“Being Number One is the Biggest Obstacle”:
Implementing the UN Convention on the Rights of Persons with Disabilities within Nordic welfare services

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ABSTRACT
This paper was inspired by a peculiar theme that emerged from qualitative interviews in Iceland, Norway and Sweden with leaders of Centres for Independent Living (CILs). CILs are peer-led organisations that maximise user-control of disability services. Paradoxically, the Nordic reputation as forerunners in deinstitutionalisation and independent living was considered an impediment to implementing Article 19 of the UN Convention on the Rights of Persons with Disabilities which requires “access to a range of support services, including personal assistance necessary to support living and inclusion in the community”. This contradiction prompted the questions: How is Article 19 implemented in Nordic welfare services? And why is previous progress towards independent living and personal assistance seen as an impediment to implementing the rights-based approach required by the Convention? The findings suggest that it is difficult to change a developed welfare system in which there are vested interests in maintaining the status quo. The reputation of “being number one” conceals problems such as inflexible services and the imbalance of power where the control of services lies with the system and the professionals, not the users.

Keywords
CRPD, disability, human rights, independent living
INTRODUCTION

Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) recognises the “equal right of all persons with disabilities to live in the community, with choices equal to others” and requires state parties to ensure that disabled people have “access to a range of support services, including personal assistance necessary to support living and inclusion in the community”. Personal assistance “implies that disabled people employ their own assistants as an alternative to receiving assistance from the established services” (Askheim, Bengtsson, & Bjelke, 2014, p. 3). This paper was inspired by a peculiar contradiction that arose from a qualitative study of the implementation of Article 19 of the CRPD in Iceland, Norway and Sweden. The Nordic countries have a reputation for having advanced disability services in the community to prevent institutionalisation. The participants acknowledged this reputation. However, many considered it to be an impediment to implementing a rights-based approach to service delivery that is required by Article 19 of the CRPD. This contradiction prompted two questions, both of which are addressed within this paper. Firstly, how is Article 19 implemented within Nordic welfare services? Secondly, why is it that the leaders of Centres for Independent Living (CIL) view progress towards deinstitutionalisation, independent living and personal assistance as an impediment to implementing the rights-based approach required by Article 19 of the Convention?

The findings reflect the perspectives and experiences of a group of individuals who are active leaders of CILs in all three countries. CILs are peer-led, grassroots organisations that provide support, training and information about services that promote independent living in the community, including personal assistance. They also demand a high degree of user-participation in all aspects of the service planning and delivery. CILs emphasise user-control over services and user-led service provision. This approach is in line with the UN Committee on the Rights of Persons with Disabilities (2017) which states that “persons with disabilities who require personal assistance can freely choose their degree of personal control over service delivery according to their life circumstances and preferences” (Committee on the Rights of Persons with Disabilities, 2017) (General Comment No. 5 section 16). Furthermore, the Convention requires that states “closely consult and actively involve a diverse range of persons with disabilities through their representative organizations on all aspects concerning living independently in the community, in particular, when it comes to developing support services and investing resources in support services within the community” (Committee on the Rights of Persons with Disabilities, 2017). This paper explores the implications of the shift from welfare to rights-based services in three Nordic countries with relatively advanced welfare services.

A RIGHTS-BASED APPROACH TO SERVICE DELIVERY

Since it was founded in Berkeley, California in the late 1960s, the independent living movement has “phrased their demands in terms of broader human rights” (Degener, 2017, p. 5). Likewise, the United Nations adopts a rights-based approach to disability, viewing disabled people as rights holders rather than recipients of welfare (Lawson, 2006). The human rights approach to disability seeks to “provide moral principles or values as a foundation of disability policy” (Degener, 2016, p. 4). These values are reflected in the general principles of
the Convention (Article 3) which include “respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons” as well as “full and effective participation and inclusion in society”.

The Icelandic, Norwegian and Swedish governments have ratified the Convention. Sweden ratified the Convention in 2008, Norway in 2011 and Iceland in 2016. In doing so, they are responsible for bringing services in line with the requirements of the Convention. The UN Committee on the Rights of Persons with Disabilities (2017) has clarified that:

States should ensure that personnel working or on the step to enter working in disability-related services including staff, decision-makers and civil servants monitoring services for persons with disabilities, are adequately trained on independent living within the community, in theory and practice. States also should establish criteria in line with article 19, concerning entities applying for being allowed to deliver social support for persons with disabilities to live in the community, and assess how they perform their duties (General Comment no. 5 section 65).

Furthermore, the Committee warns against the misappropriation of services:

Providers of support service often wrongly describe their support service by using the terms “independent” or “community living” as well as “personal assistance” though in practice such services do not fulfill the requirements posed by article 19… The concept of personal assistance where the person with disabilities does not have full self-determination and self-control are to be considered not compliant with article 19 (Committee on the Rights of Persons with Disabilities, 2017, General Comment no. 5 section 17).

Hence, the Committee has provided clarity on the types of services that can rightfully be referred to as “personal assistance”.

INDEPENDENT LIVING AND THE WELFARE SERVICES

The independent living movement originated in Berkeley, California where “independence and self-reliance are strongly held American values” (Zola, 1982, p. 3). The movement in the USA emphasised the marketization and consumerisation of welfare services (Askheim, 2005; Dejong, 1979; Pflueger, 1977). In other words, individuals received a direct payment in lieu of welfare services, which they used to purchase services from a market of competitive services providers (Barnes, 1997; Campbell, 2006; Dejong, 1978; Glasby & Littlechild, 2006; Ratzka, 1986; Zarb & Nadash, 1994). Direct payments were introduced as a means to have more user-choice and control over a range of services and the opportunity to directly hire personal assistants. The basic idea behind direct payments is that the receivers are not “passive recipients of services, but are in control of how they are delivered” (Pearson, 2000, p. 461). CILs were established throughout the USA in the 1970s to assist people to manage their direct payments. They provided peer-led support and training programmes including employment skills, assistive technology and personal assistance. They compensated for the lack of social security networks and social welfare support in the USA (Dejong, 2001). For instance, “in the 1980s, the Berkeley CIL provided direct services to over 140,000 people, built 500 residential ramps free of charge for wheelchair users, helped 1,000 people secure jobs, and assisted over 600 students to complete the Independent Liv-
ing skills training program” (Racino, 1993, p. 8). “For disabled people the opportunity to employ personal assistants as an alternative to the established welfare services is seen as vital to achieve the goal of an independent life” (Askheim, 2005, p. 247). However, the concept of direct payments became controversial when the independent living movement spread from the USA to Europe in the 1980s. The USA has relatively undeveloped welfare services compared with many Western European countries (Degener, 1993; Shakespeare, 2004). CILs in the USA filled a void, whereas several Northern and Western European countries, including the Nordic countries, had relatively well established welfare services. When independent living spread to Europe, there were concerns that the emphasis on markets and consumerism were inappropriate and potentially damaging in the European welfare state context. When the first Scandinavian conference on independent living was held in Stockholm in 1984, Adolf Ratzka noted that “most participants found the concepts presented refreshing but hardly applicable to Sweden, since they originated in a different social climate” (Ratzka, 2003 para 25). There were concerns that principles with origins in the USA could be misappropriated by European governments and bureaucrats. There were fears that direct payments would be hijacked by neo-liberal governments seeking to cut their expenditure on welfare and services (Carmichael & Brown, 2002; Glasby & Littlechild, 2006; Oldman, 2003; Pearson, 2000). Despite this, the European movement was highly influenced by the movement in the US and many of the guiding principles, such as choice, self-determination and independence, remained similar in Europe. Yet in practice, personal assistance was implemented and arranged differently within diverse European welfare states. Most countries did not emphasise the marketisation and consumerisation of welfare services (Askheim, 2005; Dejong, 1979; Pflueger, 1977). An early comparative study of personal assistance in the USA, Sweden and West Germany, pointed out that every “welfare program has its own historical, economic and social background which shapes the values and goals incorporated in each country’s system and the relationship between individuals, government and society” (Degener, 1993, p. 13). Hence, it is important to examine personal assistance in context.

THE NORDIC CONTEXT
Nordic countries have earned a reputation as European leaders in deinstitutionalisation, independent living and personal assistance. Nordic disability services “have been championed as some of the world’s best” (Goodley, 2010, p.16). Indeed, there is reason to suggest that the Nordic countries have made significantly more progress towards community-based services compared with European counterparts. In the early 1990s “Norway and Sweden, decided to close all institutions as a matter of public policy” (Tøssebro et al., 2012, p 135). As a result, human rights scholars have looked to the Nordic countries for promising examples of deinstitutionalisation and community-based services. For example, referring to the implementation of the CRPD in Europe, Quinn and Arnardóttir (2009, p. xv) suggest that the Nordic models of reshaping social services “to support independent living and in ensuring adequate community support to hasten deinstitutionalisation is worthy of study in its own right”. However, residential services did not close down altogether; rather, most were replaced by group homes, smaller residential services and apartments (Brennan,
While many countries are at the initial stages of developing laws and policies, the Nordic countries have relatively extensive laws and policies addressing deinstitutionalisation, independent living and personal assistance. Previous studies have suggested that Nordic disability policies are not always implemented in practice. For instance, a study of services for people with intellectual disabilities (ID) in the Nordic countries acknowledged "the gap between the national policy ideals and the practical realities confronting people with ID. It appears as if national government ideals evaporate on their way to implementation" (Tøssebro et al., 2012, p. 141). A recent study of access to services in Iceland warned that the entrenched values and methods of service provision that exist in Iceland, which support and reinforce the "right" of various authorities to govern the lives of disabled people (or ignore and trivialise their needs) will prevent the progressive spirit of much recent legislative work and action plans from being meaningfully translated into practice (Rice, Björnsdóttir, & Smith, 2015, p. 136).

This highlights the disjuncture between laws, policies and service provision in the Nordic context. This is not only a Nordic phenomenon. Despite laws and policies on deinstitutionalisation in Europe, it is estimated that more than 1.2 million Europeans live in institutions (European Coalition for Community Living, 2009; Mansell, Knapp, Beadle-Brown, & Beecham, 2007). Hence, it is important to conduct qualitative inquiry into how laws, policies and human rights principles are applied and experienced by the people whom they are supposed to benefit.

In all three countries under study, personal assistance is just one of a range of services that are supposed to support independent living in the community. For instance, independence is one of the key goals of the Swedish Act concerning support and service provision for persons with certain functional impairments, LSS (1993:387). LSS contains ten rights, including the right to personal assistance. However, some of the other rights, such as residential arrangements for children who cannot live with their family and residential arrangements for adults appear contradictory to the goal of independence (Brennan, Traustadóttir, Anderberg, & Rice, 2016). In Norway, personal assistance is seen as one of a menu of services available to people who require significant support to live independently in the community. It may be combined with other municipal services including home help and home nursing (Askheim, 2014). Personal assistance has only officially been available in Iceland since 2012, when the government initiated a pilot project that will be in place until a new Act on services for people with long term support needs will take effect in October 2018 (Alþingi 2018). The Icelandic Ministry of Welfare has stated that personal assistance will become “one of the main pillars in the services to disabled people” in Iceland (Ministry of Welfare, 2012). In April 2018, the Icelandic Parliament, Alþingi, adopted a law that legalises personal assistance as one of the services available for disabled people with long-term support needs (Alþingi, 2018).

The Nordic experience of deinstitutionalisation, independent living and personal assistance highlights the differences between the Nordic countries. This challenges previous...
classifications of the Nordic welfare state as similar in nature. Famously, Gösta Esping-Andersen (1990, 2002) classified the welfare regimes of the Nordic counties as social democratic. He suggested that a key goal of the Nordic welfare states was to “strive for greater individual independence” (Esping-Andersen, 2002, p. 13). Yet, there are differences in the generosity of the welfare services in the Nordic countries. For example, Stefán Ólafsson illustrated how the Icelandic welfare services are less generous than other Nordic countries and demonstrated that “welfare rights in Iceland [have] been eroded gradually since the early 1970s and a significant shift towards liberal welfare principles… has exacerbated that trend” (Ólafsson, 2005, p. 230). Since the 1980s the Nordic welfare states have been accused of being “bureaucratic, inefficient and having little ability to adapt its services to the individual needs and interests of the users” (Askheim, 2005, p. 249). This is particularly problematic in relation to independent living, which requires flexibility and individualisation of services. Yet, developments in independent living and personal assistance indicate the changing nature of the Nordic welfare state. A study of Iceland, Norway, Sweden, Finland and Denmark noted a “trend toward a strengthening of consumer rights and more formalization regarding the services the individual can expect. Issues such as self-determination, empowerment, and individual tailoring of services gained a stronger ideological position” (Tøssebro et al., 2012, p.138).

METHODS

This paper draws on a large qualitative research project which aimed to explore the meaning of independent living and personal assistance as well as the implementation of Article 19 of the CRPD in three Nordic countries: Iceland, Norway and Sweden. The qualitative inquiry, conducted between 2012 and 2014, included visits to Centres for Independent Living and interviews with leaders in the independent living movement in all three countries, as well as interviews with other stakeholders such as policy makers and government officials overseeing independent living. The findings reported here are based on the personal perspectives of a group of individuals who are leaders in the Nordic independent living movement. All participants were involved in the initial campaigns to implement personal assistance within their home country. The participants were highly involved in the movement to establish and develop personalised services in their home countries. They were clear about their agenda to promote personal assistance, and their desire to replace mainstream social services with personalisation and direct payments. Hence, the findings represent their personal perspectives and are not generalizable. Instead, they provide an insight into the views of some of the most influential people in the Nordic independent living movement and individuals who are at the forefront of implementing personal assistance services. Qualitative research “embraces the idea of multiple realities” (Creswell, 2007, p. 16). Understanding the views and perspectives of disabled people and their representative organisations is vital for assessing the implementation of the CRPD. Mladenov (2012, p. 69) recommends “that disabled people’s collectives should be recognised and admitted as important stakeholders and contributors in the community of interpretation that gives the CRPD its meaning”. A qualitative approach offers an in-depth exploration of the meanings of human rights principles and their implications from the research participants perspectives.
The data that form the basis for this paper include interview transcripts and field notes from visits to CILs. Interviews were conducted with 29 leaders of CILs, comprising five Icelanders, six Norwegians and eighteen Swedes. The interviews were carried out during fieldwork in Iceland, Norway and Sweden. Five CILs were involved in the study: two in Sweden, two in Norway and one in Iceland. The data was analysed using the constant comparative method of grounded theory. The constant comparative method involves analysing the data, creating analytical memos during the data collection process and searching for central themes, “and to continue looking (and interviewing) until the new information obtained does not further provide insight” (Creswell 2007, p. 160). This method yielded rich and in-depth findings covering a broad range of themes relating to the implementation of Article 19 in Iceland, Norway and Sweden. This paper is one of several that have been published as part of the larger study (Brennan, 2017, Brennan, Traustadóttir, Anderberg, & Rice, 2016; Brennan, Traustadóttir, Rice & Anderberg, 2016; Brennan, Rice, Traustadóttir & Anderberg, 2017). Each of the papers focuses on a major finding that emerged from the study.

**FINDINGS**

The findings indicate that the reputation of the Nordic countries as forerunners in independent living and personal assistance conceals problems such as inflexible services, poor access to information about personal assistance and the imbalance of power where the control of services lies with the system and the professionals. Hence, participants believed that the current service ideology is incompatible with the disability rights approach and, therefore, significant welfare reforms are necessary to shift towards the rights-based approach to service delivery, which is required by Article 19 of the Convention in the Nordic countries.

Implementing a rights-based approach in Nordic welfare services

All of the participants understood independent living and personal assistance from a human rights perspective. They welcomed the CRPD because it reflected their rights-based understanding of independent living and personal assistance. All participants actively campaigned for personal assistance in their home country. They saw personal assistance as a remedy to the inadequacy of other welfare services, particularly the residential services. Some participants embraced the language of the Convention and used it as a tool to communicate with the government. A Swedish participant explained the advantages of doing so:

> It is important that people talk about rights, rather than disability. That will make the government do something. They are not interested in disability but when you speak about rights, they understand the language.

Similarly, a Norwegian participant described how the CIL borrowed language from the CRPD to campaign for equality when accessing personal assistance in Norway:
[The Norwegian government] can’t discriminate against a certain group of people. We use these words “equality” and “discrimination” to get them to understand our goals of equality for everybody who needs assistance.

Many participants suggested that the Nordic welfare services are based on an ideology that is incompatible with key principles of the Convention. Some participants distinguished between the human rights principles that are outlined in the Convention, and the Nordic welfare service ideology. For instance, a Norwegian participant complained that the welfare state’s approach to service delivery was irreconcilable with the equal citizenship required by the Convention. He compared and contrasted the welfare approach and the rights-based approach:

The Nordic welfare state is based on the principle of “be nice to them”… In my opinion it is not very democratic because we, as people, are not considered to be people with equal rights, equal citizenship or rights in the Nordic welfare state.

An Icelandic participant also argued that the welfare ideology and approach was incompatible with disability rights. He suggested that:

The Scandinavian welfare system takes care of everything. It takes the power from people and takes the responsibility from the people. There’s a danger that you become passive … The social system ensures that you have enough to eat and have an apartment. But you have the same goals in your life as other people, to have an income and decide what you learn and choose where you live. I think if you are going to be part of the society, a full member of it, you need rights.

Most participants argued that substantial service reforms were required to implement the rights-based approach required by the Convention. They emphasised the need for more choice, flexibility and variety of services, individualisation and better information on how to access personal assistance. For instance, an Icelandic participant explained:

The present public services have to look within and review their ideology and service policy, it has to conform to the Convention. We need more freedom for people to choose what kind of a service they would like to have that meets their needs.

Participants agreed that personal assistance should be incorporated into law, so that people are entitled to personal assistance if they meet the eligibility criteria. A Norwegian participant explained how the personal assistance law obligated municipalities to provide information:

Bureaucrats want services to allow people to exist, but life is more than just existing. The bureaucrats are afraid to lose power or changing the staff. Now municipalities have an obligation to inform people [about personal assistance].

Overall, the participants agreed that significant reforms were required in order to meet the requirements of Article 19 of the CRPD.
Good reputation conceals other problems

The participants problematised the Nordic reputation as forerunners in deinstitutionalisation, independent living and personal assistance because it masks other issues within the welfare services. This reputation was seen as an impediment to the implementation of Article 19 of the CRPD within the service system. Sweden has the most advanced independent living and personal assistance policy of the three countries under study. However, Swedish participants saw their reputation as European leaders as unhelpful for the further advancement of the rights approach to service delivery. They complained that their reputation as forerunners in the field of personal assistance distracted from the shortcomings of other services. One participant argued that Sweden's reputation as a world leader in disability policy is undeserved. He complained that besides personal assistance, Sweden was lacking in other disability rights. For instance, he argued that wheelchair accessibility is poor compared to many other European countries and the USA. He said:

They all are convinced that Sweden is the best place in the world for disability policy. If you talk to them about access and tell them that Sweden is not so great, they don't believe it. So this thing about being number one is the biggest obstacle to us.

Another Swedish participant complained that the reputation as the European leader in independent living and personal assistance ignored the prevalence of residential care. She was frustrated that people who did not have access to personal assistance often had no other choice but to live in residential care. She pointed out that “group homes are growing in Sweden. Sweden is the envy of the world for group homes. People from all over the world visit Sweden to learn about the group homes here”.

An Icelandic participant complained that the government was misusing its reputation as a Nordic welfare state, while continuing to deliver services that were incompatible with the principles of the Convention. She argued that the Icelandic welfare system was misrepresented abroad as generous and rights-based. She illustrated how inflexible welfare services were denying basic human rights:

They (the government) always say when we are abroad that we have a good welfare system and everything is great here, but I don't see that. People with disabilities can't go to the toilet when they are at the university because they don't have any assistant with them.

Participants agreed that the Nordic countries had made significant progress towards independent living, particularly when personal assistance was implemented. Yet for this reason, many participants were concerned that services were going backwards, rather than forwards. Regression was a fear in Sweden and Norway. Regression is characterised by an action “that directly or indirectly leads to backwards steps being taken with regard to obligations under international law” (Office of the High Commissioner for Human Rights 2010, p. 28). A Norwegian participant was concerned that their reputation as a leader in deinstitutionalisation distracted from regressive developments and expansion of segregated residential care facilities instead of supporting people in their own homes in the community. This participant said:
I don't think (the CRPD) has had an effect. We are already quite ahead when it comes to services and attitudes towards people with disabilities… I think we took a huge step when we shut down the institutions, but now they're trying to go back to the early days when they removed people from the community.

The possibility of losing personal assistance was a concern for some of the Swedish participants because they felt that other welfare services could not possibly replace personal assistance. They were uncertain about the future of their personal assistance scheme following several reviews of the eligibility criteria that have narrowed the interpretation of who is entitled to personal assistance (Brennan, Traustadóttir, Anderberg & Rice, 2016). Some feared that they could lose their right to access personal assistance services under revised eligibility criteria. Participants agreed that personal assistance was the only way in which their individual needs could be met because other welfare services were inadequate. For example, a Swedish participant explained that the group home was the only alternative to personal assistance in her local municipality. She complained that although the old institution was rebranded as a group home, the ideology remained unchanged:

The [former] organisation looked like a hospital and then the group home moved from a county council to a municipality, but it was the same thing, it was an institution, the same group of personnel worked there.

Many participants felt that professionals in the welfare services wanted to maintain the current residential services and that this was a barrier to more people accessing personal assistance. Several participants reported that they were discouraged by service professionals from transitioning from the service system to personal assistance services. An Icelandic participant described how she was actively discouraged by municipal staff when she applied to replace her residential services with personal assistance. The municipal staff told her “What are you doing? This is very dangerous”. Many participants pointed out that professionals, bureaucrats and direct service staff had vested interests in maintaining the existing power relations when the control of services lies with the system and the professionals. For instance, an Icelandic participant complained that individuals within the welfare services were withholding access to personal assistance services because they wanted to maintain the existing residential social services. Like several other participants, she referred to group homes as “institutions”. She said:

The professionals in the institutions, in the social care system, they are afraid, afraid of losing their jobs. It's always the same when they began to speak about direct payments. The institutions see it as a challenge to them.

Several Icelandic participants said it was difficult to access information about personal assistance services and some of them complained that municipal staff withheld information or discouraged disabled people from accessing personal assistance. Getting information about how to access personal assistance was a long and frustrating process for many.

You have to dig for everything, you have to ask for everything and I have to try and find out because there is no one to help you with it because it is always like you are taking something you shouldn’t have. They always make you feel like you are begging for something.
Overall, the participants identified numerous barriers that they believed would impede the implementation of Article 19 of the CRPD. These problems included service ideologies that are incompatible with human rights principles, particularly the inflexibility of services. Furthermore, they complained that it is difficult to change a system that wants to maintain power imbalances between the users and the professionals. As a result, the participants reported difficulty when accessing information about individualised services.

DISCUSSION
Our findings suggest that the Nordic reputation as leaders in deinstitutionalisation, independent living and personal assistance conceals other problems within the welfare services. “Being number one” is problematic because it has proven difficult to implement a rights-based approach within relatively advanced welfare services. Many participants problematised this reputation of being number one and feared that the current service ideology and delivery is an obstacle to implementing Article 19 of the Convention, which requires a high level of user-control and self-management of services (UN Committee on the Rights of Persons with Disabilities, 2017). There is evidence to suggest that the Nordic welfare services are falling short of meeting the rights-based approach required by Article 19 of the Convention in several areas. The participants’ accounts of service provision in the Nordic countries illustrates that, besides personal assistance, there is a long way to go to meet the requirements of the CRPD. Many of the key goals and principles of the Convention, such as “antidiscrimination, universal design, independent living, personal assistance and supported employment have been developed within countries associated with completely different welfare models from the Nordic one” (Hvinden, 2004, p185). Our study suggests that it will be difficult to implement a right-based approach in a relatively advanced Nordic welfare system in which there are vested interests in maintaining the current services and status quo. The participants agreed that significant reforms were required to meet the requirements of the Convention in all three countries. They agreed that more choice, flexibility and variety of services, individualisation and better information on how to access personal assistance were required to implement the Convention within the welfare services.

Recent studies suggest that countries that have made progress towards deinstitutionalisation and independent living are reducing access to personal assistance services. In an earlier paper we found that “since the Swedish government ratified the Convention in 2008, there has been an increase in the numbers of people losing state-funded personal assistance and an increase in rejected applications” (Brennan, Traustadóttir, Anderberg & Rice, 2016, p. 85). Another recent study reported significant growth in the size of residential care in Norway. “Whereas the typical group size was 3–4 people in the mid-1990s, new group homes tend to be for two or three times more people, and a number of reported cases have 25 people or more” (Tossebro et al. 2012, p. 138). Hence, participants feared that the loss of personal assistance could result in the institutionalisation of persons who could otherwise live in the community with access to personal assistance. This trend is not unique to the Nordic region. There is also evidence of cuts to personal assistance in other countries that were once considered leaders in independent living and personal assistance. The UK, the Netherlands and Sweden were among the first European countries to implement personal
assistance in the late 1980s and early 1990s. In the UK the Independent Living Fund (ILF) fund closed in 2015. The closure of the ILF was presented by the government as “welfare reform” (Garthwaite et al. 2014; Grover 2015, Porter & Shakespeare, 2016). Likewise, in the Netherlands 117,000 people are at risk of losing their personal budgets as a result of policy changes (ENIL, 2016). These figures highlight a worrying trend and the importance of examining developments in countries that were once considered leaders in the areas of independent living and personal assistance. It has been suggested that the Nordic countries “ratified the Convention at a time of turmoil and uncertainty about the future of independent living and personal assistance and are struggling to uphold and sustain the current system” (Brennan, 2017, p.164). This is not only a Nordic phenomenon. The Convention came into force in May 2008, the same year that the financial crisis emerged. This sparked fears that the UN Convention would be viewed by governments as an “unaffordable luxury” in times of austerity (Portero, 2011, p.582).

CONCLUSION

Article 19 of the CRPD requires that a range of services are available to ensure that disabled people can live independently in the community on an equal basis with other citizens. Based on the findings, we suggest that a holistic approach is required to monitor the implementation of Article 19 of the Convention, particularly in relation to user-control of services. The findings of this study highlight the problematics within states that promise access to personal assistance services, but offer little else for people who do not meet the eligibility criteria, despite the fact that other supports and services do not meet their needs. Human rights violations should not be overlooked if countries appear to be progressive in some areas. Clearly, many countries that have made previous progress, still need to review their services in order to be in line with the Convention. When examining the implementation of CRPD, it is important to pay attention to the countries that are considered fore-runners in disability services.

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