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Tracing the refinement of policy tools for disability rights: a content analysis of how the granting process of state-funded personal assistance in Sweden is aligned with the LSS Act

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ABSTRACT

Purpose: According to the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments (The LSS Act), personal assistance (PA) aims to enhance good living conditions for people with disability. The Act is operationalised by a policy tool, an instruction developed and refined by the Swedish Social Insurance Agency (SSIA) to grant PA. The study explores how this instruction is aligned with the LSS rationale and goals.

Material and method: Qualitative content analysis was applied on the material i.e., a government bill preceding the LSS Act and the policy tool, i.e., the SSIA instruction, versions 1994 and 2019.

Results: The result shows that the instruction has deviated from the LSS Act over time, by decreasing users' access to community life, a shift towards health care activities, lack of support for the PA user, increased control and service-granting criteria.

Conclusion: This paper emphasises that the selection of policy tools goes beyond mere pragmatism, as they are subject to refinement procedures that have significant impacts over time. The deviations observed in fulfilling the objectives of the LSS Act highlights the importance of ongoing adjustments to policy tools to align with the original policy goals in order to promote disability rights.

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Public policy; policy refinement, personal assistance, disability rights, social insurance

> IMPLICATIONS FOR REHABILITATION

- The study explored how policy tools, which serve as compulsory guidance by outlining the personal assistance granting process for local caseworkers, align with the rationale and policy goals of the Swedish Disability Act and policy goals, aiming to enhance good living conditions for people with disabilities.
- The designs of policy tools are frequently revised and adjusted and consequently influence policy outcome over time.
- Since policy tools are important for the implementation of government policy they need to be reviewed and monitored in order to secure original policy goals with the ultimate aim of enhancing good living conditions and advancing disability rights.

Introduction

Policy tools, aimed at operationalising policy rationales and goals, provide an important step to implement governmental policy. Each policy tool constitutes a condensed form of guidance on how to control and apply a government policy. How the administration in charge of policy implementation perceives and acts on the policy is a possible bias and may influence the choice of policy tools [1]. Thus, choosing the appropriate policy tool for policy fulfilment is most important in strategic political planning [2,3]. Policy tools, however, are not neutral devices, as they produce specific effects independent of the policy and operate according to the logic on which they are constructed [1,4].

Although policy tools have been the topic of continuous research, there is a need to deepen knowledge on how these tools work, moreover, how designs of policy tools develop and how they are refined over time [5]. The procedure of successively

refining policy tools is crucial in adjusting to changing conditions, such as changes of a legislation or organisational mandates. Government administrations, assigned to refine policy tools, emerge in this aspect as central players for the implementation of governmental policy [6,7]. It is thus of particular importance to understand how those refinements reflect the original policy rationale and goals, and further to identify and investigate deviations in order to understand what is being implemented and to apprehend possible unintended effects and consequences of the policy tools used [4–8].

Personal assistance: a measure of the LSS Act

In the mid-90s, the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments, known as LSS Act [9] was a ground-breaking reform to enhance disability rights,

by measures that support the user to live like others and promote good living conditions. A crucial aspect of the LSS reform is the promotion of user independence, minimising the need for state interventions. Personal assistance (PA) is one of the ten measures in the LSS Act. The hallmark of PA is that an assistant helps with activities that the user would otherwise have done if it were not for his or her impairment. PA is individually granted from birth to the age of 65 and covers a wide range of eligible groups with regard to impairment and intellectual, physical or special needs [9,10].

Allowance to grant costs for PA for users with severe needs is administered by the Swedish Social Security Agency (SSIA). The PA-allowance service-granting process is outlined in a policy tool, an instruction, developed and successively refined by the SSIA over time [11]. This policy tool comprises guidance, i.e., interpretations of legal requirements, assessment criteria for PA needs, SSIA's working routines and processes. Thus, the instruction can be viewed as an overall implementation strategy of a Swedish social security scheme, where the content of a legislation or a reform is operationalised and applied. The instruction constitutes the primary and compulsory guidance for local SSIA caseworkers in applying the PA-allowance granting process. Over time, the SSIA's instruction for the PA-allowance granting process has undergone recurring refinements and have been produced in different versions.

Case law has been shown to influence the refinement of the SSIA's instruction of PA-allowance [12–14]. According to studies, refinements of the SSIA's instruction has resulted in an increased number of withdrawals of PA-allowance and more PA allowance applications being rejected [12,15,16]. SSIA's use of case law has also shifted the PA-allowance criteria towards needs for basic health and care. Moreover, the case law has not been developed to cover the whole LSS legislation. A lack of case law to operationalise the LSS policy goals of living independently was found, which hampers SSIA's efforts to develop the PA-allowance criteria to fulfil the LSS policy goals [13–15]. Yet other studies found that the content of PA activities has over time shifted towards health and care efforts, with decreased access to community life and severe risks of social isolation [10,16].

A systematic literature review highlights the importance of PA in promoting personal autonomy and independent living for PA users and the need to better understand and strengthen the governance of PA programs [17]. Several challenges in the implementation of PA, including insufficient resources in particularly PA hours, overly complicated administration to grant and administer PA schemes, and a lack of awareness about the concepts of independent living for persons with disability were identified [18–20].

The research also emphasises a need for user-led PA schemes, for robust legislation and policies aligned with the social model of disability, increased funding, and improved governance to enhance the quality and effectiveness of PA programs [19,20]. Moreover, a tension is noted between cost-cutting governmental approaches and the fulfillment of policy for independent living [20]. Additionally, one study discusses the importance of developing a tool for evaluating PA schemes [21]. The results of these studies demonstrate the need to further investigate how the management of PA is designed and how policy for PA is implemented in practice [17–21].

Regarding PA in Sweden, there are no previous studies on how the SSIA's instruction itself, and the changes and refinements made over time may have affected PA. Hence, the aim of this study was to explore how the SSIA's instruction used to guide the PA-allowance granting process aligns with the LSS Act's rationale and policy goals outlined in the original government bill.

Background: the LSS Act

The LSS Act is based on a biopsychosocial model of disability, which defines disability as the distance between hindering and facilitating circumstances in the surrounding environment and a person's impairment. Thus, environmental conditions are decisive for whether or not a congenital or acquired physical, mental or cognitive impairment entails a disability for a person [22].

The LSS Act aligns with Article 19 of the United Nations Convention on the Rights of Persons with Disabilities, which aims to enhance empowerment by personal assistance to promote equal opportunities in life and full participation in society for the user in order for him or her to live independently in order to be able to live in a way that is equitable with others [23]. Since 1994, the PA administration has been a shared responsibility between the municipalities and the state. While the municipality remains primarily responsible for implementing the LSS Act, the SSIA administers, assesses and grants PA costs by PA-allowance for applicants who have certain basic needs stated in the LSS Act that exceed 20h per week [9,10]. Thus, PA grants are given by either the municipality or the state depending on the number of hours needed. Like in Norway and Denmark, PA can be combined with mainstream services such as municipal homecare [24].

Method

In the study, we explore whether and to what extent the first and the last version of the SSIA's instruction used to guide the PA allowance granting process were aligned with the LSS rationale and goals. This was done by tracing changes in the SSIA's instructions over time and comparing them with the preparatory work preceding the LSS Act, i.e., the original LSS bill.

Design

The analysis has three steps. The first analysis was based on a model inspired by Vedung's intervention theory [2]. Questions derived from Vedung's intervention theory were formulated and used to describe the content of the LSS rationale and goals found in the original LSS bill. The questions informing the analysis were as follows: *Which was the problem the policy was about to solve and the policy goals?; Which were the intended activities and outcomes?; Who were the recipients? Who were the actors of implementation and administration?; Which processes were suggested for the implementation?; What follow-up were required?*

The second analysis was based on the description of the LSS rationale and goals, based on responses to the above-mentioned questions. A comparison was made of the content to find similarities and differences between the description of the LSS rationale and goals and the SSIA's instructions.

The third analysis was based on the SSIA's instructions to find content that was not stated in the content description of LSS rationale and goals in the original LSS bill.

Material

The preparatory work preceding the LSS Act was used in the first analysis to describe the LSS rationale and goals, henceforth referred to as "the Bill" [22].

The material used for the second and third analyses were the SSIA's instructions used to guide the local SSIA caseworkers in the PA-allowance granting process. The first version containing

61 pages [25] and the last version containing 197 pages [11] of the instruction were chosen for the analyses, in order to achieve the longest possible timeline of refinements made. The instructions are henceforth referred to as I¹⁹⁹⁴ [25] and I²⁰¹⁹ [11]. The Bill was downloaded as an open source from the website of the Swedish parliament, the Riksdag [22]. I¹⁹⁹⁴ and I²⁰¹⁹ were collected upon request to the SSIA in printed and digital form.

Data analysis

Qualitative manifest content analysis (QCA) was applied for all three analyses in different ways [26].

In the first analysis, a QCA was applied to the Bill, using questions from Vedung's intervention theory presented in the design section. The relations between Vedung's questions and the eight themes found are presented in Table 1.

In the second analysis, those themes, categories and sub-categories yielded from the Bill in the first analysis were used to analyse the compliance of the SSIA's instructions I¹⁹⁹⁴ and I²⁰¹⁹ to the LSS rationale and goals. We assessed the compliance by using three alternatives: (1) Aligned content, (2) Absence of aligned content and (3) Adjusted content. There were two requirements to assess the content as aligned: One was there should be a similar meaning as stated in the Bill, and second was that the content should also be explicitly defined and described, i.e., operationalised. "Absence of aligned content" was defined when the content in the Bill was not found in the instructions or if the content was found but not operationalised. "Adjusted content" was defined as changes in the description of the content compared to the Bill.

In the third analysis, QCA was applied to the instructions to identify additional content, not found in the previous analysis. This inductive analysis yielded two new themes, "Time measurement" and "Reporting." The two additional themes are highlighted (italics) in Table 1.

Coding and categorisation were done using a text analysing programme [27].

Trustworthiness

The analyses were conducted by the first author who is well acquainted with, but has not worked with, the refinement process

Table 1. The relation between the intervention theory questions and themes forming the LSS rationale and goals yielded from the Bill and from the second and third (italic) analysis of the instructions.

| Intervention theory questions | | Themes yielded from second and third analysis | |
|-------------------------------|---|---|-------------------------|
| 1 | Which was the problem the policy was about to solve and the policy goals? | 1 | Empowerment |
| 2 | Which were the intended activities and outcomes? | 2 | Self-fulfilment |
| 3 | Who were the recipients? | 3 | Health and care |
| | | 4 | Individuals |
| | | 5 | Families |
| 4 | Who were the actors of implementation and administration? | 6 | Position of actors |
| 5 | Which processes were suggested for the implementation? | 7 | Application |
| | | 8 | <i>Time measurement</i> |
| 6 | What follow-up were required? | 9 | <i>Reporting</i> |
| | | 10 | Quality assurance |

of the SSIA's instructions and is thus able to recognise salient and distorted elements, adding credibility to the findings [28].

Reviews of the results were jointly performed by all authors to enforce dependability and conformability [28]. Dependability and credibility of the study were further strengthened by the choice of data and by thoroughly and systematically tracking changes in the policy instrument over time. By analysing the data both deductive and inductive, it was possible to assess impact of the rationale and policy goals of the LSS Act on the SSIA policy instrument and further to identify new aspects. By using both approaches, a comprehensive picture was created as the categories cover the data. Analysing the results by a systematic procedure and a high level of detail was chosen to enhance authenticity and transparency of the context [28].

As the refinement process for policy tools is a recurring and central task for governance, the method is expected to be potentially transferable to similar studies of policy tools. However, the results might differ depending on how the sub-categories and sorting between categories are assessed.

Ethical consideration

Public documents, open sources, from the Swedish parliament (The Riksdag) and SSIA were used. There are no consequences for individuals connected with the collection or analysis of data.

Results

The LSS rationale and goals according to the Bill

The rationale of the LSS reform, expressed in the Bill preceding the LSS Act, was to compensate for past efforts that were not considered sufficient to enhance disability rights. The Bill describes how persons with disabilities and their families experience being vulnerable, subordinated and excluded from society. Examples of hindrances for good living conditions are also mentioned, such as perceived prejudice about disability, patronising attitudes by the healthcare and social service professions, inflexible regulatory systems and a lack of individualised planning and social service capacity.

The result forming the LSS rationale and goals yielded eight themes. First, the LSS policy goals is to achieve *empowerment* (Table 2) for persons with disability, i.e., to shape and direct the user's own life by measures that enhance *social rights* by enhanced equality and by providing opportunities to participate in society. Further, the LSS expects to promote *autonomy*, i.e., enhanced independence and freedom of choice for the user based on the individual's wishes. The LSS also intends to provide *safety* for the user by ensuring continuity and duration of the measures, which should be based on a comprehensive holistic view of the user's situation and needs. A limited number of PA is a quality aspect of LSS that can support the user's integrity.

Second, PA is described as a flexible support that is, the user should be active in planning and implementing the *PA activities* ensure the user a degree of *self-fulfilment*, see Table 3. Access to "Arenas," such as work, leisure and *own living* arrangement is highlighted in the Bill in order to enhance good living conditions, and to live a life like others. Equality in living conditions underlies demands for certain standards, life conditions, facilities and programmes for persons with disabilities, as close to normal circumstances as possible. However, the Bill does not elaborate more on how this vision is supposed to be realised. Besides PA for "Health and Care," such as meals or selfcare, the Bill to a

Table 2. Theme, categories and subcategories consisting of policy goals and sub-goals encompassed by the Bill and the SSIA's instructions 1994/2019.

| Theme | Category | Subcategory | Bill | I ¹⁹⁹⁴ | I ²⁰¹⁹ |
|-------------|---------------|-------------------------------------|------|-------------------|-------------------|
| Empowerment | Social rights | Biopsychosocial model of disability | 1 | 1 | 2 |
| | | Participation in society | 1 | 1 | 2 |
| | | Equality | 1 | 1 | 2 |
| | Autonomy | Independent | 1 | 1 | 0 |
| | | Self-determination | 1 | 1 | 2 |
| | | Influence | 1 | 1 | 2 |
| | | Participation in PA | 1 | 1 | 2 |
| | | Freedom of choice | 1 | 1 | 2 |
| | Safety | Continuity | 1 | 1 | 2 |
| | | Duration | 1 | 0 | 0 |
| | | Holistic view | 1 | 1 | 0 |
| | | Integrity | 1 | 1 | 1 |

I¹⁹⁹⁴= PA instruction 1994.I²⁰¹⁹= PA instruction 2019.

0 = not found.

1 = found.

2 = adjusted.

Table 3. Themes, categories and subcategories consisting of PA activities and outcomes encompassed by the Bill and the SSIA's instructions 1994/2019.

| Themes | Category | Subcategory | Bill | I ¹⁹⁹⁴ | I ²⁰¹⁹ | |
|-----------------|---------------------|-------------------|------|-------------------|-------------------|--|
| Self-fulfilment | Arenas | Work | 1 | 1 | 2 | |
| | | Daily activities | 1 | 1 | 2 | |
| | | Study | 1 | 2 | 2 | |
| | | School activities | 1 | 1 | 2 | |
| | | Leisure | 1 | 1 | 2 | |
| Health and care | Own living | | 1 | 0 | 0 | |
| | Nursing concept | | 0 | 0 | 1 | |
| | | Basic needs | | | | |
| | Personal hygiene | Dressing | 1 | 1 | 2 | |
| | | Meals | 1 | 1 | 2 | |
| | | Enteral nutrition | 0 | 0 | 1 | |
| | | Communication | 1 | 2 | 2 | |
| | | Supervision | 0 | 0 | 1 | |
| | | Other needs | | | | |
| | | Other basic needs | 0 | 0 | 1 | |
| | Hab-/rehabilitation | 1 | 1 | 0 | | |
| | Daily rest | 1 | 1 | 1 | | |
| | Self-/healthcare | 1 | 0 | 2 | | |
| | Multiple assistants | 0 | 1 | 1 | | |

I¹⁹⁹⁴= PA instruction 1994.I²⁰¹⁹= PA instruction 2019.

0 = not found.

1 = found.

2 = adjusted.

Table 4. Themes, categories and subcategories consisting of support for applicants and recipients of PA encompassed by the Bill and the SSIA's instructions 1994/2019.

| Themes | Category | Subcategory | Bill | I ¹⁹⁹⁴ | I ²⁰¹⁹ |
|-------------|------------------------------|-------------------------|------|-------------------|-------------------|
| Individuals | Children | Participation | 1 | 0 | 0 |
| | | Care | 1 | 1 | 2 |
| | Own control Eligible persons | | 1 | 1 | 0 |
| | | | 1 | 1 | 1 |
| Family | Spouses | | 0 | 0 | 1 |
| | Parents | Relief for family | 1 | 2 | 0 |
| | | Parents with disability | 1 | 1 | 1 |
| | | Parental responsibility | 1 | 1 | 2 |

I¹⁹⁹⁴= PA instruction 1994.I²⁰¹⁹= PA instruction 2019.

0 = not found.

1 = found.

2 = adjusted.

Table 5. Themes, categories and subcategories consisting of processes and actors involved in the assessment of granting assistance-allowance for PA encompassed by the Bill and the SSIA's instructions 1994/2019.

| Theme | Category | Subcategory | Bill | I ¹⁹⁹⁴ | I ²⁰¹⁹ |
|--------------------|--------------------------------|----------------------------------|------|-------------------|-------------------|
| Application | Responsibility by municipality | | 1 | 1 | 0 |
| | | Changes after initial decision | 0 | 1 | 1 |
| Position of actors | Legal position | Reappraisal | 0 | 1 | 1 |
| | | Changed conditions | 0 | 1 | 1 |
| | | Systematic review | 1 | 1 | 0 |
| | | Medical opinion | 0 | 0 | 1 |
| | | Delegating self-care | 1 | 1 | 2 |
| | Non-medical positions | Health and care actors' opinions | 0 | 0 | 1 |
| | | Municipality opinion | 1 | 1 | 2 |
| | | School/Daily activities opinions | 0 | 0 | 1 |
| | | PA provider opinion | 1 | 2 | 2 |
| | | Individual opinion | 1 | 2 | 2 |
| Time measurement | Activities | | 0 | 0 | 1 |
| | Distribution of time | On call | 0 | 1 | 0 |
| | | Dwell time/Contingency | 0 | 1 | 1 |

I¹= PA Instruction 1994.I²= PA Instruction 2019.

0 = not found.

1 = found.

2 = adjusted.

lesser extent exemplifies activities intended to fulfil the LSS policy goals.

Third, the individual user's *own control* of PA is described in the Bill as essential for fulfilling the LSS policy goals, emphasised by acting as own employer of PA assistants. However, the intended *recipients* for the LSS measures are also families in cases when *children* need extensive care due to disability (Table 4). The LSS Act targets *eligible persons* with an acquired or congenital physical or mental disability. In line with the biopsychosocial model of disability, neither the cause, the nature of the disease or the injury, nor the medical diagnosis are of decisive importance to be eligible for support according to the LSS Act. The Bill states that impairment must be of such a nature that it strongly affects several important life arenas simultaneously.

Fourth, a structure of *actors*, responsible to implement the LSS Act aimed to secure the *application* process and opinions of both *medical* and *non-medical professions*, i.e., representatives of school or other form of daily activities, and moreover to support the opinion of the *individual* (Table 5).

Fifth, a close *collaboration* was envisioned as crucial for *quality assurance* of the LSS measures (Table 6). The Bill states that the LSS measures should be made in conjuncture with other social services according to the Social Service Act [29], moreover granted regardless of budget constraints. The municipalities were suggested as head principal of the reform, while the SSIA was given an administrative function for handling the PA costs. Strategic initiatives, such as comprehensive follow-up, i.e., *monitoring* and *individual plans* to clarify the outcome of PA, were stressed to ensure the user's opinions were taken into consideration. Challenges to act as employers for persons with less ability to

Table 6. Themes, categories and subcategories consisting of aspects of quality assurances encompassed by the Bill and the SSIA's instructions 1994/2019.

| Themes | Category | Subcategory | Bill | I ¹⁹⁹⁴ | I ²⁰¹⁹ |
|-----------------------------------|--------------------|----------------------------------|--------------|-------------------|-------------------|
| Reporting | Internal reporting | Reporting obligation within SSIA | 0 | 0 | 1 |
| | | Children at risk | 0 | 0 | 1 |
| | | Control investigation | 0 | 0 | 1 |
| | External reporting | | 0 | 0 | 1 |
| | Quality assurance | Collaboration | PA providers | 1 | 1 |
| Municipality basic responsibility | | | 1 | 1 | 0 |
| Health and Medical service | | | 0 | 0 | 1 |
| Individual plan | | | 1 | 0 | 0 |
| Customize operations | | | 1 | 0 | 0 |
| Monitoring Guardianship | | | 1 | 0 | 0 |
| | | | 1 | 1 | 2 |

I¹⁹⁹⁴= PA instruction 1994.I²⁰¹⁹= PA instruction 2019.

0 = not found.

1 = found.

2 = adjusted.

control his or her support are also mentioned in the Bill. Legal *guardianship* is suggested so that the user's voice is heard to ensure that the user receives the support he or she wishes.

How do the SSIA's instructions comply with LSS rationale and policy goals compared to the Bill?

The analysis of the Bill revealed that the LSS policy goals are divided into sub-goals, presented as sub-categories in Table 2. The result in Table 2 shows a comparison of how these sub-categories are described in the Bill and in the SSIA's instructions.

The result yielded one theme, three categories and 12 sub-categories (Table 2). Compared to the Bill, one difference was found in I¹⁹⁹⁴, and 11 differences emerged in I²⁰¹⁹. The sub-category "Integrity" was found to be consistent over time, while "Duration" was not found in the instructions. In I²⁰¹⁹, eight adjustments were found when comparing to the Bill, and three sub-categories were not found. Neither of the two instructions addressed operationalisation or provided a description of the sub-goals.

I¹⁹⁹⁴ portrays SSIA as an active actor with an obligation to enhance social rights and autonomy for the users of PA. In I²⁰¹⁹ the LSS goals are described in an introduction section, however, no references to how PA can enhance user autonomy was found, nor references to an obligation or mandate of the SSIA to fulfil the policy goals of the LSS Act.

Furthermore, categories and sub-categories in Table 2 are operationalised in I²⁰¹⁹ with demarcations in relation to the Bill. For example, the category "Autonomy" is described to be limited to the user's relationship with his or/her assistants. The sub-category "Influence" is described to be important in situations related to certain physiological needs and "Freedom of choice" when choosing an assistant. Moreover, in I²⁰¹⁹, the category "Safety" was found to be limited to the importance of a few individual assistants for privacy-sensitive needs, while the sub-category "Continuity" was found to be related to continuous support 24 h a day, albeit not over a period of time, nor by a continuum of assistants.

A comprehensive view of the individual's needs, identified as an essential aspect of the rationale expressed in the Bill, was not found in I²⁰¹⁹. Further, I²⁰¹⁹ does not contain a description of how

different PA activities support compliance with the LSS policy goals, for instance, by stating the potential effects of PA.

In all, the results show that the LSS policy goals are only to a small extent operationalised in I²⁰¹⁹. Also, development of the sub-goals found in I²⁰¹⁹ limits the rationale set out in the Act.

How do the instructions comply with expected PA activities and outcomes compared with the Bill?

Table 3 shows PA activities and expected outcomes described in the Bill, compared to I¹⁹⁹⁴ and I²⁰¹⁹.

The result yielded two themes, five categories and 16 sub-categories. In I¹⁹⁹⁴, five differences emerged between the sub-categories when compared to the Bill, one of which was not found in the Bill. In I²⁰¹⁹ 17 differences emerged, of which five were not found in the Bill. An addition of one category "Nursing concept," three sub-categories and ten adjustments were found, with reference to extensive case law and legal assessments.

The category "Own living" was not found in the instructions, while sub-category "Daily rest" was found to be consistent over time. In I¹⁹⁹⁴, "Self-/healthcare" was not found. Furthermore, adjustments in I¹⁹⁹⁴ regarding sub-categories "Studies" and "Communication" were also found in I²⁰¹⁹. The sub-category "Multiple assistance," i.e., more than one assistant at a time needed for lifting and moving, was found in I¹⁹⁹⁴ and also considered an eligible reason for PA according to I²⁰¹⁹.

While enhanced access to and participation in life arenas were mentioned as being of central importance in the Bill, limits to PA-allowance for activities promoting participation were found in the instructions. In I²⁰¹⁹, PA for school or daily activities was found only to be granted for users in need of the sub-categories "Supervision" and "Communication" and thus excludes access to PA to these arenas for other users. Correspondingly, limitations to PA-allowance were found for children in I²⁰¹⁹ due to regulations defining "Parental responsibility." Moreover, while the Bill emphasises leisure time as being of great importance for living a life on one's own terms, very few references were found regarding leisure in either of the instructions. A list of leisure activities was found in I²⁰¹⁹, however without description or references.

Although the Bill exemplifies needs such as hygiene, meals, or training, none of these are cited as prerequisites for PA eligibility. A concept "Basic needs" was found in I¹⁹⁹⁴, i.e., "Hygiene," "Meals" and "Dressing/Undressing," henceforth referred to as physiological needs, moreover "Communication." These needs must amount to a minimum of 20 h per week in total for the applicant to be granted PA-allowance. In I²⁰¹⁹, another "Basic needs" was added, "Supervision."

The activities within the theme "Health and care" are of a nursing character and extensively described in I²⁰¹⁹. In particular, the activity "Supervision" was described in I²⁰¹⁹ to prevent self-harm, violence and aggression against others, property and to prevent escape. "Supervision" can also be granted to activate and motivate the user to manage other "Basic needs," also regardless of the users' own wish or understanding why the activity needs to be undertaken.

Criteria for the physiological needs have not only been fragmented in I²⁰¹⁹ i.e., divided into several delimited and separate sub-parts, moreover with a prerequisite that requires a physical contact between the user and assistant when these activities are performed. Examples include assessment of "Personal hygiene," where needing the assistant to brush the user's teeth qualifies as a "Basic need," but merely having the assistant apply toothpaste on the toothbrush does not. Correspondingly, "Dressing" includes

the assistant helping the user put on the underwear, but not outerwear. As for "Meals," if PA is needed to take the fork to the mouth, it is considered a "Basic need," however not for preparing or cutting up food. Furthermore, while the purpose of "Communication" in the Bill and in I¹⁹⁹⁴ was to participate in society, in I²⁰¹⁹, "Communication" was limited to maintain social contacts and for communication regarding physiological needs, such as hygiene and meals. PA for "Supervision" may be granted either as an activity in its own right or in conjunction with "Meals" and "Enteral nutrition" in cases where the PA user needs to be fed and does not understand the need for nutrition.

Correspondingly, "Basic needs" of children are instructed to be assessed in the same way as adults, but the criteria for PA-allowance depends on the age of the child.

The influence of nursing is also strengthened in I²⁰¹⁹ by the term "Other needs." "Other needs" includes various PA activities such as leisure or habilitation in I¹⁹⁹⁴. The description in I²⁰¹⁹ regarding "Other needs" is primarily of a basic nature, but not regarded as fulfilling the criteria for the first 20h of PA "Basic needs," therefore not taken into consideration in the initial SSIA's decision. Examples may be PA for putting on shoes, outerwear or preparing food.

In sum, additions in I²⁰¹⁹ related to nursing and care were found and limitations to PA activities for promoting participation in society. A trend was found towards fragmented and stricter criteria for physiological needs and for PA concerning children. As a result, the extensive fragmentation of "Basic needs" implies stricter criteria for the user's need to be assessed as basic, i.e., to qualify for PA-allowance.

How are the applicants and recipients described in the instructions compared to the Bill?

The Bill presumed that PA promotes enhanced self-determination for the user and his or her family. Table 4 shows the approach expressed in the Bill towards PA-allowance applicants and recipients compared to the SSIA's instructions.

The result yielded two themes, five categories and five sub-categories. There were two differences found in I¹⁹⁹⁴ compared to the Bill, and six differences emerged in I²⁰¹⁹, of which one was an addition in the theme "Family" compared to the Bill.

Justification for eligibility for PA, "Eligible persons" and sub-category "Parents with disability" was found to be consistent over time. The sub-category "Participation" found in the Bill was not found in any of the instructions. The category "Own control" and sub-category "Relief for family" were not found in I²⁰¹⁹.

Even though children's participation is mentioned in the Bill, the needs of children are primarily described as care, which is also reflected in the instructions. Equality in up-bringing conditions is stated in I²⁰¹⁹ and a reference to the UN Convention on the Rights of the Child [30]. Neither the Bill nor the instructions distinguish between how support or care differs between children and adults.

Moreover, responsibility for a spouse was identified in I²⁰¹⁹ but not in the Bill. The responsibility entails that a division of household chores between the PA user and the spouse will be considered in the PA-allowance granting process. The responsibility of the spouse diminishes with their increasing age, thereby more PA hours by PA-allowance may be granted.

A change found in the analysis of I²⁰¹⁹, "Parental responsibility," implicates restrictions and delimitations of PA-allowance for children. I²⁰¹⁹ includes a detailed and comprehensive model to assess

children's needs based on age groups, i.e., the needs of children of the same age without a disability is used as a comparative reference. When "Basic needs" of an applicant exceed beyond those of the reference groups, the criterion for granting PA-allowance is met. Thus "Parental responsibility" is expected to decrease as the child grows older and more PA-allowance can be granted.

In all, PA for the user's participation and own control were found weakened in the assessment criteria for PA-allowance over time. Also, more restrictions and regulations were found to grant PA-allowance for the purpose to relieve family, parents or spouse.

How are actors and processes of implementation and administration described in the instructions compared to the Bill?

According to the analysis of the Bill, the autonomy of the individual would be strengthened by limiting the influence of professionals. However, the result in Table 5 shows that over time, the design of the SSIA's instruction reflects a decisive influence of medical and legal actors.

The result yielded three themes, seven categories and 12 sub-categories, which is an addition of three categories and seven sub-categories compared to the Bill. In I¹⁹⁹⁴, six differences emerged compared to the Bill, of which four were not found in the Bill, i.e., they were new additions. In I²⁰¹⁹, 14 differences emerged, of which eight were new additions.

According to I²⁰¹⁹, the user has to notify SSIA when the need for PA is reduced, alternatively may apply for more PA-allowance if needs are increased. Requirement for a systematic reappraisal for quality control of PA was not found in I²⁰¹⁹ which stands in contrast to the Bill and I¹⁹⁹⁴. As shown in Table 5, the influence of legal and medical professionals in the PA needs assessment is prominent in I²⁰¹⁹. Further, I²⁰¹⁹ refers to extensive legal references, i.e., 59 judgments, 24 legislations and regulations and 5 EU directives, all beyond the LSS Act. For example, the EU directives address specific aspects of organising assistants working schedule and the coordination of social security systems, rather than focusing directly on disability rights. I²⁰¹⁹ also contains references to 24 government bills, which refer to other legislation besides the LSS Act. Moreover, 36 legal interpretations by the SSIA were found in I²⁰¹⁹. Thus, the result illustrates a decisive influence by the legal profession on the content and design of I²⁰¹⁹.

I²⁰¹⁹ also testifies to medical influence. Medical statements are mandatory in the PA-allowance granting process according to I²⁰¹⁹, but not in I¹⁹⁹⁴. Opinions on the applicant's needs for PA can also be given from other health and care professions, and so may influence the PA-allowance granting process. In addition, medical doctors are seen as advisory in I²⁰¹⁹, primarily to assist the local SSIA caseworkers in identifying and describing the applicant's diagnosis, disability and activity restrictions. The applicants' needs can also be expressed by legal guardians, assistants or PA providers.

Non-medical actors shall according to I²⁰¹⁹ report which additional support the applicant has received from other agents. While the municipalities' responsibility for PA as the LSS head principal was described in the Bill and in I¹⁹⁹⁴ no description was found in I²⁰¹⁹.

A discrepancy between the Bill and the two instructions was found regarding that the applicant is supposed to partake in the PA-allowance granting process. The result in Table 5 shows that the SSIA's instructions state the importance of maintaining dignity for the applicant during the need assessment and further during

the granting process. However, how the local SSIA caseworkers is supposed to ensure that the applicant's wishes are met is not described. In contrast, if the applicant themselves declines to participate in the PA-allowance granting process, the application is considered valid according to I²⁰¹⁹. However, the role of guardianship is extensively addressed, for instance, including a right to sign time reports regarding the PA provided.

The Bill stipulates an overall time limit of 40h of PA per week but it does not further elaborate around the conditions for the time calculation. A thorough calculation of time for PA "Basic needs" (Table 3) was found central to the PA needs assessment in both of the SSIA's instructions. The procedure of time calculation in I²⁰¹⁹ can be described as detailed, elaborative and comprehensive, calculating needs down to the minutes and seconds. Terms such as "active" and "inactive" time have been added and redefined, distribution of time around-the-clock has changed compared to I¹⁹⁹⁴, and exceptions with regard to family relationships are found in I²⁰¹⁹ (Table 5).

Importantly, once 20h of PA "Basic needs" has been assessed and granted, additional PA-allowance can be applied for "Other needs" (Table 3). These needs lack a guidance for time calculation and have no upper limits of PA hours that can be granted.

In sum, legal and medical actors were found to have a decisive influence on the I²⁰¹⁹ design. It is also clear that the instruction is largely based on SSIA's use of case law. As a result of this, the influence of the municipalities and users have decreased over time. Furthermore, a thorough system for calculating PA needs was found only in I²⁰¹⁹.

Is the required follow-up stated in the Bill realised by the instructions?

A collaboration structure among LSS actors was suggested in the Bill to ensure comprehensive follow-up and supervision, in order to secure quality for the LSS user. The result shows that the meaning of quality assurance has changed over time.

The result yielded two themes, five categories and eight sub-categories. The theme "Reporting" is a new addition compared to the Bill. Three differences were found between the Bill and I¹⁹⁹⁴. In I²⁰¹⁹, 11 differences emerged, of which five were not found in the Bill, i.e., they were new additions.

I²⁰¹⁹ testifies to extensive control and report obligations internally within the SSIA. The primary objective of collaboration with other actors according to I²⁰¹⁹ is to counteract erroneous costs of PA and for financial control of PA providers. Additionally, I²⁰¹⁹ states that the SSIA lacks a mandate to monitor PA's performance to favour the user's right to exercise own control over PA. This approach differs from the Bill and I¹⁹⁹⁴, which enforce support to the LSS user to uphold his or her right to quality assurance, coherent planning and follow-up of LSS measures. This support is to be provided by the municipality as the head principal of the LSS, in close collaboration with relevant agents and agencies. However, in I²⁰¹⁹, the municipality's role is downplayed and only mentioned in cases where the PA needs to be temporarily extended. Further, tools for a support system stated in the Bill such as individual plans, were not found in I²⁰¹⁹. While the Bill and I¹⁹⁹⁴ enforce the user's autonomy, I²⁰¹⁹ holds references to guardianship for PA users with less ability to plan and organise PA.

In all, Table 6 shows that the content and the process of follow-up has shifted over time, from a quality assurance of PA for the individual user, to monitoring the SSIA's PA-allowance granting process. In particular I²⁰¹⁹ testifies to a comprehensive reporting obligation in order to prevent fraud regarding PA costs.

Discussion

The aim of the study was to explore how the PA policy tool, i.e., the SSIA's instructions to guide local SSIA caseworkers in the PA-allowance granting process is aligned with the LSS rationale and policy goals, outlined in the original LSS bill.

The findings show that the original vision in LSS is only to a limited extent realized in the latest instruction. As a result, efforts to enhance empowerment for the PA user appeared weakly anchored in I²⁰¹⁹. The discussion below addresses how the refinement process of the PA policy tool, traced by the development of I²⁰¹⁹ may have affected the ability to fulfil the goals of the LSS Act.

The LSS policy goals have a weak impact on the refined SSIA's instruction

As shown in the results, I²⁰¹⁹ was found to be designed to assess applicant's needs primarily for nursing care. Due to additions made over time, I²⁰¹⁹ proves that PA has evolved into a form of care, characterised by interventions such as supervision, enteral nutrition as well as extended form of self-care rather than support the person's participation in society.

The purpose of PA in I²⁰¹⁹ was also found to be unclear and ambiguous, regardless of the LSS policy goals that have remained unchanged over time. The unclear purpose of PA may have developed due to several reasons. One reason may be that the revisions in I²⁰¹⁹ were necessitated by many legal changes, in particular descriptions of "Basic needs" in the LSS Act and moreover by SSIA's own legal interpretations of case law. Over time, these additions may have changed the focus of PA towards "Basic needs," i.e., activities for mainly care. It may also be that the LSS Act lacks necessary prerequisites to operationalise its policy goals by case law [15].

Moreover, lack of systematic follow-up of the PA provided offers limited feed-back for the SSIA to refine the instruction to align them the LSS Act [31]. A hampered knowledge of how PA is used in practise may have resulted in a gradual move of the concept of PA towards a model that deviates profoundly from the LSS Bill. Furthermore, a very far-reaching marketisation of PA providers and lack of government inspections have over time resulted in a lack of transparency regarding PA performance [32]. Thus, these results align with a need for an evaluation tool, presented in a study by Mladenov [21].

Another finding in the study was the extensive fragmentation in I²⁰¹⁹, i.e., a detailed and comprehensive description of criteria of both basic physiological needs and of children's needs, with references to peer groups of children without a disability. This fragmentation implies that stricter requirements are placed on the applicants' needs in order to grant PA-allowance. This stands in contrast to the rationale of the Act, i.e., that the needs of applicants and families should be assessed based on a comprehensive view of the applicants' life situation, rather than on details of a specific need.

A sharp decline in PA-allowance between 2015 and 2021 [12,31] came as a result of the fragmentation of "basic needs" and age for children. Since fragmentation leads to added criteria to be granted assistance-allowance, it has been referred to as a strategy to control PA costs by the government [33]. The additions of granting criteria may therefore point to a dilemma in reconciling the LSS policy goals. This finding aligns with a review of user-led PA schemes which shows that European governments tend to limit access to the services or to provide basic care services only [20].

Due to case law, additions of regulations as conditions for appraisals were found in I²⁰¹⁹. This means that depending on the time of application different conditions apply for access to PA across user groups. Also, since case law is based on individual cases, rather than on an impact assessment of the heterogeneous group of PA users, the use of case law will affect sub-groups of PA users differently [10,13]. In all, changed granting conditions in I²⁰¹⁹ reveals obstacles for getting access to PA on equal terms over time, which raises questions on how the instruction aligns with the LSS policy goal of equality.

The development of the SSIA's instruction testifies of a move towards a medical model of disability

Although the result suggests that eligibility for PA has remained unchanged over time, modified assessment criteria regarding the "Basic needs" may have affected the profile of users granted PA-allowance. In particular, the basic need "Supervision" resembles in-patient psychiatric care, with extensive elements of control and surveillance by assistants, i.e., elements of coercion to deal with aggressiveness or escape and physiological needs. Moreover, there is no description in I²⁰¹⁹ on how "Supervision" is compatible with the LSS rationale of promoting empowerment for the user, in particular autonomy, as expressed in the Bill. This is an important finding that aligns with challenges raised in previous studies, which indicate a lack of awareness of the concept of independent living among actors responsible for implementing PA schemes [18–20]. Also, since PA is not covered by a regulatory framework corresponding to a care context, "Supervision" may indicate flaws in patient security. Thus, the presence of "Supervision" illustrates that PA has evolved towards users with a lower ability to exercise autonomy [34].

According to previous studies, a dilemma arises when users are expected to be able to live in a way that is equitable with others with equal opportunities in life and full participation in society, but in reality, are impeded from exercising autonomy [34,35]. Thus, this dilemma may occur when the fulfilment of LSS policy goals is reserved for users who are more inclined to assert their right to autonomy.

Medical statements were found mandatory in I²⁰¹⁹ as a requirement to initiate the PA granting process. These statements could also include extensive delegation of self-care from the health care sector to the PA. This regulation constitutes a second dilemma by opening up for potentially extensive medical interventions within PA, thus entailing a risk that PA may function as a relief for the healthcare sector [36]. A far-reaching medical delegation may also be a hindrance to promote "Autonomy" for the user since PA transfers to a nursing care relationship [37–39]. Thus, the I²⁰¹⁹ design implies a risk that the PA will overlap with the responsibilities of the healthcare sector.

In sum, the refinement of the SSIA's instruction illustrates a shift to more users with extensive care needs, and that PA activities mostly are provided for maintaining basic health needs. This is a tilt that risks undermining the purpose of the LSS Act.

A decline of PA for participation and well-being

Beside "Basic needs," I²⁰¹⁹ lacks descriptions and operationalisation of "Other needs," such as work or leisure. Due to a change made in the SSIA's instruction between I¹⁹⁹⁴ and I²⁰¹⁹ more PA was available for users needing "Supervision" to access life arenas. For the other users, PA to participate in activities outside the home, such as daily activities at a day care centre, is supposed to be provided and financed by the municipality.

This makes the user dependent on being granted other services that may in turn hamper opportunities to participate in society. This finding is in line with previous studies that reveal significantly decreased PA for daily employment or work, studies and leisure [16].

Since non-work, rather than paid employment, is common for persons with severe disabilities, leisure is of significance for a meaningful life, and plays a vital role in habilitation and rehabilitation processes as well as for creating and maintaining social relationships [40,41]. Moreover, the regulation may also affect families since stricter criteria for granting PA-allowance for children were found in I²⁰¹⁹. This is contrary to what is stated in the Bill, where support for families due to disability was emphasised.

In sum, changes indicate that the refinement of the SSIA's instruction over time has shifted towards users with lower ability to exercise autonomy and less PA is offered for activities that represent participation in society.

A shift from support and quality assurance for the individual to a dominance by professions and to an organisational focus

The analysis of I²⁰¹⁹ illustrates that the medical and legal professions have a decisive influence on the PA-allowance granting process. In contrast, the municipality and other actors representing social sectors were found to have a more subordinate role in spite of lobbyist activities by disability stakeholders and civil society [42]. The findings suggest that the PA-allowance granting process by I²⁰¹⁹ only includes requirement for medical assessments and also state that medical doctors have an advisory role to the local SSIA caseworkers. As shown in a study by Lindqvist [43], the SSIA governance model uses medical opinions to strengthen legal certainty of the SSIA's decisions. However, the influence by medical opinions entails a risk that contributions from social actors will be overlooked.

Even though the Bill proposed guardianship for the user with less ability to exercise autonomy, it also states that an application for PA must be based on the individual's freedom of choice, i.e., the application is done voluntarily and according to the applicant's wishes. However, the applicant's ability to influence the PA-allowance granting process was not reflected in I²⁰¹⁹. The Bill states that the user's subjective experience of PA should guide the fulfilment of the LSS policy goals. The guidance by I²⁰¹⁹ provides the local SSIA caseworker that by own discretion, i.e., own judgement and/or estimation could decide whether a certain amount of PA-allowance is adequate to fulfil the LSS policy goal of good living conditions for the applicant. This finding is in line with studies that show that the PA-allowance granting process leaves extensive space for discretion by the local SSIA caseworkers, due to lack of standardised procedures [10,14]. Another example is that representatives or guardians may apply for PA on the individual's behalf, without his or her formal consent. In all, these regulations constitute weakened conditions for individual empowerment and are in line with a study which found that applicants are not heard during the PA-allowance granting process [33].

Additionally, an ambitious structure to ensure quality of LSS measures was found in the Bill, i.e., collaboration, monitoring and follow-up. In I²⁰¹⁹, only monitoring and control requirements aimed to secure SSIA's granting process were found. Instruments to ensure quality according to the Bill, an individual plan to support the user, and systematic monitoring were not found in I²⁰¹⁹. Consequently, there is no administrative review of LSS policy fulfilment to ensure systemic corrections. One explanation might be that SSIA does not consider it to be within its mandate to

exercise authority beyond the PA-allowance granting process. This is concluded for ensuring policy alignment, which was suggested in previous studies of PA [19–21].

¹²⁰¹⁹ was found to be refined by extensive legal positions, based on adjudgments and characterised by a high level of abstraction and complexity. Consequently, the refinement procedures may aggravate the PA user's possibility to pursue his or her case, in particular, users with less ability to exercise autonomy. Also, legal access, i.e., the right of the applicant to have his or her case tried based on the Bill, was found to be unclear in both the SSIA's instructions. Findings of another study also show that the SSIA is characterised by a governance to ensure a uniform application of cases [44]. However, as users of PA is an extremely heterogeneous group, legal positions that aim to ensure that cases are treated equally, may fail to consider decisive differences and different conditions among PA users.

Hence, the SSIA's mandate, the domination of legal and medical professions in the complex design and execution of ¹²⁰¹⁹, the municipalities' subordinate role, as well as the focus on SSIA's own operation for control and unclear legal access for the user, may have undermined the intended support structure set out in the Bill. As a result, the applicant and/or user face crucial difficulties to without representatives who have legal skills handle his or her case, i.e., to participate, follow and express own will in the PA granting process. Moreover, the findings show that a description in the SSIA's instructions of what PA is supposed to pursue is lacking.

Policy implications and future research

Taken together the changes brought about by the refinement of the SSIA's instruction may have undermined the framework for empowerment set out in the Bill. PA has resulted in a multifaceted support, characterised by activities to maintain basic health, rather than formed to fulfil the expected policy effects of the LSS Act.

This study stresses that the choice of policy tools is more than a pragmatic matter, and that they will be influenced by refinement procedures over time resulting in deviations from the original rationale and goals. Thus, the findings demonstrate clearly that the governance of social reforms need to include continuous calibrations of the policy tools over time in order to guarantee that the original policy goals are fulfilled.

The results highlight the importance of complementing this study with further studies to better understand why these changes in the SSIA's instruction have occurred and to identify the factors that have driven these changes.

Conclusions

This content analysis demonstrated that the SSIA's instruction for determining PA granting criteria did to a limited extent reflect the rationale and policy goals set out in the Bill preceding the LSS Act. Deviations include: a shift towards PA activities for medical and nursing care; a decline in PA for empowering the user; a shift to more users with extensive medical and nursing care needs implying less ability to shape and control PA; as well as a strengthened professional influence on the process of granting and controlling PA. In all, these changes hinder the fulfilment of disability rights. Further, a strong focus by the SSIA to control its own operation, the municipalities' subordinate role and a weakened support system for the PA user. The results conclude that the SSIA policy tool for assessing PA need is an ambiguous measure to fulfill disability rights. Thus, the aim of fulfilling the LSS rationale and goals in accordance with the Bill by PA-allowance

seems to have diminished over time. In order to promote disability rights in Sweden, this study illustrates the importance to maintain continuous calibrations of the instruction used for the PA-allowance granting process to ensure that refinements align with the LSS rationale and goals. This is of particular importance for PA users with less ability to voice their case.

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