



Supported Decision-Making for People with Intellectual Disabilities: An Employee Perspective

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RESEARCH



ABSTRACT

This article examines the understandings and experiences of municipal frontline employees regarding supported decision-making for individuals with intellectual disabilities. It analyses experience-sharing dialogues and focus group interviews with staff members working in group homes and day-care services in Norway. The data were transcribed verbatim and analysed thematically.

The findings suggest that authentic supported decision-making may be constrained by staff members' limited willingness to tolerate risk, as well as by their values, attitudes and interpretations of what constitutes professionally sound practice. The participants in the study agreed that time is a crucial factor, as clarifying individuals' will and fostering decision-making skills are often time-intensive processes. Participants also emphasised the influence of relatives' roles and attitudes in shaping opportunities and limitations for self-determination. In the absence of clear-cut solutions, staff must exercise professional judgement to balance competing values within tricky relational and structural contexts.

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KEYWORDS:

Intellectual disabilities; municipal health and care services; CRPD; supported decision-making; dignity

TO CITE THIS ARTICLE:

Linde, Sølvi, Frode F. Jacobsen, Toril Marie Terum, Arnt Egil Ydstebø, and Oddvar Førland. 2026. "Supported Decision-Making for People with Intellectual Disabilities: An Employee Perspective." *Scandinavian Journal of Disability Research* X(X): 1–15. DOI: <https://doi.org/10.16993/sjdr.1344>

This study aimed to explore understandings, practices and experiences of frontline employees in providing supported decision-making to individuals with intellectual disabilities in municipal group homes and day-care services. The data are taken from Norway, and to contextualise the study, we begin with an overview of relevant current Norwegian legislation and local conditions.

THE NORWEGIAN CONTEXT

According to Norwegian legislation, health and welfare services are mandated to ensure and support service users' 'right to be involved in the provision of health and care services' (Ministry of Health and Care Services 1999a). Furthermore, service provision must be adapted 'as far as possible by the user's or patient's right to self-determination' (Ministry of Health and Care Services 2011a).

Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) emphasises state obligations to assist and support individuals who require help in exercising their legal capacity. It mandates that states establish systems and practices for supported decision-making. Norway decided to incorporate the CRPD into the Norwegian Human Rights Act on 5 December 2025, with the amendments entering into force on 1 January 2026. The right to supported decision-making is stated in the national guideline *Good Health and Care Services for Persons with Intellectual Disabilities* (Norwegian Directorate of Health 2021). This guideline highlights municipalities' responsibility to facilitate supported decision-making for this group and to ensure that 'service users can exercise self-determination and live as much as possible in accordance with their own wishes and needs'. In this guideline, supported decision-making is defined as 'any process that enables persons to make their own decisions and/or to express their own will and preferences' (Norwegian Directorate of Health 2021, 23). The guideline underscores the municipality's responsibility to ensure that service providers possess the necessary competence in topics such as human rights, intellectual disability, self-determination and supported decision-making (HDIR 2021). A review of the literature reveals that individuals with intellectual disabilities express a clear desire to participate in decisions that affect their lives. However, they are often given limited opportunities to do so (Linde 2022). A commonly cited justification for excluding individuals with intellectual disabilities from decision-making processes is a perceived lack of decision-making capacity (Skarstad 2018). This rationale stands in contrast to the principles enshrined in the CRPD, which is grounded in a social and human rights model (United Nations 2006). This model emphasises that it is often societal attitudes and environmental barriers, rather than individual impairments, that hinder persons with disabilities from participating on equal terms in society.

Ongoing professional and political efforts aim to align Norwegian legislation with the CRPD. Currently, provisions in the Guardianship Act and Chapter 9 of the Health and Care Services Act permit coercion towards persons with intellectual disabilities, challenging Article 12 of the CRPD, which guarantees equal legal capacity. Proposals include replacing guardianship with supported decision-making and revising Chapter 9 in line with human rights and the principle of self-determination.

KEY CONCEPTS AND BACKGROUND LITERATURE

Participation, as described by Hammel et al. (2008), goes beyond simply taking part in activities. It reflects a sense of belonging and meaningful engagement in life situations, shaped by choice, control and social connection. *Self-determination* denotes having control over one's own life and making independent choices, supported by appropriate opportunities and resources (Wehmeyer and Abery 2013). Rather than replacing autonomy, *supported decision-making*, according to Browning, Bigby and Douglas (2014), is a rights-based approach that provides tailored assistance to help individuals with cognitive disabilities make their own decisions, ensuring respect for their will and preferences while promoting equal legal capacity. Supported decision-making *processes* refer to the concrete steps, strategies and relationships that enable such support. These ideas are deeply interconnected: participation and self-determination can be said to flourish when supported decision-making is in place, and this is realised through effective, individualised processes (Wehmeyer and Abery 2013).

According to Bigby and Douglas (2020), key components of supported decision-making include staff competence in identifying significant decisions, presenting information about alternatives, and their consequences in accessible ways, and maintaining openness to the possibility of poor or risky choices.

Bigby and Douglas (2020) distinguish between formal and informal supported decision-making. Formal support involves assistance with applications, entering into legal agreements, voting and similar activities. Informal support, on the other hand, refers to care and practical assistance in everyday life. The body of literature on supported decision-making for people with intellectual disabilities is growing (Casey et al. 2025; Stancliffe et al. 2020). Research indicates that the structure of services, characterised by standardisation, daily schedules, routines and staff shifts, can hinder self-determination (Gjermestad et al. 2017; Tøssebro 2014). Melbøe et al. (2020) emphasise that self-determination is a relational phenomenon, shaped through interaction with the environment, where 'external conditions' influence the scope for making decisions. The context in which decisions are made is therefore of critical importance. For instance, Kittelsaa (2019) demonstrates how individual autonomy is often subordinated to efficiency demands within municipal services.

The ability to influence and make decisions about one's own life is fundamental to the development of a positive identity for all individuals (Blanck and Martinis 2015; Dinerstein 2012). This includes the right to take risks and, potentially, to make poor choices. A reluctance to allow risk-taking is a well-documented barrier to development in children and young people (Sando, Kleppe and Sandseter 2021), as well as for people more generally (Beck 1992). Vosz et al. (2020) reviewed research on young people with various disabilities, including intellectual disabilities. Their synthesis found that when young people perceived participation in decision-making processes as meaningful, it contributed to empowerment in areas such as improved communication skills, enhanced social and emotional well-being, stronger social networks and a greater sense of mastery and control over their own lives.

Bigby et al. (2019) argue that employees and family members conceptualise supported decision-making in fundamentally different ways. Employees typically adopt a neutral stance, whereas family members often position their own knowledge as authoritative in determining what is best. Such contrasting perspectives may generate tensions and conflict in practice.

Decision-making skills are developed through experience. For individuals with limited experience and practice in making their own choices, systematic training may be necessary (Agran and Martin 2014). Such development is only possible when individuals are given space and are recognised as competent to influence decisions concerning their own lives (Bailey, Willner and Dymond 2011; Linde 2022).

PERSPECTIVES ON DIGNITY, AUTONOMY AND STIGMA

The international community recognises the inherent value and fundamental rights of all human beings through the *Universal Declaration of Human Rights* (United Nations 1949). This declaration serves as a clear affirmation of human worth and dignity and constitutes a foundational backdrop for this article. Violations of bodily integrity and personal space are central themes in the work of sociologist Erving Goffman, who links such experiences to the concept of stigma. Stigma refers to the reduction of a person to a single attribute, such as an illness, diagnosis or disability, through the gaze of others (Goffman 1963). Threats to a person's dignity can thus draw others' attention towards the person's ailments and shortcomings rather than the person as a whole and unique individual. This may cause others both to view the person in an unfavourable and undignified way, and to treat the person in an undignified manner.

Intrinsic dignity is a fundamental aspect of being human and requires that individuals be treated with respect and care, regardless of their circumstances or status. Understanding and acting in accordance with the inherent nature of dignity can strengthen individuals' sense of self-worth and autonomy, while also setting ethical boundaries for how we intervene in others' lives (Frost 2005).

The right to make one's own choices, and to have those choices respected, regardless of illness, disability or intellectual impairment, should be a core value underpinning all service provision

for people with intellectual disabilities (Devi 2013). Nevertheless, this principle is frequently challenged in contemporary service and housing arrangements for this group (Gjermestad et al. 2017; Linde 2022; Norwegian Board of Health Supervision 2017). Barriers exist at multiple levels: at the societal level through legislation; at the organisational level through the structuring of housing services; and at the relational level through the opportunities service providers have to support autonomy, as well as through the attitudes of staff, relatives and others towards human dignity (Owren 2022).

When the right to make personal choices is denied, and hence, the autonomy of the person is limited, human dignity is also violated (Frost 2005). However, what is perceived as dignified is neither straightforward nor universally agreed upon; it varies across time, context and individuals. People with intellectual disabilities may make choices that, according to prevailing cultural norms, place them in undignified situations, potentially undermining their recognition and respect in broader society. Safeguarding their dignity, therefore, requires a reflective approach to the ethical dilemmas that may arise when seeking to promote autonomy and self-determination (Gjermestad et al. 2017). There is therefore a need to acknowledge autonomy as one of the prerequisites for dignity. Where autonomy is limited, others may come to view the person as less than a full and whole individual, attaching stigma in the process (Goffman 1963). At the same time, it must be recognised that increased autonomy can sometimes conflict with the achievement of dignity.

RESEARCH QUESTIONS

The research is guided by the following two questions:

1. What understandings, practices and experiences do frontline employees in group homes have regarding supported decision-making for residents with intellectual disabilities?
2. What conditions may be important in enabling supported decision-making processes in group homes for people with intellectual disabilities?

METHOD

PARTICIPANTS AND CONTEXT

This study draws on data from a larger research and development project, led by the four Centres for Development of Institutional and Home Care Services (USHT, *Utviklingssenter for sykehjem og hjemmetjenester*) in western Norway. The larger project aimed to adapt a framework for supported decision-making to a Norwegian context and develop support materials for managers and employees, to strengthen such support for people with intellectual disabilities. The project team sought to collaborate closely with municipal employees on this and invited twenty-five regular employees from five municipalities in western Norway to participate.

All those invited gave their informed consent to participate at the beginning of the first gathering. The participants were employed in services for individuals with varying degrees of intellectual disabilities, specifically in municipal group homes and day-care centres.

Among the participants, 15 were social educators, two social workers, three child welfare educators, three occupational therapists and two auxiliary nurses. A total of 15 participants had worked at the same group home or day-care centre for more than ten years, while only three had worked for less than three years.

During two sessions held over four days in autumn 2023, participants received instruction on the CRPD, with particular emphasis on self-determination and supported decision-making, principles of decision-making processes and systematic ethical reflection. In the first session, the participants received a one-hour lecture on Bigby and Douglas's (2020) framework for decision support. Three core principles were reviewed: commitment, coordination and continuous reflection. The model is intended to facilitate an assessment of alternatives and consequences, ensuring that the person's will, preferences and rights are upheld. Between the two sessions, the 25 participants were divided into five groups, each facilitated by representatives from one of the four USHTs. Participants were asked to reflect on their own experiences of providing supported decision-making and to discuss conditions that promote or hinder such processes in various situations.

DATA COLLECTION

Five researchers, all authors of this article, observed a total of 15 experience-sharing dialogues. Observations were guided by an observation guide developed in advance, which emphasised concrete descriptions of decision-making processes and participants' justifications for their actions. At the end of the final session, four researchers conducted four focus group interviews with participants, using a semi-structured interview guide.

The observation guide included open-ended questions about how participants balanced their practices when core values such as autonomy, health or dignity came into conflict, and how they supported service users in developing their decision-making abilities. These interviews were audio-recorded and transcribed verbatim.

DATA ANALYSIS

The empirical material consisted of notes from the 15 experience-sharing dialogues and transcripts from the four focus group interviews, totalling approximately 80 pages of text. Focus group interviews are understood here in accordance with Krueger and Casey (2014) and experience-sharing dialogues according to Knapik (2006). A thematic analysis approach was employed (Braun and Clarke 2021). The analysis followed five phases: (1) familiarisation with the data, (2) coding, (3) generating initial themes, (4) reviewing and refining themes and (5) defining and naming themes (Braun and Clarke 2021).

All five researchers first read through the entire dataset and noted their initial impressions, which were then shared and discussed collectively. Each researcher subsequently conducted a detailed first-round coding of their assigned experience-sharing dialogues and focus group interviews. The resulting codes were shared and discussed in a follow-up group meeting. A matrix containing codes, original text excerpts and reflections was developed and used in further analysis meetings. Through this process, the codes were refined into preliminary themes, which were then discussed, developed and agreed upon by the research team. The Table 1 below shows an example of the process from quote to theme.

QUOTES	CODE	PRELIMINARY THEME	THEME
Young people expect to make more decisions	Young people expect to decide	Young people expect to decide for themselves	Generational value conflicts
Young people are used to deciding for themselves	Used to deciding	Generational differences among users	
They decide for themselves who will enter the apartment	Deciding who will be allowed in		
Young people have more knowledge about their rights	Knowledge of rights		
Some of the old people still struggle with the routines from their time in the institution.	Experiences from institutions		

Table 1 The process from quote to theme: an example.

RESEARCH ETHICS

The study was reported to SIKT (Norwegian Agency for Shared Services in Education and Research) and assessed and determined to be in compliance with data protection regulations (reference number 717753). All 25 participants received written information about the research project prior to the gatherings and provided informed consent to participate at the beginning of the first gathering.

FINDINGS

The participants described a range of everyday dilemmas related to supported decision-making: (1) generational values conflicts; (2) risk acceptance; (3) time, priorities and attitudes and (4) the voice and role of relatives.

The participants reported that the values prioritised in decision-making varied among service users and staff, as well as across generations. Several participants observed that younger service users tend to be more aware of their rights and have greater experience in making their own choices. One participant noted: 'We're seeing a generational shift among residents – they expect to have more say.'

Participants also noted generational differences among staff. Younger staff were often more focused on promoting independence and decision-making skills among younger users but sometimes encountered resistance from older colleagues. One participant explained: 'Older staff don't always let residents participate in or take responsibility for tasks, like doing laundry. They have stricter standards for clothing and hygiene.' Older service users, particularly those who had spent much of their lives in institutions, were sometimes uncomfortable with making choices. One participant shared: 'They keep asking what we think and say: "Why should I decide this?"' Some participants believed that, for certain users, safety and predictability were more important than autonomy. However, this presented dilemmas, as one participant made clear: 'We know the user so well, we can put words in her mouth.'

RISK ACCEPTANCE

Participants emphasised that accepting risk is often a prerequisite for supporting decision-making and realising users' autonomy. Statements such as 'They have to be allowed to make bad choices' and 'We can't always intervene – we have to tolerate risk' illustrate this perspective.

Risk acceptance was particularly difficult to maintain when users' choices involved potential harm. One participant described a man working in a park who wanted a chainsaw like his colleagues: 'Everyone said no – us and his family – but then we asked: what are the alternatives?' They collaborated with the park staff to find a battery-powered saw with safety features. 'He was so happy – came home with a photo of himself holding the saw.' This example illustrates how risk acceptance, collaboration and creativity can be essential in supported decision-making.

Risk acceptance also involves tolerating and managing uncertainty. One participant described a visit to a swimming pool, where a user wanted to sit in the small hot tub: 'He's a big man who leans forward and stares at people with his goggles on – right in their faces. It can be stigmatising and maybe frightening for others.' The participant reflected: 'I just must sit there, quietly, show the others I'm in control. We don't have procedures for situations like this. You must find your way.'

While participants were mindful of the public context, they agreed that everyone has the right to participate in public life. Sometimes, users' right to self-determination conflicted with the professional responsibilities of staff. As one participant shared: 'We have a resident under a compulsory food order – because of a life-threatening condition.' Still, the staff member emphasised the importance of autonomy within safe boundaries: 'She understands it, in a way, and gets to choose within certain limits.'

Participants found long-term risks harder to manage than immediate ones, such as unhealthy diets, inactivity or other behaviours affecting health. Concerns about future health outcomes created uncertainty about when and how to intervene. Balancing autonomy and professional responsibility raised dilemmas about when to accept risk and when to set limits. One example involved a user who refused help with dental hygiene: 'It ended with the dentist having to extract all his teeth.' Others described users posting nude photos online, exchanging sex for small rewards or committing crimes out of fear of losing their social network: 'They have the same rights as other adults, but they don't understand the consequences.'

Participants recognised that harm may occur, just as it does when anyone makes poor choices, and emphasised that these are adults living in their own homes. This left staff uncertain about whether to intervene — and if so, on what grounds. In navigating these dilemmas, staff often collaborated with relatives or other professionals. One young man wanted to obtain a driving licence, so a driving school was contacted. After reviewing the theoretical requirements, it became clear — even to the young man — that it would be too difficult, and he accepted

this. Through collaboration with public and private actors, alternatives and consequences were explored in ways that fostered understanding of what was and was not possible.

Participants agreed on the duty to prevent serious harm but were more divided on whether they should intervene in what they perceived as undignified behaviour in public. One participant described a man with intellectual disabilities who loved *Harry Potter*: 'He kind of stigmatises the whole group by walking around dressed as Harry Potter. He feels cool, but he's a 30-year-old man. Everyone else sees him as a clown.'

Another participant focused more on the consequences for the user himself: 'Teenagers seek him out, hype him up, film him and post it on YouTube. He doesn't like being filmed – it makes him uncomfortable and sad.'

Participants described being caught in an *ethical split* between respecting the person's dignity and individuality, protecting them from distress, ensuring equal access to public spaces and considering how unusual behaviour might contribute to stigma – both for the individual and for the wider group.

TIME, PRIORITIES AND ATTITUDES

Every day constraints shape how staff balance residents' autonomy with the practical realities of service provision. Expectation of autonomy challenges available human resources and staff practices: 'It's an adjustment for staff. It's not necessarily welcomed that residents want to decide for themselves; there aren't enough resources, frameworks or structures for that.' Thus, users' expectations of autonomy may conflict with limited resources and the way services are organised.

Participants agreed that time is a central factor in supported decision-making processes. Having sufficient time enables such processes, while a lack of time constrains them. Exploration and planning require time, as exemplified by one participant: 'She talked about having children, but what did she mean by that? You need time to be present and curious.'

One user repeatedly said he wanted to go to a holiday destination in the south, but what he really wanted was the hotel breakfast. Another user who wished to travel abroad was afraid of airport security. Together with staff, they practised different scenarios that might occur during a security check, and eventually, the person felt confident enough to travel. Another individual needed many conversations over several years to acknowledge that he was mostly attracted to boys: 'We watched films about sex together, we went to the sex shop and we accompanied him to a sex education course.' Attitudes are crucial in determining whether staff use their time to explore, to listen and to take seriously what the person expresses. In one example, staff thought it was great that the person had a job in a kindergarten, but he did not enjoy it. He approached the local shop on his own and got a job there. The participant said: 'We should have listened to him; we should have supported him earlier.'

Time is also essential for learning and development. Participants described how they reflected with users on the consequences of not showering, cancelling plans with friends or skipping football matches – what if you miss the party afterwards? One participant described how she uses role-play ahead of social events: 'I play her and say things she might say that offend others, we talk about it, and she understands. We practise, and sometimes it works.'

Beyond time, participants pointed to barriers related to shift schedules and routines but also acknowledged that staff attitudes and individual commitment play a significant role. Users who wanted to swim often did not get the chance because staff were unwilling to accompany them. One said, 'We increase staffing in the summer, which should allow for outings, but still, little happens. Staff can't think outside the box, break routines and see possibilities.'

THE VOICE AND ROLE OF RELATIVES

Participants valued good relationships with relatives, and several noted that relatives can be an important source of support. As one participant put it: 'Relatives are not a barrier to users making decisions – they make decisions together.' In other situations, however, the involvement of relatives could be more challenging. One participant reflected: 'It's a dilemma – how much should we listen to relatives?' These dilemmas could concern anything from clothing choices

or leisure activities to differing views on cleanliness, alcohol use, the right to live an adult life and other significant life decisions. As one participant shared: 'Two of our residents have been engaged for many years. They want to get married. Relatives on both sides are aware of and happy about their relationship but refuse to accept that they can legally marry.'

It can be difficult to foreground the user's voice when engaging with relatives. One participant admitted: 'I've called relatives to avoid confrontation when the user didn't want to attend an activity.' The dilemma becomes apparent in such situations. During a phone call with relatives, the staff member must simultaneously shield the user from being scolded and deflect criticism for not persuading the person to participate in something they did not want to do.

Staff work in a shared environment where goals and values may differ among users and employees. They must balance autonomy, risk and potentially harmful consequences – both short- and long-term – for the person's health, dignity and recognition. At the same time, they work closely with relatives, whose wishes may at times conflict with the user's preferences and rights.

DISCUSSION

In this section, we discuss the findings in relation to other research and broader academic discussions.

AUTONOMY IN CONTESTED TERRAINS: GENERATIONAL SHIFTS

A group home is, first and foremost, a home and a place where people often develop close relationships with staff. At the same time, it is also a workplace, governed by duties, rules and routines. This duality can give rise to tensions and dilemmas between the right to self-determination and the standardisation inherent in service provision. Rigid frameworks for service delivery may disrupt and hinder individualised decision-making (Demic and Gjermestad 2021; Gjermestad et al. 2017).

Our participants observed that the desire for self-determination is often challenged by limited resources and the way services are organised. In contrast, more flexible services could offer greater opportunities for autonomy and influence over one's own life (Sandvin and Anvik 2020). At the same time, Sandvin and Anvik (2020) show that municipal leaders are experiencing a shift in the user group, and that traditional service models may not align with younger users' expectations of autonomy.

Statements from participants also suggest that some older users – particularly those with long institutional histories – may feel uncomfortable making choices. The right to choose also includes the right not to choose. However, reluctance to make decisions may stem from a lack of experience or skills, shaped by institutional cultures in which personal choice was not legitimised. Johansson et al. (2017) argue that older people with intellectual disabilities, especially those with long-term institutional backgrounds, may require additional support in decision-making processes. They describe how confidence and decision-making skills can be strengthened through training. Step-by-step guidance and a gradual build-up of confidence may enhance users' autonomy (Johansson et al. 2017).

Participants in this study noted that younger users often have greater awareness of their rights. Having grown up with a more normalised everyday life, they expect to make their own decisions in ways that differ significantly from previous generations.

People with intellectual disabilities are also living longer than before. While some remain healthy and active, others experience age-related changes such as deteriorating vision and hearing, as well as fatigue, inattention and reduced engagement. Moreover, the ageing process may begin earlier in some individuals with intellectual disabilities (Larsen et al. 2024). These changes can reduce individuals' capacity or motivation to engage in decision-making processes, and some may prefer a predictable and safe environment. Distinguishing between a lack of decision-making skills and age-related decline requires specific knowledge – something that may be lacking among some staff in these services (Ellingsen, Isaksen and Lungwitz 2020; Kåhlin, Kjellberg and Hagberg 2015).

A good understanding of the individual is essential for providing quality services. Yet this familiarity can become a liability. Staff may feel they know a user so well that they begin to predict what the person will say or do. The doctoral thesis of Folkestad (2003; 2005) refers to such simplified perceptions as ‘characterisations’, which can be used to explain users’ actions – but also to legitimise staff decisions. These characterisations may hinder recognition and limit opportunities for individuals to receive support for their own choices.

Making one’s own decisions is fundamental to identity development and a positive self-image. It is a skill that must be developed and maintained, requiring others to recognise and protect individuals’ right to make their own choices (Honneth 1996).

HARD CASES AND VALUE CONFLICTS: WHEN SELF-DETERMINATION MEETS RISK

A central dilemma in all service provision is the balance between autonomy and protection. This dilemma, which was significant in various forms throughout the data, was the most prominent theme overall. Carney et al. (2019, 375) argue that the CRPD’s gold standard is to respect and be guided by a person’s wishes and preferences, yet many examples from practice show that care and collaboration with people with intellectual disabilities involve balancing competing values. While political goals of autonomy and professional goals of optimal health seem straightforward, in daily practice they can become contradictory and ambiguous (Mjøen 2019).

Participants agreed that users must be allowed to make poor choices and that staff must tolerate the risks associated with such choices. This value principle is illustrated in the example where staff, together with relatives, chose to support a person’s wish to use a chainsaw. Those close to the person balanced the risk of physical harm against the harm that could result from denying autonomy. According to Skarstad (2018), the principle of proportionality is central: the more important a decision is to the person, the higher the threshold should be for denying them the opportunity to act on it.

Facilitating users’ choices presents clear challenges and limitations. Under Norwegian law, staff in services for people with intellectual disabilities may use coercion when there is a risk of significant harm to the person or others (Ministry of Health and Care Services 2011a, Chapter 9; Ministry of Health and Care Services 1999b, Chapter 4A). Such cases – where people are at risk of harming themselves or others – are difficult and are referred to in international research as ‘hard cases’ (Bigby, Whiteside and Douglas 2019). Several examples from participants involved serious health-related risks and life-threatening conditions. When users’ choices could lead to significant harm, either in the short or long term, service providers chose to intervene. The right to self-determination must be weighed against other values, such as the right to the highest attainable standard of health, as outlined in Article 25 of the CRPD (United Nations 2006).

Intellectual disability is a cognitive impairment that, depending on the level of functioning, affects the ability to regulate emotions and, consequently, the capacity to make considered decisions. For many, it is easier to learn from immediate consequences, while planning for, understanding and weighing future risks is more difficult (Bigby, Whiteside and Douglas 2019). Strategies that are beneficial in the long term may seem unappealing in the moment. Our findings indicate that participants found long-term risks more difficult to manage than short-term ones. These include issues such as excessive or unhealthy eating, lack of physical activity and the use of alcohol or other substances. The dilemmas become clear here: when and how should staff intervene when person refuses help with dental hygiene? These are harms that anyone may expose themselves to, but people with intellectual disabilities may be less able to foresee the consequences. At what point in this slow, harmful process does the risk of significant harm arise? This illustrates the challenges of balancing the right to the highest attainable standard of health (CRPD Article 25), the professional duty to provide sound services and considerations regarding dignity and harm.

Participants believed that people with intellectual disabilities have the right to be themselves – whether that means dressing like Harry Potter or participating in public life like anyone else. In the case of a person who is filmed while shouting on the bus and later feels upset, it is reasonable to assume that the person felt excluded, vulnerable and perhaps experienced a lack of recognition and dignity. For some individuals, it may be challenging to see themselves

through the eyes of others, as illustrated in the swimming pool example. Stigma is what the stigmatised person is reduced to through the gaze of others (Goffman 1963). The participant's calm presence helped normalise the situation and reduce the critical gaze of others. In contrast, another participant claimed that dressing like Harry Potter stigmatises the entire group. Preventing this might have safeguarded the group's dignity according to normative beliefs, but it would have denied the individual's autonomy and right to have their choices respected. Dignity is multidimensional, and efforts to support one aspect of it may conflict with others.

LEARNING AUTONOMY: SUPPORTED DECISION-MAKING REQUIRES TIME

Burgen (2016) argues that supported decision-making works well for many, but that it requires significant resources, time and active engagement from those around the person. Individuals with intellectual disabilities require time and facilitation to participate meaningfully in decision-making processes (Dew et al. 2019; Webb et al. 2020). The participants in our study agreed that time is a central factor, as clarifying individuals' wishes and fostering decision-making skills are frequently time-consuming processes. Sufficient time enables participation; lack of time is a barrier. Taking someone seriously when they express a desire to travel abroad, talk about having children or wish to explore their sexual orientation often requires time to understand what underlies the desire and to adopt an open, curious approach. Exploring and realising such wishes affirms the user's right to self-determination.

However, not all staff are willing to participate in activities such as swimming. This may suggest that they prioritise their own comfort over fulfilling users' wishes. The findings also indicate that few social and cultural activities are offered during the summer, despite municipal efforts to increase staffing. In these cases, time is not the barrier – rather, staff attitudes and a lack of flexibility hinder the fulfilment of users' preferences.

In one example, staff appeared to disregard a person's expressed wish for a different job. A literature review has shown that staff attitudes are often a decisive factor in whether a person's decisions are respected and supported (Linde 2022). In this case, the individual independently secured a new job, and staff later acknowledged that they should have done more to support him. Their admission also suggests an awareness that they had violated the person's right to make their own choices – and, by extension, their dignity (Frost 2005).

Self-determination must also be learned. Studies show that, with tailored training and support, individuals with intellectual disabilities can participate in decision-making and make informed choices about significant aspects of their lives (Bailey, Willner and Dymond 2011; Bigby, Whiteside and Douglas 2019). Another study found that when participation in decision-making is experienced as meaningful, it can contribute to empowerment, including increased mastery and control over one's own life (Vosz et al. 2020). Although such processes are time-consuming, participants spoke enthusiastically about reflecting on the importance of learning and applying it in various social contexts alongside users. The contrast is clear – but we lack observational data to explain or add nuance to these findings.

LISTENING TO RELATIVES WITHOUT SILENCING AUTONOMY: A PERSISTENT DILEMMA

Some participants viewed relatives as important allies and sources of support in supported decision-making processes; in contrast, others experienced them as barriers preventing people with intellectual disabilities from living active adult lives. Research reflects these same differences, with examples of both trusting, collaborative relationships and the opposite – relationships that may be experienced as difficult and exhausting for all parties involved (Casey et al. 2025; Demic et al. 2024).

Relatives and service providers can be seen as representing two different cultures: a parental culture in which relatives recognise their family members' abilities but emphasise their need for protection, and a staff culture that views the individuals as adults who should make their own choices, requiring support but less interference in their daily lives. Dilemmas may arise when staff support a person's right to self-determination in situations that relatives oppose – for example, when staff allow the person to choose foods high in fat and sugar, or prioritise skill development over relatives' preferences (Casey et al. 2025). Interviews with municipal leaders in two Norwegian municipalities indicate that prioritising users' freedom, independence and autonomy may create practical challenges and relational dilemmas with relatives (Sandvin and Anvik 2020).

Challenges related to intimate relationships are particularly sensitive. People with intellectual disabilities may experience that their relatives do not see them as adults with the right to a sexual life. It is not uncommon for relatives to forbid their adult family members from having overnight guests, forming romantic partnerships, cohabiting or getting married. Even when staff feel that such restrictions contradict their values, they often comply with relatives' wishes. This presents a dilemma: staff may not agree with the relatives but experience that conflict is extremely difficult for all parties involved (Retznik et al. 2022).

When staff do not support a person's wish to have intimate relationships, it represents a failure to facilitate self-determination and the right to live a life in accordance with one's own desires and needs. It also constitutes a violation of Articles 22 and 23 of the CRPD – the right to privacy and respect for the home.

The analyses suggest that both material resources (funding and staffing) and cultural factors constrain efforts to enhance self-determination among persons with intellectual disabilities. Cultural factors include an emerging emphasis on autonomy among younger residents and staff, indicating a possible shift towards greater risk tolerance and resistance to traditional notions of appropriate care. Nevertheless, our findings reveal persistent dilemmas that cannot be fully resolved but can be managed with varying degrees of realisation. These tensions involve autonomy versus professional judgements of sound practice, autonomy versus dignity at individual and group levels, autonomy versus risk – including long-term harm – and autonomy versus the competing interests of families and residents.

METHODOLOGICAL CONSIDERATIONS

This study is based on what participants shared in interviews and group discussions. We do not have complementary observational data to support or potentially challenge these accounts. The teaching sessions held during the gatherings – which included introductions to the principles of supported decision-making – may have influenced participants, leading them to describe their own actions in a more neutral, supportive or critical light than they might otherwise have done. The instruction and lessons may have prompted participants to recall relevant experiences; they could also have shaped which types of experiences were verbalised.

CONCLUSION

The findings on frontline employees' understandings and experiences of supported decision-making revealed conditions that appeared crucial for enabling such processes. These conditions can be conceptualised as three *interrelated dilemmas*: (1) reconciling residents' autonomy, which entails acceptance of certain risks, with safeguarding them from harm and potentially harmful outcomes; (2) negotiating between residents expressed wishes and the practical constraints of service delivery and (3) mediating competing expectations between residents and their relatives. Some participants linked these dilemmas to differences in values and work cultures, while others linked them to a lack of time and resources. We do not believe these are mutually exclusive explanations; both are likely at play. At times, these dilemmas arise from scarce resources and structural constraints; at other times, they reflect ingrained habits and work cultures.

These are genuine dilemmas in the sense that there are no simple solutions. Staff must therefore navigate between competing positions to find the best possible balance in each situation. These dilemmas do not arise in a vacuum, but rather within a range of contexts, both in the immediate contexts in which staff interact with individual users and their relatives, as well as within broader professional work cultures and legal, organisational and economic frames.

ETHICS AND CONSENT

The study was reviewed by SIKT (The Norwegian Agency for Shared Services in Education and Research) and deemed to be in compliance with their guidelines for the processing of personal data and data protection legislation (reference number 717753). Written informed consent was obtained.

ACKNOWLEDGEMENTS

The authors give thanks to the employees from the services for people with intellectual disabilities who participated in this study.

FUNDING INFORMATION

The project has been funded through support from the Norwegian Directorate of Health and existing operational resources from the authors' respective institutions.

COMPETING INTERESTS

The authors have no competing interests to declare.

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Linde et al.
*Scandinavian Journal of
Disability Research*
DOI: 10.16993/sjdr.1344

TO CITE THIS ARTICLE:

Linde, Sølvi, Frode F. Jacobsen, Toril Marie Terum, Arnt Egil Ydstebø, and Oddvar Førland. 2026. "Supported Decision-Making for People with Intellectual Disabilities: An Employee Perspective." *Scandinavian Journal of Disability Research* X(X): 1–15. DOI: <https://doi.org/10.16993/sjdr.1344>

Submitted: 16 July 2025

Accepted: 09 July 2026

Published: XX Month 202X

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Scandinavian Journal of Disability Research is a peer-reviewed open access journal published by Stockholm University Press.

