

Research article

# The meaning of the disability rights movement for the professional field of social pedagogy in Iceland

Vilborg Jóhannsdóttir,<sup>1,\*</sup> Freyja Haraldsdóttir<sup>1</sup>

<sup>1</sup> University of Iceland; freyjaha@hi.is

\* Correspondence: vjoh@hi.is

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## Abstract

The Convention on the Rights of Persons with Disabilities (UNCRPD) is a landmark for the international disabled people's independent living movement (ILM). The ILM has been a platform and a tool to resist the traditional medicalisation of disability by calling for a broader understanding where independence is no longer seen as the opposite of needing assistance. The field of social pedagogy in Iceland has evolved parallel with the paradigm shift grounded in the UNCRPD that replaces the medical model with the social and human rights models of disability. The aim of this article is to explore and interpret social pedagogues' and disabled people's perspectives on how the human rights principles and values embedded in the UNCRPD and independent living (IL) ideology can best be put into practice, as well as to cast a light on existing barriers and challenges. This study draws on qualitative data from two sources; the participants provided texts from a semi-structured questionnaire and public accounts written by disabled people. We utilise the five summarising principles of cultural-historical activity theory to further analyse and interpret the data. The contradictions drawn out of the findings show conflicts and

structural tensions that have accumulated historically due to the massive legislative and policy shifts in disability services in past decades. The findings also indicate the need for a reconceptualisation of the object and the motive of the activity, i.e. disability-related social services, in order to embrace the principles, values and recommended practices grounded in the UNCRPD and the IL ideology.

**Keywords** social pedagogy; disability rights movement; UNCRPD; independent living; cultural-historical activity theory

## Introduction

The UN Convention on the Rights of Persons with Disabilities (UNCRPD) is a landmark for the international disabled people's independent living movement (ILM) (Degener, 2017). Article 19 of the UNCRPD, *living independently and being included in the community*, sets out the right of disabled people, of all ages and across impairments, to live in the community with choices equal to others, requiring states to enable disabled people to be fully included in society (European Coalition for Community Living, 2009). The decision to add a universal human rights instrument specific to disabled people was born of the fact that disabled people have been primarily viewed as 'objects' of welfare or medical treatment rather than 'holders' of rights and duties, despite being theoretically entitled to all human rights (United Nations, 2007).

The ILM, pre-dating the UNCRPD by several decades, has been a global platform and a tool to resist traditional medical assumptions about disability by calling for a broader understanding where independence is no longer seen as the opposite of needing assistance in everyday life. Degener (2016) states that the ILM has always phrased their demands in terms of human rights and social justice with the main aim of redirecting control of services from professionals and the service systems towards disabled citizens. This situation has led to resistance among disabled people who have created their own innovative services grounded in the independent living (IL) ideology, such as personal assistance (PA), and pressed for law reforms and new legislations that give them greater control over those provided by statutory bodies (Barnes and Mercer, 2006). Even though the IL ideology did not reach Iceland formally until after the signing of the UNCRPD in Iceland in 2006, its influence, for instance on the development of theories about models and perceptions of disability, has been a fundamental factor in guiding disabled people's activism, law reform, systemic change and professional thinking within the field of social pedagogy. PA based on the IL ideology was first established in Iceland as a pilot project which laid the groundwork for a new disability legalisation (Act on Services for Disabled People with Long-Term Support Needs, 2018) in compliance with the UNCRPD which was ratified in Iceland in 2016 (Stjórnarráðið, 2018). The new legalisation aims to provide the best possible service by honouring disabled people's autonomy, independence and the right to participation in decision making on all matters that affect their lives. Furthermore, meaningful and holistic person-centred planning is mandated (Stjórnarráðið, 2018).

The UNCRPD addresses many stakeholders and actors such as the field of social pedagogy and the profession of social pedagogues (SPs) who provide services for diverse marginalised groups, such as disabled people of all ages in a variety of community settings. SPs in Iceland work within the social, educational and health systems and there is an ever-increasing demand for their services. Even though human rights principles and a person-centred approach are central to the declared values and goals of social pedagogy in Iceland today, there are many barriers and challenges that may prevent and misinform rights-based practices. It can be argued that this stems partly from existing gaps in the knowledge on how the radical elements of the human rights principles are to be applied in practice. Moreover, further knowledge on that matter is especially important now for professions such as SPs due to their long history within the service system and their leading role in implementing and applying the key elements of the UNCRPD and the IL ideology.

This article is based on a larger ongoing study focusing on the changing role and professional developmental needs of SPs in light of the rights-based demands made by the UNCRPD and the IL ideology. The aim of the part of the study presented here is threefold. First, it seeks to explore and interpret the SPs' and disabled people's perspectives on how the human rights principles and

values embedded in the UNCRPD and IL ideology can best be put into practice within the field of social pedagogy. Second, it casts a light on existing barriers and challenges. Finally, it draws out the professional expertise that the SPs bring with them into the interprofessional practices as a human rights profession. We utilise features of Engeström's (1987, 2001) approach within cultural-historical activity theory (CHAT) to further analyse and interpret our data, which is derived from two sources: the participants' (SPs') answers to a semi-structured questionnaire; and public accounts written by disabled people. The reasons for this are those described by Sannino (2009, p. 15): 'Engeström's work addresses the pressing societal challenges of change and learning in work activities'. Moreover, that activity theory, proposed as a lens seeks to analyse development within practical social activities, considers the complexities involved. Russell (2009) explains further how Engeström's activity system plays out when it is used with the unit of analysis of genre as social action to trace how documents, for example, the UNCRPD and the IL ideology, come into existence and come to be used in organisations.

We begin by briefly describing the context of the present study in the sections 'Social pedagogy in Iceland: the development of theory and practice' and 'Independent living as a human rights framework'. We then introduce the theoretical background of CHAT and the applied methods, followed by a summary of the main findings, which we then analyse and discuss in more detail with the help of the five principles of CHAT (Engeström, 2000).

## **Social pedagogy in Iceland: the development of theory and practice**

In a historical international perspective, social pedagogy goes hand in hand with political initiatives to overcome poverty and improve societal well-being (Rosendal Jensen, 2013). While the political strategy was directed against an external social reform, the pedagogical strategy was targeted at society's internal reform through education (Hämäläinen, 2003). Storø (2013) points out, by citing Madsen (2006, p. 58), that the field of social pedagogy can be described as 'individuals and groups who find themselves in conflict zones in society, in the tension field between integration and marginalisation or actual expulsion'. This reflects the origin and development of social pedagogy in Iceland, which lies deep in disabled people's and disability scholars' battles for social justice and equality in all realms of life and has influenced theory building and perspectives within the field of social pedagogy as well as international theoretical discussions (Jóhannsdóttir and Ingólfssdóttir, 2018). The first SPs in Iceland were educated in the 1950s as specialised nurses and caretakers within the largest residential institution for disabled people, Kópavogshæli. Oliver (1990) points out that it was within these institutions that disability formally became regarded as an object of medicalisation. In that light, the SPs' professional focus was on care, health, protection, safety and supervision in segregated settings in line with the medicalised interpretations of disability and social and political expectations of that era. Thus, the field of social pedagogy in Iceland is rooted in societal needs for trained practitioners in the field of disabilities and has evolved through several theoretical and ideological phases, which were affected by changes in disability theory, legislation and policy (Björnsdóttir and Össurardóttir, 2015; Jóhannsdóttir, 2003; Jóhannsdóttir and Ingólfssdóttir, 2018).

Hämäläinen (2013) notes that social pedagogy in many countries has been developed as a particular professional system dealing with people's social and educational needs. Elsewhere he stresses that 'country-specific traditions of social pedagogy can be understood, and must be studied, in the context of national histories' (Hämäläinen, 2012, p. 5). Furthermore, Eriksson (2014) emphasises that the interpretation of social pedagogy today depends not only on its historical roots but also on the theoretical, cultural and political development within different societies. As such, SPs' education in Iceland, their professional role and theoretical perspectives have developed in parallel with the paradigm shift grounded in the UNCRPD, which replaces the medical model with the social and human rights models of disability (United Nations, 2007). The medical model, which has been the prevailing ideology, views disability as a 'problem' that belongs to the disabled individual thought to be in need of specialised services in segregated settings, often treated as a victim of circumstance (de Beco, 2014; Goodley, 2011; Oliver, 1990). Oliver (1996) explains further how the medical model underlines that something is wrong, that is, an individual problem that must be put right. Resources are targeted at individuals in order to fix them for participation in the world around them, while the environment in which they live is regarded as unproblematic (Cameron, 2014). When disability is understood in this way, professionals

tend to focus on individual diagnosis, habitation planning, therapies and rehabilitation, with the goal of adjustment and adaptation to society as a main criterion. Such practices developed and evolved within the training and working environment of the SPs in Iceland during the era of institutional reform in the 1970s and the era of deinstitutionalisation towards community living in the 1980s. This was influenced by the normalisation principles formulated by Swedish scholar Bengt Nirje (1980), which were reformulated by Wolf Wolfensberger (1983) with the term 'social role valorization'. French and Swain (2008) address the issue of professional dominance relating to practices in line with the medical model of disability and illustrate that definitions of needs, solutions, interventions and evaluations of effectiveness tend to be dictated and asserted by professionals. This underpins the standpoint of professionals and their status as experts, while disregarding disabled people's claim that they know what is best for themselves and their community (Charlton, 1998; French and Swain, 2008).

However, Oliver (1990) argues that when disability is redefined as social oppression, disabled people can be seen as a collective marginalised group, disabled by a discriminatory society. This oppression can be expressed by systems, politics and professions seeking to maintain the status quo by individualising problems to the person, not to the society (Brandon, 2014; Cameron, 2014). Degener (2016) illustrates further that the new thinking about disability described as the paradigm shift from the medical model to the social model 'recognizes that disability is a social construct which is created when impairment interacts with societal barriers' (p. 1). French and Swain (2001) emphasise that this paradigm shift is central to changing professional–disabled people relations regarding working with disabled people in confronting the barriers of systemic discrimination. Moreover, it has been suggested that a stronger focus should be put on partnership, alliance and empowerment, as well as exploring ways of better supporting disabled people and ensuring that they live more included lives (Shakespeare, 2006). The social model of disability, which emerged as a result of the self-organised activity of disabled people, as discussed above, offers an alternative framework where disability is reconceptualised as a social structural issue with social justice and human rights as a criterion (Cameron, 2014; Campbell and Oliver, 1996; Degener, 2016; Lawson and Beckett, 2021). Lawson and Beckett (2021) discuss that an array of alternatives to the social model have been presented over the past decades and claim in the context of human rights law and policy 'that the human rights model is by far the most important and influential' (p. 349).

Degener (2016) emphasises that the UNCRPD is based on the human rights model of disability which builds on the social model but develops it further. On this subject, Lawson and Beckett (2021) highlight the complementary relationship between the two models which they claim have distinctive roles to play in furtherance of human rights for disabled people with the common goal of making disabled people's resistance to unjust disabling societies possible. An example of distinctive functions of the two models depicted by Lawson and Beckett (2021) is that the social model creates a sense of belonging to the collective of disabled people with different impairments, whereas the human rights model is between disabled people and all others and as such creates a sense of belonging to the human race. Thiersch (in Schugurensky, 2014) highlights from the social pedagogical perspective that the international field of social pedagogy has a strong role to play in bridging the gap between a rights-based vision and reality. A study by Jóhannsdóttir and Liliendahl (2015), which focuses on SPs in Iceland in an international context, shows that their working theory coincides with the shared professional competences of the International Association of Social Educators (AIEJI) in areas such as ethics and ideological background, with human rights treaties being the common denominator.

The social pedagogy profession in Iceland has in recent years been progressively developing as a human rights profession. This is clearly reflected in their newly revised *Ethical protocol and ethical standards* where it is highlighted that SPs' professional goal is to promote disabled people's full participation in an inclusive society. Furthermore, SPs' aim is to safeguard and support disabled people's battles for social justice, equality and human rights in all realms of life in accordance with human rights treaties and laws and regulations which they, as professionals, abide by (Landlæknisembættið, 2016; Proskapjálfafélag Íslands, n.d.). Thus, the SPs' professional role, theoretical base and practices have evolved via fundamental changes in response to social and political understandings and expectations expressed in disability movements and policy, legislation and human rights treaties. Hence, social pedagogy in Iceland, an academic discipline since 1998, contains strong disability theory foundations, the field of disability studies being an important pillar in academic education and ethical guidelines (Jóhannsdóttir and Ingólfssdóttir, 2018). Taking a lead from disabled people's political and cultural struggles for recognition, disability studies has advocated that disabled people be placed at the centre of the picture and their voices are prioritised (Shakespeare, 2006). The development of social pedagogy

in Iceland depicted here shows that disability models have played a pivotal role in SPs' professional development and in the formulation of their academic field and practices. It is also important to note, as mentioned earlier, that the principles that drove the deinstitutionalisation era in Iceland, as in the rest of Scandinavia, were different from the human rights principles embedded in the UNCRPD (Degener, 2016). Thus, we argue in line with Degener (2016, 2017) and Lawson and Beckett (2021) that greater clarity of the social and the human rights models and the relationship between them would be beneficial for guiding professional practices, development and future scholarship within the field of social pedagogy.

Current dilemmas today are in line with Cameron (2014), who describes the impact of the medical model of disability on disabled people's lives still being a dominant factor in services, not only in professional judgements and assumptions about what are appropriate services, but also the restriction of life opportunities, experience and roles. Oliver (2004) addresses this issue when he claims that not enough attention has been paid towards the implementation of the social model of disability, which could be the cause of disabled people's continuing oppression and discrimination. This concern is reflected in recent Icelandic studies, situated within the field of social pedagogy, which shed light on the professional and systemic tension caused by the mismatch between disabled people's entitlement to services in accordance to the UNCRPD and the reality of services and practices in line with the medicalisation of disability. There is a consensus among the SPs in these studies that the biggest barriers they face – that is, the unclear and contradictory role and agency and lack of shared vision – are rooted in mismatching views on disability among service providers as well as within the systems themselves (Bergsveinsdóttir and Jóhannsdóttir, 2015; Björnsdóttir and Össurardóttir, 2015; Jóhannsdóttir and Ingólfssdóttir, 2018; Jóhannsdóttir and Liliendahl, 2015; Reykjavíkurborg, 2006).

## **Independent living as a human rights framework**

Disabled people, as well as other marginalised groups, have been systemically oppressed and discriminated against from the beginning of time, worldwide. Systemic disability oppression, often referred to as ableism, represents itself in the core belief that disabled people are inferior, victims of broken bodies and objects of medicalisation, as well as being incapable of making decisions, speaking for themselves and controlling their own lives (Campbell, 2009). Consequently, ableism has reinforced paternalistic policies and practices in service systems and cultures around disability, often leaving non-disabled people in a place of superiority and power over disabled people's lives (Charlton, 1998). The ILM is a grassroots social movement which originated in the late 1960s and is grounded in disabled people's fight against ableism and for deinstitutionalisation and control over their identity, autonomy, bodies and lives. The fundamental work of the ILM has been moving away from exclusion, oppression and the dominance of health and social care professionals to a culture of inclusion and service systems which honour disabled people's access to society, independence and self-determination (Woodin, 2014).

ILM pioneers have addressed the main cornerstones of the IL ideology that need to be taken into account when it comes to securing full participation in society. The IL cornerstones include access to information about rights and resources, peer support where disabled people support and empower each other, accessible housing in the community, mobility aids, user-led PA, accessible transportation and access to the built environment (Evans, 2001; Hasler, 2003). The IL ideology presents PA services which refer to person-centred and user-controlled human support as an important means of securing independence and encouraging deinstitutionalisation for disabled people (United Nations, 2017). Instead of government-funded institutions or group solutions, it must be allocated to and controlled by the disabled person who needs the assistance (United Nations, 2017). Furthermore, PA is based on the disabled person assessing their own needs for services and deciding 'by whom, how, when, where and in what way the service is delivered' (United Nations, 2017, 16d). PA is not shared with other disabled persons and is a 'one-to-one relationship' between a disabled person and their personal assistants (United Nations, 2017, 16d). This is an important factor due to the fact that sharing assistants with other disabled people can easily prevent 'self-determined and spontaneous participation in the community' (United Nations, 2017, 16d).

These IL cornerstones have been developed and redefined through the years but their essence is clear; the liberation of disabled people from systems that see disability as a medical problem rather than a societal one. Therefore, the ILM definition of independence is centred on living on equal terms, being included and having freedom of choice, whether or not one needs assistance. The leaders of the ILM

and disabled people in general have stressed that the meaning of independence is not rooted in the traditional neoliberal ableist understanding that people should have the physical and mental capacity to do everything on their own without support. This understanding has been the basis of a long, harmful history of exclusion and mass institutionalisation of disabled people (Goodley and Runswick-Cole, 2011). Morris (2004, cited in Woodin, 2014) points out that ILM has challenged the dominant discourse that disability equals dependence or lack of capacity for autonomy 'by demonstrating that the presence of a functional impairment need not, and should not, be used to undermine individual control and autonomy' (p. 34).

One of the core articles of the UNCRPD and a product of the IL ideology is Article 19, as discussed in the introductory section, which states that countries that have ratified and/or legalised the convention, are obligated to secure disabled people's freedom of choice when it comes to residency, housing and living arrangements (United Nations, 2017). Also, state parties have to prevent segregation and isolation from society and secure access to wide range of community support, such as PA (United Nations, 2006). General comment no. 5 on the UNCRPD explains the cornerstones of the IL ideology further and elaborates that it is essential to have 'access to transport, information, communication and personal assistance, place of residence, daily routine, habits, decent employment, personal relationships, clothing, nutrition, hygiene and health care, religious activities, cultural activities and sexual and reproductive rights' (United Nations, 2017, 16a). Article 19 also underlines how the right to inclusive lifelong education and IL is interconnected (United Nations, 2017).

In accordance with the words of Woodin (2014), the UNCRPD explains that disability is diverse, and the rights claimed in the convention consider all disabled people, across impairments and other social categories (United Nations, 2006). As acclaimed in general comment no. 5, the disabled person, regardless of the type of impairment, 'remains at the centre of the decisions concerning the assistance, the one to whom any inquiries must be directed and whose individual preferences must be respected' (United Nations, 2017, 16d). General comment no. 5 of the UNCRPD states as well that countries that have ratified or legalised the UNCRPD should ensure that professionals are adequately trained in theory and practice on IL and inclusion. Finally, it should be noted that the UNCRPD and the IL ideology provide a detailed roadmap, useful for the development of law, policy and practices.

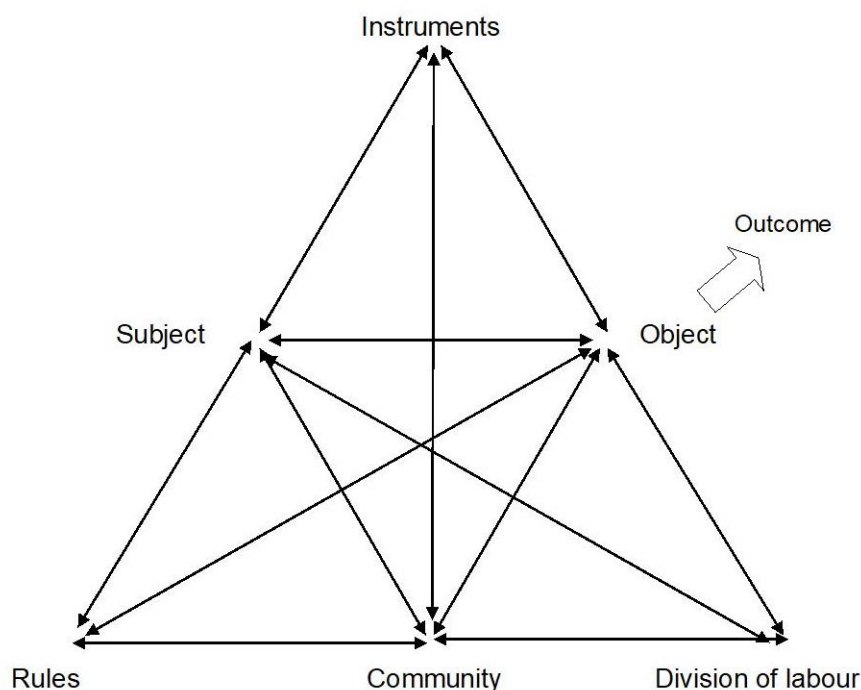
## Cultural-historical activity theory (CHAT)

Activity theory has its roots in the cultural-historical psychology developed by Vygotsky, Leont'ev and Luria in the post-Revolution Russia of the 1920s and 1930s (Engeström, 2008). Since the 1970s, Engeström has pioneered a form of cultural-historical activity theory that builds upon the work of Vygotsky and Leont'ev (Edwards, 2009). Engeström (1987, 2001) has developed an activity theory as an analytical framework to explore the relations between the individual and the community in any kind of human activity based on Leont'ev's theory of object-oriented joint practice, rather than individual actions, as the unit of analysis. Engeström (1987) describes how the theory helps to understand and analyse human activities in their social contexts (Engeström, 1987, 2001, 2016). Moreover, he sees instability, internal tensions and contradictions within the systems as the drivers of change and learning in human practice. Within CHAT, Engeström has suggested an approach for analysing organisational and professional learning in complex systems, and put forward a triangular diagram of 'activity systems' as explained in Figure 1.

The *subject* refers to an individual or a group of individuals whose agency is chosen as the point of view in the analysis. The *object* of activity refers to the ends or the outcome towards which the activity is directed. The subjects act on the object by *instruments*, giving the activity a specific direction. The mediation occurs through the use of many different types of instruments – material instruments as well as mental – including culture, role positions, ways of thinking and language. The instruments mediate relationships between the subject and the object. The *rules* refer to the set of norms and conventions that regulate the activity, while the *community* consists of the people involved in the activity who share the same object, and the *division of labour* mediates the hierarchy of labour and division of tasks between its members. In this context, the SPs can be seen as the subject of the activity, their agency as a human rights professional in disability-related social services and its declared goal as the outcome. To be able to analyse multifaceted interactions and relationships such as the complex and

evolving systemic and professional perspectives within disability-related social services, a theoretical account of the constructive elements of the system under investigation is needed.

**Figure 1.** The mediational structure of an activity system (Source: Engeström, 1987, p. 78).



Engeström (2001) emphasises that CHAT is not a predictive theory but an analytical framework within which different theoretical perspectives may be employed. In our study we take the influence of the paradigm shift from the medical understanding of disability to the social and human rights understanding embedded in the UNCRPD and IL ideology as a theoretical standpoint when analysing the lived experiences of disabled people and SPs within the service system. One of Engeström's most important contributions to activity theory, according to Blackler (2009), has been his suggestion that the historically located activity system should be the fundamental unit of analysis rather than the socially mediated individual. He elaborates further on this thought and suggests that 'particular actions need to be analysed in the context of longer-term historical dynamic' (Blackler, 2009, p. 29).

Engeström (2001) summarises and explains the function of activity systems according to five principles which we utilise for further analysing and interpreting our findings. First, that the primary unit of analysis is a collective, artefact-mediated and object-oriented activity system. Second, he describes multi-voicedness in activity systems and builds on the assumption that an activity system is always a community with several viewpoints, traditions and interests. The third principle is historicity, where it is stressed that activity systems take shape and are transformed over lengthy periods of time. The fourth principle highlights the central role of contradictions as sources of change and development. And finally the fifth principle, the expansive transformation in activity systems, sheds light on how activity systems can go through changes and expand.

## Methodology and methods

The study presented in this article is part of a larger ongoing study as stated in the introductory section where the main aim is to examine how the UNCRPD and IL ideology push for change in professional learning, practices and policy making within the diverse field of social pedagogy. The aim of the study presented here is threefold. First, it seeks to explore and interpret the SPs' and disabled people's perspectives on how the human rights principles and values embedded in the UNCRPD and IL ideology can best be put into practice within the field of social pedagogy; second to cast a light on existing

barriers and challenges; and finally, to draw out the professional expertise the SPs bring with them into the interprofessional practices as a human rights profession.

This study draws on qualitative data derived from two sources: a semi-structured questionnaire completed by SPs; and public accounts by disabled people. The questionnaire consists of 30 questions, many with the possibility of further explanations and expression of views and opinions. The questionnaire was designed in line with the purpose and aim of the study in collaboration with the Educational Research Institute at the University of Iceland and the Association of Social Pedagogues in Iceland. The questionnaire, complemented with an introductory letter, was sent to the members of the Association of Social Pedagogues in Iceland through the Educational Research Institute (N = 789 in December 2016 and January 2017). A total of 468 SPs responded (59.31 per cent). The questionnaire responses provided a rich body of information on the views and experiences of SPs working in diverse settings in terms of, for example, their education and professional development, work experience, current role, the challenges they face, as well as their professional perspectives and learning needs with regard to the UNCRPD and IL ideology. The majority of respondents had practised for under 30 years. About 50 per cent of respondents worked with children and youth within schools and leisure. Text provided by the SPs who worked as consultants or carried out managerial responsibilities within the disability-related social services were of special focus because of their important role in implementing Article 19 of the UNCRPD and their extensive overview and interconnections with other service systems, such as education. The SPs who participated in the semi-structured questionnaire were informed about the purpose and aims of the study in the introductory letter, which provided informed consent. Every effort was made to protect their identities. The project was registered with the Icelandic Data Protection Authority.

Data were also derived from public accounts presenting the views, experiences and knowledge of disabled people and their families who have been at the forefront of the struggle for PA and IL in Iceland. The public accounts involved both interviews in the Icelandic media and public writing presented on the websites of NPA miðstöðin, a PA Cooperative in Iceland run by disabled people, and Tabú, a feminist disability movement run by disabled women. The public accounts were published between 2017 and 2019 and consisted of 30 documents presenting the voices of 18 disabled people and three family members. These accounts outlined the lived experiences of disabled people advocating for PA, receiving PA and the main changes that PA has had on their lives, in terms of independence and autonomy. Also addressed were the main challenges of having PA services and what further systemic changes needed to be made so that PA, based on the IL ideology and the UNCRPD, is a reasonable option for all disabled people who need support in their daily lives. The participants were selected based on age, gender and impairment-type factors with the aim of giving a broad example of the diversity of the group. The voices of family members were only gathered when they were parents of disabled children or supporting a disabled adult expressing their experiences. Some of the voices presented were from people who took part in a pilot project on PA that existed from 2011 to 2018 while others gained access to PA after a new disability legalisation came into existence in 2018, securing the right to PA services.

The data derived from the texts provided by the participants' answers to the open questions in the questionnaire and the data from the public accounts were sources for qualitative analysis. They were carefully read and sorted by content according to the aim of the study. The data analysis was guided by the work process recommended for descriptive qualitative analysis (Bogdan and Biklen, 2007; Creswell, 2008). First, open coding was performed with codes emerging from the written text, followed by focused coding to validate similarities and differences with themes from both sources (Bogdan and Biklen, 2007). The developing coding categories were then thoroughly examined to identify relationships in order to better understand various aspects of expressed views and experiences. The mixing of these two sources gave a fuller picture of the subject under scrutiny and allowed us to grasp disabled people's and the SPs' perspectives and lived experiences in line with the aim of the study. In the following sections we begin by giving an insight into the key findings, which are then discussed and analysed further in the final section with utilisation of the five principles of CHAT introduced above.

## **Summary of findings**

In this section we give an insight into the perspectives of SPs and disabled people on how the human rights principles embedded in the UNCRPD and the IL ideology can best be put into practice, as well as to cast a light on the existing barriers and challenges.



## **The voices of disabled people**

Disabled people in Iceland, of all ages and across impairments, have collectively fought hard for the right to PA for the past decade. According to the public accounts, institutionalisation and unwanted dependence on family members was the main reason that disabled people sought PA. The mother of Arnarsdóttir, a 10-year-old with physical impairments, explains that before her daughter got PA she received assistants from many different systems, including her school and the municipality, resulting in complications and instability. However, upon receiving PA, Arnarsdóttir has the same assistants, funded from the same source, regardless of the time of day, season or where or what she is doing. Arnarsdóttir herself points out that now she is in control: 'If I want to go home to "chill out" after school, I can. If I want to bake a cake, I go to the shop to get the ingredients. This is really comfortable and has changed my life' (Hálfðánardóttir, 2019a, para. 9). Rúnarsson (2016), a teenager with intellectual impairments and chronic illness, shares this experience, explaining that with PA he is not forced to go to a segregated leisure club for teenagers with intellectual impairments after school but can go wherever he wants: 'I used to go to a leisure club but I can't be bothered any more, I'm a teen. My assistant helps me to be who I am and to become independent' (para. 2). Hallgrímsson, who passed away at the age of 10 in 2017, had physical impairments, chronic illness and was a ventilator user. He stressed the importance of being able to live at home with his family instead of being sent away to respite care: 'It's nice to be home with my family, to sleep in my own bed and play with my toys. It's also so important to choose my own staff with help from mum and dad' (Hallgrímsson, 2016, para. 15).

Sigurbjörnsdóttir, a woman in her twenties with intellectual impairments, explains that now she has PA she does not have to rely on her family for assistance in everyday life and can therefore live on her own and have autonomy. She enjoys being able to meet family members and go out spontaneously or without much preparation. Sigurbjörnsdóttir (2017) has a co-supervisor for her PA support: 'She helps me to be the supervisor. She also helps me plan my days. That makes me feel calm' (para. 3). Björnsson, a man in his thirties with an intellectual impairment, lived in a group home before he received PA, where he did not thrive. At the group home, Björnsson lived with four other men whom he had not chosen to live with. Also, there were only two staff members on each shift and he had to share them with the others, making it difficult to meet individual needs. With PA came great change, according to his mother: 'He is now active on the open labour market, he travels, parties, attends concerts, goes to restaurants, he can invite people to his home. PA has fundamentally changed his life' (Hálfðánardóttir, 2019b, para. 6).

The main barriers facing disabled people with PA is how long it takes to fight the system for the legislated services they need to be able to live independently in accordance to their wishes and needs. Many people, especially disabled people who need supported decision making, lack structures and support networks from professionals in disability services. Consequently, disabled people and their families spend a lot of energy and time fighting a system that is supposed to be built to serve them. Also, due to lack of support or information, disabled people who don't have a strong family network do not have the same choice to live independently. Hreiðarsdóttir (2016), a woman in her fifties with intellectual impairment, explains that although PA is beneficial for her, the number of hours she receives is not enough: 'My life would be so much better, both socially and physically, if I was receiving PA according to my needs' (para. 2). She went on to criticise the service system for not supporting people with intellectual impairments to live independently: 'The governmental financial resources for PA are not spread equally between people with intellectual impairment and people with physical impairments' (para. 3).

## **The voices of social pedagogues**

The SPs who took part in the study expressed a shared understanding of the core values manifested in the UNCRPD and the IL ideology. The majority saw the safeguarding and promotion of disabled people's entitled rights as their fundamental role, by referring specifically to the UNCRPD and their ethical protocol as important guidelines for practice. Many spoke about advocating and upholding those human rights principles as the core of their daily practice but highlighted that this can be a complex and time-consuming task due to a lack of shared vision in policy, administration and budgeting. The SPs in the study saw the UNCRPD as a more powerful tool and instrument in their practices following its ratification. Thus, they perceived the UNCRPD as a tool for helping them when advocating with and for disabled people and their families. One SP expressed his view on this: 'I think now it will be easier for SPs to ensure rights-based services ... although we as a profession are aware of rights to services that is

not always the story among our administrators which can cause a lot of tension.’ Another SP expressed concern on this matter: ‘there are too many grey areas regarding rights within the service systems’.

Moreover, the SPs saw it as their role to inform disabled people and their families about entitled rights as well as their co-workers. Many highlighted the need for deeper knowledge on how the demands and values embedded in the UNCRPD could best be put into practice. One articulated: ‘we have to have a clearer understanding of our role regarding human rights’. There was a common view among the SPs that there was a need for more professional learning, support and innovation regarding UNCRPD implementation. Another drew attention to how the rights-based approach was fairly new, which called for rethinking professional agency: ‘we need to read the UNCRPD carefully and compare it to our practices. The social model of disability transformed my professional thinking. Now it needs to develop further on the grounds of the UNCRPD so I can use it to justify my practices and professional ideology.’

The SPs also drew attention to the term ‘inclusive education’ and how it is conceptualised in the UNCRPD, such as the right to receive the support required for full participation in the school community without segregation, both academically and socially. One SP with a long-standing involvement in inclusive schools underlined the need for a dialogue and increased knowledge about the importance of inclusive education for all students and to build awareness of the children’s entitled rights. She articulated this thought by bringing attention to the ‘absence of human rights thinking and vision in the day-to-day practices within the school’. It seems to be an overall view among the SPs that a successful holistic approach towards inclusion involves careful planning according to needs and wishes both on a daily and weekly basis to ensure belonging and empowerment. Some of the SPs stressed that the medical model is the greatest hindrance preventing the achievement of successful inclusion and IL. SPs with long experience working in segregated settings and the school system in general were concerned about the disempowering effect of diagnostic-focused segregated placements, such as stigma, restriction of opportunities and low self-esteem.

SPs in managerial positions in adult services saw the UNCRPD and the IL ideology as an important tool which urges respect and rights-based thinking and practices at all levels of administration. In that context they drew out that the culture and practices within the service systems need to change in accordance to the key principles of human rights, for example, self-determination, autonomy and IL. On this notion, one SP claimed that it is essential to: ‘abolish discriminatory practices and segregating solutions that do not abide by the UNCRPD, such as categorisation’. Another SP in adult services said: ‘we have to rethink our structures and practices. Now the decision making and choice belongs to disabled people and we as a profession need to empower and ensure that at all levels.’ Finally, a SP in social services summarised this discussion and explained that the battle for human rights is the biggest challenge in their job: ‘resisting pressure from politicians and administrators regarding cut-backs in legalised disability services. Also striving to minimise the pressure on disabled people who often have to fight the system to have their needs met.’

## **Discussion and implications**

Our findings raise a number of important issues that we now look deeper into with the help of Engeström’s five summarising CHAT principles. We use these principles as conceptual tools to grasp disabled people’s and the SPs’ multiple perspectives that are important to acknowledge for individual and organisational learning in light of the principles manifested in the UNCRPD and the IL ideology. Engeström (2001) highlights that goal-directed individual and group actions are understandable only when interpreted against their own background together with the background of the entire activity system. Russell (2009) points out that Engeström takes organisations as a primary research object, attempting to explain change and stability both historically and developmentally. A premise in the theory of CHAT is that human activity is mediated through cultural artifacts that people use (Engeström, 2001). We will further analyse and discuss our findings with the help of the main features of each principle: unit of analysis; multi-voicedness; historicity; contradictions; and expansive learning.

### **The first principle: activity system as a unit of analysis**

Engeström and Miettinen (1999) describe an activity system as a unit of analysis which calls for complementarity of the system’s and the subject’s view. Furthermore, ‘the analyst constructs the activity

system as if looking at it from above' (Engeström and Miettinen, 1999, p. 10). An activity system has six core components, as explained in Figure 1, which all hold cultural and historical dimensions: the subjects; the objects; the instruments (tools); the community; rules; and division of labour. In the case of our study, the field setting of SPs in disability-related social services is the prime unit of analysis, with the SPs being the subject, holistic rights-based support and services the object, and disabled people's autonomy and full access to an inclusive society the outcome. The disability-related social services are in network relations with other activity systems, such as the school system and disabled people's organisations, with a common outcome grounded in the aim of the UNCRPD and IL ideology.

Sannino (2009) stresses the importance that the subject, whose agency is chosen as the point of view in the analysis, is fully taken into account in the formulation of the unit of analysis. Therefore, it is of value to underline the professional historic agency that the SPs as a profession stand for with human rights principles and a person-centred approach being central in their *Ethical protocol and ethical standards*. Further, the aim is to safeguard and support disabled people's fight for social justice, autonomy, inclusion and equality in line with the UNCRPD, the IL ideology and the Act on Services for Disabled People with Long-Term Support Needs (2018) that is in compliance with the UNCRPD and the rules by which the activity system under scrutiny must abide. When an activity system (see Figure 1) adopts a new element from the outside, such as the UNCRPD, the IL ideology and the Act on Services for Disabled People (2018), which requires fundamental changes in theoretical understandings and practices, it often leads to aggravated contradictions where some old elements collide with the new ones. One can argue that the most aggravated contradiction is caused by the existing gap between the standards, values and demands embedded in the human rights principles centred in the UNCRPD, the IL ideology and the way traditional services are implemented based on the medical model of disability. This is clearly reflected in the SPs' views where they explained that the medical model is the greatest hindrance preventing the achievement of human rights. They described that a very time-consuming part of their work is having to justify and advocate for disabled people's entitled rights. This is reflected by an SP who claimed that the battle for human rights is the biggest challenge in the SPs' professional work. There is a consensus among the SPs in the study that the UNCRPD has become a more powerful tool and instrument in their practices following its ratification. One SP expressed his view on this: 'I think now it will be easier for SPs to ensure rights-based services'.

## The second principle: the multi-voicedness of activity systems

An activity system is always a community of multiple points of views, traditions and interests, of people who share with the subject an interest and involvement with the same object (Engeström, 1987). Multi-voicedness is multiplied in complex systems such as disability-related social services. It is a source of trouble and a source of innovation, demanding a shared commitment from all actors to put human rights principles and values into action (de Beco, 2014; Engeström, 1987). When interpreting our findings against the features of this principle, we would like to underline that disabled people were fully involved and played a decisive role in the negotiation, development and drafting of the UNCRPD, which resulted in a ground-breaking human rights treaty and established the human rights model of disability (United Nations, 2017). Moreover, Article 19 of the UNCRPD, which builds on the ILM grassroots social movement, is grounded in disabled people's fight against ableism and for deinstitutionalisation and control over their own lives.

The disabled people's experiences represented in the findings show that when disabled people receive PA according to their rights and needs it can be life-altering. For disabled children in our study, having PA enabled them to grow up in their families and participate in mainstream education and after-school activities. For the disabled adults, PA gave them the opportunity to live on their own, outside institutions, without needing to rely on their families for their independence and full participation. These personal accounts teach us that when new tools, such as PA, are practised in line with the IL ideology and human rights principles, the desired outcome can be reached. Our findings show that the SPs' professional and theoretical views – the human rights model being at the heart of their ethical commitments – along with their historic experience, are important for pointing out the nature of barriers and discriminatory practices. Also key were the SPs' perspectives regarding how a deeper human rights understanding, acknowledgement and accountability could strengthen the application of rights-based practice in disability-related social services and education. Both the SPs and the disabled people in the

study shared the conviction that disabled people need to be seen as right holders instead of charity seekers (Campbell, 2009).

### **The third principle: historicity**

The activity systems take shape and become transformed over lengthy periods of time. Their problems and potentials can only be understood against their own history. Engeström (1987) illustrates further that 'history itself needs to be studied as local history of the activity and its objects, and as history of the theoretical ideas and tools that have shaped the activity' (p. 136). In a social pedagogical context, this includes the history of the SPs as a profession, intertwined with the history of their education and the cultural-historical context of disabled people's battle for human rights. These histories are interconnected since the origin of social pedagogy lies deep in disabled people's human rights struggle in all realms of life. Thus, the SPs' roles, theoretical perspectives, rules and instruments have developed in line with the historic paradigm change rooted in the UNCRPD (United Nations, 2007). This can be described as a shift from a relation of dominance towards a relation of partnership that values disabled people's lived experience and expertise (French and Swain, 2001): a partnership that ensures disabled people's rights to support and services for social participation on an equal basis with others as is outlined in the UNCRPD and the IL ideology. Our findings indicate that human rights-based practices are an underused tool in disability services, despite obligations depicted in policies towards the implementation of the common object rooted in the UNCRPD. Thus, the medical model, still being dominant, has the tendency to marginalise disabled people as well as hinder the SPs in working and developing in accordance with their professional aim and theoretical discourse. Campbell (2009) refers to this as ableism, which reinforces paternalistic practices and power imbalance and highlights the importance of looking for the root causes of exclusion and discrimination. In that light, the leaders of the ILM have stressed that the traditional medical definition of independence needs redefining and, as such, should centre on self-determination and autonomy, regardless of a need for assistance and supported decision making. On that note the SPs emphasised that the culture and practices within the service systems need to change in accordance to the key principles of human rights.

### **The fourth and fifth principles: contradictions and expansive learning**

The theory of expansive learning puts the primacy on the collective community learning for the creation of new culture. Following the theory, expansive learning is predicated upon a progression from individuals questioning the state of the art in current practice through the modelling of new forms of practice as our findings indicate (Engeström, 2016, p. 36). It captures the dynamics that arise when people who are engaged in an activity begin to recognise new complexities in the tasks they are working on and start questioning the practices that get in the way of their work. Contradictions are present in every collective activity and indicate emergent opportunity for further change, innovation and development. Moreover, they are the lenses through which participants in an activity can reflect on the developmental trajectory and understand its dynamics (Engeström, 2001).

In further analysis and interpretation of the contradictions and challenges facing the SPs and the disabled people in our study, we used Engeström's (1987) distinction between *primary*, *secondary* and *tertiary* contradictions, related to the successive phases of the expansive change of the activity system. First, we drew on the *primary contradictions*, which play a central role in the first phase in expansive learning and can arise when practitioners and stakeholders start questioning the practices within the activity. This is clearly the case with the SPs and the disabled people in our study, who question the status quo through rights-based lenses, grounded in the UNCRPD and the IL ideology, with the common object of securing human rights principles in disabled people's lives. In this context it can be argued that the most serious conflicts and contradictions at play in our findings are caused by the existing gap between the desired outcome centred in the UNCRPD, the IL ideology, the Act on Services for Disabled People (2018) and the reality in services that reflect the medical understanding of disability and historic systemic thinking and practices. Our findings show that the desired outcome embedded in the object of the activity is what the SPs seek to ensure. There is, though, a concern about the lack of common vision and agency, conflicting roles and mismatching views on disability causing tensions within the activity. This can be seen where the SPs describe that a very time-consuming part of their work is having to justify and advocate with and for disabled people's entitled rights to services within the system and administrative

sectors. This is reflected by the SP who expressed his view on this: 'although we as a profession are aware of disability rights ... that is not always the story among our administrators, which can cause a lot of tension'.

*Secondary contradictions* arise when a new element enters a system and leads to contradictions between the elements that pre-dated it (Engeström, 2001). The paradigm change in understanding disability rooted in the UNCRPD and the IL ideology requires the disability-related social services to rethink aims, structure and practices according to the core principles of the UNCRPD and the IL ideology. There was a common consensus among the SPs on the need for deeper knowledge on the principles, values and standards embedded in the UNCRPD and the IL ideology both for themselves as a profession but also for other stakeholders who share the common object. As explained by two SPs: we have to 'abolish discriminatory practices' and 'rethink our agency, structures and tools'. Another SP in an administrative position claimed that there are 'too many grey areas regarding rights within the service systems'. Thus, the SPs call for a more collaborative learning and innovative actions in line with the social and human rights understanding of disability across professional and administrative boundaries.

Finally, we drew on the *tertiary contradictions*, which entail the third strategic action in the cycle of expansive learning – the modelling. Modelling is already involved in the formulation of expansive learning and the results of the analysis of contradictions. It reaches fruition in the modelling of the new solution, *the new pattern of the activity*. The contradictions drawn out of the findings show conflicts and structural tensions that have accumulated historically due to the massive legislative and policy shifts in disability services in past decades. One can argue in line with Engeström (2016), in the case of such a cultural and historical dilemma, that it is important to ask questions about how this has come to be and under what conditions the remnants of the past remain in practice. The findings indicate as well that the possibilities of moving forward are generated within the urgency of the reconceptualisation of the object and the motive of the activity, that is, disability-related social services, in order to embrace the principles and values grounded in the UNCRPD and the IL ideology which lay out the steps that should be taken. As one SP clearly explained: 'we need to read the UNCRPD carefully and compare it to our practices. The social model of disability transformed my professional thinking. Now it needs to develop further on the grounds of the UNCRPD so I can use it to justify my practices and professional ideology.'

## Concluding remarks

Our findings raise a number of pressing issues that are important to acknowledge for further development and learning. Engeström's five summarising CHAT principles and the theoretical underpinnings helped us grasp and look deeper into the SPs' and the disabled people's multiple perspectives in line with the aim of the study. The field of social pedagogy in Iceland and the field of disability services have both undergone some significant changes in the past few decades and they are still evolving. Part of this change process entailed contradictions, challenges, tensions and innovations as our findings show. The field of social pedagogy has evolved through several theoretical and ideological phases which were affected by changes in disability legislation and policy, in parallel with the paradigm change grounded in the UNCRPD as discussed earlier. The SPs' professional agency today, as well as their professional development, is intertwined with the cultural-historical context of disabled people's battle for human rights; the principles and values grounded in the UNCRPD and IL ideology, which are also the rules that disability related services must abide by. Our findings indicate tensions between the desired human rights outcome and the reality facing the SPs and the disabled people in the activity. The SPs claim that fighting for disabled people's entitled rights can be complex and time consuming: at the cost of a time that could be used towards further innovations, development and learning in line with the object on hand. The disabled people in our study, while experiencing the ground-breaking changes in their lives followed by receiving PA, also face long struggles before receiving the correct level of service that they need to be able to lead an independent life with assistance, despite PA now being an entitled right by Icelandic law and regulations. The public accounts show that this is especially true for disabled people who need supportive decision making.

The emerging paradigm change in service delivery calls for systemic development and change in understanding of disability, the meaning of autonomy and independence for disabled people. We argue, in line with Engeström (1987), that the new form of the activity needs to be collectively generated and embedded in the everyday actions and practices within all dimensions of the activity. The contradictions

drawn from the findings underline an urgency of the reconceptualisation of the object and the motive of the activity, as previously stated, in order to embrace the principles, values and the recommended practices grounded in the UNCRPD and IL ideology. Thus, we argue strongly that the cultural-historical context of disabled people's fight for human rights needs to be acknowledged and built on in the process of expansive learning, such as the inhuman and ableist conditions of oppression, exclusion and institutionalisation. We argue that it is vital for the activity to be ready to acknowledge the impact of ableist cultures on disability-related services. Finally, it can be argued that SPs are in part driven by their historical roots, lived experiences and theoretical knowledge about the disempowering and damaging effects of such discrimination, which gives them a stronger human rights agency and understanding in their critical reflections, advocacy and emancipatory practices. Therefore, it is crucial to acknowledge the value of social pedagogical thinking and practices in the expansive learning process. On that note, we hope that this article, which gives an insight into the history and evolution of social pedagogy in Iceland, can contribute to the ongoing discussion on the core themes of social pedagogy worldwide – human rights, social justice and emancipatory practices being the common denominator.

## Declarations and conflicts of interest

### Conflicts of interest statement

The authors declare no conflict of interests with this work. All efforts to sufficiently blind the authors during peer review of this article have been made.

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