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Institutional Talk and Practices: A Journey into Small Group Homes of Intellectually Disabled Children

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Abstract

This article sheds light on a group of children who are hardly visible within the body of research: intellectually disabled children living away from home in full-time institutional settings. The purpose of the study was to contribute to the extended knowledge of these children's everyday life and to inform researchers, authorities and service providers. Participant observations have been the main method of generating data, supported by interviews with professionals and parents. An interpretive analytical approach was employed. The results presented in this article show how institutional talk and practices can evolve within institutional systems, and how these factors affect the everyday lives of children.

Keywords: institutionalised care, intellectually disabled children; out-of-home care; privacy in public; child-carer interactions

Points of interest

- Taking care of a severely disabled child could put excessive stress on a family, and the family may need caring support.
- Small group homes are designed to care for such children, and they are a home for the child and a workplace for the professional staff. The staff provide care on behalf of the parents.
- Little is known about how these children experience life within such group homes. This study aimed to learn more about this area by observing everyday life in three group homes.
- The study found that the staff's talk and practices shifted continuously between close relationships with the children and more work-related tasks, such as discussing practical issues without involving the child.

- The study recommended professional staff in such homes to reflect on how such practices are experienced by the children, and how to improve their practices.

Introduction

This article concerns the lives of intellectually disabled children living away from home in institutional residences, and how institutional frames affect their everyday life. The question to be answered is:

> How do institutional frames and practices shape the relationships and everyday lives of disabled children in group homes?

Group homes for disabled children are the one type of institution that survived, or was soon reinstated, after the deinstitutionalisation processes in Norway around 1990 (Söder, 1993; Tøssebro, 2014). In such group homes for children, all residents are under 18 years of age and diagnosed with intellectual disabilities combined with other medical or psychological disorders. Limited verbal language is typically present. Severe disabilities combined with a family experiencing excessive caring challenges are the criteria for admission to the group home. The decision for residential housing is stipulated in the Health and Care Act (Helse- og omsorgsdepartementet, 2011) as a respite provision for caretakers (parents) to enable them to participate in society on an equal basis with others. Professional staff provide care for the children on behalf of the parents. The parents still have parental rights and duties and reciprocal visits are common. The units are situated in the home municipality, and the children participate in local schools, which are typically special education units. Around 270 children in Norway live in this kind of public institutional residence (Statistics Norway, 2018). This study focused on 11 children.

The researcher has a background in case work for service provision to families with disabled children. Full-time institutional care is the most comprehensive service provided. Little is known about what the everyday life of these children is like after they are moved.

Handegård et al. (2007) conducted a study on small group homes for children in Norway. Local authorities, staff and parents were included, and the conclusion was that group homes might be a desirable service, but they were not optimal. During their research, Handegård et al. did not enter the institutions. NOU 2016:17 (Official Norwegian report, Health and Care Department 2016) emphasises the importance of knowing more about the conditions of this group of disabled children.

According to Article 23 of the United Nations Convention for the Rights of People with Disabilities (UNCRPD, 2006), small group homes for disabled children balance on the edge between ideological and practical matters. A child has a right to live with his/her family, and not segregated from the family due to his/her disability or against his/her will. The child and his/her family have a right to receiving support when the child has a disability. The UNCRPD argues that institutional placement should be the last choice. The latter is emphasised in the UN's comments on Norway's report on the implementation of the Convention (2019).

This current study follows up on Handegård et al. (2007) and was conducted inside three group homes. This paper explores the institutional aspects of group homes. The objective is to contribute to the body of knowledge in the field of children living away from home, in order to inform authorities, service providers and service recipients.

Disabled Children, Research

This section presents previous research on disabled children. It starts by positioning the research within a research field, then moves towards research on institutionalised disabled children. Lastly it brings in various perspectives on disability.

In the wake of childhood studies developing as a discipline, research that aims to promote the voices and the lives of disabled children is growing (Goodley & Runswick-Cole, 2013). Suggestions have recently been made to make research targeting disabled children a discipline on its own: *disabled children's childhood studies* (Curran & Runswick-Cole, 2014). In the United Kingdom, a nation with a huge body of research on disabled children, studies are typically situated within the paradigm of "critical disability studies" (Watson, 2012; Curran & Runswick-Cole, 2014), with the intention of including children as active participants and collaborators in research. Thus, disabled children's childhood studies tend to recruit children with an audible voice, with or without the use of alternative communication (e.g. McEvoy & Smith, 2011; Østvik et al, 2017; Nind, 2018), resulting in the exclusion of children with limited abilities to represent themselves. McEvoy and Smith (2011) found that children with complex disabilities who were living in full-time respite care were the most likely to "being silenced" (ibid:106), which again shows biased representation in the body of disability research.

There is a move towards the inclusion of the most severely disabled children; and adults, employing methods and methodologies that empower 'voiceless subjects' (Mietola, Miettinen & Vehmas, 2017) to bring to the fore experiences of their lifeworld, informed by the children themselves through their lived bodies (e.g. Goode, 1994; McEvoy & Smith, 2011; Cocks, 2008; Simmons & Watson, 2015; Simmons, 2019). Perspectives from ethnomethodology (Goode, 1994), phenomenology (e.g. Simmons & Watson, 2015; Evensen, 2018) and interactionism (McLaughlin et al., 2016) are some of the alternative approaches applied.

Research in the field of severely disabled children is frequently located in the field of education (Simmons & Watson, 2015; Evensen, 2018). However, some scholars have conducted research in different types of residential settings for disabled children (Goode, 1994; McEvoy & Smith, 2011; Fylkesnes, 2014; Friedman & Kalichman, 2014; Stalker et al., 2015; Woodin, 2017; Franklin & Goff, 2019). Retrospective studies with people who have lived in residential institutions as children exist which as well highlight their embodied experiences (e.g. Shah & Priestley, 2010; Hutchinson & Sandvin, 2016). The main findings include regulated everyday lives (Goode, 1994; Fylkesnes, 2014), missing one's family (McEvoy & Smith, 2011; Hutchinson & Sandvin, 2016) and lack of contact with mainstream peers (Shah & Priestley, 2010; Friedman & Kalichman, 2014). Goode (1994) discloses lack of expectations and personal relational interest on the part of the professionals. Cocks (2008, 177) argues for the importance of research within the field:

> The privileging of language, perhaps inadvertently, excludes groups of people for whom language is problematic; it also obscures the horizon for researchers, decision makers and service providers alike, denying the important contribution of context and environment to life experiences. In order to continue to produce sound evidence of the impact of services on lives, researchers, ethics committees and policy makers need to embrace a wide range of methods and include the use of less-known methods of data collection in order to ensure full inclusion and to gain knowledge which goes beyond language.

Perspectives on Disability

This article concerning disabled children require some reflection on disability perspectives. A preferential approach to the study of disabled children's childhood is, as mentioned, embedded within the paradigm of "critical research" (Watson, 2012; Shakespeare, 2013). This approach avoids the much-used individualistic impairment-based focus (the medical model) and has a strong relationship with the social model of disability (Watson, 2012). Shakespeare (2006, 2013) and Watson (2012) allege that the social model's critical approach is too narrow, making too sharp a distinction between disability and impairment. Both argue that aspects of sensory and emotional impairment should be considered of significance. Coleman-

Fountain and McLaughlin (2013) insist on keeping the body present in research, taking an interactionist's stance that argues for the embodied presence within every social interaction. The inclusion of the body itself in disability matters intersects with the Nordic relational model, where disability arises out of interactions between the individual and the environment (Shakespeare, 2006; Ytterhus et al., 2015; McLaughlin, Coleman-Fountain and Clavering, 2016). Cluley, Fyson and Pilnick (2020) argue for bringing disability theory further, to view learning disability from an assemblage of multi-layered elements concerning the understanding and transfer of the theory into practice, both in research, policy and everyday life, aiming to make the theory inclusive also for people with the highest needs for support.

The present study was situated within the relational model of disability, exploring the interactions between members of the group-home and the institutional frames surrounding them. From this perspective, the recognition of the body as a means of expression is crucial for identifying experiences from persons with limited verbal language (e.g. Simmons & Watson, 2015). The importance of the body in disability research is often grounded in phenomenological philosophy (Merleau-Ponty, 1994), appreciating the body as relational, emotional and experienced (Engelsrud, 2006). Intersubjective social meaning and understanding occur, according to Merleau-Ponty (1994:89), in the 'space between' bodily subjects, embodied with individual experiences and stock of knowledge (Schütz, 1999). Mead (2015) shows how bodily intersubjective interactions and others' responses to an act create and develop our understanding of others and of ourselves as the social being we are and are to become. "Asymmetric reciprocity" is a concept used by Young (1997), meaning that two bodies in communication never occupy a symmetric, reciprocal level. There will always be a spatial and temporal distance, which is inevitable and necessary for communicative interactions to start. In contexts with huge differences in cognitive levels (Schütz, 1999), asymmetries increase.

Theoretical Framework

In this section I constructed a theoretical framework of institutional care and for the categorisation of people, which, together with the above-mentioned perspectives on disability and body, will guide the analysis of the empirical material.

Goffman's (1991) book *Asylums* has had much impact on the general understanding of institutional culture and practice. His analysis points out several phenomena constituting practices in institutional systems. Goffman draws images of members occupying different hierarchical levels in institutions: patients or residents on the one hand and staff on the other. He discusses how the first group adapts to institutional routines and how relationships with staff could develop. The residents themselves generally have little impact on the institutional structures; however, they can influence micro-processes through their bodily presence. The staff members hold higher organisational levels of responsibility and privilege, albeit in an in-between position, with instructions to follow and routines to keep. The routines might be partly decided from the top level of the system and loyally executed by the staff. According to Goffman, the opportunity for staff to influence these practices can be limited. Bigby et al. (2014) argue that a system's policy is often abstract, appearing challenging for professionals to translate into practice. Another phenomenon that Goffman (1991) points out is how boundaries between private and public spheres in institutions might be vague, as individual routines are often carried out in common areas.

Focusing on social work, Järvinen and Mik-Meyer (2003, 2012) give empirical and theoretical descriptions of how clients (2003) and professionals (2012) are constructed within society. One of the main issues is how clients adapt, or must adapt, to the social services' system in order to be found worthy to benefit from services. The authors argue that the system of social work is organised within categorial understandings, and services are provided within these predetermined understandings. To meet demands from above, i.e. delivery of effective services and satisfactory results (Bigby et al., 2014), the professionals are often preoccupied with diagnoses and labels in order to establish manageable structures. On the other hand, the client should ideally be met respectfully as an autonomous citizen. Professionals are often put in an ambiguous position, with claims on their loyalty both from the clients and from the administrative system (Järvinen & Mik-Meyer, 2012; Bigby et al., 2014). In Goffman's (1991) institutions, systemic claims might have priority. Reinders (2010) suggests the same, pointing to neoliberal politics that demand cost-effectiveness and positive results. Reinders contests neoliberal trends for primarily measuring objective quality indicators, missing out features that vouch for a good quality of care, such as professional experience and the ability to create personal and emotional relationships with those being cared for. Correspondingly, routines for medicine and nutrition are a few of the issues measured by Norwegian supervisory authorities (Norwegian Board of Health Supervision, 2010).

An institution such as a group home for children should fulfil divergent purposes: to be a home for the children and to be a workplace for the professional staff. This might give rise to ambiguous roles for the staff, between parental-like emotional expectations and a professional care role, or between "maternal warmth and paternal discipline" (Mol, 2008).

McLaughlin, Coleman-Fountain and Clavering (2016) discuss the ongoing monitoring of people's developmental capabilities throughout the course of their lives compared to a standardised norm. People who deviate from the "gold standard of normalcy" are labelled as deviant. For childhood impairment and disability this means diagnosing children medically or psychologically and generating label(s) to relate to. Hacking (1986) discusses how names and labels have a looping effect in "the making up of people" to be or behave according to determined categories. Giving a child the diagnosis of severe intellectual disability might influence how those surrounding the child react to and treat this child, and how the child develops self-understanding. Hacking (1986:165) postulates: “A kind of person comes into being at the same time as the kind itself was being invented.” The society tends to make up definitions of different kinds of people, which can constitute institutional truths, and thus constructs manageable categories in institutional contexts as suggested by Järvinen and Mik-Meyer (2012).

Cocks (2000) raises critical concerns about institutionalised childhoods by directing her attention towards disabled children attending respite care. Her point of departure is a quote from Jenks (1996:69): “The way that we control our children reflects, perhaps as a continuous microcosm, the strategies through which we exercise power and restraint in the wider society.” Cocks (2000) asks how disabled children’s childhood differs from that of mainstream children’s, and whether institutionalised disabled children are recognised as active participants in everyday life or as passive recipients of care. When children are segregated from 'normal' living contexts into places built specifically for institutional purposes, they are also segregated from mainstream peers, who, Simmons (2019) argues, could have a positive impact on a profoundly disabled child’s experience. Cocks (2000) further asks whom the respite care is to serve: the children, the parents, the professionals in need of work or the policymakers. Cocks argues that when legislation is directed towards the needs and diagnosis of the child when parents ask for help, the child is put into focus and becomes the problem (2000:510).

The ideology of the family as the best place for a child to grow up is a common policy in many countries (Söder, 1993; Tøssebro, 2014; UNCRPD, 2006). Woodin (2017:79), who led a European study aiming to measure how disabled children in institutional residencies are recognised and cared for, states: “Even with the best of intentions, growing up in an institution is no substitute for growing up in a loving family.”

When society makes up people – in this case as intellectually disabled children – it creates a divergence between *us* (mainstream people) and *them* (deviant people) (Goffman, 1991; Hacking, 1986). This divergence might then be a factor lending acceptance to accommodating disabled children in institutional care. The making up of intellectually disabled children as a special kind might additionally deprive the children of opportunities available for others in society. Hacking (1986:168) concurs, "Each of us is made up. We are not only what we are, but what we might have been, and the possibilities for what we might have been are transformed". According to Cocks (2000), institutional provisions for disabled children might be a step towards an anticipated adulthood within institutional contexts. The institutional care could be a facilitator for or an obstruction to the future life of disabled children who are not yet recognised as normal citizens (McLaughlin, Coleman-Fountain & Clavering, 2016).

Research Process

Method

The main research method for this study was participant observation. Through observation, the children can use the whole communicative repertoire of their bodies to tell their stories (Merleau-Ponty, 1994; Simmons, 2019). The researcher employs her perceptive and reflective repertoire to generate knowledge of and give meaning to the children's expressive bodily activities. The social interactions of staff with the children were also observed, as the activities of the staff are intertwined with those of the children in the group home's everyday life. The observations (32) were unstructured, meaning that no pre-designed tools were used. Field notes were written once an observation was conducted, as recommended by Cocks (2008). Occasional informal conversations between staff and the researcher occurred during the observations. On two occasions the researcher participated as "co-staff" for one child due to an acute lack of staff in that unit .Some of the staff members (ten, of whom three were leaders) and three parents were interviewed at the end of the observation period to clarify some questions based on the observations, as well as to give their own understanding of small group homes as a phenomenon. All interviews were audiotaped. To get a clearer picture of the institutional discussions, the researcher participated in a number of staff meetings in the units. Only employees in high positions participated in staff meetings, leaving part-time employees out of the discussions concerning the units. It was said that the staff were given relatively good opportunities to discuss practical and ideological issues.

This study was conducted in three group homes located in two different municipalities. The homes accommodated one to six residents, aged 11-18. All eleven residents were labelled as having a severe intellectual disability, with additional diagnoses being epilepsy, cerebral palsy, autism, syndromes and other medical issues. The children had limited or no verbal language. One child had his own flat, while the others had their own private rooms, sharing a bath in pairs, and all of them sharing the rest of the space. In every unit the kitchen and dining area were the centre of everyday life. Most of the observations were conducted in this area.

Analysis

Given that the main informants of this study were intellectually disabled children with limited verbal capabilities and that the main method was unstructured observations, an interpretive analytical approach was regarded as a suitable and necessary choice. The interpretive approach attempts to "push beyond the surface [...] to grasp the deeper set of meanings that inhere in the actions under study" as proposed by Reed (2011:10), or, in the phenomenological tradition, "to explore the lived meaning of a phenomenon, a lived experience or event" (van Manen, 2019, xiii). In employing interpretive and phenomenological approaches the aim is not to generate clear categories and explanations but more to wonder what possible meaningful experiences are expressed in social interactions (van Manen, 2018).

The analysis was conducted through traditional pathways: reading data material, coding meaningful situations and interactions, and re-reading and structuring the coded material. Even though the objective of the whole research project was to explore the everyday life of the children in group-homes, institutional practices became visible throughout the analysis. This article focuses on those practices. Through modes of talk and activities, the professionals dominated the scene. For the staff, verbal language was a tool for organising work, for practical and relational activities with the children, and for collegial social interaction. Different modes of talk were combined into one theme: *institutional talk*. In line with Goffman (1991), vague boundaries between private and public spheres were present, leading to the theme of *privacy in public.* Additional themes were *regulating regimes*, which concerns behaviour, and "*We are not their parents*", which concerns staff attitudes. These themes formed the structure of the presentation of the findings.

Ethics

The unit leaders distributed information letters to the parents, who gave informed consent on behalf of their children. The procedure of using proxy persons for consent is discussed and approved by researchers such as Cocks (2008) and Nind (2008). Parents and staff were asked to inform the children in a manner that they felt as convenient. Throughout the visits, a sensitive attitude towards the children was adopted. If any discomfort was expressed about the researcher's attendance, she withdrew. This practice is called "deliberate objection" and is regarded as a valid and respectful way to deal with the issues of consent and attendance (Cocks, 2008; Nind, 2008; Mietola, Miettinen & Vehmas, 2017). The house managers informed their employees, and the researcher informed staff in staff meetings before starting the research.

Interviewees consented individually. The study was approved by the Norwegian Social Science Data Services (NSD).

The reporting of findings touches on ethical boundaries: no harm should be inflicted on the participants (Helsinki Declaration, 1989). Children are vulnerable, with limited understanding of the research process as such and as continuing residents in their respective houses. Parents are the children's advocates and might be included in the vulnerability concept. The staff's vulnerability lies in the possibility of feeling criticised or misunderstood. The staff will also continue their work in the units. Neumann and Neumann (2015) emphasise the researcher's responsibility towards the participants at every stage of the research process.

Findings

In this section the findings are presented in the following order: (1) The Group Homes (2) "We are not their Parents" (3) Institutional Talk (4) Privacy in Public and (5) Regulating Regimes.

To preserve anonymity, the observed children in the group homes are referred to by pseudonyms in this section. Girls' names start with L, boys' names start with J, and adults names with A. The author was responsible for translating the Norwegian verbal quotes into English

The Group Homes

In the interviews, the leaders described the main missions of the group home as that of providing flexible respite care for parents, by thus fulfilling a societal responsibility. Parents (during the interviews) described the group home as a service to exhausted families. They wished for good care and meaningful activities for their children and admitted that their children appeared happy within the living arrangement. The staff were committed to providing satisfactory medical, nutritional and personal care for the children, as well as to advance basic skills and support the children individually with a positive experience. The managers of the units provided their employees with time to collaborate regularly to improve the care for the residents. In a staff meeting, referring to several institutional features in the visual environment, one parent asked, “What constitutes a home?” Employees and parents showed ambiguity in terms of where the child’s home was - with the parents, in the group home or in both places. Ambiguity between a home and a workplace was also expressed by one employee: “We must remember that we are visiting the children in their homes”.

Personal qualities required for working in group-homes were said to be respect, reflectivity, a positive attitude, and the ability to meet each child where he or she is. One employee emphasised, “We must remember we are here for *him*, not for us”.

To run the units, staff employed rotating shifts operated 1:1 (some 2:1), which was said to be good staffing. Staff rotated in caring for each child to care on each day. This was a desirable arrangement; when every employee knows every child, it provides flexibility. Staff appreciated this structure as it brought variation to their workweeks. Some employees, however, expressed that this might not be the desired arrangement for the children.

A task for the professionals was to help maintain or improve the practical skills of each child, promoting independence as far as possible. This can be challenging in an institutional system, as one employee said:

> Like with dressing and maintaining his skills, not everyone, I don’t know how many works around him, but not everyone remembers it, cares about it or has patience with it. As primary carer I find it very challenging to insist that he maintains what he can and acquires new skills.

This quotation displays an attitude as a facilitator of practical independence. However, it contains a critique of employees who might have a different understanding and perform the practical tasks themselves, leaving the child passive. The critique could be taken further, to the core of the institutional system, that is, the necessity of certain numbers of staff, the rotating shift system, full or part-time positions and different professional backgrounds. The shifting presence of carers made it challenging to establish unified and yet individual approaches to each child.

The future of the child was also a concern, as one leader expressed, "We shall equip them with the best possible skills, to ease the work of the receiving (adult) unit", making the children as autonomous as possible.

A few employees mentioned that the group of children in the units had changed over the last decade from "mainly wheelchairs" to "more behaviour". This development was assumed to create some challenges for future group composition.

"We Are Not Their Parents"

A positive and warm atmosphere in the units was observed in terms of engagement and the children's well-being was the focus.

The everyday life was based on common routines as well as individuality, "What to do depends on who I am on, the period of the day and how she appears that day. However, there are also plans to follow for each one". The follow-up of individual routines was highlighted differently in the different units. In one unit, written individual routines were attended to quite closely: "What is decided and written in the child's files is what's valid." The two other units had a more flexible attitude towards what was written. However, everyone was committed to the main mission for their work, namely, fulfilling the children's basic needs.

Some employees showed confidence in closeness, such as giving hugs and having bodily contact, to meet the child's emotional requirements. Other employees kept a slight distance, apart from the bodily touch necessitated by care. Some difference between experienced employees and younger, short-term employees were recognised. One said, "I have long worked with people, and boundaries have moved. In the beginning my touching of people was with stiff arms, but they've become more and more flexible. When you work with people and get to know them, intimate zones become narrower". One reason for keeping a distance could be, as some employees reflected, "We are not, and should not be, their parents" – a deliberate attempt not to involve themselves too emotionally with the children, respecting the parents' privilege to be the closest to their own children. The staff's ambiguity about being close to and at the same time keeping a professional distance from the children was a continuing discussion in the group home, touching on institutional aspects.

Some children showed close attachment to one or another adult, giving rise to emotional dependency (reciprocally). The 'ownership claim' limited the child's tolerance for 'their adult's' interaction with other children. This led to playing pranks, crying and other attention-seeking manoeuvres. The attachment behaviour towards one specific adult might reflect the vast number of adults to relate to, a longing for closeness and a need for control and stability. This attachment behaviour was discussed and problematised by the staff. The institutional solution to this "problem"' was to limit everyday contact between the employee and the child for a period.

Institutional Talk

A number of close face-to-face encounters occurred in the houses and relational bonds evolved. The anecdote below shows one moment of reciprocal interaction:

> Lena sits in her chair in the common area, playing with her toy. Anna approaches Lena, crouches down, comes to eye level with Lena and talks to her in a quiet voice. Anna says what they are up to (bath). Lena turns her head towards Anna, gazing at her, listening. Lena leans towards Anna, and Anna lets her cheek touch Lena's cheek for a moment. The two of them proceed to the bathroom.

The adult person showed respect to the child by adjusting her own position to come to the same level with the child, making this a private encounter between the two of them, although occurring in a public atmosphere. For a moment Anna reduced the power asymmetry to a minimum, thus narrowing the space between them. Lena responded to Anna by turning her head and the cheek offer, a gift of confidence as Young (1997) puts it. Lena expressed a situational experience of interest and contentedness.

Many messages towards individuals were conveyed from a distance, with a louder voice. Using the name of the child would ensure the directedness of the message. Privacy and intimacy were, however, lost; publicity dominated. Messages could be loaded, and some children showed dislike when they were told, “Go and wash your face!” or “Should we go to the toilet?” Such instructions touch the child’s private space, forming an image of the child as an individual whose private tasks can be addressed in a public setting, which is very different from the above encounter between Lena and Anna. Kofod (2012) argues that such actions would probably not be accepted by people outside such specific contexts, while compromising the individual’s dignity. Grumbling or rejection of such messages could indicate that the child is experiencing the situation as unpleasant.

Another frequently observed communicative pattern was the employees’ internal talk over the head of a child.

> Lydia sits at the dining table. She has greeted the adults and received responses, smiles and appears to be in a good mood. Three employees are sitting around, having a cup of coffee. Lydia is included in the situation. Suddenly Amanda looks at Lydia

> and comments that Lydia's hair is dirty and greasy, touching it. The other two look at Lydia and agree verbally. Amanda goes on, “But showering is not scheduled until tomorrow”. Another employee argues, “You can, however, shower her tonight”. Lydia moves her gaze between the speakers, her smile fading.

This story presents a pleasant social encounter where Lydia appears to be included. The attention towards Lydia entailed a positive directedness embedded in a greeting ritual. The situation changed, however, when the attention switched to Lydia’s hair. Suddenly Lydia was no longer part of the ongoing social interaction; she became an object. The issue was concrete: her hair. However, it was abstracted to a level that excluded Lydia. The conversation was now *about* Lydia, taking an institutional turn. The employees engaged in a practical matter, using loaded words. They might have felt that they, as professionals, were entitled to have this discussion. What Lydia understood from the discussion was poorly observable. Her body, however, displayed that she noticed the looks and the changing conversational tone. Her expression turned from joyous contentedness to that of a more insecure state

Another episode concerning Lydia took place in the corridor when she passed the open door to a fellow resident’s room. Sounds escaped the open door, and Lydia repeated the sounds accurately. “She is copying Laura,” one employee said. “That’s what kids do. She is after all only 19 months,” another answered, revealing the cognitive age given Lydia by the specialist health service. Lydia was a teenager, possessing embodied experiences that reached beyond her cognitive age. Such comments, however, indicate a medical attitude of identifying children by their impairment label.

Privacy in Public

The dining area was identified as the heart of the home. It was an area where everyone could come and go as they liked. Many discussions and practical matters occurred here. Some children conducted table activities, food was eaten, medicine was distributed, and medical and practical instructions were transferred to new employees.

> Lena is placed at the end of the dining table. Two adults collaborate to give her medicine through her gastrostomy, one instructing the other. Lena plays with a toy, paying little attention to the ongoing process.

In such practical matters, the child’s bodily and emotional experiences are put aside, making up an institutional being for whom institutional duties are accomplished. Such practical tasks occurred as a natural part of everyday life in the group homes, seemingly without any regard for the child’s feelings. Knowledge transferrals about the child and on practical matters were on the agenda. In such exchanges, unwritten rules and taken-for-granted assumptions were transferred as well.

In another scenario:

> Jonas is sitting at the kitchen table, one employee on either side of him. Suddenly he has an epileptic seizure, stiffening, nodding his head and stretching his arms forward. The adults take care to protect Jonas. When he, after 5-10 seconds, comes “back”, the two employees discuss thoroughly what sort of seizure this could be in order to write a report in his files. They are still sitting on each side of him, one holding a pen and a paper. Jonas has a distant gaze.

Epileptic seizures are relatively normal occurrences in these contexts and are accompanied by institutional routines such as the obligation to record. The employees were attentive to Jonas during the seizure. He was a subject to care for, as part of their professional duty. They had, however, another professional duty which they took seriously: deciding what to name the type of seizure and reporting it. Once again, the young person, this time Jonas, was made an (medical) object and appeared invisible. One wonders how Jonas experienced the expressions of uncertainty from his carers, who were alternating between care and diagnosis.

Regulating Regimes

The children in the units were encircled by educational approaches as part of the caring system. Most obvious were the practical instructions in everyday tasks such as eating and dressing. Some received tokens when “being nice”, with an opportunity to receive a reward. Looking forward to a reward had a disciplining effect on the children (Goffman, 1991). The reward could be snacks, a smiley, time with an iPad or another desired activity. For some, the praise for being nice was the reward itself. “Being nice” had a different meaning for each child. For example, Jacob was nice when sitting down eating neatly, Jack was nice when joining a tour, Lisa was nice when going to the toilet. When the children behaved in desired ways, the workload for the staff became lighter.

Some children had challenging or peculiar behaviour, which could put stress upon employees participating in such situations and created a need for tools or routines to handle the situations and to prevent future similar incidents. Such behaviours include outrage towards an employee, throwing things at someone, spitting, hitting oneself or hitting others. Some incidents had a visible contextual cause-effect connection, while others occurred seemingly unexpectedly. The units had guidelines on how to react to unacceptable behaviour, giving instructions to meet the situation in a calm manner. This included talking calmly to the affectionate child, removing triggering factors or withdrawing from the situation until the child had settled down. When the child had gotten a grip on her/himself again, the employee could comfort the child, eventually talk with the child about what just happened. None of the units had a formal decision on coercion, that is to physically stop or hold the child.

On some occasions, an employee might be perplexed by an unexpected action by a child. Actions such as being hit or spat at may evoke emotional reactions, and leave an employee feeling offended, which could make the employee react in an emotional way, sometimes in front of the child. A visible emotional reaction from an employee, whom the child and society expect to be a safe and predictable person, could leave the child feelings of frustration or offence, even though it was the child who initially disrupted the social relationship. In a here-and-now situation, someone else could help calm the child as the employee in focus was not in a state to do so. On one occasion, when a child’s behaviour was experienced as particularly offensive, the employee decided to talk to the child about the incident a few days later, to tell the child how her (the employee's) feelings were hurt by the child’s provocative action. The adult in such an interaction lifted the child’s “sins before her, to make her realise her faults” (Goffman, 1991:269), thus accentuating an educative and admonishing message. In the observed situations the child did not explain or defend herself, nor was she given an opportunity to do so. The fact that the situation was carried out in a common area, and the existing asymmetry in speaking skills, stock of knowledge and power, were barriers for the child to participate. A private setting might have given the child a better opportunity to understand, to learn and to “speak out” for herself in that situation.

From the first day of observation, one young man, John, who had a stricter regime than all the other children did, attracted attention. He had rules and routines to comply with, based on a written contract showing what “not to do”. The agreement regulated his opportunities for conversation (nagging) and indicated that he should not shout. The daily token for complying with the rules was a smiley, which led to the desired activity. John put a lot of effort into keeping to the rules and constantly asked for confirmation of compliance. All of the staff participated in his regulation, providing comments such as, “Don’t shout!” The evaluation of his behaviour occurred daily in the common area. He showed satisfaction when he received a positive token on his evaluation form. This occurred most of the time. He looked forward to the desired activity. However, he strongly disliked getting negative tokens, which deprived him of the activity. When he received a negative token, he stood up, shouted repeatedly in astonishment and showed a weary and sad facial expression. It seemed that the negative token took him by surprise.

If the contract *was* a joint agreement between John and staff, one wonders why he was caught off guard when his behaviour was not approved. Did he really understand the contract? Was it a joint agreement? Here, the asymmetry between parties in the institutional context became visible. The agreement might be a "prescription of control" (Goffman, 1991), a demonstration of power disguised as an agreement, or, as Järvinen and Mik-Meyer (2003) argue, a claim of adaptation to the desires of the system. When asking the staff why John had this regime, most answered in modes of "it is necessary and to the best interest of everyone".

Discussion

The multiple purposes ascribed to the group-homes may give rise to ambiguity about how to balance positions between a home and a workplace (Mol, 2008), between clinical and personal care (Goode, 1994), between 'maternal warmth and paternal discipline' (Mol, 2008) and between claims for autonomy and efficacy (Reinders, 2010; Bigby et al., 2014). As Järvinen and Mik-Meyer (2012) discuss, much effort and adaptivity are required from both parties to fulfil the societal expectations attributed to the service-recipient/service-provider dyad. Challenges arise in institutional systems where the service-providers employ rotation-shifts, indicating a need for the group homes actors to construct routines and structures to create social order and control, thus creating conformity in a role-divergent environment (Goffman, 1991; Bigby et al., 2014).

The children's role is to settle their everyday lifeworld in the group home in which they are placed, which differs greatly from the lifeworld of their peers. The staff's role is more complex, as their main obligation is to create a home away from home for the children, based on the rights stated in Article 23 of the UNCRPD (2006). This imperative was challenged by the parent who asked, “What constitutes a home?”, indicating that there might be a visible difference in what we expect a home to be like and how the institution is equipped for practical reasons as a workplace. The empirical findings reveal the staff’s ambiguity and uncertainty in their understanding of where the children’s home is, like the reluctance of some to show closeness and attachment and the viewpoint of “We are not their parents”. A phenomenological approach to this issue (Merleau-Ponty, 1994; van Manen, 2019) makes one wonder what the children’s experiences of “home” are within this unstable (rotating shifts) and at the same time regulated (routines) context. In addition, as the parents said, the children frequently express contentment with returning to the group-home, which could be interpreted as an experience of the group-home as a stable habitat, a home.

As discussed by Bigby et al. (2014), the staff in the group home for children are also captured in a regulated political care system, with its demands for results and efficacy. This underpins the ambiguous and sometimes conflicting roles shown by Järvinen and Mik-Meyer (2012) of the emotional service provider and loyal employee. In the group homes, the demand for good service and qualitatively good care are held paramount in practice. The accomplishment of these intersecting and partly conflicting tasks becomes visible in the frequent shifts between subjective relational employee-child interactions and objectivation through practical procedures and discussions. Kofod (2012) describes such shifts as moving from a “host role” to a “parental role”, providing staff with legality to command and talk over the heads of their clients. In the group homes, the staff emphasise that “we are not their parents”; however, they execute a parental role, blurring the idea that they are “visiting the child’s home”. On the other hand, the professional care staff are instructed to take care of the children on behalf of their parents. How this mission is to be accomplished, is perceived and handled differently due to the different employees’ confidence in their role as caretakers. The objective of this article, however, is not to discuss thoroughly whether the parents' and professional employees' legalities in emotional and practical acts differ or coincide, although common sense might indicate that parents have more opportunities to react than paid professionals do.

The execution of private and intimate tasks in public exemplifies a paternalistic institutionalised pattern (Mol, 2008; Woodin, 2017). The instructions of new, inexperienced employees conducted in common areas transfer attitudes that are taken for granted regarding practices, and limit the opportunities for ethical reflection on the same practices and how the practices are experienced by the child (Goode, 1994; van Manen, 2018).

In line with Hacking (1986), the staff, or the institutional frames, might make up an image of the children as people to inflict service upon (Cocks, 2000) rather than as people to recognise and relate to in every aspect of daily routines. The children are, however, able to participate in and shape parts of their everyday life, and do so, through their bodily presence and their engagement, whether positive or negative, in intersubjective relations (Mead, 2015; McLaughlin, Coleman-Fountain & Clavering, 2016; Simmons, 2019). The children's bodily actions *might* position them as citizens with agency, despite their ascribed limitations.

The group home as a step towards adult life is an issue that concerns leaders, employees and parents. For the institution, the goal is to hand over a well-adapted young person to adult care provision. For the children, it might be a new, unknown place to orient in and many new people to relate to. Perhaps it is a frightening experience that is inflicted upon them, as they are not allowed to decide for themselves where to move and with whom, although this is a decisive right as stated in UNCRPD (2006). This decision is again made in collaboration between the service system and the parents, with the service system having a more powerful position. Parents can express fear regarding the transitional process. The quote cited above from Jenks (in Cocks, 2000), stating that the way we control our children may reflect the strategies through which we exercise power and restraint in the wider society, might have relevance not only in everyday life in the group homes and in preparations for transition to adult life, but also in how the policy of service provision is reflected upon.

Limitations This study includes only a small number of institutions and residents and is thus not representative of a wider population. However, the discussion related to the theoretical framework, makes it possible to draw some analytical lines, which situate this study from a poorly researched context, within the broader body of disabled children's childhood research, which needs to be investigated further.

Concluding remarks

In this article, the children in the group homes are given the role of co-actors as the employees take centre stage. The main finding was that the institutional frames of the group homes generate institutional practices and their own patterns of talk, which have an impact on the everyday life of children accommodating this specific cultural context. Based on the analysis of the empirical material, one characteristic of these institutional talks and practices, is the tendency for frequent shifts between relational subjective interactions with the children and practical, objectivating terminology and actions. These shifts in perspectives seem to occur without reflection, as institutionalised and taken-for-granted practices, and might in other contexts be judged as oppressive actions.

Another characteristic institutional practice is the execution of private individual routines in public areas, which tends to threaten the child's intimacy boundaries and his or her inherent human dignity.

These institutional practices could be ascribed to the professionals' ambiguous position between ideological, child-focused attitudes, which produce positive relational practices, and demands for institutional efficacy. The latter implies that some institutional aspects seem to flow through the course of history, making Goffman's analyses of 60 years ago still relevant.

In this article, some aspects of institutional talk and practices have been deliberately highlighted, and they tend to overshadow the positive atmosphere, attitudes and reciprocal social interaction found in the group homes. This has been done based on the analysis of the data as well as to provide a possible implication for the practice field and to encourage reflection on taken-for-granted institutionalised practices, by employing a wondering attitude about how such talk and practices are experienced by and shape the lives of children in such residences and how the practices could be improved.

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References.

Bigby, C., M. Knox, J. Beadle-Brown and E. Bould (2014): Identifying Good Group Homes: Qualitative Indicators Using a Quality of Life Framework. *Intellectual and Developmental disabilities.* 52(5), 348-366 DOI: 10.1352/1934-9556-52.5.348

Cluley, V, R. Fysion and A. Pinick (2020): Theorising disability: a practical and representative ontology of learning disability. *Disability & Society* 35(2), 235-257

Cocks, A.J (2000): Respite Care for Disabled Children: Micro and Macro Reflections. *Disability & Society* 15(3), 507-519 DOI: 10.1080/713661961

Cocks, A.J. (2008): Researching the Lives of Disabled Children. The Process of Participant Observation in Seeking Inclusivity. *Qualitative Social Work* 7(2), 163-180 DOI:10.1177/1473325008089628

Coleman-Fountain, E. and J. McLaughlin (2013): The Interactions of Disability and Impairment. *Social Theory and Health.* 11(2), 133-150 DOI:10.1057/sth.2012.21

Curran, T. and K. Runswick-Cole (2014): Disabled Children's Childhood Studies: a Distinct Approach? *Disability & Society*, 29:10, 1617-1630, DOI:10.1080/09687599.2014.966187

Engelsrud, G. (2006): *Hva er Kropp?* [*What is Body?*] Oslo: Universitetsforlaget.

Evensen, K.V. (2018): Give Me a Thousand Gestures: Embodied Meaning and Severe, Multiple Disabilities in Segregated Special Needs Education. *PhD dissertation* Norwegian school of sport sciences, Oslo

Franklin, A. and S. Goff (2019): Listening and Facilitating All Forms of Communication: Disabled Children and Young People in Residential Care in England. C*hild Care in Practice*, 25(1), 99-111, DOI: 10.1080/13575279.2018.1521383

Friedman, S.L. and M.A. Kalichman (2014): Out-of-Home Placement for Children and Adolescents with Disabilities. *Pediatrics* 134(4), 836-848 DOI:10.1542/peds.2014-2279

Fylkesnes, I. (2014): Barn i Barnebolig: Hverdagsliv og Trivsel. [Children in Small Group-homes: Everyday Life and Well-being] *Master's thesis.* NTNU, Trondheim

Goffman, E. (1991): *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates.* London: Penguin Books

Goode, D. (1994): *A world without words: The social construction of children born deaf and blind.* Philadelphia: Temple University Press

Goodley, D. and K. Runswick-Cole (2013): The Body as Disability and Possability: Theorizing the Leaking, Lacking and Excessive Bodies of Disabled Children. *Scandinavian Journal of Disability Research*, 15(1), 1-19, DOI: DOI.org/10.1080/15017419.2011.640410

Hacking, I. (1986). 'Making Up People.' pp. 222–36 in Heller, T.C., M. Sosna and D. Wellberg (eds): *Reconstructing Individualism: Autonomy, Individuality, and the Self in Western Thought.* Stanford: Stanford University Press

Handegård, T.L., T. Bliksvær, A.K. Eide, H. Gjertsen and W. Lichtwarck (2007): Barnebolig – Beste eller Nest Beste Alternativ. En Kartlegging av Barnebolig som Omsorgstiltak. [Small Group-homes for Children – Best or Second Best Alternative?] Nordlandsforskning, arbeidsnotat 1003/2007 Bodø: Nordlandsforskning

Helse- og omsorgsdepartementet (2011): *Lov om Kommunale Helse- og Omsorgstjenester.* [The Health and Care Act]

Hutchinson, G.S. and J.T. Sandvin (2016): Hva har Ansvarsreformen Betydd for Selvbestemmelse for Mennesker med Utviklingshemming? [What has the Deinstitutionalisation Reform Contributed to Autonomy for People with Intellectual Disability?] *Fontene Forskning* 9(2), 29-39

Järvinen, M. and N. Mik-Meyer (2003): *At Skabe en Klient. Institutionelle Identiteter I Sosialt Arbeide*. [To Construct a Client. Institutional Identities in Social Work] København: Hans Reizel

Järvinen, M. and N. Mik-Meyer (2012): *At Skabe en Professionel. Ansvar og Autonomi i Vælferdstaten.* [To Construct a Professional. Responsibility and Autonomy in the Welfare State] København: Hans Reizel

Kofod, J. (2012): Hold Hænderne i Lommerne. Om Hjælp til Selvhjælp i Plejecentre. [Keep Your Hands in the Pockets: On Help to Autonomy in care Centres] In Järvinen, M. and N. Mik-Meyer (2012): *At Skabe en Professionel. Ansvar og Autonomi i Vælferdstaten.* København: Hans Reizel

Mead, G.H. (2015): *Mind, Self and Society: The Definitive Edition.* Chicago: Chicago University Press

McEvoy, O. & M.E. Smith (2011): *Listen to Our Voices. Hearing Children and Young People Living in the Care of the State*. Dublin: Department for Children and Youth Affairs

McLaughlin, J., E. Coleman-Fountain and E. Clavering (2016): *Disabled Childhoods: Monitoring Differences and Emerging Identities.* Oxon*:* Routledge

Merleau-Ponty, M. (1994): *Kroppens fenomenologi*.[Phenomenology of Perceptions] Oslo: Pax forlag AS

Mietola, R., s. Miettinen and S. Vehmas (2017): Voiceless Subjects? Research Ethics and Persons with Profound Intellectual Disabilities. *International Journal of Social Research Methodology*. 20(3), 263-274 DOI: org/10.1080/13645579.2017.1287872

Mol, A. (2008): *The logic of care: Health and the problem of patient choice.* Oxon: Routledge

Neuman, C.B. and I.B. Neumann (2015): Uses of the Self: Two Ways of Thinking about Scholarly Situatedness and Method. *Journal of International Studies,* 43(3), 798-819, DOI: 10.1177/0305829815576818

Nind, M. (2008). Conducting Qualitative Research with People with Learning, Communication and Other Disabilities: Methodological Challenges. (NCRM/012). S*outhampton: National Centre for Research Methods*

Nind, M. (2018): Multimodal Listening and Attending to Children with Complex Disabilities in Educational Settings. In Twomey, M. and C. Carrol (eds): *Seen and Heard: Exploring Participation, Engagement and Voice for Children with Disabilities* pp 105-123 Oxford*:* Peter Lang

NOU 2016:17 (2016): På lik linje. Åtte løft for å realisere grunnleggende rettigheter for personer med utviklingshemming. [On Equal Basis: Eight Proposials for Realisation of Fundamental Rights for Persons with Intellectual Disability. Official Norwegian Report]. Regjeringen.no, Barne- og likestillingsdepartementet

Reed, I.A. (2011*): Interpretation and Social Knowledge: on the Use of Theory in the Human Sciences*. Chicago: University of Chicago Press

Reinders, H. (2010): The Importance of Tacit Knowledge in Practices of Care. *Journal of Intellectual Disability Research.* 54(1) 28-37 DOI:10.1111/j.1365-2788.2009.01235.x

Schütz, A. (1999): *Den Sociala Världens Fenomenologi. [The Phenomenology of the Social World]* Gøteborg: Bokförlaget Daidalos AB

Shah, S. and M. Priestley (2010): Home and Away. The Changing Impact of Educational Policies on Disabled Children's Experiences of Family and Friendship. *Research papers in education.* 25(2), 155-175, DOI: 10.1080/02671520802699224

Shakespeare, T. (2006): *Disability Rights and Wrongs.* London: Routledge

Shakespeare, T. (2013): *Disability Rights and Wrongs Revisited.* London: Routledge

Simmons, B. (2019): From Living to Lived and Being-with: Exploring the Interaction Styles of Children and Staff Towards a Child with Profound and Multiple Learning disabilities. *International Journal of Inclusive Education.* DOI: 10.1080/13603.2019.1569732

Simmons, B. and D. Watson (2015). From Individualism to Co-construction and Back Again: Rethinking Research Methodology for Children with Profound and Multiple Learning Disabilities. *Child Care in Practice.* 21(1), 50-66, DOI: 10.1080/13575279.2014.976179

Statistisk Sentralbyrå [Statistics Norway] (2018): https://www.ssb.no/statbank/table/11875/tableViewLayout1/

Stalker, K., J. Taylor, D. Fry, and A.B.R. Stewart (2015): A Study of Disabled Children and Child Protection in Scotland – A Hidden Group? *Children and Youth Services Review.* 56, pp. 126-134 DOI: http://dx.doi.org/10.1016/j.childyouth.2015.07.012

Söder, M. (1993): Normalisering og integrering: Omsorgsideologier i et samfunn i endring. [Normalisation and Integration: Ideologies of Care in a Changing Society] in Sandvin, J.T. (red). *Mot normalt? Omsorgsideologier i forandring [Against Normal? Ideologies of Care in Change]* Pp 41-66 Oslo: Kommuneforlaget

Tøssebro, J. (2014): Introduksjon. I Tøssebro. J. and C. Wendelborg: *Oppvekst med funksjonshemming. Familie, livsløp og overganger*. [Introduction. In: Growing up with Disability. Family, Life Cycle and Transitions] pp 11-32 Oslo: Gyldendal Akademisk

UNCRDP (2006): United Nations Convention on the Rights of Persons with Disabilities

United Nations Committee on the Rights of Persons with Disability (2019): *Concluding Observations on the Initial Report from Norway.* file:///C:/Users/06022217/Downloads/G1913256%20(2).pdf

Van Manen, M. (2019): *Phenomenology of the Newborn. Life from Womb to World.* New York: Routledge

Watson, N. (2012): Theorising the Lives of Disabled Children: How can Disability Theory Help? *Children & Society,* 26, 192-202, DOI:10.1111/j.1099-0860.2012.00432.x

Woodin, S. (2017): *The CHARM Toolkit Piloted: Findings from Monitoring Visits: Bulgaria, Czech Republic, Hungary and United Kingdom*. Budapest: Mental disability advocacy centre

WMA Declaration of Helsinki – Ethical Principles for Medical Research involving Human Subjects (2013)

Young, I.M. (1997): Asymmetrical Reciprocity: On Moral Respect, Wonder and Enlarged Thought. *Constellations* 3(3), 340-362

Ytterhus, B., S.T. Egilson, R. Traustadottir and B. Berg (2015). Perspectives on Childhood and Disability. In Traustadottir, R., B. Ytterhus, S.T. Egilson and B. Berg (eds) *Childhood and Disability in the Nordic Countries: Being, becoming, belonging*. Pp 15-33 UK: Palgrave Macmillan

Østvik, J, B. Ytterhus and S. Balandin (2017): Friendship among Children Using Alternative and Augmentative Communication and Peers: A Systematic Literature Review. *Journal of Intellectual and Developmental Disability* 42(4), 403-415, DOI: 10.3109/13668250.2016.1247949