

Autonomy and Human Rights Dilemmas in Supported Housing for People With Intellectual Disabilities

Maya Christiane Flensburg Jensen , Nichlas Permin Berger , Maria Røgeskov ,
Pernille Skovbo Rasmussen , and Leif Olsen 

The Danish Center for Social Science Research, Denmark

Correspondence: Maya C. Flensburg Jensen (maje@vive.dk)

Submitted: 14 April 2025 **Accepted:** 22 July 2025 **Published:** 11 September 2025

Issue: This article is part of the issue “Accessibility, Integration, and Human Rights in Current Welfare Services, Practices, and Communities” edited by Suvi Raitakari (Tampere University), Jenni-Mari Räsänen (Tampere University), and Anže Jurček (University of Ljubljana), fully open access at <https://doi.org/10.17645/si.10522>

Abstract

The right to individual autonomy, including the freedom to make one's own choices, is a central tenet of the UN Convention on the Rights of Persons with Disabilities and is increasingly emphasized in policies promoting deinstitutionalization of social care services for people with intellectual disabilities. However, realizing this right in practice remains a complex challenge. Existing literature often frames social care workers (SCWs) as either hindering or enabling autonomy, but such binary perspectives obscure the everyday moral and institutional tensions that shape social care work. This article draws on ethnographic fieldwork from two supported housing facilities in Denmark to explore how SCWs experience and navigate these tensions. Using Mattingly's concept of moral scenes, we show that the tensions involved in realizing autonomy sometimes arise from competing concerns and demands both within social care services and within the UN Convention on the Rights of Persons with Disabilities framework. We identify four interrelated dilemmas: the health, social inclusion, adequate standard of living, and resource dilemmas. Rather than viewing SCWs solely as facilitators or barriers to human rights realization, these dilemmas recognize SCWs' role as situated frontline agents who navigate competing concerns within institutional constraints. Acknowledging and encouraging reflective, collective dialogue about these dilemmas may offer a critical pathway to support people with intellectual disabilities' accessibility to human rights realization.

Keywords

autonomy; care work; human rights; intellectual disability; professional dilemmas; social care workers

1. Introduction

The UN Convention on the Rights of Persons with Disabilities (UNCRPD; UN, 2006) establishes individual autonomy as a fundamental human right. Article 3(a) of the UNCRPD associates autonomy with the “freedom to make one’s own choices, and independence of persons” (UN, 2006, p. 5). These rights are increasingly emphasized in policies promoting the deinstitutionalization of social care services for people with intellectual disabilities (IDs), which form the context of the present article. In this article, we understand autonomy as the right of all individuals, including those with ID, to make choices and decisions about their own lives and independence. ID refers to “an early and enduring impairment of mental capabilities essential to function in daily life” (McKearney, 2021, p. 155). The UNCRPD framework acknowledges that certain disabilities, including ID, may affect decision-making capacity. Accordingly, it includes complementary articles and principles that require states to ensure individuals receive the necessary support to exercise their autonomy without discrimination on the basis of disability. Article 21 underscores that “state parties shall take all appropriate measures to ensure that people with disability can exercise the right to freedom of expression and opinion” (UN, 2006, p. 14). This includes ensuring the right to supported decision-making, such as access to information that helps individuals exercise their rights (see also Davidson et al., 2015). Concurrently, the UNCRPD seeks to ensure that efforts to promote autonomy do not give rise to new forms of discrimination. It obliges governments to ensure that people with ID have accessibility to full participation and inclusion in society (Article 19), the highest attainable standard of health (Article 25), and an adequate standard of living (Article 28; UN, 2006). In this article, we explore how this human rights framework is realized in a Danish social care services context from the viewpoint of social care workers (SCWs)—the frontline professionals responsible for fulfilling the government’s obligation to uphold the human rights of people with ID.

The UNCRPD’s emphasis on the rights of people with disabilities to autonomy stems from criticism, beginning in the 1950s, of total institutions as dehumanizing and oppressive disempowering (Goffman, 1961; Hall et al., 2021; Juhila & Löfstrand, 2022). By the end of the 20th century, this critique had led to several phases of deinstitutionalization of social care services. Large institutions and asylums were replaced by supported housing facilities and, more recently, by home- and community-based services (also referred to as the “home turn”; Hall et al., 2021; Juhila et al., 2021). Deinstitutionalization has been underpinned by wider welfare discourses of active citizenship (Juhila et al., 2017) and by commitments by almost all UN member states to ensure their national legislation and administrative practices comply with the UNCRPD (Denmark ratified the treaty in 2009). Furthermore, a 2018 statement of ethical principles by the International Federation of Social Workers emphasizes that SCWs should respect and promote people’s “full involvement and participation in all aspects of decisions and actions that affect their lives” (Juhila et al., 2021, p. 171).

Research on the deinstitutionalization of social care services for people with disabilities comprises two prevailing views on how social care services address client autonomy.

One optimistic view focuses on how deinstitutionalization has transformed social care services and care. These studies (Dunn et al., 2010; Engen et al., 2019; Kittay, 2011; Neuman & Bryen, 2022; Pols et al., 2017) regard autonomy as a relational and contextual phenomenon that cannot be exercised in isolation and requires “capacity” (Juhila et al., 2021). They show how the focus on autonomy in social care services has

replaced ethically questionable practices of persuasion with more humanistic orientations and care practices based on approaches such as “supported decision-making” (Davidson et al., 2015).

The other, more pessimistic prevailing view emphasizes how deinstitutionalization has not fulfilled its promises (see e.g., Hall et al., 2021). These studies (e.g., McKearney, 2021; Petner-Arrey & Copeland, 2015; Skarstad, 2018) emphasize implementation failures regarding autonomy: For instance, how SCWs continue to perceive individuals with ID as incapable of making decisions. Moreover, several studies suggest that, in fulfilling their duties as SCWs, SCWs may inadvertently infringe upon the legal right to autonomy of individuals with IDs (Juhila & Löfstrand, 2022; McKearney, 2021). Several studies also link the difficulties in integrating autonomy into social care work practices to organizational constraints, such as high turnover rates, low wages, and the priorities of other social care values such as health and safety (Bigby et al., 2019; Jormfeldt, 2016).

Previous studies have positioned the relationship between autonomy and social care services as a central issue in discussions about the accessibility to human rights (Grymonprez et al., 2017). Access to care and support has often been framed either as a crucial means of facilitating individuals’ realization of autonomy or, conversely, as a hindrance to it. While some studies have begun to explore the dilemmas that SCWs face (Bromark et al., 2024; Engen et al., 2019; Kohl et al., 2022; Ylvisaker & Rugkåsa, 2022), this binary framing has left limited space for examining the full complexity of how SCWs navigate and balance multiple, and sometimes competing, concerns and principles in their everyday care practices. Understanding these demanding situations is essential, as the realization of policy goals such as those inspired by the UNCRPD ultimately depends on how such policies are interpreted and enacted in the frontline of public service practices, as argued by Lipsky (1980). This dependency becomes particularly important to understand when we conceive autonomy as relational, contingent, and co-constructed in everyday interactions. Drawing on ethnographic fieldwork conducted in two supported housing facilities in Denmark for individuals with moderate to severe IDs, we explore the dilemmas SCWs face when supporting individuals with ID in realizing their right to autonomy.

The article is structured as follows. First, we review the literature on the intersection of autonomy and social care services and introduce our central theoretical concepts. We then present our methods and subsequently our findings, which outline four types of situated dilemmas. Finally, we offer a concluding discussion of the findings.

2. Theoretical Framework

Studies on deinstitutionalization increasingly examine how social care services affect accessibility to social care and autonomy for individuals with ID. However, whether SCWs facilitate or hinder autonomy for individuals with ID remains contested in the literature on deinstitutionalization.

One perspective in the research on the deinstitutionalization of social care services views autonomy as integral to care practices (e.g., Healy, 2008; Mapp et al., 2019; Reynaert et al., 2022). These studies position human rights as fundamental to social work, underpinning the profession’s code of ethics (International Federation of Social Workers, 2014). From this view, social work functions as a human rights profession (Healy, 2008; Knevel et al., 2023; Mapp et al., 2019; Reynaert et al., 2022) that promotes human dignity and facilitates “good” social change.

Studies related to this facilitating perspective emphasize that SCWs are transitioning toward a human rights approach focusing on “good” care and relational autonomy (e.g., Beadle-Brown et al., 2012; Bigby et al., 2019; Juhila et al., 2021; Neuman & Bryen, 2022). Neuman and Bryen (2022), for example, describe how the “dare to dream” approach transforms SCWs’ perceptions of their role, encouraging a more humanistic orientation that empowers individuals with ID to articulate their aspirations. This shift redefines the purpose of support, moving beyond the facilitation of daily activities to the enhancement of personal agency. Several studies highlight how prioritizing residents’ capacity for autonomy (see, e.g., Juhila et al., 2021) reshapes the SCW role into one that promotes supported decision-making. Supported decision-making involves supporting people with limited decision-making capacity to make their own choices, thereby fostering autonomy while reducing reliance on substitute decision-making (Davidson et al., 2015). Through ongoing dialogue, SCWs help individuals with ID to understand their rights and weigh different options (Juhila et al., 2021; Kittay, 2011; Pols et al., 2017). Similarly, studies show that the matter of active citizenship, which is related to the autonomy of people with ID, can be promoted by enhancing individuals’ physical mobility and participation in daily activities (e.g., Andersson & Gustafsson, 2016; Jormfeldt, 2016). Yet despite these advances, some of these studies also identify structural and institutional barriers that continue to hinder the realization of client autonomy within social care institutions.

A second perspective on the deinstitutionalization of social care services emphasizes how care practices hinder autonomy (e.g., McKearney, 2021; Petner-Arrey & Copeland, 2015; Skarstad, 2018). Petner-Arrey and Copeland (2015) found that while individuals with ID desired autonomy, SCWs struggle to facilitate this. The authors argue that the supportive role of SCWs either inherently facilitates or hinders autonomy (Petner-Arrey & Copeland, 2015). Similarly, Skarstad (2018) illustrated through case file analysis that autonomy rights are often denied, largely due to assumptions about the competence of individuals with ID regarding decision-making. Further, in an analysis of practices at a supported housing facility, McKearney (2021) argues that new modes of guidance and supported decision-making introduced to promote autonomy constitute forms of “masked” persuasion and subjectification because the guidance impose societal and cultural norms on people with ID and how their everyday lives should be lived (see also Juhila & Löfstrand, 2022; van der Weele et al., 2021).

We propose that the diverse viewpoints in studies on deinstitutionalization reflect a series of dilemmas that SCWs face when supporting individuals with IDs in realizing their right to autonomy. However, while some of the studies mentioned above allude to the existence of such dilemmas, these are rarely subjected to focused analysis. A few studies do address this gap: Kohl et al. (2022) discuss the “influence and autonomy dilemma” in disability work, while Engen et al. (2019) explore how SCWs balance managing risks with meeting individual needs and desires of people with ID. Traditionally, dilemmas in care work have been defined as situations in which two conflicting considerations arise, neither of which is desirable (e.g., Fisker et al., 2008, p. 17). Such conflicts are frequently oversimplified into binary oppositions (Wadmann et al., 2023) between managerial versus client-oriented rationalities or dependence/care versus autonomy. This article offers an alternative perspective on the care work dilemmas that emerge from deinstitutionalization by focusing on “dilemma-filled situations” (Kongsgaard, 2022) rather than absolutist dilemmas.

3. Central Theoretical Concepts: Dilemma-Filled Situations and Moral Scenes

The focus on dilemma-filled situations recognizes that frontline professionals' accountability extends beyond formal reporting to higher authorities; SCWs must respond to multiple, often competing, expectations of performance, responsiveness, and ethical conduct from a diverse array of individuals (colleagues, family, and clients) and institutions (Wadmann et al., 2023). These multiple accountabilities create situations where SCWs face difficult decisions, as no single perspective or course of action can be deemed objectively correct (Fisker et al., 2008; Kongsgaard, 2022)—yet SCWs remain accountable for their decisions within these contexts (Bigby et al., 2019).

To investigate how situated dilemmas emerge when accessibility to autonomy is at stake in everyday social care work involving people with ID, this article utilizes Cheryl Mattingly's (2014) "moral laboratory" concept. In her book *Moral Laboratories: Family Peril and the Struggles for a Good Life*, Mattingly (2014) uses the moral-laboratory metaphor to illustrate how seemingly mundane spaces, such as soccer games, become "spaces of possibility" for ethical inquiry even if they are not immediately recognized as such. These spaces can foster experiences that function as experiments in how life can or should be lived (Mattingly, 2014).

Although the term moral laboratory might suggest a pursuit of universal moral truth and objective answers, Mattingly's laboratory seeks to do the opposite. The metaphor illuminates the intricate role that morality plays in "the vagaries of everyday life and the difficulties of discerning what might constitute the most morally appropriate action in the singular circumstances life presents" (Mattingly, 2013, p. 304). As Kuan and Grøn (2017, p. 188), elaborating on Mattingly, explain: "What counts as 'the good' depends on changing life situations, contexts, and histories, and what complicates any one good is the fact that multiple goods are often in competition with one another."

When unique circumstances and competing ideas of "the good" converge, the capacity to cultivate moral judgment about the best course of action emerges in the moment and is often characterized by what Mattingly (2014, p. 16) calls "radical uncertainty." This article draws on Mattingly's (2014) term "moral scene" to describe situations that, while not always apparent to the participants, evoke ethical questions about moral experimentation and the ways in which autonomy and social care are balanced and navigated.

4. Methods

4.1. Case and Data

To gain in-depth insights into accessibility to human rights at supported housing facilities, particularly the challenges SCWs face in facilitating accessibility to autonomy, the researchers conducted ethnographic fieldwork at the Danish supported housing facility Anemone. Anemone comprises 26 group-based housing units, with 4–12 residents per unit. The residents vary in age (ranging from 20 to 80 years) and ID (ranging from moderate to severe). Anemone also provides sheltered employment, activity centers, and leisure activities, all organized under the same management. The majority of SCWs hold qualifications in social work. Historically, Anemone's practices have emphasized building healthy routines for residents.

Anemone was particularly suitable for studying dilemmas regarding individual autonomy and UNCRPD implementation. Following a supervisory inspection by the Danish social welfare authorities, Anemone was ordered to improve its residents' opportunities for autonomy. Since this regulatory sanction, Anemone has organized courses on autonomy and collective learning days for both residents and SCWs on autonomy and has started transitioning towards what Hall et al. (2021) call the "home turn." Additionally, to gain new insights into autonomy, the facility has welcomed the ethnographic research project that this article reports on.

The fieldwork was conducted by the authors over a period of eight months (22 visits in total) in two group-based housing units at Anemone. Both units consist of separate apartments with access to a private bathroom and, in some cases, kitchen facilities, as well as shared common areas, such as a kitchen and a living room. Support in both units is tailored to individual needs and housing is intended to be time-limited. In one of the houses, staff support is provided around the clock, while in the other, SCWs visit residents daily.

The fieldwork included semi-structured interviews with 11 SCWs, three managers, and four residents. The interviews were audio-recorded and subsequently transcribed. Additionally, informal conversations occurred with several residents, initiated by the residents themselves, who invited the researchers to engage in dialogue.

Observations were also conducted, focusing on resident–SCW interactions and staff meetings. Because residents' exercise of their right to autonomy may relate to specific activities and physical and social contexts, the researchers shadowed residents and SCWs across various settings during the day (van der Weele & Bredewold, 2021). Fieldnotes were written during or immediately after conducting observations, in a manner appropriate to each situation. Notes covered the physical and social context, the topic of the residents' choices, SCWs responses to these choices, and dilemmas regarding autonomy. Both residents' and SCW's verbal and nonverbal responses were documented, and all interviews were recorded and transcribed verbatim.

4.2. Ethical Considerations

The study was approved by the Danish Research Ethics Committee, Region of Zealand: No. EMN-2024-04576. Informed consent was regularly obtained from both residents and SCWs to ensure they understood their involvement in the research project. Prior to and throughout data collection, the researchers provided detailed information to participants—residents and SCWs—regarding the research project, including its objectives and duration, and emphasized that participation was voluntary. Both written and oral information was presented to the residents by the researchers. Confidentiality was maintained by assigning pseudonyms to participants and altering identifying characteristics.

4.3. Data Analysis

This study employed an abductive approach, moving back and forth between theory and empirical observations. During our abductive thematic analysis (Braun & Clarke, 2006), we began confronting the initial findings with Mattingly's (2014) concept of moral scenes and Kongsgaard's (2022) notion of

dilemma-filled situations. Using these as sensitizing concepts, we built “ideal types” of dilemma-filled situations by identifying similar types of tensions within discussions and practices regarding autonomy. The emerging types of dilemma-filled situations resulted from a constant comparison of findings across interviews with both residents and SCWs, as well as observations of resident–SCW interactions. Residents played a central role in informing the identification of the four types of situated dilemmas presented (illustrated in Figure 1). Without observing interactions between SCWs and residents in situ we would not have been able to identify or articulate the full range of dilemmas, as SCWs did not express all of the situated dilemmas with equal clarity. However, the data used in this article has been validated and co-produced only by SCWs and therefore reflects solely their perspectives. At several stages of the research process, we presented the dilemmas at workshops to verify findings with SCWs and search for alternative explanations and types of dilemmas.

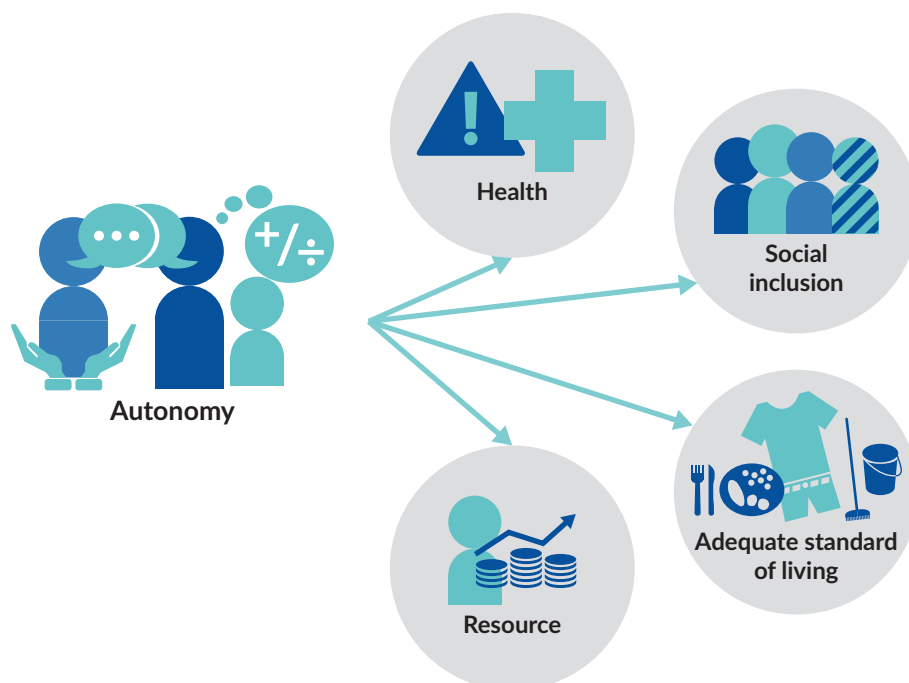


Figure 1. Types of dilemma-filled situations affiliated with autonomy.

In the final phase of the analysis, fieldnotes and interview transcripts were systematically sub-coded line by line in NVivo 11.

5. Results: Situated Dilemmas of Accessibility to Autonomy

Our analysis showed that both staff and residents at Anemone valued autonomy. Consequently, tensions surrounding the enactment of and accessibility to autonomy arose not from denial of autonomy’s value, but rather from increased awareness of, reflection on, and negotiation of autonomy. We found, as illustrated in Figure 1, that residents’ accessibility to autonomous decision-making in a social care setting sometimes competed with other issues related to human rights: (a) health/risk concerns, (b) social inclusion concerns, (c) standard of living concerns, and (d) resource concerns.

Although the dilemma-filled situations we identified were often multifaceted (Kongsgaard, 2022), we present them as four ideal types for the sake of analytical clarity.

5.1. *The Health Dilemmas*

Our ethnographic work revealed dilemma-filled situations characterized by tension between promoting residents' enactment of autonomy and the concerns of SCWs about health promotion and safety (see also, e.g., Andersson & Gustafsson, 2016; Bergström et al., 2014; Hawkins et al., 2011). This health promotion concern stemmed both from legal human rights obligations to ensure the highest attainable standard of health of residents (UN, 2006, Article 25) and from SCW's professional knowledge about health among individuals with disabilities and mental health issues, whose life expectancy is 14 to 20 years shorter than the general population (see, e.g., Wahlbeck et al., 2011). Consequently, SCWs viewed themselves as having a professional obligation to ensure residents' access to healthy lifestyles and sanitary living conditions.

SCWs noted that previous health promotion practices—such as implementing healthy food plans, restricting television viewing, scheduling bathing days, and maintaining routine cleaning—often prioritized order, hygiene, and health over residents' autonomy and self-determination. Yet even when addressing this autonomy concern through supported decision-making (Davidson et al., 2015), some situations remained challenging, particularly, when residents ignored information about health risks and persisted in potentially harmful behaviors. Examples include residents with chronic lung conditions continuing to smoke; individuals with obesity or diabetes purchasing large quantities of sugary food; residents refusing cleaning assistance despite their homes becoming inaccessible; and those with severe dental problems (such as periodontitis) declining to brush their teeth. These cases exemplify everyday ethical dilemmas in which SCWs struggled to determine the most morally appropriate course of action. As Mattingly (2013) suggests, such situations are not merely matters of compliance or non-compliance but are embedded in “moral scenes”—contexts characterized by competing values and uncertain outcomes that nevertheless require situational judgment. SCWs experienced difficulty because they risked being criticized for neglecting residents' autonomy if they attempted to persuade residents to adopt healthier choices. Conversely, SCWs also risked criticism for neglecting the residents' right to enjoy the highest attainable standard of health if they colluded with residents' unhealthy wishes. This tension created a double-bind for SCWs, where any action, or inaction, could be subject to moral and professional critique.

One SCW powerfully captures the complexity of this dilemma in relation to smoking and offers insight into how she attempts to navigate this morally charged terrain:

We've discussed smoking with Carl [who has a lung condition]. He has seen a doctor, who explained the consequences to him. Carl listens to the doctor and seems to understand. However, when he returns home, he asks for more tobacco....It is a significant part of his life. He has been smoking for many years. It provides him with a sense of security and means a great deal to him. It's difficult for him to move on from this habit...It creates a dilemma between my rational understanding of what is healthy and hygienic, and the challenge of integrating that knowledge into his life without imposing it on him. (SCW)

This quote exemplifies SCWs' awareness that imposing healthy lifestyle norms on residents is no longer acceptable. Instead, staff recognizes the importance of adhering to supported decision-making—including

educating residents about smoking's consequences with the help of a doctor, as the SCW explains in the above quote. However, as the SCW explains, ethical challenges emerge when they return home. While Carl appears responsive to this educational approach at the doctor's, the challenge lies in translating his initial responsiveness into sustained behavioral change once he returns home and asks for tobacco—without overriding Carl's autonomy.

Another example of how SCWs navigated the dual principles of health promotion and autonomy, through supported decision-making, involved encouraging residents to establish health-related goals. During one goal-setting conversation, the resident Benedicte expressed dissatisfaction over her weight, leading to the formulation of a weight-loss goal with a dietician's involvement. However, these practices did not resolve the tension between health promotion and autonomy in situations involving "temptation," as an SCW describes:

Benedicte is working with a dietician to lose weight and has agreed to follow a plan. However, she finds it challenging when faced with temptations, like cake, and has to make decisions for herself. If she struggles, I often need to step in and remind her, which requires effort on my part. Ultimately, it's in both of our best interests for her to reach her goal. She would be upset if she gained weight, and it's important to remember that she lives here for a reason. I feel it's essential to be honest with her about that. (SCW)

The moral ambivalence for the SCW here arises from the contrast between Benedicte's expressed desire to follow a diet during the goal-setting conversation and her subsequent wish to abandon that diet. SCWs face a dilemma: Should they allow space for her autonomy—her intrinsic desire to eat cake—during moments of temptation, or encourage her to resist, potentially risking accusations of covert persuasion or coercion (McKearney, 2021)? While such situated health dilemmas often involved balancing health concerns with enjoyment (such as smoking and eating), SCWs also encountered situations where no apparent benefits arose. For instance, one resident, after participating in an autonomy course, chose to skip physiotherapy entirely. This decision reduced his physical activity significantly, increased the pains he suffered from, and led him to spend most of his time in his room.

In discussing the new professional uncertainty surrounding the incorporation of autonomy into health promotion, SCWs recognized the risk of violating human rights. However, they highlighted that their professional discomfort and moral dilemmas in these situations—for example, when the residents resisted health check-ups—stemmed from concerns that individuals with ID may lack the health literacy to recognize and interpret bodily signals and take appropriate action or to allay their fears of being misunderstood or subjected to unwanted treatments. Additionally, residents' challenges in expressing themselves due to limited spoken language skills and their difficulties in understanding and applying medical instructions to their daily lives were identified as barriers (Pedersen, 2018). In this context, we found that SCWs' struggles to support residents in exercising autonomy—particularly in situations involving health concerns—could not simply be attributed to non-humanistic attitudes or to viewing residents as incompetent, as suggested by Skarstad (2018). Rather, their struggles also manifested the difficulty of discerning appropriate support when two human rights principles compete—the risk of overriding autonomy versus the risk of not ensuring health on equal footing with others. This challenge was exacerbated because supported decision-making methods such as guidance and education are not accessible to all people with ID.

5.2. The Social Inclusion Dilemmas

Another type of situation where SCWs found it difficult to discern the most morally appropriate action (Mattingly, 2013) arose when promoting residents' autonomy conflicted with their human right to full and effective participation and inclusion in society (UN, 2006, Article 19). Access to and participation in social environments have long been recognized as foundational elements of disability policies and are central values in social work practice. Research indicates that access to social communities is crucial for enhancing the quality of life among people with ID in supported housing settings (Brown et al., 2013). However, as acknowledged in the UNCRPD framework, access to social networks is limited for individuals with ID, which can lead to social isolation (Alexandra et al., 2018; Verdonschot et al., 2009). To mitigate social isolation, Anemone, like many supported housing settings, has historically implemented practices such as mandating residents' participation in recreational activities, sheltered employment initiatives, communal dinners, group vacations, and other social events. However, mandatory participation raises ethical concerns, particularly in light of the recent emphasis on autonomy.

With Anemone's focus on autonomy, many residents have actively expressed and exercised their right to withdraw from social activities, creating tensions that require negotiation. To address potential loneliness among residents, SCWs convened meetings to discuss strategies for replacing mandatory participation with motivational activities in instances where residents resisted involvement in social activities. The following fieldnote illustrates a moral dilemma, where an SCW attempts, without success, to encourage Bo to attend a birthday party in the communal living room:

Today is Poul's birthday, and the dining table is beautifully set with a tablecloth and flags. The residents have had rolls and tea cookies for breakfast. However, Bo has chosen not to join in the celebration and sing the birthday song. One of the employees says that she tried to encourage him to participate, but Bo doesn't want to. Instead, he has seated himself in one of the kitchens where he spends an hour and falls asleep, while the others sing and celebrate with the birthday boy. The employee says that she wants to bring him to join the others, because it would be good for him, but ultimately doesn't do it because he decides for himself.

Bo often prefers to remain in his apartment, which contrasts with the social inclusion goals outlined in his support plan by an external department that SCWs are required to implement. In Bo's case, facilitating his participation in social activities represents both an externally mandated obligation and a fundamental value in social care work practice. The issue is further complicated by Bo's cognitive challenges. During staff meetings, SCWs frequently discuss whether Bo understands the potential long-term negative consequences of his social withdrawal, such as increased loneliness. In the scenario above, the SCW accepts Bo's choice; however, she is left grappling with an ethical dilemma and uncertainty regarding whether she has adequately fulfilled her professional obligation to promote social inclusion.

The focus on autonomy has seen the emergence of a further type of social inclusion dilemma, which is related to residents actively asserting their right to choose whom they wish to engage with during activities. Prior to the new emphasis on autonomy, SCWs typically involved residents in decisions about the types of activities they wished to participate in, while decisions regarding social companions during these activities and cohabitation within the housing facility were made by SCWs. However, the shift towards prioritizing autonomy has altered these practices.

To illustrate this shift, we describe a sequence from the annual vacation planning at one of the housing units. The vacation planning presents several challenges, particularly concerning one resident, Kasper, who has become increasingly unpopular among his peers. Both some SCWs and other residents have expressed concerns that Kasper's participation in the annual vacation could potentially "ruin" the overall enjoyment of the experience for the other residents. Some residents have even stated that they would prefer not to attend if Kasper is present. An employee described their efforts to navigate this complex situation by proposing a compromise—allowing Kasper to attend for part of the vacation. This solution raised significant ethical questions and uncertainties that are demonstrated below:

Kasper struggles to integrate positively into the community. His presence often leads others to withdraw....During this year's summerhouse trip, the staff decided that Kasper should only stay for some days of the trip, as his presence impacts the other residents too much. This decision has been difficult for Kasper to understand. The other residents did not understand why Kasper should be included at all, as they feel he disrupts everything. Everyone must be included—even those who divide the group. Kasper does not get his right to autonomy there—everyone else was asked how long they wanted to be there except him. We must take care of everyone's well-being and right to autonomy. (SCW)

As this quote illustrates, Kasper's autonomy to make choices (he desires to attend) is compromised to preserve the autonomy of the other residents (who do not want him to attend). This situated dilemma demonstrates how navigating between inclusion and exclusion mechanisms becomes central to balancing access to inclusion in social communities with wishes of autonomy. We found that SCWs found it challenging to facilitate the enactment of autonomy when this facilitation risked overriding their obligation to ensure residents' social inclusion or when it conflicted with other residents' voices of autonomy. As shown, SCWs cope with this situated uncertainty by seeking a compromise. However, during a staff meeting, the situation also prompts some SCWs to initiate a broader discussion about whether they could open a dialogue with Kasper regarding alternative living arrangements that might offer greater potential for successful social inclusion.

5.3. *The Adequate Standard of Living Dilemmas*

Deinstitutionalization—both in Denmark and internationally—has prompted widespread criticism of supported housing facilities, including Anemone, for maintaining collective rather than person-centered structures and routines (e.g., Engen et al., 2019; Jormfeldt, 2016; van der Meulen et al., 2018). Such collective arrangements often include shared bedtimes, communal dining schedules, collective activities like cleaning days, and standardized rules governing residents' access to television or social media. These routines frequently reflect institutional priorities and organizational cultures, often at the expense of accommodating the individual preferences and autonomy of residents with ID. For example, at Anemone, requiring all residents to brush their teeth at 9 PM has long been justified by the need to complete this task before the evening shift ends. However, the growing emphasis on autonomy has increasingly challenged such organizational rationales, revealing their misalignment with the "home turn" in disability services, which advocates domestic and individualized living arrangements (Hall et al., 2021). A third type of dilemma-filled situation emerged at Anemone from the transition toward more person-centered practices. These situations involve tension between supporting residents' right to autonomy and self-determination and SCWs' concerns about upholding residents' right to an adequate standard of living—encompassing sufficient

food, appropriate clothing, secure housing, and continuous improvement of living conditions (UN, 2006, Article 28).

The following quote from an SCW at Anemone shows how everyday cleaning practices highlight the ethical tension between respecting residents' autonomy and ensuring an adequate standard of living. The SCW describes how this tension challenges her capacity for moral judgment in practice:

If the residents don't want to clean, that's okay; it's their home....But there is also a normality in that cleaning needs to be done. But is it the staff's or the residents' needs? You can hear that it is rarely the residents' needs. If they have been there for a long time, they know they have to. But some of the younger ones don't focus on it—it's not their need....But we are also an institution; it has to function. They can get sick, all their clothes can be dirty. So, there is also a duty of care. (SCW)

Here, the SCW acknowledges that residents have the right to define how they live in their own home. Yet she also notes how certain routines—particularly around cleanliness—have historically reflected staff preferences more than those of the residents. The SCW notes that staff often assume their own standards to be the normative baseline, expecting residents to eventually internalize these expectations. However, this assumption is increasingly questioned given the shift toward autonomy and deinstitutionalization. As the SCW reflects, "When we step over the resident's threshold, it is their home, their perspectives, and we must respect that."

Despite this recognition of the residents' rights, the SCW highlights the moral complexity that arises when autonomy conflicts with other concerns and principles. While SCWs aim to acknowledge residents' choices, they remain embedded within an institutional framework that carries a duty to an adequate standard of living. This dual responsibility makes it difficult to determine the most ethically appropriate course of action (Mattingly, 2013). For instance, fully deferring to residents' preferences, such as accepting very low standards of hygiene, can expose SCWs and institutions to criticism for neglecting their obligation to ensure an adequate standard of living, a duty grounded both in professional ethics and human rights. This tension is further complicated by SCWs' observations (also shared by us as researchers) that some residents, in asserting their autonomy by refusing to engage in household tasks they were previously capable of performing (despite significant disabilities), appeared to lose those competencies over time. This decline not only risked undermining their ability to remain self-reliant in daily life but also led to increased frustration among some residents due to the resulting lack of cleanliness in both personal and shared spaces.

Accordingly, SCWs experienced that transitioning from collective routines to focusing on residents' decision-making concerning their living conditions sometimes competed with the principle of ensuring the continuous improvement of the residents' living conditions (UN, 2006, Article 28). The fieldnote below illustrates how this tension was not always fully articulated within the staff group and sometimes contributed to the uncritical reproduction of collective practices:

The employee Gitte laughs a little apologetically at the fact that "there's food [afternoon coffee] again." Gitte says, with humor in her voice, that she wonders why the residents are not more overweight than they are [implying: with all the meals they have]. Gitte prepares coffee and makes cheese sandwiches for Jette, Bent, and Niels at 3 PM. The observer (the researcher) asks if the residents themselves request

afternoon coffee. Gitte pauses for a moment, thinks, and then says that it would certainly be possible to let the residents make their own food, when they get hungry. But then she adds that the fact that she takes care of making afternoon coffee at 3 PM every day is about maintaining “routines” so the residents do not become “confused.”

In this example, three elderly residents with significant disabilities receive coffee at fixed times—10 AM and 3 PM—following a routine established over many years. Gitte expresses embarrassment about maintaining this practice, using humor and apologies to signal her ambivalence. She appears aware that such collective standardization may run counter to person-centered values, potentially discouraging the autonomy and initiative Anemone seeks to foster. At the same time, she frames the routine as beneficial, particularly for residents whose cognitive impairment and social isolation make regularity and social interaction crucial for their sense of stability and well-being. Hence, in the case above, Gitte implies that collective routines facilitate social interaction for three residents, whose age and disabilities often result in them spending much of their time alone in their apartments (van der Meulen et al., 2018). This creates professional uncertainty for SCWs about the potential consequences for these residents’ quality of life and living conditions if the collective routines were removed. However, rather than articulating and addressing this dilemma within the staff group, some SCWs seem to cope with the uncertainty by maintaining the routines.

5.4. The Resource Dilemmas

A fourth type of dilemma differs from the previous dilemmas in our analysis. While the other dilemmas revolved around SCWs’ challenges in navigating competing ethical commitments stipulated in the UNCRPD framework, this dilemma primarily involves a tension between the principle of autonomy and the management of limited time and financial resources in social care services. In Denmark, social care is organized according to a commissioning–delivery–user model. This means that an external caseworker is assigned to each resident. In dialogue with the resident—or, when relevant, their legal guardian—the caseworker assesses the individual’s needs and commissions both the housing and the level of support deemed necessary. The support is then delivered by SCWs at Anemone. For example, the resident Walther was allocated seven hours of support per week, distributed across daily activities such as cooking, social participation, and personal hygiene. These resources were therefore linked to specific person-centered services, which SCWs aimed to provide within strict time constraints. However, in daily practice, where time was always short and SCWs were responsible for multiple residents, dilemmas often emerged. As Lipsky (1980) points out, frontline workers are increasingly held accountable for how they utilize resources, making their allocation decisions ethically significant. These resource dilemmas occurred in situations where SCWs had to balance the often spontaneous and contextual needs and preferences of a resident (that were often difficult to assess in advance) with the formally allocated resources. Such tensions frequently required complex prioritization. An example of this dilemma occurred during a staff meeting in which SCWs discussed whether resident Frans should receive support to visit his girlfriend Hanne, who lived at a nearby facility:

SCW 1: Frans and Hanne went out to eat yesterday. Afterwards, Hanne stayed at home with Frans. She asked if she could come today. I’m not sure how often they can visit each other? That requires them to be driven back and forth.

SCW 2: Hanne comes on Wednesdays—that’s their regular appointment.

SCW 1: Yes, but I'm not sure if they can visit each other all the time they want?

SCW 3: We probably also tend to service them too much when they're together. We shouldn't. We shouldn't feel like we have to go in there with food and Coke.

SCW 2: I've been at work where both Hanne and Frans were there. Then I had to drive Hanne home on Sunday evening, and that just doesn't fit in [with the schedule]. Hanne also takes up a lot of time. She tried to contact me a lot, and it took time.

SCW 1: Yes, Sunday evenings are chaotic. I'm asking about the framework. When can they visit each other, and who decides? I miss a framework when they call and ask [if they can visit each other].

Manager: I suggest that you hold a meeting with Hanne's contact person as well as Hanne and Frans. There, you can ask what their needs for a relationship are? Then you can discuss: Who drives? And on what days.

This scene highlights how romantic relationships in the context of social care services, in some situations, give rise to professional uncertainty, as the love and intimacy of people with ID can be complicated by their dependence on others. The SCWs must navigate between, on the one hand, Frans's emotional needs and requested access to a relationship with Hanne, and on the other hand, the allocated resources and logistical and temporal demands of social care services. Frans and Hanne's love story raises key questions for SCWs: (a) what support is needed—transport, meals, or facilitating romantic evenings?; (b) how often should this support be offered?; (c) what emotional care, if any, should be provided to Hanne, who is a non-resident?; and (d) what staffing levels are appropriate when they are together? The manager proposes a pragmatic solution—coordinating a meeting with both residents and their contact persons—but the fundamental dilemma remains. The SCWs are left to navigate a tension between enabling residents' autonomy in intimate relationships and aligning with institutional time, staffing constraints, and undefined resource boundaries. Frans and Hanne's relationship underscores the emotional and ethical complexity involved in supporting human rights obligations within constrained care settings (often requiring long-term planning). In addition, the example reveals both the frustration SCWs feel when faced with ambiguous mandates and dilemmas, and the value of creating space for collective, professional reflection about how to address such dilemmas more intentionally in practice.

6. Concluding Discussion

Most literature on the deinstitutionalization of social care services tends to frame the role of SCWs in supporting individuals with ID in realizing their right to autonomy in binary terms—either as obstacles to (e.g., McKearney, 2021; Skarstad, 2018) or enablers of (e.g., Hawkins et al., 2011; Kittay, 2011; Pols et al., 2017) human rights. Guided by Mattingly's (2014) concept of “moral scenes,” this study set out to move beyond such reductive framings. By examining the moral and practical challenges, as well as the professional uncertainty SCWs encounter when navigating dilemma-filled situations related to the promotion of client autonomy, we identify four ideal-typical situated dilemmas: the health, social inclusion, adequate standard of living, and resource dilemma. The four ideal types of situated dilemmas illustrate how SCWs' efforts to facilitate residents' autonomy are not always supported by, and may at times conflict with, other principles and institutional demands. By exploring these dilemmas, this article provides insights into how SCWs (with

more or less success) reflect on, negotiate, and attempt to navigate the values and expectations embedded in the UNCRPD framework and in everyday social care work, which sometimes cause competing pressures.

Our ethnographic lens reveals how autonomy is both welcomed and enacted within the institution Anemone. Residents increasingly assert their rights—saying “that is something I decide for myself,” and decline participating in long-standing routines such as physiotherapy, communal meals, and cleaning schedules. Staff members express a desire to support this shift, but also report experiencing significant ethical strain or “ethical headaches” (Fisker et al., 2008), as they struggle with the uncertainty of making the “right” choices in situations that offer no clear solutions. This discomfort is not merely about resisting change, but reflects a deeper institutional dilemma. SCWs are accountable not only for facilitating client autonomy, but also for safeguarding residents’ health, promoting social inclusion, and ensuring adequate living conditions—all within the constraint of limited resources (Lipsky, 1980). Thus, emphasizing client autonomy can come at the perceived cost of neglecting other essential human rights. Although the principles of the human rights framework are often understood as mutually reinforcing, they may, in practice, come into tension with one another. This requires SCWs to prioritize between them, make moral judgments, and allocate resources accordingly. Yet, insufficient resources (e.g., time) and competences may affect this prioritization negatively (see also Ylvisaker & Rugkåsa, 2022).

By foregrounding the situated multiplicity and interplay—rather than simply conflict or alignment—between autonomy and other care concerns, we challenge the human rights discourses in current research. Much of the literature reduces the realization of human rights to the provision of autonomy alone. Consequently, SCWs’ efforts to minimize health risks, adequate standard of living, or foster social inclusion are often framed as covert forms of inhumane control, persuasion, or normalization (e.g., McKearney, 2021; Munson, 2020). While our findings recognize that advice giving by SCWs has a “normative tone” (see also Juhila & Löfstrand, 2022, p. 102), they also reveal an alternative interpretation: From the SCW perspective, such efforts can themselves constitute rights-based practices—especially when viewed through the lens of ensuring that people with ID have access to health care, inclusion, and adequate living conditions on an equal footing with others.

At the same time, SCWs risk being accused of violating human rights when they question whether health or safety should override autonomy (see also Skarstad, 2018). This accusation may be highly relevant given the historical paternalism that has characterized social care services. However, as our findings show, SCWs’ supported decision-making does not always result in residents’ recognizing SCWs’ advices or information (see also Juhila & Löfstrand, 2022; van der Weele et al., 2021). This resistance to SCWs’ support may be a sign of agency; however, in some situations, it may also be a result of residents’ cognitive and bodily challenges that may limit the use of supported decision-making. In this light, the relationship between an autonomy-centered approach and care-oriented practice is neither inherently aligned nor opposed. Instead, the dilemma-filled situations emphasize that choice-making in morally charged situations often emerges as collective and supported processes and that these processes are not inevitably a human rights violation. Rather, the dilemmas make salient that all valuable principles may not be addressed simultaneously, in particular in group-based housings, and that all choices may not be equally feasible in every context or situation. Thereby, the dilemmas also highlight that autonomy involves a relational and contextual dimension that SCWs need to be aware of and use to qualify and innovate their social care provision.

6.1. Recommendations and Limitations

Previous research on dilemmas in social care work (e.g., Kohl et al., 2022) emphasizes the importance of individual reflection to help SCWs navigate dilemmas. While individual reflection is valuable, our study suggests it is not sufficient. The ethical complexity encountered by SCWs, such as in the dilemmas illustrated by Frans and Hanne's intimate relationship, demands collective reflection. Such dilemmas highlight the need for structured, dialogic spaces—what Mattingly (2014) calls “moral laboratories”—where workers can bring individual interpretations and moral concerns into collective view.

We therefore recommend establishing collective forums and regular supervision as critical infrastructures for addressing the often ambiguous and emotionally charged nature of human rights facilitation by SCWs. Such settings could help uncover routinized blind spots and foster ethical awareness among SCWs. We propose that the four situated dilemmas outlined in this article may serve as a reflective framework within such forums—supporting SCWs in articulating what is at stake when they experience professional (dis-)comfort, doubt, or moral friction in providing access to care and autonomy.

Ultimately, our study calls for a shift in how human rights practices are conceptualized and supported within care work: not as straightforward implementations of normative frameworks, but as situated, contested, and morally charged choice-making that requires both individual sensitivity and collective deliberation. However, a limitation of this article is that the data used pertains solely to the perspectives of SCWs. Future research is needed to explore the dilemmas from the perspective of people with ID.

Acknowledgments

The authors are very thankful for the openness and cooperation of the research participants at Anemone.

Funding

This work was supported by The Social Area, Region Zealand (grant number/ID 3991661).

Conflict of Interests

The authors declare no conflict of interests.

References

- Alexandra, P., Angela, H., & Ali, A. (2018). Loneliness in people with intellectual and developmental disorders across the lifespan: A systematic review of prevalence and interventions. *Journal of Applied Research in Intellectual Disabilities*, 31(5), 643–658. <https://doi.org/10.1111/jar.12432>
- Andersson, G., & Gustafsson, H. (2016). *Självbestämmande—ett dilemma i gruppbostäder? Ett annat sätt att se på saken*. FoU södertörns skriftserie nr 149/16. FoU Södertörn.
- Beadle-Brown, J., Hutchinson, A., & Whelton, B. (2012). Person-centred active support—Increasing choice, promoting independence and reducing challenging behaviour. *Journal of Applied Research in Intellectual Disabilities*, 25(4), 291–307. <https://doi.org/10.1111/j.1468-3148.2011.00666.x>
- Bergström, H., Elinder, L. S., & Wihlman, U. (2014). Barriers and facilitators in health education for adults with intellectual disabilities—A qualitative study. *Health Education Research*, 29(2), 259–271. <https://doi.org/10.1093/her/cyt111>
- Bigby, C., Whiteside, M., & Douglas, J. (2019). Providing support for decision making to adults with intellectual

- disability: Perspectives of family members and workers in disability support services. *Journal of Intellectual and Developmental Disability*, 44(4), 396–409. <https://doi.org/10.3109/13668250.2017.1378873>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Bromark, K., Weitz, Y. S., Erlandsson, S., & Schön, U. K. (2024). Practitioners exploring intertwined challenges and possible solutions for user participation in social services. *Nordic Social Work Research*, 14(2), 283–295. <https://doi.org/10.1080/2156857X.2022.2069148>
- Brown, I., Hatton, C., & Emerson, E. (2013). Quality of life indicators for individuals with intellectual disabilities: Extending current practice. *Intellectual and Developmental Disabilities*, 51(5), 316–332. <https://doi.org/10.1352/1934-9556-51.5.316>
- Davidson, G., Kelly, B., Macdonald, G., Rizzo, M., Lombard, L., Abogunrin, O., Clift-Matthews, V., & Martin, A. (2015). Supported decision making: A review of the international literature. *International Journal of Law and Psychiatry*, 38, 61–67. <https://doi.org/10.1016/j.ijlp.2015.01.008>
- Dunn, M. C., Clare, I. C. H., & Holland, A. J. (2010). Living “a life like ours”: Support workers’ accounts of substitute decision-making in residential care homes for adults with intellectual disabilities. *Journal of Intellectual Disability Research*, 54(2), 144–160. <https://doi.org/10.1111/j.1365-2788.2009.01228.x>
- Engen, M., Rømer, M., & Jørgensen, A. (2019). Public care for people with intellectual disability in Denmark—Ideals, policy and practice. *Scandinavian Journal of Disability Research*, 21(1), 228–237. <https://doi.org/10.16993/sjdr.582>
- Fisker, A., Høybye-Mortensen, M., Jensen, F. T., Nørgard-Nielsen, S., & Jacobsen, B. (2008). *Socialrådgiveren på arbejde: Portræt af en profession og dens dilemmaer*. Hans Reitzels Forlag.
- Goffman, E. (1961). *Asylums: Essays on the social situation of mental patients and other inmates*. Anchor Books.
- Grymonprez, H., Roose, R., & Roets, G. (2017). Outreach social work: From managing access to practices of accessibility. *European Journal of Social Work*, 20(4), 461–471. <https://doi.org/10.1080/13691457.2016.1255589>
- Hall, C., Raitakari, S., & Juhila, K. (2021). Deinstitutionalisation and “home turn” policies: Promoting or hampering social inclusion? *Social Inclusion*, 9(3), 179–189. <https://doi.org/10.17645/si.v9i3.4300>
- Hawkins, R., Redley, M., & Holland, A. J. (2011). Duty of care and autonomy: How support workers managed the tension between protecting service users from risk and promoting their independence in a specialist group home. *Journal of Intellectual Disability Research*, 55(9), 873–884. <https://doi.org/10.1111/j.1365-2788.2011.01445.x>
- Healy, L. M. (2008). Exploring the history of social work as a human rights profession. *International Social Work*, 51(6), 735–748. <https://doi.org/10.1177/0020872808095247>
- International Federation of Social Workers. (2014). *Global definition of social work*. <https://www.ifsw.org/what-is-social-work/global-definition-of-social-work>
- Jormfeldt, M. (2016). *Tid, rum och självbestämmande: Möjligheter och hinder i vardagen för äldre personer med intellektuell funktionsnedsättning på gruppboende* [Unpublished doctoral dissertation]. Jönköping University.
- Juhila, K., & Löfstrand, C. H. (2022). Subjectification, advice giving and resistance in mental health home visit interactions. In C. H. Löfstrand & K. Jacobsson (Eds.), *Transforming subjectivities: Studies in human malleability in contemporary times* (pp. 88–105). Routledge. <https://doi.org/10.4324/9781003146681-6>
- Juhila, K., Raitakari, S., & Hall, C. (Eds.). (2017). *Responsibilisation at the margins of welfare*. Routledge.
- Juhila, K., Ranta, J., Raitakari, S., & Banks, S. (2021). Relational autonomy and service choices in social worker-client conversations in an outpatient clinic for people using drugs. *British Journal of Social Work*, 15(1), 170–186. <https://doi.org/10.1093/bjsw/bcaa011>

- Kittay, E. F. (2011). The ethics of care, dependence, and disability. *Ratio Juris*, 24(1), 49–58. <https://doi.org/10.1111/j.1467-9337.2010.00473.x>
- Knevel, J., Wilken, J. P., & Schippers, A. (2023). Social workers putting into practice the convention on the rights of persons with disabilities. *Journal of Human Rights and Social Work*, 8(3), 302–315. <https://doi.org/10.1007/s41134-023-00255-2>
- Kohl, K. S., Amilon, A., & Olsen, L. (2022). Trust and mistrust in public services for people with disabilities: Analysing the gap between the perspectives of caseworkers and disabled people in Denmark. *British Journal of Social Work*, 52(6), 3288–3306. <https://doi.org/10.1093/bjsw/bcab243>
- Kongsgaard, L. T. (2022). *Faglig Refleksiv Praksis: En undersøgelse af organisatorisk dilemmahåndtering og refleksivitet i velfærdsarbejdets frontlinje* [Unpublished doctoral dissertation]. Aalborg Universitetsforlag.
- Kuan, T., & Grøn, L. (2017). Introduction to “moral (and other) laboratories.” *Culture, Medicine, and Psychiatry*, 41, 185–201. <https://doi.org/10.1007/s11013-017-9534-y>
- Lipsky, M. (1980). *Street-level bureaucracy: Dilemmas of the individual in public services*. Russell Sage Foundation.
- Mapp, S., McPherson, J., Androff, D., & Gatenio Gabel, S. (2019). Social work is a human rights profession. *Social Work*, 64(3), 259–269. <https://doi.org/10.1093/sw/swz023>
- Mattingly, C. (2013). Moral selves and moral scenes: Narrative experiments in everyday life. *Ethnos*, 78(3), 301–327. <https://doi.org/10.1080/00141844.2012.691523>
- Mattingly, C. (2014). *Moral laboratories: Family peril and the struggle for a good life*. University of California Press.
- McKearney, P. (2021). What escapes persuasion: Why intellectual disability troubles ‘dependence’ in liberal societies. *Medical Anthropology*, 40(2), 155–168. <https://doi.org/10.1080/01459740.2020.1805741>
- Munson, A. B. (2020). Framing life as work: Navigating dependence and autonomy in independent living. *Qualitative Sociology*, 43, 89–109. <https://doi.org/10.1007/s11133-019-09438-8>
- Neuman, R., & Bryen, D. N. (2022). Dare to dream: The changing role of social work in supporting adults with intellectual and developmental disabilities. *British Journal of Social Work*, 52(5), 2613–2632. <https://doi.org/10.1093/bjsw/bcab195>
- Pedersen, P. V. (2018). *Socialt udsattes møde med sundhedsvæsenet*. Statens Institut for Folkesundhed.
- Petner-Arrey, J., & Copeland, S. R. (2015). “You have to care:” Perceptions of promoting autonomy in support settings for adults with intellectual disability. *British Journal of Learning Disabilities*, 43(1), 38–48. <https://doi.org/10.1111/bld.12084>
- Pols, J., Althoff, B., & Bransen, E. (2017). The limits of autonomy: Ideals in care for people with learning disabilities. *Medical Anthropology*, 36(8), 772–785. <https://doi.org/10.1080/01459740.2017.1367776>
- Reynaert, D., Nachtergaele, S., De Stercke, N., Gobeyn, H., & Roose, R. (2022). Social work as a human rights profession: An action framework. *British Journal of Social Work*, 52(2), 928–945. <https://doi.org/10.1093/bjsw/bcab083>
- Skarstad, K. (2018). Ensuring human rights for persons with intellectual disabilities? Self-determination policies and the use of force in the case of Norway. *International Journal of Human Rights*, 22(6), 774–800. <https://doi.org/10.1080/13642987.2018.1454903>
- UN. (2006). *Convention on the Rights of Persons with Disabilities (CRPD)*. Microsoft Word - 0722663E.doc
- van der Meulen, A. P. S., Taminiau, E. F., Hertogh, C. M. P., & Embregts, P. J. C. M. (2018). How do people with moderate intellectual disability evaluate restrictions in daily care? *International Journal of Developmental Disabilities*, 64(3), 158–165. <https://doi.org/10.1080/20473869.2018.1442182>
- van der Weele, S., & Bredewold, F. (2021). Shadowing as a qualitative research method for intellectual disability research: Opportunities and challenges. *Journal of Intellectual & Developmental Disability*, 46(4), 340–350. <https://doi.org/10.3109/13668250.2021.1873752>

- van der Weele, S., Bredewold, F., Leget, C., & Tonkens, E. (2021). The group home as moral laboratory: tracing the ethic of autonomy in Dutch intellectual disability care. *Medicine, Health Care, and Philosophy*, 24(1), 113–125. <https://doi.org/10.1007/s11019-020-09991-y>
- Verdonschot, M. M. L., De Witte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. G. (2009). Community participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research*, 53(4), 303–318. <https://doi.org/10.1111/j.1365-2788.2008.01144.x>
- Wadmann, S., Hauge, A. M., & Navne, L. E. (2023). Good conduct in a context of rationing: A case study of how frontline professionals deal with distributive dilemmas of novel gene therapies. *Sociology of Health and Illness*, 45(3), 684–704. <https://doi.org/10.1111/1467-9566.13608>
- Wahlbeck, K., Westman, J., Nordentoft, M., Gissler, M., & Munk Laursen, T. (2011). Outcomes of Nordic mental health systems: Life expectancy of patients with mental disorders. *British Journal of Psychiatry*, 199(6), 453–458. <https://doi.org/10.1192/bjp.bp.110.085100>
- Ylvisaker, S., & Rugkåsa, M. (2022). Dilemmas and conflicting pressures in social work practice. *European Journal of Social Work*, 25(4), 643–654. <https://doi.org/10.1080/13691457.2021.1954884>

About the Authors



Maya Christiane Flensburg Jensen is a researcher with a PhD in organization. Her research focuses on social care policies and the professional dilemmas that arise in frontline interactions within social care services.



Nichlas Permin Berger is a senior researcher with a PhD in sociology. His research examines how institutional structures and professional discourses on human rights, evidence, and risk influence social work practices.



Maria Røgeskov is a senior analyst with a PhD in sociology. Her research focuses on social policy and social care services for adults in vulnerable positions.



Pernille Skovbo Rasmussen is a chief research analyst with a PhD in sociology. Her research focuses on social care services for children, adolescents, and adults with disabilities.



Leif Olsen is a senior researcher with a PhD in sociology. His research explores welfare and social interventions, with an emphasis on inclusion and disability.