ORIGINAL ARTICLE

Whose Voices Matter? Use, Misuse and Non-Use of Augmentative and Alternative Communication (AAC) Among Severely Disabled Children in Small Group Homes

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The article explores whether and how severely disabled children living in small group homes are supported in their communicative efforts to participate and have a voice in their everyday lives. The study, framed within a human right's perspective, is inspired by Merleau-Ponty's phenomenology of the body. The empirical data material has been collected through a multi-method approach, including participant observation of everyday interactions between the children and staff in the group homes and semi-structured interviews with staff and parents. Our findings reveal that children and adolescents are communicative subjects who initiate different means to convey their messages and opinions. However, the staff appear to have little awareness and competence in communicative interactions and use of AAC, which have left the young residents marginalised and ignored. The discussion focuses on how the institutional context can support as well as impede on the children's abilities to develop and employ their full range of communicative capabilities and exercise their human rights.

Keywords: AAC; Institutional living; Intellectually disabled children; Participation; Disabled children's human rights

Introduction

The aim of this article is to identify how the staff in small group homes for intellectually disabled children facilitate the children's voices in everyday life in line with their human rights. UNICEF (2019) has claimed that disabled children and adolescents are often prohibited from realising their human rights when it comes to healthcare, education and even survival as their personal needs and rights are not sufficiently addressed by the majority. Even though we have the United Nations Convention on the Rights of the Child (UNCRC) (UN, 1989) and the Convention on the Rights of Persons with Disabilities (UNCRPD) (UN, 2006), much work needs to be done. The UNCRC states that the best interests of the child must be taken into consideration (UN, 1989: Article 3) and the rights children have for expressing their views on matters that affect them, according to their age and maturity, must be addressed (UN, 1989: Article 12). Article 7 of the UNCRPD expresses disabled children's rights explicitly, and Article 9 of the same convention guarantees a person's right to have access to communication technologies and systems that promote the participation of people with disabilities and the right to receive necessary and appropriate support for their participation. These communication systems are called Augmentative and Alternative Communication (AAC).

The International Society of Augmentative and Alternative Communication (ISAAC) defines AAC as:

> …a set of tools and strategies that an individual uses to solve everyday communicative challenges. Communication can take many forms, such as speech, a shared glance, text, gestures, facial expressions, touch, sign language, symbols, pictures, speech-generating devices and so on. Everyone uses multiple forms of communication based upon the context and communication partner. Effective communication occurs when the intent and meaning of one individual is understood by another person. The form is less important than the successful understanding of the message. (ISAAC, accessed 6 May 2020)

The American Speech-Language-Hearing Association (ASHA) states that 'AAC is augmentative when used to supplement existing speech, and alternative when used in place of speech that is absent or not functional' (ASHA, accessed 5 May 2020). There are two main types of AAC: (1) unaided forms of AAC, which require no tools with the exception of the

body but where some motor control might be required, and (2) aided forms of AAC, where an external tool is used, such as symbols, pictures or electronic devices.

In this article, we report on severely disabled children's voices and the extent to which their rights to be heard are satisfied when living in small group homes. When connecting maturity to intellectual disabilities, a fundamental is to decide when an intellectually disabled child has the maturity to express reliable opinions on everyday life matters and who has the authority to decide this. In Norway, this is a relevant question because the United Nations Committee on the Rights of Persons with Disabilities (UNCRPD), responding in April 2019 to Norway's first report on its implementation of the UNCRPD (UN, 2019), pointed out that the country lacked available and accessible mechanisms that disabled children could use to express their views on important matters that concern them. Children living in small group homes do not have parents available in the same way as children living with their own family, even though the parents still have custody. These children and adolescents are surrounded by staff who then become important actors for them, collaborating with the parents and the children themselves to develop available and accessible mechanisms to improve their opportunities to be heard and use their voice in everyday matters.

We understand participation as relational and, in line with the International Classifications of Functioning (ICF), 'as engagement in a life situation and [it] does not occur in a "vacuum"' (Maxwell et al, 2012: 34). In this article, participation is further connected to everyday life in the group homes, not to being active participants in the research process.

Contextualising the Research Venue

This study was conducted within small group homes for severely disabled children. The term small group homes has been chosen to distinguish this form of residential care from institutional care given for child-protection reasons. In Norway, small group homes provide fulltime residential services designed to support families with severely disabled children. The care the professional staff provide on behalf of the parents in these institutions, as laid down in the Health and Care Act (2011), is the most comprehensive service available for disabled children. The two main criteria for placement of a child in a group home are (i) the child's diagnosis as severely disabled and (ii) the family's excessive burden of care. The children are rarely consulted on the path leading to their move into a group home (Jessen, 2014; Sigurdsen, 2011).

The children in the group homes are under the age of 18 and attend local schools, typically at special-education departments. All the children need extensive support in everyday tasks due to their impairments. Limited or no verbal communication is a common feature shared by all the children in the study, and it is important to note that they seldom collaborate with their so-called 'mainstream' peers in any of their everyday arenas. Their main interlocutors are adults (parents and professional caregivers).

The staff provide care to the children in compliance with the regulations established by the central authorities. As Bigby et al. (2014) argue, the providers of direct care translate the governmental policy into local contexts, thus occupying an in-between position between institutional duties and individual care.

Voices of Disabled Children Living in Residential Care

For years, researchers have been aware of the problem that severely disabled children's voices are not being heard. Jenny Morris, for example, stated more than twenty years ago that:

> We need to know much more about the experiences of disabled children and young people, and such research must offer an opportunity for their accounts to be heard. Only when this happens will policy and practice be driven more clearly by the interests of disabled children themselves (Morris, 1997: 257).

A year later she added that '...there is an assumption that they [severely disabled children] do not have a view to express or a way of expressing it. Our society operates as if communication only takes place through written or spoken language' (Morris, 1998: 36). The number of studies conducting research on severely disabled children and their communicative challenges has increased in recent years. These studies have found that severely disabled children are able to communicate when adults and peers offer them an opportunity to be heard through their use of alternative and augmentative communication (Söderström, 2016; Evensen, Standal & Ytterhus, 2017; Østvik, Balandin & Ytterhus, 2018; Doak, 2018; Iacono, 2019; Ytterhus & Åmot, 2019). None of these studies have been carried out in small group homes, but rather in educational settings and schools. However, their common findings that are relevant for our study are that the use of alternative and augmentative communication must be individually adapted, and demands must be put on the competence and willingness of the environment to communicate on the child's premises. They also point out that a large variety of research methods has been used, including pictures, drawings, objects, film and artefacts especially designed for children and adolescents with little or no verbal communication. For example, Evensen, Standal & Ytterhus (2017) used crackling golden paper to explore the existential meaning of 'queer things' to understand how two children with disabilities reach out to objects in a special-education section. Østvik, Balandin & Ytterhus (2018) pointed to the importance of the staff's efforts to build goodwill with students by using AAC, and the importance of fellow students at inclusive schools having confidence in using AAC. These findings and the fact that there has been very little research on small group homes and severely disabled children, as highlighted in Stalker (2008), have stimulated our interest in

exploring the quality of communicative interaction in these contexts ten years after Stalker first voiced her concerns and called for this type of research. In this context and according to the sociologist Erving Goffman's definition of total institutions (1957: 44) we have defined group homes as living places 'established to care for persons thought to be both incapable and harmless'. Characteristics of these residential homes are that all aspects of life are carried out in the same place under a public authority, the residents' daily activities are carried out in close association with the staff, and the activities are scheduled and interrelated through an overarching plan (Goffman, 1957: 45). However, our group homes are not complete total institutions as Goffman defines them because the residents also have activities outside the institution (e.g., school, family visits and some leisure activities). So, what did we identify from previous studies of living places for severely disabled children?

David Goode's (1994) seminal ethnomethodological study of profoundly disabled girls provides insight into an institution where there were limited opportunities and little support for the girls to express their own views. Goode showed that close relational interaction enhanced the girls' communicative expressiveness. The Viper Project (2013), which investigated disabled children and adolescents' opportunities for participation in everyday life and research, identified a lack of understanding, training and skills in using AAC, both for the disabled children and caregiving staff. The project found that limited time and available resources were barriers to achieving efficient use of the relevant systems. Motivation and attitude are other important qualities in deciding to use supportive communicative tools. Wilson (2013) advocates environments of 'total communication', pointing to 'a multisensory approach using tactile, auditory and visual information' in the living context, in other words, valuing all means of communication. Total communication, she argues, 'is more about a shift in thinking than the practical application of a method, and this will take longer to be absorbed into the culture of the unit' (Wilson, 2013: 40). Recently, Franklin and Goff (2019) discussed how children lacking verbal abilities and living in child-protection institutions were rarely heard when it came to their experiences. Similar findings were made by McEvoy and Smith (2011) during their research project in Irish residential settings where AAC was used as a methodological tool. In their conclusion, they presented the concept of 'being silenced', describing the most complexly disabled children as difficult to reach, even when using an AAC tool (ibid: 106). Some glimpses into intellectually disabled children's and adolescents' lives in institutional settings are provided by Fylkesnes (2020). She examines various modes of communicative initiatives and how these are dealt with by sensitive and engaged institutional staff and demonstrates that institutional frames and the staff's practical care duties for the residents in many everyday situations override the children's attempts to raise their voices. Fylkesnes (2020) included minimal use of supportive communicative tools in her discussion.

In sum, severely disabled children growing up in institutions or group homes are still given little attention in research. Even though some inroads have been made when it comes to increasing knowledge in this area, it does not seem to have had much effect on everyday practices, according to the empirical findings. We must question whether the human rights of these children and adolescents' are fulfilled, and in this article, we aim to answer the following research question: How do the practices of the staff in encounters with disabled children and adolescents in small group homes facilitate their voices in everyday life?

The Voice of Non-Verbal Children – Theoretical Framework

Children with limited or no verbal speech who have an intellectual disability, are, irrespective of their challenges, communicative in everyday life. When we cannot rely on traditional, well-used communicative methods, we must conceptualise 'voice' differently as, in line with the phenomenologists Simmons and Watson (2015: 51), 'something that can be expressed in action towards the physical and social worlds, and hence is contingent upon the relationships people develop over time and across contexts.' Such an understanding of voice positions and communicative actions as messages given and received through social interactions between members of a social community. Expressing a message 'in action' includes the body. Through the body, the actors in the group home can express themselves in a multitude of ways, whether through spoken words, sounds, mimicry, laughter, behaviour or any bodily act that can be perceived by others as constituting a communicative utterance. Merleau-Ponty (2002) established the concept of the phenomenological body as a reliable means of expression, as the body contains all our lived experiences, and every bodily gesture is imbued with meaning. Thus, the lived body becomes a competent provider of meaning, a communicative tool through its gestures exchanged in social interactions.

Conceptualising the voice as relational (Simmons and Watson, 2015) means that communication is dependent on reciprocity, a social interplay between communicative bodies to create mutual understanding, as elaborated by Merleau-Ponty: 'In the experience of dialogue, there is constituted between the other person and myself a common ground; my thought and his are inter-woven into a single fabric' (Merleau-Ponty, 2002: 413). With our bodies, we create and occupy a we-relation with others in the world (Schütz, 1999). Thus, meaning and understanding are established in close relational interactions.

However, the relational, expressive body might need support in the form of augmentative and alternative communication tools. Satisfying this need could further enhance the expressive subject's ability to participate in everyday conversations. This rests on the assumption that both interlocutors, the verbal and the non-verbal, will jointly benefit from the arrangement. Use of technology, such as AAC, requires time and effort to develop knowledge and

understanding of how and when to use the communication systems, and how to implement them as useful tools in everyday relationships (Viper, 2013; Rombouts, Maes & Zink, 2017). However, an artefact, such as crackling golden paper, or an electronic device can become barriers to such encounters if they are not a natural part of the social relation and the experienced body. Merleau-Ponty (2002) describes how a blind man's stick can become an extended part of his body, as the blind man learns through experience to 'see' through the tip of the stick; the stick becomes the blind man's eyes. Similarly, a communication tool has the theoretical possibility of becoming a natural part of the body of a child who is striving to communicate. As people communicate through their bodies every moment of the day, it is important to create and maintain a communication tool as an integrated and extended part of the body. But if we are to reveal whether this is the case and identify what is taking place in the group homes with respect to children's voices and participation, we need to be aware of our choice of methods.

Method(s)

This article is based on qualitative data constructed through a multi-method approach. The fieldwork was conducted by the first author in three small group homes accommodating from one to six children and adolescents, five girls and six boys ranging from 11 to 18 years of age. The children have been diagnosed with intellectual disability in combination with several other diagnoses. Communicative capabilities range from some verbal speech, via single words and signs, to mere bodily gestures and behaviour. Some have supportive communication tools, such as key-word signing, pictures on paper and electronic devices.

A group home with six children has a staff of 35 to 40 personnel in full- or part-time positions employing shift rotation. The adult-child ratio is 1:1. The staff vary on which child they work with on each workday, so they are acquainted with all the children and to ensure flexibility in running the institution. For the children, the number of adults in rotating shifts might be a disadvantage when it comes to continuity in building communicative relations. The group homes in this study are situated in both urban and rural areas in Norway.

The fieldwork was carried out using participant observations, and a total of 32 observations (approximately 115 hours) were made. The staff were included in the observations, as their activities were intertwined with the children's. A semi-participatory role was established. The observer attempted to situate herself at a distance from the activities; however, she was invited to collaborate and was included more in the activities further into the study (Schütz, 1999; Buscatto, 2016), but was still not considered on the same level as the regular staff. The researcher's eyes and ears were the main observational tools utilized. What was observed was transcribed immediately after each observation, as recommended by Cocks (2008) and Goode (1994).

After the observation period, thirteen semi-structured interviews with ten staff members and three parents were audiotaped. The interviews were conducted to expand the understanding of the observed activities, as well as to reveal the interviewees' understandings of small group homes as a phenomenon. It was not the intention to use the interviews to validate the children's communication.

As our data material has been constructed on 'unstructured' observation and semi-structured interviews, an interpretative analytical approach was applied by both authors during the analysis. Reed (2011) suggests that reflective interpretations may be suitable, and necessary, for analysing data generated through observing bodily actions and interactions. The analysis was conducted through phenomenological pathways (Rapley, 2016): reading the data material, coding meaningful situations and interactions, and re-reading and structuring the coded material in an inductive manner. For this paper, the focus has been on how the staff's practices in encounters with disabled children facilitate the children's voices and the children's participation in everyday life so they can have influence on their surroundings. The presence and use of supportive tools for conducting agency and social relations in the group homes were particularly noted. The generated analytical categories were: 1) signing enhances dialogue and safety; 2) communicative tools in use and non-use; 3) know-how and motivation.

Ethics

This study was approved by the Norwegian Social Science Data Services (NSD) in accordance with the personal data-protection regulations and ethical guidelines in force. The parents gave their written informed consent on behalf of their child. The parents and staff in the group homes were asked to inform the child about the visiting researcher in ways that they believed suited the child best. The researcher informed the personnel in each of the group homes before commencing the work. A sensitive attitude towards the participants was maintained throughout the fieldwork, for example such as by withdrawing when sensing any discomfort, as suggested by the concept of situational assent, an ethical approach reported by Cocks (2006). To maintain anonymity, the participants cannot be described in detail because they are few in number in Norway. They have been given fictive names in the presentation.

Findings

The everyday life in the group homes is teeming with communicative actions. A variety of sounds and movements fill the spaces. Most of the audible communication comes from the staff members exchanging messages, or the staff talking to the children, asking something, giving directions or just attending to a social encounter. The children also make sounds: a few talk, some laugh, some scream, some make constant rumbling sounds and others knock on tables

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or slam doors. Child-adult conversations are the main communicative pattern, fewer are observed taking place between the children. Face-to-face child-adult dialogues can be carried out in different ways, always with an asymmetry in how the interlocutors convey their messages. Much of the everyday conversation from adult to child is in the form of verbal instructions or 'yes' and 'no' questions. Most of the children have quite distinct 'yes' and 'no' statements, using words, nods, private signs or gazes. 'No' statements could be more behavioural, for example, by turning away from food, crying out or protesting loudly and with body language.

One director said in the interview that their home had a focus on communication as a pillar in helping the children to be seen and understood on their individual level. She told us about a municipal project on the use of AAC in the health and care services where the objective was to motivate professionals to participate in enhancing the service recipients' communicative participation. However, a lack of resources (e.g., time for training) could prevent the staff from gaining competence and skills in AAC, the director added. An expectation that each staff member should also acquire qualifications outside working hours was expressed. An overview of different types of AAC in use in the group homes is presented in **Table 1**.

Signing enhances dialogue and safety

Key-word signing is an unaided type of AAC. Signing key words in conversations means making gestures and emphasising main words in a sentence so that the receiver of the message has more channels through which to perceive and code the message (Rombouts et al., 2017). The signs typically mimic the thing or object they symbolise, or they can be adopted from formal sign language. Both universal and private signs were in use in the group homes. Private signs meant that those with fine motor challenges adapted signs that were manageable.

Key-word signing was used with variable consistency in relation to some of the children in the group homes. James' (17) caregivers used a variety of key-word signing, although he seemed to understand many of the spoken words. For James, this had two purposes: (1) it was assumed he felt safe and content with the doubling of understandability, and (2) he himself learned to use signs to communicate his own wishes, in combination with his single words, sounds and mimicry. James' keyworker said that he was a patient young man trying to convey his messages in different ways if his interlocutor failed to understand, indicating that conversations were a co-productive activity.

While Lydia (17) appeared to understand simple speech directed at her, she had few words herself. Instead of speaking, she used some single signs to make herself understood, such as signs for singing, coffee, sweets, her own name and more. Such signs were also employed by her caregivers, albeit in a random manner. There was a discussion in the home concerning one specific sign Lydia had used frequently for a period of time without anyone grasping the meaning. The staff had made unsuccessful suggestions, asked her mother and sent photos to her school in attempts to figure it out. No-one could figure it out. Lydia also used the same sign towards the researcher, apparently trying to start a conversation – unsuccessfully. When Lydia's mother was interviewed, she could reveal that the mystery had recently been solved: One day Lydia came home from school with an arts and craft product, and she made the mysterious sign. 'Oh, that's what the sign means!' the mother said, and Lydia confirmed. The efforts made to find a solution to the sign mystery showed how the staff and parents could become engaged and involve each other in solving impediments to communication. Seeing an unknown sign once would probably not have triggered the adults' efforts, but the repetitive and insistent presentation underlined that this was important to Lydia.

There were no observations of the staff using key-word signing between themselves to help the children understand what was being discussed, nor was a consistent use of pictures observed. This means that there was no universal supportive AAC environment in the group homes, except for James' home. When asked whether this was an issue that the staff discussed, the answer was that the children were not interested in what the staff talked about, even though some of the staff (in the interviews) admitted that a more universal communication environment might have been a good idea. Considering how children normally learn by observing others, the children in the group homes might be deprived from having such opportunities.

Table 1: Types, users and benefits of different alternative and augmentative communication.

Type of AAC	Who uses the tool	Benefits
Key word signing	James, Jacob, Jack, Lydia, John, Julian	Readily available (hands). Enhances understanding.
Pictures	James, Julian, Jonas, Jacob, Lydia	Provides opportunities for joint focus and reciprocal dialogues. Could clarify the child's meaning (wish, need...).
Communication passport	Lena, Laura	Provides ideas for staff on how to address and interpret a child, and what to talk about.
Electronic devices	James, Jack, Jacob, John	Provides opportunity for the child to specify what to convey and to determine what subject to talk about, in a manner that might be intelligible for the carers.

Communicative tools in use and non-use

Pictures used in direct face-to-face communication were only observed to a small degree, and the following episode reveals one of the rare examples of a productive use of pictures to enhance communication:

> Julian (18) has a ring-binder containing several folders with pictures and symbols. A word is attached to the pictures. At the first observation in this house, Julian directed the researcher's attention towards the binder, which is usually placed on a table in the hallway. Julian opened the binder and pointed to a picture that showed a taxi to tell the researcher that he was waiting to be picked up. He then pointed to pictures of a bathroom and toilet, grinning, watching for the researcher's reactions when she phrased the pictures' meanings. He had no intention of going to the bathroom.

By using a few pictures in this situation Julian could inform a stranger about his near future (taxi), as well as test out the stranger's reactions when he teased her (toilet). A dialogue was initiated. Julian's binder had a combination of pictures that encompassed activities he could do, food he liked and emotional reactions he might have. Throughout the observations conducted in the house, the binder was only used on a few occasions as Julian's few single words, his bodily gestures and the staff's worded questions were used instead.

Some of the children had electronic devices as support for communication. Jack (15) had a tablet which he could use to give simple answers, write simple questions and store pictures and videos. The observations showed that the device was used on some occasions in close interaction between Jack and his keyworker. On the second day of observation, Jack sat beside his keyworker, Annie, on a sofa in the common area. The researcher positioned herself behind the sofa to observe what Jack was doing on the tablet. Jack then wrote: 'What she', and the device produced the words in a male voice. Annie answered the question verbally. On another occasion, Jack brought his tablet to Annie, showing a short video of a young man. He wrote a question: 'What he'. Annie told him what the video showed. Jack repeated the question, and Annie tried to figure out what exactly Jack was asking, explaining in detail what happened. Jack carried his device around with him and asked the same question several times the same evening, apparently preoccupied with the story. Annie answered patiently. Other than his tablet, Jack just had private signs for yes, no, help and finished.

The tablet could expand Jack's communicative ability significantly. However, this device was not always readily available whenever he needed it. When not in use, it was stored in the staff office, and it needed charging. To use the electronic aid, he needed encouragement and his interlocutor had to fetch the device and hand it to him. These are obstacles that undermine use: someone must initiate things by bringing the tool into the communicative setting. Nor did every member of staff know how to use the device. It might have been easier to use 'yes' and 'no' questions, limiting the boy's opportunities to initiate expanded dialogues, and to decide what themes to focus on. This practice underlines the staff's power over Jack, and others, ability to exercise agency as an equal person and to use every accessible means to do so. Another observation is that such devices were mostly used as a leisure activity and not employed very often as guides for practical matters. One exception was Jacob, who could be led to his room and use his pictures or devices to specify a practical choice.

Here we turn our attention to a story referring to James' schedule: Pictures placed on a board identified planned activities. The pictures were used immediately before the activity (otherwise they could have distracted James), and the staff member pointed to the pictures, explaining to James what was to happen next. One day, the plan was to drive by car, take a bike with them and make a campfire in the woods. This was explained through two pictures – the car and the bike. James said 'no!' several times, pointing insistently at the board. Suddenly one of the staff members realised that one part of the activity sequence lacked a picture: the campfire. The missing picture was then drawn and put onto the board and James relaxed. Two features became evident here: James understood the words, however, when supporting aids are used, they needed to be used consistently.

One staff member said in an interview that they were planning to make a system of pictures for Jonas (17), however, the work had not yet been finished, indicating an institutional challenge: it is time-consuming to make new systems, and they can be difficult to implement in a large group of employees. However, she went on to say, 'we have to try to establish something before we send him off to adult care'. More staff expressed concerns about which practical and communicative skills they should be able to teach the adolescents when preparing them for the transition to adult life.

Other picture systems were less used or not accessible for use without significant effort, here demonstrated by their spatial placement. A child with low motor abilities could not reach the communication aid when it was placed behind furniture, and the adult, for the same reasons, might find it too laborious to use it. Jonas' picture selection was placed behind a chair. A staff member sat in that chair, her back to a picture system hanging on the wall, commenting that it was a pity that Jonas could not convey his thoughts and feelings in a more intelligible way for the staff. She said that he apparently did not get any communication teaching at school. The caregiver said that earlier a tablemat with pictures, belonging to another adolescent, had enabled Jonas to choose what to eat by pointing at pictures; however, it eventually went missing, and she did not know what had happened to it.

Another version of pictorial AAC is the 'communication passport', used by Lena (15) and Laura (15). This is a small booklet of pictures and words presenting the child's family, likes and dislikes, how the child should be addressed and how actions could be understood. While the booklet was for the girls, it was kept out of their sight or reach ('hidden'

behind their backs), but available to the staff. The intention was to provide the adults with knowledge and ideas for dialogues and interactions. However, one member of staff said that Lena's communication passport was rarely used as 'you need to know her to read her', suggesting that communicative actions involve a variety of bodily expressions that cannot be described in a few sentences. In the same interview, the 'communication passport' was described as 'something the school has produced', indicating a limited interest in AAC systems provided by others. Thus, the people possessing 'communication passports' have to rely on unaided expressiveness in daily life. It is also possible that some of the children are not aware of the existence of or their need for the communication device when it is kept out of sight.

Know-how and motivation – obstacles in the system

Some children were trained at school in the use of electronic AAC systems. When asked about how these systems functioned, the typical answer was that the staff did not know exactly, it was a school matter for the time being. Perhaps in the future, the staff would learn to use them, one member of the staff said. However, another staff member who had attended a network meeting about one of the residents talked enthusiastically about how this young person was able to use both his communication device and specific gestures at school and hoped for the ability to implement the systems for this child in the group home.

Which strategies were planned to secure the staff's AAC competence was a question that was not asked nor specifically talked about during the observation period. Two exceptions occurred: Linda (17), who used modified official sign language, was ensured that the staff in charge of her were able to communicate with her in a skilled manner, and James' staff participated regularly in internal sign training.

One mother said that she had wanted to learn to use her daughter's electronic communication tool, which was under development at school, but she had to pay for the training course herself, an expense she could not afford. Another mother said that several communication tools had been tried with her child throughout the years; however, the tools were relatively quickly rejected by the school, because they failed to have an immediate effect. She also said that there had been a lack of information on which opportunities were available, both for the child and the family.

Discussion

The research question in this paper is related to how the human rights (UNCRC, 1989; UNCRPD, 2006) of severely disabled children in group homes are secured by the staff's practices in face-to-face-encounters between children and staff in these small group homes.

All the children in the group homes practised bodily gestures and had very little verbal communication. The children's dependency on their significant others in communication is highlighted by Smith's (2018) notion that their vocabulary available through AAC is designed by others and based on assumptions of what could be suitable words or sentences for them to know. Much demand is placed on the staff if they are to gain intimate knowledge about each child and their needs for expression and about how capable each child is in learning how to use and using AAC. If the children are not given the right support for self-expression, they may be obliged to 'tailor their voice to the competencies of their communication partner, if communication is to be successful', as argued by Smith (2018:181). In our institutional setting with staff in rotating shifts, this means that the child is given the responsibility for tailoring his or her communication to suit several adults.

Non-aided AAC, such as key-word signing, seemed to be the system most frequently in use, probably due to the simplicity and immediate availability. However, we observed in our study, as Rombouts et al. (2017) also noted, that key-word signing was used to a relatively low degree, and just with a few of the children, as practice in using the non-aided tools is also dependent on having awareness and skills. We did not observe key-word signing in use between staff in general as an institutionalised way of communicating. Consequently, the children had fewer opportunities to follow the conversation when it was not directly aimed at them. Some staff members even referred to electronic AAC devices as 'school-things', and, by doing so, indirectly defined such devices as irrelevant to their own work. The observation that there was no universal use of key-word signing or other forms of AAC in the group homes, as also commented on by Wilson (2013), implies that a 'total communicative' environment is absent, which undermines the possibility of AAC becoming a natural part of the everyday conversations in the group homes, or, as Merleau-Ponty (2002) argues, as an extended part of the individual and environmental body. Such poor AAC environments deprive the children of the opportunity to benefit from the dialogues of others to enhance learning, understanding and inclusion (Iacono, 2019). There is still much left to do before AAC is included in all parts of everyday practice in the group homes.

However, the analysis shows that the staff made efforts to communicate with and respond to the children. Impediments to the use of supportive communicative tools in the institutional context were nevertheless present for various reasons. The staff's main responsibilities were to care for the children, where they had to balance between practical institutional requirements and the children's need for closeness and participation. Ideally, all practical caring tasks should be performed in agreement with the child, where acceptance is obtained through adapted dialogue in accordance with the rights established in the UN convention. In practice, tasks seemed to be carried out as taken-for-granted routines, and here our findings concur with Fylkesnes (2020): in a system of multiple practical duties, the need to learn and use AAC can be looked upon as an additional task to undertake. Thus, despite positive managerial attitudes, the staff signalled an ambivalence to AAC and indicated a need for motivation and training to be able

to practise AAC efficiently on a daily basis. In Norway, the statutory requirement relating to children's use of AAC only applies to educational settings (The Education Act, § 4a-13). An additional statutory requirement for its use in residential settings could probably reduce the staff's ambivalence and make them more aware of what they are doing. In the busy everyday life, it cannot be the individual staff's responsibility to upgrade their own competence to fulfil the children's human rights to have their voice heard. This is the responsibility of the national and local authorities, as commented on by the UN Committee on CRPD (UN, 2019). Our finding is in line with Rombouts et al.'s (2017) research, which also identified the belief that AAC was related to school, and that it may be found somewhat laborious to implement the communication system in the group home, thereby rejecting the applicability of and benefits from the tool.

Rombouts et al. (2017) discuss challenges for staff and link these challenges to the lack of motivation, lack of immediate effect and the struggle to learn the skills to make key-word signing a habit in everyday conversations. These challenges might be even more prominent when it comes to the use of AAC that involves pictorial systems and electronic devices, which might require a higher level of competence and maintenance of learned skills. In the group homes, the practice seemed to be that it was more effective simply to carry out practical tasks according to routines, where the children were mainly included through instructions or the use of 'yes' and 'no' questions. Thus, some AAC tools were more related to leisure activities than to participation in practical decision making in every daily activity. In a busy everyday practice, the simplest and fastest solutions may be convenient but do not meet the requirements of the two UN conventions (UNCRC 1989; UNCRPD 2006).

A critical element was discernible in the analysis: the boundaries between school, family and group homes. The school is given the responsibility for teaching communication skills to the children, adapted to each child's competence, and for providing support to develop and improve their communicative abilities, with or without AAC. Whilst responsibility is assumed by the school, it may, however, be pertinent to question how the parties collaborate on the mutual aim of strengthening the children's communicative repertoire. While the parents show an interest in how to communicate better with their child, they also point out the difficulties they have in obtaining access to the tools, thus signalling the lack of possibilities to acquire the necessary competence. Our findings indicate that both a lack of intersectoral collaboration (school, family, group home) and the shifting staff involved in everyday life (staff in rotating shifts), fragment the responsibility of providing efficient support for the children's communicative abilities and accordingly, their opportunity to participate in decisions made in their everyday lives (Evensen, Standal & Ytterhus, 2017). Moreover, we cannot ignore the fact that the number of staff members in a rotating shift system, working full-time or part-time, different professional backgrounds, different attitudes and personal appearances can all be obstacles to the use of AAC, both in the group homes visited in our study and in the Viper Project (2013). The organisation of rotating shifts needs to be a topic in future studies of group homes for severely disabled children.

Conclusion

This article contributes to the research field by showing that there is a method that can be utilised before we secure optimal opportunities for children and adolescents living in small group homes to participate by being able to express what they think about their everyday lives. This issue should be addressed in accordance with the urgent request of the UN Committee on CRPD (UN, 2019) that Norway should make use of the full and effective participative mechanisms for disabled children in decision-making processes on matters affecting their everyday lives. Even though signs, pictures and symbols had their place in the communication, everyday life in the group homes seemed to be more regulated through routines and mundane activities. Barriers to achieving the goal of a communicative environment are identified primarily as being related to institutional aspects, such as the number of staff in rotating shifts, the staff's practical duties and the ability to acquire knowledge, skills and continuity in communicative activities in the group-home, school and family arenas. For the children, the shortage of accessibility and support in the use of communication tools is a limiting factor. The directors of the small group homes claim that having a clear focus on communication is important. However, they had, to a certain degree, left it up to the staff themselves to improve their individual skills and knowledge in AAC. Such a disavowal of responsibility is not in line with the underlying human rights principle of supporting the children's best interests and giving them the opportunity to have a voice. Thus, securing the children's rights to expression is not an optional choice but an imperative duty.

To establish a unified approach to each child's communicative development, collaboration between and continuity within the child's different arenas are crucial elements. This paper reports a gap in this area and suggests that there is much to be gained by improving intersectoral collaboration and organisational structures. The findings, however, indicate that using AAC alone is not enough; a multimodal approach to intersubjective meaning exchange must be established, recognising every expression from the most subtle bodily gesture to aided AAC at the highest technological level achievable and manageable for each child. In today's situation, we find an ethical challenge and an infringement of the children's human rights.

Competing Interests

The authors have no competing interests to declare.

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