including the younger brother, feel better. The goal is also to be able to give Kim's custodians relief and give them more time with the little sister and their own leisure activities. (Doc 15)

[Respite care should be granted so] that Ian's parents are given the opportunity to spend time with Ian's siblings without Ian being present. (Doc 22)

[Respite care will provide] the opportunity to give Mary's siblings unparalleled attention and also satisfy the siblings' need for relaxation. (Doc 83)

To summarise, when children with disabilities go to respite care, their parents have opportunities to relax, participate in leisure activities and spend time with their other children. The family has the chance to do things together that would be difficult to do with the child with disabilities. The family members who stay home are given a chance to relax and enjoy non-demanding activities. This goal is in line with approving respite care.

## Need for practice

Children with disabilities might also get the chance to relax when they go to respite care, but the visits are more commonly connected to developmental tasks, activities, training and practising. The law stipulates that children with disabilities must be provided 'environmental change and recreation' and with 'the opportunity for personal development'. The goal of development is salient in most of the social documentation.

The goal ... is that Eve will get environmental change and it will give her an opportunity to leave home. Through social training in the respite care, she will have the opportunity to continue to develop in a social context. Eve gets the opportunity to practise managing different social contexts and events in interaction with others. (Doc 61)

Many children are granted respite care to 'practise social interaction', 'develop a social network and social interaction' and 'be trained to manage more independently'. One document says:

She also needs to develop her ability to participate in group activities. She also needs help in guiding her behaviour and learning to see and understand the consequences of her actions. (Doc 33)



Concerning the children with disabilities, there is a strong focus on developing skills and abilities. It brings to mind the medical model of disability, in which disability must be medicated, mitigated or corrected if possible (Oliver, 1990).

Other goals, according to the documentation, are for the children to develop independence and be liberated from their parents. Teenagers are supposed to be emancipated from parents (read mothers), and respite care might facilitate this process by fostering independent and socially skilled individuals.

Moa has, because of her disability and age, a certain need for environmental change and recreation, likewise the need for a safe environment to train and create contacts outside the home and as a part of reducing one-sided dependence on her mother. (Doc 9)

Tanja is just like other girls of her age, needing to free herself from her parents. The efforts that are granted and executed may support her in this. (Doc 35)

The best interests of the child' also means that investigation and decisions are made with regard to the child's need for independence and [the understanding] that he or she should be given optimal conditions for developing this. This includes creating their own social network outside the family and feeling that they can manage without their parents. For children with disabilities, this can sometimes only be made possible by giving the child other support in this process. (Doc 63)

### Children with disabilities as 'becomings'

In the documentation, children with disabilities and their siblings are described very differently and are given different prerequisites concerning their childhood. In this assessment process the children are put in discordant positions. Whereas siblings are described as needing to spend time with their parents and just hang around, children with disabilities are supposed to practise and develop. The well-being of the siblings seems to be dependent on the children with disabilities staying away from home and from the parents. It resembles the historical way of describing children with disabilities as 'a burden to the family'. If we apply the child sociological concepts of 'being' and 'becoming', it becomes obvious that the children with disabilities described in the documentation are perceived as 'becoming', whereas their siblings are seen as 'beings'.

There are also references to 'recreation' concerning the children with disabilities, but these are often combined with other aspects of practising. As already noted, respite care can also be used as a means of '... breaking an interdependence between children and parents', and for many teenagers this is an argument for getting respite care. There are phrasings such as 'independence', 'managing without parents', 'emancipation from parents'. The teenagers with disabilities need to practise in order to become more independent and to catch up with the development of teenagers without disabilities, according to the documentation. They are described as 'becomings' also in this respect. The overarching goal of independence, in this case defined as creating a social network of one's own and managing without parents, is self-evident and is based on 'normal development'. Slater (2013) highlights the fact that even though young individuals usually prioritise 'here-and-now' experiences of fun and friendships, young individuals with disabilities are offered leisure activities focusing on learning life skills and increasing independence and/or self-esteem. Not only are children with disabilities perceived as 'becomings', they are also treated as children who need to practise in order to adapt to normative life course expectations, for example, to act in age-appropriate ways. This might be interpreted as children with disabilities needing to be rehabilitated or 'normalised' to be offered a chance of a future (Cooper, 2013).

### Discussion

This article has studied social workers' constructions of childhood within the social documentation of application for respite care in Sweden. The results show that there are different views of what

constitutes childhood for children with disabilities and for their siblings. Our results indicate that children with disabilities are often portrayed both as a 'burden of care', from which parents and siblings need a break for rest and recreation, and as 'problematic children' who need access to a short-term stay in order to practise and develop social skills (developmental tasks). Using the concepts from childhood studies, children with disabilities are perceived as 'becomings' in constant need of training and practice in order to achieve levels of 'normalcy', whereas their siblings are seen as 'beings' who need to spend quality time with their parents in the absence of their siblings with disabilities.

Consequently, Swedish SDA assessments may serve as an example of how the arbitrary and discretionary character of the bureaucratic system of evaluation and intervention around children and families is informed by developmental psychology. According to Burman (2007), developmental psychology fails to theorise the relation between the individual child and the wider social and political context, blaming difficulties on the child, the family or both, and it also fails to implicate the wider social forces which construct and maintain the child's relations within his or her family.

Swedish disability politics promote 'equality in living conditions and full participation in social life'. The goal of the individual is to be able to 'live like others'. It is in interpreting what it means to live like others that norms and normativity are made visible. Within the social documentation it is obvious that the yardstick for what is 'normal' is the development typical of children without disabilities. Such comparisons can be both beneficial and detrimental.

The ambition of Swedish disability politics is to provide resources to narrow the gap between individuals with disabilities and those without them in terms of life conditions, experiences and development. This gap is referred to by social workers in their arguments to approve respite care. In comparisons with other children, some children with disabilities lack friends, social activities, experiences of handling friendships and emancipation from parents. In order to achieve these experiences and abilities, the children with disabilities are offered short-term stays where they can practise and get support to develop. The comparisons with 'normal' children highlight their rights to 'a life like others' have. Referring to 'normal development' might transfer the focus from the impairments to the children themselves (cf. Mietola & Vehmas, 2019).

On the other hand, the comparisons with 'normal' children raise the risk of obscuring the impairments and their disabling consequences. As already mentioned, more than 60 percent of the applicants were ascribed a diagnosis within the autism spectrum, where challenges concerning social relations are common and a criterion of the diagnosis. Having a diagnosis within the autism spectrum often includes difficulties with social interaction that sometimes lead to conflicts with classmates and siblings, outbursts and difficulties in understanding and following rules of games. If we apply the definition of disability as the product of barriers in society and not an individual characteristic (Oliver, 1996), the focus on training and practice becomes worth questioning. It exemplifies how, for disabled children and youth in respite care, ableist perceptions of normality serve to reinforce professional practices of engaging children and youth in developmental tasks, such as practising and learning 'appropriate' social interaction.

In a social world dominated by non-autistic people (neurotypicals), people with autism are often assumed to be either unable to form relationships or in need of educational interventions through which they are to learn how to manage relationships (Brownlow et al., 2015). An alternative is to consider people with autism as contributing to neurodiversity (Brownlow et al., 2015), in which social interaction is a *double empathy problem* where there is mutual difficulty in understanding the social motives of the other (Milton, 2012). The inability to 'read' the subtext of a social situation is only deemed a deficit of those diagnosed as being on the autism spectrum, which could be improved by practising social skills that are considered appropriate in terms of prevailing societal norms.

### **Children's own construction of their childhoods**

It is obvious that children with disabilities are constructed as 'becomings' in need of practice, learning and training in the assessment process. Their voices are vague and seldom heard in the

documentation (Engwall & Hultman, 2019). This gives rise to the issue of how children with disabilities are given chances to express childhood. Laz (1998) emphasises the link between the individual's ability to enact and perform age and structural factors that constrain or facilitate the creation of age. Can respite care, despite the adult world's perspectives and norms, still be a place for creating room for 'being'?

Children who have experienced respite care are asked by the social workers how they like it. Their answers are used to show that the children accept respite care. Yet, these answers also reveal something more. The children never say that they practise social relationships or on social skills. Instead, they talk about making friends. A mother says: 'They are the same group of boys who meet there every weekend, which means a lot to Lars. When he comes home, he counts the days until he will go there the next time, [marking it] on the family's calendar' (Doc 5). The children talk about spending time with their friends (Doc 36). They transform their 'development tasks' into social interactions here and now. This aligns with another study where British researchers compared parents' and children's views on respite care. The children talked about doing new activities while the parents instead emphasised new lessons that could contribute to their children's development in the future (Welsh et al., 2014).

The children's answers to the social workers' question show how they may transform the normative discourse of practising into something else. This is an example of what McLaughlin et al. (2016, p. 15) describe when they say that '... an important distinction is made between the formation of the norms of *childhood* and the lives of actual children and young people.' Even though the assessment and institutional setting of respite care are imposed on the children and these restrict their lives, the children act within as well as challenge these boundaries (Hardman, 2001). Children try to arrange it so they can spend time with their new friends at respite care, they talk about new friends as well as conflicts with specific children, they discuss activities they like and dislike, and sometimes they refuse to go to respite care. Luckily, they shape and create their stay at respite care in their own ways regardless of expectations of the adult world, and their lived lives are not always in accordance to normative behaviour.

## Limitations and practical implications

This study is based on written social documentation. From other research, as well as group interviews with social workers, we know that many social workers work more with participation and interaction with children than their documentation reveals (Engwall & Hultman, 2019; Hultman et al., 2018; 2019). We also know that social workers' possibilities to act are circumscribed by local routines based on political initiatives (National Board of Health and Welfare, 2015) which might lead to conflicts between the social worker's personal ethos and recommended policies. Consequently, it would have been interesting to discuss how social workers argue concerning their way of describing children with disabilities and their siblings. Such a discussion would have been a chance to cross validate our conclusions and this is of course a limitation of our study.

Nevertheless, the social documentation which constitutes the data of this study, reveal the administrative discourse, which the social workers utilise in their argumentation for how and why the child is granted or not granted respite care. It may be used in juridical processes, the child and her or his parents have the right to read it and due to a culture of 'cut-and paste', formulations are recycled. Therefore, our call to social workers is to be careful with how they express themselves, written and orally, in order to document all of the communication they actually have with children and to avoid stereotyping descriptions.

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No potential conflict of interest was reported by the author(s).

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