Article

'It's my life': Autonomy and people with intellectual disabilities

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Abstract

This article discusses autonomy in the lives of adults with intellectual disabilities. The article draws on inclusive research in Iceland with 25 women and 16 men and employs ideas of relational autonomy from the perspectives of the Nordic relational approach to disability. In this article, we examine autonomy in relation to private life, that is, homes and daily activities. The article demonstrates how practices have improved with time and seem less paternalistic. However, the article also demonstrates that the assistance people with intellectual disabilities receive in their homes often has institutional qualities, and they are often met with belittling perspectives from staff and family members. Furthermore, many did not have access to important information needed to develop individual autonomy and independence, including making their own choices. The research findings suggest that people with intellectual disabilities can with appropriate support develop individual autonomy and make their own choices.

The Convention on the Rights of People with Disabilities (CRPD) is an International Human Rights Treaty, which specifically recognizes the 'importance for persons with disabilities of their individual[1] autonomy and independence, including the freedom to make their own choices'

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(United Nations, 2007). Historically, people with intellectual disabilities have lacked access to individual autonomy, have not been allowed to make their own choices and have argued that due to their impairment they are not capable to do so (Carlson, 2010). This article reports on a qualitative research carried out in Iceland, with 41 individual with intellectual disabilities aged 26–66. The aim of this ongoing research is to explore autonomy in the lives of adults with intellectual disabilities and to identify various sociocultural factors that either motivate or discourage them in exercising autonomy with a particular focus on their own perspectives and how they actualize autonomy in their daily lives.

Disability studies have mainly been dominated by the social sciences, where research, particularly in the Nordic countries, has focused primarily on disability policy and the daily lives of disabled people. The academic fields of disability studies and ethics seldom intersect, with few noticeable exceptions (e.g., Carlson, 2010; Louhiala, 2004; Reeve, 2009; Vehmas, 1999) that mainly focus on issues such as research ethics, biomedicine, euthanasia and other (bio) ethical and clinical issues. This research project brings together these two fields of study, creating a space on one hand for new ways of thinking about disability and on the other hand the ethical issue of autonomy.

The academic field of ethics involves the philosophical examination of values in human life. Applied ethics is contextual and employs the concepts from theoretical ethics on real examples in daily life in an attempt to identify and better understand contemporary ethical and moral issues and propose a morally appropriate approach or solution to these issues (Toulmin, 1982). The interdisciplinary field of disability studies challenges the medical conceptualization of disability that focuses on impairment as the source of difficulties in disabled people's lives. Instead, disability studies critically examine the role of society and culture in shaping the lives of disabled people (Gabel, 2005). This research is located within the Nordic relational approach to disability that has its roots in the Nordic welfare states that is based on ideas of citizenship and equality of all people (Gustavsson et al., 2005). In the Nordic context, disability is viewed in relational terms and understood as the result of the discrepancy between the disabled person's capabilities and the functional demands made by the society, which does not assume the full range of human diversity. A person is therefore defined as disabled if she/he faces barriers in everyday life due to limited abilities, diseases or other impairments (Tøssebro, 2004). Disability is also viewed as contextual and situational rather than an absolute essence of the person and relative to the environment (Tøssebro, 2004). This article is guided by the Nordic relational approach to disability and the autonomy of people with intellectual disabilities will be explored through the theoretical lens of relational autonomy, which focuses on the self in a relative context rather than an individualistic approach to the self (Mackenzie and Stoljar, 2000).

There is a growing body of literature concerned with people's autonomy within the context of intellectual disabilities. However, there does not seem to be a common understanding of autonomy, and it is seldom conceptualized and often interchangeably used with terms such as self-determination, independence and empowerment. This body of research comes from different traditions and includes philosophical approaches (Meininger, 2001), statistical measurements (Martorell et al., 2008; Nota et al., 2007) and qualitative approaches (Gilmartin and Slevin, 2010), and these traditions seldom intersect.

The literature on autonomy of people with intellectual disabilities has largely focused on the perspectives of parents and professionals, and the voices of people with intellectual disabilities have, with few exceptions, been absent from this discussion. The transition from youth to adulthood is an important milestone in one's life course, and it has been given considerable attention

within the research literature, which has demonstrated the difficulties that parents and youth with intellectual disabilities are faced with. Parents often fear the risk associated with their children's increased independence and autonomy and the young people often need continuous support and assistance in their daily lives (Björnsdóttir, 2009; Mill et al., 2010; Murphy et al., 2011). When young adults leave home, this tension is often transferred to professionals and support workers who are conflicted by the intersection of duty of care, professionalism and their duty to recognize people's autonomy (Hawkins et al., 2011). This is an important issue because there is evidence that people with intellectual disabilities can develop and employ individual autonomy if they are provided with adequate support (Nota et al., 2007; Wehmeyer and Garner, 2003; Wullink et al., 2009). These studies have shown that various environmental factors can contribute to the opportunities to make choices regarding such issues as employment and residential settings (Jahoda et al., 2008; Nota et al., 2007; Wehmeyer and Palmer, 2003). Other factors influencing people's sense of control over their lives have been named such as taking part in self-advocacy, which has been defined as the act of fighting for one's needs and wishes, rather than relying on others to speak on their behalf (Gilmartin and Slevin, 2010; Goodley, 2000). Studies focusing on self-advocacy have mainly focused on social barriers instead of individual limitations and emphasized the importance of having control of one's life and having the freedom to make choices (Atkinson, 2002; Boxall et al., 2004; Chapman and McNutty, 2004). Self-advocacy groups have proven to serve as an important and powerful tool in the empowerment of people with intellectual disabilities and have the potential of providing space for the development of individual autonomy (Aspis, 1997; Björnsdóttir and Svensdóttir, 2008; Goodley, 2000).

Autonomy is an important issue to investigate in relation to people with intellectual disabilities because on the one hand international human rights treaties, national legislations and policy recognize their right to individual autonomy. On the other hand people with intellectual disabilities have lacked a voice, authority and control over their lives throughout history. It has not been until recently that people with intellectual disabilities have been acknowledged as valuable contributors to the discussion concerning intellectual disabilities (Walmsley and Johnson, 2003). In this article, we examine autonomy in the lives of adults with intellectual disabilities by focusing on the private sphere, that is, their home and daily life.

Relational autonomy

Individual autonomy in its simplest definition refers to governing one's actions. Classical theories of autonomy based on the ideas of Immanuel Kant (1785) and Gerald Dworkin (1988) base the concept on the ability of individual to reason and evaluate his/her own situation. They go from the notion that individual is a free rational being, an autonomous agent. This has made the concept of autonomy of questionable value in the discourse on the lives and even rights of people with intellectual disabilities.

In this research, we draw on the works and criticism of feminist writers on the classical definition of autonomy and build on what has been called *relational autonomy* (Mackenzie and Stoljar, 2000; Meyers, 1989). These theories aim at giving a more adequate explanation of autonomy among oppressed individuals and are concerned with various ways at which oppression can diminish autonomous agency. They describe a richer account of the autonomous agent where she is conceptualized as having feelings and desires as well as being rational. The innovation of describing autonomy this way is the contextual definition of the self, instead of

regarding the self as a separate entity isolated from for example age, gender and culture. The feminist criticism on the Kantian notion of the self points out that if the self is regarded as an isolated entity the individual is placed in a position independent of others and of the forces of society. Important aspects of life like care, age and disability are therefore ignored. Furthermore, factors shaping our social identity like gender, sexuality, race and class become invisible. Feminist scholars have argued that this view on the self is both impossible and unrealistic (Meyers, 2010). Furthermore, if the moral subject is to be reduced to the capacity of reason and is situated outside and above all context, it will be difficult to account for internalized oppression (Meyers, 2010). To illustrate her point, Meyers quotes the writings of Bartky and Babbitt that claim it is common for women to view themselves in the light of being women and hence limit their expectations. They internalize feminine goals that are not equal to masculine goals (Meyers, 2010). These destructive goals will then be internalized in their thoughts, emotions and the very instincts of the self. A contextually based definition of autonomy on the other hand describes the problem of internalized oppression and how external situations can influence the development and growth of the individual and how it becomes possible for one to oppress herself from within (Meyers, 2010). Theories on relational autonomy aim at researching the connection between the agent's self-conception, her social context and her capacities for autonomy. The relationship between autonomy and feelings such as self-respect, self-worth and self-trust are therefore in focus (Mackenzie and Stoljar, 2000).

In this research we claim that the valuable insight of this feminist criticism can be transferred to other marginalized groups in the society that experience structural domination. The values of defining autonomy contextually are not only in the sensitivity towards internalized oppression but also in opening ways to relieve the oppression and prevent it. This is of special importance when addressing the situation of people with intellectual disabilities. From a relational perspective, the development of the self is a process that takes place in relations with other people, and autonomy therefore is not understood solely in terms of independence and self-determination (Mackenzie and Stoljar, 2000). In the concept of relational autonomy, people with intellectual disabilities, including those who have been labelled as having severe disabilities, can develop autonomy because it is not simply determined by the evaluation of individual competency. Furthermore, it has been argued that this understanding of autonomy creates space for the empowerment of people with intellectual disabilities (van Hooren et al., 2002). However, the concept of empowerment has not been clearly defined within the disability studies literature (Björnsdóttir and Sigurjónsdóttir, 2013). Nonetheless, it has been argued that 'for many disabled people the search for empowerment begins with, and is generated by, the experience of disempowerment' (Swain and French, 2008: 139) and the disempowerment among people with intellectual disabilities has been clearly argued in the current literature (e.g., Rapley, 2004; Sigurjónsdóttir, 2006). For the purpose of this article we will however not focus on the concepts of empowerment and disempowerment but instead use the idea of internal oppression and interdependence drawn from the concept of relational autonomy.

The relational approach to autonomy fits well with the Nordic understanding of disability and the CRPD, which assumes that disability stems from interaction between people with impairments and attitudinal and environmental barriers. In the attempt to add to the understanding of autonomy in the lives of people with intellectual disabilities, we will from a relational point of view aim at answering two questions, that is, (1) how do people with intellectual disabilities make choices in their homes and daily lives? (2) What factors hinder and encourage their development of individual autonomy?

Methods

This research is located within the qualitative research tradition that involves the collection and study of empirical data that describe the experiences and meaning in people's lives (Denzin and Lincoln, 1998). The qualitative research design is flexible and does not rely on standardized questionnaires or guidelines, but people are instead asked to describe their lives, values and experiences in their own words (Bogdan and Biklen, 1998; Taylor and Bogdan, 1998). Qualitative research is inductive in nature. 'Qualitative researchers develop concepts, insights and understandings from patterns in the data rather than collecting data to assess preconceived models, hypothesis or theories' (Taylor and Bogdan, 1998: 7). Qualitative approaches are commonly used in research with people with intellectual disabilities and assume that everyone has a story to tell and all perspectives are equally important.

This is an ongoing research study that started in 2011 and is scheduled to end in 2015. Data were collected through a combination of semi-structured interviews and participant observations, which involved the researcher to enter the field of study, observe the participants in their natural settings, which in this case were their homes, and document their behaviours, practices and interactions (Creswell, 2008). The purpose was to gain better understanding of the daily lives of the research participants, which was particularly important in those cases when the participants did not speak and communicated without using words by, for example, using sounds, body language, facial expressions and gestures. We find it important to include individuals in our research with more significant levels of intellectual disability and higher support needs, but we did not include them in the interview part of data collection. Instead we spent more time with them and collected their stories through participant observations.

Most of the participants were able to tell their stories through interviews and 21 women and 13 men were interviewed and described with their own words their perspectives, values and life experiences (Kvale, 1996). The interviews focused on autonomy in their private lives with a particular emphasis on their living circumstances. The purpose of the study was explained to all participants but instead of relying on theoretical definitions of the concept they were asked to tell about decision-making in everyday lives and what that meant to them. All interviews were recorded and transcribed and took place in the participants' homes and lasted from 20 to 60 min. The interviews and observations were undertaken by members of the research team, which includes the authors of this article and six graduate students and one undergraduate student at the University of Iceland, Iceland, over a 3-year period, that is, 2011–2013. The participants were interviewed two or more times for the purpose of establishing trust.

The analysis and identification of themes and patterns were done in collaboration by the authors of this article. 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). Coding is not a precise science but more of an interpretive act. In order to validate the accuracy of our finding, we triangulated among different data sources (participants), methods (interviews and observations) and multiple researchers (authors). We did also use member checking, that is, asked participants in the study to determine if our findings are accurate.

Participants

Forty-one participants were selected based on the following two criteria: (1) participants who were labelled as having intellectual disabilities and (2) those who were adults and were willing to participate in this research. The age range selected for the study is 26–66 years and the lower age limit

Table 1. Overview of participants.

	Frequency
Gender	
Women	25
Men	16
Age	
26–35	17
36–45	6
46–55	8
56–66	10
Living arrangements	
Parents' home	7
Group home	10
Assisted living arrangements*	11
Independent	13
Location	
Rural area	8
Urban area	33

*Assisted living arrangements refer to the Icelandic concept *íbúðakjarnar*, which are apartments that disabled people can rent in the community. These flats are usually located in 'mainstream' apartment buildings and the level of assistance the residents receive varies according to their needs. In some instances small apartment buildings, with four–six flats, have been built specially for disabled people but are located in the community and have the same appearance as 'mainstream' buildings.

corresponds to the end of youth (18–25 years) and the upper limit to senior citizenship (67 years). Maximal variation sampling strategy was employed and participants were selected because they had knowledge relevant to the research and displayed different characteristics, for example, in relation to age, gender, location, housing, education and employment. Maximal variation sampling was used in order to reflect the great variation in the lives of people with intellectual disabilities (Creswell, 2008). A special effort was made to include people who needed the most assistance in daily lives, used alternative ways of communication and have been labelled as having severe or profound intellectual and/or multiple disabilities. Twenty-five women and 16 men took part in the research, and it was easier to get women involved and interested in the issue under study. This is a common and unexplained trend in Icelandic research carried out with people with intellectual disabilities. Also, more women with intellectual disabilities seem to be actively involved in self-advocacy in Iceland than men. The participants come from all-around Iceland, but most of them live in the capital area. An overview of the participants is provided in Table 1.

Carrying out a qualitative research in Iceland does raise some ethical issues due to the small size of the country and lack of anonymity. Ethical procedures in this research complied with the Icelandic Law on Data Protection Authority (No. 77/2000) and Regulation on Scientific Research in the Health Sector (No. 286/2008). The research proposal was sent to the Data Protection Authority in Iceland and received a formal receipt of notification. The research was also approved and funded by the University of Iceland Research Fund, Iceland. Precaution has been taken to remove all identifiable characteristics. All participants gave their informed consent and understood that they could terminate their participation at any time. In those cases when the participants did not speak and communicated without using words, caretakers and family members were involved in ensuring

that these individuals were willing to participate in the research. Scholars like David 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 are essential for the inclusion of that group of people in research and also involve the involvement of those, staff or family, who understands his/her wishes best. People with intellectual disabilities have been identified as a vulnerable group in the context of exploitation through research and informed consent can be questioned (Iacono and Murray, 2003; McDonald and Raymaker, 2013). To ensure that all participants were willing to participate in this study, measures were taken to increase their decisional capability by providing all information, written and spoken, about the research purpose, methods, plans for publications and potential risks associated with being involved in this research in accessible language. Also, member checking during the data analysis stage provided opportunities to confirm that participants still consent. Ferguson and Nusbaum (2012) argue that people with intellectual disabilities and especially people labelled as having significant intellectual disabilities are underrepresented in the disability studies literature. Therefore, there is a great need for including their experiences in research, and they should not be excluded on the bases of belonging to a vulnerable group. Instead researchers need to find ways to include them, while at the same time protecting and honouring their human rights.

Findings

The aim of this article is to demonstrate, through the lenses of relational autonomy, how people with intellectual disabilities make choices in their homes and daily lives and to explore what factors influence, help or hinder them from developing and achieving individual autonomy. First, we focus on the perceptions of people with intellectual disabilities. Second, we talk about their access to information, and third, we describe the assistance that people with intellectual disabilities receive in their homes. Finally, we discuss these three factors in the context of relational autonomy.

Perceptions of intellectual disabilities

Other people's perceptions, negative and positive, was a recurrent theme in the interview data, and our findings demonstrate how perceptions can either hinder or encourage the development of individual autonomy. Eight of the older participants had been institutionalized in their youth and spent most of their lives in some kind of segregated residential homes, workplaces and programs specially organized for disabled people. They told how they had learned in the institutions that they were not supposed to make decisions and felt that they had little control over their lives. Anna, who was the oldest woman (66 years) who participated in the research, said, 'You should never complain. You should be grateful and appreciate what the carers do for you. I allow them to decide and they know what is best for me. If I am nice to them then they are also nice to me'.[2] Not all of the participants were as willing as Anna to let staff members make decisions on their behalf and many told stories of how they resisted the governance of the institutions and struggled to achieve their individual autonomy even though they were aware that by not conforming to the paternalistic and often belittling attitudes they were risking punishment. Birna, a woman in her 60s was institutionalized in her youth and when discharged she moved to a group home for disabled women. She has now been successfully living independently for two decades with her husband in a

rental flat in central Reykjavík. Her experience with staff in the institution and group home was negative, and she had consequently declined all assistance in her current home:

> I did not want any help from these people not from staff. If I had not declined their assistance I would not be where I am today. If I had believed everything that the institution's staff said about me and to me then I would not be where I am today [living independently]. I do not want them to treat me like a child that needs care and supervision. I want to make my own decisions.

In her quest for independence, she had developed and achieved individual autonomy, but she did not get the assistance she needed. When her health deteriorated she was forced to accept assistance in her home and found to her relief that practices and attitudes had improved:

> I like the staff that I have now. I am in control. In the institution and the group home they controlled everything. Staff now supports me and do not make decision on my behalf or try to train me and teach unless I want them to.

There were other examples of improved attitudes and practices, but there were also many examples of the constant struggle for accessing adult roles and actualizing individual autonomy. Díana, a 30-year-old woman who lived with her parents described how they made all decisions for her and, for example, decided what clothes she should wear, when she should go to bed, and what she should eat, 'I think they do this out of love ... They want me to feel good in the morning when I wake up and when I go to bed and I just tell them OK but I do not go to sleep right away ... I want to decide for myself when I am tired'. The age range of the participants was broad but all shared experiences of paternalistic views and were commonly told that they 'could not', 'did not know how to' and 'were not allowed to' do different things and they argued that the biggest hindrances to their independence and social participation were prejudice and other people's negative attitudes.

The stereotypical perception of people with intellectual disabilities as eternal children who need care and protection was most evident in those cases when the participants needed a lot of support in their daily lives and did not speak and communicated without using words. Their basic care took up much space in their lives and it is our opinion that staff showed affection towards them but seemed to lack knowledge of how they should assist and talk to them appropriately as adults. We observed that the staff did not always respect people's age and often spoke to them in a childlike tone, and each day was structured around the same routine with little variations. Staff sometimes talked about them to other staff members in their presence but did not include them in the conversations. Ella, a woman in her 30s, labelled as having severe intellectual and multiple disabilities lived in a group home and communicated her wishes through different sounds, which we learned by time to interpret as for example happy and sad. When she needed assistance, she would communicate it loudly in order to get the staff's attention. The staff often ignored her because they claimed Ella needed to learn that she could not get assistance whenever she wanted and in many instances they ignored her even though they were not busy with other tasks. Another more positive example is the case of Daníel who is in his 30s and does not communicate by using words. To increase his sense of security, the staff showed him pictures of upcoming daily activities so he would know in advance what he would be doing. Daníel liked this arrangement and smiled when he was shown pictures of going out for a walk but was less interested in pictures that showed for example dinner time. His schedule was rather repetitive with few variations, and he was never shown two different activities to choose from. The main purpose of the schedule was, according to staff, to increase his sense of security but not to promote his decision-making.

The participants who lived in group homes explained how they had to synchronize their daily lives to the schedule and routine of the group home and other residents that limited their opportunities to make choices. Another recurrent theme from the interview data was the attitude of 'We've Always Done It That Way', which seems to be common among group homes staff. One example of this was in the case of Björn who is a young man also labelled as having profound intellectual and multiple disabilities. He was scheduled to sit on the toilet three times per day even though he had communicated strongly that he did not want to and it did not serve any purpose since he was unable to control his bowel movements. The staff told us that this had always been done this way and they did not seem to question these practices nor perceive Björn's objections as important or relevant.

Access to information

Many of the research participants argued that they could not make decisions about their lives because they lacked information to base their decisions on and access to information was a recurrent theme in the interview and observation data. The findings suggest that the participants often lacked information both regarding big and everyday issues. Examples of everyday information would be when the spring sale begins, dates for the Justin Timberlake concert in Reykjavík and what films are coming up at the local theatre.

One of the bigger decisions in life is deciding when one is ready to move out of one's parents' home and where to live. The research participants had limited choice regarding living circumstances and for most it was either accepting what the municipality had to offer or getting no support at all, which could result in a long waiting period, sometimes years, until they got a better offer. The findings suggest that the participants were seldom informed of their rights to choose where to live and rarely involved in the preparation for the transition of moving out of their parents' home. Ari, a man in his 40s, shared an apartment with two other disabled men. He neither chose to live with them nor chose to live in this particular place:

> I used to live in a group home with four other people. The staff at the office [Municipal Service Centres] decided I should live there and also that I should live here. They talked to my mother, but not to me. This place is OK, better than before. The office decided [that he would live there] but I got to see this place before I moved in.

It was noticeable how difficult it was for the participants to access information about services related to housing and independent living. Fanney, who is one of the older women, had been living in a group home for over 20 years and had wanted to live independently for years and voiced her wishes to the staff, 'I told them I want to live independently. But I do not know how to apply for independent living or where I can find an apartment to rent. I need information'. The findings also suggest that moving away from home can cause tension within families. There were instances where people had to move out before they felt they were ready or wanted to. In those instances it was due to special circumstances that had presented themselves, for example, a vacancy at a group home or their family was not able to care for them any longer because of medical or financial issues. There were also instances where individuals were ready to move out but their family was not ready. Einar, a 30-year-old man, who lived with his mother explained, 'I want to move out and live on my own but mum says I cannot because of my disability'.

The evaluation of when individuals with intellectual disabilities are ready to move out seems to be left to family members and municipality staff. Dóra recalled when she wanted to move out and

live with her boyfriend whom she later married, her sister tried to prevent her from doing so. Both Dóra and her partner were employed and did not need any assistance in their daily lives and decided to invest in an apartment and start their life together independently as a married couple. She described how her sister had no faith in her abilities to pay off the mortgage, live independently or be in a relationship and wanted to move her into a group home. Dóra said she was not happy with her sister and told her, 'It's my life. I want to make my own choices … I am NOT moving into a group home'. And she has successfully been living together with her partner in their own apartment in Reykjavík for over 15 years.

Three people who participated in this research had moved between municipalities far away from their families, against their will and were told they had no other options. Gréta, a woman in her 30s was very unhappy living far away from the city where she previously lived independently with some assistance, for example, with finances and housekeeping. Her mother decided she should move to a group home located in a rural town more than an hour drive from the capital area because she believed she would be safer there than in the city. Gréta said that the group home did not feel like her home and that she felt isolated from family and friends. She did not know she had the right to choose where she lived, which is ensured in the CRPD (article 19) and national legislation and policy (Ministry of Welfare, 2010).

One of the factors that influence the freedom of people with intellectual disabilities in Iceland to choose where to live is their financial status. Most rely on disability pensions and low-income jobs and there are very few who have been granted direct payments, which make it difficult to make financial commitments such as renting or buying apartments. Finances were a recurring topic in the interviews and only 13 participants claimed they had full control over their finances even though the CRPD does recognize the right of disabled people to control their own financial affairs (article 12). It was common that the participants had to get permission from their parents or the group home managers to spend their money, to use their debit or credit cards and even to buy necessities. Karl, a man in his 50s who lived in a group home, was very unhappy with his lack of financial control:

> The manager controls the money. She says I will spend it all and have nothing left. But if I get to control my money this will not happen. I know I need to make it last. But sometimes I want to take my girlfriend out to dinner. It is OK sometimes but then sometimes they [staff] say no.

Karl described how the staff did not trust him to manage his finances and instead of informing him and assisting him to become independent they took over his affairs and he experienced lack of control over his life. Birna spent most of her life in an institution and she described how she had to learn to manage her finances when she was discharged from the institution. It was difficult to begin with and she often had no money at the end of the month, but she learned how to manage her spending and took some money-managing courses for disabled people:

> I used to spend all my money the first week of the month but now it is different. But it is difficult to make ends meet with the disability pension. We are often broke at the end of the month. But I always have food in the freezer that we can have at the end of the month when we are broke.

Birna explained how she had learned through experience as well as formal training how to manage and control her financial affairs that reiterates the importance of access to information in the development of individual autonomy.

Appropriate assistance

The final recurrent theme that we will present in this article is centred on what the participants had defined as appropriate assistance. The participants who lived in group homes or assisted living arrangements usually had to share staff with other residents and were assisted by many different people. They claimed that these arrangements limited their opportunities to make choices in their daily lives and the schedules reminded us of typical timetables in the old institutions and were not individualized at all. Understaffed shifts were another factor that limited the support that was available to the residents. There were some noticeable exceptions from this and two of the participants who had been labelled as having severe or profound intellectual and multiple disabilities had one-on-one assistance and did not have to share support with other residents. Therefore, they did not have to synchronize their days to other residents and had more opportunities to make choices in their lives.

Tómas a man in his 30s lived in a group home and once a week he had dinner with other residents because it was convenient for staff who then decided what would be for dinner. Other days of the week he was assisted making his own meals and choose what he wanted to eat. He could not explain why the residents were not involved in choosing the menu for the once-a-week common dinner, 'It just has always been done this way'.

Some of the participants did not have access to the staff's work schedule or roster and that impacted their sense of security and prevented them from choosing which staff member would assist them with which activity. Lára, a 30-year-old woman who lived in an assisted living arrangement was very pleased that she could choose who would assist her and she planned for example what to have for dinner according to who was on shift and would assist her, 'because not all people know how to make good fish'. In rare instances, the manager would consider the roster to be a staff- or management-related issue and of no concern to the residents and did not want them to pick favourites for different activities. Helga is another woman in her 30s who also lived in an assisted living arrangement did not have access to the roster and hated it when one of the staff members would assist her with cooking dinner, 'because I want to tell her how to cook and spice and how long to boil. But she just wants to do it like she does at her house. But this is my dinner'. The participants who lived in group homes and assisted living arrangements complained about a lack of privacy and how in some instances they could not close or lock the washroom door and staff and family members rarely knocked before entering their rooms or flats. Strangers often walked straight in without ringing the doorbell at group homes as if it was public space, institution or company. The fact that someone, staff, family members or even strangers, could walk in on you at any time in your own home must have significant impact on people's sense of security and individual autonomy and needs to be explored in further research.

The issue of gender becomes central when studying the field of disability because most of the staff working with people with intellectual disabilities are women. Some of the women who participated in this research did not want to be assisted by male staff, especially not with some daily activities such as bathing. This is one of the reasons why it was important for them to have access to the roster in order to plan activities, such as bathing; at days or times they could get assistance from female staff. However, they often had to obey strict schedules such as bathing being on certain predetermined days at a fixed time with no flexibility. Therefore, they were not guaranteed assistance from women and experienced limited privacy and control over their own bodies and lives. The men who participated in this research did not seem to mind as much to get assistance from female staff and few of them were able to get assistance from men at all.

The participants who lived independently got some support in their homes, for example, with cleaning and washing clothes. They could apply for assistance from the Municipal Service Centres and complained that often they had to talk to many different professionals and it could get confusing and time consuming. Harpa, a woman in her 20s who lived independently with her partner in rural Iceland said, 'I wish I could have just one person to talk to instead of talking first to one and then another social worker and tell everybody everything'. The relations with the professionals at the service centres varied greatly and Ása recounted:

> I have had good relations with the service centre and it is almost like my second home. I have given a presentation there at a staff meeting. It was a big step for me. I could tell them my opinions … It has been a struggle.

In 2011, the affairs of disabled people were transferred from state to municipality and this was following the 2008 economic crisis in Iceland. The Organization of Disabled in Iceland, among others, was concerned that this would not be successful and the quality of assistance and services would be different depending on the varying financial status of the municipalities. The findings suggest that different municipalities offer different services and there could also be some differences within the bigger municipalities depending on which neighbourhood people live in and which service centre they get support from. The findings also suggest that there are differences in qualities of services and Gréta for example who lived in a group home and expressed how she did not feel secure in her own home because she did not trust the staff, 'It is not too bad here but the support could be better … I don't feel love and care in this place as I did the first years I lived here. I feel more hatred and betrayal and I do not trust anyone'. Trust was for Gréta the bases for appropriate support. Jón a man in his 60s talked about what he believed to be best practices:

> It is all about respect. This is my home. I need assistance but the staff should not boss me around and make decisions on my behalf. I can do that for myself. Do not lie to me and pretend to be my friends. It is important to listen, not boss me around and I want to decide for myself when I tidy and clean my home.

The CRPD recognizes the personal mobility of disabled people (article 20) but the level of mobility freedom varied in this research. Some of the participants drove cars, others travelled with public transport, walked or rode bicycles, but others relied on the transport services for disabled people. Those who used the transport services argued that it was limiting because all trips have to be planned in advanced which excludes spontaneous or last-minute decisions. Two of the participants who used the transport services did not feel safe in the vehicles and did not want to use these services any longer. Halldór a man in his 40s who uses a wheelchair described falling over in a transport service car while on the road because his wheelchair had not been securely fastened. Halldór was injured badly and has not travelled since with these services and relied on family and friends for transport. This has diminished his freedom to travel, and he misses out on activities and events because he does not have appropriate transport, at least not where he feels safe.

Another factor that limits mobility are rules and curfews the participants had to obey, which were set by staff and family members. Although the participants were all adults aged 26–66, some of them, for example, were not allowed to go out after dinner time and could only invite guests over if previously planned. Heiðar, a man in his 40s who lived in an assisted living arrangement, had struggled for years to gain more freedom and said, 'I have just recently gotten freedom … I decide when I come home … I am an adult. I am not a child anymore'. Limited personal mobility and

freedom and the need for support have in many places created a tradition of people with intellectual disabilities paying staff members for 'extra' assistance. For example, if a resident of a group home decides to get fast food for dinner instead of dining at home, he can get one of the staff members to give him a lift to the restaurant, that is, if a staff member is available to do so. The resident has to pay for food for the staff member who often has opinions about what kind of food to get, which can result in the resident not deciding where to eat.

Many of the participants who lived in group homes and assisted living arrangements complained about understaffed weekend shifts because it had great impact on their opportunities to participate in social activities. The participants described how they often had to settle for activities that the majority of the residents wanted to do and consequently missed many events they preferred. Jónas a man in his 30s liked going to Sunday services at his local church but since there were so few people working at his group home, on Sundays he rarely got opportunity to do so. When family members were not available to accompany him to church, he would settle for bowling or the movie theatre instead of staying at home and doing nothing. The participants described substandard support due to these understaffed weekend shifts, which made it difficult for them to make choices according to their preferences and self-identity.

Discussion

In this article, we have demonstrated how carers' perceptions, access to information and appropriate assistance can shape the individual autonomy of people with intellectual disabilities. Historically, people with intellectual disabilities have not been trusted to make their own choices and the focus has been put on their impairments and inabilities for the purpose of justifying their lack of autonomy (Stefánsdóttir, 2008). The older participants who had been institutionalized described paternalistic and dehumanizing perspectives and practices in the institutions where they were subjected to institutional governance and learned that they should be non-critical, obedient and to some extent grateful for whatever assistance they got. The Canadian sociologist, Erving Goffman (1961), argued that the timetables and schedules in the institutions provided the inmates with daily routines and predictability and the staff was responsible for making and following these schedules and made most of the decisions. The inmates internalized these schedules and perceptions and learned that staff should govern their lives and few attempted to make choices. This can be understood as internal oppression where the inmates internalize oppressive norms that would never be accepted outside the institutions (Mackenzie and Stoljar, 2000). They simply believed that they were not entitled to anything better. Theories of relational autonomy explore how social and internalized oppression diminishes the opportunities for increasing individual autonomy. An oppressed individual may be unable to develop abilities to achieve individual autonomy (Mackenzie and Stoljar, 2000). Relational autonomy emphasizes the problem of internalized oppression and describes how external circumstances can influence individual development and how this context can lead to the individual imposing oppression onto themselves (Meyers, 2010).

The findings suggest that perceptions of individuals with intellectual disabilities have improved and are less patriarchal than at the times of institutions and segregation, and these external circumstances are probably more encouraging towards the development of individual autonomy. After being discharged from the institutions, many of the participants in this study had opportunities to develop their autonomy and demonstrated oppression in their lives rather than internal oppression. Although they often struggled to achieve individual autonomy, they felt they should be allowed to do so. A couple of the older participants had however not developed individual

autonomy and seemed to have internalized the predictability and perceptions of the institution. Consequently, they did not make much effort to take control of their lives even after being discharged and showed evidence of internal oppression. The staff and family members also learned to believe they did not want to make their own decisions. Among the younger participants, who had not been institutionalized, there was little evidence of internal oppression. However, the fact that the men did not object being assisted mostly by women instead of male staff and participants not refusing living circumstances that they were not pleased with could be interpreted as internal oppression. But these participants also seemed to lack information about their rights to choose and what to choose from.

To be able to make choices in life the individual needs to recognize his/her options and rights and therefore have access to the relevant information. The CRPD recognizes the importance of having access to information in order to live independently and participate fully in all aspects of life (article 9). The findings of this study demonstrate that people with intellectual disabilities often lack access to information, and it is too simplistic to explain their lack of access to information by emphasizing their individual capabilities or impairment because the reason also lies in their circumstances, environment and other people, and staff and family members share the responsibility to encouraging their participation and decision making in society. For example, the staff who supported those who had been labelled as having severe or multiple disabilities made little effort to figure out their wishes and each day was structured around the same routine with little variations. These practices have institutional qualities, but it also seemed common that the staff lacked knowledge and training regarding the care of adults who are labelled as having multiple disabilities and do not communicate by speaking. A study conducted in Ireland, which explored communication strategies adopted by staff nurses in a residential centre for people with severe and profound intellectual disabilities, demonstrated that staff nurses did not always use optimal strategies in interactions with individuals who do not speak (Healy and Noonan Walsh, 2007). Healy and Noonan Walsh emphasize the importance of continuing education and training for staff, and the CRPD recognizes the importance of alternative communications for disabled people, which can enable them to express their wishes and opinions (article 21). Furthermore, the convention recognizes the importance that staff is trained to use and understand alternative ways of communication (article 23).

Our freedom over our own choices is never complete since we all need to compromise and be considerate to other people in our lives. The theoretical framework of this research, Nordic relational understanding of disability and relational autonomy, focuses on the interconnectedness of all people in the context of their environment and that the individual develops his or her identity and autonomy through interactions with other people (Mackenzie and Stoljar, 2000; Tøssebro, 2004). From that perspective, staff and family members, are a crucial factor in the development of an individual autonomy for people with intellectual disabilities. When they are perceived as adults, experience encouraging practices and involved in making decisions about their own lives, and when schedules and plans are organized and adapted to individual needs and wishes, it can encourage them to develop and increase their individual autonomy.

When the participants received sub-standard support, it influenced their well-being and their opportunities to make choices. The tradition of paying 'extra' is an example of sub-standard support. To have the option to pop-out for a meal can increase their sense of individual autonomy but having to compromise and settle for something you don't want can be discouraging. In light of the high percentage of disabled people experiencing financial difficulties (World Health Organization, 2011), the rule of paying for staff member's dinner becomes questionable and makes it twice as

expensive for a person with intellectual disabilities to dine out compared to a non-disabled person. This emphasizes the importance of staff being aware of their own actions, best practices and perceptions. It is important for staff to be sensitive to the needs and wishes of the individuals they are working with and to create an atmosphere in which they would encourage them in communicating their choices. This is fundamental to the development of individual autonomy for people with intellectual disabilities. When individuals have to compromise to the staff's demands to great extent, they might risk developing internal oppression where they express themselves as not having an opinion except to follow the orders of others. Thereby they will lose their chance of developing self-trust and the capacity to form a will in accordance with their own self-identity (Mackenzie and Stoljar, 2000).

The findings of this research suggest that how people with intellectual disabilities make choices is dependent upon their relationship with their carers and the quality of support they receive. As stated before, the CRPD recognizes the right of disabled people to make their own choices and they should be involved in decision-making and policy development with regard to their own lives. The Icelandic representative signed the convention on behalf of the Icelandic nation and even though it has not yet been ratified, Icelandic disability legislation states that the execution of the law should be guided by the convention (Ministry of Welfare, 1992). From the standpoint of the CRPD, staff and family members should respect disabled peoples' autonomy and all practices and policy development should be based on that recognition that is fundamental to their dignity and well-being.

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Notes

1. The Convention on the Rights of People with Disabilities uses the term individual autonomy instead of personal autonomy which is more common in the literature.
2. Data were collected in Iceland and the authors translated all direct quotations.

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