

RESEARCH

Guardianship for Adults with Intellectual Disabilities: Accountant, Advocate or 'Family' Member?

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The overarching aim of this study is to explore guardianship in terms of its impact on daily lives of adults with intellectual disabilities in Sweden. Based on qualitative interviews, the article focuses on the expected and actual role of limited guardians for people with intellectual disabilities in the context of Swedish laws. Our findings show that the legal definition of limited guardianship is unclear and that this lack of clarity, among other dilemmas, creates conflict among clients, guardians, relatives, professionals and care workers. The guardian may be expected to act as an accountant, a legal advocate, or even a surrogate family member. The result is consistent with previous research in other countries on the consequences of guardianship. The current legislation on limited guardianship is in need of amendment in order to avoid legal uncertainty and ambiguity among clients and their support network.

Keywords: Limited guardian; Guardianship; Intellectual disability; Assisted decision making; Sweden

Introduction

In many Western countries, considerable efforts are made to improve various forms of support for people with intellectual disabilities to give them the opportunity to defend their rights (Schmidt 2014). One way is to develop laws governing assistance in the form of legal representation (i.e., guardianship) for people with limitations in their ability to handle societal rules and regulations in daily life, such as managing bank transactions and signing contracts (Devi et al. 2011). This article explores the impact of Swedish guardianship in everyday life for adults with intellectual disabilities. Guardianship refers to a legal relationship between one person (the client) and a legal representative (the guardian). If a court rules that a person is incapable of handling her own affairs, a legal representative is appointed to assume responsibility to varying degrees for legal rights, possessions and decision-making in everyday life. Across countries, there are differences between which terms are used and what they include, but guardianship, guardian and 'client' are common legal terms and will be used in this article. Here, client huvudman, refers to an adult person with an intellectual disability and who is in need of support by a limited guardian. Disability in this text refers to limitations that arise in the individual's encounter with the environment. Living conditions for people with disabilities are formed in a dynamic interplay of biography, social values, social context and environment (Barnes, Mercer and Shakespeare 1999). Depending on how the society is adapted to their citizens' various needs and capabilities, different physical and intellectual functional limitations appear. Intellectual disabilities refer to generalised impairments in intellectual functioning and adaptive behaviour that are present before the age of 18 (Patel et al. 2014; Schalock et al. 2010). In all, 33 interviews were carried out with adults with intellectual disabilities, with limited guardians and with staff in social work. By examining the research question from these three perspectives, roles and consequences are highlighted in relation to the people in need of this kind of assistance.

Research on guardianship in a human rights context

Human rights can be considered an overarching theme, and people with disabilities have focused on human rights in many countries during the last few decades. The issue of adult guardianship has been on the agenda in various countries since the 1960s (Doron 2002). Guardianship research relates to human rights, self-determination and the principle of minimum intervention. The consideration of basic rights is important from both non-discriminatory perspectives and in terms of supporting self-determination in daily life, including full participation in society (Quinn and Arstein-Kerslake 2012). The UN Convention on the Rights of Persons with Disabilities (UNCRPD), which came into effect in 2008, is considered one of the main reasons for this shift in thinking about disability from a social welfare concern to a human rights issue (Harpur 2012; Mégret 2008). One of the ambitions of the UNCRPD is ensuring that people with disabilities have the right to support in reaching and acting upon decisions: 'States Parties shall take

appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity' (UN General Assembly 2006: Art. 12, Sec. 3). A person who lacks the full ability to communicate her will has the right to be assisted by a legal representative in order to apply for social welfare and to perform other legal actions (Devi et al. 2011; Fridström Montoya 2015).

However, it is a difficult balance and a complicated distinction between an individual's autonomy and right to self-determination and the need for information and applied support (Giertz 2012; Heller et al. 2011). Balancing the need for assistance in relation to the design of information and support is different for different groups in society. This is especially true for people with dementia (Smebye, Kirkevold and Engedal 2012) and people with intellectual disabilities, mainly regarding the person's ability to participate in decision-making and to express wishes and needs (Arstein-Karslek 2014; Wright 2010). Active participation is well-recognised as a crucial part of the concept of autonomy regarding people with disabilities (Wehmayer and Bolding 2001) and is most relevant to this article.

There is an on-going critical discussion about autonomy and self-determination in relation to guardianship (Carney 2012; Millar 2007; Millar 2013; Wright 2010). People who are assigned a guardian often need support to develop and practice skills for an independent adult life (Payne-Christiansen and Sitlington 2008). In accordance with the principle of minimum intervention, a less restrictive form of support has been suggested to prevent marginalization (Flynn and Arstein-Kerslake 2014). As shown above, guardianship is an issue of global interest and some comparative research has been carried out.

Guardianship in the Swedish context

Swedish legislation has a clear focus on the individual's right to a life like any other citizen and on promoting equality and participation in society. 'The activities pursuant to this Act shall promote equality in living conditions and full participation in the life of the community' (SFS 1993: 387 sec. 5). Especially in the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS), this is clearly expressed: 'The activities concerned shall be based on respect for an individual's right to self-determination and privacy' (SFS 1993: 387 sec. 6). Formal assisted and substituted decision-making in Sweden takes the form of guardianship.

This is a short introduction to the legislation concerning guardianship in Sweden according to the Parental Code (SFS 1949: 381). The fundamental principle in law and regulatory practice is that all adults are responsible citizens regardless of gender, ethnicity or disability. However, people with cognitive impairments may have difficulties with decision-making and understanding information. The need for assisted decision-making and legal representation then arises (Fridström Montoya 2015; Hall 2014; Schmidt 2014). There are three categories of formal guardianship in Sweden: förmyndare, god man and förvaltare. Förmyndare in this article is translated into trustee. A trustee is relevant for individuals under the age of 18. A limited guardian (god man) is an assisting decision-maker, and a full guardian (förvaltare) acts as a substitute decision-maker. As previously explained, a person receiving assistance by a limited guardian is called a client huvudman.

First, the client must assent to having a guardian and second, the client must accept decisions made by the guardian in everyday life. An important exception is that a physician can declare a person incapable of assenting due to illness or impairment. The district court may then decide on guardianship without the client's assent, and the guardian does not need to have the client's assent in all decisions made in everyday life.

According to the Parental Code (SFS 1949: 381), limited guardians and full guardians should assist and protect clients regarding economic and personal issues in his or her best interest. Limited guardianship is the most common form and is, therefore, the focus here. In 2000, there were 51,400 people that had a limited guardian and 4,800 people that had a full guardianship (SOU 2004: 112).

The client retains the power to perform legal acts, to vote and to get married and has the right to be informed of and give consent to decisions on various issues. The appointment of a limited guardian has no consequences for an individual's legal capacity. If a person lacks the capacity to consent, the law can be interpreted as if limited guardians are authorised to act properly in the individual's name. The law is not clear on whether a guardian can apply for support measures without consent from the client (Fridström Montoya 2015). According to preparatory works to the Act, limited guardians are supposed to monitor the quality of interventions:

... limited guardian or a full guardian should [...] keep himself informed of [...] the client's need for care or social services [...] if there are shortcomings, the limited guardian or the full guardian shall as far as possible ensure that they are remedied (Prop. 1987/88: 124 sec. 188).

Many people with intellectual disabilities have a limited guardian for assistance, mainly due to cognitive impairments (Giertz 2012). A limited guardian can have different responsibilities: to organise the client's financial or legal affairs and/or to ensure that decisions are made in the client's best interest. The assignment as limited guardian or legal administrator is voluntary and usually performed by laymen. The District Court decides whether to appoint a limited guardian, full guardianship, or a trustee to people under the age of 18. The Municipal Council appoints a Chief Guardian with responsibility for regulation and supervision in the area.

Legislation may be general and comprehensive; hence, it is important that clients, guardians and others involved understand its implications for everyday life. It is also important to include the voices of people with disabilities and the guardians themselves in the discussion about guardianship and to understand how the given support is perceived. The present study seeks to answer these questions and investigates the expected and actual role of limited guardians in the daily lives of people with intellectual disabilities.

Aim and Research Questions

The overarching aim of this article is to explore guardianship in terms of its impact on the daily lives of adults with intellectual disabilities. The starting point is how adults with intellectual disabilities, limited guardians and professionals, including care workers, define guardianship and their expectations of guardianship, with a view of reaching an understanding of its meaning in everyday life for people with intellectual disabilities. The following questions form the basis for the study:

- What is the role, generally and in daily life, of a limited guardian according to adults with intellectual disabilities, guardians and professionals in social work?
- What expectations do adults with intellectual disabilities, guardians and professionals have of guardianship generally and in daily life?
- What are the implications for people in need of this kind of support?

Method and Materials

The article is based on one part of a larger qualitative study concerning self-determination for people with intellectual disabilities or autism who depend upon daily support according to the LSS Act in residential homes and day care centres. The study is based on qualitative interviews in different forms: individual interviews and group interviews. One part focused on personal assistance (Giertz 2008), and this article is based on a part that focuses on guardianship and LSS measures (Giertz 2012). This part of the study was conducted from 2009–2010 in one county in southern Sweden. There are no changes in laws, regulation and practice since then.

Data Collection and Participants

The focus of this study is on clients' (adults with intellectual disabilities), limited guardians' and professionals' experiences of and perspectives on guardianship in every-day life. Data was collected through extensive interviews with clients themselves and guardians. Professionals—people engaged in social work—were also interviewed. This group included care managers, administrators and care staff (see **Table 1**). Employees working with people with intellectual disabilities may give another picture of the role of the limited guardian and their impact on every-day life. As a matter of ethics, the guardians participating in the study were not guardians to the clients that were interviewed.

All clients interviewed had measures from LSS, which means they had some form of intellectual disability. Semi-structured interviews lasting approximately one hour were conducted first with the clients face-to-face, mostly in their homes. Two smaller groups of clients were interviewed as a group to provide discussions and exchange of experiences. The interview guide had themes related to the aim of the study, such as daily-life, decision-making, choices and financial questions. The study design was inspired by Krogstrup's (2003) evaluation method with a participatory approach. This method was selected to encourage an open approach to the concept of guardianship. The first interviews focused on clients' lived experience of guardianship and its impact on their daily lives. According to Krogstrup's model, the clients' reflections and examples then served as a basis for the subsequent interviews with guardians and professionals (Krogstrup 2003). Those interviews included vignettes (Jergeby and Soydan 2002) from the interviews with the clients in order to create space for the guardians' and professionals' reflections about guardianship from the client's perspective (Krogstrup 2003). To obtain comprehensive data, interviews were conducted with people working in different parts of the organization.

Table 1: Participants.

Participants	Number	Male/female	Age	Interviews
Clients with mild or moderate intellectual disability	14	4 male/10 female	25–60	Individual interviews (8) and two group interviews (2 × 3)
Limited guardians to clients with LSS measures	19	8 male/11 female	45–76	Individual interviews
Care administrators (4) and care managers (3)	7	All female	30–65	Group interviews (2)
Care staff working at group homes for persons with ID	7	All female	42–60	Group interviews (2)
	47			33

Krogstrup (2003) emphasizes in-depth group interviews. Group interviews were conducted with professionals based on the idea that this format can yield information that could surface only in the context of mutual communication between people in the same position, providing opportunities for reflection and discussion (Krogstrup 2003). It was not possible to gather guardians for group interviews.

The main discussion with clients addressed the impact of guardianship, the guardian as a person and the impact of the guardians' decisions on the clients' daily lives. The vignettes in the subsequent interviews with both guardians and professionals focused on clients' lived experiences of guardianship and its impact on daily life. The vignettes described five different decision-making dilemmas the clients had given in the interviews. The vignettes were presented with follow-up questions about decision-making, self-determination and inclusion. The same vignettes were used with guardians and professionals.

Participants were contacted by user organisations and municipal administrators for client interviews. The municipality heads of social services were contacted. They agreed to the study being carried out as long as the employees themselves consented to participate. The interviews were conducted at their workplace.

Interviews were conducted by the principal researcher. Personal interviews lasted about one hour, and group interviews lasted two to three hours. Interviews were audio-taped where participants gave their consent, otherwise they were written down. All interviews were transcribed from tapes or notes.

There are limitations to the present study. First, the clients in the present study are people who can be expected to be actively involved in the guardianship relationship, as they are able to verbalise their experiences of decision-making in every-day life. Second, to provide broader reflections, the plan was to conduct interviews both in groups and individually with all three groups of participants. This was not possible for reasons such as lack of time and participant disinterest. Starting with interviews with clients and then presenting narratives to guardians and professions provided the advantage of getting deeper into the questions (Krogstrup 2003).

The research project was approved by the Ethical Committee in Linköping (Dnr: 212-09). Before the interview, written informed consent was obtained from each interviewee according to ethical principles (SFS 2003: 460). Special emphasis was placed on the design of the information provided to the clients, with forms approved by the Ethical Committee. Names and other details that may identify participants have been changed.

Theoretical Framework and Analysis

Data analysis started with an empirical approach, rereading the transcripts and identifying recurrent themes related to expected and actual roles of guardians in daily life. By comparing themes and interviews, the initial reading process resulted in preliminary focused themes (Braun and Clarke 2006). Three different ideal approaches have been discerned: accountant with financial commitments, defender of rights and surrogate family member.

The analysis continued with a theoretical approach, connecting the empirical themes to analytical concepts, such as Goffman's (1959) self-presentation, roles and social interaction. Goffman (1959) argues that the impression people give by acting and talking in a certain way helps them and others to define their role and the situation. The definition of the situation, in turn, influences the experiences, expectations and perceptions of the people interacting. Goffman's (1959) theoretical discussion of individuals and encounters takes place at the micro-level. Decision-making and self-determination presuppose a meeting between individuals. Goffman's interaction tool is used to analyse the relations that surround the client in everyday life.

Honneth's (2004) theory of recognition also provides a tool for analysing interactions and ways of describing the expectations of others. Recognition is necessary for an individual to have self-respect, as well as respect from others as a capable and equal citizen. According to Honneth (2003) and Taylor (1994), recognition serves to emphasise mutual respect for the differences, as well as the similarities, between all human beings.

Respondent validation is a process by which researchers ask participants to check the accuracy of analysis and findings. The design by Krogstrup (2003) meant that we could test the themes and quotes in the interviews. The first interview with clients gave vignettes that were used in the subsequent interviews with guardians and professionals (Creswell 2011; Krogstrup 2003). The quotes presented have been selected because they are typical or illustrative of the interviewee's conception of guardianship in daily life. Quotes are translated from Swedish into English by the author.

Findings: Roles and Expectations

The presentation of findings is based on the themes that emerged through the data analysis. The interviews with clients, guardians and professionals indicated large differences in the views of guardianship. Roles and expectations were superior concepts, which are introduced as follows:

- Accountant with financial commitments
- Defender of rights
- Surrogate family member

These may be either expected or actual roles, depending on perspective, and should be regarded as ideal types designed to visualise the findings. In reality, these expected and actual roles overlap to some extent, depending on situation and individual. All groups expressed differing expectations of the role a limited guardian should have.

Accountant with financial commitments

All interviews revealed a clear focus on the financial aspect of guardianship, and several of the limited guardians focused solely on this, saying that they rely on care staff to ensure the client's quality of life. Regulations on the financial responsibilities of limited guardians are quite clear, according to interviews. According to the law, a limited guardian is expected to account for the client's economic status once a year. All 14 client participants have moderate intellectual disabilities, were living in public housing with their own apartments and received benefit payments from the state. Also, the clients themselves seemed to have a picture of guardians as being responsible for financial matters first and foremost:

My health is taken care of by the nurse, my money is taken care of by my limited guardian and I take care of myself. (Client 3)

This is one example of how people construct a picture of themselves and their lives in order to feel in control and to understand their situation. It is what Goffman (1959) called self-presentation—as self-determined with a need of support.

All the limited guardians in this study had been given responsibility for their client's finances. The interviews revealed many examples of what Odlöw (2005) calls 'an accountant approach' in the role of limited guardian. Finances were also the main cause of conflict between clients and guardians:

We try to agree on how her [the client's] shopping might be limited. If we can't, I have to take a decision over her head and make small and definite payments to her. And pay most of her expenses by invoice. (Limited guardian 4)

According to the guardians themselves, it was not always clear to the client what a budget means and includes. Some of the clients knew their right to make their own decisions and do their own shopping; to have a limited guardian does not constrain this right. Both clients and guardians showed a tendency to define their roles without discussing expectations with the other part:

My latest guardian did not do as I wanted, so I dismissed her. She didn't visit me. (Client 4)

Autonomy implies control over one's own finances, including earning money and managing a budget (Webmeyer and Bolding 2002). None of the clients with a guardian had an income from work, and none of the guardians had a client with a salary in this study. Only very few clients were allowed to manage a budget, something Odlöw (2005) objects to in how guardianship has evolved. Only 2 of the 19 guardians interviewed discussed the possibility of teaching the client about what a budget means and training them to manage it. Involving the client means recognizing the right to participate in an individually adapted way and recognition of the client as a person capable of understanding and learning (Honneth 2003). There is a delicate balance between recognition of individual autonomy with the right to self-determination and the provision of adapted information and support:

I quit as guardian if he doesn't do as I say. I know and he knows, that he is free to buy whatever he wants, whenever he wants—that's the law. But if that's the case, I can't have all the financial responsibility. Slowly, he is beginning to respect that. (Limited guardian 17)

This was one example of the dilemmas involved in being or having a guardian in the role of accountant with no mandate. Freedom of action was limited for the guardian if the client did not accept being governed, and this gave rise to conflicts in everyday life.

One of the main issues in this study is the balance between self-determination and the need for support. Today's laws are based upon a growing social and judicial recognition of the right to citizenship for people with functional impairments (Honneth 2004). The intention is that people with functional impairments should be treated like all other citizens. It is understood as recognition of status. The law is thus an official recognition of the fact that a group has special needs. Judicial recognition at the macro level has resulted in formal support systems that recognize the group as being of equal value and that compensates them for being different, according to our analysis influenced by Honneth (2003, 2004). However, recognition at the macro level was not always replicated at the individual level in the interviews. Care staff, relatives and guardians often had different opinions on how financial matters had to be

dealt with. Also, if the terms are quite clearly stated in the law, they were often not known or accepted by all those surrounding the client and guardian:

The care staff has a lot of opinions, but they have no insight into her [the client's] finances. It happens that care staffs lend her money when they think she should do some shopping, and that's not in her budget. There is no money for it. That's a big problem! (Limited guardian 6)

According to the UNCRPD, people with disabilities have the right to support in reaching and acting upon decisions. The risk with an accountant approach is that it does not incorporate an effort to involve the client (and care staff) in the management of the client's finances.

Defender of rights—advocate

According to findings, another expected and actual role was that of advocate, or defender. Some clients and some guardians get nervous about the importance of knowing the relevant legislation for advocacy. Many guardians emphasised the need to fight both to obtain information and to have certain measures put in place. If the client could not express herself, the guardian was responsible for speaking for the client in different contexts as they understood their mission. Most of the guardians interviewed had as their formal mission to monitor rights, the client being unable to exercise her rights and perform her obligations alone. However, understandings of this mission vary. One guardian said:

It's my duty to push the social workers and act as her [the client's] advocate. I need to know more than the social workers to monitor her rights and the quality of measures put in place. (Limited guardian 10)

In our sample of respondents, some of the guardians expressed an understanding of their role similar to the one above, while others were not at all familiar with legal rights or the welfare system. Professionals get nervous about both empowerment and protection:

People with intellectual disabilities often have difficulty understanding their own rights and obligations. Some may be able to learn, while others will need an advocate throughout their lives. (Care manager, group 1)

A crucial factor was the client's own ability to formulate and assert her will. A person who could not express her opinion became dependent on interpretations made by the guardian. The degree and nature of the client's impairment significantly affected possibilities for influence and self-determination. Some clients regarded it as obvious that they were competent to make decisions and should be given the opportunity to participate:

I have the right to do my own decisions and I do! They have to listen to me [...] and they do [...] but it is also good to have someone to ask for support in some questions. (Client 7)

The client was recognised as the expert on her own life, which is important for self-confidence and recognition (Honneth 2003).

Knowing and speaking of what is "best" for the client requires knowledge of the individual as well of laws and regulations. According to professionals, the current law is not clear regarding what is included in the assignment as a limited guardian. For example, it is not stated whether the guardian should oversee the quality of the measures put in place for the client by the welfare system:

It's me who is responsible for his best interests. I take care of my assignment as a limited guardian, but the care staffs have not really understood what a limited guardian is in charge of. (Limited guardian 4)

The interviews with professionals in social work revealed a disagreement among themselves, and the same was observed among guardians. There were disagreements about guardianship, responsibility and speaking of the clients' best interest. Knowledge was required in order to protect a client's rights and obligations. Both guardians and professionals believed there was a lack of knowledge about guardianship in general, and this was a crucial point. Furthermore, there was a lack of knowledge within all groups about the other groups' responsibilities. Some clients, who had close relatives as guardians, had "furious mothers" (Lewin 1998: 225) fighting for their children's rights. In Sweden, a relative can assume the role of limited guardian and simultaneously act as a personal assistant for the same client/child:

I'm a mother, a personal assistant and a guardian to my son. I think the care staffs have to listen to me; I am his voice. They know that I know him well and that I know his rights. (Limited guardian 1)

Parents acting as guardians both formally and informally were the most common in this study. Findings showed that family guardians seemed to be influential on an individual level in ensuring access to support and service. Family guardians had a deep personal knowledge of the client's life and personality:

My sister is my guardian and I really want that! I feel safe with having a family member. (Client 6)

In this study, the limited guardians that were relatives also had a good knowledge of law and regulations. Having a relative as a guardian was a strong form of support according to many of the interviewees in this study and others (Olin and Ringsby 2006). However, as Flynn (2010) states, staff saw a potential risk for conflict of interest:

Family guardians may be advocating for the best of the family, not for the client. [...] and sometimes the family is overprotective and restricting the client in daily life. (Care staff group 1)

Professionals were worried about having a family member performing all support tasks. In these cases, the client's living conditions were known only by a few individuals, which limited the professional's control of the person's needs and rights. Roles were mixed, and this could be confusing (Goffman 1959). The study revealed various dilemmas involved in being a limited guardian and, simultaneously, a relative. For people with intellectual disabilities, a strong representative may always be needed. To perform this role effectively, the guardian must be someone who, first of all, knows the client well and, secondly, knows the law and can fight for the individual's rights. But it is not clear in the current legislation if the last issue is something that is included in the role of limited guardian.

Surrogate family member

One theme that emerged regarding roles and expectations on a guardian was surrogate family member. Some guardians argued that the most important part of their assignment was being a substitute family member. This meant, for example, celebrating birthdays when the biological family might not exist or was absent:

I've been like a mother, you might say. I've been taking care of her [the client] for many years and have to be engaged during Christmas and all that. We have enjoyed each other like a substitute family for many years now. (Limited guardian 12)

Some limited guardians stressed the expectation on them to act like a substitute family member, involving themselves in the client's social life in different ways. There was sometimes another family aspect to the relationship between guardians and clients: in the interviews, some guardians spoke about their clients as a child who needed protection and whose best interests were to be decided by others. Limits were imposed in terms of correct behaviour, money, ways of spending free time, and appropriate food. One client said the following:

If I get to decide for myself, I buy lottery tickets and sweets. Now it's been decided that I should eat special food (low-carb, high-fat diet) and go for a walk every day. (Client 2)

The attitude of being responsible for a grown-up child who needed to be raised by a good parent figure could be seen as disrespectful of the client as an adult person (Honneth 2004).

One difference observed between guardians who were relatives and those who were not was that non-relatives tended to lack knowledge about the client's disability and what it meant in everyday life:

This ignorance of disability is a problem. Supporting a person with special needs requires knowledge about their impairments and its effects on daily life. (Care Staff group 2)

The client here was an adult person with special needs; hence, it is a question of recognition of distinction (Honneth 2004). The care staff noticed that seeing oneself primarily as the parent of a child put the issue of knowledge about disability, regulations and rights in the background.

It was mostly the guardians themselves, but also a few clients, who talked about guardianship as primarily a social support or even as a substitute family member, while professionals' expectations tended to centre on defending rights and taking care of financial issues. All these different expectations of the role of limited guardian led to conflicts in everyday life.

Conclusion

When individuals have difficulty expressing their will and making decisions, their influence and participation needs to be enabled by others. Experiences of the guardianship system have a focus on independency in every-day life, as we can see in findings, but this is framed by social policy, together with the UNCRPD, and therefore this has to be taken

into account. The definition of the role of limited guardian in Sweden is unclear to clients, to guardians and to other staff and professionals supporting the client. The assignment as a limited guardian contains the expectation of acting as an accountant, as a legal representative and sometimes as a surrogate family member. These different expectations create conflicts and dilemmas.

In addition to a limited guardian, support may be provided by relatives, care staff and social workers. Within this support network, conflicts may arise over personal and financial issues and the question of who knows what the client's needs or best interests are. It is important that the client knows what to expect from the guardian and receives adequate assistance to express concerns and wishes. People with cognitive limitations may require various forms of support. We can see that the lack of clarity in legislation is a source of conflict between people surrounding the client. For instance, if the client or guardian expects only financial responsibility from the guardians, confusion can arise if the guardian claims quality checks on care measurements and defending the client's rights. The client's and the guardian's opinions are at risk of being neglected or challenged.

There is a consensus that financial assistance is an important part of the assignment as a limited guardian. Clients themselves often see the financial aspect as the most important part of the support they receive from guardians, even if this does not always translate to a general acceptance in everyday life. On one hand, there is a general acceptance of the limited guardian as accountant; on the other hand, different actors surrounding the client, such as care staff or relatives, also make efforts to control the client's finances. Previous research by Odlöv (2005) argues that according to the law and preparatory works to the Parental Act, one of the missions of a guardian is to help the client participate in and understand her own financial situation. Odlöv's objections are consistent with the findings of this study; participation is still not a big issue according to all the interviews.

Other expectations of limited guardians, such as acting as a surrogate family member or advocate, can, for obvious reasons, lead to emotionally charged disputes about who may claim to know what is best for the client.

According to the UNCRPD, every country must provide access to support that enables individuals with disabilities to understand situations, make daily life decisions and participate in society. It is a question of recognizing the client as a full member of society with special needs. It is, therefore, of great importance that the person with intellectual disability and those providing them with support are clear and in agreement about the rights and responsibilities of all involved. The Swedish law on limited guardianship was enacted in 1989. Prior to this legislation, people with disabilities were regarded as incapable of making any kind of legal or financial decisions. Sweden may be one of the leading countries in social work with people with disabilities, but this study shows that the current legislation on limited guardianship is in need of amendment in order to avoid legal uncertainty and ambiguity. Those findings are congruent with research, such as Devi et al. (2011) and Millar (2013). Tools for participation are still missing within the Swedish guardianship laws. Shared decision-making methods and knowledge about alternative ways of communicating are tools that may reduce conflicts and dilemmas in assisted decision-making, as would a mandate to work with empowering the client.

According to the Swedish legislation related to social work, as well as the UNCRPD, providing support for individuals to express their will is of great importance. The legislation on limited guardianship in Sweden is unclear, leaving vulnerable people with intellectual disabilities and communication problems at risk. Findings also indicate that special attention should be paid to develop client-driven approaches in guardianship and to assist the participation of clients whose disability gives them difficulty expressing their needs.

Competing Interests

The author has no competing interests to declare.

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