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## RESEARCH

# Public Care for People with Intellectual Disability in Denmark – Ideals, Policy and Practice

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Denmark, internationally known for its high level of welfare and solidarity with vulnerable groups, has been in the forefront promoting the ‘normalisation principle’ regarding people with intellectual disability (ID). Formulated in the 1950s by Niels Erik Bank-Mikkelsen to ensure people with ID have equal rights to live and participate in the community, social policy has since shifted toward individual rights, self-determination and active citizenship. However, these ideals and social policy goals have proved difficult to realise in practice. Drawing on two empirical studies of professional practice in Danish accommodation units for people with ID, this article investigates how care is practised vis-a-vis people with ID, who – for different reasons – depend on daily interaction with professionals for care, support or treatment. Finally, the article discusses current conditions for providing individualised care and support and how autonomy and active citizenship can be in opposition to empowerment through individual care and support.

**Keywords:** re-institutionalisation; intellectual disability; social pedagogy; individualised care; practice

## Introduction

De-institutionalisation—the move from large residential institutions to small-scale services that enable people with intellectual disability (ID) to live in the local community—has probably been the most important development in social services for people with ID since the 1950s (Mansell and Ericsson 1996; Mansell et al. 2010). According to Mansell et al. (2010: 104), the process of de-institutionalisation is well advanced in Scandinavia, as well as in the United States of America, Canada, the United Kingdom, and Australia. In Scandinavia, important reforms involving further de-institutionalisation in public services for people with ID—a process that started in the 1960s—were introduced during the 1990s. For example, in Norway and Sweden all institutions for people with ID were closed and replaced by supported accommodation in the community (Tossebro 2012). In Denmark all institutions were not closed. Instead, with the Social Services Act in 1998, the concept ‘institution’ was abolished from legislation and statistics, creating a separation between social service and residence, which means that today services are provided in what is considered the citizen’s own home with legislated rights to privacy and self-determination regardless of the type of housing (Ministry of Social Affairs 2007). The intention was to break with the institutionalised care of the past that attributed power to the staff and to support the resident’s individual rights and dignity.

In the years after the 1998 Act, evaluations showed the reform meant positive changes for people with ID regarding living conditions and possibilities for making everyday decisions, but problems with practising the legislated ideals of self-determination, inclusion, and active citizenship persisted, particularly in relation to people with higher support needs, challenging behaviour, or social impairment (Hogsbro et al. 2012; Langager et al. 2009). This gap between ideals of independent and community living and their outcome is not, however, only a Danish phenomenon. Indeed, as Mansell (2010: 11) has stated, the gap between ideals, policy, and practice has been a general concern from the beginning. Altermark (2018: 28) characterises this as a ‘history of deinstitutionalisation, liberation, and disappointment’, which refers to the fact that in spite of political aims of normalisation, de-institutionalisation, and citizenship, people with ID are still far from being fully included, independent, and responsible citizens. As Altermark (2018: 28) states, ‘this group lags behind in more or less every standard of living or socio-economic measurement scale there is’, and the problems with coercion and use of force in public care for people with ID persist in what is now formally identified as their own home (Engen 2014; Handegård 2005; Taylor 2005; Traustadóttir & Johnson 2005; Walmsley 2005).

A common response from both researchers and legislators is that this is due to bad implementation. However, this way of perceiving the problem seems to take the value of the ideal of ‘autonomous citizenship’ for granted (Altermark 2018). The point is that if conceptions and ideals of self-determination, independent living, and active citizenship

are automatically used as a normative framework for evaluating public care for people with ID, there is a risk of not seeing what is more fundamentally at stake: people with ID often depend on interacting with professionals on a daily basis in order to receive the care, support, or treatment they need and the quality of public care is crucial for their life conditions and opportunities. Perceiving power over people with disabilities as an ‘anomaly’ or an ‘implementation failure’ (Altermark 2018) blinds us to the fact that ideals of autonomy and active citizenship can sometimes be in opposition to empowering people with ID through individual care and support.

The purpose of this article is to contribute to an understanding of how this dependency on interacting with professionals on a daily basis in a specific context constitutes conditions and possibilities of receiving individualised care and of being responded to as an individual with particular needs, personality, and life circumstances (Burrell & Trip 2010; Engen 2014). By drawing on empirical research into professional practices in Danish accommodation units for people with ID, the article investigates how care is practised in relation to people with ID, who, for different reasons, depend on interacting with professionals in these social settings: people with ID who cannot care for their own needs on a daily basis and people with ID who have been convicted of committing a crime (we will return to this). Furthermore, we are going to discuss the possibilities of receiving individualised care for people with ID in the present era of politics of inclusion, where the shaping of people into active, participating, and self-determining citizens are ruling ideals and policy goals (Altermark 2018: 29). The Danish social policy reflects corresponding developments in the Western world, which generally represent an increased focus on individual rights, citizenship, and autonomy (Engen 2017), and where similar paradoxes are built into public care for people with ID, thereby constituting the current conditions and possibilities of receiving individualised care, support, or treatment. In this way we wish to contribute to understanding the current living conditions and daily lives of people with ID in Denmark, but in other contexts as well, where people with ID depend on professionals on a daily basis.

First, we will focus on the current policy framework for public care for people with ID in Denmark. Then we will define how we understand the concept of care, before we continue with describing the research methods applied.

### **Social policy and public care for people with ID in Denmark**

In Denmark people with ID, who cannot care for their own needs on a daily basis, are mainly cared for in larger-scale accommodation facilities providing 24-hour supervision, care, and support by trained staff (§ 107/8 in the Consolidation Act on Social Services and § 105 in the Consolidation Act on Social Housing). The official purpose of residential care for people with ID is to

provide accommodation in facilities suitable for long-term accommodation for persons who, due to substantial and permanent impairment of physical or mental function, need extensive assistance for general day-to-day functions or care, attendance or treatment, when such needs cannot be addressed in any other way. (Social Services Act § 108)

The assistance in the accommodation units ‘must be provided on the basis of a specific individual assessment of the recipient’s particular needs and circumstances and in consultation with the individual recipient’ (Social Services Act § 1, our translation). Consequently, the social pedagogical assistance, care, and support (Social Services Act § 85) provided by the staff in the accommodation units must be given with the resident’s consent and with respect for his or her right for asserting self-determination. In practice, the responsibility for assessing needs and deciding when and how to intervene in relation to the residents is placed with the professionals, who continually make decisions, which can have far-reaching consequences for the residents. However, as noted by Altermark (2018: 184), there is very little direct control of how these legislated goals are met in professional practice, and small, everyday interventions into the autonomy of people with disability can happen without any repercussions.

As mentioned, today such units are legally defined as the resident’s home, not as institutions. However, many people with ID in Denmark are still living in accommodation facilities with institutional qualities, with small private rooms, large communal areas, and office facilities for staff (Tossebro et al. 2012). Because the typical form of housing for people with ID, whose social and intellectual functioning does not make it possible for them to live in their own house or apartment, consists of accommodation units with permanently attached staff, a choice regarding place of residence and where and with whom to live and receive help from virtually does not exist (Jensen 2011: 246).

In this way, the professionals in the accommodation units must manage several dilemmas, which are embedded in the social organisation of public care: in principle, people with ID have the right to privacy and self-determination as all other citizens, but in practice, they are obliged to live and receive care and support in institutional settings regardless of their ability to actually use their right to self-determination or to respect that of others. Due to intellectual and communicative impairment, which varies in scope and depth from person to person and for the same person according to the situation and context, people with ID often have difficulties understanding and communicating their needs to their carers, and they can have difficulties agreeing to the care, the professionals think they need and have a responsibility for delivering (Engen 2017). In light of this, the resident’s legislated right to only receive care and support they have consented to can also be regarded as diminishing their right to receive care that they themselves do not see or understand the importance of, which can result in neglect (Jensen 2011).

Before we analyse how care is practised in the accommodation units under these conditions, we are first going to describe how we understand the concept of care.

### Theoretical framework: The concept of care

In his classical investigations of ‘total institutions’, Goffman (1961) drew a clear picture of ‘the opposites of care’, how the handling of large numbers of people in segregated and isolated institutions enable depersonalised care and block treatment (i.e., the processing of people in large groups without privacy, individuality, or humanity and irrespective of personal preferences and/or needs) (King, Raynes & Tizard 1971 in Mansell et al. 2010: 105). Goffman primarily focuses on what happens when people or groups are being perceived and interacted with as ‘not quite human’, and, while not describing why or how people care, the caring opposite of this is having your individual needs met and being perceived as a person and not as a disregarded member of a stigmatised category (e.g., disabled people) (Goffman 1963: 40).

Bogdan and Taylor (1998: 242) on the other hand have focused explicitly on ‘how nondisabled people who are in caring and accepting relationships with severely disabled people [...] define the other party’. Their point of departure is that the definition of a person is created by the nature of the relationship between the definer and the defined, not by particular characteristics of the person, and they show how the nondisabled form close, affectionate, and accepting relationships with people with ID by focusing on their humanness as persons. Their difference is not denied, but it does not bring discredit or humiliation.

In this way Bogdan and Taylor address important themes of an ‘ethic of care’ (Tronto 2009): humans are fundamentally relational and interdependent. Human beings can only exist through and with each other within networks of care; it is not possible to create and maintain societies if they are not to some degree able to satisfy basic human material, social, and psychological needs (Sevenhuijsen 1998; Tronto 2009). In an ‘ethic of care’ perspective, vulnerability is a constitutive feature of the human condition. We are all, and in some situations and periods of our lives more than others, vulnerable and dependent on others to thrive and function as autonomous and self-directed individuals. This also means there is no theoretical or formal distinction between being autonomous and dependent, when a person’s competence, identity, and agency is understood not as a sum total of individual characteristics but relationally, collectively, and in terms of interdependence (Vehmas 2011: 161). Other people’s (lack of) care and support can be defining for a person’s agency, and an important insight to be gained from ‘care ethics’ is that qualities such as trust, attentiveness, and responsiveness to the other’s perceptions of reality are central for professional practices of care. In professional care, the social relationship between caregivers and – receivers is asymmetrical due to differences in position and competence, and this makes it even more important that care relies on an open, interactive process that is continually formed in relation to the care receiver’s response, making qualities such as attentiveness, sensitivity, and flexibility central (Engen 2017). Social, cognitive, and communicative resources can be considered key elements of a person’s agency—his or her ability to create a meaningful response in relation to other persons—and people with ID are often highly dependent on the staff’s attentiveness and ability to interpret their forms of communication.

In the following, we will present the methods and empirical material from two investigations into social pedagogical practices in Danish accommodation units for people with ID. The findings from the investigations illustrate how care and support is practised in relation to residents with ID who have different needs, problems, and background but who all depend on interacting with the professionals in the accommodation units in order to receive care, support, or treatment.

### Methodology and empirical material

The empirical material presented in this article is based on two qualitative and ethnographically inspired studies of professional practices in Danish accommodation units for people with ID. The investigations draw on different qualitative methods and interviews (individual and focus group), as well as direct observation of interactions between employees and residents. The observations were done by way of ‘shadowing’, a form of participant observation where the emphasis is on the role of a follower (Czarniawska, 2007: 56) and recorded in the form of field notes. All interviews were audio-recorded and transcribed verbatim in full length.

Engen (2014) has conducted fieldwork in three different accommodation units for persons with ID who need help and support on a 24-hour basis with tasks of daily living, such as eating, cleaning, personal hygiene.<sup>1</sup> Most of the residents involved in Engen’s study have higher support needs: they lack verbal communication skills and need help on a 24-hour basis to live a daily life. The field work included about 270 hours of participant observation of the interactions between professionals and residents when help and support were delivered and focus group interviews with the staff in the three accommodation units. At the time of investigation, 10, 16, and 30 residents, respectively, lived in the accommodation units (in the third unit the observations were done in a smaller group for six people with ID and an Autism Spectrum Disorder (ASD)). The staff counted around 70 full-time employees in total and consisted almost exclusively of women,

<sup>1</sup> The study is a part of and published in full length in the PhD dissertation *Professional practice in accommodation facilities for people with intellectual disability – the daily struggle for (a human) care* (Engen 2014).

the majority were educated social pedagogues, but other professions, such as social- and health assistants, were also represented.

Romer (2015, 2016) has done participant observation for about 90 hours and interviews with the professionals and the residents (altogether six social pedagogues and four residents) in an accommodation unit for eight people with ID who have been convicted of committing a crime.<sup>2</sup> The residents are characterised as having behavioural problems (e.g., problems of aggression and violence, abuse problems, and psychiatric problems). The four residents interviewed have relatively good verbal communication skills and are able to do many of the tasks of daily living without support. In Denmark, adults with ID are not sentenced to imprisonment if they have committed a crime. Due to their ID, they are sentenced by the criminal court to involuntary placement in accommodation units; they are sentenced to receive care, support, or treatment (Penal Code § 68; Social service Act § 108). Seen from the perspective of the criminal justice system, the purpose of the placement is that the residents, who are also regarded as offenders, receive social support and treatment to prevent new criminal offences (Romer 2015). In other words, the crime preventive measures in relation to this group are defined as individualised care, support, or treatment delivered on the basis of the Social Services Act and its focus on self-determination and consent.

Together the investigations show how care is practised in relation to people with ID, who, in different ways, depend on interacting with professionals on a daily basis in order to receive care, support, or treatment. As noted by Yin (2003), evidence from multiple cases is often considered more compelling, thus making the overall study more robust, and studying different cases makes it possible to compare and thereby deepen our knowledge about how care is practised in relation to people with ID and their possibilities being responded to as individuals with particular needs, personality, and life circumstances in the present era of active citizenship (Altermark 2018).

### **Ethical considerations**

All participants who were able to have given their informed consent to participate in the investigations. However, several residents were not able to understand the purpose of and give their formal consent to participation. In relation to these residents, we sought the permission of their next of kin. Furthermore, we saw it as our responsibility to evaluate, if the residents consented to our presence in each situation. Noticing and showing sensitivity to the reactions of the residents was extremely important, and throughout the research process, we have been particularly observant of the principle of 'doing no harm'. If, for example, the residents seemed to be negatively affected by our presence, we would leave the room. This ethical awareness 'on the spot' during the field work is particularly relevant when researching vulnerable people in a marginalised position (Shaw & Holland 2014). The material has been fully anonymised: employees are given fictional names starting with 'E' and the residents are given names starting with 'R'.

### **The effectiveness of care**

Overall, the studies show that the staff in the accommodation units share fundamental motivations and ideals of giving individualised care, of helping and taking care of the different needs of the individual resident (Engen 2014; Romer 2015). The professional practices revolve around establishing good relationships with the residents, and the staff is generally observant of the residents' legislated rights for privacy and autonomy (Engen 2014; Romer 2015).

Daily life in the accommodation units is structured around different activities and tasks to be done and a daily program for the residents, which they are expected to participate in or cooperate around. However, for many of the residents what might seem like basic tasks, such as taking a morning shower, cleaning their room, or getting dressed, is challenging and requires a lot of effort. To be able to do these practical tasks the residents need support from the staff. The ideal for the staff is to provide flexible help adapted to the individual resident, thereby making it possible for the residents to participate and do the tasks as independently as possible. This requires the staff be attuned to and continually adapt to the resident's responses in the concrete situation, and it also requires a form of 'other emotion management', where the staff creates a good atmosphere and mood in order to make the resident feel safe and relaxed, while at the same time making it clear what the task is (cf. Poder 2010). An example of this is Emily helping Ragnar clean his room:

Emily prepares the cleaning cart and enters Ragnar's room. They are going to do the cleaning. Ragnar starts to laugh, when he sees the cart. Emily: 'What's it with you? You always find it so funny, when you're going to do the cleaning. As if you don't quite think it can be right!' (she says this in a humoristic tone of voice). Ragnar gets a cloth with cleaner and polishes the lamp beside the door. He is laughing. Emily polishes the picture of Ragnar hanging by the door: 'We should also clean this ugly man'. Ragnar is laughing. Emily: 'Now you should clean the table, Ragnar'. Ragnar wipes it thoroughly. He moves the flowerpot on the table and the remote control, wipes underneath them, and carefully places them again. Emily: 'that's good work, Ragnar! Can you tie a knot on this?'

<sup>2</sup> The study is a part of and published in full length in the PhD dissertation *Sentenced to social pedagogy – a study of the dilemmas in an accommodation facility for offenders with intellectual disabilities* (Romer 2016) and *Offenders with intellectual disabilities – social pedagogy in an accommodation facility* (Romer 2015).



Emily hands Ragnar a garbage bag full of trash. Emily: 'Yes, you don't usually do this, but you're able to tie a knot on the other bags'. Ragnar tries a couple of times with his deformed hands (he has a syndrome, which involves deformity of hands). He cannot tie the knot and hands the bag to Emily. Emily: 'Give it another try. You can do it!' Ragnar tries again, but cannot. Emily: 'Is it because the bag has to...' She takes it and tightens it in order to make it easier for Ragnar to handle, and gives it back to him. This time Ragnar succeeds. Emily: 'That's good, Ragnar! You *could* do it! Now we've done that and you can sit here and relax, and then we'll go on a trip later' (Engen 2014).

Emily is Ragnar's contact person in the accommodation unit, and they know each other well. Their relationship is warm and friendly and builds on humour and shared acceptance. Because of the character of their relationship, cleaning the room is not just a practical task for Ragnar. It is also an occasion to be together with Emily, and his laughing clearly indicates that he enjoys it. Emily is guiding him through the process, and he cooperates by doing what she tells him to do. She also challenges Ragnar by giving him a new task: tying the knot on the garbage bag. When the task is too difficult for Ragnar, she does not take over but adapts it so that he is able to succeed in doing it himself. In this way, Ragnar is able to do tasks he could not do without her support and encouragement.

Daily life in the accommodation units is characterised by situations like this, where the staff's sensitivity, responsiveness, and ability to interact with the residents make it possible to perform the practical tasks of everyday life in partnership, thereby supporting the agency of the residents. In this way, their emotional and relation competences make it possible to realise the twofold purpose of care: practical help and support as well as taking care of the relationship between the professional and the person with ID (Engen 2014). Thus, professional care has its own logic and effectiveness, which makes it possible to bridge the often conflicting experiences of staff and residents and to realise good solutions.

However, the fact that a smaller group of employees have to distribute their time, attention, and help on a larger group of residents puts the possibilities of providing care that is adapted to the individual person's needs under pressure.

### Care under pressure

Mornings in the accommodation units were characterised by time pressure, intensity, and shortage of staff resources. Most of the residents needed help getting out of bed and getting ready for the day, and one employee had to help several residents, making it difficult for the staff to live up to and carry out the ideals of individualised care in practice. In the accommodation unit for six residents with ID and ASD, the mornings were particularly intense. Every weekday, the residents had to be ready to be picked up by a bus that left at precisely 8.30 a.m. to drive them to their place of sheltered employment or day activity centre. The sharp timeframe created by the departure of the bus meant the staff had to distribute and prioritise time among the residents, and the mornings often involved a special form of multitasking for the employees.

For example, Emma started off one morning waking up Roger, who was known to be fast, and so could be 'stretched'. After she woke up Robert, they estimated she had just enough time to brush Richard's teeth so he could get on with the morning program before she had to be ready to help Robert, who would be frustrated if she was not there when he was ready for his bath, all while watching if Roger had started showering by himself, which meant that she would have to help him shower again anyway, because he was not able to wash himself properly (Engen 2014: 266). While one resident had his breakfast, the employee could help another resident shower, and the staff's focus was on solving tasks quickly and effectively. However, not all residents ate at a suitable speed. One resident had a habit of pausing in the middle of his meals, and consequently—out of efficiency concerns—he did not get much food in the morning. The employees did not want him to miss the bus.

The mornings were characterised by an intense focus on effectiveness and the progression of the residents in the morning program, which diminished the possibilities of individualised care and support adapted to the individual resident's rhythm and needs (Engen 2014, see also Clement & Bigby 2010). This was especially the case because the staffing did not make it possible for a resident to stay at home or be driven to the work place when he was ready. Thus, the staff was keen on getting the residents ready, and they talked a lot about the balance and difficulties in sensing when 'you push too hard or too little'. For the staff, this was about putting just enough pressure on the resident to make him 'move on' or 'take the next step', but not so much that he gets stressed and acts out. For that reason, the staff tried to attune their body language and tempo to the rhythm and mood of the individual resident, but as the departure of the bus closed in, the more pressure they put on the residents, asking them several times to 'hurry up', clapping their hands hard, and so forth.

Not all residents managed to cooperate under this intense pressure and exhibit the speed and ability required to stick to the program. Some residents did not want to get out of bed; they did not want to shower. This caused great frustration among the employees, who put a lot of effort into getting the resident to follow the program, and in some cases this led to a sort of struggle with the residents who did not follow the plan (Engen 2014). At other times, the staff had to give up, and this caused feelings of powerlessness and perceptions of the 'non-cooperating' residents as problematic (see also Handegård 2005, Christensen & Nilssen 2006).

In this way, the institutional order of the accommodation units conditions how time can be understood and managed for both the residents and the staff. The daily activities are organised so as to utilize staff resources as efficiently as possible, and when this is given higher priority than being able to adapt to the residents' responses, both staff, residents,

and the caring practices that unfold in interaction are put under pressure. The pedagogical practices risk sliding into manipulation or force, with negative consequences for the residents and their relationship to the staff (Engen 2017).

### When efforts to create 'independence' become the opposite of care

As we have demonstrated, caring support from the staff is crucial for the residents' possibilities of performing tasks of everyday life, and at the same time, their agency depends on the quality of the relationship with the employees. When the residents feel safe with their carer, because their relationship is defined by acceptance, acquaintanceship, and responsiveness, they are able to act more independently. In this way, their competence, skills, and agency are defined relationally and in terms of interdependence.

However, in some cases—and especially in relation to residents who were considered problematic in the light of the institutional demands described above—the staff seemed to use ideals of autonomy and active citizenship to justify the implementation of behavioural modifying programs with the aim of making the resident cooperate. For example, this happened in relation to Ronan, who has ID and ASD and is one of the residents the staff has difficulty motivating to cooperate in the morning. He often acts headstrong and seems entirely unaffected by the staff's attempts to motivate him. The employees tell about the strain they experience:

Problems keep *dragging on* and almost *no matter what we do, it continues...day in and day out*. For example getting Ronan up in the morning. It's been difficult for a long period. Then you can actually *get a pain in your stomach*, before you go to work by the thought: 'how are we going to manage today? Who's coming to work? Is it someone who can manage to get him up?' (Several others nod their heads in consent)

Problems such as this challenge the emotional and relational competences of the staff in a fundamental way. When they experience the resident as unresponsive to their efforts, their feelings of disappointment and powerlessness grow. In this institutional framework, some residents' lack of flexibility, adaptability, and ability to cooperate, which is a part of their functional limitations that they need compensation for, becomes pressure on the staff.

The pedagogical strategy was to argue for Ronan's need for 'system-dependency' instead of 'person-dependency' (he had a special relationship to one employee with whom he always cooperated). He needed to be able to follow the program independently of who was helping him. Accordingly, the staff developed a program with detailed and written rules for how Ronan's mornings were to proceed, which all employees were obliged to follow in the same way. They also took some of his personal belongings (music cd's, magazines, chocolate) and used them as 'reinforcers': tools in training Ronan to do what was expected of him. This was done by locking his favourite things in a cabinet and only taking them out as a means to motivate him (e.g., to get out of bed and take a shower within the given timeframe); he usually got up by himself before noon in the weekends.

The risk of this strategy is that the resident's ability to adjust to institutionally defined demands dressed in ideals of 'independence' becomes more important than relational trust and acceptance of his experiences and individuality. The fact that some of the residents have a different tempo and disposition for living up to expectations and demands becomes a problem on the grounds of specific expectations created by an institutional order, where all residents must be able to go through the same daily tasks in predetermined time intervals independent of who is providing the support. In other words, this is a clear example of how institutional practices are maintained in what is formally defined as 'community care', of social pedagogical assistance, care, and support not adapting to the person's individuality and particular life circumstances because of the institutional organisation of professional practice.

### Residents' resistance

Caring for people who often do not cooperate with well-intentioned initiatives is a challenging and demanding task that can foster feelings of powerlessness and frustration. Caring practices build on the relationship between the caregiver and the care-receiver, but these relationships can be difficult to establish and maintain, and as we have demonstrated, residents with higher support needs can resist cooperating around daily tasks. However, the residents also resisted in other and more manifest ways. In the interviews, the residents with a criminal conviction clearly expressed refusal to accept an identity as a care-dependent person with ID, and they did not understand why they had to live with 'a bunch of morons', as one resident put it (Romer 2016: 93). The staff categorised this group of residents as better functioning, and they described them as being so close to the normal level of IQ that it can be difficult to tell that they are intellectually disabled (Romer 2015). This group does not see themselves as persons with ID. Rodney explains:

I'm not very proud of being here you see, I don't mind people with ID, and I don't mind people, who can't take care of themselves. But why did they send me to live with 117 people, who can't take care of themselves?

**Rømer:** you are thinking about the other residents here at [name of regional accommodation and activity centre]?

**Rodney:** yes, all the people around here. If you are intellectually disabled, you cannot handle your daily life. And if this [he points to his head] does not work according to your age. Just see a guy like Reynold. He is almost 30 years old. But in his head, he is barely 5 years old. That's not funny at all! (Romer 2016: 93)



Rodney, as well as the other residents interviewed, does not identify himself with the common trait of the residents in the accommodation unit: intellectual disability. On the contrary, he finds it shameful to be grouped together with people who obviously depend on professional help. The 'better functioning' residents generally felt that they were able to take care of themselves and to work as any 'normal citizen' would, which is expressed by Rob:

**Rømer:** you live here at [name of regional accommodation and activity centre], and the people who live here are what someone would call intellectually disabled...

**Rob:** I don't think I'm that!

**Rømer:** No. Do you know what it means to be intellectually disabled?

**Rob:** No. I don't understand that, because I'm applying for jobs on my own. Someone like that cannot do that! You are not intellectually disabled because you cannot read and write. A lot of people out there in society cannot do that. There are a lot of people who cannot read and write today, and they're doing fine! I do everything myself, also the bank. I always do my payment services. I do that myself. I do the cleaning myself. I don't need help from anybody! (Rømer 2016: 91–92)

For these residents, having ID means a person is not able to take care of himself and is not a part of society. In this way, they draw on able-bodied norms and discourses of 'ableism' (Campbell 2009) as an interpretive frame when trying to understand themselves and their situation. They actively resist being perceived as 'other'—as disabled and dependent—and in doing so they reproduce norms of independence, autonomy, and active, productive bodies and the devaluation of its 'opposites'.

These residents did not want to participate in their daytime employment in the activity centre, common meals, and other collective activities arranged by the staff. They mostly spent their time in their private rooms avoiding contact with the other residents as well as the staff, which resulted in them receiving very little help and support—help and support they needed because they struggled with economic problems, criminal behaviour, mental illness, and drug abuse. The gap between the residents' self-understanding and their need for care and treatment made it difficult for the staff to respond appropriately, thereby leaving them without the individualised support they depended upon.

### Withdrawal of care

The staff met the residents' resistance with a sense of disillusionment. As one employee put it: 'They [the residents] don't give a shit! They laugh at us behind our backs: what are you going to do about it? What can you do about it?' (Rømer 2015: 105). The staff's experience of powerlessness is shaped in relation to the residents' rejection of understanding themselves as person's with ID that can benefit from social pedagogical assistance, care, and support and treatment combined with the fact that the residents were well aware of and verbally claimed their right to self-determination and to reject contact with the staff. They not only resisted participating in activities planned by the staff, they occasionally 'acted out' on the staff or other residents verbally or physically. One of the employees explains the challenging behaviour this way: 'When I started here, no one would fight – no one! But this has changed, because it's also a way to push something through...when the staff becomes scared. They [the residents] learn this subconsciously' (Rømer 2015: 107).

The violent behaviour made the staff scared, which resulted in minimal interaction with some of the residents: they stopped insisting on contact with and placing demands on the residents, and they legitimated this lack of communication and contact with their respect for the residents' self-determination (Rømer 2016). This contributed to further frustration among the residents. For example, Rodney felt that he was given responsibility for seeking out the staff and initiating talks about his temper: 'They don't return to you and ask, why you behaved like that; why did you say this, or why did you do that?' (Rømer 2016: 165). The residents experienced the staff withdrawing into 'a mental glasshouse' (Hogsbro et al. 2012: 123); they withdrew themselves from interactions and caring practices with the residents.

In this way, residents, especially the 'better functioning' residents, are fundamentally ambivalent in relation to the staff; on the one hand, they call for a relationship to the employees, and on the other hand, they reject it (Rømer 2016: 164). They see themselves as independent and not in need of social relationships or help from others, and at the same time, they express longing for a closer relationship, for being perceived as persons. As one of the residents put it: 'It's because, they do not know me – not even after two years. They don't!' (Rømer 2016: 119).

This necessitates the staff see beyond the challenging behaviour, understand the resident's specific personality and struggle for being 'normal' (Goffman 1963) and 'able' (Campbell 2009), and build a trusting relationship that enables the individual resident to receive the help and support they need.

### Discussion

Our investigations of how care is practised in relation to people with ID in Danish accommodation units show how the staff struggle to live up to professional ideals of individualised care and support and at the same time manage the dilemmas, which are embedded in the social organisation of public care for people with ID. In principle, people with ID have the right to autonomy and self-determination as all other citizens, but in practice, they are dependent on interacting with professionals in institutional settings regardless of their ability to actually use their right to self-determination or

to respect that of others. Through practices of care that build on attentiveness, trust, and responsiveness, the employees are able to form relationships to the individual resident, enabling them to receive both practical help and support. In this way, caring practices have their own effectiveness: this way of practicing makes it possible to simultaneously take care of different needs (e.g., bodily and material needs connected to daily living and needs for social agency within trusting and accepting social relationships). However, caring practices require time and flexibility, and they are put under pressure by the institutional order of the accommodation units that conditions how time is understood and managed for both the residents and the staff, converting struggles to care into struggles between staff and residents. For example, some residents resist by not conforming with the morning program, and this resistance is met with targeted attempts to train the residents to be autonomous and independent. Paradoxically, these interventions take the form of discipline and manipulation; they disregard the resident's experiences of the situation and possibilities of saying no with negative consequences for the residents and their relationship to the staff.

Other residents resist in more verbalised and reflexive ways. They resist an identity as 'intellectually disabled', insist on their status as 'normal citizens' and their independence in relation to the staff. At the same time, they express longing for a closer relationship, where they are recognised as persons, but resist being confronted with how their actions affect others.

In this way, ideals of autonomy, independence, and active citizenship in different ways influence professional practice in the accommodation units and sometimes contribute to undermining the possibilities of residents and staff creating caring practices in partnership. When confronted with the strenuous experience of working in close relation to people who do not cooperate around institutional demands, the staff evokes discourses of independence to legitimise disciplining practices that are in opposition to their own ideals of caring relationships to the residents. In relation to residents who are aware that the ideal is to be autonomous and independent, who find it shameful to rely on professional help and occasionally behave aggressively towards staff and other residents, the employees become insecure about when and how to intervene. As a consequence, they withdraw from the relationship, worried about violating the residents' right to self-determination. Consequently, the residents are not confronted with how others experience and are affected by their actions, and they are left without meaningful relationships of care.

Thus, everyday life in the accommodation units at the same time seems very distant from and affected by the discourses of individual rights and citizenship. As noted by Altermark (2018: 182), the 'moral ontology of self-sufficient individuals striving to be independent' and the language of citizenship and individual rights do not account for the human experience of interdependence in the accommodation units, for the complex problems, needs, feelings, and experiences that must be acted on in daily practice. The gaps between ideals, policy, and practice become particularly obvious when caring practices that have the potential to bridge the sometimes conflicting experiences and needs of residents and staff are put under pressure by paradoxes created by the institutional organisation of public care and the ideology of citizenship. An institutional organisation where time has to be managed effectively makes it difficult to accept the individuality of residents who do not adapt flexibly to these demands and to provide care conditioned on the behavior of the resident. In this way, intellectual disability is constituted by the overlap of bodily and discursive vulnerabilities: on the one hand, the fragility of when body meets world, and on the other hand, by being perceived discursively as 'deviant', 'other', and fundamentally different (Altermark 2018: 191).

## Conclusion

Caring for people with ID who depend on professionals in institutional settings is a complicated task. Practices of care build on forming trusting relationships with the individual resident and is a delicate, interactive processes. Relationships that can be difficult to establish and maintain, especially under the paradoxical conditions created by the institutional organisation of public care and the ideology of independent citizenship. While differences in position and competence attribute power to the staff, the employees can also experience powerlessness in relation to the residents. Thus, professional care requires emotional and relational competences and attentiveness to the experiences of 'the other', particularly in situations of conflicting interests. This in turn requires institutional conditions that support these qualities and ways of practising, time being one of the most important. Ideals and discourses of independence and 'active citizenship' fail to provide an adequate language for making sense of the lived experiences of both residents and staff in the accommodation units, creating paradoxes that put practices of care developed in partnership under pressure. The separation between 'able' and 'disabled', 'dependent' and 'independent' does not give meaning to the shared experience, here articulated by Bogdan and Taylor (1989: 146, our emphasis): 'what and who others, as well as we, are *depends on our relationships with them* and what we choose to make of us'.

## Competing Interests

The authors have no competing interests to declare.

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