

From the Department of Neurobiology, Care Sciences and Society

Karolinska Institutet, Stockholm, Sweden

Live life!
**Young peoples' experience of living with
personal assistance and social workers'
experiences of handling LSS assessments
from a Child perspective**

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Young peoples' experience of living with personal assistance and social workers' experiences of handling LSS assessments from a Child perspective

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Stones taught me to fly
Love taught me to cry
So come on, courage, teach me to be shy
'Cause it's not hard to fall
And I don't wanna scare her
It's not hard to fall
And I don't wanna lose
It's not hard to grow
When you know that you just don't know

(Lyrics by Damien Rice)

To all of you who fight, love, try, fail, succeed, laugh and cry – Don't give up!

ABSTRACT

The Act Concerning Support and Services to Persons with Certain Functional Impairments, in which the provision of personal assistance (PA) is included, came into force in 1994. It paved the way for strengthened rights for people with disabilities, in which the overall intention was to give disabled people equal opportunities and enable full participation in society.

This thesis explores adolescents' and social workers' perspectives on and experiences of personal assistance. The overall aim of this research was to gain empirical knowledge and a deeper understanding of young assistance users' experiences of living with PA and the social workers' experience of assessing children's right to PA and other LSS interventions. In paper I, a grounded theory (GT) analysis showed that the adolescents' main concern was to achieve normality, which was about doing rather than being normal. The findings underline and discuss the interconnectedness between the different enabling strategies adopted by the adolescents, and to a lesser extent discuss disabling barriers for which PA cannot compensate. In paper II the adolescents describe their experiences of the assessment process which precedes possible access to PA. The content analysis reveals that the adolescents' participation was determined by the structure of the meetings, in which the assessments tools played a decisive part. The adolescents adapted their behaviour in response. Paper III is based on a phenomenological approach to social workers' responses to children and young peoples' ability to participate in meetings and decision making concerning their own support interventions. It reveals difficulties in grasping what participation should be and result in. In paper IV, a GT study, the emerging theory explains how case workers tried to maintain their professional integrity by adopting various strategies.

The synthesis of the four studies has resulted in a clarification of how the individual, organizational and societal levels interact through legislation and policy documents, meetings and norms to create certain processes and interactions between the different stakeholders. However, further research is necessary to explore the long-term effects of the current changes to Swedish LSS-legislation regarding both the professional conduct of the case workers responsible for assessing LSS interventions and the consequences of such decisions for assistance users and their families.

Keywords: Personal assistance, children with disabilities, social workers, LSS legislation, discretion, decision making, assessment, participation, norms, professionalism

LIST OF SCIENTIFIC PAPERS

The thesis is based on the following papers, which are referred to in the text by their Roman numerals.

- I. **Hultman, L.,** Forinder, U., and Pergert, P. (2016) Assisted normality: a grounded theory of adolescent's experience of living with personal assistance. *Disability and Rehabilitation*, vol. 38, no.11, 1053-1062.
- II. **Hultman, L.,** Pergert, P., and Forinder, U. (2017) Reluctant Participation: the experiences of adolescents with disabilities of meetings with social workers regarding their right to receive personal assistance. *European Journal of Social Work*, no. 4; 509-521.
- III. **Hultman, L.,** Öhrvall, A-M., Pergert, P., Fugl-Meyer, K., and Forinder, U. Elusive participation: Social workers' experience of disabled children's participation in LSS assessments. Submitted.
- IV. **Hultman, L.,** Forinder, U., Fugl-Meyer, K and Pergert, P. Maintaining professional integrity: Experiences of case workers performing the assessments that determine children's access to personal assistance. Accepted for publication in *Disability & Society*.

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ABBREVIATIONS

ACC	Alternative Augumentative Communication
BO	Barnombudsmannen [Children's Ombudsman]
CRC	Convention on the Rights of the Child
CRPD	Convention on the Rights of People with Disabilities
FUB	För Utvecklingsstörda Barn, ungdomar och vuxna [The Swedish National Association for Persons with Intellectual Disabilities]
GT	Grounded Theory
ICF	International Classification of Health
IL	Independent Living
LSS	Lag om Stöd och Service till vissa funktionshindrade [Support and services for people with certain functional impairments]
NPM	New Public Management
PA	Personal assistance
PIMD	Profound Intellectual Multifunctional Disabilities
RBU	Rörelsehindrade Barn och Ungdomar [Children and adolescents with mobility Impairments]
STIL	Stockholm Independent Living
SIA	Social Insurance Agency
SRV	Social Role Valorization
WHO	World Health Organization

INTRODUCTION

When I drafted the project plan for this thesis project in 2012, I was certain that I wanted to learn more about personal assistance (PA) from an ‘insider’s perspective’ and to understand how young PA users experienced living with PA in their everyday lives. Although this is not a user-initiated project, it was conducted with an honest intent to understand PA from a user perspective. I wanted to learn from those who had first-hand experience of living with PA, ‘the experts’. My own experience of being a mother has taught me that I can never have a child’s perspective in the sense that I am no longer a child. Although my experience of being a parent of a disabled child has hopefully made me more sensitized to some of the aspects of living with PA, it can never replace the first-hand experience of being a child or young person living with PA in everyday life. I believe that all our stories are rooted in a historical time and place, separated by our different experiences crafted from the intersections of gender, ethnicity, class, sexual preference, and experience of our own and others’ disabilities. Before I became a mother I worked as a counsellor at a habilitation centre for young adults and adults with different types of impairments and diagnoses. At that time I had limited knowledge, and awareness, about disability, since my basic training for becoming a social worker had not included any courses on disability and none of my circle of friends and acquaintances consisted of people who identified as disabled. Looking back, with the knowledge and experiences that I have today, I would have handled some things differently. One thing I would not have changed, however, is my attempt to connect with people on a personal level. This approach often resulted in collegial discussions about professionalism that is, what professionalism is and what could be said in relation to the distinction between being a professional and a being a fellow human being.

As a social worker, I deliberately chose to work in counselling, where part of my work or duties consisted of assisting clients and family members with formulating their applications to social services, as well as attending assessment meetings concerning applications for various types of support. My professional background has contributed to an interest in how different professional roles and positions affect relations with clients and their families. It has made me eager to understand how social workers think and act in relation to their different professional roles and assignments. The social worker’s perspective is important to understanding the level of participation disabled children and young people are allowed.

In this compilation thesis the area of interest is the perspectives of children and adolescents’ living with PA as well as the perspectives of the professionals assessing the right to PA and other LSS interventions. The first paper deals with adolescents’ experiences of living with PA in their everyday lives. Papers II, III and IV look at adolescents’ and social workers’ experiences of and participation in the social investigation that precedes decisions about possible access to PA or any other support intervention according to the Lag om Stöd och Service (LSS) legislation (SFS 1993: 387).

There is an ongoing discussion about the value of the assistance reform and I hope that these studies will contribute knowledge about adolescents' perspectives on the value of PA, while also providing insights into the consequences of the current interpretation of the legislation and implementation with regard to decision making.

OUTLINE

The background provides an introduction to PA, the historical and legislative development of PA in Sweden and, to a limited extent, a comparison with the parallel development of PA across Scandinavia. The background also provides an overview of previous research on PA. Then the aims of the four studies are presented, followed by theoretical concepts of importance to the thesis, most notably the concepts used in the articles, and the new concepts and theoretical perspectives in order to clarify the connection between the articles. Before the results are described, synthesized and discussed a description and discussion of the methods applied in this thesis will be provided. The final chapter of this introductory text contains conclusions and reflections, and discusses the implications for future research.

CONCEPTUAL CLARIFICATION

Before proceeding further into the text, it is necessary to introduce and clarify the meaning of some of the key concepts used in this thesis. Other concepts, such as participation, normalization and professionalism, are further developed and discussed in the theoretical chapter.

According to the World Health Organization (WHO), 'disability is an umbrella term that covers impairments, activity limitations, and participation restrictions. It is a complex phenomenon that reflects the interaction between the features of a person's body and the features of the society in which he or she lives' (WHO, 2018). In the term bank of Socialstyrelsen [the National Board of Health and Welfare] (2018) disability is defined as; 'the limitation that a disability implies for a person in relation to the environment'.

The social model regards disability as the result of structural and physical barriers in society (Lindqvist, 2012). The social model seeks structural change in society rather than the medical or psychological correction of individuals (Shakespeare, 2004). By defining disability as structural barriers in society, disability can be considered a form a social oppression that opens up for/ demands societal change, which includes the removal of socially created barriers and institutional forms of discrimination (Barnes, 1991). For many disability researchers the British social model of disability (Oliver, 1990) has become synonymous with the social model of disability. When the social model was introduced by the British activist and scholar, Mike Oliver (1990), it served an important role in raising awareness and acting as a counterweight to a medical paradigm that, to a large extent, saw disability as an individual problem – 'something broken' that needed to be fixed (Barron, 1997). With intentions to remedy the injustices faced by disabled people (Oliver, 1990), the British Social model of disability has been considered a 'strong social model' (Shakespeare, 2004). Representatives of the strong social model do not deny the occurrence of illness or

injury, but are critical of rehabilitation, which they argue is in line with claims for normalization (Oliver & Sapey, 1999). However, ever since the early 1990s there has been a growing critique that analyses based on a strong social model of disability provide only a limited understanding of disability (Thomas, 1999). According to Thomas the critique can be summarized as too much focus on socio-structural barriers (material aspects of disability), the exclusion of groups of people with different types of impairments, such as learning difficulties (Corbett, 1996), and that to a large extent it denies the importance of the impairment in itself (Abberly, 1996; Morris, 1996).

Shakespeare and Watsons (2001) claim that: People are disabled both by social barriers and by their bodies' (ibid: 17). According to Thomas (2004) 'the core of their rejection of the social model is its conceptual separation of impairment from disability and its assertion that people with impairment are disabled by society, not by their impairments' (ibid: 573). Their argument seeks to dissolve the binary conceptualization of the supposed opposition between impairment and disability.

Impairment and disability are not dichotomous but describe different places on a continuum or different aspects of a single experience. It is difficult to determine where impairment ends and disability starts but such vagueness need not be debilitating. Disability is a complex dialectic of biological, psychological, cultural and socio-political factors, which cannot be separated with precision (Shakespeare & Watson, 2001: 22).

'By solely focusing on either the individual or the environment the complexity of the historical, social and cultural context is lost', (Ytterhus et al., 2015: 21). In this thesis disability is conceptualized in accordance with the Nordic relational approach to disability, in which 'disability is understood as resulting from complex interactions between the individual and the socio-cultural, physical, political and institutional aspects of the environment' (Ytterhus et al., 2015: 21).

The choice of terminology in the articles is pragmatic: sometimes 'people with disabilities' is used and sometimes 'disabled people'. The wording has not been ideologically informed. There is a plethora of words to describe identity in relation to functional capacity: disabled person, person with disability, differently abled, and so on. Moreover, 'proper utilization' of terminology is difficult, since different people prefer different expressions depending on whether they consider disability to be a primary or a secondary identity. The intention is not to offend anyone. Nonetheless, this is an important discussion since it concerns the reproduction of dichotomous categories, such as able vs disabled, and does not consider the fact that it is not an either or situation, but rather that the degree to which a person is disabled depends on the environment and the situation.

PA is the individualized support provided by a limited number of people. The disabled person is in control and decides what is to be done, who is to work and how, where and when the work is to be carried out. In order to gain access to PA the applicant must participate in a social investigation in which decisions are based on a social needs assessment. The right to obtain PA depends on the level of basic needs a person is

considered to have. 'Basic needs' are defined as: '...personal hygiene, meals, dressing and undressing, communication with others or other help that requires extensive knowledge about the person with a functional impairment' (SFS 1993: 387).

In this thesis, the term 'assistance user' is used to signify a disabled person who utilizes PA. The word child or children is sometimes used to refer to young assistance users. If it is necessary to make a distinction by age, the terms teenager/adolescent and youth are used to refer to older children.

Adolescence is the life-phase when a person attends upper secondary school, which explains the variation in age between 16- and 21-years old. The term adolescence has its roots in developmental psychology, whereas the term young people is used in childhood sociology. In this thesis both concepts are utilized to signify the same group.

The term case worker is used to refer to administrative staff at the SIA and social workers in the municipalities.

Participation is a complex phenomenon and often defined as a prerequisite for high quality. This makes the conceptualization of the phenomenon of participation important. There is no uniform definition of participation, however, and it is instead dependent on different perspectives and frameworks. Participation can be exercised to different degrees. It can be about being listened to or actually sharing power to gain real influence (Shier, 2001). In this thesis participation was not predefined since it was part of the research question to find out how the social workers interpret and enact participation in their day-to-day practice, which involves decision making concerning LSS interventions for children and adolescents.

'Normality can be understood to have three aspects: statistical normality; normative normality, or the prevailing norms and values; and medical normality, or what is considered healthy' (Tideman, 2000: 53). In this thesis normative normality is discussed in relation to discretion. Norms are an essential part of the social structure. Norms prescribe behaviour and coordinate actions, and they are reproduced through the actions of individuals and groups (Baier, 2013). All norms have three properties in common: imperatives ('ought'), social facts ('is') and subjective beliefs (Svensson, 2013).

BACKGROUND AND PREVIOUS RESEARCH

In order to contextualize and explain the rationale for the present study this chapter provides a brief description of the differences between disability research and disability studies. A condensed and select historical overview of national disability policy and legislation is described, followed by a comparison of the development of PA in the Scandinavian countries. Finally, a research-based summary of previous studies of PA is presented.

Historically, disability research and disability studies have been constructed as two separate entities: disability research implies medical and rehabilitation studies, while disability studies are concerned with the social aspects of disability (Roulstone, 2013). In the Nordic countries the dividing line between the two are not as sharp as is the case in the United Kingdom, where scholars have been more engaged in materialist and Marxist constructions of disability (ibid, 2013). These different understandings have led to tensions within the field and among different scholars from different academic backgrounds and different cultural contexts. These tensions are related to differing views on what constitutes disability. Three such tensions can be detected: research vs. political action, impairment vs. disability and theory vs. empirical research. In the UK, for example, there is a closer relation between research and political action than there is in the Scandinavian countries (Söder, 2009).

Söder (2013) describes how disability research in the Nordic countries from the outset have had a strong connection to the welfare state, where early research was funded by state authorities to evaluate existing reforms. During the 1970s disability research received increased attention within social policy and research policy. Four areas were given priority: factors that transformed impairments into disabilities, the effects of welfare measures, language and verbal communication, and the effects of rehabilitation and treatment. Development in the past decade has been characterized by a growing interest in research among disability organizations, on gender, intersectionality and theory in general, which has spurred a growing interest in disability studies (Lindqvist, 2012).

SWEDISH DISABILITY POLICY AND THE DEVELOPMENT OF PERSONAL ASSISTANCE

The emergence of the welfare state

From a historical perspective, disabled people have all too often been discriminated against and excluded from large parts of society. Dependence on other people's goodwill has limited their ability to design a life on its own terms (Prop. 1999/2000: 79). In the 19th and 20th centuries, responsibility for people with disabilities was divided between relatives, the local community and the state (Olsson & Qvarsell, 2001). Families and households were primarily responsible for the provision of social security but when this was not possible, the disabled became the responsibility of the municipal poor law or the state hospital, which

cared for the ‘severely physically disabled, insane, chronically ill and those with infectious diseases’ (ibid., 2001: 20). In 1808, Pär Aron Borg was the first to establish an institute for special education for the deaf-mute, which later became the Manilla School (Bengtsson, 2005). Philanthropic initiatives such as Borg’s institute subsequently received government funding, which also contributed to an increase in state control (Karlsson, 2007).

In the latter part of the 19th century, philanthropy began to be replaced by science in the form of ‘objective assessments of help needs and opportunities for good results’ (Förhammar & Nelson, 2004: 22-23). The perceived need to keep certain groups of disabled people separate from the outside world developed at the beginning of the 20th century (Olsson & Qvarsell, 2001). Influenced by genetics and Social Darwinism, the idea of protecting the disabled people from the outside world gradually shifted towards protecting the outside world from disabled people (Karlsson, 2007). The Act on Forced Sterilization was passed 1934 and was not repealed until 1976 (Förhammar, 2004). Overall, the state assumed increasing responsibility for detaining but also developing facilities for disabled children and adults in order to rehabilitate, educate or help them to join the work force. School attendance became mandatory for children with hearing impairments in 1889, followed by children with visual impairments in 1896 and children with intellectual impairments in 1944. Not until 1962, school attendance for children with mobility impairments became mandatory (Bergval and Sjöberg 2012).

The general welfare policy with its income support, basic health care and social services did not exist until after World War II (Lindqvist & Hetzler, 2004). In 1948, the Kjellman Committee report formulated a principle that would later become an indicative principle of disability policy, to offer work to as many disabled persons as possible on the basis of their prerequisites (Olsson & Qvarsell, 2001). In 1954 legislation was passed making county councils responsible for the activities of the development-impaired, with the exception of those catered for by the state hospital (Söder, 2003). In the 1950s and early 1960s new nursing homes and new specialist units were planned and built. In the 1960s the segregated forms of housing and education which prevailed came to be questioned for both economic and humanitarian reasons (Söder, 2003). In 1961, Karl Grunewald became the inspector general of the institutions. Staff at Grunewald's office severely criticized the conditions they encountered (Nirje, 1999). Combined with the critique from representatives of Swedish disability associations, such as the Swedish Association for the Development-Impaired Children, Adolescents and Adults (Swedish acronym, FUB), Grunewald helped to change the disability discourse (Karlsson, 2007). A new policy emerged in which the large residential institutions for were closed from the 1970s onwards (Ericsson 2002).

The impact of the Normalization principle in Scandinavia

‘Normalization’ was frequently mentioned as a guiding principle in major legislative documents concerning social reform in all three Scandinavian countries’ (Kristiansen, 1999: 397). Early formulations of normalization in Denmark by Niels Erik Bank-Mikkelsen and in Sweden by Bengt Nirje sought to achieve ‘normal’ living conditions for people with

intellectual impairment. A central factor in the Normalization principle is the recognition of all peoples' equal worth. In the 1960s the growing awareness and recognition that disabled people were suffering in inhumane conditions fuelled a growing moral outrage. The introduction of the normalization principle became a rallying point for social critique. Parents, advocates and other concerned citizens joined together in a common cause (ibid, 1999). This resulted in people with intellectual disabilities being considered entitled to living standards and living conditions similar to those of other citizens (Prop. 1999/2000: 79). In July 1968, the Swedish Law on Care for the 'Mentally Retarded' came into effect (SFS 1967: 94 repealed). Both the Danish and the Swedish legislation has been described as a 'Bill of Rights' for people with intellectual disabilities. 'In both Norway and Sweden, it is common to find normalization and integration formulated alongside each other as dual policy goals. Policy documents have claimed that "Normalization is the goal, integration the means", while others state the exact opposite' (Kristiansen, 1999: 398).

In the 1960s and 1970s, when institutional conditions were identified as unacceptable, the first solution was to improve the existing institutions (Hollander, 1999), by the expansion and extension of the existing institutional care system (Kristiansen, 1999). 'Expansion of the institutional system was partly a response to the demand for services for people who previously received little or nothing, but it was also influenced by the idea of separate environments for different normative daily and weekly activities' (ibid., 1999: 401).

Perlt (1990) has described three phases of institutional reform that are relevant to the developments in Sweden and Norway:

- The struggle for institutions
- The struggle within institutions
- The struggle against institutions

Disability rights legislation and the assistance reform

The first Swedish state disability investigation (1965-1975) resulted in the introduction of housing adjustment grants and state grants for transportation services (Prop. 1999/2000: 79).

The second state disability investigation, carried out in 1989, led to a reform of national disability policy (SOU 1992: 52) which resulted in a new disability legislation, the LSS Act (SFS 1993: 387), in which PA is incorporated. PA can be described as a right in itself but also as a tool for realizing other rights, such as disability policy goals for equal living conditions for all people regardless of level of functioning (Larsson, 2008).

The influence of Independent Living ideology on the Swedish assistance reform

The Swedish assistance reform was influenced by Independent Living (IL) ideology, which proclaimed self-determination by means of user control with the ultimate goal of having control over one's life (Westerberg, 2010). IL ideology emerged as a reaction to the medical model (DeJong, 1983). Rather than adapt to the rehabilitation paradigm, the IL ideology encouraged disabled people to take control over their own lives by abandoning the patient role and assuming the consumer role in which advocacy, peer-counselling, self-help, consumer-control and barrier removal become of utmost importance (ibid, 1983).

IL Ideology was influenced by the US civil rights movement that occurred in the United States in the 1960s, when Ed Roberts and fellow students with mobility impairments demanded equal opportunities to study as students without mobility impairments (Gough, 1994). Europe's first IL cooperative was founded in Stockholm in 1983.

The LSS Act

As noted above, LSS is the Swedish acronym for Support and Service for persons with certain Functional Impairments (SFS 1993: 387). The need for new legislation was partly a result of the ideological changes in the social policy debate that took place in Scandinavia in the 1970s and 1980s. The welfare state's ideas about standardized solutions were gradually being exchanged for values that emphasized individual solutions (Erlandsson, 2014). The introduction of LSS was preceded by extensive investigative work where over 200 referral bodies expressed their views. Although the majority of the referral bodies were positive, the municipalities and local communities were critical of the lack of precise rights (ibid, 2014).

The LSS Act of 1994 specifies rights for people with considerable and permanent functional impairments. The intention behind the LSS Act is that the people with disabilities should be given the same right to live as others (5 § LSS). Key features of the LSS legislation, which underline the qualitative aspects, are: self-determination, influence, participation, accessibility, a holistic perspective and continuity. Support granted according to LSS legislation and support granted according to the Social Services Act (SoL) should complement each other.

The LSS Act applies to: (a) people with an intellectual disability, autism or a condition resembling autism; (b) people with a significant and permanent intellectual impairment after brain damage in adulthood due to an external force or a physical illness; and (c) people who have other major and permanent physical or mental impairments which are clearly not due to normal ageing and which cause considerable difficulties in daily life, and consequently have extensive need of support and services.

LSS (SFS 1993: 387) provides entitlement to ten different interventions for specific support and services that people may need beyond what they can get through other legislation. These are: counseling and other personal support, PA, companion service, personal contact, respite services in the home, short stays away from home, short periods of supervision for

schoolchildren over the age of 12, living in family homes or in homes with special services for children and young people, residential arrangements with special services for adults or other specially adapted residential arrangements and daily activities.

Gaining access to personal assistance in Sweden

In Sweden PA is regulated by two different pieces of legislation – the LSS Act – and in the Code of Statutes. The state or the municipality is responsible for implementing PA. If the need for assistance is less than 20 hours / week, then it is the municipal social workers who are responsible for performing the social investigation, but if the need exceeds 20 hours / week, officials at the SIA investigate and make decisions about allocation. In order to obtain PA the disabled person has to identify a need for support and make an application. The application is submitted by the applicant, or her/his parents if the child is under the age of 15. When the application is received, the case workers must determine whether the applicant is entitled to apply for PA. If the formal assessment criteria are met the application will result in a social investigation that will assess the applicant's needs. If the outcome of the decision is considered to be incorrect, the person has a right to appeal to the courts. For all those who are granted assistance allowance, until recently a continuous two-year follow-up of the decision was supposed to be carried out. However, these follow-up reviews have been temporarily suspended due to the adverse consequences of interpretations and decisions made by staff at the Swedish SIA, based on rulings by the Supreme Court (RÅ 2009; HFD 2012; HFD 2015). The intention of the follow-up meetings was to evaluate whether the individual is still eligible for assistance allowance (ISF 2014: 22), or if needs and thus the amount of assistance allowance required have changed. This has meant that the right to obtain PA is continually reviewed, and the assistance user cannot be certain that support will continue to be provided.

According to the SIA's statistics (2018), 14 886 people were entitled to PA in 2017. Since 2014 the total amount of granted assistance allowance has decreased by 7.9 per cent (N=1275 people). For children and young people, the most significant drop has been in the age group 0-14 years, where the number of assistance allowances granted decreased from 2276 in 2014 to 1800 in 2017.

In her thesis, Larsson (2008) comes to the conclusion that PA is shaped by the context and the period of time in which it is allocated. In 1996, soon after the implementation of the LSS legislation, PA was restricted by the introduction of a new legal norm on 'Basic Needs', which resulted in a more homogenous application at the expense of granting support. At the legal level the norm on Basic Needs was put in a strong position but in practice its meaning became unclear, which often resulted in a reduction in rights. In June 2009 the Supreme Administrative Court established that basic needs have to be privacy-sensitive in order for a person to have the right to obtain PA (STIL, 2014). A national assessment policy was implemented in 2011 by officials at the SIA resulting in the publication of an assessment protocol [Behovsbedömningsstödet] (National Board of Health and Welfare, 2011). The assessment protocol is very detailed and signals a

restriction in the allocation of PA (Guldvik et al., 2014). The Swedish Social Insurance Inspectorate [Inspektionen för Socialförsäkringen] was commissioned by the government to provide data on, and assess the causes and outcomes of, the SIA's decisions on assistance allowance. ISF interim report (2012: 18) based on an analysis of the Swedish SIA [Försäkringskassan] records on Benefit Assistance shows that since 2007 relatively 'large changes have been evident in the proportion and number of refusals of new applications'. According to the Swedish Social Insurance Inspectorate, the number of times assistance allowance has been granted to people applying for the first time has decreased over the years, from 66 per cent in 2004 to 43 per cent in 2013. The most recent report (2014:19) concludes that both the legislation and the application of Assistance Benefit is lacking. Problematic aspects include that key concepts, such as participation, independence and living as others, have not been defined in law or legal precedent. As a result, when evaluating entitlement to personal assistance, it is difficult for the administrators at the SIA to make a coherent, transparent and legally secure assessment. Another difficulty is the shared responsibility for assessing the right to PA (ibid, 2014). Furthermore, LSS interventions provided by local authorities vary depending on where in the country people live, a fact that can be explained by the lack of uniform guidelines and by local interpretations that do not fully comply with the intentions of the law (National Board of Health and Welfare, 2015). A recent study has showed that decentralized service provision becomes problematic when local municipalities with fewer financial resources have to take financial responsibility for service interventions (Brennan, et.al, 2016a). Lewin, Westin and Lewin (2008) have established six features to explain this variation: earlier presence of residential institutions, population density, human capital (age, education, employment and health), local culture, land area and stable left-wing government. Lack of uniform guidelines also affect the ability of social workers to include a child's perspective. Children's needs were assessed in different ways by social workers within and between municipalities. Children's perspectives and the perspective of the child must be given greater weight in the LSS processing relating to children and adolescents (National Board of Health and Welfare, 2009).

The complex laws regulating PA require a high degree of cooperation between different local authorities (Bengtsson & Gynnerstedt, 2003). The main obstacles to efficient administration of personal PA consist of ambiguities in the legislation combined with the shared responsibility between authorities (RiR, 2004: 7). Difficulty arises when social workers do not understand the intentions of the laws (Lewin, 1998). The most common reason for not approving an application for PA is that the person is not considered to have basic needs that add up to a sufficient amount of support hours (Socialstyrelsen, 2015). A report by Stockholm Independent Living (STIL) describes what happens to adults who lose the right to obtain assistance benefits from the SIA. The main finding is that the loss of assistance allowance is equivalent to the loss of full citizenship (STIL, 2014). The importance of providing adolescents with assistance instead of replacing it with home care services is underlined in the annual report of Rörselehandrade Barn och Ungdomar (RBU,

2014), a user organization for children and adolescents with different types of mobility impairments.

Development of Personal Assistance in the Scandinavian countries

The concept of empowerment has been closely linked to the development of PA in all of the Scandinavian countries (Bonfils, et. al, 2014). A common denominator is a bottom-up initiative driven by disabled people and their organizations in opposition to the policies and services designed for disabled people (Storgaard et al., 2014). The development of PA started in the 1970s in Denmark, where physically disabled people in the county of Aarhus were able to hire assistants. STIL was established in Sweden in 1983, and the National Association of Persons with Physical Impairments introduced PA in Norway in 1990. In Norway and Sweden the introduction of PA was inspired by Independent Living ideology. In Denmark users did not have a pronounced ideology but their main objectives were the same.

Table 1. Different organizational models of PA

Informal Support Model	IL model	Medical Model
Family direction	Consumer direction	Provider direction
No physician plan of treatment	No physician plan of treatment	Physician plan of treatment
No nurse supervision	No nurse supervision	Nurse supervision
Family or friends provide care	Assistant recruited by consumer	Aide provides care
No formal training	Assistant trained by consumer	Aide provides care
No payment	Payment to consumer to assistant	Payment to provider
Little accountability	Accountability to consumer	Accountability to provider
Dependent Role	Consumer Role	Patient Role
No government benefit	Social Service benefit	Health Care benefit

The main difference between IL and the other types of organizational model (the informal support model and the medical model) is that IL emphasizes user control, in which individualized support, not care is the means for achieving self-determination.

The Scandinavian countries have developed different solutions for the implementation of PA. Differences have become salient in areas such as: the extension of the arrangement, the strength of the actual right to PA, the organization and implementation of PA, the degree of

free choice for users and how user groups are defined (Askheim et al., 2014). In Norway user organizations have demanded that PA should be governed by rights legislation (Storgaard et al., 2014). This is the case in Sweden where LSS is intended to be a political tool to strengthen citizenship for people with disabilities (Lewin, 2011). ‘Sweden combines strong rights with implicit requirements, while Denmark and particularly Norway combine a weak right to PA with rather explicit requirements that must be met in order to get access to it’ (Guldvik et al., 2014: 1). In Sweden strong individual rights for users are applied at the same time no demands are put on assistance users in terms of being capable of managing the assistance (Bonfils, et. al, 2014). In Denmark and Norway users must be able to manage their assistance, which limits the target group for assistance (Storgaard & Askheim, 2014).

With the development of PA, the government’s role has become more significant. A coalition between service users and New Public Management models in the welfare services has stimulated a movement towards a market-based consumer orientation where freedom of choice to consider how services should be organized and who should implement the service provided (Storgaard & Askheim, 2014). User control is considered an important aspect of creating quality in PA but it can be problematic when users with weak user control are the target group (Social Insurance Agency, 2014: 8). Critics (Barron et al., 2000; Lewin, 1998)] have questioned whether this consumerist approach mainly favours those disabled people with the cognitive abilities that enable them to represent their interests. Lewin raised the question of whether ‘more paternalism is necessary to strengthen their individual autonomy’ (1998: 226).

PREVIOUS RESEARCH ON PERSONAL ASSISTANCE

Studies of PA have been conducted at micro, meso and macro levels, and from different perspectives. Most of the research comes from the Western European countries where PA is available, and deals with experiences of PA such as the relation between assistants and users, the quality of PA and the experience of care providers. Another perspective is related to social policy and citizenship, which encompasses the implementation and organization of PA. A third overarching research area is concerned with participation from both a medical and a social perspective. A fourth area is theoretical papers on Independent Living (IL) ideology.

Adult experiences of personal assistance

Studies of PA have mostly concerned adults. Research topics have evolved around the quality of PA, roles of and relations with assistants, and power relations.

Quality in personal assistance

In 2008, on behalf of the National Board of Health and Welfare, the Cochrane Collaboration made six systematic reviews of PA (Mayo-Wilson, 2008a; Mayo-Wilson, 2008b; Mayo-Wilson, 2008c; Mayo-Wilson, 2008d; Mayo-Wilson, 2008e; Mayo-Wilson, 2008f). The purpose of the reviews was to assess the effectiveness of PA for various groups of people

eligible for assistance. The groups were divided according to age and type of disability (physical and/or mental). Although few of the studies meet the criteria for inclusion, the results of the overview showed that PA was preferred by the assistance users over other forms of care, and that PA replaced informal support. Other conclusions were that PA was expensive, difficult to organize and not implemented uniformly. A conclusive remark was that further research was needed to establish which models of assistance were more effective in relation to various groups of users. Roos (2009) discovered that adult assistance users in an urban area wanted their assistants to be responsive, reliable, informative, alert, respectful, considerate, friendly, cheerful and practical. Furthermore, users wanted assistance providers to have a well-defined ideology on PA, interact with the user in a service-minded way, mediate between users and personal assistants, provide good working conditions for personal assistants and represent the user politically. An average assistance user with a private assistance company had received more assistant hours than an average user with a municipal provider. Users of PA were more satisfied with private companies and user-cooperatives, than with municipal assistance providers.

The lack of a uniform definition of what characterizes quality in assistance resulted in a literature review published by the SIA (2014: 8). This review includes the above-mentioned studies with the specific aim of enhancing understanding of how people who are eligible for PA experience quality of PA in relation to the concept of good living conditions as stated in the LSS legislation. The main findings revealed that central aspects of perceived quality were related to users' perceptions of being in control of their assistance, feeling safe and secure in relation to their assistant, and experiencing that the assistance contributed to the well-being of both users and their families. Furthermore the review confirmed that many users of PA experienced a greater increase in independence than alternative forms of support could provide (ibid, 2014).

Experience of providing personal assistance

There is no formal training required for personal assistants (Clevnert & Johansson, 2007; Guldvik et al., 2014). According to Guldvik and colleagues, 'PA work is typical part-time work, with flexibility dictated by the needs of the user' (ibid: 51). The PA scheme has many inherent dilemmas, such as user-control versus assistants' co-determination, continuity of help versus continuity of relations, and intimacy versus distance (Guldvik, 2009). In a survey study distributed to 680 Norwegian assistants with a response rate of about 70%, Guldvik (2009) discuss the possibility of matching assistants and user profiles. Guldvik distinguishes between two ideal types of PA who prefer different types of relations: service-oriented relations vs. care-oriented relations. Service-oriented relations emphasize user management and work in accordance with IL-ideology. In this kind of relation the assistant's motivation to work as an assistant was paid employment and the possibility of combining work with other types of activities. Care-oriented relationships were characterized by the assistant's wish to work with people, and user-control was more influenced by co-determination. In studies carried out from the perspective of personal

assistants, quality was related to the interpersonal dimension of providing assistance. Good assistance is achieved when the relationship moves beyond necessary routine tasks. These relationships have qualities that involve authentic listening, negotiating, trust and respect (Romer & Walker, 2013). Assistants have to be perceptive about the unique needs of each individual (Ahlström & Wadensten, 2010). The close relationship developed between assistants and users can be complicated and assistants found it difficult to be reduced to 'tools' by the user or other family members. The relational aspects were among the most challenging parts of the assistants' work (Larsson, 2004; Egard, 2011). Assistants found it hard to define their professional role since there is no clear job description that makes a distinction between instrumental tasks and what should be considered social interaction (Ahlström & Wadensten, 2010). The assistants take on different roles in relation to the user (Guldvik et al., 2014). If assistants get emotionally committed to their users they might help them with tasks that are not considered as part of their job (Egard, 2011). However, other studies (Ahlström & Wadensten, 2012; Guldvik et al., 2014) indicated that most of the problems were ascribed to the work situation rather than the relations between assistant and user. Assistants found it difficult to be in a subordinate position, which could be summed up as lack of knowledge, loneliness and missing a work community, being exposed to uncomfortable situations, employer problems, lack of control, mental pressure and lack of stimulation, and too much responsibility and overtime (Ahlström & Wadensten, 2012). Another dimension that affects relations between user and assistant arises where the assistant is a family member. Dunér and Olin (2018) explored what happens to the relationship between user and assistant when family members are employed as assistants. The study focused on how both parties experienced independence, what kind of strategies they developed to deal with tensions and conflicts, and how they managed to negotiate the needs for freedom, responsibility and caring. The results indicated that receiving personal assistance from a family member can have advantages and disadvantages.

Roles and relations

The relationship between user and personal assistant is fundamental to self-determination in everyday life (Meyer et al., 2007; Wadensten & Ahlström, 2009; Hugemark & Wahlström, 2002; Giertz, 2012). When there is well-functioning cooperation between user and assistant, both parties perceive that the user's autonomy is being respected. Users 'were required to identify and balance the strengths and weaknesses of each assistant in order to live their lives' (Yamaki & Yamazaki, 2010:43). In addition, the assistant had to be capable of providing sufficient and appropriate support without being intrusive (Giertz, 2012), which required a responsive preparedness on the assistant's part (Egard, 2011). From a user perspective, flexibility and person-continuity on the behalf of the assistant resulted in greater independence in private relationships and increased participation in public life (Hugemark & Wahlström, 2002). Interactions between PAs and people with learning disabilities showed that 'there were frequent shifts between 'being a person with learning disabilities' and 'being an employer' or 'being a friend' (Williams et al., 2009: 621). In relationships between users influenced by IL ideology and their assistants, three dimensions were detected: one

functional, one interpersonal and one collective. The functional dimension was expressed in viewing assistants as ‘instruments’. In the interpersonal dimension assistants were characterized as ‘employees’ (from a task-orientated aspect) and ‘companions’ (from a socio-emotional aspect). In the collective dimension assistants were considered ‘social assets’ – individuals without disabilities who understand the importance of user control and IL ideology (Yamaki & Yamazaki, 2010).

In the relationship between assistant and assistance user, power is relational. Talking in terms of superior and subordinate positions is an oversimplification of reality since adaptation from both parties is required (Giertz, 2012). Jacobson (1996) describes how the change from housing services to PA meant being provided with coherent support instead of a patchwork of various support efforts granted by different authorities. Although PA has meant a power levelling, significant inequality remains due to the dependency built into the relationship between people who give and those who receive help. The subordination of personal assistants could also be explained by the construction of the work as both non-professional and gendered, and the interrelatedness between the two dimensions. In addition, it is suggested that solidarity could be enhanced by emphasizing equality, mutual respect and recognition between assistants and users (Guldvik et al. 2014).

Children and adolescents with personal assistance

Studies of children and adolescents have been concerned with how being dependent on PA affects their development, peer relations, and opportunities for and barriers to participation. Studies indicate that assistants can be perceived as both enablers and barriers to participation. A mixed method study (Axelsson, 2015) with parents of children with profound intellectual multifunctional disabilities (PIMD) and external personal assistants showed that the assistant’s role was to reinforce the child while at the same time balancing the need for privacy among other family members, which included a shared understanding of the situation and the assistant’s relational skills in respect of other family members. The reinforcing role in relation to the child included substituting basic functions, providing support with everyday life routines, facilitating the child’s engagement and supporting the child in building relations with others. In a study by Skär and Tam (2001) disabled children’s roles and relations with their assistants were described from the children’s perspectives. The children had different types of physical disabilities and were between 8- and 18-years old. They viewed the ideal assistant as a person under the age of 25, somebody who was able to give them confidence and security and was available on their own terms. Children also preferred the assistant to be the same sex as themselves. If the assistant was perceived as a parent or someone who wanted to be in control, their presence was perceived as intrusion, especially in relation to contact with peers. The presence of the assistant can inhibit children from taking their own initiatives, which has negative effect on developing self-confidence (Jarkman, 1996). A good assistant was a person who treated children as individuals (Skär & Tam, 2001). When assistants were considered friends they could facilitate contact with peers, but at the same time friendship could make it difficult

for the adolescent to be critical of the assistant (Barron, 1997). Barron's dissertation demonstrated interesting gender differences in relation to developing autonomy. Young women internalized the external view of themselves as passive recipients, while young men distanced themselves from belonging to the category of people with disabilities. Receiving assistance from parents was perceived as natural but could at the same time complicate the transition to adulthood (Brodin & Fasth, 2001). A report from the National Board of Health and Welfare (2014) suggested that assistance providers should take into account that young people with family members as assistants should also have external assistance due to the risk of limiting children's right to self-determination.

Disabled children's participation in school and spare-time activities

How disability affects participation in school is a theme that has been dealt with in several studies (Almqvist & Granlund, 2005; Eriksson & Granlund, 2004). Children with disabilities perceive themselves to be less involved in school than their non-disabled classmates. Students without disabilities rated their perceived participation higher, especially in unstructured activities (ibid, 2004). Students with a high degree of participation were characterized by independence and interaction with peers and teachers, and a feeling of having control over their lives (Almqvist & Granlund, 2005). Every third child with physical disabilities say they do not have access to technical aids in school and several of the children wanted more time with assistants in school (BO, 2002). Conflicting perspectives between assistants and children arose when children were more concerned with social interaction with peers than the ability to perform well in school (Hemmingsson, 2002), or used their breaks for movement between different classrooms (Heimdahl Mattson, 1998). In a study of Norwegian adolescents in school settings with non-disabled peers, appearing to be like everyone else became important (Asbjornslett & Hemmingsson, 2008). The experience of being just like their classmates, while at the same time being aware that others perceived them as different was an implicit challenge to their participation at school. Students who needed support from assistants emphasized the importance of assistants' sensitivity in relation to knowing when to pull back and when to assist. The interaction was also dependent on the assistant's ability to fit in with the physical environment. In that sense age became an important aspect. If the assistants themselves had only recently left adolescence, teenager users thought they could provide important knowledge and have a better understanding of their situation (Lang, 2004). A key finding from Asbjornslett and Hemmingsson's study (2008) was the value students placed on being where things were happening even if it meant not being able to do the same things as the other students.

A survey by the Children's Ombudsman [Barnombudsmannen, BO] of living conditions among children with and without disabilities showed that children with disabilities are too often excluded from activities both at school and in their spare time. Limited opportunities to participate in various recreational activities were explained by the lack of appropriate activities, assistance and transport (BO, 2002). A literature review (Axelsson et al. 2014) found that children with cerebral palsy had a reduced level of participation, and those with

the greatest functional impairment were the most restricted (Imms, 2014). They described facilitating strategies for improved participation and engagement for children with PIMD. The main finding was that children were dependent on the active involvement of support persons in their environment, which included external assistants. Having ‘a good knowledge of the child’ and a positive attitude towards her or him were prerequisites for being able to support the child.

Children’s participation in meetings with authorities

Another survey by the BO was distributed to 84 government agencies. The aim was to find out whether children and young people of different ages were given the opportunity to influence the authorities’ activities and if their views were sought in investigations concerning them. The impact of a children’s perspective on government agencies was low. The survey showed that only a few agencies had guidelines on analysing the consequences of decisions that affected children and young people. Moreover, 54 of the 84 agencies did not ask for children’s views on matters that concerned them. Authorities that had contact with children mostly targeted children and young people in the upper age groups (13 to 17 years) and it was not routine to document the comments of children and young people (BO, 2007). One conclusion from a review from Nordenfors (2010) is that participation is often on adult terms and it is difficult to learn how to make decisions and handle risk if the chance to undertake either of these activities is denied (Hudson, 2003). Traditionally, there has been a reliance on parents/carers to provide insight into their children’s experiences, but a qualitative study of children’s and parents’ experiences of medical consultations revealed that the views of children and parents were different (Garth & Aroni, 2003). Sheppardson’s study (2001) in South Wales, reveal that parents were keen to encourage decision making in theory, but unwilling to allow it in practice. Children rarely had a voice in planning and decisions that concerned them, even though they themselves wanted to express their opinions (Hudson, 2003; Stenhammar, 2009). Children and adolescents often lacked influence and autonomy in both the design of PA and the direct relationship with the personal assistant (IfA 2009).

Some of the results from studies with children and adolescents are equally valid when it comes to adult users. For both gender and age, studies show that both assistance users and assistants prefer working/being with a person who is the same age and sex as themselves. The relation with the assistant entails different dimensions and assistance users of all ages and assistants try to find a balance in the relationship. Interdependency seems to be a possible solution, although some users inspired by Independent Living ideology prefer user control over co-determination.

Children and adolescent’s participation in social investigations

In 2008–2009 the National Board of Health and Welfare conducted a pilot study of the problems and opportunities social workers encounter when they try to ensure that children and young people’s needs are met in the social investigation regarding LSS interventions.

Social workers mentioned lack of instruments or models on how to include a child's perspective. When the child was under the age of 13, social workers often talked to the parents about the needs assessment without the child being present. Talking with the child and/or youth was dependent on age, type of disability and parents' wishes. If the child used alternative communication, many social workers, regardless of the child's age, decided to talk to the parents instead. Children's needs were assessed differently by social workers within and between municipalities (National Board of Health and welfare, 2009; BO, 2002). Parents described it as a challenge to emphasize negative things about their children's abilities (Engwall, 2013; Gundersen, 2012), and parents often felt obliged to disclose sensitive information about themselves and their family (ibid, 2012). Children with disabilities had little influence over decisions that concerned them. The SIA and the Social Services were, for those children whose parents had contact with them, however, completely unknown. Children had, for example, no idea of who decided whether they were entitled to an assistant. The children rarely participated in these meetings. If they did, they were not involved in the conversation. Several children described that they did not remember having any opportunity to express what they wanted and what their needs were (Handisam, 2014). A study that included young people with intellectual and psychiatric disabilities revealed how the social identity young people construct differs from how professionals perceive them (Olin & Ringsby Jansson, 2006)). Many adolescents preferred mainstream solutions and the desire to fit in resulted in them not considering or using specialized services or technical aids (Egilson, 2014). Support should be provided in less stigmatized forms and be individually and flexibly designed, and not limit adolescents' capacity for self-determination (Barron, 1997). Egilson (2015) identified three types of reaction that young people had to the challenges within the service system: conformity, signified by adaptation to the current situation and making few demands for services that are not available; efficacy, attributed to a positive and active disposition; and criticism, characterized by strong opinions on disability issues and society in general.

STUDY RATIONALE

The roles of and relations between young assistance users and assistants appears to be an area which has been thoroughly explored. However, knowledge of disabled children's own perspectives on their living conditions is generally lacking (Handisam, 2014). Overall, disabled children's voices are absent in studies concerning their own experiences, especially those of young children under the age of 10. Furthermore, there are knowledge gaps regarding disabled children's agency and contribution in formal settings, both in the Nordic countries and internationally (Traustadóttir et al., 2015). Although several conventions and laws have clearly formulated requirements that children should be involved in decisions that concern them, many researchers have come to the conclusion that children's participation does not work in practice (Stenhammar, 2009; Alderson, 2010). The fact that children do not speak on matters that concern them can have serious consequences for the child's life situation. The Children's Rights Committee expressed concern that Swedish professionals who meet disabled children lack necessary knowledge

(2015). At the same time disabled children describe how important it is for adults to have knowledge about their disability and situation (BO, 2016).

Writing this thesis has been an attempt to address the described knowledge gap by asking adolescents how they value and experience everyday life with PA, which includes the assessment meetings that precede any possible access to PA. In addition to adolescents' perspectives, the assessment process is examined from the perspective of the professionals responsible for making decisions about PA and other LSS interventions. This dual perspective aims to provide insights into how the implementation of policy goals is dealt with and experienced by two of the main actors – young assistance users and the professionals responsible for administering PA.

OVERALL AIM

The overall aim of this thesis was twofold: to explore young people's experiences of living with PA, which includes their experiences of participation in meetings regarding access to PA; and to explore social workers' experience of assessing children's right to PA and other LSS interventions. The focus of the thesis was to gain knowledge about experiences of living with PA and experiences related to the application process for PA and other support interventions. The specific aims were:

Paper I

To explore how adolescents with disabilities experience everyday life with personal assistants.

Paper II

To gain understanding of the experiences of adolescents with disabilities concerning meetings that affect the possibility of receiving PA in Sweden

Paper III

To gain deeper understanding of social workers' perceptions regarding disabled children's participation in the social investigation, including their involvement in meetings prior to the social worker's decisions about access to possible interventions in accordance with the LSS Act.

Paper IV

To explore Swedish case workers' experiences of handling the decision-making process on whether disabled children are entitled to PA.

THEORETICAL FRAME

The first study addressed disabled adolescents' experiences of living with PA in everyday life. When they reflected on their experiences of PA they talked about how access to assistance enabled them to live a 'normal life'. It is therefore important to discuss concepts such as normality, normalization and norms. Professionalism is another key concept. The factors influencing the social workers' professional discretion are discussed in relation to austerity and New Public Management ideology as well as the legal requirements that determine access to support. Children's participation is discussed in relation to different understandings of children's participation, first and foremost from a rights perspective.

NORMALITY, NORMS AND NORMALIZATION

The meaning of normal tends to be associated with something ordinary as it constitutes deviance, a deficiency or something undesirable. We tend to value the normal as an ideal or how something is meant to be (Hacking, 1990). Although normality is supposed to denote the average, the usual and the ordinary, in actual usage it functions as an ideal (Baynton, 2013).

We consider what the average person does, thinks, earns or consumes. We rank our intelligence, our cholesterol level, our weight, height, sex drive and bodily dimensions along a conceptual line from subnormal to the above average....There is probably no area of contemporary life in which some idea or norm, mean or average has not been calculated (Davis, 2013: 1).

Normality as an identity is primarily based on having a functioning body and being able to earn a living (Ljuslinder, 2002). A well-functioning body has become a symbol of 'the normal' based on prevailing ideological values in contemporary society. Hence disability comes to represent the entire person's identity instead of a small part of the person that constitutes the restriction (Ljuslinder, 2002). 'To understand the disabled body one has to return to the concept of the norm, the normal body' (Davies, 2013:1). The concept of a norm implies that the majority of the population should be part of the norm. The idea of a norm in relation to the human body creates the idea of deviance or a 'deviant body' (ibid, 2013).

Norms

Societal norms permeate almost all parts of society and are thus essential for what we call society. By reducing complexity, norms coordinate actions and contribute to an effective organization of society (Baier, 2013). The relationship between legal norms and social norms can be expressed in terms of living law and state law. Living law is based on the social norms that regulate society from within (through moral standards and collectively agreed upon actions). State law represent formal law which regulates society from the outside (Friis, 2013). In the theory of communicative action, Habermas (1987) argued that law can be seen as either an institution or a medium. As an institution law is part of the lifeworld; as a medium it operates instrumentally. A pure application of the law is not always possible, and might even lead to unjust decisions. However, these norms are mixed

and cannot easily be classified into distinct categories (Åström, 2013). In his later works Habermas (1996) states that law is in fact always part of the lifeworld, in the sense that the instrumental parts must be complemented by a moral dimension. This implies that the normative structures of the lifeworld are always relevant to the application of law. Consequently, there are complex relations between law, politics and the lifeworld which become prominent in relation to the changed interpretation and increased utilization of precedent rulings that have a great impact on the outcome of decisions about possible access to PA.

Normalization

The Normalization principle was introduced by Nirje in the 1960s and ‘was primarily constructed around the idea of changing everyday life for people with intellectual disabilities living in government institutions’ (Pettersson, 2015:44). The normalization principle involved, ‘patterns of life and conditions of everyday living that are as close as possible to, or indeed the same as, the regular circumstances and ways of life of their communities and their culture’ (Nirje, 1969: 17). Normalization was conceptualized in eight descriptive components which gave meaning to the phrase ‘normal life’. Thus, attached to the normalization principle came beliefs and values about what constituted ‘normal everyday life’ in society: ‘the proper use of the Normalization principle rests on an understanding of how the normal rhythms, routines, and patterns of life in any culture relate to the development, maturity, and life of disabled persons’ (Nirje, 1999: 17) Thus, access to a more ordinary life was considered a human right, which implied the rights to a normal life rhythm and normal experience of the lifecycle. Nirje’s (1992) revised definition of Normalization expanded it to other disabilities. In contrast, Wolfensberger thought that Normalization could and should be generalized to all conditions considered deviant by society (Wolfensberger, 1999). Embracing the concept of normalization, he believed that it was important to change societal values which pushed certain groups into devalued identities. However, the concept of normalization has often been misinterpreted as the intent to make people normal (Perrin, 1999).

‘In 1982, Tullman and Wolfensberger reformulated the Normalization principle, ‘stating that Normalization hinged upon the attributions of valued social roles to otherwise devalued individuals’ (Lemay, 1999: 219). Hence Wolfensbergers insights about Normalization was transformed into Social Role Valorization (SRV), which states that prevailing cultural values and arrangements are oppressive of certain groups, and that unless these values are changed people will be devalued, often through no fault of their own (Wolfensberger, 1999). This new concept underlined the interrelatedness of personal competencies, social expectations and social perceptions.

The critique of normalization and Social Role Valorization

Normalization as a societal goal and as a discourse of welfare state policy occurred in Nordic disability law from the late 1950s well into the 1990s (Pettersson, 2015). The

Swedish welfare state has been criticized by the Swedish disability movement for generalizing the identities of dominant groups in society (Hugemark & Roman, 2007). 'From a cultural point of view, the welfare state plays a role in shaping normality, constructing people with disabilities as different and the emancipatory efforts to aid and empower disabled people' (Lindqvist & Sauer 2007: 27)

Normalization is part of a discourse that is predicated on the normal/abnormal distinction (Grue & Heiberg, 2006) and 'when disabled people are measured against this norm they will always be constituted as different, as other' (Grue and Heiberg, 2006:232). In relation to this, the main problem becomes intrinsically linked to the perception of this norm, 'that locates agency, mobility and subjectivity in a naturalized and given body' (ibid, 2006:232). Moreover, Mike Oliver (1999) asserts that the concept of Normalization lacks the capacity to transform the lives of disabled people, one of the main reasons being that Normalization/SRV does not address the crucial power dimension between devalued/ valued people and how power should be distributed in order to change the material and social conditions of disabled people (ibid, 1999).

Crip theory and performativity

Common dichotomies in relation to disability discourse are: abled bodied/ disabled or disabled/ non-disabled, as if these categories are absolute instead of fluid. McRuer (2006) invented the term 'Crip', [word 'reclaimed' from 'cripple'] which can be described as an umbrella term for a number of theoretical attempts to understand how disability is socially constructed. 'Crip theory' underlines the relationship between biology, normality and power. According to Mc Ruer, able-bodiedness still masquerades as a non-identity, or the natural order of things, while disability is operating as its opposite – a deviation to be discovered, examined, categorized, and labelled.

Referring to Butler's queer theories of gender 'performativity', Mc Ruer claims that the same logic can be applied to the social construction of disability. Butler's (1993) perception of performativity provides an understanding of how subjectivity is constituted in relation to the social categories that define who we are. Her point of departure is that subject positions are premised on pre-existing discourses and exclusions. However, 'Butler does not suggest that identity itself is performed, as in 'acted', but that performativity as a societal and ritualized repetition of norms is the condition that makes it possible for subjects to emerge' (Altermark, 2016:36). In Butler's (1993: xxi-xxiv) analysis, categorizations are constructed discursively and thus we can never be sure of belonging, which implies that we constantly have to confirm these ideal subject positions by performing ritualized repetitions of the norms that recognize us as subjects and secure our sense of identity. Hence, the performativity of subjects is how our behaviour unconsciously mimics the unattainable ideals of subject positions to produce our identity.

SOCIAL JUSTICE AND THE WELFARE STATE

The Nordic welfare states are often described as being universalistic (Pettersson, 2015, Earles, 2011) and based on the assumption that all citizens are included in social welfare system which provide citizens with universal access to benefits and services (Earles, 2011). However, ‘the distribution and funding of social justice are influenced by perceptions of what constitute normal and ideal social requirements for citizenship’ (ibid, 2015: 10).

The concept of social justice is discussed by Nancy Fraser (2003). Her general idea is that social justice is a two dimensional concept that requires both redistribution and recognition, which represent different but equally important aspects of social justice since economic disadvantage and cultural disrespect are currently intertwined (Fraser, 1997). Redistribution is concerned with the material aspects of social justice which is based on the socio-economic redistribution in society. Recognition, on the other hand, focuses on the subjective experience of social justice and shed light upon the interaction between social actors. Recognition is based on subjectivity, “where one becomes an individual subject only in virtue of recognizing, and being recognized by another subject” (Fraser, 2003:10). Furthermore, to understand the impact of recognition it has to be viewed as, an issue of social status;

To view recognition as a matter of justice is to treat it as an issue of social status. This means examining institutionalized patterns of cultural value for their effects on the relative standing of social actors. If and when such patterns constitute actors as peers, capable for participating on a par with one another in social life, then we can speak of reciprocal recognition and status equality. When, in contrast, institutionalized patterns of cultural value constitute some actors as inferior, excluded, wholly other, or simply invisible, hence as less than full partners in social interaction, then we should speak of misrecognition and status subordination. I shall call this the status model of recognition, (Fraser, 2003: 29).

Fraser (2003) uses the term ‘parity of participation’ as a signifier for the state when social justice is achieved, in which both the objective condition (redistribution) and the intersubjective condition (status recognition) of justice are fulfilled. Viewed from a disability perspective, a prerequisite for social justice is equal participation in society (Lister, 2007) in which all members of society should be able to ‘interact with one another as peers’ (Fraser, 2003: 36). As a bivalent collective, Shakespeare (2005) argues that ‘people with disabilities suffer both socio-economic injustices, such as marginalization and deprivation, and cultural injustices, such as non-recognition and disrespect’ (ibid:164).

The tension between systems based on work and need is regarded by Stone (1984) as the fundamental distributive dilemma of the welfare state. To resolve it society must develop a set of rules to determine the boundaries between different systems, rules that specify who belongs to each system. Since there is no natural boundary, each society creates or re-designs it in the face of changing social conditions. Thus, eligibility criteria depend on whether a person belongs to a formally defined category that is entitled to seek and gain access to support (ibid, 1984). As a consequence a form of mass management of clients is built up where sorting of clients will provide the basis for who has access to the rights and

benefits available to the organization (Cedersund, 1992). Hence, 'the categorization of being sufficiently disabled become the main qualification for inclusion and access to service provision' (Pettersson, 2015: 8) in which disability evaluation serve as an instrument for determining whether a person is entitled to an intervention (Stone, 1984).

Global austerity and New Public Management

Austerity measures that affect people with disabilities are not an isolated Swedish phenomenon, but present in large parts of Western Europe, (Altermark, 2017; Goodley et al., 2014) and in the USA (Stone, 1984). In this context, New Public Management (NPM) ideology has been utilized as a tool for taking such measures. NPM is a market-based approach with a core belief that market orientation improves public service performance (Hood, 1991). Market models have emerged as a political reaction to prior models which have been criticized for being bureaucratic and expensive. The purpose of NPM is to reduce public spending, strengthen the influence of politicians at the expense of officials, strengthen leadership and improve the services provided to citizens through increased freedom of choice (Pollitt & Bouckaert, 2004). NPM has also led to decentralization of decision making, greater scope for locally adapted solutions and collaboration across different networks (Lindqvist & Borell, 1998). After utilizing NPM in the public service sector for some 20 years, adverse consequences of implementation can be detected, such as increased fragmentation of the service provided and difficulties in cooperating with other stakeholders at different levels in the decision hierarchy (Lindqvist, 2012).

Discretion

Decision making in key areas has increasingly shifted from higher to lower levels of administrative hierarchies – to municipalities and local authorities, but also to the individual who has to claim the rights provided in legislation. This means that civil servants and professionals at the local level and those concerned have gained an increasingly important role in welfare design. (Lindqvist, 2012). A strong activation requirement is placed on the individual. In this process of allocation the individual must apply for support, a diagnosis must be obtained and the person must demonstrate the need for support (Christensen, et.al, 2014).

The social workers' duties consist of investigating, assessing, deciding and commissioning support while it is the unit manager's responsibility to carry out these orders by planning and guiding the work of employees (Lindqvist, 2012). Since the work consists of decisions made about people during the interaction itself, the subjects of routinization will be affected by the processing (Lipsky, 1980/2010). According to Lipsky (1980/2010) the exercise of discretion is a critical dimension of much of the work performed by 'street-level bureaucrats', which include social workers, and other public sector employees who interact with citizens in the course of their job. By definition, street-level bureaucrats work at jobs characterized by relatively high degrees of discretion and regular interaction with citizens.

‘Discretion refers to an area where one can choose between permitted alternatives for action on the basis on one’s own judgment’ (Molander et. al, 2012: 219). Discretionary power is given on the basis that professionals are viewed as capable of making assessments and decisions, within certain structural frames which make them accountable for their judgment. The discretionary powers of social workers are troublesome for two reasons. First, it means relinquishing democratic control and trusting the social worker to implement policy in practice. Second, extensive practice of discretion threatens the principle of formal justice: ‘equal cases should be treated equally, and unequal cases should be treated unequally’ (Molander & Grimen, 2010: 68). On the one hand discretion is a cognitive activity that requires reasoning and good judgment. On the other hand it is regarded as a space for making decisions, which is formulated and discussed in depth by Dworkin (1978) referring to the classic doughnut metaphor in which, ‘Discretion, like the hole in the doughnut, is an area left open by a surrounding belt of restriction’ (ibid.: 31).

Discretion and professionalism

The classic view of professional autonomy is that it allows decision making based on discretionary assessments (Molander, 2011). Molander and Terum (2008) have defined a professional’s jurisdiction as a combination of autonomy and monopoly over specific work tasks, which can be formalized in legislation. This is the case for the municipal social workers making decisions according to LSS legislation.

Evans (2011) argues that discretion occurs in relation to top-down policy implementation, which creates a conflict between managers and street-level bureaucrats, but also in relation to the everyday context in which policy has to be applied, understood and adapted by street-level bureaucrats according to the available resources and to circumstances (Evans, 2011). Thus, to understand management in social care organizations, attention must be paid to the intersection of professionalism and management in public organizations, which entails considering ‘the particular impact of professional status and commitments on the extent and performance of discretion’ (Evans, 2011: 371). With reference to previous research (Friedson, 2001; Evetts, 2002), Evans argues that ‘professional status influence the degree of freedom that an occupational group exercises and entails a commitment to values that should inform the use of that discretion’ (ibid, 2011: 371). McClelland (1990) presented a way to discuss differences between professions using the concept of professionalization and the argument that professionalization comes both ‘from within’ and ‘from above’. Evetts (2003) further developed McClelland’s concept by underlining that professionalization comes from within and that it is the profession that constructs the professional identity and in a position to bargain with states to secure and maintain regulatory responsibilities. To clarify the difference between contrasting types of professionalism, Evetts (2009) discusses two ideal types: organizational professionalism and occupational professionalism. Organizational professionalism is manifest by a discourse of control which incorporates rational-legal forms of authority and standardized procedures. Occupational

professionalism, on the other hand, incorporates collegial authority and involves relations of trust based on practitioner autonomy and discretionary judgment.

The contexts for different occupations are complex and diverse, and consist of variable situations that entail changes and continuities that include both structural and relational aspects (Evetts, 2009). The place of professions can be understood in terms of three distinct types of institutional logic: managerialism, consumerism and professional (Freidson, 2001). Unlike the others, 'professional logic presupposes autonomy, i.e. freedom from too much bureaucratic or profit-seeking governance' (Brante, 2011).

The construction of the broad welfare systems created a demand for 'new professional types' or rather old occupations were professionalized by being equipped with superstructures and long educational training (Brante, 2010). In this context, social work was remodelled and classified as a semi-profession. The main features that distinguish semi-professions from classic professions is that they are subordinated to other professions or they lack a robust, systematized and generally recognized model of performance which makes them easily questioned by the layperson, such as clients and politicians (ibid., 2010).

Social workers are in a complex situation with different types of requirements and expectations directed at them (Norman & Schön, 2005). This makes them wish they had more rules and guidelines, as this would create more structure in their work. It is in meetings with clients that a large part of social work is carried out (Fredin, 1993) and social reforms and measures taken at the political level enforced (Lipsky 1980/2010). The problem of street-level bureaucrats is one of decision making under conditions of considerable uncertainty, where the resource problem is in most cases not resolvable and decision making takes place under conditions of limited time and access to information (ibid., 1980/2010). Moreover, street-level bureaucrats encounter conflict and ambiguity in the tension between client-centred goals and organizational goals (ibid., 1980/2010).

These contradictory demands lead to the contemporary paradox of: 'on the one hand, the concepts of profession and professionalism are being applied increasingly to work and workers in modern societies; on the other, the conditions of trust, discretion and competence thought traditionally to be necessary for professional practice are being challenged with greater frequency – and certainly are changing' (Evetts, 2009: 261). Professionals are thus faced with the simultaneous demands of governance and discretion, (Evetts, 2010). The phenomenon known as 'commercialized professionals' addresses the contradiction embedded in the market model when providers are supposed to do the best for their clients within ever tighter financial frameworks (Hanlon, 1998).

The orientation towards independently working professionals and safeguarding of clients' needs and demands has its antithesis in control and management at the organizational level (Svensson, 2010). This change from internal collegial control to external bureaucratic control can be considered a political agenda influenced by neoliberalism to abolish professional organization (Grimen, 2008). The emphasis on results alters the content

orientation of knowledge, as well as knowledge application. Another consequence is that clients are objectivized and instrumentalized with evidence-basing, but at the same time subjectivized with greater freedom of choice, which could be referred to as a transition from responsibility to accountability (Svensson, 2010).

Moral distress and emotional labour

The structures that social workers encounter can contribute to positions that are not consistent with how they wish to view themselves ethically, which can result in a state of 'moral distress'. According to Jameton (1984), moral distress arises when 'one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action' (ibid, 1984: 6). The results of a study of social work practice in the Nordic countries (Meeuwisse et. al, 2011), resonates with the phenomenon of 'moral distress', 'where restrictive practice environments and working conditions limit the social worker's capacity to deliver high standards of care in frontline as well as management roles' (Lynch & Forde, 2016:96) The social workers in the study of the Nordic countries (Meeuwisse, et.al, 2011) expressed how the daily work practice in municipal social services differed from the 'ideals' of practitioners. The reasons given were 'incompatible' work demands and unacceptable time pressures, which affected their ability to help clients effectively (ibid, 2011).

Allegiance to organizational professionalism sometimes requires emotional labour on behalf of employees. Hochschild (1983/ 2012) argues that emotional labour is based on social norms, and the way that emotions are experienced, performed and managed by workers depending on institutional settings. A study of nurses' working conditions in northern California indicated that a combination of 'invisible' emotional labour and clinical administrative tasks was considered highly stressful (Bone, 2002), since time spent on doing 'invisible work' (such as emotional labour) did not count in the current production model that treats time as a commodity (ibid, 2002). In this sense, emotional labour was an aspect of work that had less accountability than other tasks, which explained why it could be more easily omitted in rationalized work processes (ibid, 2002).

'Good practice in social work requires that the social worker develop skilful ethical behaviour as a practitioner' (Tham & Lynch, 2014:713). However, research indicates that there are different views on what counts as professionalism in social work. Fenton (2016) found that younger, less experienced social workers objected significantly less to the neoliberal managerial direction of social work than their older, more experienced colleagues. Sheedy's results (2013) also underlined that many social work students had no interest in wider issues of politics and social justice, which might make them less likely to protest against organizational professionalism. Differences in decision making among newly qualified and more experienced social workers were underlined by Fook et al. (2000) where the newcomers were more likely to follow rules while their experienced colleagues were able to use critical reflection in their decision-making processes. The same pattern was discovered in a Finnish study (Pösö & Forsman, 2013), where the 'novice social

workers' were concerned with following organizational and legal norms while the 'old' social workers were more concerned with relationship-based work.

Ethical values, norms and power

Professional groups such as social workers can establish norms of their own related to their profession. Such professional norms tend to be strategic rather than concrete instructions on what to do in a specific situation (Molander & Terum, 2008). Ethical awareness is particularly important in professions where work can have a profound impact on people's lives and living conditions – in activities that exercise power in any form. Social work is that kind of work. Professionals are key actors in the development of social norms. They participate in the definition of the public good and in processes of normalization (Weinberg, 2016). Control of professional services is achieved by means of normative values and self-regulated motivation (Evetts, 2009). Inspired by Foucault (1977), Brante (2010) identified social workers as the guardians of normality, in which their 'specialist competence resides in the ability to identify the good and proper way of living and to guide the citizens to internalize appropriate norms, and thereby also to point out social malfunctions' (ibid: 94).

There is a fundamental structural paradox at the heart of social work practice. As public servants, social workers are at the intersection of responsibilities for both care and discipline (Weinberg, 2016). Despite the intention of being non-judgemental, social workers are instructed to engage in divisive practices that distinguish one individual from another in order to determine eligibility for support interventions (Stone, 1984; Lipsky, 1980/2010). Power relations determine what is considered truth. Social workers have a mandate to develop knowledge on what constitutes normal behaviour and then to evaluate whether individuals are meeting that standard. The position of frontline workers in organizational settings, legislative requirements and restrictions on resources all shape and limit the directions in which professionals can perform their work (Weinberg, 2016).

Even when social workers adopt subjective positions that they themselves prefer, harm may be done. The literature on moral distress underlines the importance of practitioners engaging in critical self-reflection (see Burston and Tuckett, 2012). Although ethical reasoning and critical awareness are important features of social work education, these are considered insufficient without improvements in workplace ethical climates and support structures (Ulrich et al., 2007). Weinberg (2009) discuss the importance of a supportive organizational culture to encourage and enable 'safe spaces' to explore ethical questions. Questioning authority is central to finding alternative ways of practice: questioning who has defined something as a problem and why it is perceived as such. Critical thinking creates opportunities to contest interpretations of norms by allowing an examination of what stake a person may have had in defining the problem in a particular fashion and what possible benefits can be provided from such a construction (Weinberg, 2016).

CHILDREN'S PARTICIPATION

Participation is a wide concept and can be defined broadly as in the International Classification of Health (ICF), which considers participation as a health-related concept. It is defined as a person's involvement in a life situation, which means being included, engaged, taking part or having access to the required resources (WHO, 2007). This definition is closely related to the performance of daily activities and its focus on typical performance of particular activities in a specific setting. Participation can also be defined more specifically. Gustavsson (2004) suggests that participation can be divided into three separate but interrelated dimensions: the experience of participation, active participation and accessibility and interaction with the environment. In a systematic review by Imms et al. (2016) the participation experience consists of two elements: attendance and involvement, with attendance being a necessary prerequisite to involvement.

Children's participation from a rights perspective

In this dissertation, children's participation takes place within the framework of the exercise of authority. Important aspects of participation include 'equal opportunities, membership of the school community and being treated as a valued human being – issues strongly linked to civil rights and citizenship' (Egilson & Traústadóttir, 2009: 59).

Participation can be exercised to different degrees. Four levels of involvement can be identified in the decision-making process: to be informed; to express an informed view; to have that view taken into account; and to be the main or joint decision maker (Alderson & Montgomery, 1996). The realization of children's rights involves a transition from viewing children as passive recipients to validating their competence as active actors (Lansdown, 2010). The extent of children's actual participation can be assessed by considering the degree of children's involvement and their point of entry. Consultative participation is when adults seek children's views in order to understand their lives and experiences. Collaborative participation enhances children's participation by providing partnership, with an opportunity for active engagement in decision making. Child-led participation is when children are allowed to identify issues of concern and initiate action to resolve these issues.

One of the best-known metaphors for children's participation is the ladder of participation, adapted to describe children's participation by Roger Hart (1992) from Arnstein's ladder which was developed in the context of adult civil rights (Arnstein 1969). Hart's ladder consist of eight rungs. The bottom three rungs represent different degrees of non-participation, in terms of manipulation, decoration and tokenism, while the top five rungs represent varying degrees of participation. Despite being criticized for its hierarchical structure, the ladder has considerable value in distinguishing between actual participation and tokenism, when children are used as mascots without any actual power to decide over the conditions of their participation. Shier (2001) developed Hart's model further by identifying five levels of children's participation: being listened to, expressing a view, having views taken into account, being involved in decision making, and sharing power and

responsibility for decision making. Moreover, these levels were combined with three stages of commitment which adults could engage in at each level: openings, opportunities and obligations.

For many people, children's rights have become synonymous with participation (Landsdown, 2010). A child's right to influence in situations where they are directly concerned is often problematized in relation to children's right to protection and care. One of the major challenges of the Convention on the Rights of the Child (CRC) is the view that children are competent citizens with a right to be heard on decisions that affect their lives (BO, 2002).

According to Article 12 of the CRC, children have the right to express their views and have those views taken seriously. Despite the fact that article 12 applies to every child capable of forming his or her views, very young children and disabled children are often denied their right to participate (ibid, 2010), particularly children with complex needs or communication impairments (Sinclair and Franklin, 2000; Sinclair, 2004). Compared to their non-disabled peers, disabled children and young people experience multiple types of discrimination, low expectations and social exclusion (Russel, 2003). The social construction of disabled children as vulnerable (Priestley, 2000) affects professional attitudes to their involvement and is often reflected in the power adults exert over children (Martin and Franklin, 2010).

METHODS

This chapter presents my research position, the ontology and epistemology, the design and flow of the studies in the project, my sampling methods, the participants, data collection, data analysis and ethical considerations. It also contains reflections on the research process.

ONTOLOGY AND EPISTEMOLOGY

Epistemological questions (how we know things) and ontological claims (how the world is constructed) cannot be completely separated from each other because they are intrinsically related (see Layder 1997). Knowledge production involves different ways of interpreting the meanings that participants prescribe to their actions (Benton & Craib, 2001). It is therefore important to clarify how data is valued and handled in the research process.

The studies in this thesis are based on empirical data on the experiences of disabled participants and those of the social workers in charge of decision making on access to support interventions, using the disability act. This makes it interesting to study the interactions between classifications of people and the people being classified (Hacking, 1999), as well as the structures that determine, constrain and oppress our activities (Houston, 2001). Classifying changes people, but the changed people themselves cause classifications to be altered (Hacking, 1999). A central point of departure in critical realism is that reality exists independently of the observer, but at the same time it stresses that our knowledge of this reality is socially influenced (Danermark, 2008). Critical realism is consistent with my ontological beliefs about how the world is constructed since it does not necessitate a choice between either a materialistic or an idealistic ontology. Rather, it opens up space for an examination of the multiplicity of mechanisms involved in the formation and reproduction of disabilities, since ‘In critical realism, the exact weight, role and influence of particular kinds of mechanism is something that must be determined empirically in each specific case’ (Bhaskar & Danermark, 2006: 25). With reference to Bhaskar (1991), Houston argues that science cannot be value-free, ‘since the role of critical realism is not only to uncover psychological and structural mechanisms but to challenge their existence where they lead to oppression’ (Houston, 2001: 851). Furthermore, critical realism is compatible with the chosen definition of disability, which considers both physical and social barriers in society and impairment (individual restrictions due to bodily functions). It therefore seems to be an appropriate meta-theory.

DESIGN

The present research project was conducted using a qualitative inductive approach, with the overarching ambition of either exploring the personal meaning of the participants’ actions or conveying their descriptions of a certain phenomenon. The project was based on two studies that utilized different qualitative methods for analysing data. Grounded theory was used in the analysis of papers I and IV. Inductive content analysis was applied in paper II and phenomenology in paper III. The first study was conducted from the perspectives of

disabled adolescents who were either were living with and/or had the experience of applying for PA. The second study was undertaken from the perspectives of the professionals in charge of the meetings that precede decision making about PA and other LSS interventions. The first study data consisted of individual interviews combined with naturalistic observations while the second study data consisted of focus group interviews (paper III) and focus group interviews combined with individual interviews (paper IV).

Table 2 Overview of the Papers in the Project

Title	Population	Sample	Data collection	Analysis
Paper I <i>Assisted Normality: a grounded theory of adolescent's experiences of living with personal assistance</i>	Adolescents living with PA	16 adolescents (n= 10 young men, 6 young women)	Individual interviews (n=33) combined with naturalistic observations regarding experiences of living with PA	Grounded theory
Paper II <i>Reluctant participation: the experiences of adolescents with disabilities of meetings with social workers regarding their right to receive personal assistance</i>	Adolescents living with PA	13 adolescents (n= 7 young men, 6 young women)	Individual interviews (n=26) about the adolescents participation in meetings and decisions concerning possible access to PA	Inductive qualitative content analysis
Paper III <i>Elusive participation: Social workers' perceptions about the anticipated participation of disabled children</i>	Municipal social workers	35 social workers (n= 34 women and 1 man)	7 focus group interviews about their experience of disabled children's participation. Each focus-group consisted of 4-7 participants.	Phenomenology
Paper IV <i>Maintaining professional integrity: Experiences of case workers performing the assessment that determines children's access to personal assistance</i>	Municipal social workers and administrators at the Social Insurance Agency	35 social workers (n= 34 women and n= 1 man) 11 administrators (n= 11 women)	7 focus group interviews and 11 individual interviews	Grounded Theory

SAMPLING AND PARTICIPANTS

The two studies included in this thesis were performed between 2013 and 2018.

Paper I

The starting point of the entire project was an interest in disabled children's and adolescents' experiences of living with PA in their everyday lives. In accordance with grounded theory, purposive sampling was initially used to include children and adolescents who were knowledgeable about the phenomena being studied. In the beginning, the plan was to include both young children and adolescents, but difficulties in attracting young children meant that this part of the study had to be postponed. Thus, eligibility criteria for initial inclusion in the study were adolescents with mobility impairments who: (a) attend senior high school; (b) have or have had access to paid external assistants who were not family members or relatives; (c) have at least six months experience of using PA; and (d) have the ability to tell of their experiences either verbally or through alternative communication. The participants were recruited from three of the four national upper secondary schools catering for children and adolescents with mobility impairments and from user organizations whose target groups were disabled children and youth. Contacts with the adolescents were either mediated through staff at school and contact persons at user organizations, or made directly by the adolescents. However, school staff and contact persons at user organizations were informed that they should only provide information about the study – not select participants who they considered 'suitable'.

This resulted in 19 adolescents agreeing to participate. However, three of these adolescents later decided not to participate: two changed their minds and one had misunderstood the purpose of the study. Thus, the initial sample consisted of sixteen adolescents (n=10 male, n = 6 female). The adolescents were between 16 and 21 years old. Two of them used graphic language to communicate. Theoretical sampling was performed within the same group of adolescents and in the sense that a subsequent set of interviews was guided by the emerging theory (Glaser and Strauss, 1967) This meant that the new interviews were performed in order to expand and refine the concepts that had already emerged. Data collection ceased when theoretical saturation of the categories had been reached in the analysis, which means that 'no new properties emerge and the same properties continually emerge' (Glaser, 1978: 53).

Paper II

The second paper involved the same participants as the first paper. However, not all of the adolescents had experience of meetings before gaining access to PA. This meant that 13 of the adolescents were included in the second study (n= 6 women, n= 7 men).

Paper III

Participants in the third paper were social workers who worked on the implementation of LSS legislation and had experience of making decisions about children's access to different

LSS interventions. The population was of 35 social workers divided into seven focus groups. Some of the groups consisted of social workers from the same workplace, while some groups were composed specifically for this study. However, social workers who were the sole representative of a specific workplace were placed together with other social workers in a similar position. The focus groups consisted of social workers from different parts of Sweden, and both rural and urban communities. The sample was homogenous with regard to gender and ethnicity: it consisted of one male and 34 female social workers. Academic women predominated, mirroring the situation in the social work profession. The groups consisted of 4–7 participants. Their individual experience of performing social investigations according to LSS legislation ranged from 0 to over 10 years. 14 of the 35 social workers had more than 10 years' experience of working with LSS legislation. Finally, 15 of the social workers had a university degree with a major in social work and 13 had a university degree with a major in other social and behavioural sciences.

Table 3. Demographics of the participants

Characteristics	Women	Men
Age		
20-40	8	1
41-60	22	
> 60	4	
Working with LSS (years)		
<1	1	1
1-5	11	
6-10	8	
>10	14	
Education		
Social work university degree	15	1
Other type of university education	13	
Missing data	6	

Paper IV

The initial, purposive sample was the same as in paper III. The theoretical sample, which corresponded to the need to incorporate more data relevant to the emergence of new categories and properties (Glaser, 1978), consisted of 11 individual interviews with female administrators at the SIA. Information about their educational background was not reported. All of the administrators at the SIA had more than 13 years' experience of working with assistance allowance.

DATA COLLECTION

The major source of data collection was interviews, both individual interviews and focus group interviews.

Study I, paper I and II

Data was collected through individual interviews. In total, 33 individual interviews were performed with 16 adolescents. Initially, purposive sampling was used. All of the participants were interviewed at least twice, some were interviewed four times. A semi-structured interview guide was initially used for the individual interviews for study I. The interview guide was employed as a checklist to cover the different contexts in which adolescents utilized PA. The interview guide was combined with the technique of using open conversations. All of the individual interviews started with a broad question, such as: 'What does an "ordinary day" with PA look like?' The purpose with this type of question was to encourage the adolescents to share their unique experiences of living with PA. Open questions were often followed up with probing questions in order to clarify or further develop the interviewees' thoughts.

Augmented and alternative communication and naturalistic observations

The adolescents who utilized AAC used a combination of technical aids and body language to make themselves understood. Communicating non-verbally was more time-consuming than communicating with somebody who had access to verbal speech. Communicating with AAC often altered the expected turn-taking since the timespan between posing a question and receiving an answer was prolonged compared to time spent between two persons with access to verbal communication (Heister Trygg & Andersson, 2001). In addition, it took more time for us to communicate since we were not familiar with each other's communicative style. Being in a school environment occasionally resulted in being interrupted by teachers or students entering the room. These involuntary interruptions sometimes made it difficult to return to the topic of conversation. However, meeting adolescents in their school environment provided me with the opportunity to carry out naturalistic observations of the environment, and helped me to become more sensitized to the environment in which the adolescents spent most of their time. It also gave me an opportunity to observe the interaction that took place between adolescent and adults, some of whom were PAs or student aids.

Managing preconceptions

Moving beyond preconceptions was challenging. In the first GT analysis (paper I) preconceptions were handled by acknowledging them and thus making them available to be questioned. Before the initial set of interviews were performed, the author 'interviewed' her daughter in order to clarify their common knowledge and understanding of living with PA. This information was used to sensitize the researcher in the forthcoming interviews, and if considered relevant, referred to when asking probing questions. According to GT

methodology, the data from the previous interviews was analysed between the interviews (Glaser and Strauss, 2008; Glaser, 1967). This ongoing analysis shaped the questions in the forthcoming interviews, which meant less use of the existing interview guide, since the questions served to further elaborate and saturate the emerging categories. Emergence was fostered as the researcher sought patterns in the data, and avoided interpretations that followed the original preconceptions and existing patterns of thought (Glaser, 1998). Theoretical sampling (Glaser, 1978) was initiated when the category ‘normality’ emerged, in order to explore how adolescents’ perceptions of normality differed in various contexts.

Contrary to the prescriptions of classical GT, all of the interviews were audio recorded (Glaser, 1998). This can be explained by the need for transparency in the research process, in which the supervisors contributed to the analysis, audio recordings facilitated the comparison of data from different interviews and enabled the use of quotes to illustrate different incidents and key concepts.

Study II, Paper III and IV

The focus group interviews took place between February and June, 2016, and lasted between 2 and 3 hours. In the second study contacts were made with group leaders at local social services offices. After being provided with oral information about the study, written information was sent to the group leaders who distributed it to the social workers, who were selected according to inclusion criteria. Sometimes names and telephone numbers were given to social workers and they were contacted by telephone, to give them an opportunity to ask questions. Once the social workers had agreed to participate in the study, two information letters were distributed about the focus group interviews. The first letter provided general details and information about the voluntary nature of participation. In the second letter, the social workers were asked to think/ reflect about an ongoing case that concerned children’s participation.

The responsibility for conducting the focus group interviews was shared by a supervisor, the author and a researcher (Forinder, Hultman and Öhrvall). Two of the three attended each group interview. One of them took responsibility for acting as a moderator and initiating group discussions. However, they shared responsibility for asking probing questions in order to clarify statements or engage all of the participants in the conversation.

The focus group interviews were initiated with questions aimed at stimulating exchange between the participants, such as: ‘In what ways are children involved in meetings?’; and ‘How do you plan for children’s participation?’. The social workers were also asked to talk about and reflect on ongoing ‘cases’ during the interviews.

In study IV it was decided that administrators at the SIA should be theoretically sampled. However, we were not given permission to do interviews with the administrators. Instead, we were provided with previously transcribed interviews undertaken with the aim of exploring PA from a slightly different perspective. Before using these interviews an assessment of the quality and completeness of the data set was performed (Hinds et al.,

1997) by the author and supervisor (Pergert). They were judged to contain enough relevant information for the needs of this study. The individual interviews were conducted in 2015 by staff at the analysis division of the SIA. The government commissioned the SIA to analyse and report on why both the number of people receiving PA and the number of weekly hours per person had increased (SIA, 2015).

ANALYSIS

Paper I

After the initial set of interviews had been performed, it was discovered that the individual interviews covered two main topics: everyday life with PA and the meetings that determined whether adolescents would be given access to PA. This resulted in the data being divided into two parts. Hence, the data pertaining to everyday life experiences was further explored and analysed in the paper I.

The risk of having prior knowledge of a subject area is that you already ‘know’ what is considered important knowledge. To avoid this as far as possible, Grounded Theory (GT) seemed to be an attractive choice for method of analysis. Grounded theory is guided by the participants’ main concern, which means that the research question is developed on the basis of what the participants think it most important to discuss. In this paper classic GT (Glaser, 1978; Glaser, 1998) has been used to develop a substantive theory based on the substantive area, living with PA. What distinguishes GT from other qualitative methods is the discovery of theory from data, in which constant comparative analysis was used to generate general ‘hypotheses’ of what is going on in relation to personal assistants and disabled adolescents.

The analysis commenced with the author transcribing the data in Swedish and analysing it according to classic GT (Glaser, 1978, 1998). The co-supervisor (Pergert) and the main supervisor (Forinder) read through the first three interviews line by line and discussed the emerging categories with the author. The software program NVivo 10 was used during the open coding. Open coding meant staying close to the data – analysing it line by line in order to identify which category different incidents indicated (Glaser, 1998) and to discover the main concern of the participants (Glaser, 1978). Open coding was used until the core category and related categories had emerged, when selective coding was initiated. ‘To selectively code, for a core variable, then, means that the analyst delimits coding to those variables that relate to the core variable in sufficiently significant ways to be used in a parsimonious theory’ (Glaser, 1978: 61). Conceptualization of the core category and related categories was further discussed at a GT seminar, hosted by Dr Barney Glaser. Memos were written about the data throughout the analysis. According to Glaser, ‘memos are the theorizing write-up of ideas of codes and their relationships as they strike the analyst while coding’ (Glaser, 1978: 83). The integration of categories was aided by the memos and theoretical coding. Saturation of the core category and related categories was achieved when different incidents indicated the same categories.

Paper II

Qualitative inductive content analysis (Elo & Kyngäs, 2008) was used to analyse the part of the data where the adolescents talked about their involvement in the application process for PA. Data had previously been sorted from the complete interviews. After the interviews had been transformed into written text, the so-called unit of analysis, this was read through several times by the first author in order to get a sense of the data. Coding was then done manually by the first author. The coding resulted in the text being divided into smaller meaning units, which consisted of one or two sentences. The meaning units were then coded into different subcategories. Each subcategory was named using content characteristic words that were indicative of the manifest content of the interviews. In order to validate the ongoing analysis, individual coding was performed separately by the author and the supervisors (Forinder and Pergert). Categories were compared and renamed so that similar data was grouped into the same subcategories. The supervisors and the author maintained a continuous dialogue about categories and alternative interpretations of the meaning of the categories, and final decisions about them were not made until a consensus was reached.

Paper III

A phenomenological approach was used when analysing the focus group interviews with the social workers. The analysis started by reading through all the interview transcripts. While reading, the author tried to bracket her own perceptions of and beliefs on the reality by trying to grasp the essence of the phenomenon described – disabled children's participation. The interview transcripts were read through several times in order to get an in-depth understanding of the material. After the interview transcripts had been read in detail by the research team – author, supervisor (Forinder) and researcher (Öhrvall) – the analysis proceeded by searching the text for meaning-bearing units related to disabled children's participation. The text was then sorted into meaning-bearing units which reflected different aspects of the phenomenon and transformed into descriptions of how the phenomenon presented itself. The final step was to synthesize the transformed meaning bearing units from each interview into coherent themes. The intention with the analysis was to provide a full description of how the social workers experienced young disabled people's participation and make 'as pure descriptions' as possible' in order to outline their lived experience of handling and understanding children's participation within the framework of disability assessments.

Paper IV

In the fourth paper, GT was used to analyse the data. The analysis started by separating data about meetings and decisions regarding PA from data about other LSS interventions. Once all the data had been sorted, open coding was performed and recurring interchangeable indicators in the data created substantive codes. One of the supervisors (Pergert) commented on emerging categories and assisted with the conceptualization of the participants' main concern and core category. During an international GT seminar, there

were further discussions about the main concern and related theoretical sampling. After the main concern was discovered it was decided that the theoretical sample should consist of administrators at the SIA, to find out how they dealt with the main concern, ‘maintaining professional integrity’, since they belonged to the other main authority responsible for administering and making decisions about access to PA. In parallel with the coding process, memos were written and put aside. In this study theoretical coding resulted in strategies for resolving the participants’ main concern.

ETHICAL CONSIDERATIONS

This project was approved by the regional ethical review board in Stockholm (201/671-31/5). Due to the changes in inclusion criteria and data collection methods in both of the studies, three additional ethical approvals were sought and granted (2013/7-32; 2015-12-16; 2017-786-32). In the first study, which involved adolescents and children, oral information was provided to contact persons at schools, habilitation centres and user organizations. The contact persons usually sent this information to families who had children or adolescents who matched the inclusion criteria. Written information was given to children and adolescents and if the children were under the age of 15, written information was also provided to their parents. For children under 15 years of age consent was sought from both the children and their parents. Children and parents were informed that the participating children and adolescents had the right to change their mind and could decline to participate without having to explain why. Furthermore, the consent of the children and adolescents was treated as an ongoing process.

Before the individual interviews began it was decided that every adolescent should be interviewed on at least two separate occasions, and that if somebody needed more time to express their opinions they would be provided with an opportunity to meet on more occasions. Furthermore, considerations were made with regard to individual circumstances, needs and wishes. If an adolescent showed signs of being tired or reluctant to answer a specific question, they were not pressured to continue. With regard to time and space, the researcher tried to be responsive to the requests of the adolescent. Most of the time, adolescents chose the venue for the interview. It was often convenient to meet at school during longer breaks or after the school day had ended. Most of the adolescents wanted to be interviewed without their assistants present. When assistants were present in the room, they were often asked to stay in the background. If they were called on it was concerning practical matters: adjusting the adolescent’s position, taking out equipment, and assisting with snacks or a drink. Only one of the adolescents was assisted in a communicative situation. In that situation the assisting person was informed that she should only support the adolescent and not engage in conversation with her own opinions, since she was not the one being interviewed. Furthermore, the assisting person was a class aid, which meant that her role was to assist several students in the class, which made her role and function different from that of a PA. Nonetheless, it is difficult to say whether her presence restricted the participant in her ability to speak freely. She chose this specific class aid to assist her

during the interview, which indicates that she trusted her to understand the context and conditions associated with her presence. On another occasion an interview had to be rescheduled because the adolescent did not wish to have his PA present in the room when talking about his experiences of living with assistance. In that specific situation, the battery in his communicative aid had discharged and we discovered that it was difficult to have a nuanced conversation without access to the technical aid.

Ethical awareness in relation to research with young people

Qualitative research usually involves a power asymmetry. This power asymmetry becomes even more important to consider in relation to research with children and young people. One important aspect to consider concerns children's informed consent, or whether they understand what they have agreed to be involved in. To address this concern, all of the interviews began with a brief explanation of the overall purpose of the research project, combined with an account of how the interview would proceed and what would happen afterwards with the audio files. All of the children and young people were encouraged to interrupt me if they did not understand a specific question, and tell me if they did not want to answer some of the questions or if they needed to take a short break. During the interviews some of the young people wanted to talk about issues that were not directly linked to PA but still had a great impact on their everyday life, such as the transportation service, the school system and experiences of bullying. Even though these descriptions were not included in the analyses, I considered it important to pay attention and listen to what they wanted to share with me. I am deeply thankful to all of the young people for trusting me with their stories, especially since many of them talked about sensitive issues concerning self-esteem, loneliness and being subjected to prejudicial treatment. In relation to that it became important to monitor the body language of the participants, and to ask question such as: Are you ok to keep on talking about this? or Do you want to change the subject?; or Do you need a break?

During the interviews some of the young people made critical remarks about qualitative aspects of PA. Even though they wanted to share these experiences, they felt afraid to criticize PA since they could not imagine a better alternative. A few of the young people asked about my background and wondered why I had chosen to do research about PA. On those occasions I tried to answer in an honest and personal way, which might have affected the information that they chose to share with me.

Some of the young people who participated in this research project stated that they wanted their opinions to make a difference, which I consider to be a reasonable demand. However, this is not always easy to achieve since the researcher does not have full control over how the research is valued and interpreted either inside or outside the scientific community. During the course of this research process, the assistance reform has been challenged. This fact underlines the importance of questioning the role of researchers and research. Sweden does not have the same tradition as the UK and the USA of combining activism with

research. Nonetheless, we have to ask when it is no longer legitimate to maintain a neutral position

VALIDITY AND GENERALIZABILITY

The quality of research is often judged by its validity or generalizability. Validity is the technical term that refers to credibility of the research. The researcher's efforts to ensure validity take different shapes according to the type of data on which the research is based (Silverman, 2011). Validity in qualitative research should not be linked to 'truth' or value. Rather, it should be judged by different criteria. Koch (1994) refers to the need to leave a 'decision trail', which makes the research process open for the readers to follow and verify the findings. According to Koch, 'trustworthiness (rigour) of a study may be established if the reader is able to audit the events, influences and actions of the researcher' (ibid, 1994: 91).

In this thesis, the data consist of individual interviews and focus group interviews. The dialogic aspect of the interviews raises questions about validity and 'claims of truth'. In this regard I consider the interviews to be mutually created in the sense that they are contextually produced, designed for a particular purpose and embedded in a Swedish, (western European) context.

The qualitative research interviews and other human research activities were also analysed as practices that constitute subjects – during the interview, in the understanding of consent to participate in the research, and through the production of the interview transcript' (Alldred and Gillies, 2002:155).

However concerns about objectivity are not considered problematic since our research is not concerned with 'objective' truth claims, as we are interested in the subjective experience of the participants. Rather, the limitation with interviews is related to trust building between participants and researcher. Although field observations were not a part of the actual analysis, they helped to sensitize me to how data collection could be performed. Time was of crucial importance and being able to 'hang around' and have informal conversations with other young people and staff was very valuable for creating more relaxed relations with the young people who were being interviewed.

In judging the credibility of a grounded theory (papers I and IV), one should use the four criteria of fit, workability, relevance and modifiability (Glaser, 1978; Glaser, 1998). Fit refers to validity, since emerging theory must relate to the data; adequately articulating what is happening in the empirical situation. In Paper I this was in relation to what happens when adolescents talk about their experiences of PA. In Paper IV the topic was social workers' experiences of discretion in relation to disabled children's and adolescents' applications for LSS interventions. Workability means that the theory should be able to explain how the participants' main concern can be resolved, which in both studies resulted in different strategies. When the research deals with what the participants consider their main concern, which is grounded in the data, emerging theory is important and relevant.

Last but not least, when compared with new data, the theory must be modifiable. Although GT is exploratory in its nature, generalization may be applicable since theoretical insights, such as the discovery of concepts like ‘maintaining professional integrity’ and ‘discovering distorted claims’, allow for projections to other contexts. Grounded theories can have different conceptual levels and generality: ‘The higher the level of conceptualization of the unit data, makes for a higher level of generalization’ (Glaser, 1998: 137).

In regard to the inductive content analysis performed in Paper II, reliability first and foremost referred to reproducibility and stability (Lederman, 1991), which indicated high intercoder reliability, meaning that the classification for content showed the same results when the text was coded by the author and the supervisors (Forinder and Pergert).

Validity in phenomenology (Giorgi, 1985) is discussed with reference to the researcher’s ability to make consistent pure descriptions that capture the essence of the phenomenon, in this case disabled children’s participation (Paper III). Overall, the reader should be able to understand and follow each step of the research process (transparency) and from that description be able to draw conclusions on whether the findings are valid, that is if a phenomenon is described in a recognizable manner (Fisker and Strandmark, 2007).

Problematizing my research position

My involvement in the user organization, Rörelsehindrade Barn och Ungdomar (RBU), has given me invaluable experience and joy in getting to know disabled children and adolescents, as well as their siblings and parents. RBU is a family organization whose target group is children, adolescents and young adults with different types of mobility impairments. As children grow older, the differences between children’s own perspectives and parents’ perspectives becomes more visible. This convinced me of the importance of listening to disabled children’s and young people’s own perspectives. The opportunity to research a topic that has been close to my heart has been both stimulating and challenging. Through qualitative research, it has become possible for me to depart from personal experience and look for patterns and experiences that can relate this individual experience into a wider societal perspective and theoretical understanding. Having personal experience can be both a strength and a weakness (Glaser, 1998). In the interview situation I believe that it has been an advantage that I am used to meeting and socializing with children and adolescents with disabilities, I am not afraid to ask questions, and I have the lived experience of having a family member who has access to PA. The downside with personal experience is that it may make me believe that I understand things that I actually do not understand, and that my previous knowledge might affect the type of questions posed. However, being aware of those pitfalls made me chose GT as an analytical tool in the first article, which concerned the everyday life experiences of adolescents. It has also been helpful to have access to an interdisciplinary group of supervisors. I believe that the combination of medical and social perspectives has made us scrutinize our ‘taken for granted knowledge’, which has contributed to the discussions about methodology, ethics, data collection and analysis. The focus group interviews with the social workers were

difficult to perform and sometimes it was a deliberate choice for me not to moderate the sessions. In those interviews I was reminded how value laden social work practice is, and sometimes it was difficult for me to empathize with what can be perceived as the social workers' 'indulgence' of the adverse consequences that have flowed from decisions about PA. However, this particular emotional response could be handled by using GT and phenomenology. In the GT analysis it was the focus on the participants' main concern that allowed me to proceed with discovering the emerging categories instead of being preoccupied with my own values. In the third study a phenomenological approach made me more sensitized to the social workers' experiences. This, however, was still the hardest paper to write.

Reflections about the research process

During the initial study, the emphasis was supposed to be on children's and adolescents' experiences of PA in their everyday lives. Before the project was initiated contacts had been established with user organizations, as well as staff at schools and habilitation centres who had agreed to provide contacts with disabled children and adolescents, as well as their parents. At that point, I thought that it would be easy to get in contact with young children who were interested in talking about their experiences of PA. It was surprising and frustrating to realize how difficult it was to involve young children in the project. As time passed by there was a joint decision within the research group to stop looking for young children to interview and focus instead on the informants who had agreed to participate – adolescents attending upper secondary school.

While doing the interviews I realized that many of these young people wanted to share their experiences of meetings with professionals who had been in charge of the assessment that decided whether they were entitled to assistance allowance. During our conversations they described assessments that resembled a time study, in which their daily life was classified in terms of activities, sorted into 'neat boxes' with estimated expenditure of time added to every moment. This was the first time I had been given detailed examples of how the highly structured assessment tool (behovsbedömningsverktyget) was perceived by the people in need of support. The adolescents' descriptions of how they experienced these meetings made a profound impact on me since it so clearly exposed their resentment and powerlessness towards the bureaucratic process which transformed them into welfare objects. It became a stark reminder that certain elements of individual experience represent a structural pattern that reveals the inherent tension between balancing the provision of support and the need for control, by transforming a life into pieces and individual experience into categories. This contributes to a questioning of the structural patterns of power in which these categories are constructed and maintained.

In 2013–2014, when I was in contact with representatives from user organizations, I recall that some of the representatives expressed concerns that it would be difficult for me to engage with young people to talk about PA. One of the representatives said that people had expressed fears about losing access to PA, and she thought that they would probably be

reluctant to talk about PA with a researcher. Concerns about me being able to recruit participants were also expressed by the Principal at one of the schools. She suspected that severely disabled adolescents would feel restricted when talking about PA since they were so dependent on their assistants for support. Neither of these contacts resulted in any participants. However, it reveals the difficulty in using contact persons as ‘gate-openers’ in order to gain access to participants. Although I was clear about informing them that they should not make any selection of ‘suitable’ or ‘likely’ informants, I could not be sure how information was distributed. This also raises ethical concerns about power issues, which voices are heard and what stories can be told in certain contexts. Whenever it was possible I went out to schools and user organizations and held an information meeting where everyone who was interested was invited to take part. Information letters about the study were available so that adolescents, parents or school staff could choose whether they wanted to contact me for further information or to express an interest in participating.

SUMMARY OF THE ARTICLES

This chapter provides a brief summary of the key findings of the four papers, a synthesis of the results and a discussion of the combined findings. For a complete and separate presentation of the results, all four papers are attached at the end of the thesis.

ASSISTED NORMALITY (I)

The participants in the first paper were young disabled people attending upper secondary school, all of whom had access to PA to varying degrees. All of them had had PA for at least six months and most of them had both external assistants and family members working as assistants.

In the first paper, *achieving normality* emerged as the adolescents' main concern. For those adolescents normality did not mean being normalized but being able to do normal things, i.e., that is being able to have the same opportunities to participate in society as their non-disabled peers. The adolescents tried to resolve this by means of *assisted normality*, which was achieved by the utilization of PA. Assisted normality included different enabling strategies used in their interactions with their PAs, but it also underlined the barriers faced by the young people which access to PA could not overcome. The enabling strategies were divided into three main categories: tool and/ or professional friend, normalizing cooperation and situational placement, all of which are mutually reinforcing. Barriers were divided into four categories: lack of acceptance, different expectations, dual role of parenting and assisting, and forced dependency.

Relations between the adolescents and their assistants ranged from being of a functional nature, as a tool to being a professional friend. The level of emotional engagement varied depending on time, individual preferences, previous experiences and different contexts. In order to achieve normalizing cooperation, adolescents tried to find the best ways to cooperate with the individual assistant, which included sensitizing, routinizing and communicating. The situational placement was connected with spatiality. Some adolescents perceived difficulties in handling the duality of having a parent as a PA, and for those with the most severe disabilities the impairment sometimes forced them to accept the presence of an assistant to a degree with which they were not content. The adolescents wanted to be able to regulate the physical proximity of their assistants, by which they experienced control, by knowing that the assistant was available if and when the need for support arose. However, the presence of the PA could not compensate for disabling barriers such as lack of acceptance from oneself and others. It could also entail different expectations of what the relationship between the PA and adolescent should be. Forced dependency underlined the complexity of self-determination since people are disabled by both their bodies and society.

Conclusions

The findings indicate that living with PA is an individual process that must be adapted to the unique relations that develop between the assistance user and the PA.

Access to PA is important to enable social interaction in everyday life but if the intention of control and self-determination is to be fulfilled, the assistants need to be properly sensitized. If not, the assistance user risks becoming an ‘object of care’.

RELUCTANT PARTICIPATION (II)

In Paper II the focus was on the decision-making process in which the adolescents were asked to be involved. The findings of the second paper revealed an overall theme of reluctant participation. The adolescents were reluctant to participate in the assessment which resulted in the overall theme reluctant participation in meetings. A summary text on the overall theme and categories is presented below. Table 2 provides an overview of the analysis in study II.

Table 4. *Overview of the categories in the theme ‘Reluctant participation in meetings’ in study II.*

Overall theme	Categories	Subcategories
Reluctant participation in meetings	Taking part	Presenting their worst self Giving requested information Using support Raising their voices
	Taking part by proxy	Not being involved Being involved

Reluctance to participate in meetings was explained by the adolescents’ perceived lack of influence over the structure and content of the meeting. Two main approaches were detected: *taking part* and *taking part by proxy*.

Taking part

Taking part concerned those adolescents who attended the meetings in which the social needs assessment took place. During these meetings the adolescents participated to varying degrees and used different strategies to increase their chances of gaining access to PA. The adolescents who took part in the meetings adapted their self-presentation to fit with the social workers’ requirements by *presenting their worst self*, *providing the information requested*, *using support* and *raising their voices*. Presenting their ‘worst self’, involved adolescents downplaying their skills and competencies and promoting a disabled identity that emphasized the consequences of their impairments. To ensure that they would be given enough assistance they would base descriptions on how things were on ‘the worst day’. Providing the information requested refers to their attempts to provide the case workers with as detailed an answer to their questions as possible. For some of the adolescents it was important to have access to support from parents or PAs during the meetings. Only a few adolescents had the

courage and confidence to raise their voices, which could be to talk about PA from their perspective even if the case workers had not asked them to.

Taking part by proxy

Taking part by proxy meant being represented by parents or legal advisers employed by assistance companies. The adolescents who choose to participate by proxy were either being involved or not being involved. The reasons for letting somebody else represent them were: (a) previous negative experiences of meetings which had resulted in a being denied PA or being granted fewer hours; (b) meetings were perceived as boring; or (c) that parents thought that it would difficult for the adolescents to participate in the meetings. Being involved implied either joint preparations before the meetings or discussions afterwards.

Conclusions

A significant part of the social needs assessment is grounded in a medical model of disability.

This medicalization of disability is not compatible with how adolescents wish to participate in their social needs assessment. Participation is therefore reduced to tokenism

ELUSIVE PARTICIPATION (III)

In the third paper the purpose was to describe the lived experience of the social workers who were mandated to promote and implement children's participation in the social investigation that took place during meetings. The social workers tried to capture the meaning of children's participation: how it should be accomplished, when it was accomplished and what it should result in. The essence of children's participation was *elusive participation*, which comprised a *discrepancy between policy and practice*; *the judgment of children's abilities*; *norms and perceptions of normality*; and *conflicting perspectives and needs*.

Discrepancy between practice and policy

The discrepancy became visible both in relation to the legal and bureaucratic aspects of the social investigation, and in relation to senior managers and local politicians who embraced children's participation at the rhetorical level but did not provide adequate resources to enable its implementation in practice. Children's participation was perceived to be complicated in relation to the individual child or proxy representing the child. Some of the social workers questioned whether participation was even compatible with discretion since their focus was on carrying out a social investigation in which they had to implement the law and the administrative procedures involved in making a proper investigation that would be the basis for decision making. Other social workers thought that even though participation was difficult to achieve they should make an effort to involve children to the extent that they thought possible. However, the kind of participation children were offered, to a large extent, depended on the social worker's judgement of their abilities.

Judgement of children's abilities

The social workers thought that it was difficult to judge children's abilities and age was often equated with maturity. In general terms, children's participation increased as they got older, but the degree of children's participation and their ability to influence decisions shifted depending on age and type of disability. The combined effect of a young age, intellectual disability and the need for alternative augmentative communication (AAC) decreased a child's ability to be an active participant. Social workers had less confidence in the child's ability to make an informed decision if the child was young, lacked access to verbal speech or had been diagnosed with an intellectual disability. Children's involvement ranged from taking part in meetings to having influence over decisions.

Norms and perceptions of normality

Norms and perceptions of normality played a part in decision making, since social as well as legal norms had an influence over the decisions that the social workers considered they were able to make. Some of the social workers found it difficult to translate the intentions of the law into decisions, for instance it is far from self-evident what to 'live like others' means. When making decisions some of the social workers told how they compared the needs of disabled children with same age children following 'normal development'. By making comparisons they thought it more likely that fair decisions would be made regarding what should be considered reasonable demands.

Conflicting perspectives and needs

The social workers described how it was difficult to handle the conflicting perspectives and needs that arose between children and their parents due to their different perceptions of need for support. When children were under the age of 10 the social workers were more inclined to listen to parents, but as children got older they found it difficult to ignore a child's own perspectives and by the age of 15 the child's perspective overrode the parents' perspectives, provided that she or he was able to make an informed decision.

Conclusions

In judging the individual child's abilities it was the social workers who had interpretative precedence.

MAINTAINING PROFESSIONAL INTEGRITY (IV)

In the fourth paper, *Maintaining professional integrity*, the subject was the assessment process for PA. Compromised professional integrity, which occurs under various shifting conditions, emerged as a major concern. The case workers attempted to resolve this using different approaches that served to maintain their professional integrity. Maintaining professional integrity was linked to the case workers' ability to perform a 'correct' social investigation. The case workers used various strategies in an attempt to maintain their

professional integrity: struggling with the division of responsibility, bureaucratizing, and justifying and protecting.

Struggling with the division of responsibility was linked to defining the limits of discretion, either by transferring responsibility to other authorities and stakeholders or adapting discretion to a top-down agenda set by other authorities. The latter implied following guidelines and making decisions consistent with precedent rulings in the Supreme Court. *Bureaucratizing* served to objectify decisions, which meant the use of structured assessment surveys, the application of precedent rulings, collecting medical certificates and ‘discovering distorted claims’. In the social investigations the case workers were dependent on knowledge from other fields and professions, in which precedent rulings to a large extent governed their decisions. The impact of media discourse on fraud and exaggerated assistance needs made them suspicious of the occurrence of distorted claims from parents and assistance companies. The case workers tried to justify their role and obligations by blaming the adverse consequences of organizational structures that compelled them to make assessments in accordance with current praxis.

Conclusions

The results indicate that social work practice has undergone a shift from occupational professionalism to organizational professionalism (Evetts, 2010), which leaves social workers without adequate tools to protect the assistance users’ interests. Social workers must take responsibility for challenging structures at the societal level and take ethical action on behalf of service users.

OVERALL ANALYSIS AND DISCUSSION

The overall aim of the thesis was to explore adolescents' experiences of living with PA in their everyday lives, which was done in the first paper (*Assisted Normality*), and to explore the experiences of participation in the meetings which precede decision making about possible access to PA and other LSS interventions, which took place in Paper II (*Reluctant Participation*), III (*Elusive Participation*) and IV (*Maintaining professional integrity*). The second paper was written from the perspective of the adolescents, while the third and fourth were written from the perspective of the professionals.

The common ground for the papers was the ongoing process of handling different aspects of PA. From the assistance users' perspectives PA concerned both a negotiation with case workers to gain access and living with PA in everyday life – the actual implementation of the intervention. For case workers it meant assessing and investigating children and adolescents' right to obtain PA – the implementation of policy and legislation.

NORMALITY AS A GUIDING PRINCIPLE

Both in the social investigation and in relation to living with assistance in everyday life, normality appeared to be a concept that both adolescents and social workers related to. The findings in paper I indicated that it was important for the adolescents to have access to what they considered an ordinary or 'normal life' (paper I). This was achieved through 'assisted normality', that is having access to a personal assistant who could provide the support needed to perform activities that required different kinds and degrees of assistance. In this sense, achieving normality corresponded to the adolescents being able to do what they saw as important, to the same extent as their non-disabled peers.

For many adolescents, 'the disabled identity' did not define who they were. Instead, they saw themselves as young women and men with the same aspirations as their non-disabled peers. However, this need to assert that their aspirations were similar to those of their non-disabled peers is telling since it speaks to the general assumption that to be disabled is to be different (Slater, 2013).

Access to normality by displaying disability

During the assessment meetings all of the adolescents and many of the social workers expressed discomfort about handling the standardized assessment tools. The adolescents were offended by having to answer questions about how they spent their time and give intimate details about their need for support in relation to basic needs such as taking a shower and going to the toilet. The social workers felt equally uncomfortable about having to ask such questions. They felt that they were being intrusive when they had to ask detailed questions about personal hygiene issues. To manage the social needs assessment both the adolescents and the social workers developed different types of strategies.

What seemed to motivate the adolescents to answer these questions was an awareness of what was at stake – being granted access to PA or not. In order to secure access to what they

perceived as the correct amount of support, many of them exaggerated their needs by presenting their ‘worst self’. From their perspective, ‘exaggerating’ the need for support was not done to get access to more support than they needed, but to ensure that they had enough assistance hours to cover needs that exceeded basic care needs. The adolescents gained access to ‘normality’ by ‘displaying disability’. This paradoxical experience implies that access to a redistribution of material rights (in this case assistance allowance) is achieved by performing a certain kind of disabled identity (McRuer, 2006) that is in accordance with the administrative/legislative definition of what it means to be disabled. By performing culturally accepted modes of ‘being disabled’ (Butler, 1993) their performance served to underline the functional limitations – disability – that could be related to their in/capability to attend to basic care needs. This kind of ‘forced performance’ of a specific disabled identity underlines the binary division between being able bodied and being disabled (McRuer, 2006), in which the focus is on their ‘shortcomings’ in regard to functionality rather on what they want to achieve in terms of independence by exertion of control through PA.

Discretion and the reproduction of disability

As Weinberg (2016) suggests, one aspect of professionals’ power and authority is to determine what constitutes a problem. Judgment is intrinsic to the positioning of social workers (Lipsky, 1980/2010; Stone, 1984). It is a necessary component of attempts to facilitate change, but it carries with it disciplinary and dominating aspects (Weinberg, 2016). As representatives of the welfare system, the municipal social workers perceived that it was their main responsibility to make a factual social investigation that should result in correct decisions about who is entitled to support (paper III and IV). By doing so, the social workers had to place people into appropriate administrative categories (Lipsky, 1980/2010; Stone, 1984). In this context, the adolescents had to be categorized as disabled, fulfilling the eligibility criteria pertaining to the target group entitled to apply for LSS interventions and having needs that corresponded to the specific requirements for obtaining PA. When performing the social investigation, the social workers put much effort into making ‘objective assessments’, which meant investigating the type and amount of support considered reasonable in relation to the applied amount of support (Stone, 1984). In the case of applications for PA (paper IV) this necessitated the use of structured assessment surveys, collecting medical certificates and being updated on and informed about precedent rulings.

Papers II, III and IV dealt with the bureaucratic process of transforming ‘life world experiences’ into administrative categories, and the results raise questions about the reproduction of normality. The strong focus on governance through normalization procedures puts an emphasis on norms (Baier, 2013). Making decisions grounded in the LSS legislation is not just a matter of organization and governance, but also a question of the values that are expressed in the meetings between the individuals in need of social support and the social workers who make decisions about access to support. As Habermas (1987) points out, lifeworlds (not systems) provide the values which underpin the internal aspect of norms. This means that normativity can have sources other than social norms, and in fact normativity per

se can be a source of norms. To maintain professional integrity (paper IV) the social workers developed different strategies in which they tried to achieve legitimacy for their actions. One strategy (bureaucratization) included seeking confirmation for their decisions by referring to legal norms, such as precedent rulings. However, when their competence regarding legal literacy was insufficient their decisions were grounded in social norms, which were discussed in the workplace among the group of social workers. Sometimes social norms could be traced back to the social workers' personal situation or were situated in a wider cultural context in which disabled children were compared with reference to what their non-disabled peers should be able to do without the support and supervision of adults.

In its current form the social investigation emphasizes functional abilities in which 'normality' is used as a reference point when social workers decide what should be considered legitimate needs in relation to assistance allowance or other support interventions. In the context of the social needs assessment, abled-bodied children's normal development was utilized as a yardstick, separating the functionally impaired children from their able-bodied peers. At the same time, this procedure served to separate 'normal parental' responsibility from the extended parental responsibility that could be referred to as extra support provided due to the child's disability. In this case medical normality was being utilized to create standards for normative normality.

Although normalization is not a concept that is found in legislation it seems to prevail in practice since normality is used as a comparative measurement when judging what it means 'to live like others'. However, normality is difficult to grasp because it is inherent in Western culture. This could probably be explained by different perceptions of independence, where professionals have a tendency to define independence as the capacity to perform daily living activities without the support of another person (Lindqvist, 2012). Another way of defining independence is to view it as a mind-process, where independence is achieved by taking control over one's life situation (ibid, 2012).

Normality is a concept that permeates social work practice (Weinberg, 2016). Previous research has shown that social workers rely on moral evaluations to determine acceptable behaviour and responsibility (Chu et.al, 2009). The results from studies III and IV indicate that social norms and the concept of normality were utilized and interpreted by social workers to motivate decisions in the social investigation. When references to 'normal development' occurred in precedent rulings, the concept of normality was not questioned. But when parents asked for interventions that did not fit with the social workers perceptions of what was in the best interests of the child, parents could be blamed for trying to normalize their children. In this sense, it becomes important to discuss interpretative prerogative and question how professionals respond to difference. Valuing difference can be difficult. As Minow suggests, 'the stigma of difference may be created both by ignoring and by focusing on it' (cited in Weinberg, 2016: 132). Instead of impartial reason, social workers could use broad empathy (ibid, 2016). In order to maintain equity and to respond to difference ethically, disabled

children and youth may require differential responses, which makes impartial reason inadequate.

SOCIAL WORK AND SOCIAL JUSTICE

A recent study of a Swedish disability activist blog post (Sepulchre, 2018) shed light on the injustices faced by disabled people, ‘in which the blogposts share a common claim for full citizenship understood in terms of social justice’ (ibid: 555). Without an elaborate position on human agency and social justice, it is doubtful that social work can promote the models of empowerment that are necessary in a world where social exclusion exists (Lister, 1998). In addition, as a result of the inbuilt paradoxes in social work practice (Weinberg, 2016), ‘Social workers are caught between an ethic that informs social work as a *vehicle of social justice* dedicated to the welfare and self-realization of human beings, and a bureaucratic regime where professionals are responsible for social regulation and the ongoing discipline of others’ (Weinberg, 2016).

The need for redistribution and recognition

Despite having access to PA (redistribution) some of the adolescents told of their experiences of discriminatory practices in their everyday life (paper I). One of the young men told how the parents of his non-disabled friends had opinions about the role and obligations of his assistants, and the kind of relationship that should exist between him and his assistants. Another adolescent had experienced people staring at him, asking intrusive questions about his disability, and/ or uttering normative statements about his drinking habits.

Adolescents also described situations of ‘forced dependency’ in which adolescents with severe medical conditions due to the limitations of their bodies had to accept the presence of a PA. These types of experiences indicate that the redistribution of material rights is not sufficient to come to terms with disabling barriers in society (Fraser, 1997). Attention must also be given to cultural recognition and the socio-emotional aspects connected with impairment effects (Thomas, 1999). In the absence of access to redistribution and recognition, parity of participatory (ibid, 1999) still has to be achieved.

Restricted participation

Overall the results from papers III and IV underline the difficulties involved in the decision-making process in which many of the social workers experienced pressures from other stakeholders (such as habilitation and school staff) and from people in their own organizations. The goals of self-determination, inclusion and participation are proclaimed in policy documents and LSS legislation, while at the same time the social workers/ street-level bureaucrats (Lipsky, 1980/2010) found it difficult to translate these abstract goals into practice. This became obvious in relation to the accomplishment of children’s participation in meetings regarding various LSS interventions (paper III). Despite the existence of legal requirements and policy documents, the social workers were not able to provide all disabled children with opportunities to participate. Many of the social workers experienced a

discrepancy between practice and theory, since they were often told by their managers to prioritize children's participation but in reality had limited time and resources to work in accordance with such a practice. They also thought it was hard to determine whether children's participation was a goal for future fulfillment (to be enacted in relation to obtained interventions) or was supposed to be achieved during the assessment meetings in which children and parents were asked to participate. In relation to the social needs assessment, the social workers thought that there was a big difference between assessing the right to PA and assessing the right to other support interventions. In general they found it easier to engage children in meetings about support interventions other than PA (paper III). Furthermore, they found it easier to involve older children with mobility impairments and access to verbal communication. The opinions of young children, children without access to verbal speech and children with intellectual disabilities were often neglected in the actual decision making (paper III).

When it came to meetings regarding PA (paper II), participation was often just tokenistic, (Hart, 1992). Although adolescents were asked to attend they had no influence over the structure and content of the meetings. The participant structure and the conversation gave the social workers the opportunity to ask questions, which gave them the ability to define topics, while the adolescents who answered the questions had limited opportunities to take action. The use of structured assessment questionnaires (paper II, IV) does not allow for an in-depth understanding of participants' perspectives, since that would require another type of questioning with more space for young people to speak freely. In an institutional context, participation is reduced to the obligation to provide the information requested in response to questions posed by social workers (paper II). In this way, dialogue is dictated by the needs of the organization where answers are filtered and risk being taken into account only when they fit in with the thought or performance of the social worker who posed the question (Fredin, 1993).

Papers I, II and IV indicate that much attention during the assessment meetings was given to 'restrictions of activities', which only focuses on a limited part of the WHO's disability definition. By making a division between basic needs and other needs, people who do not reach the level of 20 hours of basic needs do not get access to other services, which are usually provided for those activities that the adolescents (paper I) associated with participation, such as being able to do spare-time activities, going to the cinema or theatre, meeting friends, and so on.

Paradoxical spaces in social work practice

In meetings with children, adolescents, their family members and/or proxies, social workers are assigned the role of 'the state's extended arm'. Being professional demands that they perform the social investigation, which includes the ability to interpret legislation and to transform policy goals, such as participation, into practice. To do so, they must be able to navigate between legal and social norms, in which politics mediate society's norms in welfare legislation (Baie, 2013; Åström, 2013). Findings from a report concerned with multi-level

governance in Iceland indicated that the provision of disability services, 'are constantly in a state of flux; eligibility requirements change, responsibilities are shifted, organizations are merged, renamed or reformed' (Traustasdóttir and Rice, 2009:2).

The legal requirement for children's participation emphasizes the social work paradox of being both supportive and controlling. On the one hand, the social workers have to work to build trust, making parents and children confident about revealing information about themselves. On the other hand they must make assessments that focus on children's individual failures, which distracts attention from external conditions (Weinberg, 2016). Despite the intention to be non-judgmental, social workers are mandated to engage in divisive practices and in this process children and young people are constructed as disabled or able-bodied; and deserving or undeserving (ibid: 2106). Determining eligibility for support interventions according to the LSS Act is an ongoing enactment of judgements required by social workers in order to meet their obligations to society at large (ibid, 2016).

The distributive dilemma

In Sweden assistance allowance is applied for and accessed through administrators at the SIA and social workers at the local municipalities. Either way the process of applying for support follows a certain course. In this sense the disabled children, their parents and the professionals have their 'roles to play' in the social investigation. In fact, a considerable part of accessing PA or services is problematic since the rules and regulations provide only a measure of guidance in determining eligibility (Lipsky, 1980/2010; Stone, 1984). One possible 'explanation' for this could be the fact that the categories into which clients fit are not fixed, which is problematized by Stone (1984) in relation to the disability category because 'no single condition of "disability" is universally recognized, and because physical and mental incapacity are conditions that can be feigned for secondary gain. Hence, the concept of disability has always been based on a perceived need to detect deception' (ibid: 23).

This could serve as an explanation for the social workers' zeal for 'discovering distorted claims' and by doing so providing support only to those who are 'truly disabled'. In relation to the exercise of discretion in the decision-making process, the need for legitimate decisions was often referred to as an important qualitative indicator by case workers (Paper IV). However, Peczenik (1995) states that substantive legal certainty entails more than formal legal certainty, as it is the result of a balance between formal legal certainty in terms of predictability, while at the same time taking account of ethical consequences. Decisions made according to LSS legislation require good knowledge of the legislator's intentions and values. However, in the practical application of social law legislation (law in action) there seem to be a confusion between legal norms and other norms that may affect local government and its resources (Erlandsson, 2014). Erlandsson's studies (ibid., 2014) of three different arenas that make decisions using LSS legislation – the municipalities, the SIA and regional administrative courts – found that social workers lacked knowledge of legal principles and

procedural rules that are important for legal certainty, and that legal norms are replaced by internal policy documents.

Another plausible explanation for the social workers attempts to expose distorted claims (paper IV) is the impact of the recurrent media discourse on the occurrence of fraud and cheating, with headlines telling of individuals who pretend to be disabled in order to receive money. Altermark (2017) suggest that the construction of PA as a ‘cost problem’ has been central to justifying general cutbacks which affect assistance users, a phenomenon that has already occurred in the UK (Wood, 2012; Goodley, et al., 2014).

This ‘need to prove disability’ could also explain the adolescents’ experiences of being successful in convincing the social workers (paper II), that they are ‘disabled enough’ since that is the prerequisite for access to support.

Assessing the right to interventions is done by comparing disabled children’s development with non-disabled children’s age-based development (papers III, IV). This becomes problematic when child development discourses use age-based stages and therefore fail to account for disabled children’s ‘normal’ development (Oliver & Sapey, 1999). In terms of participation this raises concerns about what kind of participation children and adolescents are able to achieve within these structures.

Figure 1. *The interconnectedness between the main findings of papers II, III and IV*

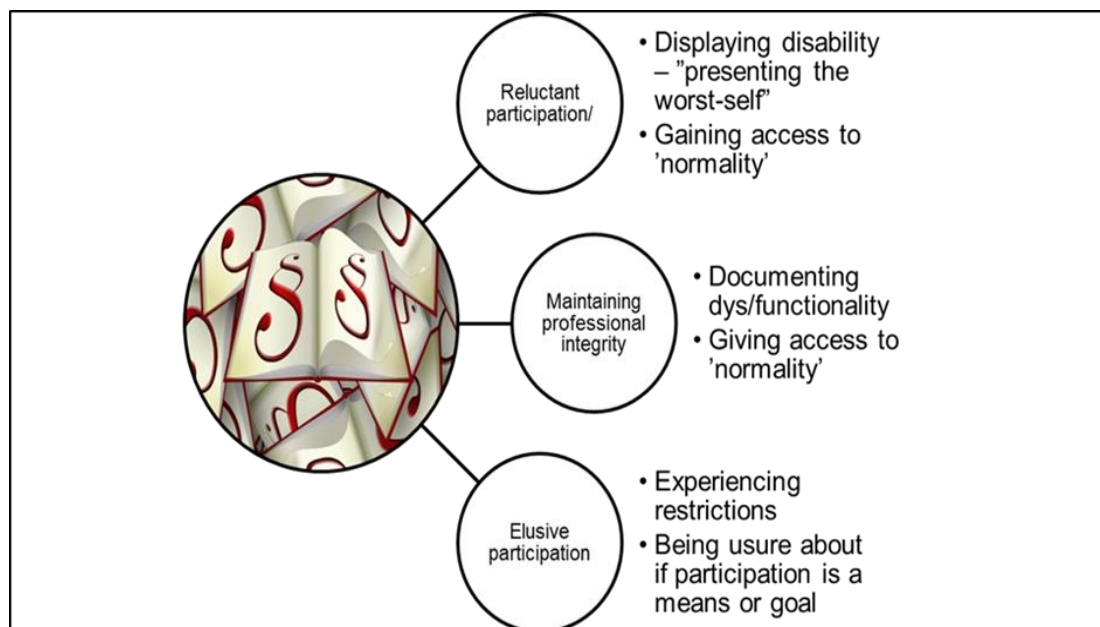
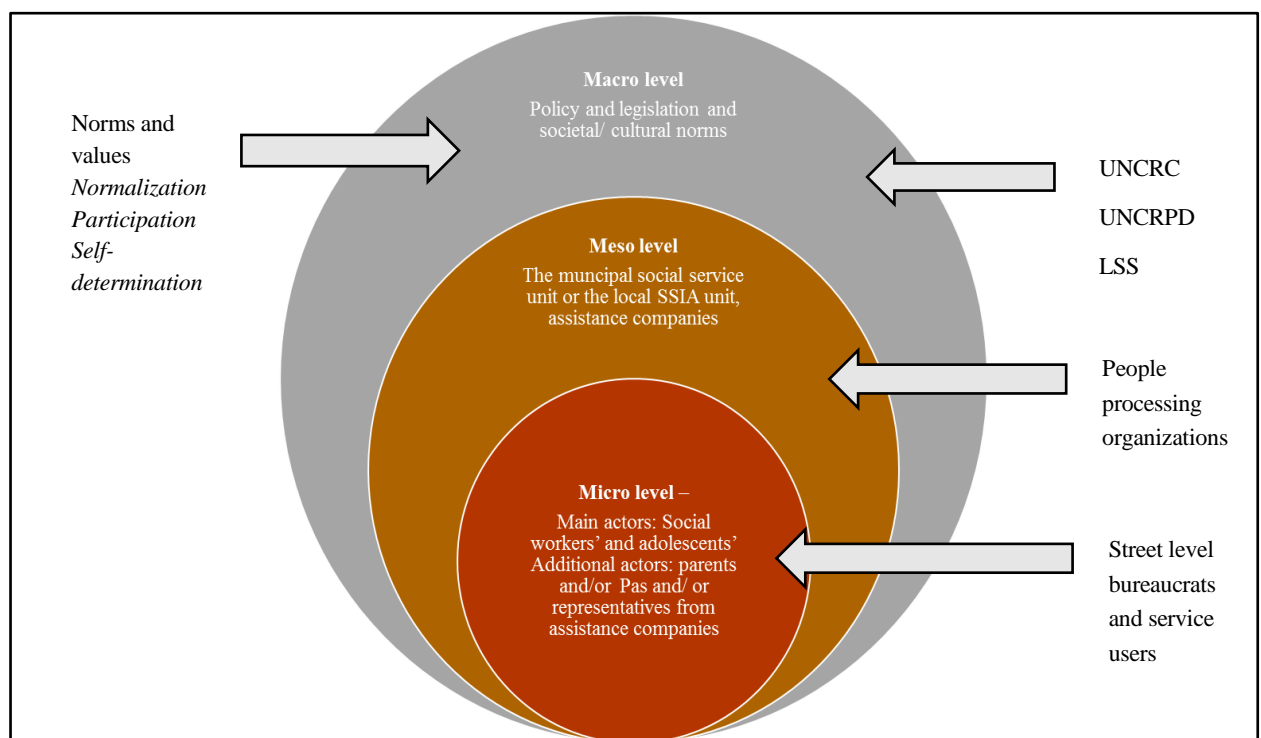


Figure 1. shows that neither the applicants nor the social workers perceived themselves as ‘game changers’. Instead, they adapted their actions to the current ‘*rules of the game*’ by finding strategies for handling the social investigation process (paper II, III and IV). Agency

was performed within existing structures, in which roles and relations at the individual level were affected by structures at the organizational level. From the perspective of the social workers, agency was restricted by other actors and authorities who either shared responsibility for providing the intervention or whose expertise was needed in order to perform the social investigation (paper IV). In addition, both the individual and the organizational levels are influenced by policies made at community level, which is further clarified in figure 6.2.

Figure 2. *The relation between different structural levels in the decision-making process*



Professionalism in social work

Professionalism is a contested concept in social work (Weinberg, 2016; Evetts, 2010). In the social investigation that precedes possible access to PA the social workers (paper IV) had limited opportunities to exercise discretion, since they had fewer possibilities to make professional judgments and determinations from case to case. Instead of being encouraged to apply ethically grounded judgment and knowledge, and proven experience (Svensson, 2010), they had to use structured assessment tools and local guidelines that did not align with their values grounded in occupational professionalism (Evetts, 2009). Studies on decisions on municipal elderly care (Dunér and Nordström, 2006) showed that social workers were extremely loyal to the municipality's policy documents and guidelines, which resulted in the applicants getting not what they needed, but what the organization could offer.

Furthermore, the social workers had to rely on the expertise of other professional fields. In the social investigation, medical certificates and precedent rulings were used as evidence in the social needs assessment. In relation to the changes in the assessment criteria and the impact of precedent rulings, the social workers could no longer guarantee that children with severe physical impairments would be granted assistance hours to cover their needs. As a response to these adverse consequences, many of the social workers tried either to transfer responsibility for the decision to other authorities or to justify their behaviour by blaming other stakeholders for submitting distorted claims, which necessitated an increased need for control.

However, some of the social workers experienced *ethical stress* (Jameton, 1984) when they were unable to consolidate discretion with ethical values. An important value in social work is social justice. This holds a central place in social work internationally (Weinberg, 2016; Fenton, 2016), but is not as prominent in Sweden – the reason being that fair-mindedness is viewed as a norm that should routinely impact on legislation. Justice then becomes first and foremost a political issue (SSR, 2015). In the light of current changes regarding the possibility of gaining access to PA, such a claim might be questioned. Houston (2001) argues that ‘social work has retreated from a preoccupation with understanding causation and cure, to embrace instrumental responses governed by NPM’ (ibid: 853).

IMPLICATIONS FOR PRACTICE

The social investigation is not limited to a single event, but is an ongoing process that is repeated at regular intervals throughout a person’s life. This necessitates a holistic approach since the outcome of the decisions affect people’s chances of education and employment, and future opportunities for family formation. Moreover, the implementation of LSS legislation affects not only the individual child, but the entire family. Research has to make clear the potentially devastating effects of removing service provision from disabled children and their families (Slater, 2013). Thus further longitudinal research should examine how the effects of current changes in service provision affect the entire family system, that is how a change in LSS service provision affects the long-term well-being of the entire family. How does denying access to support interventions affect gender equality, relations between parents and children, relations between disabled children and their siblings, and relations between disabled and non-disabled children?

For children with disabilities, the disability often becomes the centre of attention. This requires an increased awareness of how childhood disability is framed and presented in society at large. Even though children themselves do not consider difference as negative, what happens when, in order to gain access to support, they are continuously obliged to promote a disabled identity that is framed in terms of failure and shortcomings?

This makes it crucial to acknowledge young people with disabilities as social actors with views to share, and to enable them to reposition themselves, which includes ‘being able to be recognized not just through narratives of disability, but through their aged identities, gendered

identities, raced identities, and so on' (Slater, 2013: 190). Nonetheless, the repositioning of disabled youth must not remain in academia, as disability researchers we should support, enhance and spread these stories. Critical realism seeks to explain and critique social conditions. This means that critical realism should be of central relevance to social work: 'Its relevance lies in its capacity to offer a meta-theory to guide our analysis of core social concerns and processes occupying service-users, social work practitioners, managers, policy makers and politicians seeking to redefine social democracy' (Giddens, 1998).

CONCLUDING REMARKS AND REFLECTIONS

When the LSS Act was introduced in 1994 it was supposed to provide support and services for people with severe disabilities so that they could ‘live like others’ and participate in society. In February 2013 I enrolled as a part-time PhD student at the division for Social Work at Karolinska Institutet. During the course of my work on this dissertation, PA has gained increased attention in the national media. In media representations, the occurrence of ‘assistance fraud’ has been constructed and presented as a threat to the welfare state. Before 2008 there were no articles that discussed the concept assistance fraud, but between 2009 and 2015 there were over 500 published articles that could be related to alleged over-claiming of assistance allowance (Hall, 2015).

In February 2013, Cecilia Blanck, director of the user-cooperative, JAG, warned that the ongoing media debate regarding fraud and cheating would strike back at assistance users by framing them as ‘cheats’ (*Aftonbladet*, 2013). In 2014, the disability organization, FUB launched its ‘Application for a Regular Life’ campaign. The purpose of the campaign was to draw attention to the fact that there are citizens in society who are unable to participate in everyday activities that most of us take for granted – the possibility of watching a movie or a soccer game, or having a spontaneous meeting with a friend (FUB, 2014).

In October 2015 representatives of service user organizations claimed that Ann Marie Begler, the director of the SIA was exaggerating the occurrence of assistance fraud (SvD, 2015a, SvD, 2015b). A report by Altermark and Nilsson (2017) confirmed that the data on the size of assistance payments comes from a number of government investigations and reports, all of which use the Expert Elicitation Method (EEM), where people in state control can estimate the magnitude of incorrect payments. Furthermore, the results of the review indicated that the state investigations using EEM differ so strongly from scientific recommendations on how the method should be applied that its results, viewed from a scientific perspective, provide no meaningful knowledge about incorrect payments of PA (ibid, 2017).

Changes in the SIA’s application procedure and interpretation of case law began in 2009. However, they accelerated at the beginning of 2016 when the government formulated a directive to the SIA instructing the authority to help ‘break’ the increased cost of the number of hours of compensation for PA (Social Department, Regleringsbrev för budgetåret 2016 avseende Försäkringskassan). Following this directive the SIA began to apply legal precedent and judgments as assessment criteria in the social investigations that determine access to PA. The SIA has influenced these legal developments through its internal guidelines and rules, as well as by being proactive in having court rulings from the Administrative Court of Appeal reviewed in the Supreme Court. Four rulings have had a significant impact on the outcome of decisions: RÅ 2009, HFD 2012, HFD, 2015 and HFD 2017. As a consequence of the increased use of legal precedent, the total amount granted in assistance hours decreased. According to the conclusions from a recent study, this ‘reinterpretation of the criteria for accessing personal assistance constitutes regression beyond what can be justified and, thus,

violates the progressive achievement called for in the CRPD' (Brennan, et., al, 2016b:12). Furthermore, the annual progress report by the National Board of Health and Welfare, 'Interventions and Support for People with Disabilities 2016', indicated that several of the LSS interventions for children were decreasing: companionship services and short-term stays have decreased since 2010.

In 2016, the Ministry of Health and Social affairs appointed an LSS investigation (Dir. 2016: 40) with the overall aim of ensuring the long-term sustainable economic development of assistance allowance and making other eligible interventions in the LSS legislation more effective. Equivalence and improved quality were used as arguments for conducting the investigation, which is supposed to be completed by 1 October 2018. Furthermore, the directive stated that improvements to other LSS interventions, if considered necessary, should be made at the expense of the cost of assistance allowance.

The media has continued to report on fraud and cheating, but also on the adverse consequences for people in need of assistance and their families. The number of people being denied access to PA has increased at a rapid pace. As a response to the continuous decline in grants of assistance allowance to disabled people in general, but severely disabled children in particular, the national organization, RBU demanded an emergency cessation of all assistance assessments.

On 14th November, 2017, the government issued an emergency halt on the two-year reassessments, which resulted in an interim period until new legislation comes into force. However, this will not benefit those disabled people who have already lost their PA or are applying for the first time.

In December 2017, the National Board of Health and Welfare published a report which stated that, although the municipalities have increased their support to disabled people, fewer awards were made to children with disabilities. Since 2007, the number of children granted short-term stays has decreased by 5 per cent. During the same period, the short-term supervision programme, which provides safe and meaningful free time before and after school, and short term stay for school leave and other vacancies, decreased by 15 per cent. This indicates that support interventions directed towards disabled children and their families have become more restricted.

On 30 January 2018, the Social Affairs Committee held an open hearing on PA and the effects of legal developments. The government continued to suggest that the legislation had to be modernized, and proposed increased supervision and control to ensure that 'LSS interventions were provided to the "right people"'. Despite the increased knowledge of the adverse consequences for assistance users (National Board of Health and Welfare, 2017), the savings directives remained in force (Dir 2016: 40).

Today, many members of disabled people's user organizations describe a situation in which the entire LSS legislation is at risk of being eroded (DN, 2018). The erosion of the LSS Act

would apply not only to PA, but also to other type of LSS interventions such as companion services and contact persons (Dagens Samhälle, 2016). Lack of adequate support restricts the freedom of disabled children and adolescents, as well as their families. It seems clear that the political climate in which Swedish disability policy is being implemented has hardened. The politics of scarcity raise questions about fairness. There is an important distinction that must be made between equality and equity. Equality does not take into account that everyone does not start from the same point, and that some people have greater barriers to face than others. In this sense the use of legal precedent becomes problematic since this implies that another person's circumstances can be applied as if there were a 'universal child', and where disability and context do not matter. Equity considers difference and compensates for it, so that everybody has the same opportunities.



The illustration by Bengt Elmér portrays a disabled youth and a caseworker from the SIA. Standing in front of the young person, the case worker is saying: 'Now your mum and dad have to help you when you go out'.

The results of the ongoing LSS investigation will be presented in October 2018. Due to government directives the investigation has had a unilateral focus on reducing the cost trajectory of PA, and improvements in interventions for disabled people other than assistance users can only be made from cost reductions in PA: 'Enhanced quality, accuracy, overall perception and diversity in the support efforts covered by LSS will be financed with savings in the provision of assistance' (Dir, 2016: 40). However, conclusions of a report concerning the alternative costs of PA (Knutsson, 2017) underline that it is not possible to discuss the cost options for PA without considering the quality differences and values inherent in the different options (ibid, 2017).

Government officials claim that people who need support will receive it and that nobody should ‘fall between the chairs’. Nonetheless, the directives of the current LSS investigation have not changed the focus from decreasing cost trajectories to improving quality. This could explain user organizations’ distrust of the government’s intention to restore and enhance quality in LSS legislation.

Article 19(b) of the UN Convention on the Rights of Persons with Disabilities (United Nations, 2007) obliges 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’. Even so, municipalities are once again beginning to build residential institutions for disabled children whose parents are unable to care for them without access to personal assistance.

I will conclude with a reflection from a social worker who made a comparison between what it was like when the LSS legislation came into force and current developments:

From the beginning there was a holistic view of disabilities and the intention was to be able to take part in society and so on – very good thoughts. Through the application of landmark rulings it has become bits and pieces, when you look at every little piece as a limited part and you are not involved in the entire process, and then you should combine it with home service, everything becomes so tiny and small. So there will be no holistic approach. I think you've lost the idea.... (Anna, social worker)

SVENSK SAMMANFATTNING

Leva livet! Unga personers erfarenhet av att leva med personlig assistans och socialarbetares erfarenheter av att hantera bedömningar enligt LSS utifrån ett barnperspektiv.

I Sverige är personlig assistans en av tio råd-och stödinsatser som ryms inom ramen för Lag om Stöd och Service till vissa funktionshindrade (1983: 387). Syftet med insatsen personlig assistans är att den ska vara ett personligt utformat stöd, som bidrar till att ge den enskilde förutsättningar att leva ett självständigt liv. Stödet ska tillgodoses av ett begränsat antal personer, s.k. personliga assistenter, som är knutna till den enskilde personen. Det är den enskilde individen, eller vårdnadshavaren om den sökande är under 15 år, som söker insatsen. För personlig assistans råder ett delat huvudmannaskap mellan stat och kommun. Om behovet av assistans understiger 20 timmar/ vecka så är det kommunala LSS-handläggare som ansvarar för att göra behovsbedömningar, men om behovet överstiger 20 timmar/ vecka så är det tjänstemän på Försäkringskassan som utreder och fattar beslut om assistans.

I Sverige har personlig assistans medfört en ökad livskvalité för många barn med funktionshinder (Socialstyrelsen, 2014) av vilka majoriteten har en kombination av utomstående och anhöriga som personliga assistenter (ibid., 2014). Studier om barn – och ungdomar med assistans, (Skär & Tam, 2001; Axelsson, Imms & Wilder, 2014) samt vuxna assistansanvändare (Yamaki & Yamazaki, 2010; Giertz, 2012; Egard, 2011) understryker betydelsen av att ha tillgång till ett individuellt utformat stöd, där en välfungerande relation mellan assistent och assistansanvändare, är en grundläggande förutsättning för förveckligandet av den assistansberättigades självbestämmande. Hur relationen utformades berodde på det sammanhang barnet befann sig i (Skär & Tam, 2001), samt omfattningen av barnets stödbehov (Axelsson, Imms & Wilder, 2014).

Studier som har sin utgångspunkt i barns upplevelser av delaktighet visar att tillgången till personlig assistans kan upplevas både som främjande och hindrande. För barn med omfattande intellektuella funktionsnedsättningar bidrog assistenternas närvaro med att förstärka barnens möjlighet till samspel med andra personer (Axelsson, Imms & Wilder, 2014), men för barn och unga med rörelsehinder kunde assistentens närvaro uppfattas som ett hinder för deras möjlighet till kontakt med jämnåriga kamrater (Skär & Tam, 2001).

Slutsatser från två litteraturöversikter om barn och ungas delaktighet i myndighetsutövning visade att barns delaktighet ofta ägde rum med utgångspunkt från de vuxnas villkor (Nordenfors, 2010) och att barn sällan erbjöds möjligheter att ge uttryck för sina åsikter, trots att de själva önskade det (Stenhammar, 2009).

SYFTE OCH FRÅGESTÄLLNINGAR

Det övergripande syftet med avhandlingen var att få en djupare förståelse av personlig assistans, dels från unga assistansanvändares perspektiv, dels från de handläggare som fattar beslut om rätt till personlig assistans och övriga LSS insatser.

Avhandlingen består av två studier, fördelat på fyra artiklar. I den sammanfattande kappan kontextualiseras resultaten och vägs samman genom en syntetisering av de resultat som framkommer ur samtliga artiklar. En övergripande analys och diskussion görs av ungdomars och handläggares upplevelser av behovsbedömningsprocessen, där olika teorier bidrar till att synliggöra samband mellan olika aktörer och strukturers inverkan på varandra. Dessa resultat utmynnar i några kliniska implikationer, samt förslag till fortsatt forskning.

TEORETISKT RAMVERK

För att tydliggöra innebörder och möjliga tolkningar av empiri används ett teoretiskt ramverk bestående av koncept som; normalitet, professionalitet och myndighetsutövning (discretion). Då erfarenheter av myndighetsutövning är den röda tråd som binder samman ungdomars och handläggares perspektiv, så har tar den övergripande analysen sin utgångspunkt i Lipsky's klassiska verk om s.k. gräsrotsbyråkrater (street-level bureaucrats), som kompletteras med Stone's (1986) exempel av omfördelningsdilemmat som uppstår i samband med distribuering av välfärd. Dessa perspektiv kompletteras med andra teorier och begrepp som syftar till att ge läsaren en vidgad förståelse för hur samverkan mellan olika aktörer och strukturer på olika nivåer bidrar till den komplexa process som omgärdar beslut av personlig assistans, men även andra LSS-insatser.

METODER, EMPIRI OCH ANALYSMETODER

Den första studien utgick från ungdomarnas perspektiv och tog fasta på deras upplevelser av att leva med assistans i sin vardag, vilket även omfattade de behovsbedömningsmöten som låg till grund för deras möjlighet att beviljas personlig assistans. Datainsamlingen för artikel I och II var gemensam och bestod av 33 individuella intervjuer med totalt 16 unga assistansanvändare, som vid tidpunkten för intervjuerna var i åldrarna 16-21år och gick på gymnasiet.

I artikel I, Assisted normality, som analyserats enligt Grundad Teori (Glaser, 1998), ingick samtliga intervjuer. Uppföljande intervjuer med samma ungdomar användes för att göra det teoretiska urvalet, vilket innebar fördjupade frågor kring deras huvudangelägenhet (main concern), dvs. det som deltagarna själva vill prata om.

I den andra artikeln, Reluctant participation, ingick 13 ungdomar. De intervjuade ungdomarna som var med i denna artikel var de som hade erfarenhet av att delta i behovsbedömningsmöten, vilket var fokus för den induktiva innehållsanalysen (Elo & Kyngäs, 2008).

Den andra studien utgick från socialarbetarnas perspektiv där deras beskrivningar och upplevelser av barn och ungdomars delaktighet var den gemensamma utgångspunkten för artikel III, Elusive participation och artikel IV, Maintaining professional integrity. Datainsamlingen för artikel III och IV bestod av sju fokusgruppsintervjuer med 35 socialarbetare från olika delar av Sverige, vilket omfattade både rurala och urbana områden. Populationen bestod av 34 kvinnor och en man, 29 av socialarbetarna hade en längre

högskoleutbildning, vad de resterande 6 kvinnorna hade för utbildning framgick inte av svaren. I den fjärde artikeln bestod den ursprungliga populationen av de 35 kommunala socialarbetarna, men till följd av behovet av ett teoretiskt urval inkluderades 11 individuella intervjuer med handläggare på Försäkringskassan.

RESULTAT

I Artikel I utforskas ungdomars vardagsliv med personlig assistans. Resultaten visar att ungdomarnas huvudangelägenhet (main concern) var att uppnå normalitet, i bemärkelsen att få möjlighet att göra samma sorts val och delta i aktiviteter som jämnåriga ungdomar utan funktionshinder kan. Ungdomarna försökte lösa sin huvudangelägenhet genom 'assisterad normalitet' (assisted normality), vilket omfattar tillgången till personlig assistans, samt de strategier som ungdomarna använder sig av för att assistansen ska utformas och fungera i enlighet med deras önskemål och vilja. De samverkande strategierna utgjordes av; relationen som skapas mellan den enskilde ungdomen och assistenten, deras förmåga att samarbeta, samt assistentens fysiska placering i relation till ungdomen, vilken reglerades utifrån vad som ska göras, hur det ska genomföras samt vid vilken tidpunkt.

Resultaten visar att tillgång till personlig assistans är betydelsefull för att möjliggöra ett liv utifrån egna premisser. Samtidigt kan assistans inte kompensera för funktionsnedsättningen som sådan eftersom kroppens fysiska begränsningar bidrar till situationer som ungdomar inte kan välja bort, till exempel att behöva ha assistenter närvarande under natten för att hjälpa till med andningsproblematik. Assistenten kan inte heller kompensera för samhälleliga barriärer i form av andra människors fördomar och föreställningar om funktionshinder och personlig assistans.

I Artikel II berättade ungdomarna om sina upplevelser av delaktighet i de möten som låg till grund för beviljande eller avslag av personlig assistans. De möten som krävs för den behovsbedömningsprocess som föregår beslut om ansökan av personlig assistans är något som ungdomarna motvilligt deltar i (Reluctant participation). Ungdomarnas deltagande styrdes av rädslan att förlora sin assistans. Bland dessa ungdomar framstod två huvudsakliga förhållningssätt; att närvara i samband med möten eller låta en person som de litar på föra deras talan. Ungdomarna som deltog på möten beskriver en situation där handläggarnas bemötande framstod som uppgiftsorienterat med begränsat utrymme för att skapa en relation till ungdomen eftersom syftet med mötet är att genomföra en behovsbedömning av grundläggande – och övriga behov. I samband med dessa möten reducerades ungdomarnas deltagande till att svara på detaljerade frågor om det hjälpbehov och den tidsåtgång som uppstod i samband med olika praktiska situationer, som exempelvis toalettbesök och måltider. För att kunna hantera dessa möten använde sig ungdomarna av olika strategier, vars övergripande syfte var att säkerställa att de fick möjlighet att behålla eller utöka antalet assistanstimmar. En av de strategier som ungdomarna tillämpade var att 'visa sig från sin värsta sida', vilket handlade om att övertyga socialarbetarna om att man var 'tillräckligt funktionshindrad' och att t.o.m. överdriva sina behov för att inte riskera att tiden inte räcker till för att få det stöd som man behöver i olika situationer. Andra strategier inkluderade att ge

handläggarna den information som de efterfrågade, använda sig av stöd från andra personer som de litade på, samt i undantagsfall 'göra sin röst hörd' genom att säga vad de ansåg även om handläggarna inte hade efterfrågat deras åsikt. Resultaten visar att ungdomars deltagande i stor grad reduceras till en skenbar delaktighet, vilket väcker frågor om den reella innebörden av ungdomars deltagande (participation).

Den andra studien hade sin utgångspunkt i de kommunala socialarbetarnas perspektiv. I artikel III beskrivs socialarbetarnas förståelse av barn – och ungas delaktighet samt deras erfarenheter av att skapa förutsättningar för delaktighet i de sociala utredningar och möten som föregår beslut om ansökt LSS- insats. Den fenomenologiska analysen visar att essensen i socialarbetarnas upplevelse var 'undflyende delaktighet' som bestod av upplevda motsättning mellan a) policy dokument, den praktiska verksamheten och lagstiftning, b) normer och föreställningar om normalitet, c) bedömningar av det enskilda barnets kompetens samt d) förekomsten av motstridiga perspektiv och behov. Delaktigheten beskrevs som svår att uppnå och socialarbetarna brottades med att förstå när barn förväntades vara delaktiga, vad delaktigheten skulle bestå av samt hur de skulle veta när den uppnåts. Handläggarna fick själva hantera utmaningen att väga barns rätt till delaktighet mot bedömningar av barns förmågor, samhälleliga normer samt motstridiga perspektiv bland olika aktörer kring barns behov. Ibland kunde föräldrar och barn ha olika uppfattningar om behovet av stödinsatser. I dessa situationer hade barn olika inflytande beroende på samverkande faktorer såsom ålder, diagnos och förmåga att förmedla sina åsikter. Ju yngre barnet var desto mer tenderade socialarbetarna att lyssna på föräldrarna. Om barnet var äldre men hade en intellektuell funktionsnedsättning och/ eller behov av alternativ kommunikation minskade socialarbetarnas benägenhet att låta barnet/ ungdomen få inflytande över det fattade beslutet. Resultatet indikerar behovet av att ha en levande dialog kring barns delaktighet, där medvetandegörandet av socialarbetarnas normer och föreställningar och kunskap om funktionshinder är en viktig förutsättning för att ungdomars deltagande inte ska riskera att reduceras till en tvingande närvaro utan möjlighet att påverka sin egen livssituation.

I artikel IV undersöks hur handläggare gör för att upprätthålla sin professionalitet vilken manifesterar sig inom ramen för myndighetsutövning. För socialarbetarna kännetecknades professionalitet av deras förmåga att på ett korrekt och objektivt sätt genomföra den sociala utredningen som ligger till grund för beslut om personlig assistans. Ett beslutsfattande som försvåras av det delade huvudmannaskapet mellan kommun och försäkringskassa samt behovet av andra professioners kompetens för att kunna fastställa 'legitima stödbehov'. Resultatet visar att handläggarna försöker att bevara sin professionalitet genom att tillämpa olika typer av strategier i samband med handlägningsprocessen; de kämpar med ansvarsfördelning, byråkratisering och rättfärdigande av sitt eget agerande samt bevarandet av sin självbild. Resultaten visar att nuvarande praxis när det gäller sociala utredningar i hög grad styrs utifrån bedömningskriterier för grundläggande behov i kombination med prejudicerande domar och medicinska intyg. Detta har medfört att handläggarna har svårt att göra individuella bedömningar som tar hänsyn till de negativa konsekvenser som uppstår för assistansanvändarna i deras vardag vilket innebär att handläggarna inte kan ta hänsyn till hur

den enskilde individen drabbas vid ett eventuellt avslag. Nuvarande bedömningar och beslut väcker frågor om handläggarnas syn på, och uppfattning av, sin yrkesprofessionalitet. Var ligger deras lojalitet? Hos barn-och ungdomar i behov av assistans eller hos arbetsgivaren/organisationen de arbetar hos?

ÖVERGRIPANDE ANALYS OCH DISKUSSION

Den svenska översättningen av syntetiseringen blir mer komprimerad och utgår från de centrala begreppen; normalitet, social rättvisa och professionalitet, som förekommer i den övergripande analysen och efterföljande diskussionen.

Normalitet som en vägledande princip

Normalitet är ett begrepp som återkommer i artiklarna. Även om normalitet inte nämns i några policydokument eller lagar så är det ett begrepp som både ungdomar, handläggare och föräldrar på olika sätt förhåller sig till. För ungdomarna (artikel I) handlar normalitet om att kunna göra 'vanliga saker', som att delta i de vardagliga aktiviteter och sammanhang som de själva vill. För att få tillgång till normalitet behöver ungdomarna synliggöra sin funktionsnedsättning. Endast genom att vara övertydliga med sina hjälpbehov (artikel II) kan ungdomar säkerställa tillgång till assistans (assisterad normalitet). I bedömningsprocessen behöver handläggarna säkerställa att ansökta och beviljade insatser går till rätt person av rätt orsak, vilket innebär att de behöver försäkra sig om att konsekvenserna av ungdomens funktionshinder motsvarar de sökta stödinsatserna. För att kunna göra en objektiv bedömning jämför handläggarna funktionsnedsatta barn och ungdomars förmågor och behov med jämnåriga icke-funktionshindrade barns behov (artikel III, IV). På så vis anser handläggarna att de kan kunna göra en rimliga och rättvis bedömning som endast ska kompensera för de hinder som kan relateras till funktionsnedsättningen (artikel III). Handläggarna ansåg att föräldrar inte alltid såg till 'barnets bästa' utan att de snarare drevs av ett egenintresse där normalisering av barnet var en viktig del av deras självbild (artikel III).

Social rättvisa

Social rättvisa är en viktig etisk princip i socialt arbete. Rättvisa kan skipas genom omfördelning av materiella resurser (redistribution), men oftast är detta inte tillräckligt för att säkerställa goda levnadsvillkor. Fraser (1997) talar om betydelsen av både omfördelning och erkännande (recognition), där det sistnämnda handlar om att barn och ungdomar med funktionshinder tillskrivas ett kulturellt erkännande. I den första artikeln beskrev ungdomarna hur tillgången till assistans (redistribution) bidrog till att de kunde hitta på aktiviteter, men att assistansen inte kunde skydda dem mot andra människors fördomar och förutfattade meningar. Slutsatsen av detta är att både omfördelning och erkännande behövs. För att uppnå samhällelig rättvisa har socialarbetarna ett ansvar att agera som språkrör och företrädare för barn och ungdomar med funktionshinder istället för att anpassa sig till gällande regler och lokala riktlinjer (artikel IV).

Professionalitet

Socialarbetarna förknippade professionalitet med förmågan att göra en korrekt social utredning i vilken den strukturerade behovsbedömningen ingick. Få socialarbetare vågade öppet ifrågasätta nuvarande regler och riktlinjer. Istället anslöt de sig till den organisatoriska formen av professionalism (Evetts, 2010) som ideologiskt anses ligga i linje med New Public Management (NPM). Förespråkare av en organisatorisk professionalism välkomnar standardiseringen av riktlinjer och frågeformulär. Samtidigt som handläggarna förväntas göra självständiga utredningar är de begränsade att fatta självständiga beslut, då många beslut antingen fattas i samband med kollektiva kollegiala diskussioner eller fattas högre upp i hierarkin av överordnade chefer eller i en politisk nämnd. Dessutom är handläggarna beroende av andra professioners kompetens (i främsta hand läkare och domare) för att kunna sammanställa den sociala utredningen.

Slutsatserna av de olika artiklarna i avhandlingen blir att både assistansanvändare och socialarbetare upplever sig ha ett begränsat handlingsutrymme till följd av andra aktörer och övergripande strukturer som policydokument, lagar och förordningar. Viljan att agera professionellt finns, men frågan är om det saknas relevant kompetens för att kunna göra det? I sin nuvarande roll behöver socialarbetarna stärka sin yrkesidentitet och förlita sig mer på förtroenhetskunskap om socialt arbete där kritisk reflektion och etisk medvetenhet är viktiga verktyg för att säkerställa social rättvisa för de grupper som de säger sig värna.

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