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Title: Guardianship for Adults with Intellectual Disabilities: Accountant, Advocate or ‘Family’ Member?

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Short title: Guardianship for Adults with Intellectual Disabilities

Abstract

The overarching aim of this study is to explore guardianship in terms of its impact on the 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 to people with intellectual disabilities purposed at giving them the opportunity to defend their rights (Schmidt, 2014). One of the ways going on is to develop laws governing assistance in the form of legal representation (guardianship) for people with limitations when it comes to the abilities to handle societal rules and regulations in daily life (Delia et al, 2011). For example manage bank transactions and sign contracts in different contexts. This article explores the impact of Swedish guardianship on the 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 for legal rights, possessions and decision-making in everyday life, to varying degrees. There are naturally differences between countries in which terms are used and what they include, but 'guardianship', 'guardian' and 'client' are common legal terms and will be used in this article. Client refers to an adult person with intellectual disability in need of support by a limited guardian but generally means a person in need of a legal guardian (huvudman). 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 & Shakespeare, 1999). Depending on how the society is adapted to their citizens' various needs and capabilities, different physical and intellectual functional limitations appear. Arising out of findings from a qualitative study this article focuses on the role of limited guardianship for people with intellectual disabilities in Sweden. Intellectual disabilities refer to generalised impairments in intellectual functioning and adaptive behaviour that are present before the age of 18 (Schalock, 2010; Patel et al, 2014). 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 the three perspectives that the respondents represent, roles and consequences of the formulation of the act is especially highlighted in relation to the people in need of this kind of assistance in daily life.

Research on guardianship in a human right context

The issue of adult guardianship has been on the agenda in various countries since the 1960:s (Doron, 2002). Research on guardianship can be related to human rights, self-determination and the principle of minimum intervention. Human rights can be considered as an overarching theme and for people with disabilities it has been an issue in focus in many countries during the last few decades. The consideration of basic rights is valid both regarding non-discriminatory perspectives and in terms of support to ensure self-determination in daily life, including full participation in society (Quinn & 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 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' (Article 12, § 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 perform other legal actions (Fridström Montoya, 2015; Delia, et al, 2011).

However, it is a difficult balance and complicated distinction between individual autonomy with the right to self-determination and the need for information and applied

support (Giertz, 2012; Heller et al, 2011). The question of balance between the need for assistance in relation to the design of information and support is different for different groups in society. It is especially true for people with dementia (Smebye, Kirkevold & Engedal, 2012) and people with intellectual disabilities, mainly regarding the ability to participate in decision-making and to express wishes and needs (Arstein-Karslek, 2014; Wright, 2010). The importance of active participation is well-recognised as a crucial part of the concept of autonomy regarding people with disabilities (Wehmayer & Bolding, 2001) and the most relevant to this article.

There is an on-going critical discussion about autonomy and self-determination in relation to guardianship (Flynn & Arstein-Kerslake, 2014; Millar, 2013; 2007; Carney, 2012; Wright, 2010). People who are assigned a guardian often need support to develop and practice skills for an independent adult life (Payne-Christiansen & Sitlington, 2008). In accordance with the principle of minimum intervention a less restrictive form of support has been suggested to prevent marginalization (Flynn & Arstein-Kerslake, 2014). As shown above guardianship is an issue of global interest and some comparative research has been carried out. Doron (2002) focuses on legislation on guardianship in five different countries. Following each country's specific legal culture and traditions the research exposes an effort to reform guardianship laws in order to promote the autonomy of individuals. In Japan and Israel, a strong expectation on the family contribution was found, while in the US, Germany and Sweden, the individual and the limited guardianship were focused based on the principle of minimum intervention.

Guardianship in the Swedish Context

The 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 §5) Especially in the Act Concerning Support and Service for Persons with Certain Functional Impairments, abbreviation 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 §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 (SFS1949:381). 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 of 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' is in this article 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 "substitute decision-maker". The Swedish legislation concerning guardianship emphasises the client's ('huvudman') right to assent. In this article, a person receiving assistance by a limited guardian is called a client.

The client has first to assent to have a guardian, and second to 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 therefore the focus here. In 2000 there were 51 400 people that had a limited guardian and 4 800 people that had a full guardian (SOU 2004: 112).

The client retains the power to perform legal acts, to vote, 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 is not able to apply for support measures, a guardian may do this. 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 do this 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 s. 188.

Many people with intellectual disabilities have a limited guardian for assistance, mainly due to cognitive impairments (Giertz, 2012). A limited guardian can have up to three different responsibilities: to organise the client's financial and/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 investigate 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 and guardians. 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?
- Which 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 and/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 in 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 guardian's and professionals experiences of and perspectives on guardianship in every-day life. Data was collected through extensive interviews. The empirical material was collected from clients themselves and guardians. Professionals were also interviewed to understand reactions in the context of guardianship, here called "professionals", a person engaged in social work in the field. This group include care managers, administrators and care staff, see table 1. Employees working with people with intellectual disabilities may give a more nuanced picture of the role of the limited guardian and their impact on every-day life. The guardians participating in the study were not guardians to the clients that were interviewed of ethical reasons.

All clients interviewed had measures from LSS which means that they needed to have 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. The first interviews focused on clients' lived experience of guardianship and its impact on daily life. 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 & 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). This method was selected to encourage an open approach to the concept of guardianship. 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 (2x3)
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 group interviews as in-depth. The interviews with professionals were conducted as group interviews based on the idea that this format can yield information which could surface only in the context of mutual communication between professionals, and provides opportunities for reflection and discussion (Krogstrup, 2003). Guardians were not possible to gather to group interviews.

The main discussion with clients addressed the impact of guardianship, the guardian as person and how decisions they may do have a direct impact on daily life, following the interview guide. The vignettes in the following interviews with both guardians and professionals focused on clients' lived experience of guardianship and its impact on daily life. The vignettes described five different narratives of situations that the clients had given in the interviews regarding dilemmas of decision-making. The vignettes were presented with follow-up questions about decision-making, self-determination and inclusion. The same vignettes were used to guardians and professionals.

Participants were contacted by user organisations and municipal administrators for client interviews. The municipality heads of the county's social services were contacted. They accepted the study to be carried out, as long as the employees themselves consented to participate. The interviews were conducted at their social work office.

Interviews were conducted by the principal researcher and personal interviews lasted about one hour and group interview 2-3 hours. Interviews were audio-taped where

participants gave their consent to this, otherwise written down, and then 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, as they are able to verbalise their experiences of decision -making in every-day life. Second, the plan was to conduct both interviews in groups and individually with all three groups of participants; professionals, clients and guardians, to be able to broaden reflections. This was not possible for reasons like lack of time and wishes from participant. To start with interviews with clients and then confront the others with stories of dilemmas was of advantage to get a deep in the questions (Krogstrup, 2003)

The research project was approved by the Ethical Committee (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 to the clients, forms approved by the Ethical Committee. Names and other details that may identify participants have been changed in findings.

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 initial themes and each interview with each other, the initial reading process resulted in preliminary focused themes (Braun & 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 (ibid) 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 take 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 themes of findings. The design by Krogstrup (2003) meant that we could test the themes and quotes in the following interviews. The first interview with clients gave vignettes that were used in the following 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 care and 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 analyses of data. 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 situations and individuals. 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 and 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 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 a 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, according to Webmeyer & 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 two 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 recognition of 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 of the examples of dilemmas involved in being or having a guardian in the role

of accountant but with no mandate. Freedom of action was limited for the guardian if the client did not accept to be governed according to the law, 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 of support. The law of today is based upon a growing social and judicial recognition of the right to citizenship for people with functional impairments using the concept of Honneth (2004). The intention is that people with functional impairments should be treated like all other citizens. It is here 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 give the group recognition as being of equal value and also compensation 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 are 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 UN Convention on the Rights of Persons with Disabilities (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`

Another expected and actual role was that of advocate or defender according to our findings. Some clients and some guardians spoke about the importance of knowing the relevant legislation in order to maintain 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 we 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 spook both about 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, gr 1)*

A crucial factor was the individual'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 was "best for the individual" requires knowledge of the individual as well of laws and regulations. The current law is not clear with regards to what is included in the assignment as a limited guardian, according to professionals. 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 staff 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 within the group of professionals, and the same was observed among guardians. There were disagreements about guardianship, responsibility and speaking of the clients best of interest. Knowledge was required in order to protect 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, have "furious mothers" (Lewin, 1998, p.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.

I'm a mother, a personal assistant and a guardian to my son. I think the care staff 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 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 & 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 gr 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 control of the person's rights. Roles were mixed, and this could be confusing (Goffman, 1959). The study revealed various different 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 to be a substitute family member. This meant, for example, celebrating birthdays as a substitute for the biological family that 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 with guardians, we observed a way of speaking about the client as a 'child' who needed protection and whose best interests were to be decided by others. Limits were imposed in terms of correct behaviour, enough 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 mother or father figure could be seen as disrespectful of the client as an adult person, 'disrespect' according to 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 their 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 gr2)

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 to see oneself primarily as the 'parent' of a 'child' puts the issue of knowledge about disability, regulations and rights in the background.

It was the guardians themselves, and a few of the 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 UNCRPD and therefore this has to be taken in 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 clients according to this study. The assignment as

a limited guardian contains the expectation of acting as an “accountant”, but also as a legal representative and sometimes as a “surrogate family member” in our findings. These different expectations create conflicts and dilemmas. 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. 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. 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 is in reality supposed to claim quality checks on care measurements and defend 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, different actors surrounding the client, such as care staff or relatives, also make efforts to control the client’s finances. Previous research by Odlöw (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. Odlöw’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 UN Convention on the Rights of Persons with Disabilities (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 recognition of 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 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 like Devi, et al (2011) and Millar (2013) and tools for participation are still missing within the Swedish guardianship. Shared decision-making methods and knowledge about alternative ways of communication are tools that may reduce conflicts and dilemmas in assisted decision-making. And a distinctly mandate to work with empowerment.

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.

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