



How can states ensure access to personal assistance when service delivery is decentralized? A multi-level analysis of Iceland, Norway and Sweden

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ABSTRACT

Article 19 of the United Nations (UN) Convention on the Rights of Persons with Disabilities requires states to ensure that persons with disabilities have access to a range of support services, including personal assistance. The Convention is an agreement between state parties and the UN. However, in practice, disability services are often implemented at the local level. Drawing on the findings of qualitative research in Iceland, Norway and Sweden, this paper examines a paradox whereby states commit to ensure access to support services, but decentralize responsibility to autonomous and independent local governments. A multi-level governance framework is applied to analyse the findings of qualitative inquiry with policy-makers, local government officials and leaders of independent living organizations in all three Nordic countries. A multi-level analysis highlights the tensions and contradictions between decentralization and human rights commitments.

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Introduction

Under the heading ‘Living independently and being included in the community’, Article 19 of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD)¹ (United Nations 2007) obligates states to ensure ‘access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community’. Article 19 does not define personal assistance. Yet, the general principles of the Convention reflect the goals of the international independent living movement, which has advocated for personal assistance services since it was established in Berkeley, California in the late 1960s (Dejong 1983). Article 3 of the Convention outlines its key principles including ‘independence of persons’, ‘freedom of choice’ and ‘full and effective participation in society’. From an independent living perspective, personal assistance epitomizes these principles. Personal assistance is an individualized, tailor-made service. Users exercise maximum control over how it is organized and custom-design their personal assistance service according to their individual preference, which includes hiring, training and managing personal assistants (Ratzka 1996). In some cases, users receive cash payments to purchase personal assistance services from a wide choice of service providers. Centres for independent living or independent living organizations (ILOs) were established by and for disabled people and their family members. Some ILOs developed a personal assistance user co-operative to employ personal assistants and therefore served as peer-led alternatives to state-run services. ILOs offer a wide range of independent living

services and training programmes including employment skills, assistive technology and personal assistance.

When a state ratifies the Convention, it commits to develop and reform national laws and bring them in line with the CRPD (Stein and Lord 2009). This is an agreement between the UN and the national government. In many countries, a paradox has arisen whereby national governments ratify the Convention, but autonomous and independent local governments are responsible for providing and financing disability services. The Convention does not specify how the services should be organized. However, it stipulates that state parties must ensure that 'public authorities and institutions act in conformity with the Convention' (Article 4.1). Furthermore, Article 33 recommends that states should give 'due consideration to the establishment or designation of a coordination mechanism within government to facilitate related action in different sectors and at different levels'. Municipal variation is a concern for the UN Committee on the Rights of Persons with Disabilities. In their concluding comments to the Swedish Government, the Committee (2011, 2) identified a 'serious gap between the policies followed by the state party and those followed by the municipalities with respect to the implementation of the Convention'. This criticism by the UN Committee raises the challenge of ensuring access to personal assistance when service delivery is organized, delivered and financed at the local level.

This paper addresses a gap in knowledge about the implications of the Convention in countries that have decentralized disability service delivery to the local level. Decentralized service provision is common in the Nordic context. Tøssebro et al. (2012, 141) identified 'a major common theme in contemporary debates in all Nordic countries is the gap between the national policy ideals and the practical realities'. Drawing on the findings of qualitative research in Iceland, Norway and Sweden, we ask how states can ensure access to personal assistance when service delivery is decentralized. The qualitative methods included policy analysis and qualitative fieldwork, comprising interviews with leading members of ILOs and government officials responsible for policy-making and administration at local and national levels. We outline the nature and the implications of multi-level governance within each county, and discuss the tensions and dilemmas that arise between the state's commitments under the CRPD and local government discretion and autonomy. In conclusion, we suggest ways in which the CRPD offers practical guidance that could address some of the problematics identified in the study.

Decentralization and the CRPD

The Convention was ratified by Sweden (2008), Norway (2013) and Iceland (2016) (UN Enable 2016). All three countries implemented national personal assistance policies, to varying degrees, prior to ratifying the CRPD. Service delivery, financing and governance of disability supports and services are often decentralized to the local level in the Nordic countries. In Iceland and Norway, local governments are responsible for administering, governing and the majority of the cost of personal assistance services. Whereas, in Sweden, the cost, administration and governance of personal assistance are shared between the local and national levels. Tøssebro et al. (2012, 139) explain that there is political support for decentralization in Nordic countries because municipalities are 'in a better position to adapt services to local circumstances ... Thus, it is part of the ideal that local autonomy leads to local variation in services'. However, local autonomy and variation present a challenge if there is uneven access to services throughout the country. Previous studies reveal variations between the regions when local governments are responsible for service delivery and governance of personal assistance. These variations are known as a 'postcode lottery' in the United Kingdom (Riddell et al. 2006). This phenomenon was also reported in Scandinavia. A study of disability policy in Sweden concluded that 'it still matters where you live' (Lewin et al. 2008, 237).

When a state ratifies the CRPD, the national government is responsible for overseeing its implementation throughout the country. The national government must report to the UN Committee on the Rights of Persons with Disabilities two years after it ratifies the Convention, and every four years thereafter. Decentralization does not relieve national governments of their duties under the Convention. A report by the UN General Assembly (2015, 5) affirmed that 'as a matter of international

law, the state is one single entity, regardless of its unitary or federal nature and internal administrative division'. The same report by the UN General Assembly (2015, 6) acknowledges that if a state devolves responsibility to local governments it will 'need to take necessary measures at the local level, in particular, to establish procedures and controls in order to ensure that the state's human rights obligations are implemented'. It also compels governments to involve disabled people and their representative organizations in the policy-making process. Article 4.3 of the CRPD requires that: 'states parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations when developing and implementing policies and legislation concerning persons with disabilities'. These obligations complicate the relationship between the national and local-level governments in relation to disability policy, particularly in countries that recognize the independence and autonomy of local governments.

Multi-level governance

Scholars have expressed concerns that, even with strong national laws and policies, there will be weak enforcement of the Convention in practice (Kanter 2006; Lewin et al. 2008; Traustadóttir and Rice 2009; Tøssebro et al. 2012). Hence, a comprehensive framework is required to provide a thorough overview of access to personal assistance within countries. Multi-level governance refers to the 'reallocation of authority upward, downward and sideways from the central state' (Hooghe and Marks 2003, 233). It is characterized by 'co-decision-making across several tiers of government, ill-defined and shifting spheres of competence (creating potential for conflicts about competencies) and ongoing search for principles of decisional distribution' (Marks 1993, 104). Multi-level analysis was developed by political scientist Marks (1993) to examine the structural policy of the European community. Multi-level governance frameworks have been applied widely in the social sciences to study a wide range of services including health care (Magnussen, Hagen, and Kaarboe 2007; Mosca 2006). It is considered to be a useful framework for examining wider trends in social services throughout the European Union (EU). The 'White Paper on Multi-Level Governance' reported that almost 95,000 local authorities hold significant powers over public services and social policies in the EU (Committee of the Regions 2009). This demonstrates the importance of analysing policies at multiple levels. Decentralization and supranational influence are key components of multi-level governance (Hooghe and Marks 2003). A multi-level governance framework is an alternative to state-level analysis of policies and services. It provides in-depth insights into how policies percolate from supranational to national, and down to the local level. This is a useful framework for analysing the implementation of the CRPD. There is a rich and comprehensive ongoing analysis of personal assistance in the Nordic countries (Anderberg 2009; Askheim, Bengtsson, and Bjelkec 2014; Tøssebro et al. 2012; Traustadóttir and Rice 2009). We aim to contribute to this ongoing analysis by applying a multi-level approach to examine the finding of qualitative inquiry in Iceland, Norway and Sweden.

Methods

Data collection

This paper draws on qualitative data comprising interview transcripts, policy and legal documents, field notes and the findings of an extensive literature and policy review. Thirty-seven in-depth, semi-structured interviews were conducted in Iceland (September–December, 2012), in Sweden (January–May, 2013) and in Norway (August–September, 2013). Interviews lasted between 60 and 90 minutes. Five of the interviews involved two people. Purposeful sampling was used to identify and recruit participants who had a comprehensive overview of personal assistance policies at European, national and local levels. The most prominent ILOs in each country were contacted and the purpose of the project was explained to them. The organizations agreed that the first author would undertake a study visit at the organizations. Five ILOs were studied: two in Sweden, two in

Norway and one in Iceland. Additional interviews were conducted with policy-makers and government officials who were responsible for the governance and administration of personal assistance policy at national and local levels. These participants were also purposefully selected based on their involvement in personal assistance policy-making and administration.

Participants

All participants had an extensive overview of personal assistance within their own country and some were knowledgeable about personal assistance at European and UN levels. Hence, this is best described as a study involving policy experts and leading activists for personal assistance. Forty-six people participated in the interviews, 24 in Sweden, 11 in Iceland and 11 in Norway. The distribution of participants reflects the different scales of personal assistance in each country. There are approximately 16,000 people entitled to personal assistance services in Sweden, 2900 in Norway and 51 in Iceland (Askheim et al. 2013; National Board of Health and Welfare 2015). Table 1 provides a detailed breakdown of participants by country and by stakeholder groupings.

Data analysis and ethical issues

All data were analysed according to the constant comparative method of grounded theory. The constant comparative method of grounded theory is a constructivist approach to data analysis, which focuses on developing subjective understandings of the meanings that participants attach to social phenomena (Charmaz 2006). This involves analysing the data through coding, creating analytic 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, 160). We began with broad questions about the development of personal assistance law and policy and the implementation of Article 19 of the CRPD. Interviews were transcribed, analysed and coded soon after the interview was conducted. This provided the opportunity to narrow and refine the questions based on specific issues that arose from the interviews (Creswell, 2007). The final stage of data analysis involved comparing the major themes and categories with the relevant literature and the state obligations under the CRPD (Charmaz 2006).

The focus of the study and the approximate length of the interview were explained to the participants prior to the interviews. All participants gave informed consent and agreed to have the interviews recorded. All recorded material, transcripts and field notes were stored in a locked cabinet. Participants are a relatively small group of public figures and activists. Every effort has been made to protect their identities by removing identifiable material from the interview transcripts, in the field notes, in this paper and in other writings based on this data.

Findings

Multi-level governance in Iceland

Iceland is a Nordic state with approximately 330, 000 citizens. Despite its relatively small population, there are 74 municipalities throughout the island. The largest municipality, Reykjavik has a population

Table 1. Breakdown of participant numbers and groupings in each country.

	Leaders in the independent living movement	Policy-makers/ national government officials	Local government officials
Iceland	6	3	2
Norway	6	1	4
Sweden	18	4	2
Total	30	8	8

of approximately 119,000 people, whereas four have less than 60 citizens (Samband Íslenskra Sveitarfélaga 2013). Iceland is a clear example of shifting competencies between different levels of government. Traustadóttir and Rice (2009, 2) recognize that disability services 'are constantly in a state of flux; eligibility requirements change, responsibilities are shifted, organisations are merged, renamed or reformed'. In 2011, disability services were decentralized from the central state government and its regional offices to the municipalities. That same year, guidelines for a personal assistance (NPA, *Notendastýrd Persónulega Adstod*', which means User-Led Personal Assistance in Icelandic) pilot project were developed by a committee at the Ministry of Welfare. The committee comprised representatives of the Association of Municipalities and the two largest umbrella disabled people's organizations in Iceland.

The national guidelines say that NPA will become 'one of the main pillars in the services to disabled people' (Ministry of Welfare 2012b, 3). Yet, personal assistance lies within the competency of relatively autonomous and independent local governments. Municipal independence is recognized in Article 78 of the Icelandic Constitution which ensures that 'the municipalities shall manage their affairs independently as laid down by law'. The personal assistance pilot project is entirely voluntary for the local governments. If they choose to volunteer, local governments are expected to pay the majority of the cost of personal assistance. A Local Authority Equalization Fund (*Jöfnunarsjóður sveitarfélaga*), which is controlled by the Ministry of the Interior, covers 25% of municipal expenditure on personal assistance (*Jöfnunarsjóður* 2015). The national guidelines say that NPA contracts must be based on the individual's support need 'in order to be able to live an independent life', and 'not the financial capacity of the municipality' (Ministry of Welfare 2012a). Municipalities are permitted to make their own internal rules in addition to the national guidelines (Ministry of Welfare 2012b). For instance, municipalities can develop their own assessment criteria for measuring and allocating hours of personal assistance. Furthermore, municipalities can choose whether the user co-operative or other service providers can offer personal assistance within that municipality (Ministry of Welfare 2012a).

The pilot project was supposed to last for two years and legislation was expected to follow in 2014. However, in 2015, the government announced that the pilot project would be extended until the end of 2016. Hence, access to personal assistance is discretionary until personal assistance is incorporated into law. The latest statistics reveal that only 10 of the 74 Icelandic municipalities partook in the pilot project in 2014 (*Jöfnunarsjóður* 2015). Fifty-one persons received NPA contracts as part of the pilot project. The largest municipality, Reykjavik, had 14 of the 51 contracts. Three local governments had just one contract (*Jöfnunarsjóður* 2015).

The Icelandic government ratified the UN Convention in September 2016. In a progress report prior to ratification, the Ministry of the Interior (2013) identified the personal assistance pilot project as a positive step towards implementing Article 19. All Icelandic participants in our qualitative study considered personal assistance to be a human rights issue. Policy-makers who were involved in developing the NPA guidelines claimed that the Convention was a major consideration when the guidelines for the personal assistance pilot project were drafted.

Personal assistance emerged from grassroots organizations in Iceland. ILOs were at the forefront of raising awareness of independent living, personal assistance, and the CPRD at national and local levels. Members of the only existing personal assistance user-cooperative at the time, the NPA Centre (*NPA midstöðin*), received state funding to travel to municipalities to train municipal staff in the independent living ideology, personal assistance and the CRPD. Participants from Icelandic ILOs highlighted the problematics of decentralization of personal assistance services. Personal assistance was only available in a minority of Icelandic municipalities, on a voluntary basis. Some participants distinguished between the qualities of the personal assistance services in the municipalities that took part in the pilot project. They argued that personal assistance should be mandatory throughout Iceland. Many were frustrated when the pilot project was extended, not least due to the fact that it was voluntary for the municipalities. Denial of access to personal assistance had a profound personal impact on the participants from Icelandic ILOs. Several participants needed personal assistance for

education or employment or to move into their own apartment. Decentralization of personal assistance also limits liberty of movement between municipalities. If an individual receives personal assistance from one municipality, there is no guarantee that she or he will retain the service elsewhere. One participant from an ILO complained that his life would be on hold if his municipality decided not to participate in the pilot. He argued for equal access to personal assistance regardless of where one lives. 'The government should have been in charge of this. If I want personal assistance I should go to the government, because it will be different if I go to Reykjavik or ... (another municipality)'.

Municipal resistance to personal assistance services was a concern among participants from Icelandic ILOs. There were fears that municipal officials were unwilling to implement new policies and new ways of providing services. Most participants from ILOs described applying for personal assistance as a 'fight' or a 'struggle' against municipalities. They complained that municipal officials wanted people to live in the existing residential services. A participant who was a founding member of an ILO argued that municipal officials 'think in a very small box. (We are) trying to make them see that group homes are not working'. Another participant from an ILO explained:

They think they are being forced (to implement NPA). There is a lot of fear. They are afraid people will move out of the group homes and they will be empty and they will still have to spend money on the group homes and pay staff.

People living in group homes were not permitted to have personal assistance unless they moved into their own home. Hence, participants from ILOs feared that people would have no option to leave the group home if a local government was unwilling to put mechanisms in place to support their transition to community living. Even if access to personal assistance became mandatory in Iceland, participants were sceptical about municipal support for the transition from residential services to independent living services.

In interviews with Icelandic policy-makers and local government officials, the financial capacities of municipalities emerged as a primary challenge to implementing national policy at the local level. Local government officials complained that the eligibility criteria developed by the Ministry of Welfare were out of touch with financial capabilities and, therefore, some municipalities had to make their own rules to manage the cost and demand. A participant who was a member of the committee that developed the national guidelines explained that the government was misrepresenting NPA as 'a cost reduction exercise which doesn't work at all and can be a huge hindrance'. Policy-makers and municipal officials were concerned about the cost of the transition from group homes and other social services to personal assistance. For instance, a policy-maker who was involved in developing national guidelines at the Ministry of Welfare feared that there was not enough money to 'bridge the gap' in the transition from traditional social services to personal assistance. However, their greatest financial concern was in relation to a group of people who had not used social services in the past and relied on family members and others to provide informal care. A policy-maker described the risk municipalities were taking as 'walking into the Sahara without water'. They were uncertain of the demand for NPA in each locality. Hence, there was a lot of fear and uncertainty about the future and the sustainability of personal assistance in Iceland.

Multi-level governance in Norway

Norwegian municipalities are responsible for the delivery, allocation and the majority of the cost of Brukerstyrt Personlig Assistanse (BPA), which translates as User-Controlled Personal Assistance. There are 428 municipalities in Norway, which have a population of just over five million people. In the year 2000, personal assistance was incorporated into the Norwegian Social Services Act. It is outlined within Sections 4–2 of the Social Services Act 2000 as 'practical assistance and training including user-controlled personal assistance for those who are in special need of assistance owing to illness, disability or other reasons'.

Prior to 2015, municipalities were obligated to offer personal assistance as part of a 'menu' of disability services, but they had 'the final word in deciding what services is the most suitable' for each individual (Askheim 2005, 255). A Norwegian study found considerable variation between municipalities regarding eligibility criteria and the ways in which personal assistance is administered (Rambøll 2012). The same study found variations between municipalities regarding their interpretation of who should have access to personal assistance. For example, it was reported that some municipalities require that the user should be involved in education or employment and live an active life (Rambøll 2012). Municipalities provide the majority (54%) of personal assistance services in Norway (Askheim, Bengtsson, and Bjelkec 2014). The municipalities have control over which, if any, non-government personal assistance providers can offer personal assistance at that local government. For-profit and non-profit companies must apply and make contracts with each individual municipality. Municipalities can terminate contracts with personal assistance providers whenever they deem it necessary. As a result, the choice of assistance providers may vary between municipalities.

Since its ratification of the Convention in 2013, the Norwegian Government has strengthened a right to access to personal assistance. In 2015, a new law containing a stronger right to personal assistance came into force. It should, in theory, weaken municipal autonomy and discretion. However, this only applies to some users. Under the law, users who are assessed as requiring more than 32 hours of assistance each week are entitled to personal assistance. The legislation furthermore states that individuals who need between 25 and 32 hours of personal assistance each week may be entitled 'unless the municipality can demonstrate that such an organization will result in substantially increased costs for the municipality' (Directorate of Health 2013, § 2-1 d).

The cost of providing personal assistance is a concern for local governments in Norway. In 2013, a study reported municipal concerns that there would be considerable cost increases if stronger rights to personal assistance were enacted (Ministry of Health and Care Services 2013). Furthermore, the 'national authorities in Norway also express a fear that the expenditures to personal assistance will get out of control' (Askheim et al. 2013, 363). The national government covers some of the cost of the transition from other municipal services to personal assistance €12,000 in the first year and €6,000 can be applied for a further three years (Tøssebro 2009).

Despite the national government's commitments under the Convention and despite the strengthened access to personal assistance, participants from ILOs feared that municipal resistance would hinder the implementation of the new law. A participant from an ILO believed that 'bureaucratic thinking' at the local government level was the biggest obstacle to implementing personal assistance services. She explained that 'bureaucrats want services to allow people to exist, but life is more than just existing'. She feared that the new law for personal assistance would be compromised because 'bureaucrats are afraid to lose power or change the staff'. Another participant who was a founding member of an ILO predicted that some municipalities would challenge the new law. She explained: 'I have learned more and more about how difficult it is for the municipalities to change their tradition, they don't like changing. It's very, very difficult to change'. Interviews with municipal officials reflected the concerns of participants from ILOs. For instance, a participant who was in charge of personal assistance services at a municipality complained that local governments were going to be 'forced' by the government to offer personal assistance services. He believed that mandatory provision of personal assistance was 'punishment' for municipalities that provided inadequate alternatives to BPA. He argued that because personal assistance is demand-driven, the 'municipalities should fear that if you run bad services, you should be worried 20 people will apply for BPA'.

Freedom of movement between municipalities was a key concern for participants in receipt of BPA. A participant from an ILO, who had a comprehensive overview of personal assistance nationally, explained that:

... it's very different from one municipality to the next. There are problems with the municipal system. You cannot take personal assistance allowance from one municipality to the next. You can't move it with you and you risk getting a 'no' from another municipality.

Multi-level governance in Sweden

Personal assistance had been available in Sweden for 15 years before the government ratified the Convention in 2008. Personal assistance is 1 of 10 rights outlined in the Act concerning supports and services for persons with certain functional impairments (LSS 1993, 387). While most of these rights are provided at the municipal level, personal assistance (known as Personlig Assistans in Sweden) is the exception because Swedish ILOs called for a right for disabled people 'to be able to live in any municipality with the same quality of life' and argued that 'the responsibility for financing must be as centralised as possible' (Ratzka 1996, unpagged). As a result of their campaign, responsibility for personal assistance policy is shared between municipalities and the national Social Insurance Agency (Försäkringskassan). The Social Insurance Agency (2016) provides financial protection including pregnancy and parental benefit, child, childcare and family allowances, disability, unemployment and sickness allowances. If an individual requires more than 20 hours of personal assistance per week, the remaining hours are funded and administered by the Social Insurance Agency (Anderberg 2009). Askheim, Bengtsson, and Bjelkec (2014, 14) suggest that personal assistance was implemented during a recession in Sweden and therefore the 'handing over of the main financial responsibility to the state could ... be seen as a strategy for 'protecting' vulnerable groups against financial cutbacks in municipalities'.

Sweden signed the CRPD on its opening day in 2007 and ratified it in 2008. There are 290 municipalities in Sweden, which has a population of 9.5 million people. One study has likened Swedish municipalities to small nation states because some local governments have larger populations than Iceland (Lewin et al. 2008). Local self-government is enshrined in the Swedish Constitution and means that municipalities and county councils have the right of independent and free self-determination (Government Offices of Sweden 2016).

Recent figures illustrate the shifting spheres of governance between the national and the local levels. There has been an increase in the numbers of people losing personal assistance at the national level since Sweden ratified the Convention (Assistanskoll 2015; Brennan et al. 2016). In 2007, the same year that the Swedish Government signed the Convention, 56 persons lost their personal assistance at the national level upon assessment of their needs. This figure rose to 145 in 2015 (Assistanskoll 2015). People who lost state-funded personal assistance at the national level had to reply at their local municipality. On average, people lost 25% of their hours (from 54 to 72 hours per week) when they transferred from the national to the municipal system (National Board of Health and Welfare 2015). The UN Committee on the Rights of Persons with Disabilities (2011, 6) raised this issue in its concluding observations to the Swedish report:

The Committee is concerned that state-funded personal assistance has been withdrawn for a number of people since 2010 due to a revised interpretation of 'basic needs' and 'other personal needs', and that persons who still receive assistance have experienced sharp cutbacks, the reasons for which are unknown or only seemingly justified.

There is evidence to suggest that there is considerable variation in personal assistance services between municipalities in Sweden. A survey by the National Board of Health and Welfare (2015) found that more than 35% of the responding municipalities had developed or were developing their own rules for personal assistance in addition to national law and policy. The report found that approximately 40% of the additional guidelines contained more restrictive criteria to access personal assistance than the national law (LSS 1993, 387).

A multi-level examination of the delivery of personal assistance at both levels revealed an overwhelming preference for centralized governance among Swedish participants from ILOs. Many participants from Swedish ILOs had experienced personal assistance at both local and national levels. They distinguished between the quality of personal assistance at local and national levels. For example, they used terms such as 'au pair', 'help', 'personal care taker' and 'qualified babysitting' to describe their dissatisfaction with municipal personal assistance. One participant described the

inflexibility she experienced at the municipal level explaining that ‘there was only one assistant so if she was ill then there was no one to fill in. It could take six months for them to hire a new assistant if someone quit’. Furthermore, some participants complained that individuals faced discrimination if they required large contracts because they were considered to be financial burdens on the local budgets and were treated by municipal staff as such.

Freedom of movement between municipalities was one of the primary reasons why participants preferred state-funded, national-level personal assistance. Centralized personal assistance meant that people were free to travel within Sweden or to move to another municipality for work, education or other reasons. A participant from an ILO described the situation when a person receives municipal personal assistance: ‘If you’re lucky and live in a good municipality, no problem, you’re just stuck there for the rest of your life. You can’t move away for studies or for work or to get married someplace else’.

The Swedish Social Insurance Agency is not a service provider. Instead, individuals receive direct payments in lieu of services from the state and have a choice between a range of non-government for-profit and non-profit providers (Ratzka 2003). However, non-government providers are not obligated to provide for all users; they may choose which users can avail of their services. The Swedish Association of Local Authorities and Regions (2015) reported that the cost of providing personal assistance was higher for municipalities because it is mandatory to provide access, whereas non-government providers can refuse to provide service for individuals. For-profit personal assistance providers, which are not necessarily led by disabled people, account for a large proportion of non-government providers in Sweden. User co-operatives account for 9.2% of personal assistance providers in 2015, while for-profit providers represent 54% (Assistansskoll 2015).

The ability to control and monitor payments, particularly those made to for-profit providers, was another concern for participants who were responsible for administration at the national level. For instance, one participant explained that the majority of payments were not made directly to the user, but to a third-party company or co-operative. She described this as ‘a unique situation for the agency and is something that makes it quite difficult to control’. Prior to 2012, there was very little regulation of third-party personal assistance providers by the Social Insurance Agency. This situation changed in 2012 when, for the first time, third-party providers were required to register and needed to be approved by the Social Insurance Agency.

Discussion

Problematics of multi-level governance

The findings highlight the tensions and contradictions between decentralization of service provision and human rights commitments. Below, we discuss the multi-level issues that were most problematic or contentious in all three countries.

Unequal access

When a state ratifies the CRPD, it commits to ensure ‘access to a range of in-home, residential and other community support services, including personal assistance’. Icelandic municipalities offered personal assistance on a voluntarily basis. Only a minority of municipalities (10 of 74) chose to participate in the pilot project. Some states, including Sweden and Norway, have taken measures to ensure mandatory access to personal assistance at the municipal level. Our findings suggest that mandatory access at the municipal level does not guarantee standardization or equal access for all users. The findings indicate that in all three countries, some municipalities deviated from the national policy and created their own guidelines regarding who can access personal assistance services. This is problematic when national governments report to the UN Committee on the Rights of Persons with Disabilities as a single entity. Furthermore, despite mandatory access at the municipal level in Sweden and Norway, non-government providers may choose which users can avail of their services.

Varying interpretations of personal assistance

While the CRPD requires access, it does not define personal assistance. The quality and nature of service provision are determined, not necessarily by the independent living definition, but by the local government's interpretation of personal assistance. Our findings revealed municipal resistance to implementing personal assistance and the distinction between 'good' and 'bad' local governments. The UN Committee on the Rights of Persons with Disabilities is due to release a general comment on Article 19 in 2017, which may clarify their interpretation of personal assistance. The Committee has closely consulted with disabled people and their representative organizations when drafting the general comment (UN Committee on the Rights of Persons with Disabilities 2016). Hence, it can be expected that any clarification regarding personal assistance will reflect the input of an international network of disabled people's organizations.

Civil society at the local level

The Convention requires that states parties 'closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organisations when developing and implementing policies and legislation concerning persons with disabilities' (Article 4.3). The UN General Assembly (2015) recommends that civil society should play a central role and that 'measures should be taken, both nationally and internationally, to strengthen civil society capacity to monitor and engage with local government'. ILOs are particularly well positioned to advise governments on the independent living goals and policies, and to monitor its implementation (Brennan et al. 2016). However, we found very little evidence of ILO involvement at the local government level. One example emerged in Iceland, where members of an ILO, the NPA Centre (NPA mid-stöðin), received state funding to travel to municipalities to provide training for municipal staff about personal assistance, the independent living ideology and the CRPD. Yet, this stood out as an exception of ILO involvement at the local level. The lack of civil society involvement at the local level is problematic in relation to states that have ratified the CRPD.

Restricting liberty of movement

Restricting liberty of movement was problematic in the three countries. In Iceland, it was voluntary for municipalities to offer personal assistance services during the pilot project. Hence, there was no guarantee that people would get personal assistance services if they moved to another municipality. Despite the stronger laws and policies, this was also an issue in Norway and Sweden. The only exception to this was when personal assistance was funded by the national Social Insurance Agency in Sweden. A right to liberty of movement and to freedom to choose their residence is recognized under Article 18.1 of the CRPD, which requires that 'States Parties shall recognize the rights of persons with disabilities to liberty of movement, to freedom to choose their residence and to a nationality, on an equal basis with others'. Liberty of movement is recognized elsewhere in international law. For instance, liberty of movement is protected under Article 12 of the International Covenant on Civil and Political Rights (Parker and Clements 2008). States that do not allow citizens to retain personal assistance if they move from one municipality to another are violating the right to free movement. This is one of the key tensions between state-level obligations under the Convention and decentralization of services. It is a challenge not only for provision of personal assistance, but also for other social services in decentralized systems of governance.

Financial pressure on local governments

Finally, responsibility for covering the cost of personal assistance emerged as a primary obstacle for multi-level governance of personal assistance policy. Each country had a different approach to

distributing the cost of personal assistance between the national and the local levels. The general obligations of the CRPD (Article 4) specify that states must 'take measures to the maximum of its available resources' to implement the rights of the Convention. However, this does not take into account countries like Iceland and Norway, where the majority of financial responsibility is passed on to the municipalities. This is an implementation barrier for local governments with relatively fewer financial resources than the state. Our findings reveal that municipal officials fear a rise in the cost of personal assistance. Therefore, the guidelines that determine access to personal assistance are often restricted to control the demand. The UN General Assembly (2015) warned that 'whatever powers that are conferred upon local authorities, they would not be effective if no financial resources were available to carry them out'. This is problematic if states offload costs onto municipal budgets without adequate financial compensation.

Conclusion

Our study highlights how national policy goals are compromised at local levels. Decentralization of disability services is a significant challenge for ensuring access to personal assistance and a challenge for human rights advocates and monitors. A state-level analysis of the implementation of the Convention risks overlooking regional differences within countries. This is not to say that decentralization is incompatible with the Convention. However, some the consequences of decentralization that emerged from our qualitative study are in conflict with the commitments made by state parties under the CRPD. It is problematic if the responsibility for implementing the Convention is offloaded onto autonomous municipalities that have less financial resources and little or no accountability to the state. Based on our findings, we suggest that it is important to monitor the implementation of the Convention at the local level and to involve disabled people and their organizations in this process. This applies not only to personal assistance, but also to other social services that fall within the competencies of the local government. Otherwise, there is a risk that human rights violations will be hidden at the local level.

Note

1. Hereafter referred to as the Convention or the CRPD.

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