



Degree of autonomy in making independent choices by frail older people with intellectual disabilities in a care home: A descriptive ethnographic study

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Abstract

Background: We aimed to gain more insight into autonomy of older people with intellectual disabilities in a residential care facility in making choices.

Methods: We performed a descriptive ethnographic study in a residential facility in the Netherlands for 22 persons, aged 54–89 years, with mild to moderate intellectual disabilities (IQ <70) and low social–emotional development levels. We combined participant observations and qualitative interviews.

Results: Based on the observations, the main themes for the interviews were established. Residents indicated to be free to make independent choices, and experienced less autonomy with regard to health issues and finances. Support staff stated that residents' level of autonomy depends on residents' characteristics, needs, preferences, the attitude of support staff and the rules of the care institution.

Conclusion: Residents had a clear view on their autonomy in making independent choices. Support staff is mindful of preserving residents' autonomy, which in practice is limited.

KEYWORDS

autonomy, choices, decision-making, frail elder people, people with intellectual disabilities

1 | INTRODUCTION

According to article 12 of the Convention on the Rights of Persons with Disabilities (United Nations, 2006), people with intellectual disabilities have the right to legal capacity (United Nations, 2006). This is defined as ‘the right to be recognised by law as a person equal to others’ (United Nations, 2006). Szmukler adds that people with intellectual disabilities are entitled to the support they need to make a decision, even if they lack the capacity to make the specific decision (Szmukler, 2019). This is underlined by the Dutch Care and Coercion Act (Law Care and

Coercion, 2020). Nevertheless, studies have shown that people with intellectual disabilities are often not included in decision-making processes regarding their care (Wagemans et al., 2013). A review by Wullink et al. showed that people with intellectual disabilities have less control and fewer choices than people without intellectual disabilities in the choice making process regarding their health (Wullink et al., 2009). Since the average lifespan of people with intellectual disabilities is increasing (Schoufour et al., 2013), they are more likely to be confronted with chronic conditions (Lougheed, 2019) and expected deaths. In research conducted by Wiese et al. support staff indicates that the

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conversation needs to be started with people with intellectual disabilities about death and dying, both about their own death and the death of those around them. Yet the conversation about this is not always started with them (Wiese et al., 2013). The palliative care phase could provide space to align care to the values and preferences of people with intellectual disabilities (Vrijmoeth, Christians, Festen, Groot, Tonino, & Echteld, 2016; Vrijmoeth, Christians, Festen, Groot, van der Heide, et al., 2016). Timely identification of such preferences is not easy, and people with intellectual disabilities' lack of experience with thinking about their preferences adds an extra layer of difficulty. Bigby examined the experiences of support staff and family members in guiding someone with an intellectual disability during the decision making process and indicates in her study that characteristics such as protectionism of past care regimes, lack of confidence to take decisions and not being able to comprehend all the information, were frequently mentioned in the choice making process with people with intellectual disabilities (Bigby et al., 2019). If we better understand how people with intellectual disabilities make choices about their care, it may give us insight into the extent to which people with intellectual disabilities believe they have control over their health and therefore we might be better able to involve people with intellectual disabilities in making end-of-life decisions, since many end-of-life decisions are in fact common decisions. For example, choices of what to eat and where and with whom to spend your time.

Approximately 142,000 people in the Netherlands have intellectual disabilities, of whom around 74,000 have mild intellectual disabilities and 68,000 have moderate or severe intellectual disabilities. About 50% of people with intellectual disabilities live in a care organisation (Nederland, 2020). Making choices, taking decisions and asking for help is often challenging for people with intellectual disabilities (Embregts & Hendriks, 2011). Self-determination is a strong predictor of quality of life (Wehmeyer, 2020a). Wehmeyer uses the following definition of self-determination 'Self-determined behavior refers to volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life' (Wehmeyer, 2005). Shogren et al. (2015) elaborated this framework and developed the Causal Agency Theory to show how self-determination can develop over a lifetime. The Causal Agency Theory consists of three essential characteristics, namely; volitional action, agentic action and action-control beliefs (Shogren et al., 2015). Related to the three essential characteristics are key skills that support the development of the three essential characteristics. Since decision-making, goal-setting, choice-making, planning and problem-solving skills are the elements, which are essential in supporting palliative care, volitional action can be seen as the most essential characteristic for this study (Shogren et al., 2017).

People who are highly self-determined experience a higher quality of life than people who lack self-determination (Vicente et al., 2020; Wehmeyer, 1997, 2020b). To what extent people can express self-determination depends on various contextual aspects such as the degree of intellectual disability and the degree of inclusion, among others (Di Maggio et al., 2020). Little is known about the extent to which frail older people with intellectual disabilities are involved in making everyday choices (Bigby et al., 2009; Dowling et al., 2019; Dunn et al., 2008; Kählin et al., 2016). For example, the

findings from the study by Dunn et al. are based on the experiences of one support staff member (Dunn et al., 2008). Dowling et al. used video recordings to observe the concept of relational autonomy in practice. One of the important findings was that support staff members tended to look for 'teachable moments' that focused more on the capacity of the people with intellectual disabilities than really finding out what their needs and values are (Dowling et al., 2019). Kählin's study shows how the level of choice and control is consistently influenced by the social, cultural and physical environment unique to group homes (Kählin et al., 2016). In this study, we aimed to explore the level of autonomy frail older people with intellectual disabilities have in making independent choices in a Dutch care home. In doing so, we hope to gain insight into the decision-making processes in the palliative phase for frail older people with intellectual disabilities.

A study of Tuffrey-Wijne showed that people with intellectual disabilities may have limited experience in making important decisions that will affect their lives and may lack the skills to do so (Tuffrey-Wijne et al., 2018). We therefore aimed to gain more insight into the autonomy people with intellectual disabilities experience in making choices and in how their autonomy is being formed by support staff.

2 | METHODS

2.1 | Setting

We performed our study in a care home which houses 22 people between the ages of 54 and 89 years with mild to moderate intellectual disabilities (IQ <70) and low social-emotional development levels. People with and without intellectual disabilities live side by side in this building of 73 apartments for elderly people. All residents have their own apartment, with a kitchen, bathroom, living room and bedroom. The care home offers communal activities in a meeting room in the building where people with intellectual disabilities could have coffee, participate in day care activities, join a cooking club or play games. People with intellectual disabilities can choose in which activities they want to engage. The meeting room is also used for meetings and breaks of the support staff.

In the Dutch care system for people with intellectual disabilities, three types of support staff can be distinguished. All support staff are expected to perform certain tasks, such as helping people shower. In addition, keyworkers write care plans for people with intellectual disabilities, supportive workers take care of practical matters such as doctor's visits, and assistant workers mainly take care of housekeeping.

2.2 | Design

We performed a descriptive ethnographic study combined with participant observations and qualitative interviews (Atkinson, 2001). Ethnographic research has as its goal to understand the nature of phenomena (DeWalt & DeWalt, 2002). Through participant observation 'a researcher participates in the daily activities, rituals,

interactions and events of a group of people as a way to get to know the explicit and tacit aspects of their life routines and culture' (Atkinson, 2001; DeWalt & DeWalt, 2002). Participant observation can uncover unspoken rules and norms.

2.3 | Participant selection

Via the care home letters were sent to support staff, asking them if they agreed to have an observer present. The study was discussed with all residents and they were also asked for their informed consent.

2.4 | Procedure

When people with intellectual disabilities did not have the capacity to give informed consent, their legal representatives were asked instead. All residents and support staff were informed that they could withdraw their consent at any time, without having to give a reason and without any consequences for their care, their work or the care of their relative. All support staff, and all but one resident, gave written informed consent prior to the start of the participant observations and interviews.

One of the researchers (H.N.) is an anthropologist by training and observed the people with intellectual disabilities living in the care home and their interactions with other residents, support staff and visitors over a period of 3 weeks. To get people with intellectual disabilities and support staff accustomed to the presence of the researcher, she participated as much as possible in daily activities (e.g., setting the table, going to daytime activities), leisure activities (e.g., cooking club, darts club) and accompanied support staff during care activities (e.g., getting groceries, delivering medication). The researcher made observations during morning, afternoon, evening and weekend shifts. To guarantee the privacy of the residents, the observations only took place in the shared facilities, unless a person with an intellectual disability invited the researcher to his/her apartment. In her observations, the researcher focused on choices that were made, for example in informal conversations or observations with people with intellectual disabilities and support staff. Choices can be explicit choices such as what kind of groceries do you want to get, to implicit choices such as this is not how we do things in this residential facility. The focus was on the choices in which autonomy played a role, in which residents could decide something for themselves or not. When something happened or was brought up, where asking questions would change the situation, questions were asked at a later time. The observations made were noted (without names) in a booklet that she carried with her. In these notes, the researcher described how the choice was made, who was involved in what way, and what the situation was in which the choice was made. The notes were stored on a daily basis on the digital secure environment of the Erasmus MC. The notes made in the booklet were destroyed subsequently.

The researcher contacted her supervisors (I.K. and M.E.) at least twice a week to discuss her observations and to determine next steps. To check whether the main themes that emerged from the observations were indeed important to people with intellectual disabilities

and support staff and to prevent misinterpretation of observations, H.N., I.K. and M.E. (further referred to as the research group) compiled a topic list and selected and invited the residents and support staff for semi-structured interviews (DeWalt & DeWalt, 2002). If integral analyses revealed unanswered questions or uncertainties, additional interviews were conducted. This process continued until data saturation was reached.

2.5 | Data analysis

To analyse the observations the researchers used 'thick descriptions': detailed descriptions which also include the role of the researcher and some atmospheric impressions. Thick descriptions provide contextual details when observing and interpreting social meaning, which can contribute to discovering social and cultural patterns (Geertz, 1973; Lincoln & Guba, 1985). After re-reading and interpreting the thick descriptions, the research group decided on preliminary themes.

The content and interpretation of these preliminary themes were then verified in semi-structured interviews. Only if the preliminary themes were also considered important in the semi-structured interviews were they included in the final main themes, see Data S1 for the topic list. The interviews were recorded and transcribed verbatim. Transcripts were analysed using the 'constant comparative method'. Two researchers H.N. and L.v.d.S. independently coded and analysed the data, using the interview topic lists as a framework for the codes. The independent coded data were compared. Where these differed, H.N. and L.v.d.S. made a decision. If they could not agree together, they presented the findings to the larger research group. Saturation of the data was reached when no more new codes emerged from the interviews. After coding the first six interviews, the researchers checked whether all interview data fitted into the code tree or if adjustments needed to be made. When no more adjustments needed to be made to this axial coding process, selective coding started, in which main themes that emerged from the codes were studied (DeWalt & DeWalt, 2002). After clustering the main themes, it appeared that a reduced level of autonomy was apparent in the themes that emerged. We tried to visualise this in two models. See Data S1 for the code trees used. The various themes were connected to answer our research question (DeWalt & DeWalt, 2002). In the cited quotations in the text, we use the initials I and R which stand for Interviewer and Respondent. Approval of this study was obtained from the Erasmus MC research ethics committee (METC-2018-1683).

3 | RESULTS

In structuring the data, we distinguished the perspectives of the residents ($n = 6$) interviewed and of the support staff ($n = 8$) interviewed. Two models were developed, model 1 shows the degree of autonomy that people with intellectual disabilities experience in making choices and model 2 represents the factors on which support staff grant autonomy to people with intellectual disabilities in making choices. In the

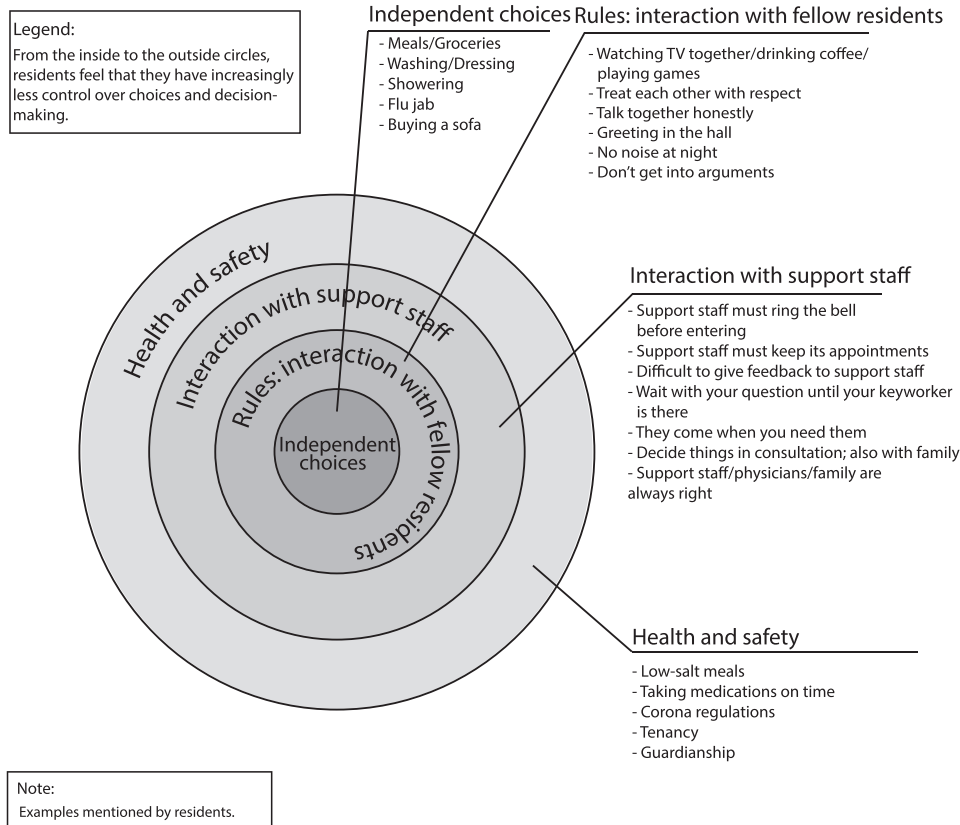


FIGURE 1 Model 1: Degree of autonomy in making choices—perspective of the residents

models, we use the same terms that participants used during the interviews, for example, people with intellectual disabilities refer to themselves as residents and support staff refer to people with intellectual disabilities as clients. Within the circles, there can still be considerable variation in the experienced degree of autonomy. The possibilities for people with intellectual disabilities to make their own decisions depend, also within the circles on, the characteristics of the client, the situation and the support staff on duty. Some clients will dare to create their own plan more easily than others, and the way in which this plan is established can also differ greatly

3.1 | Model 1: Degree of autonomy in making choices—Perspective of the residents

Model 1 (Figure 1) shows the degree of autonomy as experienced by residents in making choices. The following areas with diminishing degrees of autonomy are distinguished: (1) independent choices; (2) rules: interaction with fellow residents; (3) interaction with support staff; and (4) health and safety.

3.1.1 | Circle 1: Independent choices

When asked which choices they make, many residents indicated they are allowed to choose (almost) everything themselves. When asked

for examples, residents referred to everyday choices; for instance choosing which clothes to wear and whether or not to take a shower. According to a resident, freedom of choice depends on a person's level of independency.

R: (...) I don't know about other residents, but when I walk in here at four o'clock, [in the morning] they don't say anything about it. But if someone else who needs more guidance wants to do the same, they say that's not possible. I: And why do you think that is? R: Because I may be more independent than they are.— Resident 6

3.1.2 | Circle 2: Rules: Interaction with fellow residents

The interviews and observations suggested that there are two sets of rules. There are explicit rules about how to interact with fellow residents, stating, among other things, that people are not allowed to get into arguments with each other. These rules apply when residents undertake joint activities. The implicit rules concern, for instance, greeting each other in the hall and not making noise at night. Residents indicated in the interviews that it is important to treat each other with respect and to honestly express concerns.

3.1.3 | Circle 3: Interaction with support staff

Almost all residents indicated in the interviews that they are satisfied with the support they receive, they stated for instance that support staff comes when needed and accompanies them to hospital visits. Most residents reported making choices in consultation with both support staff and family, for instance if they want to buy something. Residents found it important that support staff adheres to the established rules. For example, visiting at the times they had agreed on, ringing the doorbell and waiting for permission before entering. Residents did not appreciate it when support staff enters their apartments without their consent. Some residents indicated that they find it difficult to give feedback to support staff.

R: (...) Support staff are not allowed to just come in, they always have to ring the bell. And if I am not at home, then I am not at home. Suppose I am not at home and it is urgent that they have to go in, they call me, and then I say yes you can come in. But they are not supposed to go in just like that.—Resident 6

Not all residents felt they need support: I: 'And what do you think of the way you get guidance? R: Well we don't like that. I: Why do you not like that? R: Because (...) then I feel that I am not my own boss'.—Resident 1

A frequently recurring case in the interviews concerned a resident who has eight dolls. She calls these her 'puppetry children' and likes to take a few of them with her when she goes out. This sometimes causes the resident to be distracted by caring for the dolls, which could create potentially unsafe situations and the resident is sometimes laughed at in the street. Some support staff are therefore hesitant about her going out with the dolls. The resident said the following:

I: 'Because why are the dolls not allowed to go everywhere? R: They're afraid we'll forget [them]. Well who forgets his children? No one. (laughs) And yes they are afraid they laugh at me. Well, I said that doesn't interest me at all, I don't care. It's my life. And I have to be able to do what I want.'—Resident 1

Some residents gave examples where they did not stick to agreements with support staff and made their own plan.

'R: (...) Every now and then they come and ask me to ride a bike. I: What do you think about that? R: Yes then I have to cycle I think. Then I say I'll come cycling when I have time. I: And do you often have time? R: Yes I have plenty of time. I: (...). Cycling is not the most important thing to you? R: [I am] Watching television, then I say I'll come when I have time. I: (laughing) When the program is over. R: Yes.'—Resident 2

3.1.4 | Circle 4: Health and safety

Residents experience the least autonomy in matters of health and safety, for instance, complying with rental rules such as not painting your walls in an unusual colour, eating low-salt meals and—for some residents—to having to ask their guardian's permission before purchasing expensive items.

The observations showed that while residents are usually free to decide which meals to have, support staff may step in when they consider the residents' choices unhealthy. For example, by accident no groceries had been bought for a resident, who was happy to have a meal of only potatoes and apple compote. He indicated not to need vegetables for the day after either. The support staff told the researcher that they would buy vegetables anyway.

3.2 | Model 2: Clients degree of autonomy in making choices

Perspective of support staff support staff indicated that they decide, based on their skills and values, what kind of support and freedom a client should receive. A staff member indicated that she intuitively senses how to tailor her support to the clients. Members of the support staff are aware of the subjective nature of this process and therefore, aiming for a more objective approach, consulted colleagues, both within and outside the team.

Model 2 (Figure 2) represents the influence on autonomy that support staff assigns to people with intellectual disabilities in making choices. The following areas of influence are distinguished: (1) characteristics of the client; (2) rules of the care home; (3) rules of the residential facility; and (4) health, safety and guardianship (Figure 2). The attitude of support staff plays a role in the entire model.

3.2.1 | Circle 1: Characteristics of the client

This circle refers to the client's characteristics, for example, the degree of their intellectual disability, their legal capacity and their ability to understand short- and long-term consequences of a choice. How a client has been taught to make choices, their contact with family and their independency are also important factors in determining the level of autonomy they are given. During the interviews, support staff stressed that they start the process of determining the clients autonomy with assessing the needs and preferences of the person.

Some observations showed where support staff did and did not respond to clients' wishes and preferences. A support staff member for instance did the dishes again when she considered them not clean enough. At another day, a support staff member asked a client which clothes he wanted to wear, and then, regardless of the answer, laid out clothes. In other instances, however, clients are not corrected: for example, two clients put their dirty towels in the dryer without washing them without being corrected.

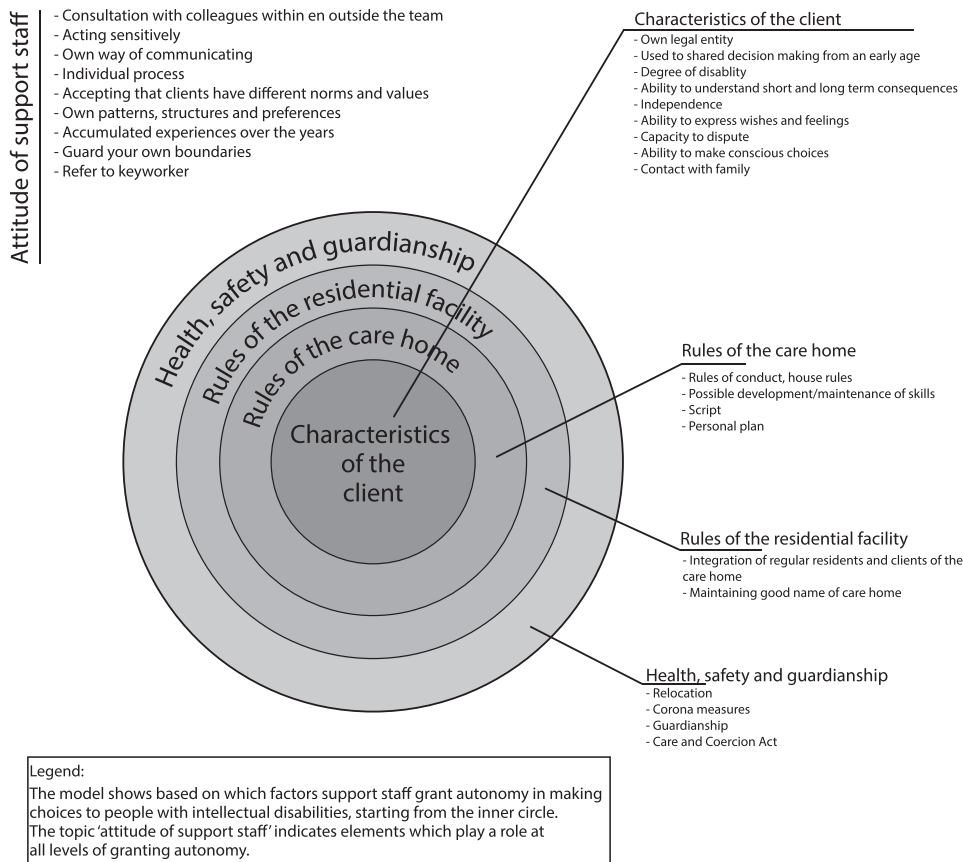


FIGURE 2 Model 2: Influences on client autonomy—perspective of support staff

3.2.2 | Circle 2: Rules of the care home

The observations and the interviews with support staff showed, that there are some explicit internal protocols established for the care facility itself, including rules of conduct, that clients and support staff are supposed to follow: for example, 'no gossiping' or 'no play fighting'. Some rules apply only to clients; those rules are more implicit and are not used consistently, such as 'no borrowing of money from each other'.

R: We have a number of house rules (...) if you cannot take care of a pet you may not have a pet for example. No borrowing money from each other or selling stuff to each other, only in consultation. Because sometimes there are conflicts about that.—Support staff 5

Agreements about the daily care of clients are listed, for example, who needs to be showered and when. Care plans per client contain a short character description, sometimes some life history, the needs of the client and the recommended guidance styles for this client. In annual meetings support staff discusses with the client whether clients are satisfied with the care they receive and if they have any wishes or things they want to learn. Based on these conversations, care is adjusted if necessary.

R: Sometimes someone wants to learn to cook, but then cooking in itself may not be feasible, but if you ask more questions you find out that he wants to fry an egg. Yes, of course the client can do that.—Support staff 3

In the quest to advise, stimulate or guide the choices clients make, support staff sometimes used nudging language. They described this as 'steer him without him realizing it', and 'give him the idea he can decide'. In addition, the observations showed that support staff sometimes preferred to end conversations on a positive note. When a resident was upset, support staff sometimes tried to find a topic to uplift the mood of the client, such as asking about a favourite hobby.

3.2.3 | Circle 3: Rules of the residential facility

The observations and interviews showed that the residential facility has external regulations that clients must adhere to, for instance to guarantee the benign coexistence of regular residents and clients of the care facility in the apartment building (they are each other's neighbours). In this way, socially accepted behaviour is promoted.

R: Yes, we had a client here once who went to get the mail [in a shared hallway] on his mobility scooter in his

underpants. Well, those things are not allowed. A lot is allowed, sometimes music is played too loud here, and clients are called to account for that, but that also happens in society. And then you hope that they are addressed not only by us, but also by the people who live here.—Support staff 8

3.2.4 | Circle 4: Health, safety and guardianship

According to the support, staff clients have least to say about health, safety and guardianship. The interviews and observations showed, for instance, situations in which clients were obliged to relocate, situations in which preferences could not be honoured because they endangered the safety and or health of clients or others. These also included Corona regulations everyone had to adhere to. Support staff for example, asked a client if they wanted to anoint their eyes, and then, regardless of the answer, proceeded to apply this medication.

R: When you talk about money matters for example. I think that if they spend too much money and at the end of the week there are no groceries left in the house, then that is a reason to sound the alarm. And you can solve that very creatively by just saying instead of once a week you get money three times a week, that's a good way to go.—Support staff 5

[Name client] has applied for quite a lot of money from the administrator lately. {...} this time they said no. So [Name client] is very angry with the guardianship. That's why we are very happy with the guardianship, otherwise they would be angry with us.—Support staff 5

If a client refuses to go to a physician for check-ups, this is discussed with the client, the client's social network, and possibly others, such as a team leader, a behavioural expert and a physician, after which the client's choice is recorded in the client file.

R: I think that you also talk about it with your colleagues, because of course you have different values and norms. What I think, may not be similar to what someone else thinks, or considers acceptable.—Support staff 7

and

R: The guidance, not everyone is on the same page. [name of client], (...) sometimes goes outside with her dolls. (...) We have colleagues who say that is absolutely not possible, we have to protect her because she is laughed at. I asked her once whether she was ever laughed at, what do people think of her? And she said

yes, people sometimes look funny at me. And then I think yes, fine, you know, if it makes you happy, just do it.—Support staff 5

Sometimes difficult choices have to be made for clients. For example, when support staff was not able to provide the care someone needed, the client needed to be relocated. In this case, to prevent prolonged stress, the search for a new suitable location was initiated before the client was notified of his/her relocation. It was unclear how the client was involved in sorting out the belongings that were or were not moved over. Twice administrative formalities such as the acquisition of a client's signature, were done in the course of day-to-day activities such as folding laundry and choosing the evening meal. One time the TV was still on loudly. A brief explanation was given as to why a signature was needed and support staff proceeded with the other care task for which they had come.

4 | DISCUSSION

The aim of this study was to explore the level of autonomy frail older people with intellectual disabilities have in making choices in a Dutch care home. We found that residents showed a clear understanding of their level of autonomy to make their own choices. Support staff indicated on the factors on which they grant autonomy to a person with an intellectual disability to make his/her own choices. The following areas of influence are distinguished: (1) characteristics of the client; (2) rules of the care home; (3) rules of the residential facility; and (4) health, safety and guardianship. The attitude of support staff plays a role in the entire model. People with intellectual disabilities and support staff have different levels of control over the content and extent of the choices to be made. In this context, a spectrum was visible from choices autonomously made by people with intellectual disabilities themselves, to choices that support staff nudged them to make, to choices in which people with intellectual disabilities had no say. The support staff was mindful of clients' autonomy, but in practice autonomy was limited to a few areas of life and depended on the attitude of the support staff and the way support staff viewed a client. The reasons for limiting these choices differed between people with intellectual disabilities and support staff and sometimes between support staff themselves.

From a legal and ethical perspective, there is a strong justification to promote and facilitate the autonomy of people with an intellectual disability as much as possible. Article 12 of the UN Convention on the Rights of Persons with Disabilities (CRPD; United Nations, 2006) and the Law on Care and Coercion (Law Care and Coercion, 2020) states that a client should be able to decide for himself what he wants and get the support he needs to make this happen. This aligns with values as autonomy, freedom of choice, equity and emancipation as expressed in the citizenship paradigm (Gennep ATGv, 1997, 2009) that describes what care of people with intellectual disabilities in the Netherlands should look like. Moreover, it has been shown that people with intellectual disabilities want to be

involved in their own decision-making processes (Tuffrey-Wijne et al., 2016).

This study shows that people with intellectual disabilities are mainly enabled to make simple daily choices autonomously. It can therefore be extra difficult for this target group to make important decisions considering their care; for instance when it comes to decisions regarding the end-of-life. However, when it comes to end-of-life decisions, it is important to bring the perspective of people with intellectual disabilities to the table because the choices made at this phase can be all-important. The same applies to everyday decisions, both large and small, which can be of great importance to people with intellectual disabilities. This research shows that the perspective of people with intellectual disabilities is not always expressed. The compliant nature of people with intellectual disabilities makes it more difficult to assess what the 'real' perspective is. This is a potential threat to the provision of good palliative care. We would like to (1) obtain more clarity on how the perspective of people with intellectual disabilities is included in the provision of palliative care and (2) recommend the use of the In-Dialogue conversation tool (Noorlandt et al., 2021). This conversation tool provides tools for support staff to better involve people with intellectual disabilities in making decisions in their palliative care. In this way, people with intellectual disabilities can learn the tools to make their own choices even more independently, skills that can be of great use when making end-of-life decisions. A few studies have shown that people with intellectual disabilities make few important choices about their care (Noorlandt et al., 2020; Tuffrey-Wijne et al., 2018; van Thiel et al., 1997). The consensus-based guidelines of the European Association for Palliative Care state that people with intellectual disabilities should be involved in end-of-life decision making with all the support they need to do so (Tuffrey-Wijne et al., 2016). Wiese et al. conducted individual interviews and focus groups with support staff members who had and did not have experience with the death of a client. The results indicate that support staff would benefit from attending training courses that teach them how to engage people with intellectual disabilities in conversations about dying and death and to leave protectionism behind. Speaking openly and respectfully about death and dying is essential for people with intellectual disabilities, enabling them to gain knowledge about death and dying and to experience autonomy in shaping their own ideas about their own end of life (Wiese et al., 2013). Bigby further indicates in her study that it would be beneficial for family members and support staff in the decision-making process to apply self-reflection to their own actions and be aware of aspects such as wanting to be neutral, avoiding influence and blocking certain options by being too realistic too soon (Bigby et al., 2019). Shared decision-making can help to better align palliative care to the wishes and preferences of people with intellectual disabilities because it provides space to look at all possible options from all perspectives. This is consistent with research of McKenzie et al. who found that involving people with intellectual disabilities in advance care planning had positive results; most importantly; it gave people with intellectual disabilities the opportunity to shape their lives as they saw fit (McKenzie et al., 2017).

In addition, it is interesting to reflect on the differences that are visible when we compare the models of the residents and of the support staff. It can be concluded that the areas of influence on the autonomy of residents are reasonably similar. Whereas the model of the residents seems to be fairly straightforward, namely, this is how it is for residents, in the model of the support staff there seems to be more room for doubts and coordination with other colleagues. This outcome is also logical, because residents generally have only one support staff member who supports them the most, and support staff are trained in supporting people with intellectual disabilities and they are professionally bound to adhere to guidelines and principles. Because support staff indicate that their own standards and skills play an important role in the way they guide people with intellectual disabilities, it would be a good idea to provide regular space for intervention, in which it is possible for support staff to reflect on certain choices they have made in the choice making process. This reflection may help to keep support staff aware of their important role in the choice making process of people with intellectual disabilities.

This study has several strengths. Firstly, we triangulated the observational data with interview data, and could therefore provide more comprehensive and reliable insights. Secondly, the results of the study were co-analysed by an 'expert by experience', who, from his own experiences with healthcare, could contribute to our analysis from a different perspective. Thirdly, in the Netherlands, the proportion of clients in healthcare organisations with mild and moderate disabilities is large, so this care facility is a good reflection of the care for people with intellectual disabilities. Fourthly, weekly conversations with two senior researchers helped the researcher to stay consciously involved in doing the participatory observations and interviews and thus limited bias. This study also has several limitations. Firstly, the observations and interviews were conducted within one residential care facility, so the results may be specific for this organisation and these residents. However, this healthcare organisation is in terms of size and composition of people with intellectual disabilities quite similar to many other organisations in the Netherlands secondly, 3 weeks is a relatively short period for participatory observation. Nevertheless, at the end of the data collection, saturation was reached where no new data emerged from the last interviews.

5 | CONCLUSION

This study shows that the level of autonomy with which people with intellectual disabilities can participate in daily decision-making processes is limited. Support staff is mindful of the importance of preserving residents' autonomy, but in practice, it is limited to a few areas of life. The reasons for limiting residents' autonomy differ within the support staff. For follow-up research, we should explore how best to support people with intellectual disabilities to make their own choices throughout their lives so that they are also able to make important decisions about healthcare. Furthermore, it is important to get insight into choice making processes for people with different degrees of intellectual disabilities in different settings.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

Data and materials collected in the study are property of the Erasmus MC, Erasmus University Medical Center Rotterdam, The Netherlands, and are archived according to international and national regulations at the Department of Public Health of the previously mentioned institution. Due to the confidentiality of the data, data is not publically available.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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