RESEARCH

Autonomy and People with Intellectual Disabilities Who Require More Intensive Support

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In this article we explore the personal autonomy of people with intellectual disabilities who require more intensive support. The authors draw on qualitative research in Iceland carried out in the homes of 24 individuals. It is demonstrated how their personal autonomy can be defined, evaluated and enhanced in their daily lives. The conclusions show that to be able to respect personal autonomy of the participants those who support them need to view them as socially embedded, where personal autonomy is formed in relation to other people. To do that we refer to the idea of relational autonomy with support, advocacy and enablement being regarded as key elements for personal autonomy to flourish. By using this approach it is possible to note a positive change regarding respect for the personal autonomy of people with intellectual disabilities who require more intensive support. Considerable advances can still be made, however, in enhancing personal autonomy in their daily lives.

Keywords: autonomy; homes; private life; people with intellectual disabilities who require more intensive support

Introduction

Personal autonomy is widely valued and increasingly present in disability policies as a result of the heightened profile of the Convention for the Rights of Persons with Disabilities (CRPD). Icelandic disability legislation emphasises the right of disabled people to exercise their autonomy and the *Act on the Protection of the Rights of Disabled Persons* stipulates that disabled people have the right to receive the appropriate assistance to make choices and actively participate in decisions regarding their daily lives (Ministry of Welfare 2011). However, since the concept of personal autonomy is often connected to the idea of mental capacity for decision-making, people with intellectual disabilities are often perceived as not able to develop their personal autonomy (Davy 2015; Carlson 2010). This is especially true in relation to people with intellectual disabilities who have been identified by health/human service professionals as having severe/profound disabilities. However, the CRPD recognizes that all disabled people have the right to receive support to be able to develop their autonomy, including "those who require more intensive support"[1] (United Nations 2007).

This article presents a qualitative study exploring personal autonomy in the daily lives of 24 Icelanders with intellectual disabilities who require more intensive support, with particular emphasis on their homes and daily lives. Much of the existing body of research focusing on the lives of disabled people who require more intensive support has been within educational and psychological research, focusing on such issues as special education, responses to communication disorders, and how staff interact with individuals who communicate with alternative modes of expression (e.g., Bradshaw 2001; Goode 1994; Griffiths and Smith 2016; Healy and Noonan-Walsh 2007; Martin, O'Connor-Fenelon and Lyons 2016). Disability research focusing on people with intellectual disabilities has generally relied on the perspectives of professionals and parents. However, within the field of disability studies efforts have been made to include people with intellectual disabilities in research and the theoretical discussion on disability (Björnsdóttir and Jónsson 2015; Boxal and Ralph 2011; Chappell 1998; Docherty et al. 2010; Goodley 2001). Through activism and participation in research collaboration, people with intellectual disabilities have demonstrated the ability to describe their lived experiences of negotiating disability in their social context and to voice their wishes and hopes for inclusion in society (Atkinson

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[1] There is a shift in terminology in the CRPD, where people with intellectual disabilities who have previously been labelled as having severe or profound intellectual multiple disabilities (PIMD) are referred to as "those who require more intensive support", thus placing the focus on supporting people's needs instead of emphasising their impairment. In this article we use the CRPD's term of requiring more intensive support when we refer to people with PIMD.

2004). However, despite this growing body of literature within the field of disability studies, the voices of people who require more intensive support have received limited attention, albeit with noteworthy exceptions (e.g., Boxall and Ralph 2011; Goode 1994; Griffiths and Smith 2016; Nind 2006; Clement and Bigby 2013; Metola, Miettinen and Vhemas 2017).

Furthermore, there does not seem to be a shared understanding within the literature as to how to understand and apply the concept of autonomy in the lives of disabled people who require more intensive support. Often the concept is used interchangeably with terms such as self-determination, independence and empowerment (see further, Guess, Benson and Siegel-Causey 2008; Wehmeyer 2005).

This article is an attempt to develop a concept of personal autonomy that does not exclude people with intellectual disabilities who require more intensive support. To do that we ground our work on the ideas of relational autonomy. The aims of the article are: Firstly, to demonstrate how personal autonomy can be understood in the lives of people with intellectual disabilities who require more intensive support. Secondly, to evaluate whether they are given the status of an autonomous agent in their daily lives and, thirdly, how their autonomy could be enhanced.

Relational autonomy

Many scholars have in their writings shown how not noticing someone or behaving as if he or she does not exist is dehumanizing and can even result in neglect and violence (Sobsey 2006; Winch 1987; Weil 1986; Gaita 2002). One way to oppose this is to see others as persons and acknowledge the importance of autonomy in their lives. In classical philosophy autonomy is understood as the capacity of the individual to make rational choices free from undue interference of others (Dworkin 1988; Kant 1981; Rawls 2009). Individualistic and rationalistic understandings of autonomy, such as these, base the concept on the ability of individuals to reason and evaluate their own situation with the self as a separate entity, isolated from, for example, age, gender and culture (Stoljar 2015). Consequently, those who need support (Friedman 2000), those who do not possess spoken language, or are perceived as lacking cognitive capacities such as reason (Davy 2015), are denied the ethical status of autonomous agents and indirectly described as "lesser moral beings" (Davy 2015; Carlson 2010). This has made the concept of autonomy of questionable value in the discourse on the lives and rights of people with intellectual disabilities.

We are here faced with the dilemma of the conception of autonomy; being on the one hand viewed as an important right used to oppose dehumanizing behaviour, but on the other hand seen as a concept that can marginalize oppressed groups. To solve this dilemma there have been attempts to reconceptualise autonomy. Instead of basing autonomy on an individualistic, rational and free self, the conception of autonomy is refigured and starts from this premise:

> …that persons are socially embedded and that agents' identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender and ethnicity. Thus the focus of relational approaches is to analyse the implications of intersubjective and social dimensions of selfhood and identity for conceptions of individual autonomy and moral and political agency (Mackenzie & Stoljar 2000: 4).

This approach, labelled relational autonomy, makes it possible to evaluate external influence on personal autonomy since the importance of context in shaping our character and personal autonomy is acknowledged. It can better detect and phrase oppressive situations, as well as establishing the responsibility of others in enhancing personal autonomy. From a relational perspective, the development of the self is a process that takes place in relations with other people, and autonomy is, therefore, not understood solely in terms of independence and self-determination. The formation of the person's desires, beliefs and emotional attitudes is influenced by social norms, social institutions, cultural practices, and relationships (Mackenzie and Stoljar 2000).

When introducing a concept of autonomy to be used in the lives of people with intellectual disability who require more intensive support it is necessary that the autonomy concept must be *inclusive* i.e., it can be applied in the lives of everyone, but it should still hold the important features of *agency*. The theoretical underpinnings of such a concept have already been laid out in an article by Davy (2015). She bases her approach on the idea of relational autonomy, grounding her understanding of autonomy on relations between persons where *support*, *advocacy* and *enablement* of autonomy capacities are seen as key elements of personal autonomy. Examples of supportive structures are family and friends, as well as emotional and financial support. Advocacy refers to the importance of interpretation and translation of meaning, as well as making space for the expression of the agent. This is of fundamental importance in the lives of those who cannot express themselves with words. It is very important that their specific interests be represented and their full humanity recognized. This recognition, as well as creating the space necessary for them to express themselves, is also a prerequisite for enablement; that is, being able to cultivate one's autonomy capacities. These ideas aim at conserving agency as the key element of autonomy, but instead of focusing on reason, language and non-interference, the focus is on support, advocacy and enablement. The responsibility for our personal autonomy is therefore not understood as being solely personal but dependent on our context and relations.

The concept of relational autonomy has already been used to interpret qualitative research results from the lives of people with intellectual disabilities (Björnsdóttir, Stefánsdóttir and Stefánsdóttir 2015). In this article, we will refer to

Davy's (2015) theoretical interpretation of relational autonomy and use it to describe and reflect on autonomy in the daily lives of the participants in this research.

Methods

In this qualitative research data were collected in Iceland during the years 2013 and 2014 through participation observation and focus group interviews.

Data collection

Participant observations were conducted in the homes and daily activities of 24 individuals with intellectual disabilities who require more intensive support. The second set of data was collected through focus group interviews with support staff. The data were collected by the first author and her research assistants (3). The researchers had considerable experience in working with people with intellectual disabilities who require more intensive support and practical knowledge of alternative modes of communication, which turned out to be valuable during the observations where the research participants communicated with facial expressions, gestures, sounds and movements.

Since the research participants do not communicate verbally, participant observations were carried out for the purpose of gaining an understanding of their everyday life and participation (Creswell 2008). Scholars like Goode (1994) have argued the importance of including people who communicate without using words in research involving their life and experience. Respect and recognition of alternative ways of communication is essential for the inclusion of this group of people in research, as is the involvement of those, who are experienced in interpreting their wishes.

Participant observations involve the researcher entering the field of study, observing the participants in their natural settings, and documenting their behaviours, practices, and interactions (Creswell, 2008). By spending time in the field the researcher becomes familiar with the rules and values of the cultures she studies; that is, she becomes more culturally aware or sensitive (Goodley 2001). Two to three participant observations were carried out in each home and lasted from three to five hours. The researcher also followed each person in daily activities such as visiting a day centre or during leisure activities, for example going to a café or other activities. Following each observation, the researcher recorded everything seen and heard as precisely as possible. These notes included practical descriptions of the homes and how they were organized, in which daily activities each person participated and how, as well as providing more detailed reports on the way participants interacted with staff, signs they used to communicate and how the staff reacted. The researchers also included in the notes all situations they could observe that seemed to either hinder or encourage participants when making choices that influenced their daily life.

The level of direct communication between researchers and research participants varied and depended on the willingness of the research participant to engage with the researcher. While some of the participants did not seem interested, others had the initiative to communicate as shown in the following example from a field note:

> When I arrived in the room Drífa, (a young woman in her thirties) was playing the piano together with her support staff member. I sat down beside her. In the beginning she didn't show any interest in me so I just sat there for about five minutes. Then she suddenly grabbed my hand and put it on the piano. We then played together for a while and Drífa smiled and laughed while we were playing. [Translated by first author from Icelandic].

Additional data were collected in three focus group interviews with twelve staff members who worked in the participants' homes. Each focus group comprised four staff members. The aim of the interviews was to collect information on the circumstances of key participants, as well as the perspectives of staff as to how to appropriately support people's decision making. Each group met once, for 60–80 minutes at a time. The interviews were digitally recorded and transcribed verbatim.

Data analysis

The participant observations and interviews were analysed by means of thematic analysis with the purpose of identifying repeated ideas and actions in the data in order to form a broad picture of how autonomy is experienced in the participants' lives. As mentioned before, in their notes the researchers described precisely what took place during the observations and how the research participants reacted to their environment. The data from each observation were analysed soon after it was carried out and again at the end of the process when all the observations had been conducted. The first author discussed each observation with her research assistants to prepare for the data analyses; that is, which phenomena she was singling out for coding. Axial coding was used for the purpose of portraying interrelationships between coding categories and in order to make the analysis process more systematic (Creswell 2008). Doubts and problems concerning the definitions of categories and coding were discussed and resolved within the research team. Three main themes were drawn from the analysis of the participants' observations; good practices, rigid routine and authoritarian attitudes. These themes where used as a source for the interview questions in the focus groups.

Participants

The 24 participants who had all been labelled as having severe or profound disabilities were aged 26–66, eleven women, thirteen men; fourteen lived in the capital area and ten in rural areas. Some of the participants lived in group homes and others in assisted living arrangements. In the group homes each participant has his/her own bedroom but all other facilities are shared. In the assisted living arrangements, each individual generally has a small flat at his/her disposal in small apartment buildings, with four to six flats. These houses have been built specifically for disabled people and usually there is also a shared area, office space and a break room for support staff. The participants were chosen by purposeful sampling which selects participants and sites intentionally; that is, seeking people and sites with experience and knowledge of the matter under investigation (Creswell 2008).

Ethical challenges

One of the fundamental principles in research ethics is the requirement of informed and unforced consent which involves, *inter alia*, that participants must know the subject of the research, how it is conducted and whether they run any risk of being harmed by participating (Bogdan and Biklen 1998). The participants in the research could not indicate in a clear and decisive manner whether they were interested, and/or wanted to participate. To seek informed consent, therefore, their support staff was contacted. They, in turn, presented the request to the closest relatives and in cooperation with those who best knew the individual in question, an assessment was made as to whether he/she was interested in participating. Subsequently permission to participate was granted. Most of the staff and relatives were positive towards the research and were willing to assist in every way. The researchers also took care to closely observe the participants' reaction to their presence and were prepared to retire if any signs of unease were noted. In addition, the researchers were careful to withdraw when participants' private needs were attended to. All measures were taken to ensure that the observations were carried out with the research participants' consent.

Another important pillar in research ethics is just distribution of benefits and harms. This rule has been used to exclude people in a vulnerable position from participating in research as they must be protected from risk. This belief has been contested, since excluding vulnerable groups from taking part in research not only protects them from risk, but also prevents them from benefiting from research advances (Shamoo and Resnik 2009). When focusing on the group under discussion here, one could also point out that protectionism and authoritarian attitudes in research towards individuals labelled as having intellectual disabilities have prevented them from having a voice, not only in their private life, but also publicly through research publications (Björnsdóttir and Jónsson 2015). Exclusion from research participation on those grounds has also resulted in the silencing of people with intellectual disabilities who require more intensive support (see e.g., Boxall and Ralph 2011).

From the above, when studying the group under discussion here, it may be gathered that securing informed consent by traditional means, using the ethical guidelines of research is a complex matter. The present research attempted to find ways to overcome these complications, emphasising, at the same time, their human dignity and the importance of allowing this group to be heard.

Every precaution has been taken to remove all identifiable characteristics. Detailed descriptions of participants were also avoided and occasionally descriptions of local conditions were modified to prevent recognition of the person in question. Ethical procedures in this research complied with the Icelandic Data Protection Act (Ministry of the Interior No. 77/2000) and Regulation on Scientific Research in the Health Sector (Ministry of Welfare No. 286/2008). The research proposal was sent to the Data Protection Authority in Iceland (Ministry of Welfare No. 88/2011) and received a formal receipt of notification. The research was also approved and funded by the University of Iceland Research Fund.

Findings

The research findings demonstrate that the old authoritarian approach, where the will and choices of people who require more intensive support are ignored, is slowly fading out. The staff generally tried their best and took great care to foster a considerate and attentive attitude toward the research participants. But despite good intentions, there are also indications that much work is still to be done regarding perspectives and practices. In this part of the article, we introduce three themes drawn from participant observations and focus group interviews and examine how the autonomy of the participants can be evaluated and in some cases enhanced. The themes are: good practices, rigid routines, and authoritarian attitudes.

Good practices

Previous research has demonstrated that the attitudes of staff and family members either hinder or support disabled people's development of personal autonomy (Björnsdóttir, Stefánsdóttir and Stefándsóttir 2015). Well into the 20th century, disabled people were not fully valid members of society; they were dependent upon the goodwill of others, looked upon as eternal children and thus expected to be obedient and grateful for any support they received (Rice, Björnsdóttir and Smith 2015).

The findings of this research indicate that the above-mentioned attitudes have changed somewhat for the better over the past decades. In some of the homes observed, the age and privacy of the research participants was respected;

they were treated like adult individuals. For example, in one home regular team meetings were held, involving the superintendent, a staff member, the residents and, in some cases, a family member. Various matters concerning autonomy were discussed and solutions were sought with emphasis on respecting the wishes of the persons involved, to make it possible for them to maintain their dignity and respect. One matter requiring immediate attention arose concerning a research participant called Gunnar, a man in his forties. According to the recommendation of his physiotherapist, he was put on a standing frame once a day. This, according to the superintendent, had been done for some time and the purpose was to give Gunnar better posture by making his body stand straighter and improve his balance. This was also to prevent osteoporosis. Gunnar disliked the frame and protested by making distressed sounds and facial expressions all through the exercise. Sometimes he cried and in an attempt to remedy the situation, the staff played music for him and read to him, but without success.

A meeting was scheduled to discuss Gunnar's situation. Attendees were Gunnar, a close family member, the superintendent, and Gunnar's physiotherapist. Gunnar's opinion was very clear – he did not want to go on the standing frame. The physiotherapist suggested that instead of the standing frame they could try some exercises, stretches, and massage, since the stress of being placed on the standing frame seemed to be making his muscles even tenser and interfering with the objective of the exercise. Gunnar showed his approval of this proposal by smiling. Several weeks later another meeting was scheduled where the physiotherapist assessed Gunnar's situation and confirmed that the exercises and massage had not caused any decline in Gunnar's condition. Gunnar also expressed with smiles and gestures that he was happy with this solution and indicated he was relieved that he did not have to use the standing frame anymore. This example shows how attitudes and practices of staff members can enhance autonomy in people's lives. By including him in the meetings along with a person that could help in interpreting his wishes they managed to include Gunnar in the decision process. A different option would have been to ignore him and not include him in the meeting, since he was unable to speak and thus assumed to be unable to take part in decision-making. That option would have undermined Gunnar's agency and respect as a human being, thus allowing the staff to forget his selfhood. It is also worth noting that Gunnar's wishes were taken seriously and respected in spite of the fact that medical experts had decided that the standing frame treatment was the most beneficial. This, however, was not done without consideration. Autonomy is in this case not just about following wishes; they have to be balanced against his welfare. The role of the support staff is to notice Gunnar's expressions, take care to interpret his gestures and thus secure his participation. His expressed will should not be accepted without deliberation. It has to be allowed to influence the conclusion, but the role of the staff is also to help him to find solutions and take his interest into account. In this case, we can conclude that Gunnar was listened to, he was taken seriously and he therefore possessed the status of an autonomous agent. By respecting his expression and by enabling him to take part in the decision he is also allowed to exercise his agency and develop his autonomy capacities.

As mentioned above, the research participants either lived in group homes or assisted living arrangements for disabled people. This means that they shared support and living space with other disabled people. The number of staff on duty at any one time differed greatly between the participants' homes. In some homes there was almost one member of staff per resident, while in other cases several residents had to share one staff member. In two of the homes there was a written policy to the effect that the organization of the home should be founded on the individual needs of the residents. In these homes each resident had his/her own personal carer who attended to his/her requirements. Even if staff shortages made this impossible to carry out to the letter, it was attempted. What made these two homes stand out was the fact that the superintendents had a clear ideological vision, their guiding lights were respect for the residents, human rights as stated in the CRPD and knowledge of alternative communication. Also, the superintendents emphasized the need to familiarize all staff members, including unqualified staff, with this ideology and explain how it could be put into practice.

The CRPD deals with freedom to express and hold opinions, and Article 21 specifically states that appropriate measures must be taken to ensure that disabled people can enjoy their right to express themselves and freely voice their opinions. It also states that all methods used by disabled persons to make their wishes known must be accepted and it is emphasized that all staff must make themselves acquainted with the various forms of communication. In the homes where staff were most successful in reading these ways of communication, staff members had a good working knowledge of the various methods used by the individuals to express themselves and showed an instinctive ability to interpret the wishes of the residents. Both the CRPD and the relational understanding of autonomy emphasise the responsibility of those giving support to enhance the capacities of residents to express themselves and give them the space they need to take part in shaping their lives, thus to act as autonomous agents. Therefore, it is fundamental for good practices not to limit support to basic bodily functions, but to extend the idea of support to functions like expression of one's will and development of character.

Rigid routines

The findings suggest that the support provided for the research participants and the organization of facilities in their homes influenced their personal autonomy. As mentioned above, many of the research participants received support from different staff members and shared support staff with many others living in the home. The most common setup

was one which was cut to suit the whole rather than the individual; in other words, there was a fixed routine in place. Meal times were usually at the same time every day for everyone, and bath times were on previously determined days. Staff argued that the support was organized this way because the homes were understaffed and it was therefore impossible to attend to the needs of each individual separately. A staff member described the situation in one such group home thus:

> Everyone has to wake up quite early. There is only one communal bathroom and only one person on night shift whose job includes waking the residents and making them ready to use the bathroom when it is their turn. In the evenings we must assist those in need of help to undress and get into bed before the night shift comes on duty, which is of course a dreadful state of affairs because then they also hear the other residents who are not already in bed in the communal area. Since there are so few on duty there must be a strict routine, but some-times it is not even possible to stick to it.

It is known that conditions as described here require a strict routine, reminiscent of the old stereotyped institutions built on inflexible rules and routines, where the staff bore all the responsibility for residents' in daily life and made all their decisions for them. It has been argued that the organizational properties of institutions and institution-oriented services are very tenacious regarding services and support for disabled people. Old-fashioned attitudes and practices have often been transferred from the institutional environment to community living arrangements (see e.g., Björnsdóttir and Traustadóttir 2010). According to our analysis of the observations conducted in the participants' homes, many such examples were found, where rigid routines, practices and authoritarian attitudes were exercised which resulted in sub-standard support and their homes having institutional qualities.

Another explanation of the rigid routine-based practices, offered by a staff member during an observation, was as follows: "We have always done it that way, and it is best for them too, they need routine … They go by what we decide". Johannes, a 32 year old man who lives in a group home, took walks every day at the same time, accompanied by a staff member. Johannes made it clear by making facial expressions and loud noises that he did not want to go for a walk. His carer was, however, of the opinion that it was in Johannes' best interest to go for a walk and keep to the routine, and argued: "it is so good for the soul to go out for a walk". Such attitudes show that Johannes' will is not taken seriously and the staff does not give him the space he needs to express his opinion, nor do they provide the necessary support for interpreting his meaning and enabling his autonomy to develop. Since we claim that autonomy is an ethical value to be applied in the lives of everyone, these attitudes are not only barriers to autonomy but can also be labelled as oppressive since the agent is not seen as capable of being an autonomous agent and hence not respected as such. When this is ignored he cannot flourish and develop as an autonomous agent.

When the support was organized to suit the whole instead of the individual there seemed to be a tendency to tailor the routine to those who could express themselves verbally, which creates circumstances where those who use alternative modes of expression need to adapt their preferences to others' needs and wishes. Helga, a woman in her thirties, lived in a group home and shared support and living spaces with two young men who enjoyed going to cafés. Helga often went with them, even though she had to be fed through a feeding tube because of difficulties swallowing (dysphagia), since there were not enough members of staff to look after her while the young men visited the café. Spending time in cafés is not only about drinking and eating, it is also about socialising, but Helga didn't seem to enjoy these trips and slept in her wheelchair for most of the time. In one of the focus group meetings with the staff this came under discussion where it was mentioned that Helga enjoyed activities like going to concerts and art exhibitions, but because the home was understaffed such trips were seldom on offer. It seemed as if her wishes were not a priority in the staff's choices. This shows the importance of speech. Most likely without realizing it in the daily routine the staff has tendencies to marginalize her wishes and expressions. When individuals time and time again have to tailor their activities to suit someone else, they do not get the opportunity to develop their autonomy capacities and this undermines their independence. They lose their belief, or never learn, that they can decide for themselves. This example clearly shows the importance of advocacy, especially for those who depend on alternative modes of expression, to provide the necessary space for the agent to act and develop. If this is ignored as in the example of Helga she has fewer options to develop her self-realization and character. She is not expressing herself in a way that influences the choices made in her life, instead she is likely to become docile and deferent (Stoljar 2015).

In order to make it easier for some of the participants to be aware of the daily routine, some homes followed a fixed daily schedule. Ragnar, a participant just over 30 years old, lived in assisted living arrangements and had a staff member who helped him for a large part of the day. A daily rota was set up for him in the form of a table with pictures indicating what activities were to be expected that day. Ragnar seemed to approve of this system and smiled when he noticed that the plan included a visit to the shops. However, he showed little interest in pictures relating to mealtimes, closing his eyes and turning his head away. According to the staff member, this system increased Ragnar's sense of security and showed him what was to be expected that day. It was, however, noticed that Ragnar was not given many choices. For example, he was not shown pictures of different activities so that he could choose what he himself wanted to do. In this example Ragnar is not given the chance to develop the sense of being an active agent. The prerequisite

for him to do that is not just to follow a plan, but to also have options presented to him. This could be interpreted as a lack of advocacy where the agent is not given the space he needs to form an opinion so his voice is not heard (Davy 2015). The above example draws attention to the importance of always showing respect to the residents' expressions and never ignoring them as if they were not autonomous agents. Respecting their will does not necessarily mean that their will is always followed without any thought, it means that it is always noticed and it is always considered honestly and seriously. Condescending attitudes, for example indifference and disrespect, are not only a form of oppression and violence, but also are a serious barrier to both exercising and developing autonomy. We will look into this further in the next section.

Authoritarian attitudes

The research findings demonstrate that staff generally tried their best and took great care to foster a considerate and attentive attitude toward the research participants. But despite good intentions, there are also indications that much work remains to be done regarding attitudes and practices. There were examples where the age and privacy of the research participants was not respected. The participants were often spoken to in a childish and loud voice, addressed in the third person, and even talked about in their presence as if they were not there. Staff would enter their rooms without knocking on the door and leave the bathroom door open while attending to the participants' personal needs.

The majority of support staff in the homes observed were unqualified; that is, they had not received any formal training or education. These employees talked of lack of professional instruction and said that they mostly learned from one another. Often the superintendent was qualified, for example as a social educator or a social worker, but the large majority of staff were unqualified. As mentioned above, some superintendents made efforts to train and inform staff members, but our findings demonstrate that often this was not enough, as, although familiar with the ideology, staff commonly found it difficult to translate it into practice. One member of staff stated: "No matter how hard we try, this ideology does not suit this particular group. They need care and nursing most of all, and it is silly to act as if they can make their own decisions." The research participants communicated in different ways, for example by sounds, movements, pointing and facial expressions, but it differed greatly how much effort staff put into understanding these efforts and how much notice they took of them. The fact that they can express themselves is often ignored and they are belittled to the point where their humanity is questioned. By referring to the relational understanding of autonomy we acquire a shift of perspective when we evaluate communication. Instead of focusing on the lack of precision in expression on behalf of those who are not using spoken language, as is done in the example referred to above, the emphasis should be on those in their surroundings to notice and interpret their signs. This is necessary to be able to respect their agency and to enhance their autonomy. Communication is always a two way process and the main responsibility of the communication here being on the staff to figure out how these individuals express themselves and how they should interpret and respond to them. As the ability to express one's meaning decreases, the responsibility of the surroundings to facilitate and support the communication and thus the autonomy increases.

Another example of authoritarian attitudes and institutional practices is the case of Maria, a woman in her twenties, who communicated by calling out and making noises when she wanted attention. The staff ignored her calls most of the time and claimed that she had to learn that it was not always possible to run around at her beck and call. If this attitude results in the defeat of the resident it happens because she is ignored and experiences constant denial. She then gives up trying to communicate wishes and choices. When it becomes futile for a person to express a choice or preference, it can cultivate a self-image where one deserves no better and puts up with a situation which is degrading and unacceptable (Stoljar 2015). Maria however, did not give up; she demonstrated resilience and protested these oppressive practices. There were other examples where it seemed that individuals appeared to demand very little and had learnt to please the staff. Katrín, a woman in her fifties, had lived for a long time in an institution but now lives in a group home. According to staff members she made few demands for attention, even though they tried their best to respect her wishes. On the other hand, she often smiled to staff and one of them pointed out that perhaps, as she had lived so long in an institution, she had learnt it was for the best to go where staff decisions led; that way she got her own way more easily than by complaining.

People's homes are expected to be a safe haven, which provides them with security and peace and should mirror their personality. Institutions, on the other hand, have their own character and those who live there have little or no say in creating their surroundings. The homes of some of the participants had institutional qualities, both regarding design and practices. The above examples show that staff attitudes had a considerable impact on the support given to participants and greatly affected whether they were given the opportunity to develop their personal autonomy and maintain their dignity.

Conclusion

In this article we have used the idea of relational autonomy to interpret findings from a qualitative study on the lives of 24 Icelanders with intellectual disability who require more intensive support. We have applied a theoretical outline of the concept that views autonomy as an inclusive concept, but still honours the importance of agency as the core of our understanding of personal autonomy.

Firstly, the aim is to demonstrate how personal autonomy can be understood in the lives of people with intellectual disabilities who require more intensive support. To be able to respect agency, and hence the autonomy of the participants in this research, we emphasise how important it is that those who support them should view them as socially embedded, where personal autonomy is formed in relation to other people. The emphasis should be on supporting them, on interpreting and advocating their wishes and enabling them to develop their autonomy capacities. Thus it is necessary to acknowledge the responsibility of the environment, family and support staff in particular, for the realization and development of their personal autonomy. In our interpretation of the research findings we have referred to this understanding of the autonomy concept and our conclusion is that by applying this approach we can define personal autonomy as a meaningful value in the lives of all the participants in this study.

Secondly, we used this approach to evaluate whether participants were given the status of an autonomous agent in their daily lives. The research participants were not always given due respect as autonomous agents; that is, support staff did not always make space for them to express their wishes and take care to interpret them and evaluate their expressions as significant when decisions regarding their lives were made. This can, on the one hand, be explained by stereotypical social norms which view people with intellectual disabilities as incapable of making meaningful choices and, on the other hand, by not admitting to the responsibility of others in the lives of the autonomous person.

Often when people with intellectual disabilities do not demonstrate the ability to make choices; that is, when they do not show initiative or when they try to please the staff, this is interpreted as characteristic of their impairment (Björnsdóttir, Stefánsdóttir and Stefánsdóttir 2015). We contend that by doing so the staff, on the one hand, underestimates how the capacity to make choices and express their agency develops in relation to the environment and, on the other hand, they fall into an essentialist trap by attributing any limitations to the impairment.

The research findings indicate that some of the support staff at different homes commonly observed had the residents' best interests at heart and tried their utmost to provide them with care and respect. However, many struggled with involving the people they were supporting in decision-making, unintentionally undermining their agency and often the practices benefited the whole instead of the individual. In contrast the residents had to adapt to the wishes of others. This hinders the presence of factors like a supportive environment and advocacy which are necessary to enable autonomy to develop. Further, there is a risk of oppression and even violence where people accept situations that are unacceptable. The overall results do indicate, however, that there is a positive change regarding the perception towards people with intellectual disabilities who require more intensive support and the old authoritarian approach to support, where their will and choices are ignored is slowly fading out.

Lastly, our aim is to show how the autonomy of people with intellectual disabilities who require more intensive support could be enhanced. We claim that it is important, for support staff to be aware of their responsibility in enhancing the autonomy of residents. One prerequisite for people being able to show different wishes is having significant options. As stated above, few participants were provided with significant options to act upon. Exemplary situations were observed where the participants were included in decision-making, for example at team meetings, and when staff made efforts to understand how the individual communicated his/her desires and attitudes. In such cases it became apparent that with appropriate support, where their choice was interpreted, participants were included in the decision making process and were given the opportunity to develop their agency and personal autonomy.

From the findings we draw the conclusion that a considerable advance can be made in the homes of disabled persons who require more intensive support to increase their personal autonomy. To do that, it is necessary to understand autonomy relationally and define it as an inclusive concept where the support staff becomes responsible for the development and practice of the personal autonomy of the residents. Hence, those who require intensive support need to be given the space to act as agents; that is to say, their way of expression must be respected by noticing them and interpreting their signs, thus allowing their character and meaning to influence their daily lives. The benefit of this approach lies in making personal autonomy meaningful as a value in their lives, thus enhancing the quality of life of people with intellectual disability who need more intensive support.

Competing Interests
The authors have no competing interests to declare.

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