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Enabling disability rights in practise

*Understanding how the governance of state-funded
personal assistance is fulfilling the Swedish LSS Act*

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Abstract

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Personal assistance (PA) is stated in Article 19 of the UNCRPD as an internationally recognised disability right and is operationalised as a measure in the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments (the LSS Act). The Act's overall policy goal is to promote good living conditions for the eligible persons by enabling participation in society on equal terms with others. The governance of PA is a divided responsibility between the municipality and the Swedish Social Insurance Agency (SSIA), which assesses and grants PA-allowance if the PA applicant exceed 20 hours of certain needs per week. The overall aim of the thesis was to explore how the governance of PA-allowance enables to fulfil the LSS Act policy goals. The main findings of the thesis demonstrate a tilt in PA towards a medical model of disability, marked by a domination and an increase of healthcare activities over time. Less activities representing participation in society were found and unequal access to PA activities across age, gender and groups of persons with disabilities. The findings imply an increased risk to social and financial exclusion of PA users. Further, the LSS Act's rationale and policy goals were shown to have a weakened impact on the SSIA instruction, the refined policy tool which outlines the PA-allowance granting process. A development towards a medicalised application of PA-allowance was found, characterised by healthcare measures to support medical conditions and a shift towards PA users with less ability to partake in the PA-allowance granting process. Factors shown to have influenced the governance of PA-allowance include: case law, changed policy priorities, weakened PA collaboration structures, inadequate monitoring of PA outcomes, strained working conditions at the SSIA and extensive complexities of the PA-allowance application. This thesis illustrates that the SSIA regime logic has thoroughly influenced the LSS policy outcome with time and emphasises the need for social reform policy tools to be continuously calibrated towards the original policy goals to uphold policy compliance. The regression of PA, by gradually resigning to a medical model of disability, demonstrates weakened conditions for Swedish disability policy through the LSS Act to fulfil Article 19 of the UNCRPD.

Keywords: Activities of daily living, disability policy, LSS Act, governance, ICF, participation in society, personal assistance, policy refinement, policy tool, public policy, social security, Sweden, UNCRPD

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To my family

List of Papers

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

- I. von Granitz, H., Reine, I., Sonnander, K., & Winblad, U. (2017). Do personal assistance activities promote participation for persons with disabilities in Sweden? *Disability and Rehabilitation**. Vol. 39(24): 2512-2521. Published online: 29 October 2016. <https://doi.org/10.1080/09638288.2016.1236405>
- II. von Granitz, H., Sonnander, K., Reine, I., & Winblad, U. (2021). Do personal assistance activities promote participation in society for persons with disabilities in Sweden? A five-year longitudinal study. *Disability and Rehabilitation**. Vol. 44. (15):
1. Published online: 15 March 2021. <https://doi.org/10.1080/09638288.2021.1897691>
- III. von Granitz, H., Sonnander, K., & Winblad, U. (2022). Tracing the refinement of policy tools for disability rights; a content analysis of how the granting process of state-funded personal assistance is aligned with the LSS Act. Manuscript.
- IV. von Granitz, H., Sonnander, K., & Winblad, U. (2022). From citizen to patient; how can the medicalisation of personal assistance for persons with disabilities in Sweden be understood? Submitted.

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Abbreviations

ICF	The International Classification of Functioning, Disability and Health	WHO, 2001
The LSS Act	Abbreviation of the Act concerning Support and Service for Persons with Certain Functional Impairments In Swedish: Lagen om stöd och service till vissa funktionshindrade	SFS, 1993a
PA	Personal assistance	
PA-allowance	Swedish security scheme for persons eligible to state-funded personal assistance In Swedish: Assistansersättning	
SFS	Swedish Code of Statues In Swedish: Svensk författningssamling	
SOU	Swedish Government Official Reports In Swedish: Statens offentliga utredningar	
SSIA	The Swedish Social Insurance Agency In Swedish: Försäkringskassan	
UNCRPD	The United Nation Convention on the Rights of Persons with Disabilities	OHCHR, 2008
WHO	World Health Organisation	

Prologue

My interest in human rights has been a common thread throughout my career, beginning in the 1990's with my first assignment to improve people's living conditions in bilateral and multilateral settings. The results varied and I began a quest to better understand the visions behind human rights conventions. After years of working as a Swedish government public official in various social policy agencies, I began working with national disability policy issues in 2008, when Sweden ratified the United Nation Convention on the Rights of Persons with Disabilities, or the UNCRPD. The convention is a powerful instrument for amplifying the voices of persons with disabilities worldwide, in line with the LSS Act's level of ambition and innovative approach. In 2011, I experienced the implementation the LSS Act by partaking in a study of one of the Swedish social security's most complex schemes, the allowance eligible to persons in need of the LSS measure personal assistance. The data gave a unique opportunity to better understand the realisation of rights by the UNCRPD. With these points of departure, I began my dissertation work in 2013. The LSS Act however gained greater personal insight outside of the interest in the fulfilment of human rights. During the course of the thesis, I experienced first-hand the need and importance of support for persons with disabilities through my family members. Our family has used vital support structures and hovered between hope and doubt through many efforts achieved and failed. This experience profoundly opened my eyes and exposed me to the reality of persons with disabilities on a day-to-day basis, of the hard struggles to face due to social expectations and ableism. I hope this thesis will provide you with some thoughts and insights on the importance of studying, supporting, and protecting disability rights.

Heléne von Granitz
Stockholm, 27th of June 2022

Introduction

The realisation of social citizenship is dependent on well-functioning welfare measures to enhance social rights. Social rights cover a broad scope of rights with the purpose that the citizen shall fully participate in society and be able to live a life in accordance with the prevailing community standard (Ishay, 2007). A specific social right is personal assistance (PA) stated in the United Nations Convention on the Rights of Persons with Disabilities, the UNCRPD (OHCHR, 2008):

Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community. (Article 19b, UNCRPD)

Article 19 of the UNCRPD recognises PA as a measure to promote equality of opportunity and choices with the aim to ensure full and effective measures for inclusion in society (OHCHR, 2008). Hence, persons with disabilities should be free to establish their own living conditions and be able to actively participate in the formulation and implementation of programs that directly affect them (*ibid*). The UNCRPD was launched in 2006 and displays disability rights consisting of civil, political, economic, cultural as well as social rights. The convention was influenced by the Social Model of Disability (Oliver, 1996). This model is a reaction to what is described as a medical model of disability that view impairment as a deviation to societal values (Bruce, 2014; Oliver, 1996). From this perspective, social inclusion and participation in society are limited or restricted for persons with disabilities because of exclusionary aspects, i.e. barriers which might include legislation, policies and societal norms that contribute in disabling people (Bruce, 2014; Andrew et al., 2013; Lindberg & Grönvik, 2011; Oliver, 1996). Thus, the concept “social” is key to discourses on disability and demonstrates that the realisation of social rights for persons with disabilities is dependent on their involvement in society, which would further promote civil and political rights (Sepulchré, 2019).

The realisation of social rights must be protected which requires an active state. Fundamental to enhancing a social citizenship for persons with disabilities is the provision of policies to promote social rights by economic welfare, social security and social services (Andrew et al., 2013; Magnusson & Nilssen, 2013).

The strongest expression of Swedish disability policy to enhance social citizenship by the fulfilment of social rights is outlined in the Act concerning Support and Service for Persons with Certain Functional Impairments (*In Swedish: Lagen om stöd och service till vissa funktionshindrade*), known as the LSS Act (Lewin, 1998; SFS, 1993a). The Act was designed in line with a political shift of paradigm in Swedish disability policy during the 1990's to abandon an approach of significant government influence vis-à-vis the user of support and service (Lindqvist, 2012; Lindberg & Grönvik, 2011; Hollander, 1995). The drafting of the LSS Act was inspired by the international civil rights movement in the 1960's and was preceded by reports and societal debate demonstrating exclusion and subordination of persons with disabilities in Sweden (Sepulchré, 2019; Ratska, 2013; Berg, 2008; Oliver 1996; SOU, 1990; Ekensteen, 1968). The design of the Act represented this paradigm shift, in which people with severe disabilities by the LSS measures would take a leap from being regarded as objects of care, represented by the medical model of disability, to be regarded as citizens by partaking in community life. To be regarded as a citizen implies that a person's needs are not limited to healthcare measures, but based on a holistic view on the individual's needs and expectations. The LSS Act became highly connected to these values.

Although the UNCRPD was not in place when the LSS Act was formulated, the Act reflects the social rights to participation in society stated in the convention. As this new direction of Swedish disability policy aimed to create conditions to empower persons in need of support and service, the LSS legislation was designed as a unique entitlement act (Sépulchre, 2019; Bruce, 2014; Lewin et al. 2008). The user was given a right to require service and support without financial restrictions, and strengthened by the opportunity for the LSS user to appeal against a decision to the administrative court of law (SOU, 2008; Lewin, 1998; Hollander, 1995). The overall policy goal of the LSS Act is to promote good living conditions, through full participation in society with the aim that the individual is given the opportunity to live like others. The preparatory work preceding the LSS Act enforces that the measures by the Act should be distinguished by activation. Hence, the LSS user should take an active part in decisions about various aspects of his or her support. The LSS measures must not be given in the form of protective care, where the individual him or herself plays a passive role (The Ministry of Health and Social Affairs, 1993).

Among the ten measures in the LSS Act, PA is considered to be the most prominent to strengthening the users' independence and empowerment (Sépulchre, 2019; Ratska, 2013; Lewin et al., 2008). The purpose of PA is to provide the users with control, by themselves or by a legal representative, to plan their support, choose assistants', PA providers and conduct their own activities independently (Sépulchre, 2019; Lewin, 1998). The enabling of the PA users to plan and design their support themselves was a position which marked

a reduced influence of professions and bureaucracy (Lindqvist, 2012; Hugelmark, 2004).

The governance of PA is a divided responsibility between the municipality and the Swedish Social Insurance Agency, SSIA (*In Swedish: Försäkringskassan*), which assesses and grants PA-allowance (*In Swedish: assistansersättning*) by specific granting criteria if the PA applicant exceed 20 hours of certain needs per week (SFS, 2010). The allowance cover costs for the assistants' salaries and other contributions related to the PA employer's responsibility, such as skills training (SSIA, 2003; SFS, 2010). Eligible persons of PA-allowance cover a wide range of user groups with regard to age, disability and severity of needs (SSIA, 2011). PA-allowance became available to more than 7.000 persons in 1994 and in December of 2021, there were 13.867 persons granted PA-allowance, averaging 130 hours of PA per week and user (SSIA, 2022b). In total, PA-allowance amounted to 23.5 billion SEK in 2021 (SSIA, 2021).

Repeatedly over the years, government reports have drawn attention to challenges to operationalise the LSS Act by the SSIA. Reports demonstrate concepts in the LSS Act that are difficult to operationalise and delimit. Unclear boundaries of PA towards the healthcare sector and home care have been noted. Concerns of restrictive measures by PA have been raised, in particular a need of more frequent supervision of PA users and an increased medicalisation of PA needs (see SOU, 2018; SSIA, 2016; The Swedish Social Insurance Inspectorate, 2015; SSIA, 2014; The Swedish Agency for Public Management, 2011; SOU, 2008; The Swedish National Audit Office, 1995). Due to unexpected, and partly unexplained reasons of substantial and continued rise of PA-allowance costs and moreover cases of fraud of PA-allowance, critique has been raised regarding insufficient state financial control (The Ministry of Health and Social Affairs, 2018; SOU, 2012). PA-allowance has also been characterised by ambiguity in cost-effectiveness, a fundamental principle of good governance (The Ministry of Finance, 1998). Furthermore, neither the SSIA nor other authorities have in their responsibility to undertake individual and systematic follow-ups of the outcome of PA-allowance. As a consequence, PA-allowance is characterized by a hampered transparency of its use and outcome. These difficulties and restrictions of responsibility have in all contributed to a narrative of the LSS Act and PA-allowance as being insecure. As a response, follow-ups by the SSIA have foremost been focused on financial expenses, administrative procedures and number of PA-allowance recipients (see SSIA, 2022a; SSIA 2017a; SSIA, 2015; SSIA, 2014b).

Studies imply a shift from PA towards a medical model (Brennan et al., 2016; von Granitz, 2014). The result of a literature review on perceived PA quality by PA users, shows that the use of PA resembles activities for medical and nursing care, rather than activities for fulfilling the LSS policy goals. A uniform definition of what characterises PA quality was found lacking and knowledge of how the PA outcome relates to the LSS overall policy goal of

“good living conditions” was found limited (von Granitz, 2014). Further, studies on PA-allowance development have focused on examining the reasons behind and consequences of retracted and rejected applications for PA-allowance (Nally et al., 2021; Järkestig-Berggren et al., 2019; Brennan et al., 2016; also see SSIA, 2017b). Brennan et al. suggest that the PA-allowance granting criteria have shifted from a social to a medical understanding of disability and identify this shift being the underlying cause to the rejections and withdrawals of PA-allowance. The authors consider this development to be a sign of regression in implementing PA as a social right and conclude that Sweden is violating its obligation to the UNCRPD (Brennan et al., 2016). The application of PA-allowance has caused reactions among disability activists in Sweden who claim that the social right to PA is jeopardised due to how the SSIA has changed the granting criteria for PA-allowance. These changes are claimed to have caused revocation on the right to PA (Sepulchré, 2019). The activists also reference a lack of stated conditions, i.e. prerequisites to interpret the LSS Act’s policy goals (*in Swedish: rekvisit*) and claim that the legislator has to clarify the purpose of PA (ibid). The activists in particular find the Act’s statement, that LSS measures shall promote the user “to live like others”, too vague to enhance a social citizenship (ibid).

The indications of PA shifting towards a medical model raises concern of how the implementation of the LSS Act by PA-allowance promotes social rights and enables a social citizenship for persons with disabilities. Studies investigating the conditions for the SSIA to operationalise the LSS Act reveal mechanisms which can explain difficulties in designing granting criteria for PA-allowance in order to fulfil the policy goals of the Act. The findings show that the administrative court decisions, i.e. case law, strongly influence the development of granting criteria for PA-allowance (Brennan et al., 2016; Erlandsson, 2014; Larsson, 2008). The SSIA design of the PA-allowance granting process was found to be based on extensive case law, however the findings also reveal that that existing case law does not present a uniform legal position of the LSS Act (ibid). Above all, there is a lack of case law that develop how the LSS policy goals should be defined. Larsson reveals that this situation has occurred because of the lack of stated conditions in the LSS Act (Larsson, 2008). As a consequence, the SSIA may therefore not have sufficient guidance by case law to operationalise all parts of the LSS Act, i.e. to develop granting criteria to apply PA-allowance (Larsson, 2008). Erlandsson shows that the SSIA’s own legal interpretations are used to develop granting criteria and set standards for the PA-allowance granting process where case law is not indicative. The standards are detailed regulations and rules on how the application of PA-allowance should be performed. An example of a difficulty to define and interpret concepts in the LSS Act into standards to apply PA-allowance is “participation” that varies over time and between individuals (Brennan et al., 2016; SSIA, 2016; The Swedish Social Insurance Inspectorate, 2015). The findings of Erlandsson and Larsson highlight a risk that the application of PA-

allowance, by these legal procedures, may over time have come to deviate from the original LSS policy goals.

The SSIA uses its own governance model to apply social security schemes. This model is a set of process-oriented and administrative routines, designed to meet procedural justice requirements and are intended to strengthen a reliability and legitimacy of the government by standards on how to apply PA-allowance (Erlandsson, 2014; Andersson et al., 2012; Rothstein & Theorell, 2008). The model consists of governance instruments, such as processes and instructions, used to guide the local SSIA caseworkers to apply the PA-allowance granting process. The SSIA governance instrument are very extensive, difficult to apply in their entirety and can be used selectively by the local SSIA caseworkers (Erlandsson, 2014). The difficulties for the SSIA to develop granting criteria and set standards to assess individual needs according to the LSS Act to grant PA-allowance, have been showed to impose high demands on the competence of local SSIA caseworkers when using their own discretion (Järkestig-Berggren et al., 2019; The Swedish Social Insurance Inspectorate, 2015; Erlandsson, 2014). Therefore, lack of standardised granting criteria opens up risks of path dependency, e.g. local practise and person related ways of disseminating information (Evans, 2010; Vergne & Durand, 2010). Local variations in applying PA-allowance risk regional differences which indicate asymmetrical outcome of decisions (Andersson et al., 2012; Rothstein & Theorell, 2008). These, in turn, indicate legal uncertainty of the distribution of PA-allowance, which may undermine equal access to social rights for the individual but also undermine the legitimacy of the SSIA (ibid).

Furthermore, studies display a trend of an increasing medical perspective in the application of social security schemes at the SSIA by the use of diagnostic manuals and medical opinions to assess granting criteria. Studies show that medical opinions have come to have a central function in the SSIA governance model (Lindqvist, 2018; Mannelqvist, 2012). Medical opinions are used to form a dividing line between an assessment of work ability and the right to Sickness-benefit, a central function of the Swedish social security schemes (Lindqvist, 2018). Medical opinions legitimately distinguish between the needs of support and function as means of reducing legal uncertainty to the SSIA decisions. Thus, medical opinions are used as to reinforce the decisions made by the local SSIA caseworkers. Medical opinions have developed in great detail by case law and illustrates a general trend towards an increased juridification of the SSIA governance model (Lindqvist, 2018; Mannelqvist, 2012). Juridification implies extensive application of case law and further marks an increased influence of judicial bodies over politics, e.g. enhancement of social rights (Lindqvist, 2018; Erlandsson, 2014; Sinding-Aasen et al., 2014; Magnusson & Nilssen, 2013). The studies claim that as a result of the usage of medical opinions as decisive in the SSIA governance model, the promotion of social citizenship has been narrowed (Lindqvist, 2018; Mannelqvist, 2012). In all, the previous studies demonstrate two trends, the first is a

shift towards a medical model of PA and the second is an increasing influence of medical opinions underpinning the SSIA governance model. A central question is how these two trends affect the national government's ability to promote PA as a social right and thereby enabling a social citizenship for persons with disabilities.

Most previous studies highlighting the risk for a medical model of PA are qualitative studies of smaller samples. Quantitative studies exploring the content of PA in larger samples or the whole population of PA users are needed to understand the extent and development of PA activities for medical and nursing care needs, and how activities representing participation in society have developed over time. Furthermore, no previous studies were found which show how the SSIA governance instrument used in the PA-allowance granting process, aligns with the LSS rationale and policy goals over time. There is also a need to investigate why a medical model of PA has occurred. By examining if the PA outcome constitutes sufficient conditions for fulfilling the UNCRDP Article 19, i.e. participation in society, and by examining how the SSIA design and content of PA-allowance aligns with the LSS Act rationale and policy goals, this thesis aims to contribute to an understanding of the challenges and conditions behind enabling social rights by PA in practise.

Overall and specific aims

The overall aim of the thesis is to examine how the national governance of state-funded personal assistance enables to fulfil the Swedish LSS Act policy goals.

The aims of each specific study were:

Study I: To explore how the right to participation according to Article 19 of the UNCRPD is promoted by personal assistance by examining the distribution of activities reported by persons granted government assistance allowance in Sweden across age, gender and eligible person categories.

Study II: To explore whether the personal assistance activities provided by the Swedish LSS Act in 2010 and 2015, promote participation in society according to Article 19 of the UNCRPD.

Study III: To investigate how the policy tool used to guide the PA-allowance granting process, i.e. the different versions of the SSIA instruction, aligns with the LSS Act's rationale and goals outlined in the original government bill.

Study IV: To investigate how the development towards a medicalisation of personal assistance can be understood by the experiences of public officials at the SSIA head office, responsible for developing and managing the PA-allowance granting process on the national level.

The Swedish setting

In the 1990s Sweden underwent a wave of decentralisation reforms that intended to give the municipality an increased mandate and responsibility to coordinate welfare services. During this period the LSS Act was launched with the purpose of being implemented by the municipalities to provide local anchoring, closely related to the Social Services Act (SFS, 2001; Lewin, 1998). The LSS Act has been described as a key legislation in the decentralisation reforms, with the underlying political intention to strengthen the right to a social citizenship for persons with disabilities (Lindqvist et al., 2014; Gynnerstedt, 2004; Lewin, 1998).

The LSS Act policy goals

The purpose of the LSS Act is to strengthen the user's empowerment. The individual autonomy that the legislator assumed would be achieved by the LSS Act, was considered as a given prerequisite for better living conditions and higher quality of support than previously provided by other forms of social services, such as home care (Lindqvist, 2012; Lewin, 1998). The overall policy goal of the LSS Act is that the user shall achieve "good living conditions" stated in Chapter 2, Clause 7 of the Act (SFS, 1993a; Ministry of Health and Social Affairs, 1993). The concept of good living conditions entails the LSS measures shall prevent and reduce the consequences of living with disabilities. This concept encompasses both the support achieved by ten LSS measures as well as the quality of the provided and coordinated support (von Granitz, 2014; The Swedish National Board of Health and Welfare, 2007). The operationalisation of good living conditions shall be based on the individual users' subjective experience (The Ministry of Health and Social Affairs, 1993). Hence, there are no strict definitions of quality criteria defining how the LSS overall policy goal should be fulfilled (ibid). The LSS Act expresses certain sub-goals, also described as "intentions", to fulfil the overall policy goal of good living conditions, summarised in Table 1 (ibid).

Table 1. Sub-goals expressed in Chapter 2, Clause 5, 6 and 8 of the LSS Act

Clause	Sub-goals¹ of the LSS Act
§5	Equality in living conditions Participation in society Live like others
§6	Integrity Self- and co-determination Influence
§8	Voluntary and by freedom of choice

There is an exception stated to the principle of independence in Chapter 2, Clause 8 of the Act. According to Clause 8, no conditions are placed on the user's ability to manage or control the support. Thus, a legal representative can act on the behalf of the individual if the LSS user is under 15 years of age or clearly unable to make decisions on their own. Furthermore, the individual must also be notified of his or her rights according to the LSS Act. The sub-goals mutually reinforce one another and are to some extent synonyms. For example, self-determination, influence and freedom of choice, do all reflect the political intention to empower the individual vis-à-vis authorities. Self-determination is not to be regarded as a user to be in contrast of being dependent on support, but on relying on support for an independent life on the LSS users' own terms and wishes (Giertz, 2012; Lewin, 1998). Also, in accordance with Clause 10 of LSS Act, the LSS user must be offered an individual plan in which the user decides and plan the support in consultation with the provider of LSS measures. Persons from birth up to 65 years of age are entitled to measures under the Act. Measures by the LSS Act may be granted an applicant who is assessed to belong to one of the following eligible person categories: (1) persons with intellectual disabilities, autism or pervasive developmental disorders; (2) persons with severe disability following brain damage in adulthood, caused by external violence or physical illness; (3) persons with other permanent physical or mental disability that is clearly not due to normal aging, causing significant difficulty in daily life and hence providing extensive need for support and service (SFS, 1993a). The first and second categories are

¹ In the LSS Act, Chapter 2, Clause 5 states the policy goals to promote equality in living conditions and full participation in society with the aim that the individual is given the opportunity to live like others. The activities according to Clause 6 shall be of good quality, based on respect for the individual's integrity and right to self-determination. The individual shall be given influence and co-determination over initiatives connected to the support and services. The provider of LSS measures shall conduct ongoing quality assurance which shall be systematically developed and ensured. Clause 7 states that the measures as a whole shall provide good living conditions for the individual. The efforts must be lasting, coordinated and adapted to individual needs and designed easily accessible to the user to strengthen the ability to live an independent life. Clause 8 states that measures shall be given only if the individual so requests and by own wishes. Further, Clause 8 states a special consideration for children, that LSS measures shall be aligned with the best interests of the child, in accordance with the Convention on the Rights of the Child (SFS, 2018; SFS, 1993a)

based on specified main diagnoses and were merged into the LSS Act from previous legislation. A third category was added to the LSS Act, based on the extent of “special needs” (The Ministry of Health and Social Affairs, 1993). In this thesis the three eligible person categories are referred to as (1) intellectual disability, (2) physical disability and (3) persons with special needs.

The division of governing personal assistance

The responsibility for the implementation of the LSS Act is divided among three administrative principals shown in Figure 1. The regions are responsible for the LSS measure “The service counselling and other personal support”, and the municipalities are responsible for the primary part of the LSS measures².

The preparatory work of the LSS legislation stated a main responsibility of the LSS Act shall be placed at the municipality level. However, PA quickly exceeded expected expenses and was considered to be cost-driven (The Ministry of Health and Social Affairs, 1996; The Swedish National Audit Office, 1995).

2 The ten measures under the LSS Act (The Swedish National Board of Health and Welfare, 2017; SFS, 1993a)

1. The service counselling and other personal support. Aim to ensure persons with disabilities access to professional, co-ordinated and permanent assistance from several areas of competence. The expert support shall aim to produce good living conditions and to prevent and reduce the effects of the functional disability. The assistance shall be of an advisory and generally supportive character. Medical, psychological, social and educational aspects of the functional disability shall be taken into account.

2. Personal assistance. Aimed for persons who have considerable need of personally designed care in everyday life.

3. Companion service. Aimed for persons who need help to get out to leisure or cultural activities, or to participate in social life.

4. Contact person. Consists of another human being who gives personal support and functions as a friend.

5. Relief service in the home. Assistance of a person who comes to the family home in order to assist the LSS user.

6. Short stay away from home. Aim to provide persons with functional disabilities with recreation and a change of scene, and to give relief to family. The service can be in form of a short-term home, with a family, at a camp or similar.

7. Short period of supervision for school children over the age of 12. The support include care before and after the school day and during school holidays for school children over 12 years old with functional disabilities. The service can be integrated with after-school clubs, be done in special groups or based on personal needs.

8. Resident children. Consist of living in family homes or in housing with special services for children and young persons. As a complement to, or to replace the family home.

9. Resident adults. Housing with special services for adults or other specially adapted housing for adults. The measure can be specially adapted housing, service housing or group housing.

10. Daily activities. Aimed for persons with intellectual disabilities, autism or functional disabilities following brain damage as an adult, i.e. eligible person categories 1 and 2. The activities can be carried out at a day centre or at another place of work.

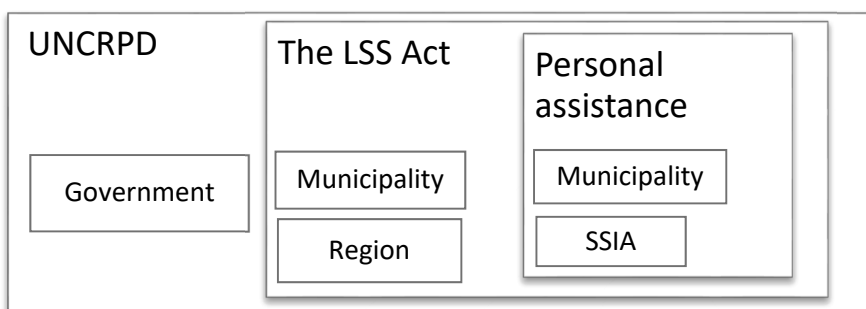


Figure 1. The relation between the UNCRPD, the LSS Act and PA, and the administrative principals responsible for implementing the LSS Act.

PA was not originally defined in the preparatory work of the LSS Act, but rather described as a personally designed support (The Ministry of Health and Social Affairs, 1993). In many municipalities, interventions similar to PA had previously emerged, however, depending on the municipality of residence local variables created different conditions for individuals with similar needs (Berg, 2008; Bengtsson, 1998). Thus, a statutory right to PA was included in Clause 9 of the LSS Act in 1996 (Bengtsson, 1998; Lewin, 1998). It was assumed that a centralised granting process would provide equal conditions to apply for PA regardless of residential location, local resources, views or attitudes. A shared financial responsibility and principal ownership was formed between the state (the SSIA) and the municipalities (Bengtsson, 1998). As a result, PA users became divided into two separate eligible groups by the launching of a second legislation, the Act concerning Allowance for Personal Assistance, which in 2010 was incorporated into the Social Insurance Code (SFS, 2010; SFS, 1993b). The division of responsibility meant that the municipality covers costs for the first 20 hours of PA, while costs above this limit are compensated by the national social security scheme PA-allowance (ibid).

An extensive number of regulatory changes has been made in the LSS Act over time (SSIA, 2003; SFS, 1993a). Shortly after the Act was launched, changes were introduced that came to have an impact on the design of PA. Additions to the eligible persons groups than originally intended were included, among them children under the age of 18 and relatives were accepted as assistants (Bengtsson, 1998; The Ministry for Health and Social Affairs, 1996). Additionally, a minimum of 20 hours of certain “basic needs” as granting criteria for PA-allowance was introduced. The formulation of basic needs was grounded upon the notion of PA needs being of a physical nature, such as hygiene or meals, which were necessary for other needs to be met and were thus seen as a precondition to promote the sub-goals of the LSS Act (SOU, 2008; The Ministry for Health and Social Affairs, 1996). Furthermore, in cases

where the basic needs granting criteria are met, the PA applicant may also be granted PA for “other needs” (ibid). Even though the concept of other needs is not specified in the Act, these needs were assumed to support PA for an active life, e.g. PA for leisure or study. Basic needs were defined as needs connected to privacy and support of practical natures; personal hygiene, meals, dressing/undressing and for communication (ibid). A fifth basic need, expressed as “personal assistance for other need of service and support that requires detailed knowledge of the person” was added in the LSS Act in 1996 (The Ministry for Health and Social Affairs, 1996). Over time, this fifth basic need has by case law been interpreted as supervision (*In Swedish: aktiv tillsyn av övervakande karaktär*). Supervision, as a PA-allowance granting criteria, is described as necessary actions to prevent a person from injuring themselves or others due to aggression and lack of impulse control (SSIA, 2003). In 2020 two additional basic needs were added in the Act, breathing and enteral nutrition (The Ministry of Health and Social Affairs, 2019; SFS, 1993a).

PA-allowance consists of a needs assessment based on individual needs and the cost reimbursement of the PA performed. Four conditions need to be met for an applicant to be granted PA-allowance (SFS, 2010; SSIA, 2003). First, the applicant must be eligible for Swedish social security. Second, PA-allowance may be provided to applicants who have basic needs of PA exceeding 20 hours a week. Third, persons up to the age of 65 are eligible to receive and retain PA-allowance, but are thereafter not entitled to receive extended support by PA. The fourth condition is that PA-allowance may be granted from birth to persons who belong to one of the three eligible person categories described previously (ibid). Notion premise for eligibility to PA-allowance is the applicant is not living in a group home or is cared for in an institution that is, owned or operated by grants from the state, a municipality or a region. PA-allowance does not cover medical and nursing care under the Health Care Act (SFS, 2017b) or for time spent in municipal activities such as child care, school or daily activities. However, certain exceptions are applied in cases where the PA user need supervision (SSIA, 2003). PA-allowance is calculated in units of time according to the amount of hours invested in meeting the PA needs within the assessed categories, and no upper limit in the scope of needs or number of PA hours exist (ibid).

The Swedish governance model of social security schemes

In Sweden, a large and divided pool of social security schemes based on taxpayer-funded services have been developed over time. These are divided into general and selective schemes. The general schemes are directed to homogeneous group, e.g. Child-allowance. Selective schemes are dedicated to specific

groups based on granting criteria, such as compensation based on a level of income, e.g. Sickness-benefit or on needs due to disability, e.g. PA-allowance.

The main task of the SSIA is to provide support and guidance to local SSIA caseworkers in performing the application of social security schemes. Even though the design of the schemes differs by target group, purpose, scope and design, the SSIA governance is based on a common model. The model is designed to meet the requirements of the Administrative Procedure Act (SFS, 2017a). The SSIA has so-called standardisation rights to design its governance over the schemes. Standardisation for the Swedish social security consists of case law and regulations but also on SSIA's own legal standards, i.e. normative positions which SSIA states on various legal issues. These internal legal standards are government-specific and more comprehensive than the legislation specifies (Erlandsson, 2014). The SSIA legal standards are detailed regulations on how an application of a certain social security scheme should be performed. The operationalisation of a policy by case law and by the internal legal standards are made by the SSIA's public officials and are continuously refined to ensure that assessment and decisions of a scheme bring legal certainty. The standardisation is developed into guidance, methodological support and processes and is outlined in SSIA governance instruments, all of which apply to the social security schemes. Even though the SSIA governance instruments do not have formal legislative power, they are mandatory for the local SSIA caseworkers to follow (Erlandsson, 2014).

The so called "SSIA instruction" is a main SSIA governance instrument that guides the local SSIA caseworkers to apply social security schemes. One instruction per scheme is designed according to the SSIA governance model and developed continuously over time, i.e. refined, to be up to date with requirements for compliance with legislation. The content of the instructions includes description of relevant government bills, current constitutions and regulations, case law and internal SSIA legal standards. The instructions also establish examples of how the standards should be applied in different situations and detailed reviews of practical approaches to different parts of the granting process. The SSIA instruction for the PA-allowance granting process has been developed extensively, by seven generations since 1994. The current generation was adopted in 2003 and was revised in 23 versions by May 2019 (SSIA, 2003).

Theoretical framework

Within policy analysis, policy tool design is central to understanding the mechanism behind the deviations between policy goals and policy outcome (Capano & Howlett, 2020; Hill & Varone, 2016; Howlett, 2012; Barret & Fudge, 1981). The deviations found in the SSIA's policy tool, i.e. the instruction for the PA-allowance granting process in relation to the LSS rationale and policy goals, could potentially be described by the literature on policy tool refinement (Capano & Howlett, 2020; Howlett, 2009). Further, the LSS Act can be viewed as a policy to enable a social active citizenship by fulfilling the LSS policy goals, e.g. to participate in society. The concept “participation in society”, according to the International Classification of Functioning, Disability and Health (WHO, 2001), constitutes in this thesis a measure for assessing the achievement of PA as a social right. Moreover, the literature on the enabling state demonstrates a shift in perspective of the state towards an enabler, i.e. to by measures promote the individual's activation and duties for self-determination rather than distributing benefits to passive recipient (Lindqvist, 2018; Miettinen, 2013; Ellison & Fenger, 2013; Hvinden & Johansson, 2007). This shift in perspective provides an explanation to the design of the SSIA instruction for the PA-allowance granting process, i.e. to assess activities by categories of needs rather than how the activities in question are fulfilling the LSS policy goals. Furthermore, the noted development towards a medicalised SSIA governance model is likely to have contributed to a medicalisation of the granting criteria for PA-allowance (Lindqvist, 2018; Mannelqvist, 2012).

Policy tools to perform a regime logic

Governance scholars have shown a shift from a perspective of a policy implementation steered by the government, to a governance model where society is less depending upon guidance from government authorities (Peters & Pierre, 2016). The concept “governance” is typically divided by the distinction of a “hard” respectively a “soft” approach (ibid). Characteristics of hard governance is an approach of steering by detailed rules and regulating with the purpose to control the way social policies are implemented and by setting a control system for compliance of the bureaucracy and frontline tasks (Peters & Pierre, 2016; Maycraft Kall, 2014) The soft governance approach is a

construction of a less authoritative and more participatory approach. Characteristics of soft governance include knowledge distribution and informal guiding to enhance policy implementation.

The legal bureaucracy model, described by Rothstein, distinguishes the governance model of the SSIA (Andersson et al., 2012; Rothstein & Theorell, 2008). The model is based on a governance that is defined by uniform, neutral and precise rules which have a great duration (Rothstein, 2001). Within this model, public officials strive to assure legitimacy and prevent arbitrariness by the use of standards. These are detailed regulations on how an application of a task should be performed (Erlandsson, 2014). The purpose of standards is to ensure objectivity and impartiality. The standards define a legal bureaucracy as a guarantee for decisions to be consistent with the forms the regulatory framework specifies. The citizen may perceive measures as legitimate through knowledge of rules, which provide for the citizen to foresee the outcome of his or her case (Rothstein & Theorell, 2008). If these rules change too often or abruptly, opportunities for foresight and transparency will be made more difficult. The Achilles heel of the model is a low degree of flexibility which leads to difficulties to find sufficiently precise criteria in order to create rules with a high degree of precision (ibid). The principles of legal bureaucracy are however not adequate to meet the requirement of all demands put on the governance tasks, since rules and regulations rarely provide unambiguous and reliable answers to what is actually a correct decision in each case (Bengtsson, 1998; Power, 1997). Moreover, political governance in Sweden has transformed from focusing on details and goals to increasingly conducting dialogues about coordination, norm formation and negotiations. As a consequence, the governance has grown in complexity due to an increasingly difficult-to-understand communication process (Maycraft Kall, 2014; Bengtsson, 1998). Thus, the operationalisation of the SSIA governance model is partly conducted by the principles of legal bureaucracy but also by normative assumptions (Andersson et al., 2012).

The literature on policy tools illustrates how the regime logic of an organisation play an important role for which policy tools are chosen and performed (Howlett, 2009). An organisation' regime logic is defined by its values, norms and rules, which are perceived as a common base for operation (Greve & Argo, 2015). Over time, the regime logic in an organisation forms a collection of given preferences, i.e. assumptions about how a particular issue or area is defined, and should be applied (Howlett, 2009). As an organisation or context undergoes changes, the regime logic will affect the implementation of a policy by gradually changes its content to fit the assumptions the organisation holds. As a result, the policy in question may become less desirable for the organisation, to the point that the original preferences which shape the approach to the policy persist to exist (Taylor, 1998).

To strengthen the legitimacy of governance, government authorities seek to ensure that not only outcomes are the same, but also that decision-making

processes are run in the same way throughout the organisation by designing policy tools (Capano & Howlett, 2020). A process starts when a policy enters the organisation as a top-down mandate and is successively refined and translated into operating governance instruments, as it moves down the hierarchy to the operative level (ibid). The study of policy tool design sprung from a need to better understand how these governance instruments operate in theory and practice, and on the connection between policy tools and policy implementation failure and success (Hall, 2012; Barret & Fudge, 1981). Policy tools have the purpose to operationalise a first step of a policy and can provide an understanding of how a regime logic of an organisation is applied in practice. Therefore, it is of particularly important to investigate what is happening to policy by the refinements made of policy tools over time. Since the policy tools are based on the regime logic of an organisation, they will adapt to changing conditions (Capano & Howlett, 2020; Peters, 2005). Studies illustrate that policy tools risk generating deviations in relation to the policy the tool is designed to implement. This risk has proven to be more evident in cases where a policy tool is extensively revised over a long period of time, largely adapted and shaped according to the organisation's internal expectations and requirements (Capano & Howlett, 2020; Hill & Varone, 2016; Howlett, 2012; Barret & Fudge, 1981). Thus, the choice of policy tool is a crucial choice in implementing a policy (Vedung, 2009; Linder & Peters, 1989).

A literature review by Campano and Howlett concludes that many studies have focused on the choice and formulation of policy tools. However, there are little empirical research on how different policy tools affects the outcome of specific policies, or how the designs of policy tools have developed over time (Campano & Howlett, 2020). In all, the regime logic of an organisation can in a consistent way influence policy outcome over time through the design of policy tools. Therefore, it is important to identify deviations from the original policy goal to avoid unintended effects in the policy outcome (Hill & Varone, 2016).

The SSIA governance, based on the principles of legal bureaucracy, is assumed to meet procedural justice requirements and intended to strengthen a reliability and legitimacy to the government (Andersson et al., 2012; Rothstein & Theorell, 2008). To strengthen the legitimacy of governance, the SSIA seeks to ensure that the applications of social security schemes are run in the same way by designing policy tools, which are refined over time to apply to current rules and regulations (Paulson, 2012). The discourses on regime logic and policy tools are indicative to explain the mechanism behind the deviations found in the SSIA's policy tool, i.e. the instruction for applying the PA-allowance granting process, in relation to the LSS rationale and policy goals.

Social citizenship and disability rights

Citizenship as a concept emerged with the establishment of the welfare state. In the European tradition, the development of citizenship has mainly concerned the relationship between the state and the individual. Through the development of the welfare state, citizens were given social rights regardless of their position in society. The discourse on citizenship does however, not display a uniform definition and demarcation of the concept. A recognised definition of citizenship however was established by Marshall, who defined a set of human rights by a historical order, i.e. civil rights to enjoy individual freedom (speech, thought, faith, and rights to justice), political rights (to contribute to political power) and social rights (Marshall, 1949).

Social citizenship should be established by providing social support and measures to individuals and thus promote human development by facilitating participation in the community. Issues surrounding social citizenship have increased in importance over time in response to economic and social inequality, especially for women, children and persons with disabilities. Marshall's definition of citizenship has therefore been criticised for being insufficiently specific in order to be used as an analytic tool for a modern and a more diverse society (Sepulchré, 2019; Gynnerstedt, 2001).

The different elements of social citizenship have been developed by specific social rights for eligible groups and by the institutions that guarantee social rights by providing social goods, e.g. social security schemes and social services (Johansson, 2006; Lewin, 1998). Hence, the literature on social rights has come to include different conceptions of welfare rights such as disability, healthcare or social services by two perspectives. The collectivist perspective emphasises general welfare while the individualist perspective emphasises specified, detailed and enforceable rights.

Certain rights are formed when the state recognises the need for specific freedoms or choices, in order to protect or enforce individual or group interests. The launching of disability rights was preceded by the medical model of disability, distinguished by the perception of disability as reduced functionality. The medical model entails persons with disabilities are considered as care objects rather than regarded as active citizens with rights (Andrew et al., 2013; Oliver, 1996). Further, the medical perspective involves a restriction of interventions by healthcare and further a domination of and dependence on professionals. As a consequence, disability is defined in terms of diagnoses and treatments to rehabilitate functionality while the individual is deemed a passive and subservient patient (ibid). As professionals determine interventions, the influence and self-determination of the person with disability is hampered (Lindkvist et al., 2014; Maycraft Kall, 2014). Demands for disability rights to enforce individual autonomy, as citizens with decision-making rights paved the way to a new relationship between the state and persons with disabilities (Maycraft Kall, 2014; Andrew et al., 2013; Lewin, 1998; Hollander, 1995).

This relationship was manifested by the United Nations when adopting the UNCRPD, one of nine core international human rights instruments, in 2006 (OHCHR, 2008). The UNCRPD was formed for the purpose to eliminate obstacles to persons with disabilities enjoying their human rights. The fundamental principles in the Convention are non-discrimination, equality of opportunity, individual autonomy and participation and inclusion with the aim to ensure full and effective participation in society for persons with disabilities (ibid).

In Sweden, disability rights were launched by a first standards of rights in the 1980's and demonstrated a transformation from a medical approach which was considered vital to enhance the social citizenship for persons with disabilities by providing measures for social inclusion (Sépulchre, 2019; Larsson, 2008; Lewin, 1998; Ekensteen, 1968). These standards have remained prominent in Swedish disability policy³ and further enforced by the Swedish ratification of the UNCRPD in 2008 (OHCHR, 2008; Gynnerstedt, 2004). The LSS Act and PA can be viewed as a policy to enhance social citizenship by the provision of measures to support individual specific legal rights, by defining social rights as participation in society and by equality in living conditions (Lewin, 1998).

Defining participation in society by personal assistance

Participation can be described as a multidimensional construct involving two dimensions, i.e. attendance by taking part in an activity and involvement, or the subjective feeling of belonging as a measure of participation (Granlund, 2013). A way to categorise and operationalise participation is by using the International Classification of Functioning, Disability and Health, or the ICF (WHO, 2001). The ICF is a systematic coding scheme, designed to serve in various disciplines. The purpose of ICF is to study all aspects of health, health-related conditions, wellbeing, consequences and determinants on a scientific basis, within the context of environmental and personal factors (Smedby & Dahl, 2002). The ICF is divided into functionalities as well as disabilities and is partly contextual. These overall divisions are in turn subdivided into components and domains. One of these components target activities and participation, include nine different domains. Each of these domains is further divided into a large number of categories that provide the opportunity for a detailed description from both an individual and a societal perspective. The ICF has however, no clear separation between activity, i.e. execution of a task, and

³ The Swedish national plan of action "From patient to citizen" was launched in 2000. The policy goals of the plan state that Swedish disability policy shall promote a community based on diversity; that society be designed so that persons with disabilities of all ages become fully involved in the life of society and equality in the living conditions of girls and boys, women and men with disabilities (The Ministry for Health and Social Affairs, 2000).

participation defined as the individual's perception of their own involvement in an activity that represents a life area. Thus, solely participation by doing an activity can be used as a measure (Granlund, 2013; Badley, 2008). This thesis defines participation in society by PA users reporting of PA activities, by partaking and frequency, through a selection of activities represented in the nine domains according to the ICF.

The enabling state and trend towards a medicalisation of social needs

The discourse on the enabling welfare state describes how the government views conditions for exercising social rights (Lindqvist, 2018; Ellison & Fenger, 2013; Miettinen, 2013; Hvinden & Johansson, 2007). The enabling state originated as a result of high unemployment in European countries, which came to develop a new direction of policy with the purpose to activate the citizen. As a result of this orientation, the welfare institutions in the Nordic countries came to modify their governance model of social security (Johansson, 2006). This shift testifies to ideological motives in perceiving the welfare state from being a protector of rights towards an enabler of rights, based on the assumption that the individual shall take responsibility for their situation and provide for their own needs (Lindqvist, 2018; Miettinen, 2013; Ellison & Fenger, 2013; Hvinden & Johansson, 2007). The change implies that it is the state's task to enable the individual to develop their abilities and competences, which demonstrates a shift in perspective from a passive recipient of benefits to activation (*ibid.*). Hence, the individual's activation and duties for self-determination becomes a given premise for fulfilling a social citizenship (Hvinden et al., 2017).

The standards which are forming the Swedish disability policy apply to the LSS Act of inclusion in society by the provision of measures, distinguished by activation. The rationale of the LSS Act state that the LSS user should take an active part and responsibility in decisions about various aspects of his or her support and further that the LSS measures must not be given in the form of protective care, where the individual him or herself plays a passive role (The Ministry of Health and Social Affairs, 1993). The Act can therefore be viewed as a policy to enable a social citizenship with an implicit activation requirement for persons with disabilities in Sweden to achieve self-determination and independent living (Sépulchre, 2019; Askheim et al., 2014; Christensen et al., 2013). In this sense, the LSS rationale is adjacent to the SSIA governance model, characterized to activate the individual by social measures. This focus on activation may however explain why the SSIA instruction for the PA-allowance granting process is designed to assess and grant PA-

allowance by categories of activities, rather than assessing if or how the activities in question are fulfilling the LSS policy goals, e.g. participation in society.

Furthermore, a change in governance of welfare measures shows that a medicalisation of social needs has become an element in the development of the welfare state (Lindqvist 2018; Conrad, 2007; Zola, 1972). The term medicalisation refers to a process in which perceived non-medical conditions are redefined in medical terms (Conrad, 2005; Zola, 1972). Medicalisation as a phenomenon developed from the 1970's where medicine came to define deviant behaviours as medical rather than social problems (ibid). Medical expertise came to be seen as superior to other professional knowledge in social issues. This direction came to mean that the medical expertise, as well as other actors whose interests in medicalised needs are promoted, categorised individual needs by diagnoses and symptoms (Conrad, 2007). According to Conrad, the medicalisation process is found in three dimensions; of the individual's health status, of interaction where interventions are given and decisions of measures are made; and a dimension of social policy level, consisting of legislation and regulation (ibid). Conrad further states that whether or not a specific diagnosis is used as a motivation to an intervention, depends on a collaboration between social factors, e.g. changing views on the individual's responsibility but also on the welfare state's forms of governance (Lindqvist, 2018; Conrad, 2007). Lindqvist uses Conrad's dimensions to discuss an influence of medicalisation on an institutional level, by changed political policy ambitions and on an organisational level, where social reforms are implemented by providing a medicalised policy application (Lindqvist, 2018). As studies display, the SSIA governance model has been medicalised over time by the use of medical opinions to strengthen legal certainty of the SSIA decisions (Lindqvist, 2018; Mannelqvist, 2012). Thus, the findings of a medicalisation of the SSIA governance model provides an explanation to the development of the SSIA instruction for the PA-allowance granting process, which demonstrates a regression from a measure to enhance a social active citizenship to a more medical model of PA.

The empirical studies

This thesis is based on four studies and four data collections consisting of empirical quantitative and qualitative data (Table 2).

Table 2. Design, participants, data collection material and method for data analyses of the four empirical studies

Study	Design	Participants	Material	Method
I	Quantitative Population study Cross-sectional	Persons eligible PA- allowance <i>N</i> =10.201	Data from questionnaire of 2010 Register data on age, gender and eli- gible person cate- gories	Descriptive non- parametric statistics Principal component analysis
II	Quantitative Cohort study Longitudinal	Persons eligible PA- allowance <i>N</i> =2.565	Data from questionnaires of 2010 and 2015 Register data on age, gender, eligi- ble person catego- ries and hours of PA	Descriptive non- parametric statistics Mixed binominal lo- gistic regression
III	Qualitative Document study		The government bill preceding the LSS Act The SSIA instruc- tion for the PA-al- lowance granting process. Versions 1994 and 2019	Qualitative content analysis ¹ Intervention theory ²
IV	Qualitative Interview study Semi-structured	SSIA public officials <i>N</i> =15	Transcripts of 15 interviews with SSIA public offi- cials, responsible for the	Thematic reflexive analysis ³

Study I – Do personal assistance activities promote participation for persons with disabilities in Sweden?

The aim of the first study was to explore how the right to participation according to Article 19 of the UNCRPD is promoted by PA by examining the distribution of activities reported by persons granted PA-allowance in Sweden across age, gender and eligible person categories. Study I is a population study based on a quantitative, cross-sectional design. The concept of “participation in society” was defined in the study according to the International Classification of Functioning, Disability and Health (ICF), as “a person’s involvement in a life situation”, by partaking and frequency (WHO, 2001). The definition consisted of the following ICF domains; domestic life, interpersonal interactions and relationships, major life areas and community, social and civic life. A questionnaire was distributed in 2010 to all recipients that were granted PA-allowance in 2010. One of the questions contained 22 items that outlined PA activities. For the analyses, variables consisting of SSIA register data were used on age, gender and eligible person categories besides the data from the questionnaire ($N=10.201$). Non-parametric statistics (chi-square test) were used to explore differences among age, gender and eligible person category and across three components. Principal component analysis with varimax rotation was used which showed a high internal consistency reliability of the components by using Cronbach’s alfa. Further, Kaiser-Mayser-Olkin’s measure of sampling adequacy showed 0.945 and Bartlett’s test of sphericity was significant. The total variance explained was 63.8 percent.

Result

Results of Study I display significant differences in reported PA between children and adults, men and women and between the three eligible person categories. Children, men and the eligible group intellectual disability received significantly more PA for activities representing participation in society than adults, women and particularly the eligible group physical disability. The findings reveal an uneven distribution of PA activities across three components, which contents are described as Health and Care; Home, Leisure and Social Interaction; and Daily Occupation. The findings also show that PA is dominated by activities for medical and nursing care, while PA for activities

representing Daily Occupation, such as work and study, were marginal. Study I demonstrates unequal access to participation in society across age, gender and disability category and testifies that PA is promoting activities of a medical nature rather than fulfilling the LSS policy goal of full participation in society.

Study II – Do personal assistance activities promote participation in society for persons with disabilities in Sweden? A five-year longitudinal study

The aim of the second study was to explore whether the PA activities provided by the Swedish LSS Act in 2010 and 2015, promote the right to participation in society according to Article 19 of the UNCRPD. Study II is a cohort study based on a quantitative, longitudinal design from two questionnaires. The first questionnaire was distributed to all recipients granted PA-allowance in 2010. One of the questions contained 22 items that outline PA activities. In 2015, a second questionnaire was sent to a cohort of participants. The same 22 items on PA activities used in the questionnaire of 2010 were included. The cohort consisted of persons granted PA-allowance (≥ 16 years), randomly sampled by gender and age. SSIA registry data were used on age, gender, eligible person categories and number of PA hours besides data from the questionnaires of 2010 and 2015 ($N=2.565$). The use of McNemar's test was motivated to test for nominal data by pairs. That is, in the case when the same individuals are measured twice and there are two outcomes, "yes" or "no". Mixed binominal logistic regression was used to examine correlation between gender and PA hours over time.

Result

The findings reveal extensive PA activities for medical and nursing care. These activities had increased over the five-year period, also among the PA users who have had received fewer PA hours during the studied period. Despite an increase of an average of 16 hours per week for two-thirds of the population, no significant changes were shown for more activities representing participation in society outside the home. The result testifies that fewer activities were revealed, for older groups, and also that PA is being carried out increasingly more at home. Other findings were that ICT i.e. information and communication technologies services, increased the most while activities related to social interaction, leisure, work and studies had over the studied period decreased. Reduced PA for participation in society were shown for women, the elderly and for the third eligible group, persons with special needs. The study further concludes that the increase of PA hours indicates a declining marginal utility, in relation to the LSS policy goal of participation in society.

Study III – Tracing the refinement of policy tools for disability rights; a content analysis of how the granting process of state-funded personal assistance is aligned with the LSS Act.

The aim of the third study was to investigate how the policy tool used to guide the PA-allowance granting process, i.e. the different versions of the SSIA instruction, aligns with the LSS Act's rationale and goals outlined in the original government bill. Study III is a document study based on a qualitative design and inspired by Vedung's intervention theory (Vedung, 2009). The material consists of the government bill preceding the LSS Act and the first (drafted 1994) and last version in time of the study (drafted 2019), of the SSIA instruction for the PA-allowance granting process (SSIA, 2003; SSIA; 1994; The Ministry of Health and Social Affairs, 1993). The SSIA uses a governance model that includes the development and management of a comprehensive instruction to apply the PA-allowance granting process. This instruction is refined over time to be in line with current case law (court decisions) and regulations. The instruction consists beside law and regulations also of strategies, SSIA's own interpretations of legal requirements and working routines. Qualitative content analysis, QCA was used (Krippendorff, 2019). In a first step QCA was conducted on the government bill preceding the Act to outline the rationale and policy goals of the LSS reform. In a second step, the 1994 and 2019 versions of the SSIA instruction to apply PA-allowance were analysed and the content were compared to both the LSS bill and in between the two versions of the SSIA instruction. In a third step content was identified in the two versions of the SSIA instruction that was not found in the LSS bill.

Result

The results display that the SSIA refined instruction from 2019 deviates from LSS rationale and policy goals by new and changes in granting criteria for PA-allowance which implies less participation in society. The result testifies that the design of the SSIA instruction is primarily oriented to assess PA for healthcare measures due to medical conditions, rather than towards the LSS policy goals. The purpose of PA-allowance was found to be unclear in the refined instruction. An extensive fragmentation of the LSS Act basic needs, i.e. detailed and comprehensive description with substantial references to case law, imply stricter granting criteria for the PA applicant to be granted PA-allowance. Together with found modified and medicalised PA granting criteria, the results show that PA has evolved towards user groups with lower ability to exercise empowerment and autonomy. The results reveal new granting criteria for extensive self-care that opens for a blurred interface towards the healthcare sector and changed granting criteria that restricts PA-allowance for access to life arenas representing participation in society, such as PA for

attending school. In all, the result shows an increased professionalisation and juridification of the SSIA instruction, where medical and legal expertise have a decisive and strengthened influence on the design of the instruction. The PA applicant's ability to influence the PA-allowance granting process was found to be weakened over time and increased requirement of reporting the hours of PA used. Furthermore, comprehensive control function over PA-allowance to ensure quality of the SSIA's internal processes was found, however no regulations were found for monitoring the use of PA-allowance or quality control mechanism to ensure the fulfilment of the LSS policy goals. The conclusion of Study III demonstrates that refinements of the SSIA instruction to apply PA-allowance have resulted in a multi-faceted support, characterised by granting criteria for activities to maintain basic health of the PA user.

Study IV – From citizen to patient; how can the medicalisation of personal assistance for persons with disabilities in Sweden be understood?

The aim of the fourth study was to investigate how the development towards a medicalisation of PA can be understood by the experiences of public officials at the SSIA head office, responsible for developing and managing the PA-allowance granting process on the national level. Study IV is an interview study based on a qualitative design of semi-structure interviews. Participants in the study are SSIA public officials at the head office that have experience to develop and manage the granting process of the social security scheme PA-allowance for a minimum of two years. Example of tasks of these officials are for example to set granting criteria for PA-allowance and to educate local SSIA caseworkers. Transcripts of 15 interviews with SSIA public officials, responsible for the development and management of the PA-allowance granting process, were analysed by using thematic reflexive analysis (Braun & Clarke, 2006).

Result

The result shows that the medicalisation of PA-allowance can be explained by external and internal factors. The findings suggest that PA-allowance do not appear anchored in the LSS policy goals. The external impact reveals that foremost legislative changes and case law are the reasons for a medicalisation of the PA-allowance granting process. The result displays a decline of PA user representative participation in SSIA consultations and a marketisation of PA providers, which in all has made it difficult for the SSIA and the government to understand and follow the PA outcome due to a lack of transparency. The SSIA public officials testify to changes of political priorities and a weakened PA collaboration structure over time. These changes have likely resulted in a

lack of insight into PA as a more medical model. An increasing number of PA users with medical needs seem to have brought about an unclear dividing line of responsibilities between PA and healthcare. The results demonstrate that the very complex application of PA-allowance hamper continuity and a long-term perspective to develop the PA-allowance granting process. Insufficient preconditions to regulate and refine the application of PA-allowance according to the LSS policy goals were shown, mainly due to fragmented granting criteria of basic needs. In all, the extensive complexity that characterises the PA-allowance granting process and strained working conditions seem to exhaust attempts to find reliable solutions to the medicalised application to improve the fulfilment of the LSS Act.

Ethical considerations

Ethical regulations and guidelines were followed according to the Declaration of Helsinki (World Medical Association, 2008) and according to the Uppsala University Codex rules and guidelines for research (Uppsala University, 2022). Studies I and II were approved by the Regional Ethical Review Board in Stockholm Sweden (Dnr 2012/1822-31/5). All participants were given written (I, II and IV) and oral (IV) information about the study; that participation was voluntary, that they could withdraw from the study at any time and that the transcript and recordings would be confidentially handled. In the questionnaire studies (I, II), informed consent was considered to have been given when the participants returned the completed questionnaire. According to the Regional Ethical Review Board in Uppsala, no formal ethical approval was needed for Study IV (Dnr 2020-03873). Written informed consent was obtained before the start of the interviews for Study IV.

Discussion

Principal findings and empirical contributions

The overall aim of the thesis is to examine how the national governance of state-funded personal assistance enables to fulfil the Swedish LSS Act policy goals. In all, the findings of the empirical studies reveal a discrepancy between reported and expected outcome of PA in relation to the LSS rationale and policy goals expressed in the bill, preceding the LSS Act. The thesis concludes that PA bears the characteristics of a healthcare measure related to dominant and increased medical conditions and further to a medicalisation of the PA-allowance granting process.

First, a shift of PA towards medicalised conditions was revealed in Study I and II, in particular by the increase of supervision, an activity with an extensive medical and nursing character. Second, the distribution of PA activities shows a reduction over time of PA for an active life, specifically by a margin of PA for daily occupation (such as work or study) and by decreased PA outside the home such as for leisure and movement (Kitis et al., 2017; Leino et al., 2015; Davey, 2007; Aitchison, 2003). Third, the studies demonstrate unequal access to PA activities that represent participation in society across age, gender and eligible person categories. These results highlight an increased risk for social and financial exclusion over time, especially evident for women, older persons and for the third eligible person category special needs (WHO and the World Bank, 2011; OECD, 2010). Study I and II reveal that the LSS legislation has developed in a discriminatory way by not providing gendered equal access to activities that represent participation in society (Reinikainen, 2004; Barron, 2004; Lister, 1990). The decline of PA activities for participation with rising age further indicate the need for adult PA users to be offered support and opportunity to participate in social contexts such as daily activities and leisure time (Kitis et al., 2017; Aitchison, 2003). In particular, the drastic reduction of PA for family over time, shown in Study II, was explained by a decline of family members who work as assistants for their adult child, which may display less support in access to social arenas (Baumbusch et al., 2017; Grossman et al., 2016; Olin & Dunér, 2016). Structures such as access to school, the labour market, accessibility or normative notions are obstacles that can be overcome to a limited extent with the sole support of PA. This finding indicates the need for greater collaboration across sectors of society in order to fulfil the LSS policy goals. Also, reduced participation in PA activities for

the eligible group special needs gives reason to question how PA functions for different groups of users, in light of the medicalised development of PA (Kelly, 2011; Kröger, 2009; Morris, 2004). The noted shift towards a medical and nursing care relationship of PA testifies to an increase of PA users with less ability to control his or her own support.

An explanation to the development of PA being dominated by healthcare measures for medical conditions could be traced to the development of the SSIA instruction, the refined policy tool which outlines the PA-allowance granting process. Study III shows that the LSS Act's rationale and goals has a weak impact on the SSIA instruction and concludes that the changes brought about by the refinements risk to undermine the LSS Act policy goals. Study III confirms findings of previous studies that state case law has had a fundamental impact on the SSIA governance of PA-allowance (Brennan et al., 2016; Erlandsson, 2014). An apparent reason for the PA-allowance medicalisation seems to be attributable to the basic needs stated in the LSS Act and the applicants' right to appeal decisions of PA-allowance to the administrative court. Thus, it can be said that an underlying reason for PA-allowance medicalisation is based on an economic model of cost-sharing between the municipalities and the state. The findings by Study III also confirm conclusions from previous studies which indicate a medicalisation of PA-allowance granting criteria of the basic needs stated in the LSS legislation. These basic needs have undergone changes in the SSIA refined instruction which imply stricter requirements for the applicant's needs to be granted PA-allowance (Sepulchré, 2019; Järkestig-Berggren et al., 2019; Brennan et al., 2016). Hence, the LSS Act rationale and policy goals seem to have decreased over time towards the aim of granting PA-allowance based mainly on assessment of health and care measures for medical conditions. As a result of the SSIA's use of the medicalised PA case law, the purpose of PA-allowance has emerged unclear by instead evolving into a medicalised scheme. As a result, a blurred division of responsibility between PA and the healthcare sector seems to have opened up for an obscure interface.

Study IV displays external factors that have contributed to a medicalisation of PA-allowance, i.e. legal changes in the LSS Act, changed policy priorities and PA collaboration structures, inadequate monitoring of PA outcomes, an extensive complexity of the PA-allowance application process, as well as internal organisational pressure on the SSIA public officials. As Study IV reveals the reasons for the extensive need of case law seems to be due to the lack of stated conditions in the LSS Act. Moreover, the indirect mandate by the design of PA-allowance represents a comprehensive and complicated management that the SSIA have to handle. The high degree of complexity, consisting of many fragmented parts without the overview necessary to comprehend the entire PA-allowance granting process was noted to exhaust the attempts made to find reliable solutions to the medicalisation and to improve the fulfilment of the LSS Act. These conditions, shaped over time, seem to

have hampered a comprehensive view of PA users' needs and contributed to the medicalisation of the PA-allowance granting process.

A scoping review covering the government approach of 40 countries on the management of PA schemes in response to the UNCRPD reveal that even though governments are obliged by the UNCRPD to safeguard participation in society, development shows a tilt towards cost-cutting strategies (Nally et al., 2021). The medicalisation of PA-allowance granting criteria has been identified as the underlying cause of the rejections and withdrawals of PA (Järkestig-Berggren et al., 2019; Brennan et al., 2016). Even though this thesis illustrates that, for example the SSIA has developed legal standards to limit access to PA for children depending on age, the overall findings do not indicate a government strategy of austerity of PA-allowance. Rather, the results indicate that the extensive and medicalised case law has led to a tightening of certain basic needs which sets limits to PA-allowance but also other needs, such as those of the psychological nature, that have few restrictions set by granting criteria and moreover extensive medical needs, e.g. breathing (SSIA, 2022a). Study IV illustrates that case law has been developed primarily by the possibility to appeal against rejected SSIA decisions to the administrative court, as presented by several studies (Brennan et al., 2016; Erlandsson, 2014; Larsson, 2008). Moreover, SSIA's focus on following mainly economic indicators to ensure its own operations, a weakened interaction with collaboration partners and a reduced dialogue with advocacy groups, i.e., disability rights movement representatives, are all factors that hamper an understanding of PA outcome. Thus, the findings of this thesis call for a more diverse ground to illustrate the development of PA.

Methodological considerations

The thesis includes both quantitative and qualitative methods. The data for Study I consists of responses from one questionnaire distributed to PA users granted PA-allowance in 2010 and Study II of responses from the questionnaire of 2010 and a follow-up questionnaire of 2015. The questionnaire of 2010 was distributed to all recipients of PA-allowance in 2010, which provides a solid base for analysis. The questionnaire of 2015 was distributed to a cohort which was large enough to reach statistical power. Since the questionnaires were distributed by mail rather than by other methods, such as digitally online, selection bias concerning limitation to internet was avoided. The respondents were also offered to fill out the questionnaire by phone and by the use of a proxy respondent. Completed questionnaires corresponded to 67 percent of the population for Study I and 65 percent of Study II (cohort). Despite a large proportion of non-respondents, the results are based on 10.201 respectively 2.565 responses, which are considered large groups and as such valuable and useful. The non-respondent analysis of the respondents of the

questionnaire from 2010 showed that these persons in most respects did not differ considerably from those responding, except for a lower response rate among younger ages. The non-respondent analysis of the respondents of the questionnaire from 2015 showed that the youngest and oldest age groups had answered the questionnaire to less extent.

The measure of participation used in Study I is by partaking and frequency in activities. The measure of participation in Study II was also by partaking and frequency in activities, and in addition measured by the development of partaking and frequency. PA activity is defined as the execution of a task or action by an individual (WHO, 2001). The data does not allow the measuring of subjective aspects in relation to participation, such as a feeling of belonging or satisfaction with PA reported. Another limitation of the chosen method for measuring participation is that no data is available to measure availability or accessibility to the activities. Moreover, the activity items of the questionnaire are broad in the sense that they include various forms of sub-activities, such as personal hygiene that may include toileting, hair brushing or showering, and meals may include preparing food, eating or drinking etc. Thus, the data does not allow for more in-depth analysis of the activity content. Still, the distribution of components between user groups displays significant differences across age, gender and eligible person categories in both of the quantitative studies conducted. This empirical material offers a comprehensive picture of the content of the PA performed. The construction of the questionnaires was based on two panels of PA users, but it cannot be ruled out that other panels would have included other activities. Furthermore, a majority had answered the questionnaires in part or completely with the help of a proxy respondent, which constitutes a risk that the answers do not fully represent the view of the respondent. There are after all, few options to capture a heterogeneous population in which a portion of the respondents have a limited ability to communicate without the assistance of another person. Since the questionnaires did not include items covering the subjective experience of participation or another form of personal views in relation to the activities, the proxy respondents were expected to be less sensitive to bias.

Study III and IV are based on a qualitative design. Four strategies in qualitative methods are all essential reflections on trustworthiness, also referred to as rigor (Morse, 2015; Guba & Lincoln, 1989). These strategies consist of *dependability* by performing audit trail; *confirmability* to ensure validity by other readers; *credibility* to provide rigorous methods and techniques for data collection and analysis including peer debriefing, and *transferability* by providing thick description of content, which enhances the degree of transfer findings to other context or study settings. *Reflexivity* is an overall strategy which emphasises the importance of self-awareness, political and cultural consciousness as well as ownership of one's perspective (Patton, 2015).

The material chosen to analyse the alignment of the governance of PA-allowance in relation to the LSS rationale and policy goals in the Study III

were the bill preceding the LSS Act and the SSIA instruction to guide the local SSIA caseworkers in the PA-allowance granting process. There are other government documents of importance in the drafting of the LSS legislation, yet, the original LSS bill is considered to be the most comprehensive in regards to outlining the policy rationale, goals and expected outcome. Further, the SSIA uses other governance instruments apart from the instruction that might have provided different content for the analysis. Even so, the SSIA instruction is considered to be the most cohesive governance instrument developed and used by the SSIA over time, which gives the longest possible timeline of refinements made. Hence the choice was made of the first and last version at the time of conducting Study III of the SSIA instruction as unit of analysis. The design of Study III was inspired by intervention theory by Vedung (Vedung, 2009). Intervention theory aims to reproduce how an imagined course of a policy will be implemented and produce consequences. That is, how the implementation process is intended, conceived, planned to function and give impetus to results. The task of the researcher is to interpret and arrange an unprocessed, “raw” intervention theory in a reconstruction as a tool for analysis. Vedung cites preparatory work as the data source to create this reconstruction, which motivates the choice of the bill preceding the LSS Act as unit of analysis. According to Vedung, a reconstruction process includes assessment elements, which means that outcome may depend on the researcher’s interpretation (ibid). This risk was sought to be minimized by performing the reconstruction by the method qualitative content analysis, QCA (Krippendorff, 2019). QCA interprets social phenomena as communication by texts that concern meanings, content and intentions. The method was chosen as it has an additional advantage of not affecting the sources of what is being analysed and moreover is able to process large volumes of data. QCA provides insight that exceed the comprehension of ordinary readers of textual matter and is widely adopted, hence provide epistemological standards for evaluating content analysis findings (ibid). The results of the analysis in Study III might even so differ due to how the sub-categories and sorting between categories are assessed. By ongoing comparing and reconstruct themes by sub-categories, an assurance of the result was sought.

Reviews of the results of Study III were jointly performed by all authors to enforce dependability and confirmability by peer debriefing and by performing an audit trail. The analyses were made by the first author who has not worked with but is well acquainted with the refinement process for the SSIA instruction. The first author would add credibility to the findings by recognising salient and distorted elements and further transferability by performing thick description of the content and context. As the policy tool refinement process is a central and recurring task for governance, the method may potentially be transferable to similar study settings. In all, these proceedings were essential to achieve trustworthiness of the results.

The data of Study IV consists of transcripts of interviews, conducted with most of the SSIA public officials who are responsible for developing and managing the PA-allowance granting process. The interviews were digitally conducted via Skype. Even though current finding has not concluded significant differences between digital means of communication vis-à-vis face to face, it cannot be ruled out that other means of conducting the interviews might have stimulated probes and answers might have been given in greater detail (Novick, 2008). The sampling procedure of Study IV was strengthening the credibility which involved all officials who met the selection criteria, i.e. a minimum of 2 years working experience of the PA-allowance governance. The interviews were preceded by two pilot tests in order to strengthen face validity and was reviewed by researchers with vast experiences of qualitative methods. A certain degree of saturation was reached and the interviews were recorded and transcribed verbatim (Silverman, 2001) Thematic reflexive analysis (TA) was used. At the general level, there does seem to be little that separates TA and QCA. According to Clarke and Braun, there is no one widely agreed upon set of procedures for QCA however TA claims to offer a recognized systematic procedure (Braun & Clarke, 2020).

Credibility might have been influenced by the principal author, who at the time during which the interviews were conducted held an employment at the SSIA. Thus, biased answers cannot be ruled out, e.g. the officials' need to defend their handling of their tasks. Nevertheless, the interviews yielded a range of responses. Another reflection is that the principal author may have influenced the analyses by own pre-understanding. Repeated discussions of the analyses were performed by all authors to enforce confirmability by the use of a strict method of analysis and peer review. A semi-structured interview guide was used and an audit trail was performed in order to strengthen dependability, i.e. to prevent instability and changes in the data collection process. A thick description of the setting, sampling and the process of analysis was performed to enhance transferability, i.e., the degree of generalisation of results to be used by other studies and in addition a comprehensive description of the PA-allowance context was enforced. PA-allowance is nevertheless complex and ambiguous, thus, other respondent groups, i.e. politicians in charge of PA and local SSIA caseworkers, may have provided different views on the development of PA and PA-allowance. Besides, comparative studies of the implementation of PA have displayed differences in execution and conditions to fulfil Article 19 of the UNCRDP, thus transferability might depend on common features of the measures and contexts (Nally et al., 2021; Askheim, et al., 2014).

Theoretical and policy implications

This thesis shows how the development of the policy tool, i.e. the SSIA instruction for the PA-allowance granting process, has become institutionalised over time by refinement processes which in a fundamental way has hampered the fulfilment of the LSS rationale and policy goals, as expressed in the bill preceding the LSS Act. The findings demonstrate a conflicting logic between the SSIA governance model and the LSS rationale and policy goals. Hence, PA as a mean for a social right to participate in society by individual support, seems to counteract the SSIA governing principle of standardisation and uniformity. The conflicting logics is likely a mechanism which reveal difficulties designing the application of PA-allowance. This thesis shows in particular how the refinement of the policy tool for the PA-allowance application over time have resulted in deviations away from the LSS rationale and policy goals. By these findings, this thesis contributes to fill the identified gap in knowledge shown by Capano and Howlett, that calls for studies which show how policy development affect policy tool use and subsequently policy success or failure (Campano & Howlett, 2020). Furthermore, the empirical findings illustrate that the regime logic of an organisation, through the design of policy tools may thoroughly influence policy outcome over time and emphasise the need for policy tools of social reforms to be continuously calibrated towards original policy goals to uphold policy compliance.

The main contribution of this thesis is nonetheless, on the policy implications due to the noted medicalisation of PA-allowance and of PA as a more medical model. The findings reveal a tilt of the PA user group over time to users in need of more medical support, which can be explained by the gradual development of medicalised needs as granting criteria of PA-allowance. Additionally, the results demonstrate a decisive influence by the medical and legal expertise on the design of the policy tool used for the application in the PA-allowance granting process. These changes illustrate that the PA applicant faces crucial difficulties for exercising influence on the PA-allowance granting process, in particular PA users with less ability to voice their case.

A professionalisation of PA stands in contrast to the political shift in Swedish welfare policy during the 1990's with the vision to abandon a model of significant government influence instead towards the empowerment of the users of LSS measures (Lindqvist, 2012; Lindberg & Grönvik, 2011; Lewin, 1998; Hollander, 1995). Studies on the medicalisation of social security schemes illustrate that the phenomena of medicalised case law apply to the SSIA governance model beyond PA-allowance. The medicalised SSIA governance model indicates a path dependency, likely to have affected the refinement of the policy tool for PA-allowance application (Lindqvist, 2018; Manneqvist, 2012). In this respect, this thesis contributes to a more general trend indicating a medicalisation of Swedish selective welfare measures for protection and security and confirms previous findings which claim that the

promotion of social citizenship has been narrowed (Lindqvist, 2018; Brennan et al., 2016; Mannelqvist, 2012). By this conclusion, the thesis also confirms the findings of Brennan et al. who claim that the development of PA-allowance shows sign of regression in implementing PA as a social right (Brennan et al., 2016). In all, the thesis confirms the conclusions made by Lewin, i.e. that the legal design of the LSS Act does not guarantee the lasting of PA as a social right, nor does it constitute any protection for changes in legislation (Lewin, 1998). The result of this thesis further implies that the policy design of an entitlement law has not been sufficient enough to achieve the LSS policy goals by PA-allowance.

Moreover, the result demonstrates a declining marginal utility of PA-allowance related to PA activities representing participation in society. This finding raises questions about how the SSIA governance model, built mainly on case law, adheres the governing principles of cost-effectiveness to ensure the legitimacy of the state (The Ministry of Finance, 1998). The risk of social exclusion, due to a reduced access to community life, as well as for social and family activities reveal that an increase of PA-allowance over the period studied does not guarantee access to an active life. Unequal access to PA activities representing participation in society also raises concern for a gendered discrimination and a decrease of inclusion in society with increasing age. The findings are in line with scholars showing disadvantage of women with disabilities rights to participation in society on equal terms with men with disabilities (Thomas, 2006; Barron, 2004; Traustadóttir, 2004). By these findings, the thesis reveals weakened conditions to fulfil the intentions set by the Swedish national plan of action to fulfil disability rights i.e. to promote a community based on diversity; that society is to be designed so that people with disabilities of all ages become fully involved in the life of society and equality is ensured in the living conditions of girls, boys, women and men with disabilities (The Ministry of Health and Social Affairs, 2000).

In summation, Article 19 of the UNCRPD, operationalised by the Swedish LSS Act, is recognising disability rights by stating that support by PA should promote full participation in society. The purpose of PA is for the individual to be able to live independently to the greatest possible extent. The thesis however, illustrates a regression of the LSS reform, by gradually resigning to a medical model of PA and a medicalisation of the PA-allowance granting process. As a consequence, Swedish disability policy by PA-allowance is facing major challenges to enable the fulfilment of disability rights as expressed by Article 19 of the UNCRPD.

Avenues for future research

The results and conclusion of this thesis give reason to further study policy implications of the LSS Act. In particular it is of interest to study how PA supports equality in living conditions for persons granted PA-allowance to be able to live like others, which is expressed as a policy goal of the LSS Act. Furthermore, there is need to supplement the results of this study with interviews of persons eligible to PA-allowance to explore the subjective experience of PA in relation to the policy goals of the LSS Act, in particular participation as level of engagement. Importantly, the thesis highlights the need of monitoring the content of PA to achieve the intention of participation in society set out in the LSS Act. Thus, studies that aim to outline a proper follow-up system related to PA-allowance users are central to improve the performance of the LSS legislation.

The results give reason to study the policy implications of the LSS Act at the municipal level in order to identify interacting factors, which can explain why and how the observed transformation of PA, i.e. from citizenship-oriented rhetoric to a model of medical and nursing care has evolved. Research should examine the extent of delegation of medical and nursing care tasks to PA providers, in particular to assess the impact on patient safety and the consequences of not fulfilling the LSS Act.

The findings of this thesis also imply a need to further study the development of case law related to PA as a social service and its implications for enhancing a social citizenship for persons with disabilities. In a broader perspective, it is necessary to acquire more thorough knowledge about the relationship between the enhancement of social citizenship and a medicalised case law with a pervasive influence on the development on disability policy, which would stand as a vital contribution to the discourse on the development of the Swedish welfare state.

Summary in Swedish

Personlig assistans (PA) är en social rättighet enligt artikel 19 i Förenta Nationernas konvention om rättigheter för personer med funktionsnedsättning, UNCRPD (OHCHR, 2008). Enligt artikel 19 ska PA främja jämlikhet och syftar till att inkludera personer med funktionshinder i samhället för att undvika isolering och segregation (ibid). I Sverige kan PA beviljas enligt Lagen om stöd och service till vissa funktionshindrade, LSS (SFS, 1993a). PA utmärks av att användaren själv, eller genom ombud, planerar och ansvarar för organisation och genomförandet av insatsen liksom det egna valet av personliga assistenter.

LSS markerade vid sin tillkomst 1994 ett paradigmskifte, från att se personer med funktionsnedsättning som främst föremål för vård och omsorg till fullvärdiga, socialt aktiva medborgare (Lindqvist, 2012; Hollander, 1995). Insatser enligt LSS syftar till att ge förutsättningar för personer med svåra funktionshinder att leva som andra och främja goda levnadsvillkor för full delaktighet i samhället. Det självbestämmande som lagstiftaren antog skulle uppstå för den enskilde betraktades som en given förutsättning för bättre levnadsvillkor (ibid). Det finns därför ingen definition av kvalitetskriterier i LSS utöver användarens subjektiva uppfattning om kvalitén på sina insatser. LSS reformen utformades som en rättighetslagstiftning vilket innebär att insatser ska beviljas den enskilde utan finansiella restriktioner och att hen har möjlighet att överklaga beslut till förvaltningsdomstol (SFS, 1993a).

LSS tillkom som en kommunal reform, men då kostnader för PA snabbt ökade infördes en delad kostnadsmodell med Försäkringskassan och assistansersättningen infördes som en socialförsäkringsförmån. Kostnadsmodellen innebär att en sökande kan beviljas assistansersättning om denne har särskilda så kallade grundläggande behov, specificerade i LSS lagstiftningen, om minst 20 timmar per vecka (SFS, 2010). Övriga beviljandekriterium är att den sökande är svensk medborgare, under 65 år och tillhör en av lagens tre grupper, eller personkretsar⁴. De första två personkretsarna baseras på en huvuddiagnos bestående av medfödd eller förvärvad funktionsnedsättning. Den tredje

4 Personkrets 1; personer med utvecklingsstörning, autism eller autismsliknande tillstånd: Personkrets 2; personer som fått ett betydande och bestående begåvningsmässigt funktionshinder efter hjärnskada i vuxen ålder föranledd av yttre våld eller kroppslig sjukdom: Personkrets 3; personer som har andra varaktiga fysiska eller psykiska funktionshinder som uppenbart inte beror på normalt åldrande om de är stora och orsakar betydande svårigheter i den dagliga livsföringen och därmed ett omfattande behov av stöd eller service (SFS, 1993a)

personkretsen bedöms utifrån om den ansökande har omfattande stödbehov för att klara den dagliga livsföringen (SFS, 1993a). Användare av assistansersättning är som helhet en heterogen grupp med en mycket bred och varierande grad av flerfunktionsnedsättning och behov (SSIA, 2011).

LSS lagstiftningen har visat sig problematisk att tillämpa för Försäkringskassan. Rapporter har visat svårigheter att i praktiken utforma instruktioner för att exempelvis bedöma vad delaktighet i samhället betyder för den enskilde ansökaren. Rapporterna har även påvisat en oklar gränssättning av PA gentemot hälso- och sjukvård. Det finns också en svag insyn i vilka aktiviteter PA genom assistansersättning i praktiken används till och hur dessa aktiviteter har utvecklats över tid. Dessa förhållanden medför sammantaget att kunskapen om assistansersättningens användning är begränsad. Forskningsresultat visar att utvecklingen av PA kommit att karakteriseras av medicinska och omvårdande insatser. En anledning till denna utveckling är att beviljandekriterium för assistansersättningen tillkommit för medicinska behov (Brennan et al., 2016). Studierna visar att denna utveckling innebär ett underminerande av PA som en social rättighet och därigenom förverkligandet av ett socialt aktivt medborgarskap för personer med funktionshinder (Sepulchré, 2019; Brennan, et al., 2016). Studier visar också det är svårt för Försäkringskassan att i praktiken definiera hur behov av PA ska bedömas för att bevilja assistansersättning. Ett problem är att förvaltningsdomar genom etablerad rättspraxis inte har utvecklat hur LSS policymål ska förstås och operationaliseras. Exempelvis finns lite vägledning från domar att tolka LSS policymål, delaktighet i samhället (Larsson, 2008). Försäkringskassan har därför fått ett begränsat stöd i att utveckla guidning för assistansersättningens handläggning (Erlandsson, 2014). Dessa svårigheter innebär problem att utforma assistansersättningens styrning enhetligt och likformigt enligt förvaltningspolitiska principer, vilket ökar en risk för regionala skillnader i handläggningens utfall. Regionala skillnader indikerar att möjligheten att beviljas PA beror på var i landet den ansökande bor. Ojämliga förutsättningar till stöd underminerar PA som en social rättighet på likvärdiga grunder, men även socialförsäkringens legitimitet (Rothstein & Theorell, 2008). Ett sätt att stärka legitimitet har för Försäkringskassan varit att använda medicinska underlag som styrker handläggningens motiv för att bevilja eller avslå en socialförsäkringsförmån (Lindqvist, 2018). Enligt studier har de medicinska underlagen, till följd av överklaganden till förvaltningsdomstol, över tid kommit att utvecklas genom rättspraxis och medfört en medikalisering av socialförsäkringens styrning (Lindqvist, 2018; Mannelqvist, 2012).

En central fråga är hur dessa trender, som visar på ett skifte mot en medicinsk modell av PA och en ökad medikalisering av Försäkringskassans styrning, påverkar statens förmåga att främja PA som en social rättighet och därigenom möjliggöra ett socialt medborgarskap för personer med funktionshinder. Avhandlingens övergripande syfte är därför att undersöka hur den statliga styrningen av assistansersättning har förverkligat LSS policymål.

Syftet med Studie I var att utforska hur delaktighet i samhället enligt artikel 19 i UNCRPD främjas av PA, utifrån aktiviteter som rapporterats av personer som beviljats assistansersättning. Registerdata över ålder, kön och personkrets samt data från en enkät riktade till alla mottagare av assistansersättning 2010 användes i analysen ($N = 10\,201$). Chi-två-test och principalkomponentanalys användes som metod. Analysen resulterade i tre områden; Hälsa- och omsorg; Hem, fritid och social interaktion och Daglig sysselsättning. Resultatet visar en ojämn fördelning av aktiviteter för PA mellan de tre områdena och signifikanta skillnader mellan barn och vuxna, män och kvinnor samt mellan personer i de tre personkretsarna. Barn, män och den första personkretsen rapporterade mer aktiviteter som representerar delaktighet i samhället än vuxna, kvinnor och den tredje personkretsen. Resultatet visar en ojämn fördelning av de tre områdena där PA för Hälsa- och omsorg dominerade, medan aktiviteter för Daglig sysselsättning, exempelvis arbete eller studier, var marginellt representerade.

Syftet med Studie II var att utforska hur utvecklingen av PA aktiviteter med stöd av assistansersättning mellan 2010 och 2015, främjar delaktighet i samhället enligt artikel 19 i UNCRPD. Registerdata över ålder, kön, personkrets, assistanstimmar samt data från två enkät riktade till en kohort av mottagare av assistansersättning 2010 och 2015 användes i analysen ($N = 2\,565$). Metoderna för analys var McNemars test och binominal logistisk regression för att undersöka korrelationen mellan kön och timmar av PA mellan 2010 och 2015. Resultatet visar att trots en ökning av antalet assistanstimmar motsvarande 16 timmar per vecka och användare av assistansersättning, hade aktiviteter för hälsa- och omsorg ökat och en minskning skett av de flesta aktiviteter som representerar ett aktivt liv utanför hemmet. Denna minskning var särskilt tydligt för kvinnor, äldre och för personer i den tredje personkretsen.

Syftet med Studie III var att undersöka hur ett av de styrinstrument som används för att instruera handläggningen av assistansersättningen inom Försäkringskassan, instruktionen för assistansersättningens handläggning, överensstämmer med LSS rational och policymål. Design av Studie III är inspirerad av Vedungs interventionsteori och kvalitativ innehållsanalys användes som analysmetod (Krippendorff, 2019, Vedung, 2009). Försäkringskassan uppdaterar sin instruktion för assistansersättningens handläggning kontinuerlig för att återge gällande rätt och andra styrsignaler och finns således i flera versioner. Analysenheterna för Studie III var assistansersättningens instruktion för handläggningen år 1994 och 2019 samt den proposition som föregick LSS reformen (SSIA, 2003; SSIA, 1994; The Ministry of Health and Social Affairs, 1993). Resultatet visar att assistansersättningens instruktion från 2019 avviker från LSS rational och policymål, främst genom att den omfattar beviljandekriterier som innebär ett skifte av PA mot mer grundläggande behov⁵ av

5 Grundläggande behov är definierade i LSS lagstiftningen och utgör hjälp med personlig hygien, måltider, klä av och på sig, kommunicera med andra och annan hjälp som enligt LSS

medicinsk och omsorgskaraktär. Vidare visar resultatet att dessa grundläggande behov innefattar kriterier för beviljande av assistansersättningen som fragmenterats eller sönderdelats. Denna utveckling medför striktare krav för en ansökan att bli beviljad. Ändrade beviljandekriterier begränsar också PA att beviljas för aktiviteter som representerar delaktighet i samhället. Studie III visar att PA har utvecklats mot användargrupper med lägre förmåga att utöva självbestämmande och att assistansersättning kan beviljas för en omfattande egenvård genom delegering från hälso- och sjukvården. Resultatet visar även en ökad professionalisering och judikalisering av assistansersättningens instruktion för handläggningen. Denna professionalisering markeras av att medicinsk och juridisk expertis över tid fått ett stärkt inflytande på styrningens utformning, framförallt att rättspraxis har haft ett avgörande inflytande på hur styrningen av assistansersättningen har utvecklats. Resultatet visar en tilltagande kontroll över assistansersättningen för att säkerställa Försäkringskassans interna processer, och att det saknas mekanismer som säkerställer en systematisk uppföljning av hur assistansanvändaren uppfattar kvaliteten på sin PA.

Syftet med Studie IV var att undersöka hur utvecklingen mot en medikalisering av PA kan förstås genom Försäkringskassans tjänstemän, med ansvar att förvalta och utveckla assistansersättningens styrning. Tematisk reflexiv analys av 15 intervjuer genomfördes och resulterade i två teman och tio delteman (Braun & Clarke, 2006). Resultatet visar att medikaliseringen av assistansersättningens styrning kan förklaras av dels externa och dels interna faktorer. De externa faktorerna omfattar förändringar och aktörer utanför Försäkringskassan och består i huvudsak av ändringar eller tillägg i LSS lagstiftningen, en privatisering av anordnare av PA, förändrade politiska prioriteringar, otillräcklig tillsyn av PA på individuell nivå och ett otydligt gränssnitt av PA gentemot hälso- och sjukvården. De interna faktorerna omfattar Försäkringskassans verksamhet och består framförallt av den omfattande komplexiteten som kännetecknar assistansersättningens styrning och en konstant och hög arbetsbelastning på Försäkringskassans tjänstemän.

Studierna visar en diskrepans mellan rapporterat och förväntat utfall av PA i förhållande till LSS rational och policymål. De övergripande resultaten visar en medikalisering av assistansersättningens styrning och en utveckling av aktiviteter för medicinska tillstånd. Resultatet visar att Försäkringskassans styrning inte har operationaliserat hur LSS policymål ska förverkligas genom assistansersättningen. En slutsats är att ökningen av assistansersättningens timmar har en avtagande marginalnytta relaterat till LSS policymål. Resultatet indikerar en ökad risk för social utslagning över tid genom färre aktiviteter som representerar ett aktivt liv, särskilt för kvinnor, äldre personer och för den

förutsätter ingående kunskap om personen med funktionsnedsättning (SFS, 1993a). Två grundläggande behov, andning och sondmatning har tillkommit (The Ministry of Health and Social Affairs, 2019).

tredje personkretsen som rapporterar signifikant mindre aktiviteter som representerar delaktighet i samhället. Resultatet visar därtill att externa faktorer, såsom rättspraxis och ändrade politiska prioriteringar, samt interna faktorer, såsom den komplexa styrningen av assistansersättningen, ytterligare har bidragit till medikaliseringen av PA.

De sammanlagda slutsatserna av avhandlingen pekar på vikten av att upprätthålla en kontinuerlig förståelse av och dialog om PA:s genomförande genom en förstärkt samverkan mellan funktionsrättsrörelsen och ansvariga partner, i syfte att främja LSS policymål. Avhandlingen visar att det finns en motstridig logik mellan den styrmodell som används av Försäkringskassan och hur LSS lagstiftningens är utformad. Avhandlingens resultat visar också att valet av såväl myndighet som styrinstrumentet är av central vikt då villkoren för styrningen kommer att påverkas dels av myndighetens tillvägagång att utveckla styrinstrument och dels av uppdateringar och förändringar som över tid kan leda till avvikelser från de ursprungliga policymålen. Det är därför av betydelse att följa upp sociala reformer och att upprätthålla en kontinuerlig kalibrering av styrinstrumenten för efterlevnaden av politiska visioner och sociala rättigheter.

Sammantaget visar avhandlingens resultat att LSS reformen har glidit från en politisk ambition att förverkliga ett socialt aktivt medborgarskap för personer med funktionshinder mot en mer medicinsk modell. Denna regression urholkar rätten till PA som en social rättighet för full delaktighet i samhället enligt artikel 19 i UNCRPD. Som en följd av detta står den svenska funktionshinderspolitiken inför en betydande utmaning att uppfylla sin målsättning.

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