

‘A Limited Guardian Should First and Foremost Get to Know the Person He Helps’—Experiences of Having a Limited Guardian from the Perspective of Adults with Intellectual Disability



RESEARCH

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ABSTRACT

One goal with the UN Convention on the Rights of Persons with Disabilities is ensuring that persons with disabilities have the right to support in reaching and acting upon decisions. The aim of this pilot study was to explore how adults with intellectual disability describe their experiences of receiving support and being represented by a limited guardian. Two overall themes emerged from eight qualitative individual semi-structured interviews: Indispensable and valuable support and Mismanagement of the assignment. Our findings showed that limited guardianship is more complex than it may initially seem due to overlaps between protecting rights, ensuring support for the person, and managing financial matters. Mutual trust and the guardian’s ability to listen and be open to the client’s changing needs reduced the risk of the client being misrepresented or receiving insufficient support. To support assisted decision-making, limited guardians must develop their pedagogical skills and gain knowledge about intellectual disability.

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The guiding principles of the UN Convention on the Rights of Persons with Disabilities (UNCRPD 2006) aim to promote respect for individual autonomy, which include the freedom to make one's own choices, and personal independence. Persons with disabilities enjoy legal capacity on an equal footing with others in all aspects of life (article 12). When an adult person has diminished capacity or is perceived as incapable of making decisions, they may need somebody representing their rights and interests. Guardianship refers to a legal relationship between a person (the client) and a legal representative (the guardian). In the Swedish legal system, there are two types of formal guardians for adults: the limited guardian (*god man*) and the full guardian (*förvaltare*). A limited guardian is an assisting decision-maker, and a full guardian acts as a substitute decision-maker (Giertz 2018). Both types of guardianship aim to organize the client's financial and legal affairs and/or ensure that decisions are made in the client's best interest. Under Swedish legislation (the Parental Code [Föräldrabalken]; SFS 1949: 381), limited and full guardians should assist the client and protect their best interests regarding financial and personal issues. A limited guardian may be assigned to protect a person's rights, manage their financial assets, or ensure support for the person. Often, a limited guardian is employed to support the client with all these tasks. Nevertheless, the assignment should be adapted to the client in need of support, in accordance with the principle of not intervening more than necessary (Odelöv 2021). The assignment requires that the limited guardian stays informed about the client's situation. Under Chapter 11, Sections 3–4 of the Parental Code, the limited guardian must take the measures that are most beneficial for the individual (Giertz, Mattson & Thelin 2021). The limited guardian should also strive to maintain active communication with the client and have a clear idea of her or his needs and desires (SOU 2004: 112, 459ff).

For a limited guardian to have the legal power to represent another person and make decisions, they must have the consent of the person being represented, whereas full guardianship does not require this (Fridström Montoya 2015). Persons who are assigned a guardian often need support to develop and practice skills for independent adult life (Payne-Christiansen and Sitlington 2008).

In Sweden, legal and mental capacity issues are approached through the legislation concerning guardianship in the Parental Code. This law underwent a significant reform in 1975. Before that, the law stated that a guardian could be appointed for persons 'unable to look after their own affairs.' The reform in 1975 was aimed at transforming the guardianship regime in the direction of supported decision-making. In the 1989 reform, the declaration of incapacity was removed completely, which can be seen as a follow-up to the 1975 reform.

Nevertheless, neither of the reforms has resulted in CRPD compliant supported decision-making because it retains 'best interest' as the basis for acting, because the CRPD insists that it be directed by the 'will and preferences' of the person (Szmukler 2019, Carney et al. 2021).

The local district court decides whether to appoint a limited guardian or full guardian. The assignment as a limited guardian is voluntary and performed by laymen. Each municipal council appoints a chief guardian with responsibility for regulation and supervision in the area (Giertz 2018). Limited guardians and full guardians are entitled to a remuneration for the assignment and compensation for the expenses required for fulfillment of the assignment (SFS 1949: 381, chapter 12 16 §). As a limited guardian, the gross income for one assignment is approximately 10,000 SEK per year and assignment, but it is determined by the complexity of the assignment. A limited guardian can have several assignments simultaneously. The remuneration is based on a fixed percentage based on the base amount that applies every year (God man Handboken, 2020).

Guardianship can be limited to specific periods in a person's life or be lifelong (Holmqvist, Eriksson & Tideman, 2022). Instead of being appointed a formal guardian, equivalent support can be provided informally by a relative or another person who the person in need of support considers to be trustworthy. However, there is a fine balance between an individual's right to self-determination and the need for support from public bodies such as municipal social services (Giertz 2012). The Swedish disability legislation, Act concerning Support and Service for Persons with Certain Functional Impairments (SFS 1993: 387) confers 10 specified interventions, some of which are aimed at children and their families. Examples include residence care outside the family, respite care, and personal assistance.

A range of people can be eligible for different forms of guardianship because target groups include persons with intellectual disability (ID), persons with mental health problems, persons with dementia, and children needing representation by a third party. In relation to social work, being represented by another places a person in a vulnerable situation.

There are only a few research studies reporting experiences of people under limited guardianship, however researchers from the Living with Disability Research Centre at La Trobe University conducted qualitative studies in receipt of support for decision-making to create a framework for supported decision-making for people with cognitive impairment due to acquired brain injury or intellectual disability (Douglas & Bigby 2018). Taken together, findings from those qualitative studies indicate the importance of being provided with support from a trusted person who has in-depth knowledge of the represented persons history and goals (including decisions and outcomes), has knowledge of their impairment and level of functioning, and adapts flexible strategies to tailor support to the unique needs of each individual (Douglas et al. 2015).

Although studies conducted by researchers from La Trobe University have contributed with valuable insights about supported decision-making (Douglas & Bigby 2018), only a few of those studies explored the perspectives of people with cognitive impairment, and none had the specific focus on limited guardianship. A review of research literature (Holmqvist, Eriksson & Tideman 2022) makes it clear that there is limited research focusing on the perspectives and experiences of people who are represented by a limited guardian due to limited decision-making capacity. The lack of research is confirmed by studies included in this review (Brown and Standen 2011; Ruegger 2001, Stötzel and Fergert 2006; Teaster 2002; Werner and Chabany 2015).

Irrespective of the forms of representation and support and how these forms of representation are legally defined and implemented in a national context, there are two recurrent themes in previous research: the balance between protecting and violating rights, and the importance of lasting and trustful relationships between the person being represented and the person representing them (Holmqvist, Eriksson & Tideman 2022).

In 2021, approximately 72 640 people in Sweden were supported by a limited guardian in everyday life (Överförmyndarstatistik, 2022), but there are few studies that examine their perspectives and lived experiences of being represented (Holmqvist, Eriksson & Tideman 2022).

AIM

This is a pilot study with the aim to explore how adults with ID describe their experiences of receiving support and being represented by a limited guardian. To clarify the purpose, the following questions were formulated:

- How does the client describe and experience the limited guardian's assignment and role?
- What kind of support does the client get from the limited guardian?
- How does the client describe the relationship with the limited guardian?

METHOD

SAMPLING AND PARTICIPANTS

Contact persons at one of the major Swedish disability associations whose target group is persons with ID, the Swedish National Association for People with Intellectual Disability (FUB), helped disseminate information about the study.

Participants were recruited from three local FUB groups in geographic regions with differing population densities. Two of the associations were in midsize towns in the middle and south parts of Sweden, and the third was in an urban area in the middle of the country. The sample included eight participants: five men and three women between 38 and 71 years old.

Two of the participants had experience of both limited and full guardianship, and four had had relatives as limited guardians during some period of life. The duration of their limited guardianships ranged between 15 and 50 years. All the informants had changed limited guardians several times; in this regard, the range was from 3 to 10 limited guardians. Two of

the participants were retired, and the remaining six were occupied with daily activities. Two of the male participants were married, one was living with his spouse, and the other man and his spouse had separate households. Three of the participants lived in serviced accommodation; five had apartments of their own, some with access to practical support from staff.

DATA COLLECTION

Data were gathered through eight individual semi-structured interviews. Data collection coincided with the COVID-19 pandemic and interviews were therefore performed either face-to-face or digitally. The locations for face-to-face interviews were decided by the participants. Three chose to be interviewed on the premises of their local FUB association, whereas a fourth interviewee wanted to be interviewed at home. The remaining four interviews were conducted via a digital platform. The interviews were recorded and transcribed verbatim. Three of the interviews were transcribed by the first author, and the remaining five were sent to a transcription company. The interviews lasted 24–65 minutes (44 minutes on average).

The research project was approved by the Swedish Ethical Review Agency (Dnr-2021-02396). Special care was taken in the design of the information provided to the participants. Participants gave either verbal or written consent. Before the recording started, they were given information about the purpose of the study and a chance to ask clarifying questions. Some of the participants asked about dissemination of results, and a few wanted to read their transcripts. In the text, the participants are given aliases to ensure confidentiality.

DATA ANALYSIS

Interviews and field notes were analyzed using thematic inductive content analysis (Braun & Clarke 2006). During the analysis, the first author listened to the audio recordings to fill in any missing words in the interviews transcribed by another person. Line-by-line coding was performed in the first three interviews, with inductive coding resulting in many codes and preliminary themes. The other interviews were also coded and categorized in line with the discovered themes. After the initial coding, the three authors discussed the emerging analysis. Codes and tentative themes were discussed to reach a consensus on the most significant themes within and between the various interviews and to strengthen reliability and validity (Castleberry & Nolan 2018).

FINDINGS

In the analysis, two overall themes emerged: *Indispensable and valuable support* and *Mismanagement of the assignment*. The former refers to informants sharing positive experiences of having support from a limited guardian. The latter draws on statements where the informants' underlined challenges associated with receiving support from a limited guardian.

AN INDISPENSABLE AND VALUABLE SUPPORT

When limited guardianship functioned as intended by the law, it was experienced as an indispensable and valuable support in everyday life, which was expressed in two subthemes: *Mutual understanding and trust* and *A flexible support that follows the client's changing needs*.

I think it's very good to have a limited guardian. It feels like a liberation, someone you can lean on if there is something you need help with ... With money and bills and such. So, I would probably not have managed without a limited guardian, I don't think so. (Hannes)

Congruency between a client's expectations of the limited guardian's role and function and the limited guardian's perception of the assignment reduced the risk of misunderstandings and problems. It was considered beneficial to have a limited guardian who had experience of working as a bank clerk or accountant. When a client was satisfied with the relationship, any change would be initiated by the limited guardian, due to either old age or a lack of time for the assignment.

Through education and experience-based learning, the participants in this study had gained knowledge about having a limited guardian and what demands they could make:

In the beginning, maybe I was more unsure about the law and everything, how it worked and everything. You've gained more experience, both that I am here in the association and what I've learned through courses, and so on ... Education and everything—how it works—and I know the law. Then you become more confident about what rules apply. (Lucas)

Mutual understanding and trust

When there was a mutual understanding between the client and the limited guardian, there was also an agreement on how the assignment was to be handled. Trust was identified as valuable for creating a working alliance. One of the men said,

I often go for trust, and if there is one thing I can't tolerate, it is when people want to decide how things should be. But on the other hand, it is important that the person, regardless of whether it is a limited guardian or ... that you can discuss the matter. That is the most important thing of all. (Christoffer)

An important step toward establishing a trustful relationship was the limited guardian's ability and willingness to discuss what the client considered to be important. Thus, limited guardians had to have or acquire an ability to use inclusive language (i.e., words that could easily be understood by the client) and to give examples that served to clarify the consequences of making certain decisions.

Regardless of whether the client had a limited guardian or a full guardian, respectful dialogue was considered crucial in creating conditions for a functioning guardianship.

Another important aspect in creating a trustful relationship was the limited guardian's ability to show that they cared about the well-being of their client and were ready to take action to enable the client to have good living conditions in both a short- and long-term perspective: 'He asked me if the bed was good and if the sofa was good and asked about details. Then my bed was, yeah, it was probably not the best ... So, then he fixed a bed, he did that' (Christoffer).

When a limited guardian was committed to their assignment and became personally engaged with their client, this also served to establish or reinforce a trustful relationship between them. Prioritizing physical meetings with a client was an important aspect in developing a trustful relationship; this gave the limited guardian a chance to get to know their client and build a personal connection to her or him. Face-to-face meetings enabled limited guardians to provide hands-on support while staying in the background and providing support only when it was asked for. One man said that this helped him and his wife, who shared the same limited guardian, to learn more about their private finances, and this contributed to making them more self-reliant, as exemplified in the following quotation:

He comes to us every month, usually when we have to pay the bills, and supports [me] if I need help. We try to enter the bills [into the payment system] ourselves ... but if we need to apply for a housing supplement and so on, if you need to apply for something, then he should be involved and help ... There has been a bit of a gap now, when we [had the] pandemic. But then we still had contact by phone, we tried to do it ourselves, but we paid [the bills] ourselves, and he checked everything. (Lucas)

Thus, all informants considered it invaluable that a guardian was able to listen and provide flexible support as requested.

A flexible support that follows the client's changing needs

Because limited guardians support people of different ages and can have assignments that extend over several years, it is considered important that they understand that clients' needs and wishes change over time, depending on their individual life course trajectories.

Two of the informants had experience with both limited guardians and full guardians. According to Tom, the difference between a limited guardian and a full guardian is that the former only has an advisory function, whereas the latter can make decisions that go against the client's wishes and intentions: 'The only thing you can do [as a limited guardian] is to explain the consequences, but then if that person wants to do it anyway, then you can't do anything.'

Unlike the other informants, he had a limited guardian to protect his rights and ensure support for him, and he had a full guardian to manage his property. This was a bespoke solution that was possible because the same person acted as both his limited guardian and his full guardian.

Another aspect that was underlined by one of the informants was that needs differ between persons of different ages. The informant said that it would be better if limited guardianship was included in the Swedish disability legislation, i.e., the LSS legislation, LSS is the acronym for Support and Service for Persons with Certain Functional impairments (SFS 1993: 387) because limited guardians needed to have a better understanding of what their role entailed in relation to younger persons, due to their life trajectories differ from those of older persons. Young and old persons, the informant said, have different goals in life, and young persons might not want to put their life on hold by not buying a new sofa or having a larger selection of TV channels, for instance. This could make them feel that their needs were not considered. Being able to treat yourself to things was more important when there were fewer opportunities to do things outside the home due to limited finances. Younger persons, Christoffer said, needed to feel that there was a balance between living in the present and saving for the future, because they had a whole life ahead of them.

As a limited guardian, it is important to be flexible and sensitive to different needs and be able to adapt to a client's needs and wishes. This requires congruence in the limited guardian's and the client's views on the limited guardian's role and function. Clients' expectations need to be adjusted with consideration to the fact that individual needs can vary between different individuals as well as for the same person, if their life situation changes. This requires that limited guardians understand that clients' needs are based on their current life situation and can change over time, due to both unwanted and desired changes and both foreseen and unforeseen situations: changing jobs, moving to another form of housing or place of residence, and having or losing access to informal supportive networks such as a partner or relatives and friends who live nearby and can help if the need arises.

I wanted my sister to take over [the assignment], but she said it was so difficult and that she could not handle it. Otherwise, it would have been good. We have the communication. She knows what I want, what dreams I have for my life: You do not have to explain it two or three more times for her to understand it. (Göran)

If informal support from a relative was available, this was preferred by some of the informants. According to those who wanted to receive support from family members, one of the advantages was that less effort was required in clarifying wishes and needs. Another advantage was that it could save money. Further, one of the older men, who had previously received informal support from his sister, had thereby gotten more support than his limited guardian was able to give him—she helped him clean the refrigerator and refilled it with groceries. In contrast, some of the younger men said that it had been important for them to separate themselves from their parents and that having access to an external limited guardian allowed them to focus on socializing instead of discussing financial transactions during family gatherings:

I need help with money, but I don't want my mother [to be my limited guardian] because when I am with my mother, I want a mother/son relationship. I don't want to go there and cook dinner at my mother's [house] and then have to go through my bills. Personally, I feel that ... I do not like when relatives are limited guardians for their children. (Christoffer)

However, the same man admitted that having relatives as limited guardians could be beneficial for persons who had severe disabilities, because it could be difficult for an external limited guardian (without previous knowledge of the person), to interpret and respect needs and wishes,

On the other hand, I have to give in a little, because if I have huge support needs, then I can see an advantage. Since my mother has known me ever since I was born, and if I cannot express myself, then maybe relatives can help interpret my signals, what I mean. (Christoffer).

Some of the informants had had relatives as limited guardians during certain periods and for different reasons. In some cases, a parent had been their first limited guardian during the transition from the parental home.

MISMANAGEMENT OF THE ASSIGNMENT

Mismanagement of the assignment was related to a discrepancy between clients' knowledge of limited guardians' obligations and how limited guardians managed their assignment. When limited guardians failed to fulfill their obligations and mismanaged their assignment, this had to do with one of four interrelated subthemes:

An inability to ensuring support for the person, Mismanagement of financial transactions and protection of rights, Lack of pedagogical skills, and Lack of knowledge about what life is like with an intellectual disability.

An inability to ensuring support for the person

Because it was not self-evident to all the clients what limited guardianship entailed in practice, it could become difficult for clients to determine whether limited guardians fulfilled the obligations included in the agreement between the client and guardian. This was particularly apparent if it was the first time a person had been provided with a limited guardian and there had not been any previous contact with other persons or organizations that could provide information and advice about or share personal experiences of having a limited guardian.

When a limited guardian had too many clients, they did not have time to build trustful relationship with their clients, which made it difficult for them to act in their clients' best interests:

When limited guardians don't take time to get to know their clients, it becomes difficult for them to understand what is important in their clients' life, which contributes to them both intentionally and unintentionally disregarding their clients' wishes. You should listen to the person you are helping, which does not work right now in my case. She [the limited guardian] talks over my head. (Anki)

Many of the participants talked about limited guardians whose assignments seemed to have replaced their full-time employment, which resulted in less time for and commitment to each client and assignment:

There are many limited guardians who collect [assignments], so they have a lot of assignments. They take it as a full-time job after retirement, and that's not how it should work ... I think it's quite common, and many [clients] do not know that that's not how it should be. I think many end up in a situation where they are never allowed to meet their limited guardian, because he or she has too many assignments and does not have time for each person. (Lucas)

Another informant said, 'Before that, I had one [limited guardian] who had 40 [clients] and lived off the assignment he had ... He earned 80,000 [Swedish crowns] through limited guardianships' (Anki).

One reason that limited guardians were unable to fulfill their obligations was what clients perceived as an inability to ensure that the person was cared for. This was partly related to the fact that few limited guardians chose to become involved and invest time in building personal relationships with their clients. Being cared for was considered by the informants to be one of the most important aspects of limited guardianship, because it promoted good living conditions for them:

Many limited guardians can be great with money and so on, but this one, taking care of the person, is the one that needs to be improved ... A limited guardian should first and foremost get to know the person he helps. If the person likes to have a cozy [home], help the person get a cozy home. That's what I feel is overlooked. (Christoffer)

Anki felt that she was routinely being ignored by her limited guardian. It had gotten to the point where her limited guardian refused to meet and discuss financial matters with her and instead talked to the staff at her serviced accommodation, even though the limited guardian had not received Anki's permission to talk to staff about her financial situation. Not talking to Anki in person made it impossible for her limited guardian to ensure support for the person: 'She talks to the staff and based on my papers, she thinks she knows me, and we have never met; we have only talked over Skype' (Anki).

Not being given help in buying certain things made one of the younger men, Christoffer, feel that his needs were neglected. According to him, people need to feel that there is a balance between living in the present and saving for the future. Christoffer had initially had a good relationship with his limited guardian, which gradually changed for the worse when the guardian became sloppy and careless; he forgot to pay his bills and became insensitive toward Christoffer's needs. He recalled that this limited guardian could call him and say that he had to come by with some papers, not taking into consideration that Christoffer was at his workplace. Christoffer said, 'And then the person could call me and say: "I'll come over in a quarter of an hour." "Yes, but I'm at work. That's not possible." The person was constantly having a hard time adapting to what I was doing.'

However, some limited guardians restricted themselves to paying bills and transferring money, although their formal assignments included taking care of the client.

Mismanagement of financial transactions and protection of rights

Mismanagement of financial transactions was an experience that was shared among several of the informants, who also had the experience of not having their bills paid. One man, Göran, recalled that his limited guardian explained his delayed payments by saying 'there is not enough money to cover your bills, you have run out.'. This was mirrored in a similar experience for Christoffer: 'Once, or a couple of times, she had forgotten to pay the phone bill. Once the electricity was turned off. Ah, it was like, my God!'

Anki remember that when she and her former boyfriend had had the same limited guardian, the guardian made a mistake when handling her financial transactions. Instead of transferring money from her bank account to a card that she used for grocery shopping, he had transferred money from her boyfriend's account. Rather than correcting his error, he told her to sort it out with her boyfriend:

He was going to transfer money to my charge card, then he happened to take money from my boyfriend's card and transfer that to my charge card ... He had transferred money from my guy's card to mine, and then he said: 'You have to pay back then to ...' Then I said: 'No, I don't, because you're the one who messed up.' (Anki)

One of the other women, Hannah, had had a limited guardian who stole money from her:

I had a limited guardian—15,000 [Swedish crowns] disappeared from my account one summer, and she claimed that I was the one who had made a withdrawal. I had lost my ID card in April and had told her that. When that happened, she quit abruptly and sent all my bills to my house, so I had to take care of it myself. That kind of thing can also happen. (Hannah)

Mismanagement of the assignment could also be unintentional, for instance when limited guardians did not stay updated concerning changes in authorities' implementation of rules and regulations. One example was when the housing supplement was converted into a housing allowance. This had adverse consequences for one informant, who ended up in debt for several years. Although she was supposed to get support in managing her financial situation from her limited guardian, she was held accountable for her limited guardian's mistake and had to repay the debt.

Neither limited guardians nor full guardians keep up when the Social Insurance Agency changes things around—because now the housing supplement has been converted so that it is like a housing allowance, [when] I earn money, it has to be reported to the Social Insurance Agency. That's where the problem was. I have a

lot of study circles where I get income and fees. Three years ago, they changed the housing supplement so that it was income-based, but we received no information about that, and how can a full guardian or a limited guardian keep track of it all? ... This is what the situation looks like, and I've also noticed that when you change [your limited guardian], when a limited guardian wants to quit, it takes so long before the mail goes to the new limited guardian. Then you've usually be imposed reminder fees and delay fees on the bills. That's how things can turn out. (Hannah)

An important main principle that some of the limited guardians disregarded was their clients' right to self-determination. Under Swedish legislation, limited guardians do not have the right to make decisions without their client's approval or let their personal values govern clients' decisions on how to spend their money,

But then there was a fuss about a lot of stuff. What I used my money for, lots of stuff. I have these food deliveries, first it was 900 that I had the right to shop for. Then she lowered it to 850 and then to 750. Although we had agreed that 900 was the amount I got to shop for, she lowered it every month. (Anki)

Lack of knowledge about what life is like with an intellectual disability

The inability to act in the best interests of the client was exacerbated by the fact that some limited guardians used their client's disability as an 'excuse' for ignoring their right to self-determination. This is exemplified by the following dialogue between Anki and interviewer:

A: So that if this limited guardian went and changed my bank. She can't change my bank without my signature. I have a limited guardian, I do what I want, so ... and I haven't signed any papers.

I: So, she just went and changed your bank?

A: Over my head. [Gestures to reinforce statement.]

I: Okay, I understand.

A: She told staff: 'She is too mentally retarded to understand the value of money.'

Tom had a similar experience when he was accused of irrationality and an inability to make an informed decision when he wanted to use some of his savings to buy a shirt:

Because even though I need help, I am a free person, so to speak. Then I think ... No, I have been in situations where it is like, where I have wanted to buy something, and then my limited guardian says: 'But I can't afford to do this, so why should you?' ... I promise you, even if I have to change both limited guardian and full guardian every day, I will never—pardon the expression—but never in hell will I accept that, never, over my dead body. Because the starting point should be what I can afford, not what he can afford, the guy who is helping me. (Tom)

These examples indicate the vulnerable situation that people can end up in when their limited guardians do not respect their wishes and abuse the power that is vested in them. Although limited guardians may be able to foresee negative consequences, they are not entitled to make decisions on behalf of their clients or persuade them to act in a certain way. Instead of trying to change her approach, Anki's limited guardian had decided that there was no point in talking to her and trying to explain things in a different manner, because she was 'incapable' of understanding the value of money. In this situation, Anki got support from staff at her residence who were willing to stand up for her right to have insight and control over her financial situation. Ultimately, her limited guardian ended up in a conflict with the staff, whom the guardian considered to be incompetent.

Even if a client was aware that a limited guardian had abused their power, they could end up at a disadvantage if the guardian disregarded or overruled their wishes based on a judgment of perceived lack of decision-making capacity due to the client's ID.

In addition, being diagnosed with ID often resulted in other people not believing that they had the ability to make informed decisions, particularly if the person with ID found it difficult to explain or justify why they want to replace a limited guardian:

Many in the target group have to explain themselves a lot. I mean, I wanted a new limited guardian. I don't want to have to explain why to anyone. What gets a little difficult is that you can have a hard time answering that question, and then it can happen that you get persuaded somehow. (Christoffer)

Tom, who did not have any staff that could support him, did not have any option other than contacting the chief guardian and asking for a replacement of his limited guardian. Previous experiences of not being listened to had convinced him that the only way for him to get rid of his limited guardian was to start a fight. By making himself 'impossible to work with,' he could make his limited guardian feel compelled to resign, which would put pressure on the chief guardian to quickly find a replacement. However, he was not able to change his limited guardian until someone else was prepared to take over the assignment. Sometimes a parent or sibling could replace a limited guardian when the informant had decided that this was necessary and there was no one else available to step in.

Lack of pedagogical skills

Limited guardians who are supposed to provide support to adults with an ID need to acquire the skills necessary for adopting a pedagogical approach when they discuss financial matters with their clients. When limited guardians had a pedagogical approach, this enabled clients to become more self-reliant. Many clients wanted to learn how to manage their finances. Several of the informants believed that limited guardians should teach them how to manage and think about their everyday finances so they could eventually become less dependent on support from limited guardians:

You should also teach the client everyday finances. I think that is very important. Then maybe you should teach them to have some savings. Now I save some money, even though I have so little, but what I can save, I do. I can save a 20 or a 50 note.
(Hannah)

All the informants needed some degree of support to manage their household finances. A common task was to get help to pay bills in time, but also to understand the value of money, that is, how much money was left after fixed expenses such as rent, electricity, water, and food. In addition, clients wanted to know how much they needed to put into their savings account if they wanted to go on vacation or buy a piece of furniture. Thus, they wanted their limited guardians to explain how to create a sustainable budget so there would be enough money to manage both fixed expenses, unforeseen costs, and a trip or sofa:

You need to teach us to understand how much money we have left after the fixed expenses have been paid. Otherwise, we think that, 'I get 12,000. Then I have 12,000. I need money.' So, it also falls on a limited guardian or a full guardian to make one aware that 'These are your fixed expenses, so that you can live and have food on the table and be able to have a bus card and be able to have internet.' When I had a trustee, she shut down my internet because she did not think it was that important.
(Hannah)

Lack of knowledge about ID could result in limited guardians not being able to provide the right kind of pedagogical support in communication. This was something that some of the clients had experienced in relation to other professionals as well. One woman says that she has become used to not receiving comprehensible explanations from people she was dependent upon, such as social workers and limited guardians:

No, you often don't get an explanation when you are a service user. It's the same when you go to the social worker, most recently when I was looking for a new home service form. She would explain to me why I was not likely to be eligible for it. Then she tells me that, 'It's like this, that you are not entitled to this because you have no lift, and you have nothing—you don't sit in a wheelchair,' and so on. So I say: 'But can you explain that a little more, because I don't really understand?' And then she starts again on the same [note]: 'You have no lift, and you don't need to be fed, and things like that.' I said: 'But what does this have to do with this?' And then my contact person says: 'No, stop, I'll explain to Hannah' ... and then my contact person said to

me that, 'You have to have a more severe handicap.' Then I said, 'Aha, okay.' Then I got it. (Hannah)

This situation exemplifies a common problem that arises when people who have power and influence do not understand that they need to make sure that they communicate in a way that enables clients to become involved in the conversation. Instead of talking to the clients, they need to focus on talking *with* them and explaining things in different ways. Using simple words, making sure that both parties understand each other, and acknowledging that they hear what their client says, even if they have a differing opinion or strongly disagree, are important skills that limited guardians need to master to build trust and succeed with the assignment.

If you want something explained like that, I usually say: 'Can you explain it in simpler words?' 'If you do not understand, you can google it,' was the answer I got once ... That's the thing ... to perhaps read a little about the diagnoses you are taking responsibility for, because it is a jungle in the legislation, you need to be familiar with what the law is. (Hannah)

DISCUSSION

The purpose of this study was to explore how adults with ID describe their experiences of receiving support and being represented by a limited guardian. More specifically, how clients describe and experience the assignment and role of the limited guardian, the kind of support clients get from limited guardians, and how clients describe the relationship with limited guardians.

Our findings show that a well-functioning relationship between a limited guardian and their client is based on mutual trust and a listening ability on the part of the limited guardian. As suggested in the first step of the La Trobe framework for supported decision-making (Douglas & Bigby, 2020), support persons, in this case, limited guardians need to know their client. Knowing the person implies having a person-centred approach that involves, 'knowing all aspects of the person and having a sense of the person's self-identity or self-concept' (Douglas & Bigby 2018: 5). In addition, to contributing to establish a trustful relationship (Boylan and Ing 2005; Douglas & Bigby 2020; Teaster, 2002), in-depth knowledge of the person is crucial for understanding the will and preferences of the person being represented (Douglas & Bigby 2018, 2020). Our findings also indicate that limited guardians need to be sensitive to the fact that clients' wills and preferences change over time. Thus, it becomes important for limited guardians to understand individual consequences of living with ID and acknowledge that wishes and preferences changes in relation to a person's life course trajectory. The informants considered it to be important to understand what kind of support different types of limited guardianship assignments entail, which is in line with the findings of Mazzotti, Kelley, and Coco (2015). Taking care of the person was perceived as the most neglected aspect of the assignment, due to the limited guardians' lack of in-depth knowledge regarding the person being represented.

In our study, dissatisfaction was related to the guardian mismanaging the assignment with regard to one or more of their tasks: protecting rights, taking care of the client, and managing finances. Although there are no legal coercive measures to use, several of them considered it legitimate to use financial management to influence the client's behavior; for example, when they thought a client acted imprudently, they could limit the client's cash flow. Likewise, the informants' experiences indicate that many limited guardians do not seem to understand the consequences of living with ID, because they often seem to underestimate clients' intellectual capacities. When limited guardians had a poor understanding of ID and a lack of pedagogical skills, this reinforced the asymmetry in the relationship and did not help clients make informed decision or support them to become more self-reliant. This became clear in the lack of a well-functioning communication, often taking the form of using difficult words or communicating only with staff. The informants found that teaching them about their legal rights combined with limited guardians being knowledgeable about their wishes and preferences increased the likelihood of being supported in decisions. Hence, limited guardians need to acknowledge each client's needs and wishes and trust the client's ability to make informed decisions through

supported decision-making, instead of assuming that they lack this capacity (Teaster 2002). Similarly, Watson (2016) found that supporters who had a positive view of the abilities of persons with IDs were more likely to be responsive to the expressed will and preferences of a person with ID. Nevertheless, being knowledgeable about rights was not always enough to ensure that these rights were upheld. This highlights the complexity of the assignment because it indicates a crucial but unresolved tension between adhering to the person's long-term goals (their 'will') and their more changeable 'preferences' (Szmukler 2019; Carney et al. 2019; Carney et al. 2021).

STUDY LIMITATIONS

The target group in this study was adults with ID who had experiences of limited guardianship. Recruiting younger people was difficult, and according to information received from elected representatives at FUB, younger people prefer to get informal support from parents or other trusted people, meaning that limited guardianship is seldom used until they have no other choice. Therefore, the inclusion criteria were adjusted in regard to age. Initially, the age range had been 18–40 years, but because it proved difficult to find young participants, the age limitations were removed. Although people with ID make up a very heterogenous group, it was difficult to involve people with different ethnic backgrounds, which is an important factor in relation to expectations and experiences of having a limited guardian.

Our results are not representative of adults with severe ID and would gain from further exploring diversity from an intersectional perspective, in relation to the characteristics of the limited guardians and clients, as well as the clients' individually formulated assignments.

CONCLUSIONS

Although formal acknowledgment of support for people with ID to participate in decision-making is important from a legal standpoint, it is essential to ensure that these intentions are realized in practice. Our findings show that the assignment of limited guardianship is more complex than it initially may seem due to overlaps between the three dimensions (protecting rights, taking care of the person, and managing financial matters).

Accordingly, there is a need for a more comprehensive education where limited guardians gain knowledge about the target group that they represent. In relation to adults with ID, limited guardians need to develop pedagogical skills so that limited guardians can explain the consequences of various decisions and justify the underlying reasoning for financial calculations or other proposals that are important, given a client's living situation. To both promote self-determination for clients and develop the limited guardians' skills, it may be beneficial to use evidence-based framework for support to decision-making.


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