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# Communicative Work: Establishing Communication by Severely Disabled Children in Small Group Homes

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# Communicative Work: Establishing Communication by Severely Disabled Children in Small Group Homes

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#### **ABSTRACT**

The aim of the article is to provide new insights into the lives of severely intellectually disabled children who are living in Norwegian small group homes. The research question is designed to address how these children, who have limited verbal language, initiate communication in order to participate in everyday life in an institutional setting. The main research method was participant observation within three residential units. Eleven children and young people participated alongside the caring staff. The author identifies and discusses four modes of communication, three of them initiated by the children in relation to the institutional residential context: communicative environment, collaborative conversations, communicative rituals, and bodily expressions laden with meaning. The analysis is framed in the context of a monologue-dialogue dichotomy. The findings indicate that in many ways the children appear to act beyond their anticipated limited cognitive capabilities through their communicative work. However, to achieve their communicative potential, the children are dependent on the staff's communicative behaviour and responses, as well as the institutional frames.

#### **KEYWORDS**

Communicative modes; intellectually disabled children: monologuedialogue; small group homes

## Introduction

The purpose of this article is to contribute to disabled children's childhood studies by adding new knowledge about everyday life for severely intellectually disabled children who are living within small residential contexts, namely small group homes. The study's importance is grounded in the dearth of these children's visibility in research literature as well as in society.

In Norway, small group homes for disabled children are full-time residential institutions that have outlived the deinstitutionalisation processes of the early 1990s (Tøssebro, 2014). Such institutions are the most comprehensive health and care services provided to families with disabled children (Handegård, Bliksvær, Eide, Gjertsen, & Lichtwarck, 2007). Placement in group homes takes place on a voluntarily basis and the parents still hold parental rights and duties. All the children attend special education units in local schools. According to Statistics Norway, 256 children lived in state-run, small group homes in 2019 (Statistics Norway, 2020).

The United Nations' Committee on the Rights of Persons with Disabilities (Committee on the Rights of Persons with Disabilities, 2019) has expressed concern about the existence of residential institutions for disabled children in the response to the report on the implementation in Norway of the Convention of the Rights of Persons with Disabilities (CRPD). The report by the UN Committee also questions Norway's lack of available and accessible mechanisms for disabled children to express their views in important matters concerning themselves, as stated in CRPD, Article 7. In the case of small group homes, the children's views on being moved out of their original home are seldom heard (Sigurdsen, 2011). Their lack of opportunity to be heard is connected to their age and maturity, as well as cognitive impairments and verbal limitations (Franklin & Goff, 2019).

The fieldwork for the study on which this article is based is conducted within three group homes. The aim of the study was to observe how the children's opportunities to communicate their views on everyday matters were met and supported in everyday life, according to CRDP, as viewed from a micro-level perspective. The research question addressed is: How do intellectually disabled children act to establish communicative relations within the context of small group homes?

## Disabled children's voices in research

Morris (1997) made an early call for bringing disabled children's voices out into the public sphere. She addressed the lack of knowledge about disabled children who attend boarding schools and other institutional settings, and claimed these children had "gone missing". Additionally, Morris (2003) raises awareness of whether institutionalised disabled children have a trusted person in their lives who will understand and listen to them when they have something important to share.

Cocks (2000) made a similar call, investigating children's experiences within residential contexts. Both scholars aimed to increase the body of knowledge about disabled children's residential living as a basis for decisions on services for severely disabled children in different sectors and at different policy levels. In Norway, Handegård et al. (2007) obtained views from authorities, parents and professionals on children in small group homes, and called for future research to focus on life inside the group homes. This article is a step in that direction.

Research on and with disabled children is increasing, and "Disabled children's childhood studies" has been proposed as a specific field (Curran & Runswick-Cole, 2014). At the interface between childhood studies and disability studies, disabled children's childhood studies have done much to promote disabled children's voices in research literature and have encouraged participant and inclusive research. Childhood research on disabled children is frequently situated within the social model of disability. According to the social model, structures in society produce disabilities, opposing the medical model's focus on impairment (Nind, Flewitt, & Pleyer, 2010; Shakespeare, 2014). The study presented in this article is based on a relational model built on an understanding of disability as an interplay between bodily capacities and social structures (Nind et al., 2010; Ytterhus, Egilson, Traustadottir, & Berg, 2015).

To date, both inclusive and participant studies have tended to recruit participants with an audible voice, thus excluding those with limited communicative resources, as such studies have often faced methodical challenges. McEvoy and Smith (2011) argue that persons with the most complex disabilities are at the utmost risk of "being silenced". Their silencing occurs both within society (Franklin & Goff, 2019; McEvoy & Smith, 2011) and as "voiceless subjects" in research (Mietola, Miettinen, & Vehmas, 2017). Traditionally, research has been conducted through interviewing parents, teachers and service providers (e.g. Handegård et al., 2007). Although such participants may give a picture of children's situations, they are not first-hand perspectives (Rabiee, Sloper, & Beresford, 2005). A growing body of research has promoted "voice" and agency for the silenced group, often within educational disciplines (e.g. Evensen, 2018; Nind et al., 2010; Simmons, 2019; Simmons & Watson, 2015), but also within residential care (e.g. Franklin & Goff, 2019; Goode, 1994; Greathead et al., 2016; Woodin, 2017). This article aims to contribute to new insights within the latter field of research.

#### Theoretical framework

This section develops a framework from which the communicative work of intellectually disabled children living in institutional contexts could be studied. Firstly, a contextual framework is constructed, secondly, an embodied perspective on communication is forwarded and finally, the disabled child is positioned within communicative relationships. This study is situated within ontological and epistemological approaches that embrace the lived body as a reliable contributor to knowledge.

According to Schütz (1999, p. 35) we are from the beginning placed in a sociocultural world, our everyday lifeworld, in which meaningful social interactions are always already established. In an ethnomethodological manner, people accommodate a "phenomenal field", a world that in sociology is regarded already ordered (Fele, 2008). However, Schütz (1999) argues that each one has to orient oneself in this world and learn to handle it, in the same way as Garfinkel (1984) argues that people in specific temporal and spatial contexts continuously seek to create social order to situations through micro-social interactions.

The phenomenal field in this study is small group homes, institutions which are regulated through governmental acts and guidelines. These regulations are to be "translated" by the staff into routines for everyday practices in each specific context (Bigby, Knox, Beadle-Brown, & Bould, 2014; Goffman, 1991). The staff are employed to execute practical duties towards the children at the same time as they should establish close individual relations with the children (Fylkesnes, 2020). A routinely ordered everyday could make working tasks manageable for the staff as well as help the disabled children to settle and grasp what is going on (Järvinen & Mik-Meyer, 2012). However, the fact that each social situation could be considered new, and that the children are living outside their primary social world (the family), might necessitate considerable efforts to cope with and construct meaning to shifting environmental demands (Berger & Luckmann, 1967). How each person adapts to unordered features (e.g. number of people) in an ordered, routinised institutional context, could be examined through how they interact bodily and communicatively with the other members of their specific society to produce and reproduce social order (Garfinkel, 1984; Merleau-Ponty, 2002).

In order to generate and analyse data to understand how young intellectually disabled residents with limited verbal capabilities communicate in the group home contexts, the body is required as a key tool. In this respect, "voice" is understood in line with Simmons and Watson (2015, p. 51) as observable, active bodily gestures "towards the physical and social worlds", and "voice" is not considered an individual feature, but "as something that is enacted or comes into being through relationships" (Simmons & Watson, 2015, p. 63). Thus, meaning making occurs as communicative actions in social interactions.

Speech is socially and culturally significant in exchanges of meanings but is just one of a multitude of bodily expressive gestures. According to Merleau-Ponty (2002, p. 213), "[t]he spoken word is a genuine gesture, and it contains its meaning in the same way as the gesture contains its". Thus, bodily movements are in themselves laden with meaning and intentionality (Morris, 2014) and provide voice as "talking bodies" (Åmot & Ytterhus, 2014). The body's capability to engage in communicative intersubjectivity is embedded in its properties as experienced, emotional and relational (Merleau-Ponty, 2002). Relational, experienced bodies can interact closely, however, we could never completely approach the other's thoughts, intentions and emotions: "I cannot know what you are thinking, but I can suppose it, guess at it from your facial expressions, your gestures and your words – in short from a series of bodily appearances of which I am only the witness" (Merleau-Ponty, 1964, p. 107). To perceive the other's communicated meanings, requires a sensitive attentional attitude: listening carefully to the other's gestural expressions in order to understand and respond, and subsequently join a dialogue.

A severely disabled child is often defined as having a low level of cognition,

thus, giving rise to limited expectations from others of the disabled child's capabilities of relationality and intentionality, and to the child's communicative capacity (Simmons, 2018). In an institutional context like small group homes, there exist communicative asymmetries between the staff and the cared for, embedded in features as verbal function, experience, knowledge, and power (Young, 1997). Young ascribes a moral responsibility to the advantaged ones in asymmetrical reciprocal dialogues.

From the asymmetrical issue, two communicative dimensions appear useful: dialogical and monological communication, as elaborated by Johannesen, Valde, and Whedbee (2008), where monologic communication holds degrees of one-way communication, and dialogical communication is considered as ideal for developing reciprocal understanding, the latter supported by Young (1997) and Merleau-Ponty (2002).

#### Method

This ethnographical study was conducted in three small group homes and included a total of 11 children (5 girls, 6 boys), aged 11–18 years. The group homes accommodated one, four and six children respectively. The variation gives opportunity to reflect on how the number of residents impacted everyday life. All children had an intellectual disability as well as other diagnoses, including epilepsy, autism, or syndromes, like Down syndrome. The group homes were the children's home and the staff's workplace. The three units (located in different municipalities) were built specifically to accommodate disabled persons. One child had his own flat, while the others had their own room, sharing bathrooms in pairs, all sharing the common areas. The dining area was the centre of daily life in every house. Most of the observations were conducted in the common areas, with some detours out of the houses.

Relying on the children's bodily actions as their communicative tool, the chosen research method was participant observation (Merleau-Ponty, 2002; Simmons & Watson, 2015). Gobo and Marciniak (2016) claim that behavioural patterns are consistent over time, promoting observation as a reliable research method. During a three month's period, 32 observational visits (115 h) were conducted; covering morning, afternoon and evening activities.

The observer sited herself on a floating continuum between participant and non-participant involvement (Buscatto, 2016). She kept a slightly distant position to the children but interacted closer when the children invited. Standardised and premade forms were not applied in the study, nor was video. Video is a much-used tool for generating observational data (e.g. Greathead et al., 2016; Griffiths & Smith, 2016), but was deliberately avoided, primarily based on ethical reasons in respect of the children's dignity and privacy. The observer's eyes and ears were the preferred tools. What was observed was written down immediately after the observations, as recommended by Goode (1994) and Cocks (2008).

After completing the observation period, audio-recorded, semi-structured interviews were conducted with ten members of staff and three parents. The interviewer asked for the interviewee's experiences of the group home as a service, as well as elaborated on some issues from the observations. The interviews added a supplemental perspective to the researcher's perspective of the children's activities, strengthening the phenomenological methodological approach.

In the group homes, any person present in the common areas was visible to others. This meant that any observations made would be overt and the observer would become part of the environment (Buscatto, 2016). Although not possessing a "normal" adult role in the units, the researcher influenced the context by virtue of her presence. Phenomenologically speaking, she observed at the same time as being observed. The researcher employed a sensitive attitude, withdrawing when sensing that her presence was inconvenient for a child, which is an accepted approach in observational studies of non-verbal individuals (Cocks, 2008; Nind, 2008). In general, the researcher was welcomed by both children and staff.

In the compact environments of group homes, the children may be active participants in a research project due to their active bodily presence, their interactions with others and their responses to the researcher made through gazes and gestural initiatives. Both visible and discrete communicative interactionsflowed between the children and the researcher.

The analysis was interpretive as the main data material consisted of observational data. Meanings given through bodily actions and interactions might not be immediately intelligible and were therefore subject to reflective interpretations (Merleau-Ponty, 2002). Reed (2011, p. 10) urges us to "push beyond the surface [...] to grasp the deeper set of meanings that inhere in the actions under study". The data material was thoroughly read and coded in an inductive manner, identifying patterns of communicative actions and interactions. For this article the children's communicative behaviours were in focus as figures in interplay with the background in the "phenomenal field" (Fele, 2008). Through a systematic analysis of communication patterns in relation to the institutional context in which they emerged, different modes of communication were identified, which also help organise the reporting in this article.

Each child in the group homes had their own communicative style, employing individual and idiosyncratic sounds, gestures and mimicry (i.e. bodily movements). The identified empirical examples and categories were generated to represent a broad picture of the heterogeneous group.

The heads of the units forwarded information about the study to the children's parents, who gave consent to participation on behalf of their child. Additionally, the heads of the units informed their employees about the study. Parents and staff were asked to inform the children in a suitable manner of the researcher's visits. The researcher gave broader information in staff meetings in each unit before the start of the study, emphasising the voluntary nature of participation. The children and staff are referred to by pseudonyms, to maintain anonymity. The author is responsible for translating the Norwegian quotes into English. Norwegian Social Science Data Services (NSD) approved the study,

### Results

Four modes of communication were identified throughout the analytical process. The first one covers primarily the staff and their initiated communicative actions, constructing a backdrop for the three other modes concerning the children's communicative initiatives. (1) *Communicative environment*, highlighting staff's approaches, detecting asymmetrical features and tendencies of monologue; (2) *Collaborative conversations* – creating meaningful reciprocal dialogues; (3) *Communicative rituals*, shaping social order and relational bonds; and (4) *Bodily expressions laden with meanings*, concerning communicative acts which might be more challenging to interpret. Although conceptualised as different modes of communication, an understanding of every communicative act as collaborative and bodily forms the basis of the study findings.

The following presentation rests on an understanding of group homes as forming a cultural society with a set of pre-established rules and routines, in which the children are socialised (Berger & Luckmann, 1967). The children are also supported in terms of their basic needs in everyday life.

#### Communicative environment

Within the four walls of the studied units, a multitude of sounds and bodily gestures met the researcher. The first impression was a dominance of adult verbal voices: comments, questions and conversations, however, the children gradually made themselves more visible and audible Their sounds and gestures appeared as situational utterings of joy or frustration and as direct initiatives or responses to communicative stimuli. The staff continuously shifted their attention between practical tasks, colleagues and children. The children's communicative gestures were typically directed towards the adults, and fewer towards the other children. One employee said, "Before starting to work here, I was eager to see how children interacted. I now realise there is next to no mutual contact between them!" An experienced employee explained that "they don't need to approach other children, as there is always an adult person available". However, the empirical data also reveal child-to-child attentiveness. The staff members' engagement in and appreciation of interaction with the children may be exemplified by the spontaneous remark made by one of them: "The best thing about this job is the few moments of total mutual contact between us!"

When the staff members approached a child, some combined verbal communication with supportive bodily gestures adapted to the child in focus. Considering that every child is unique in their communicative pattern, the staff were expected to be capable of adapting their communication to each child in their unit. The children were generally encouraged to communicate what they wanted to do or to have. Some could answer the question "What do you want?" by using words, signs or by pointing. More commonly, the question was worded as "Would you like to ...?", in order to elicit a "yes" or "no" response, which was a more achievable way of ensuring a response. However, the latter deprived a child of a variety of possibilities. Asking the question "Would you like this or that?" similarly limits the response options due to a predetermined selection of choices (Greathead et al., 2016; Johannesen et al., 2008).

When talking to colleagues, individual staff members seldom supported their words with gestures, thus depriving the children of the possibility to follow what was being said. The staff argued that the children were not interested in knowing what adults discussed and thus neglected a responsibility to give the children every opportunity to understand what was going on.

The above paragraphs point to asymmetries in staff-child communication, like the staff's power to influence the direction of the children's responses. The children's communicative modes should be understood relative to this background.

# **Collaborative conversations**

Conversations are always conducted as relational interactions (Simmons & Watson, 2015). How a conversation develops will depend on how the participants act and react to each other's communicative behaviour (Mead, 2015; Merleau-Ponty, 2002). In the studied group homes, the children initiated dialogues in different manners: John (17) waived his hands to ask for attention or brought his tablet to show someone a web page; Lydia (17) led a member of staff by the hand to her room. Jacob (16) touched a spoon in a tacit request for more gravy or signed "mum" when asking to visit his family; Julian, (18) who was to go home for a visit, showed the researcher a picture of a taxi and thereby initiated a dialogue. These examples are just a few communicative exchanges recorded during the course of a day. The following quote and subsequent ones offer deeper insights into everyday life of children in the studied group homes.

James (17) is sitting at a table with Anna and Anna asks him about his day, identifying the activities in which she knew he had participated. James smiles, nods and confirms by sounds. Suddenly, James says "iii" and when Anna asks, "What do you mean?" James repeats "iii" in a louder voice, looking at the researcher. From the previous day's observations, it seemed that he meant the researcher, whose first name contained the letter 'i', and when asked he smilingly confirms. He then utters a shorter "ii", which was interpreted as referring to a staff member from yesterday, also confirmed. He points at himself: James. Thereafter, he waves his arm and says "pah". Evidently, James tells that the researcher, another adult, and he (James) had gone to the water yesterday to throw stones and make "splashes".

In such ways, James initiated dialogues by using sounds and gestures. He took the initiative to leave the path that Anna had created for him by taking some control himself. He conveyed an invitation and established mutual engagement with Anna and the researcher on his own terms. For the dialogue to continue, the staff had to confirm the words that James tried to convey. In this manner, James told a story and received confirmation of his ability to tell. Typically, he used similar ways to confirm what was going on at a given time, such as "We are reading a book". In such ways, James continuously sets an agenda for his daily conversations, influencing his environment.

A different type of dialogue is illustrated by Jonas (16). Such dialogues were observed in specific contexts, such as when a child and staff member went for a walk and the latter's attention was fully directed towards the child. Typically, Jonas started the routine by uttering a sound:

Jonas: Ow Ada: Does it hurt? What should we do then?

Jonas: BeBe Ada: Yes, we must blow on it.

Jonas: Ow Ada: If you have got a cut, what must you get then? Jonas: Bebe Ada: Yes, you must get a bandage. What then?

Jonas: Bebebe Ada: Yes, it'll be fine.

Jonas expressed joy by smiling and maintaining eye contact with Ada. Apparently, Jonas knew when the story was nearing the end, as he more enthusiastically uttered the long phrase "Bebebe". He then started to repeat the same routine. This was a reciprocal conversation that Jonas could master and enjoy. For the staff member to participate, some familiarity with Jonas's sounds was required, as well as attentive engagement. In the quoted sequence, Jonas was the initiator, who acted by sending a verbal gesture "Ow" and invited Ada with an expectant eye gesture. Ada's answer was crucial for the conversation to continue. There was a slight pause between each uttering, giving the other person a moment to perceive, interpret and respond (Mead, 2015). Both parties were directed towards each other. Since Ada was responsible for making meaningful sentences in the co-construction, she embodied an asymmetry (Young, 1997). However, Jonas started and restarted the conversation and his responses, both verbal and bodily gestures, were equally important for the dialogue to continue. If one of them had stopped responding, the dialogue would have ended. In another situation, the "Ow" could have indicated real pain, requiring a different contextual interpretation of Jonas's being, thus leading to a different dialogue (Goffman, 1978).

# Communicative rituals

To run the group homes effectively, the staff were employed on rotating shifts, manned 1:1. Rotating staff gives rise to an unstable institutional environment for the children, with many adults with whom to relate (in a house accommodating six children, 35–40 staff members alternated). In the studied group homes, measures were taken to inform each child about who would be with them during the next shift or the next day. This was done through schedules presented in words or pictures, or by verbal information. Sometimes, it was not decided who would be with whom until the shift started, thus leaving the children unprepared. Considering this uncertainty, it's unsurprising that John and Lisa tried to gain control over their near future by repeatedly asking for confirmation about who would be at work and when.

Some children had created private rituals to frame their lifeworld. For example, Lydia employed a "naming ritual" in which she imitated her fellows' sounds accurately, as in the anecdotes below.

Lydia is sitting at the dining table with a cup of freshly brewed tea, the researcher sits opposite her, drinking a cup of coffee and returning her direct gaze. "Is the tea nice?" the researcher asks, Lydia nods, The researcher responds with "Mhmm" and Lydia looks directly at her and repeats "Mhmm" three times. The researcher smiles at Lydia, who lifts her eyebrow in response. Alice, a staff member who observed the dialogue, comments "She is used to repeating the sounds made by others."

Thereafter, Lydia greeted the researcher with the "Mhmm" sound during every subsequent observation in the same house. Another example occurred:

Several staff members are in the hallway, busy helping the children put on outer garments before leaving for school, Lydia received help from Anita. One of the other members of staff made a deep sound, which Lydia repeats and the staff member responds, "That's me!" Lydia turns, looks at another person and makes a lighter sound, to which that person responds, "And that's me!"

When observing a similar episode of imitation, a staff member said: "That's what kids do, and she is after all just 19 months old [as diagnosed by specialists]", failing to appreciate Lydia's sounds as communicative actions. Additionally, Lydia was a teenager and had corresponding embodied experience. From the researcher's experience and the reactions from the staff in the hallway, it seems likely that Lydia used designated sounds as a method to distinguish and name staff who frequented her lifeworld and as a mechanism to make social order to and frame her environment (Garfinkel, 1984). She was rewarded by positive responses. Lydia also used the naming ritual to construct social bonds with employees, for reciprocal recognition and to create a point of departure for further dialogues.

Spagnola and Fiese (2007) explain rituals as symbolic actions of meaning incorporated when conducting daily routines. Rituals may be unique to a specific community in which they appear and can connect the members with symbolic bonds and emotional ties. Pillet-Shore (2018) views greeting rituals as a starting phase for meaningful reciprocal dialogues. The next example visualises this conceptualisation of greetin rituals.

Lisa (12) was a sociable girl, fond of conversations and interactions with adults. She was verbal and able to influence how staff interacted with her in specific situations. One kind of rituals were "greeting rituals" and a close-up narrative shows how she instructed the researcher during her first observational session at the unit.

Lisa is sitting in her place at the kitchen table and the researcher is at the opposite end. Lisa looks at the researcher and says, "When you arrive tomorrow, you must say 'Hi, Lisa!", to which the researcher responds "OK." When the researcher arrives the next day, several people are in the kitchen, and Lisa sits at the table, drawing. When the researcher looks around, expresses "Hi" and smiles at everyone, Lisa stares at her in annoyance and asks; "You forgot?"

Lisa assigned different greeting rituals for different staff members, such as making a heart shape with their hands, kissing each cheek five times, or giving two hugs. After giving instructions, Lisa would order them to "Remember!" Her rituals appeared as mechanisms to recognise or "name" employees. For Lisa, the performances might have entailed important significance: Lisa was relatively young, living in a context consisting of other children and a considerable number of adults, none of them her family. She needed to be recognised and "seen". By systematically giving each person a specific role and creating closer social links to herself, Lisa added new dimensions to establish sense and meaning to frame her lifeworld. Thus, Lisa had grabbed a position of micro-power in a context in which she otherwise had a dependent and inferior position (Åmot & Ytterhus, 2014), modifying the staff-child dynamic. The employees might have perceived Lisa's need for control in these matters as important and complied with her claims in order to support her selfesteem and dignity. However, the researcher observed discussions concerning Lisa's "manipulative" behaviour. Questions were raised as to whether they should let Lisa's continue to seek contact and collaborate with every adult within her reach, disturbing their scheduled work. One suggestion was to impose restrictions on Lisa's behaviour, namely, only to relate to one carer on any given day. If staff set up regulations, they could resume control over their own working days (Järvinen & Mik-Meyer, 2012). An objection to the implementation of new rules was the risk that Lisa would feel hurt and ignored, not that Lisa's freedom of expression would be restricted.

John's and Lisa's repetitive questions about who would be at work on the next shift or next day could be understood as rituals to cope with the unstable (number of people), yet stable (routines) environment, not only to gain control but as a habitual mode of communication. The ritual mode of communication represents a partly reciprocal dialogical pattern.

# **Bodily expressions laden with meanings**

A variety of bodily expressions were observed in the units. Laughter, smiles, clapping, and peculiar movements of hands and legs were perceived as positive communicative signs. Cries, tears, self-harm, or offended postural expressions communicated discontentedness. Actions of affection and empathy occurred too, such as when Lilly (18) climbed onto Anette's lap for hugs and cuddle; Lena stretched her right arm a little and turned her head to let a staff member touch her cheek; Lydia adopted the attitude of an adult and went over to Lena to give her a gentle hug, Julian reached out to a hesitant Jacob to hug him, and Jonas made intense eye contact, nose-to-nose with an adult. Emotional frustrations were observed when a visibly upset Jack (15) left the TV room with an annoyed expression, hit his head, and growled because a fellow resident had interrupted the film he was watching, or when Lisa cried loudly when she observed "her" carer enter another resident's room. Affective bodily expressions are part of common human behavioural and communicative patterns. In the context of group homes, such expressive activities equip the actors with agency towards their environment (Nind et al., 2010; Simmons & Watson, 2015).

Some expressive behaviours may require sensitive awareness and reflectivity in the interpretation of their meanings. The following examples focus on a specific group among the studied children, namely, those with the most complex challenges, who strived to express themselves in an, for adults, intuitively intelligible manner.

When Laura (15) was lying restless and unsettled on the floor or Lena (16) was sitting in her wheelchair and crying, a top priority for the staff was to find out what was causing the children's uncomfortable state and what could be done to ease it. There was little doubt that the girls expressed that something was wrong, and that they called for attention and successive engaged action. In both observed instances (Laura and Lena), two members of staff cared for each girl by, for example, turning her body, tidying her clothes, and ensuring that nothing hurt. Sometimes, painkillers were administered because, as one staff member explained, "We have to try different ways to check what could be wrong". Physical issues were the first to be checked, but it was more complicated to know whether a child's crying was due to deeper emotional issues such as sadness. Instructions on how to interpret different modes of behaviour existed, but, as another staff member explained, "You have to know her to read her", indicating that predetermined procedures might not be applicable to every new situation, rather the child's expressions should guide the response (Greathead et al., 2016; Merleau-Ponty, 2002). In such challenging communicative situations, the staff's obligation to "care for" took priority, and the social relations were dominated more by action than by interaction, or monologue more than dialogue (Johannesen et al., 2008).

When Lena and Laura were having "a good day", meaning that nothing in particular tormented them, they expressed themselves differently. Laura would sit twiddling her fingers and making a deep sound that was perceived by the staff as "good", while Lena would waive her toys, twist her body and make high-pitched sounds, all perceived as movements of satisfaction, and the staff could diminish their attention for a while. At such moments, Lena was typically placed in an open space in the common area (so not to reach the table, tap at it and make noise), while other people moved around her, busy doing their tasks. Lena could suddenly change her attitude, twist more wildly, put her hand towards her mouth and make a cry because she wanted to convey something anew.

Some of the children also displayed what would be regarded stereotypical behaviours, including repetitive movements that could appear seemingly non-meaningful. Such behaviours are often ascribed to diagnoses as autism and profound intellectual disability (Simmons, 2018). Lena rocked her body, Laura twisted her hands, and Lilly tapped pieces of fabric against her lips, activities which were not paid particular attention to. When studying such "meaningless" bodily movements, the observer may wonder how the movements are experienced by the child and whether the movements are completely removed of sense (Simmons & Watson, 2015). Eikeseth and Grung (2017) explain stereotypical behaviour as adaptive responses to environmental over-stimulation and understimulation. Goffman (1978) would see the movements as situational and contextual expressions. The girls' repetitive movements were typically performed at times of the day when nothing much happened. When few external stimuli engaged the children, they had to create them themselves by making excessive or monotonous movements to bring about sensational experiences.

One interviewed mother reflected on her daughter's cognitive and social capabilities, drawing on her intimate knowledge of her own child:

What if we underestimate her sometimes? What if she understands everything we say? The neuropsychologist [at the hospital] said "No, it's not so ... she receives impressions, she processes them and then they go a bit away again." But [continued the mother] she understands cause and effect ... she understands much, and she has expectations ... and she knows her name, and I think she has had cognitive development to an extent. But what she understands of language, I cannot tell.

In the above quote, the mother advocated for her daughter and situated her as an agentive member of her society. The mother perceived that her daughter expressed expectations and understandings and had expectation to the girl herself. Through her perceptions she ascribed properties to her child. Goode (1994) observed a girl who interacted closely with her mother and the mother similarly ascribed to her daughter capabilities such as personality, meanings and understanding, which employees at the daughter's school dismissed as unrealistic. These mothers displayed the importance of close relationship to the child, a relationship that professional staff coming and going, would face difficulties to acquire. In the group homes, for Laura, Lena and other children to have an impact on their everyday life, every subtle expression would have to be ascribed meaning and agency.

When interacting with Lena and Laura, some utterances were more comprehensible than others. It was easy to recognise a "yes" response from Lena when she accepted the food presented to her and a "no" response when she pursed her lips and turned her head away. However, such utterings were not always readily accepted by the staff. When Lena rejected food, her carers typically encouraged her to take "one more mouthful", yet, rejecting food was one of the few distinct acts that gave Lena the possibility to have direct impact on matters concerning herself: to decide when not to eat is to take control. One staff member argued: "Lena is the best critic of my cooking. If she says 'no', I've failed", thus ascribing Lena intentionality and meaning with respect to her likes and dislikes. Ware (2004) argues that having the competence to choose is not the same as to present a point of view. The above-quoted member of staff interpreted Lena's acts as autonomous, meaningful decisions on whether or not to eat.

Pure bodily expressions as described in this section, are clearly communicative, the children expressing desires, intentions and emotions, searching for dialogue. However, as some communicative acts could be difficult to decipher, they might fail to be recognised, and appear as unproductive communicative work.

### Discussion

As a place in which to live, group homes constitute a particular environment: they are crowded, constantly shifting, often noisy, with different communicative initiatives often taken simultaneously without necessarily reach a recipient. The environment is demanding with regard to communication, which is more challenging for persons with severe difficulties in communicating.

Each child faces challenging environments in ways influenced by their individual capabilities and personalities. Children negotiate their spaces in everyday life in an ongoing process in close interaction with their environment (Nind et al., 2010). The children's being is directly impacted by the contextual stimuli, as well as by their subjective agentic desires.

# **Communication framed as monologues**

Greathead et al. (2016) and Simmons (2019) show how employees in schools and residential settings often are task-oriented in their approaches towards children. A task-oriented attitude is observed in the group homes as part of the professional's practical routines, like in feeding, providing care and giving medicines. Practical duties that have to be done could account for a lower level of relational interaction, and rather applied to the child, than with the child (Simmons, 2019). A top-down communicative manner like giving instructions or



asking questions with few, pre-determined response possibilities underlines institutional asymmetries (Fylkesnes, 2020). It also challenges the children's rights to participate in everyday matters as stated in the United Nations (2006).

# Communication framed as dialogue

In the collaborative communicative mode, the children bring forth their "voices" and influence turn-taking processes as active agents (Merleau-Ponty, 2002) and display expectations towards adults to contribute on their (the children's) premises (Nind et al., 2010; Simmons, 2018). In the studied group homes the initiatives of the children were dependent on the adults' acceptance of their communicative bid (Greathead et al., 2016). As the children's main communication partners are the professional staff, the children are put in a position of dependency (Åmot & Ytterhus, 2014; Nind et al., 2010), which expose them to vulnerability in the form of a risk of being rejected or ignored.

The group home setting provided a different stimulus for children who struggled with the constantly shifting presence of staff, and who created rituals as a mechanism to establish social order to their perceived unpredictable contexts. Through ritual-making, those children attached meaning to the contextual routines (Spagnola & Fiese, 2007). The rituals also provided invitations to social interactions and communicative dialogues (Pillet-Shore, 2018). Rituals could also be interpreted as claims for recognition and autonomy (Greathead et al., 2016). Rituals understood as claims to gain micro-power could challenge the professional autonomy of staff (Järvinen & Mik-Meyer, 2012) and invoke construction of regulating structures as an adaptation to the institutional system, thereby imposing constraints upon the children's freedom of communicative action.

# Communication framed as inverted monologues

Hardly noticeable expressions can be overlooked or ignored in a busy institutional environment or sometimes regarded as meaningless, such as when the children in the group homes occupy themselves with stereotypical behaviour (Eikeseth & Grung, 2017). Such behaviour, if accepted as communicative, could be regarded as self-talk (Goffman, 1978) or as marginalised monologues that might not reach, or need, any recipients. Olli, Vehkakoski, and Salanterä (2012, p. 801) refer to Spitzer addressing this issue: "Understanding the meaning may require seeing the action as meaningful to the child even though it may seem meaningless to an adult. This requires engaging in a communication process in which meanings are negotiated". Thus, in common with Young (1997) and, more recently, Greathead et al. (2016) and Spitzer contributed to direct a responsibility to advantaged adults for sensitive attention towards even the most silent voices.

# **Conclusions**

The purpose of this article has been to explore how severely intellectually disabled children make efforts, and partly succeed, to raise their voices in everyday life in the context of small group homes. This was done by demonstrating how everyday life unfolds within these, less well-known, living conditions. To be listened to in everyday matters concerning themselves, is a right under United Nations (2006). The analysis highlighted the initiatives

taken by the children viewed against the backdrop of the institutional context and the staff's communicative practices.

By applying Johannesen et al.'s (2008) dichotomy of monologue-dialogue, where reciprocal dialogue represents the ideal, the communicative modes within the group homes are linked to three dimensions.

- (1) Communication as monologue, shaped by asymmetrical relations in the group home context, embodied by staff members' child-directed verbal approaches, expecting limited or pre-determined responses.
- (2) Communication as dialogue, developing meaningful reciprocal communicative processes where the actors respond to each other's initiatives in an open, respectful manner, modifying the relational asymmetries.
  - Communication could also be *partly dialogical* as in communicative ritual-making or in situations where bodily expressions might challenge the staff's interpretative skills. In partly dialogical settings, the responses from the staff might turn more practical than relational.
- (3) Communication as inverted monologue takes place when the communicated message does not reach any recipient or is not recognised as a communicative uttering. Not being heard could give rise to powerlessness and resignation. Perceived stereotypic behaviour could be regarded as such inverted monologues.

The empirical analysis indicates that the children appeared to act beyond their anticipated limited cognitive capabilities in many ways (Simmons, 2018) and to possess capabilities to influence their surroundings through their bodily communicative work. How the children succeeded in participating and having an impact on their everyday life was evidently dependent on how the staff working in the group homes were able to perceive, interpret and respond to the children's expressions, partly in competition with the other residents and institutional practices (Nind et al., 2010).

This article gives a glimpse of the "hidden" lifeworld of the disabled children in group homes in Norway. Participant observation over time in relatively small settings has proven a productive approach in research, as it provides opportunities for thick descriptions of everyday life. The studied children contributed actively to the richness of data generated in the study through their bodily actions, though not in the same manner as in traditional participant and inclusive research (Curran & Runswick-Cole, 2014; Nind et al., 2010).

Despite empirical evidences of sensitive collaborative communicative encounters between staff and children, the monologue-dialogue dimension indicates a need for careful reflections on how the children are approached communicatively. To improve professional practice, it would be crucial to address the issues of how communication as monologue could take a more dialogical direction and how inverted monologues better could be perceived as communicative acts. Reflections upon these questions should be considered included both in professional training and in professional practice.

These novel insights into small residential settings for intellectually disabled children actualise another implication, namely, an urge to conduct future studies within this, until now, neglected field, to utterly raise these children's voices in society to inform policy.



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

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Ingunn Fylkesnes is a PhD student in sociology at Nord University, about to complete my thesis. I received my master degree in Health sciences from Norwegian University of Science and Tecnology (NTNU) in 2014. My bachelor is in physiotherapy from Bergen University College, 1987. My work experience as a physiotherapist and my academic interests have always been in the field of disabled children and adolescents.

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