

**Selina Griesser**

selina.griesser@gmail.com

Matrikelnr.: 20150702

Master Program Development of Social and Health Services

Catholic University of Applied Sciences Freiburg

**Personal Assistance for Disabled People  
in Germany and Sweden  
in the Context of the Independent Living Philosophy  
and the UN Convention on the Rights of People with  
Disabilities**

Interviews with Personal Assistance Users  
and Independent Living Activists

**Master's Thesis**

First examiner: Prof. Dr. Gregor Renner

Second examiner: Prof. Dr. Jens Clausen

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## **Abstract (English)**

Article 19 of the UN Convention on the Rights of Persons with Disability (CRPD) states the right for disabled people to live independently and to be included in the community. The article includes the right to personal assistance as a tool for independent living. General Comment Number 5 on Article 19 of the CRPD criticizes the inadequacy of the implementation of this right and gives clear criteria, which define the term personal assistance. These criteria have to be fulfilled in order to call a service personal assistance. The aim of the present work is to evaluate the German and Swedish systems of personal assistance on their compliance with the CRPD. The research question asks how the practical implementation of the personal assistance systems in Germany and Sweden fulfill the requirements of the criteria defining personal assistance according to the General Comment on Article 19 of the CRPD in comparison to their theoretical implementation. Besides a theoretical evaluation of the systems, semi-structured interviews with experts were conducted to answer the research question. Six interview partners who are assistance users in Germany and Sweden were asked how they evaluate the implementation of personal assistance according to the requirements of the General Comment. Qualitative Content Analysis according to Mayring (2015) was used to analyze the interviews. The results of the theoretical and practical evaluation show that neither Germany nor Sweden fulfills all requirements of the General Comment on personal assistance. In both countries, the systems of personal assistance were rated better in the theoretical than in the practical implementation. The main problem in both countries is the funding of personal assistance. The funding is not based on personalized criteria and is not sufficient to cover all assistance needed. In Germany, disabled people have to fight for a sufficient budget, which can vary between authorities. Furthermore, German assistance users often have to pay a personal contribution depending on their income and assets. In Sweden assistance users experienced cut-backs in personal assistance allowances because of reinterpretations of basic needs as an eligibility criterion. The results show that the personal assistance systems in Germany and Sweden are in need of improvement. The presented work provides a basis to promote the political discussion about personal assistance as a tool for independent living.

## **Abstract (Deutsch)**

Nach Artikel 19 der UN-Behindertenrechtskonvention (UN-BRK) haben Menschen mit Behinderung das Recht auf eine unabhängige Lebensführung und die Einbeziehung in die Gemeinschaft. Artikel 19 enthält zudem das Recht auf Persönliche Assistenz als ein Instrument für ein selbstbestimmtes Leben. Der UN-Ausschuss für die Rechte von Menschen mit Behinderung kritisiert in seinem General Comment Nr. 5 zu Artikel 19 der UN-BRK die mangelhafte Umsetzung des Rechts und gibt klare Definitionskriterien vor, die erfüllt sein müssen, um eine Dienstleistung als Persönliche Assistenz im Sinne der UN-BRK zu bezeichnen. Ziel der vorliegenden Arbeit ist es, das deutsche und schwedische System der Persönlichen Assistenz hinsichtlich ihrer Übereinstimmung mit der UN-BRK zu überprüfen. Die Forschungsfrage fragt, inwieweit die praktische Umsetzung der Persönlichen Assistenz in Deutschland und Schweden die Anforderungen der Definitionskriterien von Persönlicher Assistenz nach dem General Comment zu Artikel 19 der UN-BRK im Vergleich zur theoretischen Umsetzung erfüllt. Neben einer theoretischen Überprüfung der Systeme wurden zur Beantwortung der Forschungsfrage teilstrukturierte Experteninterviews geführt. Sechs Interviewpartner, die Assistenznutzer/innen in Deutschland und Schweden sind, wurden gefragt, wie sie die Umsetzung der Persönlichen Assistenz hinsichtlich den Anforderungen des General Comments beurteilen. Die Interviews wurden anhand der qualitativen Inhaltsanalyse nach Mayring (2015) ausgewertet. Die Ergebnisse zeigen, dass weder Deutschland noch Schweden alle Anforderungen des General Comments erfüllt. Die Systeme der Persönlichen Assistenz schneiden in der theoretischen Beurteilung besser ab als in der Bewertung der praktischen Umsetzung durch die interviewten Experten und Expertinnen. Das Hauptproblem liegt in beiden Ländern bei der Finanzierung der Assistenz. Die Finanzierung basiert nicht auf personalisierten Kriterien und ist nicht ausreichend, um die gesamte benötigte Assistenz zu decken. In Deutschland müssen behinderte Menschen für ein ausreichendes Budget kämpfen, welches wiederum vom Kostenträger abhängt und meist eine Eigenbeteiligung zahlen. In Schweden haben Assistenznutzer und -Nutzerinnen Kürzungen der Persönlichen Assistenz erfahren, da die Voraussetzungskriterien der sogenannten Grundbedürfnisse neu ausgelegt wurden. Die Ergebnisse zeigen, dass die Systeme der Persönlichen Assistenz in Deutschland und Schweden verbesserungsbedürftig sind. Die vorliegende Arbeit kann als Grundlage für die politische Diskussion dienen, um die Persönliche Assistenz als Instrument für ein selbstbestimmtes Leben für Menschen mit Behinderung zu fördern.

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## List of Abbreviations

ANED	Academic Network of European Disability Experts
CRPD	Convention on the Rights of Persons with Disabilities
ENIL	European Network on Independent Living
IL	Independent Living
ILI	Independent Living Institute
ILC	Independent Living Centre or Organization
LSS	Lagen om Stöd och Service till vissa funktionshindrade / Act Concerning Support and Service for Persons with Certain Functional Impairments
SGB	Sozialgesetzbuch / Social Code Book
GG	Grundgesetz / Basic Law of the Federal Republic of Germany
Skoll	Skollag / Education Act
SoL	Socialtjänstlag / Social Service Act
HSL	Hälso- och Sjukvårdslag / Health- and Medical Service Act

## List of Translations

### German - English

Agentur für Arbeit	Employment Agency
Ansprechstellen	Contact Centers
Eingliederungshilfe	Integration Support
Ergänzende unabhängige Teilhabeberatung	complementary and independent participation counseling
Geldleistungen	direct payments
Gemeinsame Servicestellen	Common Service Centers
Hilfe zur Pflege	Help for Care
Integrationsamt	Integration Office
Kriegsopferfürsorge	victim provision
Leistender Rehabilitationsträger	Performing Authority
Pflegeversicherung	care insurance
Rehabilitationsträger	Rehabilitation Authorities
Rentenversicherung	pension insurance
Schwerbehinderung	severe disability
Selbstbestimmt Leben	Independent Living
Sozialgesetzbuch, SGB	Social Code Book
Sozialhilfe	social benefits
Teilhabeplankonferenz	participation plan conference
Teilhabeplan	participation plan

Trägerübergreifendes Persönliches Budget	comprehensive personal budget
Wesentliche Behinderung	substantial disability
Wohlfahrtsverbände	welfare associations

### **Swedish - English**

Bilstöd	car allowance
Bostadsanpassningsbidrag	home adaptation allowance
Diskrimineringslag	Discrimination Act
Förordning	regulation
Försäkringskassan	Social Insurance Agency
Funktionshinder	disability
Funktionsnedsättning	impairment
Hälso- och Sjukvårdslag	Health- and Medical Service Act
Handikappersättning	disability allowance
Lagen om stöd och service till vissa funktionshindrade	Act Concerning Support and Service for Persons with Certain Functional Impairments
Skollag	Education Act
Socialförsäkringsbalk	Social Insurance Code
Socialstyrelsen	National Board of Health and Welfare
Socialtjänstlag	Social Service Act

Sveriges Kommuner och Landsting, SKL

Swedish Association of Local Government and Regions

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## **1 Introduction**

Since the French comedy-drama film 'The Intouchables' (German: 'Ziemlich beste Freunde') made its public appearance in cinemas around the world, personal assistance is widely known as a service for and controlled by disabled persons. Personal assistance is organized differently in many countries. The present work focusses on personal assistance in Sweden and Germany and its compliance with the UN-Conventions on the Rights of Persons with Disabilities (CRPD).

In this introduction, the topic and issue of the following thesis will be presented. To get an overview, the structure of the work will further be explained.

### **1.1 Topic and Issue**

In the US of the early 1970s, disabled students moved out of residential hospitals and started fighting for an accessible environment and independent living. The Independent Living Movement started and disability was no longer only seen as an impairment of an individual. Disability was connected to a social and political issue of missing adaptations that disables people to participate in society and live an independent life. Many years later, the concept of Independent Living played an important role in drafting the CRPD, which was adopted by the General Assembly of the United Nations in 2006 (ENIL - European Network on Independent Living 2012). Article 19 of the CRPD states the right to live independently and to be included in the community. According to the CRPD, living independently means "the equal right of all persons with disabilities to live in the community, with choices equal to others" (Art. 19 CRPD). This article also includes the right to "personal assistance necessary to support living and inclusion in the community" (Art. 19 CRPD). Personal assistance is an individual, user-led human support for disabled people to promote independent living (Committee on the Rights of Persons with Disabilities 2017, p. 5).

Sweden and Germany ratified the CRPD in the years 2008 and 2009 and, therefore, are obligated to implement the provisions and promote, protect and monitor the rights stated in the Convention. The Committee on the Rights of Persons with Disability plays a supervisory role in monitoring the compliance of the CRPD.

In 2017, the Committee published the General Comment Number 5 on Article 19 of the CRPD and recognized a common "inadequacy of legal frameworks and budget alloca-

tions aimed at providing personal assistance and individualized support” (Committee on the Rights of Persons with Disabilities 2017, p. 3). Furthermore, in state reports the Committee criticized Germany and Sweden for their insufficient implementation of the provisions (Committee on the Rights of Persons with Disabilities 2014, 2015). The Committee also criticized the inadequate implementation of Article 19 and gave recommendations on how to improve the compliance (Committee on the Rights of Persons with Disabilities 2014, p. 6, 2015, p. 7). The Committee made clear that the allocation of personal assistance is in need of improvement. But neither in state reports nor in General Comment Number 5 there is a complete evaluation of the Swedish or German system, which reveals all the aspects that need to be improved.

In Germany and Sweden, personal assistance is organized in different ways. The Committee recognizes the national differences in the implementation of personal assistance and makes clear what distinguishes personal assistance from other services. General Comment Number 5 gives clear criteria, which define personal assistance and which must be fulfilled to call a service ‘personal assistance’ in the sense of the CRPD.

According to the CRPD, disabled people have the right to personal assistance as a tool for independent living. To ensure the exercise of this right and improve its implementation, it is necessary to prove how personal assistance services are implemented in the countries and how the systems fulfill the requirements of the CRPD. Personal assistance is considered a ‘system’ since it can be seen as a complex of elements that are connected by structuring and organizing the right to personal assistance. This terminology is valid both in Sweden and Germany.

The following work reviews how personal assistance is implemented in Sweden and Germany and evaluates the systems from the perspective of the Independent Living concept as represented in the General Comment on Article 19 of the CRPD. This includes both the theory and the practical implementation. The thesis does not ask if personal assistance is available, but how the existing systems comply with the criteria defining personal assistance according to the General Comment. In a first evaluation, it is assessed how the systems of personal assistance in Germany and Sweden fulfill the criteria of the General Comment in theory. Furthermore, interviews with personal assistance users in Germany and Sweden are conducted and used to compare with the theoretical evaluation and to assess the practical implementation. The work concentrates mainly on physically disabled adults. Disabled children and mentally disabled people are not excluded, but they are not in the center of interest of this thesis.



The thesis was written in cooperation with the Independent Living Institute in Stockholm. The Independent Living Institute was founded by Adolf Ratzka in 1993 and is a “policy development center specializing in consumer-driven policies for disabled peoples' freedom of choice, self-determination, self-respect and dignity” (Ratzka n.d.a).

## **1.2 Structure of the Thesis**

To analyze the Swedish and German system of personal assistance, the work is structured as follows. The work includes three major parts: the theory, the theoretical evaluation of the personal assistance systems and the evaluation of the practical implementation of the both systems.

The first part of the thesis illustrates the theoretical basis: Independent Living and personal assistance (chapter 2), Personal assistance in Germany and Sweden (chapter 3) and the CRPD (chapter 4). As a theoretical background, the concept of Independent Living will be introduced by presenting the history of the Independent Living Movement, the definitions and the philosophy of Independent Living (chapter 2.1). Furthermore, personal assistance will be explained by describing the definitions and organizational models (chapter 2.2). To understand the German and Swedish systems of personal assistance, the specific welfare models and disability policies are illustrated. Both systems will be explained using the same structure to be able to compare them and to work out differences: the legal framework and responsibility, the eligible group of persons, the assessment of demand and calculation, the provision and models, the persons working as personal assistants and figures concerning personal assistance (chapter 3). The systems are described as they were at the time of January 2018. In a next step, the background to the CRPD, Article 19 and the General Comment on Article 19 are described (chapter 4).

The second part of the work contains the theoretical evaluation of the personal assistance systems in Germany and Sweden (chapter 5). First, the criteria defining personal assistance according to the General Comment are presented followed by the evaluation of how the systems fulfill these criteria. The theoretical evaluation is based on the description of the personal assistance systems in chapter 3 as well as further literature and sources. It focusses on the theoretical organization of personal assistance in both countries and not on personal experiences of the practical implementation.

The evaluation of the practical evaluation is the third part of the thesis. To review how the systems fulfill the criteria of the General Comment not only in theory but also in practice, a practical evaluation through a qualitative research will be conducted. Therefore, the empirical research is introduced by presenting the current state of research and the research question. Further on, the research design is described (chapter 6). In order to evaluate the practical implementation of personal assistance, the same criteria of the General Comment will be used. The qualitative research will be conducted through semi-structured interviews with experts. The experts are assistance users in Germany and Sweden who are active in the Independent Living Movement. The interview guide is based on the criteria of the General Comment. The interview partners evaluate the systems according to their experiences and opinions. The interviews are analyzed with a Qualitative Content Analysis according to Mayring (2015). The results of the qualitative research are presented and the practical implementation of personal assistance in Sweden and Germany will be discussed (chapter 7). Furthermore, the results will be compared with the theoretical evaluation of the systems. As a last step, the results will be interpreted. The work rounds up with a general conclusion (chapter 8).

## **2 Independent Living and Personal Assistance**

The following chapter describes and defines Independent Living and Personal Assistance as a general theoretical background. The terms 'Independent Living' (Selbstbestimmt Leben) and 'personal assistance' were formed by the disability movement almost 40 years ago to criticize the current disability policies (cf. DeJong 1979; cf. Vereinigung Integrationsförderung 1982). According to Steiner (1999), there is an inflationary usage of these terms and a risk of losing their original meaning. He claims that, therefore, these terms should only be used in the original sense as they were developed in their historical context.

In the following subchapters, the historical background of the terms 'Independent Living' and 'personal assistance' will be explained. Furthermore, the terms will be defined and distinguished from other terms.

### **2.1 Independent Living Movement: History and Philosophy**

Independent Living is a human right, a concept of how to understand disability in society and a social movement of disabled people (Franz 2002, p. 16). In this subchapter, the history of the Independent Living Movement, the definition of the term 'Independent Living' and the philosophy of the movement will be described.

#### **2.1.1 History**

The history of the Independent Living Movement began in the late 1960s and 1970s. Influenced by the Berkeley Free Speech Movement, the Women's Movement and the Civil Rights Movement in the 1960s, the Independent Living Movement started at various university campuses in the US. People with different disabilities worked for a barrier free campus and more independence and self-determination in their daily lives (Fleischer and Zames 2011; DeJong 1982). Especially young adults with physical impairments fought against institutionalization, which was the only way to live with a disability back then. They condemned discrimination based on their disability and considered them a political problem (Franz 2002, p. 22). Compared to the medical model of disability, the Independent Living paradigm does not see the problem in the disability of a person and the solution in fixing it. It sees the problem in society, which is not pre-

pared or adapted and does not have the necessary acceptance for disabled people. The vision of the movement is to fully include disabled people into the community, the social, economic and political life (Fleischer and Zames 2011). Key person of the movement was Edward Roberts who was co-founder of one of the first Independent Living Centers (ILC) in the US in Berkeley. “[...] Roberts deserves credit for being the founder of the ILCs because of his success in establishing a nationwide, and even a worldwide, Independent Living Movement” (Fleischer and Zames 2011). Independent Living Centers were established as agencies governed by and for persons with disabilities to provide all necessary services to support an independent life for people with disabilities (Franz 2002, p. 22). To promote self-determination and independence of disabled people, the Independent Living Centers provide peer counseling, advocacy, independent living training and information, e.g. regarding community based housing or personal assistance (Fleischer and Zames 2011). A success of the Independent Living Movement was the implementation of the Rehabilitation Act of 1973. “Section 504 [of the law] banned discrimination on the basis of handicap in any program or activity receiving or benefiting from federal financial assistance” (DeJong 1982, p. 26). The Rehabilitation Act of 1973 was also the first official or governmental text, which used the term ‘live independently’ in the context of disability rights (Government of the United States of America, Sec. 130a).

There are two opinions on how the German ‘Selbstbestimmt Leben’ Movement began. Some see its origin in the American Independent Living Movement whose ideas were imported to Germany (Franz 2002 p. 21; Miles-Paul 1992). Others point out that there were types of self-organized support even before the Independent Living Philosophy was established in Germany (Steiner 1999). Self-help groups of the Disability and Cripple Movement in the early 1970s protested against heteronomy and demanded more self-determination. As the ideas of the American Independent Living Movement became known in Germany in the 1980s, a common concept was developed (Franz 2002, p. 21ff).

The Swedish Independent Living Movement was imported from the US by Adolf Ratzka in the 1980s. “In theory, help to self-help was spoken about already during the 70s but in practice only ready-made package solutions existed – one size fits all – for persons with extensive disabilities” (Ratzka 2008). Adolf Ratzka, a wheelchair user himself, studied in the US where he got in touch with the Independent Living Movement. He came to Sweden 1973 to work on his doctoral research study. He experienced that with the Swedish home care services he would not have the same possibilities as in the US

with personal assistance. He organized a conference in Stockholm in 1983 to import the ideas of Independent Living to Sweden. In 1984 he founded the cooperative STIL – The Stockholm Cooperative for Independent Living. STIL then started a pilot project to provide personal assistance to disabled people. The work of STIL contributed to the development of a law granting personal assistance in the form of direct payments for disabled people (Berg 2008, p. 23f).

### **2.1.2 Definition of Independent Living**

General Comment Number 5 on Article 19 of the UN Convention on the Rights of Persons with Disabilities can be used to define the term 'Independent Living' in the sense of the Independent Living Movement because the concept of Independent Living is represented by the CRPD.

*The concept of Independent Living (IL) [...] is much older than the UN Convention on the Rights of Persons with Disabilities ('CRPD'). It has played a key part in the drafting of the CRPD, especially Article 19, but is also underpinning other articles, none of which can be realised without IL (ENIL - European Network on Independent Living 2012).*

General Comment Number 5 is an authoritative text of the Committee on the Rights of Persons with Disability, which has been created with the participation of treaty states, interest groups and NGOs. It explains and gives interpretations of the rights stated in the CRPD (Deutsches Institut für Menschenrechte n.d.). The General Comment on Article 19 of the CRPD defines Independent Living as follows:

*Independent Living/living independently means that individuals with disabilities are provided with all necessary means enabling them to exercise choice and control over their lives and make all decisions concerning their lives. Personal autonomy and self-determination is fundamental to independent living, [...] (Committee on the Rights of Persons with Disabilities 2017, p. 4).*

To enable disabled people to exercise choice and control over their lives and make all decisions concerning their lives, there must be suitable services. ENIL requests that these "services must be available, accessible to all and provided on the basis of equal opportunity, free and informed consent and allowing disabled people flexibility in [...] [their] daily life" (ENIL - European Network on Independent Living 2012).

The term 'Independent Living' was developed by the Independent Living Movement in the USA. The German movement uses the translation 'Selbstbestimmt Leben' (living self-determined) and not the direct translation 'Unabhängig Leben' (living independently) (Miles-Paul 1992, p. 7). The title of Article 19 'living independently' was translated (directly) to 'unabhängige Lebensführung' for the German version of the CRPD. Mladenov also refers to Article 19 as an example for the issues concerning different interpretations, which are inherent in the translations between languages (Mladenov 2013, p. 80).

Independent Living is not about being totally autonomous, self-sufficient or independent from other people but to have the chance to live as independently as other people without disability do. Ratzka (2007) explains:

*[...] differences in the attitudinal and material conditions determine disabled peoples' life opportunities, how dependent or independent we can become. I am not claiming that anyone – disabled or non-disabled - can be completely independent. As human beings we all are inter-dependent on each other. My point is that persons with the exact same disabilities can have completely different lives depending on where they live.*

'Independence' in the sense of the Independent Living Movement means to be free from constraints and heteronomy. Heteronomy can occur through practical or structural constraints in institutions or families, barriers in the environment, missing possibilities for integration, expectations of the society or the paternalism in professional care, which restrict the self-determination of disabled people (Franz 2002, p. 17f).

German literature about Independent Living often tries to delineate the term 'Independence' or 'self-determination' from 'autonomy' (Selbstständigkeit) (Mobile - Selbstbestimmtes Leben Behinderter e.V. 2001; Franz 2002, p. 19). The term 'autonomy' is not used within the movement. People who are not autonomous because of their need of assistance can nonetheless be emotionally and intellectually independent and self-determined. The need of assistance or physical dependency does not automatically result in emotional or intellectual dependency or the loss of self-determination (Ratzka 1988). "Independence is not linked to physical or intellectual capacity to care for oneself without assistance; independence is created by having assistance when and how one requires it" (Brisenden quoted in ENIL - European Network on Independent Living 2014, p. 5).

In summary, Independent Living is a human right. Living independently means to have the same choice and control over one's life as other people without disability have. Various environmental and individual factors have to be complied so that disabled people can make free and equal decisions concerning their lives. Services enabling people living a self-determined life in the community must be accessible and available.

### 2.1.3 Philosophy

Independent Living is more than an individual right. It is a philosophy and a practical approach of a social movement. Disabled people work together to fight for and defend their civil and human rights (Hasler 2003).

*Just as everybody else, we need to be in charge of our lives, think and speak for ourselves. To this end we need to support and learn from each other, organize ourselves and work for political changes that lead to legal protection of our human and civil rights (Ratzka 1997)*

The following principles count as the aims of the Independent Living Movement (Franz 2002; Ratzka 1989, 2017).

- Anti-discrimination: there is a legal basis in every country prohibiting discrimination against disabled people.
- De-medicalization: people with disabilities are not seen as patients. A disability is not an illness, which has to be rehabilitated.
- De-institutionalization and integration: disabled people do not have to live in separate institutions because of their disability. They have the choice to live how and with whom they want and to be included in the community.
- De-professionalization: disabled people know by themselves what is best for them. Paternalism through professionals is not acceptable. Services for disabled people are controlled by disabled people themselves.
- Self-representation: disabled people are experts on their needs and preferences. They speak up for themselves how they want to live and what they need. Organizations for disabled people are controlled by disabled people.
- Peer counseling and networking: disabled people benefit from sharing their personal experience and can learn from each other and support each other. Disabled people build a network to fight together for Independent Living.

The Independent Living Movement is still active to reach and implement its aims. Personal assistance is a tool to live independently, for de-institutionalization and the integration of disabled people into society.

## **2.2 Personal Assistance: Definition and Models**

The following chapter introduces the definition of personal assistance and describes the competences an assistance user can execute with personal assistance. Furthermore, different models to organize personal assistance (organizational models) are explained.

### **2.2.1 Definition of personal assistance**

“Personal assistance refers to person-directed / ‘user’-led human support available to a person with disability and it is a tool for independent living” (Committee on the Rights of Persons with Disabilities 2017, p. 5)

The etymological origin of the words ‘assistance’, ‘assist’ and ‘assistant’ is the Latin word ‘assistere’ (to place, to stand, to support) from ‘ad’ (to, at) and ‘sistere’ (stand, place, set) (Schulz et al. 2016). According to the Oxford Dictionary the verb ‘assist’ means “to help (someone), typically by doing a share of the work [,] [...] to help by providing money or information [or] [...] to be present as a helper” (English Oxford Living Dictionaries n.d.). One can find a variety of synonyms for the word ‘assist’ in different dictionaries: attend, help, lend a helping hand, serve, be of use to, work with, support, promote etc. (Collins Dictionary n.d.; English Oxford Living Dictionaries n.d.). The German dictionary Duden defines ‘assistieren’ (assist) as „giving someone a helping hand for an activity according to his or her instructions” (Duden n.d.). An assistant is “a person who ranks below a senior person [and] [...] who helps in particular work” (English Oxford Living Dictionaries n.d.).

Using the word ‘assistant’ instead of ‘carer’ or ‘attendant’ for a person supporting a disabled person, makes clear that the person is subordinated to the disabled person (Cf. Ratzka 1989, p. 10). ‘Personal’ assistance means that the assistance is adapted to the individual needs of the assistance user. The assistance user also decides who assists how, when and where (Ratzka 1989, p.10). Personal assistance enables disabled people to live independently and participate in society. It compensates disabilities and



helps to negotiate barriers. Therefore, personal assistance can include a variety of different services, depending on the disability of the assistance user, the environment in which he or she lives and his or her work and lifestyle. Personal assistance services can include personal hygiene, health care, household help, mobility help and communication aids. Personal assistance covers all areas of life and provides assistance at school, at the workplace, during free time activities and to participate in society (Frehe 1999, p. 281; Niehoff 2013, p. 53).

Since personal assistance is organized in different ways in various countries, the General Comment on Article 19 of the CRPD gives some specific criteria, which must be fulfilled to use the term 'personal assistance' in the sense of the CRPD. One criterion is the funding of personal assistance. It must be provided on the basis of an individual assessment and controlled and allocated by the personal assistance user. Another point is that personal assistance services must be controlled by the disabled person who can decide where, how, when and by whom the assistance should be delivered. The General Comment makes clear that personal assistance is a one-to-one relationship and assistants should not be shared. The last criterion is the self-management of the service delivery. Personal assistance users can choose how much control they want to have over the delivery of the service (Committee on the Rights of Persons with Disabilities 2017, p. 5).

Due to personal assistance, disabled people can live a self-determined life. The determination and competences are transferred from professionals to the disabled person as an expert for his or her life. Disabled people have the following competences concerning their personal assistance (Frehe 1999, p. 281; Franz 2002, p. 39ff):

- Personnel (who): assistance users decide who assist them. Users can choose and employ their personal assistants by themselves and do not have to accept carers from institutions. That means that they recruit and hire their own assistants.
- Organization (when): assistance users decide when the personal assistants assist them. They can plan the times and services by themselves and do not have to accept given schedules of service providers or institutions. Users have to organize the duty rosters of their personal assistants.
- Direction (how): assistance users decide how the personal assistants assist them. They instruct their personal assistants about the way, range and procedure of the assistance they want to receive. The assistance is not determined

by professionals. It postulates competences to supervise the assistants in order to solve conflicts and to give and receive feedback.

- Location (where): assistance users decide where the assistance is realized. They receive the assistance at any location they want. The place of assistance is not restricted to an institution or the own apartment.
- Finances: assistance users receive, control and manage the financial means for their personal assistance. They pay the wages of their assistants and other costs connected to the assistance.

Personal assistance enables the disabled person to decide who assists when, how and where. This is possible through direct payments to the disabled person.

### **2.2.2 Organizational models of personal assistance**

There are different organizational forms of personal assistance, which allow disabled people to execute the described competences in a variable extent. One can roughly distinguish three models: the employer model, the cooperative model and the customer model

The *employer model* allows disabled people to execute all five competences concerning the personal assistance (defined in chapter 2.2). Personal assistants are directly employed by the disabled person. The assistance user recruits, hires and employs his or her assistants and decides who assists how, when and where. Furthermore, the funds for the assistance are controlled and administrated by the user. The assistance user has all responsibilities of an employer but can also outsource responsibilities like paying taxes or wages to an accounting office for example.

In the *cooperative model*, the role of the employer is contracted out to a cooperative or an association. Disabled people choose this model if they do not want or are not able to handle the organizational effort of acting as an employer but want to keep a high level of control over the personal assistance. The assistants are employed by the cooperative, which executes the financial competences. The assistance user keeps the other competences, which are important for the quality of the personal assistance. Depending on the cooperative or association support in executing other competences is offered, like recruiting assistants or organizing time schedules.

In the *customer model*, disabled people buy their personal assistance services from assistance service providers. These can be private for-profit companies or non-profit services providers of the public sector or welfare associations. Assistance users are customers of service providers, which deliver certain assistance services or the whole assistance needed. Which competences are assigned to the assistance provider, depends on the concept of the provider and the form of the service.

According to the General Comment on Article 19 of the CRPD, disabled people can choose which organizational model of personal assistance they want. "Persons with disabilities who require personal assistance can freely choose their degree of personal control over service delivery according to their life circumstances and preferences" (Committee on the Rights of Persons with Disabilities 2017, p. 6). It is possible to organize the personal assistance in a mixed model. Disabled persons acting as an employer can also buy certain services from service providers.

### **3 Personal Assistance in Germany and Sweden**

To understand and compare personal assistance systems of different countries, one has to see them in the context of their particular disability policies and the development of the respective welfare state (Aselmeier 2008). The welfare tradition influences the social policies and how disability is seen in society. To describe the German and Swedish welfare states, Esping-Andersen's typology of welfare states can be used. He claimed that welfare states developed different sociopolitical models due to their historical development. He identified three ideal types of welfare states: the conservative, liberal and social democratic welfare state (Esping-Andersen 1990, p. 26f). The liberal welfare model is based on the principle of individual responsibility and a free market. The state intervenes only to supply basic needs if the individual is not able to. Social services are provided by public and private organizations. Indicators of the liberal welfare model can be found in the USA. In conservative welfare states social insurances and the principle of subsidiarity play an important role. The state has a subsidiary function and interferes only if there is no lower or more local level, which can perform this task. The demand for social services is connected to the payment of social insurance fees. The social democratic welfare model pursues equality and solidarity for its members. It is the state's responsibility to ensure that everybody can perform their civil rights equally in society. Therefore, the state provides a large spectrum of social support services, which are mostly financed through taxes. Germany and Sweden can be allocated to these idealized welfare state models. But in each welfare state one can also find indicators for other welfare models. Personal assistance for disabled people is part of the social services system of a country, which is influenced by its welfare tradition.

In the following subchapters, the Swedish and German welfare states, systems of social security and disability policies will be explained as a background of the specific personal assistance systems in these countries. Furthermore, the German and Swedish systems of personal assistance will be described according to a common structure to allow a better comparison of the two systems. The common structure includes the legal framework, eligible group of persons, organization of needs assessment, extent and provision of the service, persons working as assistants and figures concerning personal assistance

### **3.1 Personal Assistance in Germany**

Like other social services, personal assistance is imbedded in the German welfare state and its disability policies, which will be described in the following subchapter. The German system of personal assistance will be presented in subchapter 3.1.2 according to the common structure outlined in chapter 3.

#### **3.1.1 The German Welfare State and Disability Policies**

Germany can be allocated to the conservative welfare model. Different social insurances, which cover 'risks of life' like illness, accidents, seniority or unemployment, were already established by Bismarck in the 19<sup>th</sup> century. The care insurance complemented this insurance system in 1995. The aim of the insurances is to preserve the status of the insured. The insurances were created for employees and the contributions are paid by employee and employer. Unemployed people are excluded from this system and the state takes care of them. The principle of subsidiarity illustrates the paternalistic role of the state. Services from the state are subordinated to other services. The state helps in cases of individual need, which are not covered by insurances and in which persons are not able to help themselves. These state services are not financed through insurance contributions but through taxes. The execution of services is assigned to member organizations of the welfare associations (Wohlfahrtsverbände). Services for disabled people, which are not covered by insurances, are traditionally a state responsibility and provided in special institutions. There are liberal developments by opening the market for private service providers (Aselmeier 2008).

The German social security system is based on five social insurances. These are the pension insurance, the accident insurance, the unemployment insurance, the health insurance and the care insurance. They are subordinated to the Federal Ministry of Labor and Social Affairs and the Federal Ministry of Health. The social insurances are mostly financed through contributions paid by the employer and employee. In cases of individual need where there is no other support available the state grants social benefits (Sozialhilfeleistungen). Social benefits are only provided by the state in cases, which are not or not completely covered by insurances and if the individual is not able to help him or herself. Social services for disabled people are also imbedded in this social security system.

Germany signed the CRPD and committed to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disability, and to promote respect for their inherent dignity” (United Nations 2006, Art. 1). The CRPD became legally binding with the ratification of the CRPD and its optional protocol through a national legislation (Kreutz et al. 2013, p. 3). Also the Basic Law for the Federal Republic of Germany (Grundgesetz, GG) claims in article 3 that nobody may be disadvantaged because of his or her disability (Art. 3 GG). Since January 2018 the definition of disability in the Social Code Book (SGB) is adapted to the definition of the CRPD: “Persons with disabilities are persons, who have a physical, psychological, mental or sensory impairment, which in interaction with attitudinal or environmental barriers may hinder their equal participation in society very probably longer than six months” (§ 2 SGB IX). Disabled people can receive services to promote their self-determination and their full, effective and equal participation in society and to avoid and work against disadvantages (§ 1 SGB IX). These services are summarized especially in the Social Code Book IX. There are five groups of services: services for medical rehabilitation, services to participate in a working life, services to secure subsistence, services to participate in education and services for social participation (§ 5 SGB IX). Seven different authorities can be responsible to finance services from these groups (§ 6 SGB IX). Services for social participation fall mostly in the responsibility of the Integration Support (Eingliederungshilfe), which is part of the social benefits (Sozialhilfe). As a social benefit the service is subordinated and only paid, if the disabled person cannot pay the service by him or herself. The responsibility for social benefits varies in each federal state, because the local and supra-local authorities, which are responsible, are differently organized in the federal states.

### **3.1.2 The German Personal Assistance System**

In the following subchapter the German system of personal assistance will be presented. A common structure will be used to describe the system to be able to compare the German and Swedish system.

#### **Legal Framework and Responsibility**

In Germany there is not one specific law granting personal assistance to people with disabilities, there are many. A legal basis for personal assistance services can be found in different laws of the Social Code Books, depending on what the assistance is

needed for and how a person got her or his disability. As personal assistance covers all areas of life, several authorities can be responsible.

Personal assistance services within the range of care are normally paid by the care insurance. The care insurance finances care services if the person has been insured for at least two years in the last ten years and applies for services (§ 33 SGB XI). Services are provided as cash benefits and benefits in kind. Assistance users acting as employers for their assistants can only receive the lower cash benefits (§ 77 SGB XI). If the services covered by the care insurance are not sufficient, the social benefits (Sozialhilfe) supplements the services with the so called Help for Care (Hilfe zur Pflege § 63 SGB XII). Normally the Social Benefits Agency only has to pay Help for Care if the higher benefits in kind have been used. But this does not apply to assistance users in the employer model. Assistance users acting as employers do not have to take the care benefits in kind to acquire the claim of Help for Care (§ 63b VI SGB XII). Care at Home (häusliche Pflege) includes also support services for coping with psychosocial problems, orientation, structuring daily life, communication, upkeeping social contacts, daily activities and cognitive mobilization (§ 36 II SGB XI). Services, which are not covered by these Care at Home services, especially services outside home, have to be financed through other authorities.

Most services for disabled people are summarized in the Social Code Book IX. The Social Code Book IX describes the aims of the services. The eligibility criteria are mostly defined in the respective Social Code Book. In the Social Code Book IX services for disabled people are assigned to five service groups (§ 5 SGB IX). The seven authorities, which can be responsible for the services, are called Rehabilitation Authorities (Rehabilitationsträger § 6 SGB IX). Personal assistance services can belong to the following three service groups: services for social participation, services for participation in education and services for occupational participation. Personal assistance is a service supporting independent living and participation in society. It is not a service for medical rehabilitation or to secure subsistence.

In the group of services for social participation one can find the right to 'assistance services' (Assistenzleistungen § 78 SGB IX). It cannot be seen as the legal basis for personal assistance as 'assistance services' are services, which do not cover services for all areas of life. 'Assistance services' are services for social participation and do not include assistance for work or education. In comparison, personal assistance is a ser-

vice form, which includes services for participation according to the Social Code Book IX and care services according to the Social Code Book XI.

If the disability is a result of an accident or a recognized occupational disease the accident insurance is responsible to finance the whole personal assistance including services of the SGB IX as well as care services of the SGB XI. The employee has to provide evidence that the disability was caused through his or her work. The war victim provision (Kriegsopferfürsorge) pays if the disability was caused during military service. The youth welfare (Jugendhilfe) is only responsible for psychologically disabled children. Children with a mental or physical disability receive allowances from the Social Benefits Agency (§10 IV SGB VIII).

Adults who got their disability not through an accident, a work-related disease or in military get their personal assistance mostly paid by different authorities. Personal assistance services for social participation and participation in education are paid by the Integration Support (Eingliederungshilfe). The services for occupational participation are carried by the Employment Agency, the pension insurance, Integration Office (Integrationsamt) or the Integration Support (§ 49 VIII, § 185 V SGB IX). The pension insurance pays if special qualifying periods are accomplished (§ 11 SGB VI) and if the services can rehabilitate, improve or reach the ability to work of the disabled person. The Employment Agency has a subordinated responsibility (§ 22 SGB III). Assistance at the workplace for people with a severe disability is normally financed by the Integration Office (§ 49 VIII and § 185 V SGB IX).

Services, which are part of the social benefits, like Integration Support services or Help for Care, are means-tested and the assistance user has to pay a contribution to these services. The user has to pay if he or she has an income of over 265,85 € or assets over 27.600 € (Bundesarbeitsgemeinschaft für Rehabilitation (BAR) e.V. 2017, p. 16).

All services from different authorities can be granted as a comprehensive personal budget (§ 29 SGB IX, 35a SGB XI, § 63 III SGB XII). The personal budget is a direct payment and turns the service allowances into personal assistance services as the user receives the decision competences to buy or organize his or her assistance. As the personal budget is a service form and not a service, it can only be granted if the eligibility criteria of the service in kind are fulfilled.

The disabled person can apply for services at one of the possible authorities, no matter if this authority is responsible or not. The authority then proves if it is responsible for



services. If the authority is not responsible, the application has to be forwarded to another authority within two weeks. The second authority can forward it again, but the third authority getting the application has to carry the services even if it is not responsible. The authority carrying the services is called Performing Authority (Leistender Rehabilitationsträger § 14 SGB IX). The Performing Authority can refund the money for the services from the responsible authority (§ 16 SGB IX). An application including services from different authorities has to be forwarded to the other responsible authorities (§ 15 SGB IX).

### **Eligible Group of Persons**

In Germany there are different authorities responsible for services for disabled people. Personal assistance services can be financed by different authorities, which might have different eligibility criteria.

According to § 1 SGB IX disabled people have the right to services for equal participation in society. This includes services for social participation and services for participation in education. According to § 2 SGB IX a person is disabled when a physical, psychological, mental or sensory impairment in interaction with attitudinal or environmental barriers hinder their equal participation in society very probably for longer than six months. The Integration Support is responsible for these services if a person has a substantial disability (wesentliche Behinderung). A person is substantially disabled if his or her ability to participate in society is substantially restricted (§ 53 I SGB XII). Details are regulated in the Integration Support Regulation (Eingliederungshilfe-Verordnung).

Personal assistance for occupational participation is called work assistance and is granted to people with a severe disability (§ 49 VIII, § 185 V SGB IX). In Germany a disability can be measured in grades from 20 to 100. A person with a disability grade of 50 or higher has a 'severe disability' (§ 2 II SGB IX). Disability grades between 30 and 49 can be counted as 'severe disability' if the disability might restrict the person's participation in work life (§ 2 III SGB IX). To be classified as severely disabled, the person has to live or work in Germany.

Personal assistance covering care services are provided to insured people in need of care. A person is in need of care when his or her independence or ability is affected through health impairment and, due to this, is in need of help of others. A person in need of care is not able to compensate or overcome the physical, cognitive or mental

impairment or health burden by him- or herself. The need of care must be for a period of presumably six months and with a certain severity according to the law (§ 14 I SGB XI). The impairment must be connected to the following areas: mobility, cognitive and communicative capability, behavior pattern and mental problems, self-supply, handling illness and therapy issues and organization of the daily life and social contacts (§ 14 II SGB XI).

Figure 1 illustrates different group of persons who can be eligible for personal assistance in Germany. The figure emphasizes that the groups are overlapping. A person can have a severe disability, a substantial disability and be in need of care for example.

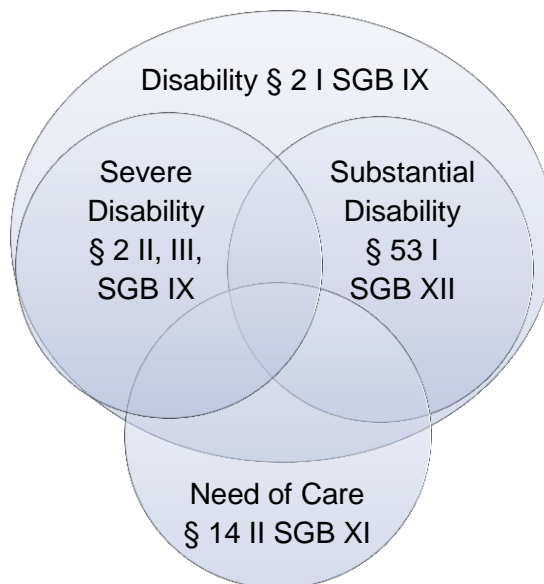


Figure 1: *Groups of persons, which can be eligible for personal assistance in Germany. Own illustration.*

### **Assessment of Demand and Calculation**

The needs of a disabled person shall be discovered as early as possible. Therefore, the Rehabilitation Authorities install contact centers (Ansprechstellen), which inform disabled people about services for participation and the personal budget (§ 12 SGB IX). The common service center of the Rehabilitation Authorities (Gemeinsame Servicestellen § 23 SGB IX old) will be abolished until the end of the year 2018. The needs

assessment is carried out by the Performing Authority. The Performing Authority requests the assessment declaration from other responsible authorities. If they do not deliver their declaration in time, the Performing Authority assesses the need for all possible services from different authorities (§ 15 II SGB IX). The authority proves if the requirements for its services are fulfilled. The assessment can be different depending on the authority and the region. In 2017 there were four common instruments for an individual needs assessment in Germany (HMB-W, IBRP, ITP, IHP) (Mertins 2017, p. 8). Needs can also be assessed through experts like the Medical Service of the Health Insurance (Medizinischer Dienst der Krankenkassen MDK), which assesses the need of care. The assessment for services, which are granted in the form of a personal budget, is executed every two years (§ 29 II SGB IX). For a personal budget the authority proves the need and discusses which services are required to cover the needs. The amount of personal budget is based on the costs of the required services. The costs of the services are stipulated in contracts between the paying authority and the providers and can be defined for groups of persons with similar needs (Hilfedarfsgruppen) (§ 125 III SGB IX).

According to the new § 13 SGB IX the authority has to execute a uniform and verifiable assessment with a standardized tool. The individual and function-related needs assessment shall also secure the documentation and verifiability. The authority records if a disability or the risk of a disability exists. Furthermore, it is checked which affects the disability has on the participation of the disabled person. The authority and the disabled person define which goals shall be achieved by the services and which services might be successful to reach the goals (§13 II SGB IX). The different Rehabilitation Authorities stipulate on common principles for the assessment tools. If there are several services from one or more authorities necessary, a so called participation plan (Teilhabeplan) has to be created together with the disabled person (§ 19 SGB IX). In the participation plan the different services are planned and modulated. If the disabled person agrees, a participation plan conference (Teilhabeplankonferenz) can be held to discuss the identified needs together with all responsible authorities (§ 20 SGB IX). For services of the Integration Support a so called Overall Plan (Gesamtplan) according to §§ 141ff SGB XII has to be set up. The Overall Plan has to be created even if the services are already part of the participation plan (Bundesministerium für Arbeit und Soziales n.d.b). The services of the Integration Support have to be planned considering the wishes of the disabled person and using an instrument, which is based on the International Classification of Functioning, Disability and Health (ICF) (§ 142 SGB XII). In the

assessment for services of the Integration Support there should be a description of the activity and participation in the following areas of life: learning and application of knowledge, common tasks and requirements, communication, mobility, self-supply, domestic life, interpersonal interactions and relationships, major areas of life and community-, social and civic life (§ 142 SGB XII).

### **Provision and Models**

Disabled people can apply to receive their personal assistance services in the form of personal budgets. Different services from different authorities can be provided as personal budget. The seven Rehabilitation Authorities, the care insurance and the Integration Office can provide personal budgets (§ 29 I SGB IX). A comprehensive personal budget is paid if several authorities are involved. Personal budgets can be provided for services for medical rehabilitation, occupational participation, participation in society, basic care, care allowance payments, non-cash care allowance, housekeeping, home care, work assistance, study assistance, mobility, communication aid and Integration Support (§ 29 SGB IX, § 35a SGB XI, § 63 SGB XII).

On the basis of a participation plan the disabled person and the authorities arrange a budget agreement. The individual visions and concrete goals of the disabled person are noted down in the budget agreement. Further, the services supporting the achievement of the individual goals are defined. The period of validity of the services is also stipulated in the agreement. There can also be an agreement on services supporting the administration and usage of the personal budget. The services are the basis for the calculation of the budget. In the budget agreement it is laid down how much one hour of a certain service costs. Furthermore, it is regulated how the usage of the budget has to be proven and how the quality of services is controlled. The agreement defines the period of validity and the regulations of notice (Lebenshilfe 2006; Assistenz.de n.d.b).

The personal budget enables the disabled person to determine how the services are provided. The disabled person can choose the employer model and recruit own assistants. In Germany there are also two assistance cooperatives in Hamburg and Bremen, which support assistance users and take over the employer responsibilities for the assistants (Persönliche Assistenz Genossenschaft Bremen geG n.d.; Hamburger AssistenzGenossenschaft eG n.d.). Furthermore, there are some associations, which help to organize personal assistance (NITSA e.V. n.d.; akse - aktiv und selbstbestimmt e.V. n.d.). Disabled people can also buy their services from private for-profit companies or

public non-profit providers with the personal budget. But it is criticized that there are only few providers offering 'real' personal assistance, which can be determined by the assistance user (Assistenz.org n.d.). Conventional service providers usually do not provide personal assistance as a person-directed and user-led service.

The amount of the personal budget should cover the individual needs of the disabled person. According to an investigation of the Federal Ministry of Labor and Social Affairs the majority of the personal budgets are between 200 and 800 Euros. The smallest budget was 36 Euros and the biggest budget was 12.683 Euros (Bundesministerium für Arbeit und Soziales n.d.a). The amount of the budget should not surmount the costs of the previous services (§ 29 SGB XII).

Assistance users do not all get the same amount of personal budget per hour of personal assistance. The amount depends on the specific service that is provided in the context of personal assistance, the authority granting it and the model in which the assistance user receives the services. If there are extra costs for example for wage or tax offices to organize the assistance in the employer model, the responsible authority has to pay for it (Sozialgericht Hannover 2007). Assistance users in the employer model can take their assistants with them when they are in hospital. Disabled people who buy their services from a assistance provider cannot receive their personal assistance services in hospital (Becker 2015,p. 4). Disabled people only get personal assistance for their voluntary work if it is unreasonable for family, friends or colleagues to provide the services (§ 78 V SGB IX).

### **Persons working as personal assistants**

Personal assistants do not need to have special qualifications. The assistance user chooses assistants with the qualifications and requirements he or she wants the assistants to have. Personal assistants can also provide care services without special care qualification. But if care services provided at home are paid by cash benefits from the care insurance, the service user has to occupy counselling from a care institution to ensure the quality of care (§ 37 III SGB XI). According to the Youth Employment Protection Act (Jugendarbeitschutzgesetz - JArbSchG) people under the age of 15 are not allowed to work longer than two hours (§ 5 JArbSchG). There are special regulations for people under the age of 18, for example more vacation days or longer pause time (§ 11, § 19 JArbSchG). Participation services that are provided by family members can be paid by personal budget if the service is not part of the parental duty (Bundesministerium für Arbeit und Soziales n.d.a).

## Figures concerning personal assistance

About 10.2 million disabled people were living in Germany in the year 2013. That was 13% of the German population. Around 7.5 million people had a severe disability. (Statistisches Bundesamt 2015). A study on behalf of the Federal Ministry of Labor and Social Affairs collected data concerning personal budgets from different authorities (Prognos AG 2012). Personal budgets can be used to pay for personal assistance services but also for other services. According to this research there were at least 14.193 ongoing and newly granted personal budgets in Germany in the year 2010 (Prognos AG 2012, p. 18). This was two years after the introduction of personal budget in German law. One can assume that the number has increased in the last years, but at the moment (2017) there are no current figures available, which take all budgets from different authorities into account. Comprehensive personal budgets granted from several authorities together are rare, only 7% of the budgets in 2010 (Prognos AG 2012, p. 34). Most personal budgets (11.493) were granted by the Integration Support, which is part of the social benefits (Prognos AG 2012, p. 18). This number is small considering the high number of around 770.000 persons receiving services from the Integration Support in the year 2010 (Statistisches Bundesamt 2010).

The Federal Statistical Office of Germany published numbers of people receiving a personal budget from the Integration Support. For the year 2013 they counted 8.516 persons with a personal budget from the Integration Support (Statistisches Bundesamt 2013, p. 4). According to the Federal Ministry of Labor and Social Affairs, there were 9.473 Persons with a personal budget in Germany in 2014. 96% of them received their budget from the Integration Support. Since 2010 the number of budget users increased by 78%. However, in the table concerning personal budgets the ministry distinguishes only the budgets granted by the Integration Support and the Help for Care. Personal budgets from other authorities are not counted in this publication (Bundesministerium für Arbeit und Soziales 2016, p. 281). The German Consortium for Rehabilitation (Bundesarbeitsgemeinschaft für Rehabilitation) collected data concerning the financial investments of some authorities for personal budgets. Among the authorities, which reported their investments for personal budgets, were the health insurance, the pension insurance and the Employment Agency, but not the Integration Support. The Health insurance had the highest reported investment with 11.6 Mio in 2013. This was ten times higher than in 2009 (Bundesarbeitsgemeinschaft für Rehabilitation (BAR) e.V. 2015, p. 2f).

A current publication with concrete numbers on how many people are using personal assistance in Germany could not be found. This has different reasons. Different authorities can grant means for different personal assistance services. These funds are not always paid in form of personal budgets. There are also care allowance payments, which can be used for personal assistance. Furthermore, the authorities might have different definitions of personal assistance. According to the study of the Prognos AG most services paid by personal budget were personal assistance services (Prognos AG 2012, p. 36). Unfortunately, the study does not define personal assistance. Services, like support for housekeeping or accompany in free time are not included in the category of personal assistance.

In 2010 Uwe Frevert, chairman of the board of ISL, the umbrella organization of the German Independent Living Centers (Interessenvertretung Selbstbestimmt Leben in Deutschland e.V.) estimated that there were around 3.000 disabled people in Germany, who employed their personal assistants (Interessenvertretung Selbstbestimmt Leben in Deutschland e.V. 2010).

## **3.2 Personal Assistance in Sweden**

As in Germany the Swedish personal assistance system has to be seen in its context of the welfare state and disability policies. In subchapter 3.2.2 the Swedish system of personal assistance will be described following the same structure as the description of the German system.

### **3.2.1 The Swedish Welfare State and Disability Policies**

Sweden is an example of the social democratic welfare model. Social insurances were introduced in the late 19<sup>th</sup> century and changed in the 1930s through the politics of the social democratic party. The unemployment and health insurance were subsidized by the state and a basic non-income-related pension was established for all citizens. The principle of solidarity can be seen in the payment of high income-related taxes as a way for equalization. The state subsidizes or finances (through taxes) social services and provides them to ensure that every citizen can participate equally in society. Disabled people are seen as equal citizens, who might need services to exercise their rights. Services for disabled people are therefore provided in the normal structures of

society and not in special institutions. Like in Germany there are liberal developments by opening the market for private service providers. (Aselmeier 2008, p. 94, 100f, 190ff).

The Swedish social security system is based on social insurances. They are subordinated to the Ministry of Health and Social Affairs and the Ministry of Employment. The Swedish "social insurance is divided into a residence-based insurance providing guaranteed amounts and benefits and a work-related insurance against loss of income" (MISSOC - Mutual Information System on Social Protection 2017). It covers everybody who lives or works in Sweden. Most of the insurances fall in the responsibility of the Social Insurance Agency (Försäkringskassan), which administers the social insurance system together with the Pension Agency (Försäkringskassan n.d.). The social insurance is mainly financed through employer contributions and is subsidized by the state. Social benefits are not a part of the social insurance. The National Board of Health and Welfare (Socialstyrelsen) supervises the social benefits and the municipalities are responsible to finance and provide them (MISSOC - Mutual Information System on Social Protection 2017).

Sweden signed and ratified the CRPD and committed to guarantee human rights for disabled people. The Swedish constitution prohibits discrimination of people because of their disability (§ 2, chap. 1 Regeringsformen). In Sweden's Discrimination Act (Diskrimineringslag 2008:567) the term 'impairment' (funktionsnedsättning) is defined as a permanent physical, psychological or intellectual constraint on a person's operational ability, which is a result of injury or disease at birth, has arisen later or may be expected to arise. The Swedish word 'funktionshinder' can also be translated as 'disability'. It describes the constraint that an impairment (funktionsnedsättning) implies to a person in relation with the environment (Socialstyrelsen n.d.). The disability policy in Sweden is based on national action plans. "The aim of the national action plan [from the year 2000] involves a strong assertion that disability issues should be taken into account in all areas of society [...]" (Socialstyrelsen 2009, p. 3). Society must be designed in a way that disabled people can fully participate in all areas of life. Authorities of a certain field, for example the labor market or education, are also in charge of disability issues in their field. The current national plan from 2016 emphasizes the human rights as its basis (Regeringen Sverige 2016). There is even a link to the CRPD in the regulation for the implementation of this plan (Förordning 2001:526). The Swedish state, the county councils and the municipalities share the responsibility for the financial, social and health security of disabled people. The state is responsible for the so-



cial insurance, county councils for health care and municipalities for social services (Socialstyrelsen 2009, p. 1). Services covered by the social insurance are for example the disability allowance (Handikappersättning) or the car allowance (Bilstöd). The disability allowance is a payment for disabled people to compensate their extra costs caused through their disability. The car allowance is a payment for necessary adaptations of a car because of a disability. An service covered by the municipality is the home adaptation allowance (Lag om bostadsanpassningsbidrag 1992:1574). Because of the different responsibilities, services for disabled people are regulated in different laws like the Social Service Act ( SoL – Socialjännstlag 2001:453), the Health- and Medical Service Act (HSL – Hälso- och sjukvårdslag 2017:30) or the Education Act (Skoll - Skollag 2010:800). If the support provided on the basis of these laws is not enough, there is another law covering basic measures for people with severe disabilities: the Act Concerning Support and Service for Persons with Certain Functional Impairments (LSS – Lag om stöd och service till visa funktionshindrade) (Socialstyrelsen 2009, p. 3).

*This Act provides for ten different initiatives: advice and support, companion service, assistance from a contact person, relief service in the home, short-term stays outside the home, short-term supervision for school pupils over 12 years of age outside the home, foster homes or specially serviced housing for children and young people who need to live outside the parental home, specially serviced housing for adults or other specially adapted housing for adults and also daily activities for people of working age not in gainful employment and who are not receiving training and cash payments for personal assistance (Anderberg 2009, p. 3).*

### **3.2.2 The Swedish Personal Assistance System**

The Swedish system of personal assistance will be described in the following subchapter using the same structure as for the description of the German system.

#### **Legal Framework and Responsibility**

In Sweden there is a specific law granting personal assistance for disabled people. The Act Concerning Support and Service for Persons with Certain Functional Impairments (Lag om stöd och service till vissa funktionshindrade – LSS 1993:387) was introduced in 1994. It contains the fundamental regulations like the eligibility criteria for personal assistance. The aim of the law is to ensure that disabled people can “live like others” (§

5 LSS 1993:387). The municipality is responsible for personal assistance if there are no other regulations (§ 2 LSS 1993:387). It is responsible to secure the supply of personal assistance services and has to provide services itself if there are no other personal assistance providers in the municipality. Details for the provision of personal assistance through the municipality are regulated in the Regulation concerning the LSS (Förordning 1993:1090 om stöd och service till vissa funktionshindrade). The responsibility for paying the services depends on the hours of assistance a disabled person needs for specific basic needs according to the law. The state pays for personal assistance through the Social Insurance Agency if a disabled person needs 20 or more hours per week of assistance for basic needs. About 77% of all assistance users in Sweden got their allowance paid by the Social Insurance Agency in the year 2017. Chapter 51 of the Social Insurance Act (Socialförsäkringsbalk 2010:110) regulates the personal assistance allowance within the responsibility of the Social Insurance Agency. Details are defined in the Regulation concerning the Assistance Allowance (Förordning 1993:1091 om assistansersättning). However, the first 20 hours of assistance are always paid by the municipality (Westberg 2010, p. 8). Persons who need less than 20 hours assistance per week for basic needs, get all their assistance paid by the municipality. The responsible authority then also grants assistance for other needs beyond basic needs like for example at work or leisure assistance (§ 9a LSS 1993:387).

### **Eligible Group of Persons**

According to the LSS § 1 people are eligible for personal assistance allowances if they belong to one of the following groups:

1. Persons with an intellectual disability, autism or a condition resembling autism;
2. Persons with a significant and permanent intellectual impairment after brain damage in adulthood due to an external force or a physical illness;
3. Persons who have other major and permanent physical or mental impairments, which are clearly not due to normal ageing and which cause considerable difficulties in daily life and consequently an extensive need of support and service.

Furthermore, a person who belongs to one of these groups must need assistance for at least one of the following fundamental needs (§ 9a LSS 1993:387):

1. Personal hygiene
2. Eating
3. Dressing and undressing

4. Communicating with others
5. Other help, which requires detailed knowledge of the person's impairment

To be eligible for personal assistance allowance from the social insurance a person must have needs of 20 or more hours of personal assistance per week for these fundamental needs. Persons who need less than 20 hours assistance per week are eligible for direct payment for assistance from their municipality.

Since the introduction of the law there have been many court judgments concerning the definition of basic needs. According to Brennan the judgments have led to less needs counting as basic needs and the group of persons eligible for personal assistance from the Social Insurance Agency has been getting smaller (Brennan et al. 2016b). The judgements were interpreted and implemented strictly by the Social Insurance Agency.

The Supreme Administrative Court judged in 2009 that only needs concerning the integrity of the close parts of the body are basic needs (Regeringsrätten 2009). According to the Social Insurance Agency a basic need is for example to get food into the mouth and eat it. If someone is able to do that, he or she has no basic need in the area 'eating'. Preparing and cutting the food is not considered a basic need, because it does not interfere in the integrity of the body. The same counts for washing hair or putting on outer clothing. Help for self-care is neither counted as a basic need according to a court decision in 2012 (Regeringsrätten 2009; Högsta Förvaltningsdomstolen 2012). As gavage feeding is considered self-care and not 'eating', it is not counted as a basic need according to the Social Insurance Agency. A court decision from 2015 defined that the (5<sup>th</sup>) basic need of so called other help, which requires detailed knowledge of the person's impairments, only counts for people with psychosocial disabilities (Högsta Förvaltningsdomstolen 2015).

The maximum age for the eligibility for personal assistance is 65 years. Disabled people have to apply for personal assistance before the age of 65. When they are 65 or older, they are allowed to keep the assistance hours they were granted before turning 65, but they cannot apply for more hours than (§ 9b LSS 1993:387). There is no minimum age to be eligible for personal assistance.

As personal assistance was introduced as service enabling disabled to live more independently, the state funded personal assistance is not paid to disabled people living in institutions (Socialförsäkringsbalken Kap. 106 § 24).

## **Assessment of demand and Calculation**

The assessment of demand is carried out by the Social Insurance Agency or the municipality. If the need of assistance for basic needs is estimated to be 20 or more hours per week, the Social Insurance Agency executes the assessment. The municipality is responsible for the assessment if assistance for basic needs is estimated to be less than 20 hours per week. In the assessment the need of assistance for basic needs is calculated in minutes to define which authority is responsible to pay for the assistance. Therefore, the basic needs according to the law are taken into account: Personal hygiene, eating, dressing and undressing, communicating with others and other help, which requires detailed knowledge of the person's impairment. The Social Insurance Agency and the municipality follow and strictly implemented the court decisions defining basic needs. The assessment for assistance through the Social Insurance Agency is repeated every two years. Assistance through the municipality is assessed every year or every two years in exceptional cases.

For the assessment disabled people have to show certificates from doctors and physiotherapists about their disability (Dahl and Bolling 2015). The assessment for needed assistance hours (not only for basic needs) is carried out in a guided interview with the disabled person. A battery of questions of an interview guideline is used (Socialstyrelsen and Försäkringskassan 2011). The applicant describes his or her everyday life including activities he or she could do with assistance. "All regularly occurring activities should be included in the assessment, without exceptions. There are no approved or disapproved activities, no lists." (Westberg 2010, p. 24). The description of the applicant is the basis for the assessment how many minutes of personal assistance is needed. The social worker evaluates if the time for activities told by the applicant are reasonable. Time, which is needed to 'motivate' (mentally) disabled people to do something by him or herself, is not covered by the personal assistance allowance (Regeringsrätten 1997). In addition a court decision was made in 2017 stating that inactive times of assistants are not paid outside the home (Assistanskoll n.d.b). Because of the negative effects this judgement and others might have on disabled people, the government proposed to work on a draft legislation in 2018. Until then the two years assessments are on hold (Assistanskoll n.d.a). The granted assistance allowance is part of an individual plan, which is set up by the authority and the disabled person to plan all provisions granted to the disabled person by different authorities. The plan contains also the aims of the disabled person, which may be reached through the different measures (§10 LSS).

## Provision and Models

The assistance allowance is provided as a direct payment to the disabled person. The disabled person decides how the assistance should be organized with this money. An assistance user can act as an employer for own assistants, organize the assistance through a cooperative or the municipality or buy services from public or private service providers. It is possible to recruit assistants who then are employed by the municipality or a private assistance company. The assistance user can also establish his or her own assistance company, which provides assistance services to him or her or to others. The amount of granted assistance hours depends on the individual needs of the disabled person and there is no maximum rate. A disabled person can also get two assistants if necessary (§ 9a LSS 1993:387). The direct payment is paid as a flat rate per hour. In 2018 the flat rate is 295,40 krona<sup>1</sup> per hour (Assistanskoll n.d.c). The flat rate is the same for all assistance users regardless which assistance model they choose. A person who employs assistants by him or herself gets the same amount per hour as a person buying services from the municipality or a private company. The amount can be up to 12% higher if assistance is necessary during night or assistants need special qualifications. In special cases personal assistance is also granted when the user is in hospital (Försäkringskassan 2003, p. 55). The maximum period of personal assistance paid to a hospitalized assistance user is normally four weeks. The period can be longer in exceptional cases (Westberg 2010, p. 9f).

Until 2013 the Social Insurance Agency and the Swedish Association of Local Government and Regions (Sveriges Kommuner och Landsting SKL) gave a recommendation on the size of the flat rate every year. Since 2014 the government defines the increase of the flat rate every year. In 2016 it increased about 1,4%, in 2017 about 1,05% and in 2018 about 1,5% (Assistanskoll n.d.c). About 87% of the flat rate is appropriated to wages and employment related costs of assistants. The other 13% of the amount is dedicated to different types of costs like administration, training or work environment (Westberg 2010, p. 10).

The assistance allowance is paid monthly in advance to assistance users who act as employers for their assistants. Users who are customers of an assistance provider or members of an assistance cooperative get their funds paid retroactively on the basis of delivered assistance hours, which were reported. The accounting of money used for assistance hours is made every six months. Assistance users acting as employer for

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<sup>1</sup> 29,98 euro according to xe.com at 01/15/2018

their assistants have to pay back money, which is left over from delivered assistance hours within this six month period. Companies do not have to pay back leftover funding. That is how they can make profit (Bolling and Westberg 2017; Westberg 2010).

“In principle, there should be no difference for the individual when it comes to receiving payment for personal assistance either from the municipality (LSS) or from the Försäkringskassan (Social Insurance Agency)” (Westberg 2010, p. 9). However, in Sweden municipalities are local self-governments with the power to regulate how they manage and implement their responsibilities on their behalf. Municipalities do not have to follow the flat rate set by the government according to a court decision of the Supreme Administrative Court (Högsta Förvaltningsdomstolen 2016). Guidelines from the Social Insurance Agency are not binding for the municipalities either. They can have their own regulations concerning personal assistance. The National Board of Health and Welfare found out that people who move from the state funded to the municipality funded assistance allowance because of reassessment receive in average 25% less hours (Socialstyrelsen 2015, p. 2). Municipalities and providers can restrict the use of the allowance. For example gardening and shoveling of snow are restricted in some municipalities (Dahl and Bolling 2015). According to the Work Environment Act all employers have to do a risk analysis of the workplace to protect their employees from health or accident hazards (§ 2 Arbetsmiljölagen 1977:1160, Westberg 2009).

### **Persons working as personal assistants**

Persons must be at least 18 years old to work as personal assistants (§ 9d LSS). But according to the law they do not need special qualifications. The assistance user decides which qualifications the assistants have to have when working for him or her. There are two different labor agreements for assistants who are employed by a municipality. One labor agreement applies to assistants working for a certain assistance user. They do not need special qualifications and do not have to be available for other users. On the other hand municipal assistants who might have to work for several assistance users have to have care qualifications according to the other labor agreement (Westberg 2010, p. 52). Family members are allowed to work as assistants for their relatives when the services are not part of the parental duties for children (Westberg 2010, p. 25). There are different working hour regulations for personal assistants employed by the assistance user than for assistants employed by a provider. The Law on Working Time etc. in Household Work applies for assistants who are employed by assistance users. These regulations are less strict than the general regulations of the

Working Hours Act, which applies to assistants employed by public or private providers (Westberg 2010, p. 33). The Social Insurance Agency only pays for assistance hours, which were delivered according to the Working Hours Act.

### **Figures concerning personal assistance**

According to Statistics Sweden there are around 900.000 disabled people in the age between 16 and 64 living in Sweden in the year 2016. This is about 15% of the Swedish population aged 16 to 64 (Statistiska Centralbyrån 2017, p. 7, 146). In September 2017 there were 19.690 persons receiving personal assistance in Sweden. 54% of the assistance users were men. The majority of the assistance users (15.115) got their assistance through the Social Insurance Agency. 4.575 persons got it paid by their municipality. The average assistance allowance granted by the Social Insurance Agency was 128,99 hours per week. The assistance carried by the municipality was in average 49,2 hours per week. Personal assistance users can choose from different service providers. In December 2016, 66% of the assistance users chose a company, 24% municipal services, 7% an assistance cooperative and 3% chose to be employer for own assistants (Assistanskoll n.d.c).

From 1994 to 2015 there was a continuous growth of the number of assistance users in Sweden. In 1994 there were about 4.000 people receiving personal assistance in an average of 66 hours per week through the Social Insurance Agency. Until 2015 the number of users has more than doubled and the average hours more than tripled. In 2015 there were around 16.000 persons who got state-funded personal assistance with an average of 124 hours per week (Assistanskoll n.d.c). The government did not expect such a development. "Concerns arose that a significant proportion of personal assistance payments were not being used for what the legislation intended. [...] The government claims that a stricter definition of 'basic needs' is required for clearer rules and guidelines to increase safety, uniformity and consistency of the assessment process" (Brennan et al. 2016b). With court decisions reinterpreting 'basic needs', the trend changed. The number of persons receiving personal assistance through the Social Insurance Agency declines since 2015. In March 2017 over 80% of applications for state-funded personal assistance were rejected (Assistanskoll n.d.c).

### 3.3 Differences between the German and Swedish Personal Assistance Systems

The differences between the German and Swedish system of personal assistance are summarized in Table 1.

Table 1 *Comparison of the German and Swedish personal assistance system.*

	<b>Germany</b>	<b>Sweden</b>
<b>Legal Framework and Responsibility</b>	<ul style="list-style-type: none"> <li>- Disabled people have the right to services to participate in society (§§ 1, 2 SGB IX), the right to personal assistance services can be based on several laws of the SGB</li> <li>- Several different authorities can be responsible to grant personal assistance depending on how a person got the disability and for what the assistance is needed for</li> <li>- Important authorities for personal assistance are the care insurance (SGB XI) for care services and the Integration Support (SGB XII) for social participation services</li> <li>- Other authorities, which can be responsible, are the pension insurance, health insurance, care insurance, Employment Agency, accident insurance, victim provision, youth welfare, Integration Office and Social Benefits Agency</li> <li>- Services can be granted as a personal budget, which is a direct payment</li> </ul>	<ul style="list-style-type: none"> <li>- According to the act LSS there is the right to personal assistance from the municipality</li> <li>- If a person needs 20 or more hours assistance for basic needs per week, the assistance allowance is granted by the state through the Social Insurance Agency</li> <li>- The Social Insurance Act Chapter 51 regulates the state funded assistance through the Social Insurance Agency</li> <li>- The responsible authority pays also for assistance beyond basic needs</li> <li>- The first 20 hours of assistance are always carried by the municipality</li> </ul>



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**Eligible  
Group of  
Persons**

- Persons, who have a physical, psychological, mental or sensory impairment, which in interaction with attitudinal or environmental barriers may hinder their equal participation in society very probably longer than six months, have the right to services to participate in society (§§ 1, 2 SGB IX)
  - Disabled people are eligible for personal assistance services if they fulfill the eligibility criteria for the specific service according to the different laws
  - The services of different authorities have different eligibility criteria according to specific laws
  - A person gets services for social participation carried by the Integration Support if he or she is substantially disabled
  - People with a severe disability receive work assistance
  - Care allowances through the care insurance are available for persons in need of care who have been insured for at least two years in the last ten years
- Disabled people are eligible for personal assistance allowances if they belong to one of the following groups:
    - (a) Persons with an intellectual disability, autism or a condition resembling autism;
    - (b) Persons with a significant and permanent intellectual impairment after brain damage in adulthood due to an external force or a physical illness;
    - (c) Persons who have other major and permanent physical or mental impairments, which are clearly not due to normal ageing and which cause considerable difficulties in daily life and consequently an extensive need of support and service.
  - Furthermore, there must be the need of assistance for at least one of the following basic needs: Personal hygiene, eating, dressing and undressing, communicating with others, other help, which requires detailed knowledge of the person's impairment
  - A disabled person can apply for personal assistance until the age of 65

<b>Assessment of Demand and Calculation</b>	<p>Application</p> <ul style="list-style-type: none"> <li>- Disabled people have to apply for assistance at a presumably responsible authority (§§ 14, 15 SGB IX)</li> </ul>	<p>Application</p> <ul style="list-style-type: none"> <li>- Disabled people have to apply at their municipalities or at the Social Insurance Agency depending on how many hours of assistance for basic needs they presumably need</li> </ul>
	<p>Assessment of demand</p> <ul style="list-style-type: none"> <li>- The assessment of demand is carried out by the Performing Authority</li> <li>- The needs are assessed with different assessment tools or procedures depending on the responsible authorities</li> <li>- The Medical Service of the Health Insurance assesses the need of care</li> <li>- A participation plan conference can be held to debate the assessed needs together with all responsible authorities if the disabled person agrees (§ 20 I SGB IX)</li> <li>- To assess and plan services of the Integration Support an Overall Plan has to be made (§§141ff. SGB XII)</li> <li>- It is assessed what kind of services the applicant needs</li> <li>- The assessment for services in form of a personal budget is repeated every two years (§ 29 SGB IX)</li> </ul>	<p>Assessment of demand</p> <ul style="list-style-type: none"> <li>- The assessment on demand is carried out by the Social Insurance Agency or the municipality</li> <li>- If the need of assistance for basic needs is estimated to be 20 or more hours per week, the Social Insurance Agency is responsible for the assessment. If it is estimated to be under 20 hours, the municipality is responsible</li> <li>- The assessment is based on an guided interview with the disabled person and his or her description of the daily life</li> <li>- It is assessed how many hours of assistance the applicant needs</li> <li>- The assessment is repeated normally every two years for state funded assistance and every year for assistance through the municipality</li> <li>- An Individual Plan is made with the disabled person where the individual aims are set</li> </ul>

**Provision  
and  
Models**

- Personal Assistance can be granted as a direct payment to the disabled person in form of a comprehensive personal budget for the assessed services
- The amount of the personal budget is based on the costs of the assessed services and can include costs for wage office or budget support services if needed
- The amount of personal budget can be limited. The extra costs for ambulatory services have to be reasonable.
- Personal budgets are paid monthly in advance.
- The disabled person and the authorities arrange a budget agreement, which defines the services and the time and way to account for the use of the personal budget
- Services of the social benefit agency are means-tested. If the personal budget includes social benefit services, like services from the Integration Support or Help for Care, the assistance user might have to pay a contribution

**Models**

- Assistance users can act as employers for their assistants
- Assistance users can buy assistance services from public or private providers

- Personal assistance is granted as a direct payment to the disabled person in the form of a flat rate per assessed assistance hour
- The flat rate per hour should be the same irrespective of the responsible authority
- The amount of assistance hours is not limited; more than 24 hours a day are possible
- The flat rate per hour can be up to 12% higher if assistance is necessary during night or assistants need special qualifications
- The allowance is paid retroactively every month. Assistance users acting as employers receive funding monthly in advance
- The accounting of money used for assistance hours is made every six month
- The flat rate per hour is the same irrespective of the chosen model

**Models**

- Assistance users can act as employers for their assistants
- Assistance users can employ their assistance through their municipality, a cooperative or a company
- Assistance users can buy assistance services from the municipality or private providers
- Assistance users can establish their own assistance company

<p><b>Persons working as personal assistants</b></p>	<ul style="list-style-type: none"> <li>- A person must be at least 15 years old to work as a personal assistant, but until the age of 18 there are special working hour regulations</li> <li>- Personal assistants do not need to have special qualifications</li> <li>- There are mandatory care counsellings if care services are carried out by an assistant without care qualifications</li> <li>- Family members can work as personal assistants for their relatives if the service is not part of their parental duty</li> </ul>	<ul style="list-style-type: none"> <li>- A person must be at least 18 years old to work as personal assistant</li> <li>- There are no special qualifications needed to work as a personal assistant according to the law</li> <li>- A labor agreement for assistants employed by the municipality requires care qualifications if the assistant works for more than one assistance user</li> <li>- Assistants employed by the assistance user might have to work longer because of different working hour regulations</li> <li>- Family members can work as assistants for their relatives if the service is not part of their parental duty</li> </ul>
<p><b>Figures concerning personal assistance</b></p>	<ul style="list-style-type: none"> <li>- There were 10,2 Mio disabled people living in Germany in 2013., this was 13% of the population</li> <li>- There were 14.193 personal budgets granted in 2010 according to a study</li> <li>- 11.493 of these personal budgets were granted by the Integration Support</li> <li>- It is not clear how many and how much of the personal budgets were spent for personal assistance</li> </ul>	<ul style="list-style-type: none"> <li>- There were 900.000 disabled people living in Sweden in 2016, this was 15% of the population</li> <li>- There were 19.690 personal assistance allowances granted in 2017</li> <li>- 15.115 allowances were granted by the Social Insurance Agency with an average of 128,99 hours</li> <li>- 4.575 allowances were granted by the municipalities with an average of 49,2 hours</li> <li>- 66% of the assistance user bought their assistance services from a company</li> </ul>

## **4 The Convention on the Rights of Persons with Disabilities**

The following chapter focusses on the UN Convention on the Rights of Persons with Disabilities (CRPD). After an overview of the CRPD and its background, Article 19 will be described and the General Comment on Article 19 will be introduced.

### **4.1 Background of the CRPD**

In the 1970s, the United Nations had introduced the Declaration on the Rights of Mentally Retarded Persons in 1971 and the Declaration on the Rights of Disabled Persons in 1975. Before the adoption of the CRPD, the United Nations also addressed human rights for disabled people in the World Program of Action concerning Disabled Persons, which was adopted by the General Assembly in December 1982. At the international conference to review the implementation of the World Program of Action in Stockholm 1987, the participants recommended to elaborate a convention on human rights for disabled people. This recommendation did not lead to a new convention. In 1993 the United Nations adopted Standard Rules on the Equalization of Opportunities for Persons with Disabilities. The Standard Rules are monitored but not legally binding for State Parties (Deutscher Bundestag 2008, p. 9ff).

In 2001 the Government of Mexico proposed the elaboration of an international convention on rights for disabled people to the General Assembly of the United Nations. Therefore, an Ad Hoc Committee was established. The Ad Hoc Committee consisted of 27 states, representatives from Disabled Persons' Organizations and a national human rights institution (United Nations Division for Social Policy and Development 2018, p. 14). From 2002 to 2006, the Ad Hoc Committee worked on and negotiated the text of the Convention and the Optional Protocol "[taking] into account all contributions from regional and national consultations, expert meetings, United Nations bodies, regional commissions and intergovernmental organizations, as well as by nongovernmental organizations (NGOs), disability and human rights institutions" (United Nations Division for Social Policy and Development 2018, p. 14). In December 2006, the General Assembly adopted the Convention on the Rights of Persons with Disabilities and its Optional Protocol.

The CRPD is based on the International Bill of Human Rights, which consists of the Universal Declaration of Human Rights from 1948, the International Covenant on Eco-

nomic, Social and Cultural Rights and the International Covenant on Civil and Political Rights from 1966 (Kreutz et al. 2013, p. 2; Deutscher Bundestag 2008, p. 11). The CRPD recognizes these declarations in its preamble (Preamble b., d. CRPD). The Preamble also recalls further conventions, like the Convention on the Elimination of All Forms of Discrimination against Women and the Convention on the Rights of the Child (Preamble d. CRPD). The CRPD does not introduce special or new rights for disabled people but concretize the human rights for disabled people (Kreutz et al. 2013, p. 1). The purpose of the Convention is stated in Article 1 as follows:

*The purpose of the [...] Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity (Article 1 CRPD).*

The Convention consists of 50 articles besides the preamble. The Optional Protocol counts another 18 articles. The centerpieces of the CRPD are the Articles 1 to 30, which contain the rights for disabled people. Articles 31 to 50 regulate the implementation and monitoring of the rights. Article 1 describes the purpose of the Convention and defines 'persons with disability'. This concept of disability expresses the social model of disability. Thus disability is not an attribute of an individual (Kreutz et al. 2013, p. 69). A person gets disabled through attitudinal and environmental barriers (Preamble e CRPD). This reflects the social model of disability, which sees disability as "a socially created problem" (Della Fina et al. 2017, p. 95). The CRPD also expresses the human rights model of disability, which focusses on the human rights and inherent dignity of disabled persons irrespective of their disabilities or health issues (Degener 2016, p. 2f). By contrast the medical model "considers disability as a feature of the individual, directly caused by disease, trauma, or other health condition" (Della Fina et al. 2017, p. 95).

In the beginning of the Convention, the general regulations are stated, like the definitions of key terms in Article 2, the general principles of the convention in Article 3 and the general obligations of the States Parties in Article 4. The centerpieces of the Convention are the human rights and the consequential obligations of the States Parties. The obligations can be grouped into obligations to respect, obligations to protect and obligations to fulfill (Kreutz et al. 2013, p. 6ff). Obligations to respect demand from the States Parties the respect of the human rights. The exercise of these rights must not be restricted directly or indirectly. States Parties have obligations to protect the rights from

interferences of others. The obligations to fulfill demand that actions are implemented to enable disabled persons to execute their rights (Kreutz et al. 2013, p. 7ff).

The Optional Protocol to the CRPD is a separate legal agreement. There is no obligation to ratify the Optional Protocol when ratifying the Convention. However, it is only with the additional ratification of the Optional Protocol that the comprehensive protection of the rights can be ensured (United Nations 2014, p. 131). The Optional Protocol complements the regulations for implementation and monitoring. It defines the complaints procedure in cases of disrespect of the provisions of the Convention by the States Parties.

Until April 2018, the Convention was signed by 161 states and ratified by 177 states (United Nations Treaty Collection n.d.). 92 states signed and ratified the Optional Protocol of the Convention (United Nations Division for Social Policy and Development n.d.). Sweden and Germany both signed the CRPD and its Optional Protocol the 30th of March 2007, on the first day the Convention was open for signatures (United Nations Treaty Collection n.d.; Deutscher Bundestag 2008, p. 11). In Germany a treaty gets ratified through a national law requiring approval (Art. 59 II GG). Through this law the Convention gets incorporated into national law and, therefore, gets legally binding in Germany. By contrast in Sweden the CRPD did not get the status of a national law. In Sweden a ratification of a treaty is not done by an incorporation of the treaty's text to national law but through adoptions, changes or complements of the existing laws in accordance to the treaty (Kap. 10, §3 Regeringsformen). Sweden ratified the CRPD and its Optional Protocol in December 2008 and Germany ratified it in February 2009 (United Nations Treaty Collection n.d.). According to Article 50 of the CRPD, only the Arabic, Chinese, English, French, Russian and Spanish texts of the Convention apply as authentic texts. The text was translated into German and Swedish for a better understanding in the respective countries, as States Parties Germany and Sweden have to "ensure that public authorities and institutions act in conformity with the present Convention" (Art. 4 d CRPD).

The national implementation and monitoring of the provisions of the CRPD are stated in Article 33 of the CRPD. Thus "states parties shall [...] maintain, strengthen, designate or establish [...] a framework, including one or more independent mechanisms, as appropriate, to promote, protect and monitor implementation of the present Convention" (Art. 33 CRPD). The Committee on the Rights of Persons with Disability plays an important role in monitoring the Convention. The Committee is a treaty body of 18 in-

dependent members who are elected by the States Parties to the CRPD for a period of four years (Art. 34 CRPD). It receives comprehensive reports from States Parties according to Article 35 (1) "on measures taken to give effect to its obligations under the present Convention and on the progress made in that regard". Furthermore, the Committee receives subsequent reports from the States Parties at least every four years or whenever the Committee requests (Art. 35 (2) CRPD). Under the Optional Protocol the Committee gets so called communications, which are complaints from individuals or organizations claiming violations of the provisions of the CRPD (Art. 1 Optional Protocol). The Committee then forwards recommendations and suggestions on these communications to the State Party (Art. 5 Optional Protocol). In addition, the Committee undertakes inquiries if there are "reliable information indicating grave or systematic violations by a State Party of rights set forth in the Convention" (Art. 6 Optional Protocol). After receiving a state's report, it is examined by the Committee. The Committee responds with a list of issues to complete the missing information in the report. The State Party has time to answer the list of issues before the Committee gives its concluding observations and recommendations (United Nations 2014, p. 116ff). Also in the concluding observations on the initial reports of Sweden and Germany the Committee expresses its concerns on the missing implementation of the provisions of the CRPD and gives recommendations (Committee on the Rights of Persons with Disabilities 2014, 2015).

## **4.2 Article 19 of the CRPD**

Article 19 'Living independently and being included in the community' of the CRPD states the following:

*States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:*

*(a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*



*(b) Persons with disabilities have access to a range of in-home, 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;*

*(c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*

The title of Article 19 is called 'Living independently and being included in the community'. It echoes the Preamble, which recognizes "the importance for persons with disabilities of their individual autonomy and independence, including the freedom to make their own choices" (Preamble n CRPD). Living independently does not mean to live self-sufficient on one's own. "Independent living' refers rather to personal autonomy, freedom to make choices concerning own life, and control over one's life and decisions" (Della Fina et al. 2017, p. 359).

Article 19 picks up some of the fundamental principles of the CRPD and turns them in legal obligations with concrete measures. Particularly the general principles according to Article 3 a), b), and c) are adopted in Article 19. The objective of this Article is the full and effective participation and inclusion of disabled people in society (Art. 3 c CRPD) by respecting the freedom to make one's own choices and the independence of persons (Art. 3 a CRPD). The equal right of all disabled persons to live in the community, with choices equal to others expresses the principle of non-discrimination (Art. 3 b CRPD). 'Others' can be interpreted as persons without disabilities (Kreutz et al. 2013, p. 206). The CRPD states that all disabled persons have the right to live in the community irrespective of their disabilities or ability to live by themselves (Kreutz et al. 2013, p. 207). There is not only the right to live in the community, which describes the opposite of separation and isolation but also the right to full inclusion and participation (Della Fina et al. 2017, p. 360).

Furthermore, Article 19 gives three measures, which States Parties have to implement to realize the rights stated in the chapeau. Subparagraph a) requires ensuring the choice of residence and prohibits forced living arrangements. This subparagraph is linked to Article 12 of the International Covenant on Civil and Political Rights to the right to liberty of movement and freedom to choose the residence (Kreutz et al. 2013, p. 209). Beside the right to choose their residence, disabled people with can also decide like others where and with whom they want to live. This right to choose and decide touches partly the obligations under Article 12 of the CRPD on the equal recognition

before and under the law. According to Article 12 “persons with disabilities enjoy legal capacity on an equal basis with others” and must have access to support enabling them to exercise their legal capacity (Art. 12 CRPD). “Ensuring genuinely free choice of residence for persons with disabilities also means challenging the legitimacy and use of guardianship and of other regimes providing for substitute decision-making” (Della Fina et al. 2017, p. 364). According to Article 19 a) persons with disabilities are not obliged to live in particular living arrangements. This means disabled people have the right to refuse institutionalization, which is linked to Article 14 of the CRPD, which states that the existence of a disability does not justify a deprivation of liberty. Article 19 a) requires deinstitutionalization because particular living arrangements are not seen to be adequate to ensure the full inclusion and participation of disabled people in the community. Despite of the demand of deinstitutionalization, disabled people have the right to choose a particular living arrangement (Kreutz et al. 2013, p. 207). The right to choose the residence cannot be restricted by a State Party because of financial reasons (Kreutz et al. 2013, p. 208).

As a second measure States Parties have to ensure “access to a range of in-home, residential and other community support services” according to subparagraph b) of Article 19. Della Fina and others describe this as follows:

*This means that States Parties have, first of all, an obligation to ensure that a wide range of support services (which can involve different, public and private, providers) do actually exist within their territory and are reachable by each person with disabilities living under their jurisdiction (Della Fina et al. 2017, p. 367).*

Services shall not prevent disabled people from participating in the community but rather support living and inclusion in the community. Article 19 b) highlights personal assistance as a service “necessary to support living and inclusion in the community”. Personal assistance as a personalized service allows disabled people to choose the degree of control over the service according to their preferences (Kreutz et al. 2013, p. 209f). In the Swedish CRPD ‘personal assistance’ was not translated directly but as ‘personal support (personlig stöd).

The third measure according to subparagraph c) requires States Parties to ensure accessibility to mainstream community services. In general all services and facilities provided for the community have to be available for disabled people like for other people (Della Fina et al. 2017, p. 369). This is linked to Article 2, which states that “products, environments, programmes and services [have] to be usable by all people” through a

universal design. Subparagraph c) has to be seen in the context of Article 9 on accessibility. States Parties have to provide “access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public” (Art. 9 CRPD). Accessibility refers to all areas of life, which are expressed in different Articles of the Convention like Article 20 (mobility), 21 (information), 24 (education), 25 (health) and 27 (employment). Services not only have to be available but also be responsive to the needs of disabled people. “To make it happen, it will require that persons with disabilities and their representative organizations are centrally involved in the planning, development, and implementation of State policies and measures concerning accessibility of mainstream services” (Della Fina et al. 2017, p. 369). That is what the general obligations according to Article 4 subparagraph 3 require.

The main issues in the application of Article 19 are the insufficient efforts taken towards deinstitutionalization and the accessibility to mainstream community services. The CRPD Committee has urged States Parties to implement concrete measures to promote deinstitutionalization. Germany was criticized by the CRPD Committee in their last concluding observation report because of the high level of institutionalization. The Committee was also concerned about the means-testing of benefits, which links the provision of support services to a certain standard of living (Committee on the Rights of Persons with Disabilities 2015). The main issue in the application of Article 19 in Sweden has been the restrictions of personal assistance. “The Committee is concerned that State-funded personal assistance has been withdrawn for a number of people since 2010 due to a revised interpretation of ‘basic needs’ and ‘other personal needs’, and that persons who still receive assistance have experienced sharp cutbacks” (Committee on the Rights of Persons with Disabilities 2014).

### **4.3 General Comment on Article 19 of the CRPD**

General Comments are authoritative statements, which clarify rights mentioned in a human rights treaty (Deutsches Institut für Menschenrechte n.d.). They describe abstract rights and “clarify issues arising from the implementation of the Convention” (United Nations 2014, p. 130). They give guidance for the practical implementation and evaluation of the obligations according to the convention. General Comments are not legally binding but highly authoritative texts as States Parties sign the Convention and

accept the Committee to interpret and clarify the rights (Deutsches Institut für Menschenrechte n.d.). States Parties, interests groups and non-governmental organizations participate in drafting a General Comment by contributing submissions (Deutsches Institut für Menschenrechte n.d.).

The Committee on the Rights of Persons with Disabilities has published six General Comments on the CRPD until May 2018 (United Nations n.d.). The General Comment Number 5 on Article 19 of the CRPD was adopted in August 2017 (Committee on the Rights of Persons with Disabilities n.d.b). The drafting process started with a Day of General Discussion in April 2016 in Geneva (Committee on the Rights of Persons with Disabilities n.d.a). The Committee encouraged interested stakeholders to send in written submissions on the draft of the General Comment on Article 19. Also Swedish and German disability organizations and Independent Living organizations contributed with submissions to the draft and criticized the situation in their countries (Swedish Disability Federation and Independent Living Institute n.d.; Interessenvertretung Selbstbestimmt Leben in Deutschland e.V. 2016).

The introduction of General Comment Number 5 highlights the importance of Article 19 and criticizes the gap between the goals of the article and its implementation in the States Parties (Committee on the Rights of Persons with Disabilities 2017, p. 2ff). The second chapter is about the normative content of Article 19. There the General Comment defines independent living, being included in the community, independent living arrangements and personal assistance. It echoes the Independent Living Principles, like the deinstitutionalization. Further on, it comments the chapeau and the subparagraphs a), b) and c) of Article 19 and gives interpretations of the content. The core elements are identified "in order to ensure that the realization of a standardized minimum support level sufficient to allow the exercise of the right to live independently and be included in the community is carried out by every State party" (Committee on the Rights of Persons with Disabilities 2017, p. 8). The third chapter describes the obligations of the States Parties, which are grouped in obligations to respect, obligations to protect and obligations to fulfill (Committee on the Rights of Persons with Disabilities 2017, p. 9ff). "The obligations of States parties must reflect the nature of human rights as either absolute and immediately applicable (civil and political rights) or progressively applicable (economic, social and cultural rights)" (Committee on the Rights of Persons with Disabilities 2017, p. 9). The right to personal assistance belongs to the group of economic, social and cultural rights and must be progressively realized. The Committee makes clear that retrogressive measures of State Parties are prohibited and are

seen as violation of the states' obligations (Committee on the Rights of Persons with Disabilities 2017, p. 9). In the end, the General Comment illustrates the relationship with other provisions of the Convention and its implementation at the national level (Committee on the Rights of Persons with Disabilities 2017, p. 13ff, 17ff).

The definition of personal assistance in the General Comment Number 5 gives clear criteria, which have to be fulfilled to call a service 'personal assistance' in the sense of the CRPD (Committee on the Rights of Persons with Disabilities 2017, p. 5). The General Comment defines personal assistance as a "person-directed/'user'-led human support available to a person with disability and is a tool for independent living" (Committee on the Rights of Persons with Disabilities 2017, p. 5). Thus personal assistance is a personalized service, controlled by the disabled person, which enables the person to live independently. The definition is further structured in the four core elements: (1) funding, (2) service controlled by the person with disability, (3) one-to-one relationship and (4) self-management of service delivery. Each core element contains a bunch of criteria for the definition of personal assistance, which clarify more detailed the term of 'person-directed/user-led human support'.

## **5 Theoretical Evaluation of Personal Assistance**

The General Comment gives clear criteria, which define personal assistance. With these criteria it can be proved if and how the systems of personal assistance in Germany and Sweden fulfill the requirements of personal assistance according to the CRPD. The theoretical evaluation is based on information given in the description of the personal assistance systems (chapter 3), legislative texts and other sources. The results of this qualitative evaluation might not always be explicit. Thus, for a better comparability and visualization the symbols '✓', 'o' and '✗' shall show if a criterion is fulfilled (✓), partly fulfilled (o) or not fulfilled (✗).

### **5.1 Criteria according to the General Comment**

Table 2 shows the criteria defining personal assistance and its explanations. The citations of the following criteria refer to General Comment Number 5 from August 2017 (Committee on the Rights of Persons with Disabilities 2017, p. 5). The criteria include the definition text of personal assistance according to subchapter 16 d), points (i) to (iv) of the General Comment on Article 19. The explanations specify the criteria to make them clearer and to distinguish them from each other. It explains what aspects will be reviewed under the certain criteria in the evaluation.

Table 2: *Criteria defining personal assistance according to General Comment Number 5 on Article 19 of the UN-Convention on the Rights of Persons with Disability.*

Criteria	Explanations
<b>1. Funding for personal assistance</b>	
1.1 The funding is “provided on basis of personalized criteria”	The amount of allowance for personal assistance depends only on facts, which are constituted in the individual person.
1.2 The funding takes “into account human rights standards for decent employment”	The amount of allowance for personal assistance is sufficient to pay the assistants a decent salary. A decent salary is at least the minimum wage plus insurances.
1.3 The funding is “controlled by [...] the person with disability”	The assistance user has the control over the funding and decides how it is spent.
1.4 The funding is “allocated to the person with disability”	The personal assistance allowance is a direct payment, which is allocated to the assistance user, e.g. on his or her bank account.
1.5 The funding has “the purpose of paying for any assistance required”	The amount of allowance for personal assistance is sufficient to pay for any assistance required, which includes all aspects of life and no personal contribution from the assistance user.
1.6 The funding “is based on an individual needs assessment”	The amount of allowance for personal assistance is based on the individual needs of the assistance user, which are assessed in an individual needs assessment.
1.7 The funding is based on “the individual life circumstances”	The amount of allowance for personal assistance takes into account the individual life circumstances, like social roles or changing capacities.
1.8 “Individualized services must not result in reduced budget or higher personal payment for assistance”	The assistance user does not get less money and does not have to pay more by him or herself because he or she uses personal assistance.
<b>2. Service controlled by the person with disability</b>	
2.1 The person with disability can “contract the service from a variety of providers”	The assistance user can obtain personal assistance from different providers and there is a variety of service providers, which one can choose from.

2.2 The person with disability can “act as an employer”	The assistance user can choose to be an employer and employ his or her own personal assistants.
2.3 “Persons with disabilities have the option to custom-design their own service [...]: decide by whom, how, when, where and in what way the service is delivered”	The assistance user decides how the service is designed: the assisting person, the place, the time and the way the service is delivered.
2.4 The person with disability can “instruct and direct service providers”	The assistance user can instruct and direct the provider by deciding how the service is designed.
<b>3. One-to-one relationship</b>	
3.1 “Personal assistants must be recruited, trained and supervised by the person granted personal assistance”	The assistance user recruits, trains and supervises the personal assistants.
3.2 “Personal assistants should not be ‘shared’ without the full and free consent of the person granted personal assistance”	A personal assistant assists only one person at the same time.
<b>4. Self-management of service delivery</b>	
4.1 The assistance user “can freely choose their degree of personal control over service delivery according to their life circumstances and preferences”	The assistance user can choose how much control he or she wants to have over the service delivery and can decide to have more or less control depending on the life circumstances and preferences by changing the model or transferring tasks to the provider or the assistants.
4.2 “Even if the responsibilities of ‘the employer’ are contracted out, the person with disability always remains at the center of the decisions concerning the assistance”	The assistance user takes all decisions concerning the service delivery even if he or she is not the employer of the assistants.
4.3 The assistance user “must be enquired about and respected upon individual preferences”	The individual preferences of the assistance user must be enquired and respected by the assistants.



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4.4 “The control of personal assistance can be through supported decision-making”	The assistance user can control personal assistance through supported decision-making. The disabled person can choose one or several persons who support him or her in taking decisions. The disabled person participates actively in the decision making process and is supported by the realization of his or her will.
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## 5.2 Evaluation of the German Personal Assistance System

In the following subchapter, it is proved how the German system of personal assistance fulfills the criteria of the General Comment.

### 1. Funding for personal assistance

#### 1.1 The funding is provided on basis of personalized criteria

No. The funding for personal assistance in the form of a personal budget is based on the individual needs of the disabled person (§ 29 II SGB IX). But the budget does not only depend on personalized criteria. It can vary between federal states in Germany and between different authorities. The social benefit agencies are organized differently in the federal states. Each agency can have own regulations and rates for services. People who got their disability through an accident might get more services paid or rather have to pay less by themselves. The funding is based on the costs of the services in kind, which are stipulated in frame contracts between authority and provider and can be defined for groups of persons with similar needs (Hilfebedarfsgruppen) (§125 III SGB IX). ( X )

#### 1.2 The funding takes into account human rights standards for decent employment

Yes. The budget covers the services required by the budget agreement. It is possible to stipulate that the budget is linked to the standard wage according to the collective labor agreement. If the standard wage rises, the budget has to rise as well (Assistenz.de n.d.b). (✓)

#### 1.3 The funding is controlled by the person with disability

Yes. The personal budget is a direct payment to the disabled person. The disabled person can control the funding. The assistance is organized as it is stipulated in the budget agreement between responsible authority and disabled person. The budget

agreement should define the goals of the budget but not the way to reach the goals to not restrict the assistance user's freedom of choice (Assistenz.de n.d.b). The assistance user can get help to administer the budget (§ 29 II SGB IX). (✓)

1.4 The funding is allocated to the person with disability

Yes. The personal budget is allocated to the person with disability (§ 29 II SGB IX). It is transferred to an extra bank account of the disabled person. (Assistenz.de n.d.a). (✓)

1.5 The funding has the purpose of paying for any assistance required

No. Personal budgets are based on an individual assessment and are calculated to cover the detected needs (§ 29 II SGB IX). The funding covers the costs of the stipulated services in the budget agreement. But disabled people have to contribute to services paid by the social benefit agency depending on their income and assets (§ 2 I SGB XII). Voluntary work of disabled people might not be covered by their personal assistance allowance (§78 V SGB IX). (✗)

1.6 The funding is based on an individual needs assessment

Yes. The funding is based on an individual needs assessment (§ 29 II and § 13 SGB IX). The assessment can be different depending on the authority and the region. In 2017, there were four common instruments for an individual needs assessment in Germany (HMB-W, IBRP, ITP, IHP) (Mertins 2017, p. 8). (✓)

1.7 The funding is based on the individual life circumstances

Yes/No. The assessment of needed assistance takes the individual life circumstances into account. Personal budgets can be used according to the budget agreement to pay for personal assistance in different areas of life: assistance at the workplace, in leisure time and so on (§ 29 I SGB IX). Some life circumstance might not be taken into account. Voluntary work might not be covered by personal assistance (§ 78 V SGB IX). Furthermore, assistance users in hospital only get their personal assistance paid if they are employers for their assistants. (o)

1.8 Individualized services must not result in reduced budget or higher personal payment for assistance

Yes/No. Personal budgets are based on the costs of the services in kind. Personal budgets for individualized services shall not be higher than the previous services in

kind, but the budgets can be smaller (§ 29 II SGB IX). The personal contribution is the same irrespective how the service is organized (service in kind or personal assistance).  
(o)

## 2. Service controlled by the person with disability

### 2.1 The person with disability can contract the service from a variety of providers

Yes/No. The disabled person has the possibility to contract the service from a variety of providers (Assistenz.de n.d.c). But not all providers offer personal assistance as a person-directed or 'user'-led service. Depending on where someone lives, there is no variety of service providers. The amount of the budget can also narrow the number of possible service providers. (o)

### 2.2 The person with disability can act as an employer

Yes. The assistance user has the possibility to act as an employer for his or her assistants. The disabled person then has all responsibilities of an employer. (✓)

### 2.3 Persons with disabilities have the option to custom-design their own service: decide by whom, how, when, where and in what way the service is delivered

Yes. The disabled person has the option to custom-design the service by choosing to act as an employer for his or her assistants. The assistance user can exercise all competences in the employer model. The disabled person then decides by whom, how, when, where and in what way the service is delivered. By choosing another model, competences can be transmitted to the service provider (Persönliche Assistenz - Das Infoportal n.d.). (✓)

### 2.4 The person with disability can instruct and direct service providers

Yes/No. There are personal assistance providers, which allow disabled persons to custom design the service, but it depends on the provider. As a member of a cooperative the assistance user has further the possibility to influence the provider through votes.  
(o)

## 3. One-to-one relationship

### 3.1 Personal assistants must be recruited, trained and supervised by the person granted personal assistance

Yes/No. Assistance users can recruit, train and supervise their assistants if they act as employers for their assistants. If the assistance user chooses to buy services from a provider, he or she might not be able to recruit and train the assistants. (o)

3.2 Personal assistants should not be 'shared' without the full and free consent of the person granted personal assistance

Yes. Until the end of 2019 personal assistants must not be shared. Personal assistants assist only one disabled person at the same time. There might be a new law in 2020, which states that assistance services can be performed together for several assistance users (§ 116 SGB XII new) (✓)

4. Self-management of service delivery

4.1 The assistance user can freely choose their degree of personal control over the service delivery according to their life circumstances and preferences

Yes. Assistance users can freely choose their degree of personal control over the service delivery. There are different models and providers, which give assistance users different degrees of control over the service delivery. Assistance users also can change the organizational model. (✓)

4.2 Even if the responsibilities of 'the employer' are contracted out, the person with disability always remains at the center of the decisions concerning the assistance

Yes/No. Assistance users in the employer model can take all decisions concerning the assistance. The disabled person can decide by whom, how, when, where and in what way the service is delivered. If the responsibility of the employer is contracted out, the disabled person might not remain in the center of the decisions concerning the assistance. Depending on the service provider, the disabled person might not be able to decide for example by whom the assistance is delivered. (o)

4.3 The assistance user must be enquired about and respected upon individual preferences

Yes. The law states that the decisions about the service and the service delivery shall meet the qualified wishes of the individual (§ 8 SGB IX). (✓)

4.4 The control of personal assistance can be through supported decision-making

Yes. Persons with mental disability can receive personal budgets to determine their personal assistance. They can get help through a budget support service or their legal guardian to organize personal assistance and make decisions. To what extent this support can be seen as a way of supported decision making and not as a way of substituted decision making cannot be analyzed within the range of this work. (✓)

### **5.3 Evaluation of the Swedish Personal Assistance System**

Further on, it is proved how the Swedish system of personal assistance fulfills the criteria of the General Comment.

#### **1. Funding for personal assistance**

##### **1.1 The funding is provided on basis of personalized criteria**

Yes/No. The funding is based on the individual needs of the disabled person. The individual need of assistance is assessed and counted in hours. The funding is granted as a flat rate per needed assistance hour. Assistance users with special needs, like assistance during night time, can get up to 12% more per hour. But the personal assistance allowance can vary between the Social Insurance Agency and municipalities or between different municipalities irrespective of personalized criteria. Furthermore, reinterpretations of the eligibility criteria according to the law can lead to different personal assistance allowances by unchanged need of assistance. (o)

##### **1.2 The funding takes into account human rights standards for decent employment**

Yes. The government defines a standard amount per hour of assistance each year. "Eighty-seven percent of the standard amount is considered to cover costs for salaries, employers' fees etc. This shall at large follow the expected wage development for the coming year. The remaining 13% shall at large follow the raise in the consumer price index" (Westberg 2010, p. 27). In 2018 the flat rate per hour is 295,40 Crowns (Assistanskoll n.d.c). It covers the minimum wage set by the union agreements (between 109,19 and 113,50 Crowns per hour in 2018) (Assistanskoll n.d.e). (✓)

##### **1.3 The funding is controlled by the person with disability**

Yes. The personal assistance allowance is granted as a direct payment for the disabled person. The assistance user can decide how the personal assistance should be organized with these payments. He or she can choose to act as an employer for his or her

assistants. As an employer the assistance user controls the budget and decides how it is spent within the range of the assistance service. The assistance user can also choose to buy services from private or public service providers. It is also possible to choose a provider, which administers the budget. (✓)

1.4 The funding is allocated to the person with disability

Yes. The funds are allocated to the person with disability. The personal assistance allowance is granted as a direct payment to the disabled person. (✓)

1.5 The funding has the purpose of paying for any assistance required

No/Yes. The funding is purposed to cover any assistance needed. Certain percentages of the funding are meant to cover certain costs. The amount can be up to 12% higher if assistance is necessary during night or if assistants need special qualifications. In the needs assessment, the social worker estimates the reasonable time for activities. But inactive times of the assistants are not counted. Furthermore, "there are restrictions on what the PA can be used for and this will depend on where someone lives" (Dahl and Bolling 2015). For example gardening and shoveling of snow are restricted in some municipalities. Because of reinterpretations of the basic needs according to the law, persons might not get the amount of assistance hours they need. (o)

1.6 The funding is based on an individual needs assessment

Yes. The funding is based on an individual needs assessment in form of a guided interview in which the disabled person gives a description of his or her daily life. In addition, certificates from doctors and physiotherapist have to be shown. The individual need of assistance is assessed and counted in minutes. (✓)

1.7 The funding is based on the individual life circumstances

Yes. The needs assessment takes the individual life circumstances into account. Assistance can be used to fulfill duties that come with different roles the assistance user has in society. Like his or her role as partner, employee etc. (Westberg 2010, p. 25). (✓)

1.8 Individualized services must not result in reduced budget or higher personal payment for assistance

Yes. There is no personal contribution to the personal assistance allowance. (✓)

## 2. Service controlled by the person with disability

### 2.1 The person with disability can contract the service from a variety of providers

Yes. The disabled person has the possibility to contract the service from a variety of providers. In Stockholm County there are 166 personal assistance providers (Assistanskoll n.d.d). There are private for-profit companies, assistance cooperatives and municipal service providers. (✓)

### 2.2 The person with disability can act as an employer

Yes. The assistance user has the possibility to act as an employer for his or her assistants. The disabled person then has all responsibilities of an employer. (✓)

### 2.3 Persons with disabilities have the option to custom-design their own service: decide by whom, how, when, where and in what way the service is delivered

Yes. The disabled person has the option to custom-design the service. The assistance user can exercise all competences in the employer model. The disabled person then decides by whom, how, when, where and in what way the service is delivered. By choosing another model competences can be transmitted to the service provider. (✓)

### 2.4 The person with disability can instruct and direct service providers

Yes. Assistance users can instruct and direct service providers by custom designing the service. Disabled persons can also design assistance services bought from private or municipal providers. As a member of an assistance cooperative, the assistance user has further the possibility to influence the provider through votes. (✓)

## 3. One-to-one relationship

### 3.1 Personal assistants must be recruited, trained and supervised by the person granted personal assistance

Yes. Assistance users can recruit, train and supervise their assistants in all models. Service providers can offer to recruit and train assistants for the assistance user. (✓)

### 3.2 Personal assistants should not be 'shared' without the full and free consent of the person granted personal assistance

Yes. Personal assistants do not have to be shared. One assistant assists only one assistance user at the time. An assistant is not allocated to two or more assistance users at the same time. But assistants are allowed to work for several assistance users. (✓)

#### 4. Self-management of service delivery

##### 4.1 The assistance user can freely choose their degree of personal control over service delivery according to their life circumstances and preferences

Yes. Assistance users can freely choose their degree of personal control over the service delivery. There are different models and providers, which give the assistance users a different degree of control over the service delivery. "Assistance users can engage several providers of personal assistance services at the same time. They can e.g. employ some assistants themselves and choose the municipality or a company/cooperative as employer for others" (Westberg 2010, p. 30). The employer model allows full control over the service delivery. But it is also possible to let the assistance delivery be managed by a service provider. "In general, users have less control over assistance received from municipalities, while assistance through cooperatives resulted in the highest degree of self-determination. Private companies provided their customers with more control over the assistance than municipalities did, but less than users' cooperatives" (Westberg 2010, p. 37). (✓)

##### 4.2 Even if the responsibilities of 'the employer' are contracted out, the person with disability always remains at the center of the decisions concerning the assistance

Yes/No. Assistance users can take all decisions concerning the assistance. The disabled person can decide by whom, how, when, where and in what way the service is delivered. "Depending on the provider, assistance users can choose to act as a supervisor for their assistants. As supervisors, they can be in charge of recruiting, scheduling, assigning and reassigning tasks, training [...]. How much responsibility the individual users are allowed, varies sharply between providers" (Westberg 2010, p. 37). A disabled person can decide to have less control over the service delivery by choosing a certain provider. (o)

##### 4.3 The assistance user must be enquired about and respected upon individual preferences



Yes. The assistance user instructs the assistants who must respect the individual preferences of the assistance user concerning his or her personal assistance. (✓)

#### 4.4 The control of personal assistance can be through supported decision-making

Yes. Most assistance providers have a support system for assistance users who do not have the possibility or ability to supervise their assistants. The supervision is carried out with the help of another person. Depending on the service provider this person is called supervisor, vice-supervisor or service guarantor. "The service guarantor is a guarantee that every member in the cooperative will receive the assistance he/she needs. [...] The aim of the guarantor is to make sure the member receives personal assistance enabling him/her to live a self-determined life" (Westberg 2010, p. 62). To what extent this support can be seen as a way of supported decision making and not as a way of substituted decision making cannot be analyzed within the range of this work. (✓)

## 5.4 Results of the Evaluation

The results of the theoretical evaluation of the personal assistance systems in Germany and Sweden are summarized in Table 3. A criterion is either fulfilled (✓), partly fulfilled (o) or not fulfilled (✗).

Table 3: *Results of the theoretical evaluation of the personal assistance systems in Germany and Sweden.*

	<b>Criteria</b>	<b>Germany</b>	<b>Sweden</b>
<b>1</b>	<b>Funding for personal assistance</b>		
1.1	The funding is provided on basis of personalized criteria	(X)	(o)
1.2	The funding takes into account human rights standards for decent employment	(✓)	(✓)
1.3	The funding is controlled by the person with disability	(✓)	(✓)
1.4	The funding is allocated to the person with disability	(✓)	(✓)
1.5	The funding has the purpose of paying for any assistance required	(X)	(o)
1.6	The funding is based on an individual needs assessment	(✓)	(✓)
1.7	The funding is based on the individual life circumstances	(o)	(✓)
1.8	Individualized services must not result in reduced budget or higher personal payment for assistance	(o)	(✓)
<b>2.</b>	<b>Service controlled by the person with disability</b>		
2.1	The person with disability can contract the service from a variety of providers	(o)	(✓)
2.2	The person with disability can act as an employer	(✓)	(✓)
2.3	Persons with disabilities have the option to custom-design their own service: decide by whom, how, when, where and in what way the service is delivered	(✓)	(✓)
2.4	The person with disability can instruct and direct service providers	(o)	(✓)
<b>3.</b>	<b>One-to-one relationship</b>		
3.1	Personal assistants must be recruited, trained and supervised by the person granted personal assistance	(o)	(✓)
3.2	Personal assistants should not be 'shared' without the full and free consent of the person granted personal assistance	(✓)	(✓)

<b>4. Self-management of service delivery</b>			
4.1	The assistance user can freely choose their degree of personal control over service delivery according to their life circumstances and preferences	(✓)	(✓)
4.2	Even if the responsibilities of 'the employer' are contracted out, the person with disability always remains at the center of the decisions concerning the assistance	(o)	(o)
4.3	The assistance user must be enquired about and respected upon individual preferences	(✓)	(✓)
4.4	The control of personal assistance can be through supported decision-making	(✓)	(✓)

At first glance, it becomes apparent that the Swedish system of personal assistance fulfills the criteria of the General Comment more than the German system does. While in Germany a lot of criteria are only partly fulfilled, in Sweden most criteria can be evaluated as fulfilled. But these results can also be put in the context of the preconditions for the eligibility for personal assistance in the both countries. While in Sweden personal assistance is not available for all persons in the need of assistance, the implementation mostly fulfills the requirements of the General Comment. By contrast, in Germany, personal assistance is in fact available for all disabled people in the need of assistance, but the implementation does not fulfill all the criteria of the General Comment. Especially the requirements of the funding are not fulfilled by the German system. The funding is not only based on facts, which are constituted in the individual person but depends on the responsible agency. Furthermore, the funding is not sufficient to cover all costs of assistance. Disabled people usually have to contribute to the funding. The budget can be smaller than the costs of the correspondent services in kind. The reason why many other criteria are only partly fulfilled is that conventional service providers usually do not provide personal assistance. It depends mainly on the provider if personal assistance is provided in the sense of the General Comment or as a conventional service in kind over which the assistance user has no control.

Although the implementation of personal assistance is better in Sweden than in Germany, there are also some challenges in fulfilling the requirements of the funding. As in the German system, it is not guaranteed in Sweden that the funding for personal assis-

tance is only based on personalized criteria and that it has the purpose to pay for any assistance required. Municipalities can pay lower flat rates per hour than the Social Insurance. Because of reinterpretations of the basic needs according to the law, many disabled people lost their personal assistance or got less hours paid. But personal assistance is a term and a service with a particular legal basis. Since the proposition of the law granting personal assistance, it was clear that it is a service that is led by the user. The disabled person decides who shall assist. Further, the assistance user can choose between private and public providers, cooperatives or to act as an employer for the assistants (Westerberg 1993). It is clear what personal assistance is and, therefore, there are more providers offering 'real' personal assistance services. Nonetheless it can depend on the provider how much control the assistance user has over the service delivery if the employer responsibilities are contracted out. However, this is also the decision of the assistance user.

## **6 Empirical Research**

The following chapter describes the conducted research by giving an overview of the current state of research, introducing the research question and explaining the analysis of the gained data.

### **6.1 Current State of Research**

The literature review for this master thesis was done in English and German. Swedish sources, which have not been translated into English or German, are not included in this research. To get an overview of the most important books, reports and papers about the topic, databases from German and Swedish libraries were used. Furthermore relevant search terms were searched in the databases of PubMed, ERIC and PSYNDEX. Search terms were for example 'personal assistance', 'independent living' and 'convention on the rights of persons with disabilities'. Besides general literature about independent living and personal assistance, specific information about the Swedish and German system of personal assistance was analyzed. Furthermore, comparisons of care systems and care policies as the background of personal assistance could be found.

Aslemeier compares the development of support systems and community based care for disabled people in England, Sweden and Germany (Aselmeier 2008). Papers about care systems for elderly people (Le Bihan and Martin 2006) and cash-for-care in long-term care policies in European countries (Da Roit and Le Bihan 2010) give a background of personal assistance services. There are also some papers about the direct comparison of the German and Swedish systems of personal assistance. The Academic Network of European Disability Experts (ANED) publishes reports on how policies supporting independent living for disabled people are implemented in European countries (Anderberg 2009; Waldschmidt 2009; Townsley et al. 2010). ANED also created the online tool 'DOTCOM – the Disability Online Tool of the Commission'. "The online tool [...] was developed by ANED in collaboration with the European Commission and the Member States to map the progress made on a range of key instruments relevant to implementation of the Convention" (ANED - The Academic Network of European Disability Experts n.d.). With DOTCOM a specific report about the availability of personal assistance schemes in Germany and Sweden can be created (ANED - The Academic Network of European Disability Experts 2017). The European Network on Inde-

pendent Living (ENIL) carried out a research about the situation of personal assistance services and legislation in European countries, too. The project goal was

*1. To gain detailed information on the situation of PA services in as many of the EU Member States (and neighbouring countries) as possible. 2. To present model legislation for PA based on the Independent Living (IL) ideology, as a vehicle to help ENIL members advocate for change in countries that have yet to enact adequate legal frameworks (ENIL - European Network on Independent Living 2013).*

The outcome of this research was published in templates for each country, like Germany and Sweden (Bolling 2013b, 2013a; Dahl and Bolling 2015). The information of the particular country templates are partly from the ANED reports. Furthermore, there is a work from the transnational partnership "Transition from School to Work" (Bazalova et al. 2005), which compares the funding of personal assistance in four different European countries. These reports are all descriptions of personal assistance systems. However, the evaluation of the system that results in clear requirements is mostly not included. A diploma thesis about personal assistance in Austria, Germany and Sweden was published in 2008, which also evaluates personal assistance (Thaller 2008). But the evaluation is not based on the CRPD, the General Comment on Article 19 or the Independent Living philosophy. It is based on interviews with assistance users and collaborators of assistance organizations. In her work from 1992, Theresia Degener describes and compares the German, Swedish and US-American Personal Assistant Service Programs and analyzes how they relate to the concept of Independent Living (Degener 1992). This was before the adoption of the CRPD, the Swedish LSS and the German care insurance. The systems and services have changed since then.

There are people and Independent Living organizations, which criticize the German system of personal assistance (Westberg 2016; Zolle n.d.; Bartz 2006). Also in Sweden with its personal assistance system still counting as a role model for other countries, people criticize the developments and cutbacks in the last years. A summary of the negative developments from an Independent Living perspective is given in the article "Independent Living under threat in Europe: Sweden" (Bolling and Westberg 2017). Brennan and others are even asking "Are Cutbacks to Personal Assistance Violating Sweden's Obligations under the UN Convention on the Rights of Persons with Disabilities?" (Brennan et al. 2016b). Their work focusses more on the cutbacks than on the whole system of personal assistance according to the General Comment. Another pa-

per works on the question if “personal assistance activities promote participation for persons with disabilities in Sweden?” (Granitz et al. 2017) and concludes that “the discrepancy between reported and expected outcome of personal assistance indicates that Article 19 of the UNCRPD has not been met” (Granitz et al. 2017, p. 1). It concentrates on the participation of disabled people as an outcome of personal assistance and not on the system how personal assistance is organized. Another paper from Brennan et al. in 2016 focusses on the access to personal assistance in Sweden, Norway and Iceland and “examines a paradox whereby states commit to ensure access to support services [according to the CRPD], but decentralize responsibility to autonomous and independent local governments” (Brennan et al. 2016a, p. 1). The paper concentrates on the access and not on the compliance of the existing services with the General Comment.

The Committee on the Rights of Persons with Disability published concluding observations on the initial reports of Germany and Sweden and criticized among others the implementation of Article 19 (Committee on the Rights of Persons with Disabilities 2014, p. 6, 2015, p. 7). These reports condemned the lacks of implementation of the right to live independently and did not focus on personal assistance in particular.

The research so far has not shown any work comparing the current German and Swedish personal assistance system, which reviews them on accordance with the General Comment on Article 19 of the CRPD in theory and in practice.

## **6.2 Research Question**

The aim of this Master's Thesis is to review if and how the personal assistance systems in Germany and Sweden fulfill the requirements of the criteria defining personal assistance according to the General Comment on Article 19 of the CRPD. This includes both the theory and the practical implementation of the services. In the first part of this work, the German and Swedish systems of personal assistance were described and compared. It was shown how the systems fulfill the General Comment's definition of personal assistance. This evaluation was based on a theoretical review of the systems. Further research is necessary to evaluate the practical implementation of personal assistance. Therefore, the research question is formulated as follows:

- How does the practical implementation of the personal assistance systems in Germany and Sweden fulfill the requirements of the criteria defining personal assis-

tance according to the General Comment on Article 19 of the CRPD in comparison to their theoretical implementation?

To answer this question the following sub-questions will be used to progress the work and research:

- How do assistance users in Germany and Sweden, who are campaigning for Independent Living principles, evaluate the practical implementation of personal assistance in their countries according to the criteria of the General Comment?
- How does the evaluation of the practical implementation correspond with the results of the theoretical evaluation of the personal assistance systems?

The research is based on the first sub-question. The results of the research will give information about the practical implementation of personal assistance. The second sub-question will be answered in the discussion of the research results by comparing the practical and theoretical implementation.

### 6.3 Research Design

The research design describes the research procedure in order to answer the research question. Table 4 gives a rough overview of the research design.

Table 4: *Research design to answer the research question.*

Why? Research Question	How do assistance users in Germany and Sweden, who are active in the Independent Living Movement, evaluate the practical implementation of personal assistance in their countries according to the criteria of the General Comment?
What? Research Material	Experiences and opinions on how the personal assistance systems in Germany and Sweden fulfill the requirements of the General Comment stated by assistance users campaigning for Independent Living principles in semi-structured interviews.
How? Research Form	Qualitative research
With what? Research Method	Semi-structured interviews with experts Interview guide based on the criteria of the General Comment



Who? Research Sample	Personal assistance users who are campaigning for Independent Living principles
How analyzed? Analysis	Qualitative Content Analysis
When? Procedure	Searching for interview partners, contacting interview partners, arranging dates, preparing interview guide, pretest of interview guide, improving interview guide, conducting interviews, analyzing interviews

To answer the research question, it is necessary to ask assistance users about their experiences and opinions on how the personal assistance systems in their country fulfill the requirements of the General Comment. Therefore, a qualitative research is appropriate. A quantitative research would not be suitable because it is not about the number of people who have a certain opinion on the compliance of the systems with the CRPD. A semi-structured interview is chosen as research method so that the different requirements of the General Comment are inquired in the interview. Personal assistance users campaigning for Independent Living principles are the experts who are expected to be most suitable to evaluate the personal assistance systems in their countries. The interviews are analyzed with a deductive approach on the basis of a Qualitative Content Analysis according to Mayring (2015). Qualitative Content Analysis is an appropriate analysis method to filter information out of texts. The aim is not to draft a theory or to analyze the hermeneutics. The rough procedure starts with searching for interview partners. After contacting them and arranging dates for interviews, an interview guide is prepared. Then the interviews are held and lastly analyzed.

### 6.3.1 Semi-structured Interview with Experts

The following subchapter describes the method of semi-structured interviews with experts. Semi-structured interviews are explained and legitimated as an appropriate method. Furthermore, the experts as the research sample are presented.

#### Semi-structured interview

The method of a semi-structured interview with experts is chosen to answer the research question. An interview is a questioning of a person through an interviewer (Di-

az-Bone and Weischer 2015, p. 200, 31ff). The aim is to gain verbal information by asking specific questions. An expert interview is a method under which different types of interviews can be subsumed (Misoch 2015, p. 120). It defines the group of interviewees and not a methodical approach. The interviewees are experts. They have special knowledge of a certain topic in the research field. This special knowledge can be distinguished into operational and contextual knowledge. Operational knowledge describes the knowhow of procedures or structures in which the expert takes part. Contextual knowledge is the knowledge about other groups and their situation or structural background (Misoch 2015, p. 121-122). This method does not focus on the expert as a person but on his or her special knowledge of a certain topic (Misoch 2015, p. 124). A semi-structured interview is an interview that is structured with the help of an interview guide. An interview guide is a structured list of questions, which shall be answered by the interviewee during the interview (Diaz-Bone and Weischer 2015, p. 243).

The method of a semi-structured interview with experts is a qualified method to work on the research question because it is a research method with which qualitative data can be generated. It is not about the number of assistance users who have the opinion that the personal assistance system in their country supports or does not support independent living. It is about how experts in this field evaluate the personal assistance situation and on which reasons their evaluation is based on.

## **Experts**

The experts, who will be interviewed for this research, are people who are personal assistance users and Independent Living activists at the same time. The experts receive their personal assistance allowance in Germany or Sweden, so they have the operational knowledge of the procedures and structures of personal assistance in their country from a user's perspective. Furthermore, as activists for Independent Living the experts have the contextual knowledge to evaluate the personal assistance situation from an Independent Living activist's perspective.

The selection of the experts is based on a purposive sample. "The logic and power of purposeful sampling lies in selecting information-rich cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research, thus the term purposeful sampling" (Patton 1990, p. 169). The characteristics of the sampling are: person with a physical disability, personal assistance user and resident in Germany or Sweden. Furthermore, the interview partners are campaign for Independent Living principles, which means they

are either members of an Independent Living Center or organization (ILC) or supporting their work actively. The interview partners should be able to clearly communicate verbally. The organizational model of the assistance users is not crucial because the aim is to gain information about the system in general.

Six experts, three from Germany and three from Sweden, are interviewed. The opinions and experiences of the interview partners do not count as representative for all assistance users, but they provide an insight into the practical implementation of personal assistance.

Gatekeeper to this field of research is the Independent Living Institute in Stockholm, by name Adolf Ratzka. Adolf Ratzka is the head of the board of ILI and, as a prominent leader of the Independent Living Movement, member in the advisory board of ENIL, winner of the European citizen award 2008 and winner of the ULOBA's Pride Award 2017 (Independent Living Institute 2017; ENIL - European Network on Independent Living 2017, n.d.; Ratzka n.d.b). As an activist in the Independent Living Movement, he has contacts to further activists. The experts, who agreed to interviews, were mostly male assistance user in the employer model. Table 5 shows the characteristics of the interview partners:

Table 5: *Research sample, characteristics of the interview partners.*

<b>Case code</b>	<b>Gender</b>	<b>Year of birth</b>	<b>Place of residence</b>	<b>Organizational model</b>	<b>Disability</b>	<b>Connection to ILC</b>
<b>G1</b>	Male	1957	Kassel	Employer	Wheel-chair user	Chair of the board of an ILC
<b>G2</b>	Male	1960	München	Employer	Wheel-chair user	Chair of the board of an ILC
<b>G3</b>	Female	1986	Berlin	Employer	Wheel-chair user	Co-worker at an ILC, supporter of ILC
<b>S1</b>	Female	1955	Stockholm, Hårnosand	Cooperative	Wheel-chair user	Director of an ILC
<b>S2</b>	Male	1943	Stockholm	Employer, own company	Wheel-chair user	Chair of the board of an ILC
<b>S3</b>	Male	1966	Stockholm	Employer	Wheel-chair user	Supporter of ILC, e.g. peer support workshops

The interviews with the experts in Sweden are held in a face to face dialogue. The German experts are interviewed in a video conference. All interviews are recorded with an audio recorder and transcribed afterwards.

### **6.3.2 Interview Guide**

The interview guide is based on the criteria defining personal assistance according to the General Comment. The same criteria, which were described and reviewed in the theoretical evaluation of the personal assistance systems, were used. The interview guide illustrates the four phases of the interview: welcome and introduction (1), main questions (2), concluding questions (3) and conclusion (4). It starts with an introduction phase where information about the data privacy, the Master's Thesis in general in the research question is given. Furthermore, the aim and the structure of the interview are described. The main questions are structured according to the four core elements of the personal assistance definition according to the General Comment: funding, service controlled by the person with disability, one-to-one relationship and self-management of service delivery. Under these headlines the criteria were summarized to main questions. It is asked how the interviewees experience the compliance of the requirements in their countries. To make sure that every criterion is mentioned in the guide all criteria are formulated as sub-questions under the main question. After the main questions, there are concluding questions on how the interviewees evaluate the personal assistance system in general. The interview closes with a conclusion phase to complete the conversation and say goodbye.

The interview guide was pretested in an interview with a co-worker of the Independent Living Institute Stockholm who has knowledge about the Swedish personal assistance system as well as the Independent Living principles. After the pretest the questions were redrafted to open questions asking about the interviewees' experiences and opinions instead of testing their knowledge about the systems.

The following excerpt of the interview guide shows an example of the main questions used in the interviews.

[...]

## **2. Main Questions**

### **2.1 Funding**

- *What determines the amount of personal assistance allowance in Sweden? The GC states that the amount of the personal assistance allowance should only be based on individual and personalized criteria.*
  - *Is the funding based on personalized criteria?*
  - *Is the funding based on an individual needs assessment?*
  - *Is the funding based on individual life circumstances?*
  - *Do individualized services result in reduced budget or higher personal payment for assistance?*
- *According to the GC the funding should be allocated and controlled by the person with disability. Do you think the Swedish system fulfills this criterion?*
  - *Is the funding controlled by the person with disability?*
  - *Is the funding allocated to the person with disability?*
- *The GC claims that the funding should be purposed to pay for any assistance required. Is the amount of allowance sufficient to pay for the assistance required?*
  - *Does the funding take into account human rights standards for decent employment?*
  - *Is the funding purposed to pay for any assistance required? Does it achieve this purpose or do you have to pay the rest by yourself?*

[...]

### **6.3.3 Analysis**

To analyze the interviews, a Qualitative Content Analysis will be carried out. This is a suitable method because the interviews will be informational interviews (Bogner et al. 2014). The aim is to gain content information from the interviews and not to analyze the interviewee. Therefore, the interviews were transcribed into text form. The interviews held in German were not translated into English to prevent the risk of translation faults or inaccuracies.

## Transcription Rules

The transcription of the interviews in the context of this Master's thesis follows the following transcription rules based on Kuckartz et al. (2008, p. 27f) and Kowal and O'Connell (Kowal and O'Connell 2010).

1. The transcription is introduced by a headline, which gives general information about the interview, like date, place, interviewer, interview partner and transcription.

2. Each interview gets a case code.

Interviews with interview partners in Germany are marked with the letter 'G' and a continuous number: for example 'G1', 'G2' or 'G3'.

Interviews with interview partners in Sweden are marked with the letter 'S' and a continuous number: for example 'S1', 'S2' or 'S3'.

3. The transcription starts with the first information about personal assistance given by the interview partner but latest with the first question from the interviewer according to the interview guide.

The transcription ends after the last information about personal assistance given by the interview partner but earliest after the answer to the last question according to the interview guide.

4. The transcription follows the standard orthography. This means:

- Spoken words are transcribed according to the current spelling rules
- Dialects are translated in literary language
- Case sensitivity and punctuation marks are taken into account
- Sounds like 'ahm' or 'hm' are not transcribed, except of when they were used to answer a question

5. The transcription follows this further rules:

- Data, which can be used to identify the interview partner, are anonymized
- Affirmative sounds or comments, which are not interrupting the fluency of words, are not transcribed
- Text spoken by the interviewer is labeled with the letter 'I'
- Text spoken by an interview partner in Germany is labeled with the letter 'G' and a continuous number: for example 'G1', 'G2' or 'G3'
- Text spoken by an interview partner in Sweden is labeled with the letter 'S' and a continuous number: for example 'S1', 'S2' or 'S3'
- The beginning and the end of a speech part is labeled with a time mark
- Words, which are spoken in another language than the interview language, are marked with quotation marks

## Procedure

The analysis procedure follows the Qualitative Content Analysis according to Mayring (2015). The research materials are the interviews with assistance users in Germany and Sweden who campaign for Independent Living principles. The research material is available in the form of a transcribed text. In a deductive approach the content of the research material will be allocated to a system of categories. This process is called 'coding'. The direction of the analysis is the question on how the experts think the personal assistance systems in Germany and Sweden fulfill the requirements of the General Comment according to their experiences. The analysis units can be defined as follows:

- Code unit (smallest textual passage that can be allocated to a category): a statement
- Context unit (biggest textual passage that can be allocated to a category): whole text
- Investigation unit (textual passage that are analyzed): textual passages in all interviews that can be allocated to a category

The system of categories is based on the definition of personal assistance according the General Comment. The categories are the criteria defining personal assistance, which were used in the interview guide. The categories were already defined in the explanations of the criteria. A coding guide was created, which clarifies the categories by giving typical textual passages as key examples and some coding rules. The coding guide can be found in the appendix.

The transcribed interviews are analyzed one after another. As a first step the transcribed text of a case is scanned through and textual passages, which can be coded, are marked. In a second scan textual passages are extracted as exact quotes to the category system mapped in a table. The case code and the line number of the specific textual passages are noted down as well. A quote with more than one statement is allocated to several categories. Further on, each extracted quote is paraphrased. Then the paraphrases of a category are summarized. All six interviews are analyzed in the same way. The categories of all Swedish cases and all German cases are summarized again to get country specific results rather than case specific results. These results per country can be used to answer the research question. Figure 2 illustrates the analysis procedure.

	Quote	Paraphrase	Summary	Summary G1-G3
G1	...	→	}	}
	...	→		
G2	...	→	}	
	...	→		
G3	...	→	}	
	...	→		

Figure 2: Procedure of the qualitative content analysis, example for one single category. Own illustration.



## 7 Evaluation of the Practical Implementation of Personal Assistance

The interviews were conducted and analyzed through a Qualitative Content Analysis according to Mayring (2015) as outlined in chapter 6. The results of the analysis show how the practical implementation of personal assistance in Germany and Sweden fulfill the requirements of the General Comment according to the experiences and opinions of the interviewed experts. As in the theoretical evaluation, the results might not always be explicit. Thus, for a better comparability and visualization the symbols '✓', 'o' and 'X' shall show if a criterion can be summarized as fulfilled (✓), partly fulfilled (o) or not fulfilled (X).

### 7.1 Results of the Interviews in Germany

The following subchapter presents the results of the semi-structured interviews with personal assistance users in Germany.

#### 1. Funding for personal assistance

##### 1.1. The funding is provided on basis of personalized criteria

According to the interview partners in Germany, the funding of personal assistance is not only based on personalized criteria. The funding is based on the individual needs of the disabled person and the costs of the correspondent services in kind.

*Da gibt es Verträge, Rahmenverträge, und da werden teilweise die Größenordnungen festgeschrieben, also die finanzielle Größenordnung. Und wenn ich jetzt mit dem Persönlichen Budget diese Persönliche Assistenz organisiere, dann ist dieser Rahmen in aller Regel an diese Sachleistung gekoppelt, also in dieser Größenordnung (G1: 39-45).*

But the amount of funding also depends on the responsible authority, the region one is living in and the adequacy of the cost according to the opinion of the authority. The dependency on the region is expressed in the following quote:

*Das kommt, wie gesagt, auch auf die Gegend an, wo man lebt. Also ich sage jetzt mal vom Bedarf her, in München bekomme ich 24 Stunden und wenn ich jetzt in Augsburg wohne, das sind ungefähr 60 km weiter weg oder 50, da kriegen ich keine 24 Stunden mehr. Ja weil die Behörde oder weil die Kommune ein-*

*fach nicht so viel Geld hat und das einfach nicht zulässt von vorne rein (G2: 403-407).*

(X)

1.2. The funding takes into account human rights standards for decent employment

The experts have different opinions on the sufficiency of the funding to pay assistants a decent salary. The following quotes are an example for this discrepancy:

*Ja, da würde ich sagen weitgehend ja. Wird zwar immer wieder gestritten oder auch schlecht gemacht, also wie vorhin bisschen erwähnt, die Budgets werden manchmal niedriger angesetzt (G1: 382-384).*

*Dass Assistenten keine ordentliche Löhne bekommen bzw. nicht bundesweit bzw. ja eigentlich ja gar nie, also nirgendwo in Deutschland aber also es gibt ja auch noch Bundesländer, wo es einfach schlechter ist (G3:568-570)*

The interview partners all mentioned cases where the funding is not sufficient for a decent employment. The funding might not be enough for employments subject to social insurance contributions. Seniority bonus, vacation benefits or Christmas bonus might neither be taken into account. Furthermore, it can be difficult to pay wage continuation to sick assistants or assistants on holidays.

*Und die Bemessung des persönlichen Budgets, die Größenordnung, wird dann auch nur so bemessen, dass wirklich gar nicht sozialversicherungspflichtige Leute zu bezahlen sind. Bis hin sogar, dass eben auch keine Lohnfortzahlungen im Krankheitsfall oder im Urlaubsfall bezahlt werden. Also solche Budgets gibt's auch, ne (G1: 457-461).*

(o)

1.3. The funding is controlled by the person with disability

In Germany, the funding for personal assistance is controlled by the disabled person with the restriction that assistance users have to use it for personal assistance only. In a budget agreement between disabled person and authority it is stipulated how and when the usage must be accounted for.

*Genau. Also wer ein Persönliches Budget beantragt, bekommt das auf ein extra Konto, was auf den eigenen Namen läuft, überwiesen und dann muss man da*

*natürlich Verwendungsnachweise einreichen. Also wir haben das nicht frei zur Verfügung und können dann mit der Summe handhaben, sondern es muss schon nachgewiesen werden (G3 124-128).*

(✓)

#### 1.4. The funding is allocated to the person with disability

According to quote above, the funding in form of a personal budget is allocated directly to the disabled person. The money is transferred to the assistance user's bank account.

(✓)

#### 1.5. The funding has the purpose of paying for any assistance required

The funding can be sufficient to pay for the required assistance:

*Naja, also wenn ich jetzt aus meiner Perspektive ausgehe, ich habe einen 24 Stunden Assistenzbedarf und die 24 Stunden bekomme ich auch also genehmigt und meine Assistenten auch bezahlt, also ja, ist gedeckelt, alles in Ordnung (G3: 141-143).*

According to the experts, the funding also covers support services to manage the personal budget and costs of a wage office. But most of the times, it does not cover all the costs of personal assistance because assistance users have to pay a contribution to the costs of their personal assistance depending on their income and assets.

*Sondern es gibt nach wie vor Einkommens- und Vermögensgrundlagen, nach denen gemessen wird. Die sind herauf gesetzt worden, aber das Prinzip ist das gleiche. Also es ist immer noch aus der Sozialhilfe und da wird erst geguckt, wo kommt woanders was her (G2: 116-119).*

Even with the personal contribution the funding might not be sufficient to pay for all the required assistance.

*Also ich finde grundsätzlich kann man sagen, in Deutschland, ich finde nicht, dass es bedarfsdeckend ist. Aber es ist natürlich so, dass sich vielleicht in 70 Prozent der Fälle keine Notlagen entstehen, aber es gibt auch einige Menschen, die unterversorgt sind, ganz klar (G2: 341-345).*

The interview partner explained which situations might not be covered by the personal budget. It might not cover assistance during voluntary work and during hospitalization. Personal assistance in hospital is only paid to disabled people in the employer model. In the future elderly people who got their disability in an old age might not get personal assistance paid by the integration support.

*Bisher gab es die Unterscheidung gar nicht und behinderte Menschen, die diese Eingliederungshilfe bekommen, können die auch im Alter bekommen. Aber Leute, die im Alter behindert werden auch altersbedingt, denen werden diese dann nicht gewährt (G1: 701-704).*

Furthermore, the funding might not be sufficient to pay for extra assistance during trips and to cover all the costs of the infrastructure to organize assistance in the employer model.

(X)

#### 1.6. The funding is based on an individual needs assessment

The funding is based on an individual needs assessments. There will be new needs assessment procedures, which will be individual as well.

*Ja. Also wir haben in Deutschland auf jeden Fall auch gerade ab diesem Jahr mit den ganzen Teilhabeplänen und so weiter eine individuell, also es wird individuell geguckt, welchen Bedarf hat der Mensch mit Behinderung, der ein Persönliches Budget beantragt (G3: 10-13).*

There might be several needs assessments because several authorities can be responsible to pay for the assistance. Every authority has its own assessment.

*Da [trägerübergreifendes Budget] kommen auch mehrere Begutachter ins Boot. genau. Und jeder einzelne Kostenträger will alleine über seinen Anteil verhandeln und bestimmen. Bestenfalls halt mit der behinderten Person natürlich auch (G1: 126-128).*

Assistance users have to negotiate their personal budget. They might have to fight hard for sufficient funding.

*Aber wir wissen halt, dass Menschen ganz, ganz viel mit Anwälten auch dagegen vorgehen, damit überhaupt dann die Zielvereinbarung so aussieht, damit*

*sie damit leben können und damit ihre Gesundheit auch nicht gefährdet ist oder sie halt auch wirklich alles machen können, arbeiten, studieren und so weiter, was man so halt machen möchte. (G3: 158-162)*

(o)

#### 1.7. The funding is based on the individual life circumstances

The above-mentioned quote states that assistance users might have to fight for funding that takes their individual life circumstances into account. In some life circumstances, like in cases of hospitalization, there is no personal assistance. In the future, disabled people might neither get personal assistance during their voluntary engagements. An interview partner also mentioned the problem to get extra assistance for trips.

*Und ich sag jetzt mal, ich kann ein Beispiel sagen, ich bin sehr viel unterwegs und wenn ich irgendwo hinfahren will für mehrere Tage, dann muss ich mit einem Assistenten fahren und das ist ja eigentlich ein Unding, dass einer praktisch 24 Stunden-Dienste macht und das eine Woche lang. Und da würde ich mir wünschen, dass man zum Beispiel sagt, klar wenn ich jetzt irgendwie eine Reise gibt, dann müsste ein zweiter mitfahren können, damit sich diejenigen die Arbeit dann aufteilen (G2: 328-334).*

(x)

#### 1.8. Individualized services must not result in reduced budget or higher personal payment for assistance

As an expert stated the personal budgets for personal assistance should not be lower than the costs of the correspondent services in kind, which they are based on.

*Naja, also da wir ja davon ausgehen müssen, dass das Persönliche Budget keine Extraleistung ist, sondern das Persönliche Budget einfach nur eine Form ist Leistungen in Anspruch zu nehmen, darf es natürlich nicht niedriger sein von der Logik her (G3: 100-102).*

But the other interview partners made the experience that personal budgets can be lower than the costs of ambulatory or residential services. Costs of individualized services must be reasonable to be paid by the authority. Also the cash benefits of the care insurance are lower than the coupons for services in kind.

*Also Grundlage ist die Sachleistung und dann kriegt die behinderte Person leider allzu oft weniger, weil die Kostenträger meinen, dieser oder jener Etat ist nicht drin (G1:384-386).*

(o)

## 2. Service controlled by the person with disability

### 2.1. The person with disability can contract the service from a variety of providers

There is the possibility to contract services from providers. It is also possible to contract services from different providers and act as an employer at the same time.

*Es ist durchaus..., immer wieder wird es auch praktiziert, dass wenn ich ein Persönliches Budget bekomme, dass teilweise Dienste bezahlt werden und teilweise die Hilfe selbst organisiert wird, ne (G1: 484-486).*

But the interview partners criticized that there is not a big variety of service providers and that in some regions there are even no personal assistance providers at all.

*Also für Deutschland allgemein kann man das überhaupt nicht sagen, weil wir zum Beispiel gerade in den ländlichen Gebieten ein absolutes Problem haben. Und im städtischen Bereich ist es besser, aber sicher auch noch nicht gut (G2: 387-389).*

*Ja. Wo [in ländlichen Regionen] es vielleicht gar keine Assistenzdienste gibt, sondern nur die klassischen Pflegedienste. [...] Genau, dann wird's halt auch schon schwieriger zu sagen, ach ja ich nehme jetzt einen Dienst oder wie auch immer (G3: 202-208).*

The variety of providers an assistance user can choose from can further be restricted through the amount of funding.

*Aber wenn dann dieses Budget niedriger angesetzt wird als die Dienste normalerweise kosten würden, dann habe ich da auch schon Einschränkungen, weil ich dann nur noch zum gewissen Anteil diese Dienste bezahlen kann, ansonsten reicht das Gesamtbudget gar nicht mehr aus (G1: 491-494).*

(o)

## 2.2. The person with disability can act as an employer

The experts confirmed in the interviews that there is the possibility to act as an employer for assistants. But this freedom to choose can be restricted through the amount of personal budget or the employment market. If in some regions the budget is very low, it is not possible to build up an employer model. Furthermore, it is difficult to find assistants when the economic situation is good and the unemployment rate is low.

*Im Prinzip ja, gesetzlich ja, ist es gegeben. Was natürlich der Markt hergibt, ist immer die Frage, der Arbeitsmarkt, ne. Dann ist die Arbeitslosenquote mittlerweile sehr, relativ niedrig, also der Markt ist angespannt und es gibt nicht so viel Personal, was verfügbar ist (G1: 444-447).*

(o)

## 2.3. Persons with disabilities have the option to custom-design their own service: decide by whom, how, when, where and in what way the service is delivered

The interview partners agreed on the possibility to custom design the personal assistance service in the employer model. As an employer the assistance user can decide by whom, how, when, where and in what way the service is delivered. But all of the experts stated that in the customer model it depends on the responsible authority and the service provider if the assistance users can custom design the service.

*Also da ist alle Macht bei dem Leistungserbringer angesiedelt bei der Pflegeversicherung und nicht bei der behinderten Person. Also das sind die Leistungserbringer, die Sachleistungserbringer. Also im Rahmen der Pflegeversicherung hat die behinderte Person überhaupt kein Recht über das Personal zu entscheiden, auch nicht über die Inhalte der Tätigkeiten, auch nicht über die Einsatzplanung hat die behinderte Person nicht entscheiden. Also sie können im Rahmen der Pflegeversicherung nicht einmal sagen die Pflegeversicherung-Leistungsanbieter sollen um 8 Uhr in der Früh da sein und mich beim Anziehen in der Früh zu helfen. Diesen Rechtsanspruch schließt die Pflegeversicherung explizit aus, ne (G1: 656-664).*

*Naja, das kommt natürlich dann immer auf den Dienst drauf an, den man gewählt hat. Also pauschal möchte ich nicht sagen, dass das machbar ist. Wenn man aber einen richtig guten Assistenzdienst sich ausgewählt hat und der auch ein bisschen oder nicht nur ein bisschen, sondern primär den Menschen mit*

*Behinderung mit seinen Bedürfnissen im Vordergrund sieht, dann ja. Aber das ist auf jeden Fall nicht gegeben in Deutschland, also nicht flächendeckend (G3 216-221).*

(o)

#### 2.4. The person with disability can instruct and direct service providers

As the above-mentioned criteria show, it depends on the services provider if the assistance user can direct the service provider.

*Naja, also erstmal ist es natürlich ganz wichtig, dass der Mensch mit Behinderung genau weiß, was möchte ich, was brauche ich. Und das muss man dann auch gut verteidigen können, also vor dem Amt, also auf Amtsseite und wenn es dann in den Punkt geht, dass man vielleicht einen Dienst gewählt hat, ob der dann respektiert, dass man nur zum Beispiel nur mit Frauen zusammen arbeiten will, das ist sehr individuell. Das liegt vielleicht auch daran, wie hoch ist der Bedarf und wie hoch ist die Fluktuation bei dem Menschen, kann man da immer Rücksicht darauf nehmen oder muss er vielleicht dann doch auch mal mit Männern und Frauen zusammen arbeiten (G3: 421-428)*

(o)

#### 3. One-to-one relationship

##### 3.1. Personal assistants must be recruited, trained and supervised by the person granted personal assistance

Assistance users acting as employers can recruit, train and supervise assistants. As customers it depends on their service provider whether this is possible or not.

*Möglich. Ja. Also im Arbeitgebermodell ist es natürlich logisch, dass wir nur die Leute anstellen, anlernen und so weiter und so fort. Bei Assistenzdiensten in Deutschland, es ist zum Teil möglich, dass die Leute sich das aussuchen können und die Anleitung machen, aber ich behaupte und ich weiß es eigentlich auch, dass es nicht bei allen möglich ist (G3: 288-292).*

The possibility to recruit assistants can be restricted by the responsible authorities and the employment market.

*Nun gibt es aber auch Kostenträger, die sagen, es dürfen nur Studenten eingesetzt werden oder nur Assistenten auf der Basis des Minijobs, der 450 Euro*



*Kräfte, ne. Die aus Kostengründen, aus rein fiskalischen Gründen machen die diese Einschränkungen und schließen damit die abhängig Beschäftigten, sozialsicherungsrechtlichen Assistenten aus, ne (G1: 447-451)*

*Und wir im Arbeitgebermodell aber auch ambulante Assistenzdienste erleben einen riesen Mangel an Leuten. Also es ist wirklich schwer Person zu finden, die in dem Job arbeiten (G2: 389-391).*

(o)

3.2. Personal assistants should not be 'shared' without the full and free consent of the person granted personal assistance

In general personal assistants can work for several assistance users, but they do not work for several assistance users at the same time.

*Bei den Assistenzdiensten ist es natürlich nicht gegeben, weil die Leute müssen ausgelastet werden und wenn irgendwo ein Notfall ist oder wie auch immer, dann werden die auch woanders eingesetzt. Also natürlich nicht parallel, aber schon dass ja, vielleicht es gibt ein Team aus fünf Leuten und die fünfte Person wird aber regelmäßig zu einer anderen Person trotzdem eingesetzt und steht dann nicht zur Verfügung für die Person, die vielleicht einen Ausfall hat. Aber Paralleleinsätze sind mir zumindest nicht bekannt, also dass Assistenzdienste sowas machen (G3: 255-261).*

But assistants have to ask their employer if they want to work somewhere else.

*Also im Arbeitgebermodell natürlich, weil da bin ich die Arbeitgeberin, ich habe meine Assistentinnen und Assistenten, die bei mir arbeiten und in der Zeit können die ja gar nicht woanders arbeiten und wenn sie noch einen anderen Job annehmen, müssen sie natürlich mich als Arbeitgeberin fragen. Also da ist es gegeben (G3: 251-254).*

Because of a new law assistance users might have to share assistants in the future. This law was criticized by all interview partners.

*Da gibt es dann so die Vorstellung von Seiten der Kostenträger, also man nennt das Poolen, dass behinderte Menschen gezwungen werden können ihre Assistenz mit anderen Behinderten zusammen zu teilen und zu organisieren. Und*

*der Kostenträger würde damit ja auch eine Einschränkung der individuellen Lebensgewohnheiten einhergehen, ne (G1: 293-297).*

(✓)

#### 4. Self-management of service delivery

##### 4.1. The assistance user can freely choose their degree of personal control over service delivery according to their life circumstances and preferences

Assistance users can choose the degree of control by choosing an organizational model. Different models give the assistance users different control over the service delivery. Assistance users can change their models and have mixed models.

*G3 348-359 Also wenn wir davon ausgehen, dass Menschen mit Behinderung das Persönliche Budget als Leistungsform haben und vielleicht auch so eine Mischform haben teilweise, dass sie sagen, ah ich bin zur einen Hälfte Arbeitgeberin, aber zur anderen Hälfte nehme auch ein Dienst in Anspruch, da hat man ja schon mal selber gewählt, was man möchte und hat natürlich auf der einen Seite die maximale Verantwortung und auch Bestimmung in dem Arbeitgebermodell und bei dem Dienst wird einem relativ viel abgenommen. Aber es kann ja auch dann im Laufe des Lebens so kommen, dass man sagt: ach ich habe mich jetzt so gut an dieses Arbeitgebersein gewöhnt, ich gehe jetzt zu 100% in das Arbeitgebermodell. Und das ist immer möglich, aber es geht auch genauso anders rum zu sagen: ich habe jetzt gemerkt, meine Behinderung verschlechtert sich vielleicht und mein Leben hat andere Prioritäten, ich möchte gerne was abgeben, ich gehe zu 100% zu einem Assistenzdienst. Das ist möglich, das geht.*

As an employer it is possible to outsource responsibilities and get support to organize the personal assistance. Assistance users can also pay an assistant who manage the employer model.

*Richtig. Also da [Arbeitgebermodell] ist es möglich, komplett. Da kann man die Verwaltung, Lohnbüro übergeben. Man kann sie auch im Extremfall selber machen, wenn man dementsprechend sich die Software und sowas kauft alles, kann man das auch selber machen (G1: 629-632).*

*Ich kann auch unabhängig von dem Betreuten Wohnen im Rahmen von dem Persönlichen Budget Assistenten höher vergüten für dieses Management von*

*dem sozusagen Arbeitgebermodell oder von der Persönlichen Assistenz, ne. Ich kann eine Kraft höher vergüten, die das für mich managt, ne (G1: 737-740).*

(✓)

- 4.2. Even if the responsibilities of 'the employer' are contracted out, the person with disability always remains at the center of the decisions concerning the assistance

If the responsibility of the employer is contracted out and the personal assistance is provided through a service provider, it is not guaranteed that the assistance user remains in the center of the decisions. It depends on the provider.

*G2 498-500 Nein, dann ist es nicht gegeben, weil dann ist nicht mehr der Arbeitgeber weisungsbefugt, sondern dann ist ja der Dienst oder die Einrichtung oder wie auch immer, die sind dann weisungsbefugt.*

(o)

- 4.3. The assistance user must be enquired about and respected upon individual preferences

Assistance users acting as employers can instruct their assistants and make sure the services are provided according to their preferences. According to an interviewed expert, assistants from providers do not have to respect the assistance user's preferences.

*Bei Diensten... mehr oder weniger, weil es gibt nicht diesen rechtlichen Anspruch, ne. Also es hängt dann eigentlich von dem "good will" eigentlich ab (G1: 648-649).*

An interview partner experienced that assistants sometimes think they know better what is good for him.

*Ich meine es gibt auch so Leute, habe ich auch in einem Team, die irgendwie meinen, sie wissen alles besser was für mich gut ist. Und das führt natürlich dann zu Konflikten, das will ja keiner von uns (G2: 321-324).*

(o)

#### 4.4. The control of personal assistance can be through supported decision-making

The interview partners had different opinions on how personal assistance can be controlled by a mentally disabled person and gave different examples. Personal assistance in the employer model is possible through the help of a social worker in an assisted living setting or through special assistants who help to instruct other assistants.

*Und da gibt es auch wieder praktische Beispiele, dass mit dem Betreuten Wohnen die Assistenz organisiert werden kann und gemanagt werden kann. Also auch in unserem Sinne, im Sinne vom Arbeitgebermodell kann die organisiert werden, ne. Und selbst das betreute Wohnen selbst wiederum kann auch budgetiert werden, ne, Also die behinderte Person könnte sogar diese pädagogische qualifizierte Kraft, das sind in der Regel Sozialarbeiter oder irgendwie anderweitig qualifizierte Kräfte, die kann die behinderte Person letztendlich auch selbst anstellen, ne und sagen du managt für mich diese Assistenzorganisation für mich, ne (G1: 729-736).*

Another expert mentioned the possibility to organize the assistance through a legal guardian.

*Als Vertreter, weil er [gesetzlicher Betreuer] ist ja vertretungsberechtigt und übernimmt dann durch diese Vertretungsberechtigung diese Funktion (Arbeitgeberfunktion). [...] Das habe ich schon gehört. Also das ist sicher nicht die Regel aber das gibt's (G2: 762-767).*

Mentally disabled persons can be supported through an individual support system to organize the personal assistance. With the help of individual case support, budget support and involved parents, the personal assistance can be provided the way the disabled person wants it.

*Ja! Tatsächlich begleite ich eine junge Frau, die ist kognitiv eingeschränkt durch einen Hirnschlag und die ist zum einen behinderte Arbeitgeberin, aber hat zum anderen auch einen Dienst mit drinnen, aber mit ganz, ganz wenigen Stunden. Und das funktioniert, weil es Einzelfallhilfe gibt, also einen Menschen, der für die ganze Bürokratie mit ihr gemeinsam verantwortlich ist, also wo nach der Post geguckt wird etc. Und weil Sie die Budgetbegleitung in Anspruch nimmt über den Verein, wo ich noch arbeite, und wir, dieses gesamte Team im Hintergrund, koordinieren. Und sie ist aber immer die Arbeitgeberin, also alles was da passiert ist mit ihr abgesprochen, es geht natürlich nur nach ihrem Willen, da*

*sind die Eltern noch ein bisschen involviert, die das auch ein bisschen mit koordinieren, weil natürlich nicht alles von den Entscheidungen unbedingt so schnell dann manchmal möglich wäre. Ja. Aber das gibt's und das finden wir auch gut und das soll's noch viel, viel mehr geben (G3: 491-502).*

The interview partners did not discuss to which extent the mentioned examples are forms of supported decision making or substituted decision making.

(✓)

## **7.2 Results of the Interviews in Sweden**

The following subchapter presents the results of interviews with personal assistance users in Sweden and shows how they evaluate the practical implementation of personal assistance.

### **1. Funding for personal assistance**

#### **1.1. The funding is provided on basis of personalized criteria**

According to the interview partners in Sweden the flat rate, which is paid per hour of assistance is not personalized. But the funding in general is personalized because it is based on the hours of assistance the disabled person needs.

*In Sweden you negotiate your hours, how many hours of need you have and then you get those hours times whatever the... I don't remember what that's called right now, the amount that they set for personal assistants... [...] Yeah, the flat rate for the year (S1: 21-27).*

But the amount of funding can also depend on the official conducting the assessment and the responsible authority.

*Das ist natürlich die Frage der Interpretation wie man da den Bedarf interpretiert. Und der ist natürlich verschieden von Sachbearbeiter zu Sachbearbeiter und vor allem von Versicherung und Gemeinde. Wir haben ja Ziffern, die zeigen dass 25 Prozent weniger Stunden werden bewilligt und das ist schon wieder vor zwei Jahren. Das heißt, dass möglicherweise ist da wieder ein Unterschied da (S2: 20-24).*

An assistance user heard that women get less funding because of their gender.

*They say that it should do it, but I don't believe that because what I hear is that women especially are not getting the same (S3: 113-114).*

(o)

1.2. The funding takes into account human rights standards for decent employment

The funding takes into account human rights standards for decent employment because it covers the collectively bargained wage levels. Furthermore, the funding covers all the personnel costs including salaries, taxes, vacation, insurances and higher salaries for shifts during night time and on weekends.

*So, I mean it covers... the funding will cover first to pay the salary and the salary increases if it's hours used the evening or hours used on the weekend or hours at Christmas are more expensive than an hour on a Monday or Tuesday. So this has to cover that, has to cover vacation, has to cover insurances and the normal costs that you have around the profession what it should cost (S1: 9-14).*

What is criticized by the interview partners is that the funding does not increase in relation to the increasing wages or the inflation.

*And I got everything. So I can't get higher. So the only problem I see is that when the union and the outside are making a salary agreement, an agreement on the salary. They can make an agreement on 2.2 percent plus, but from the state I got 1.5 percent. So... [...] That have been a growing problem the last years, the last 10 years, I would say (S3: 98-106).*

An expert mentioned that the funding is not sufficient to pay decent salaries to qualified or experienced assistants.

*I mean I find that I have to hire a lot of younger people to have a decent salary. If I want to hire somebody who had 20 years in a working experience, who's going to want to have a higher salary, no wouldn't be a decent salary for that person because you're limited within this flat rate (S1: 186-192).*

It was also stated in an interview that there might be service providers that do not treat assistants well.

(o)

### 1.3. The funding is controlled by the person with disability

The funding is controlled by the disabled person. But it can also be administered or controlled by a provider if the assistance user contracts services from a provider. There can be rules from cooperatives or opinions of municipalities that might restrict the person's control

*I think it is supposed to be that way. It should be that you still have your hours and your amount and you could administrate it through them. But then of course they would be able to give their comments. Where if I do it through a cooperative, the cooperative is not going to..., "vad heter lägger sig in", they are not going to give their opinion: oh you shouldn't be doing this, this and this or whatever. Where you will maybe have the risk that the city would. Then again the city shouldn't (S1: 135-144).*

The assistance user has to use the funding for assistance within the rules and has to account for the usage.

*Yeah, and I'm not allowed to take the money and do what I want with it. I must use it for assistance. So everything, every "krona" has to go to "assistans". And that's correct. Very good (S3: 135-137).*

(o)

### 1.4. The funding is allocated to the person with disability

The funding is allocated to the disabled person, but the assistance user can also decide that the money is allocated directly to the provider.

*In der Theorie ja. Es ist dann..., wie sagt man auf Deutsch, es bleibt dann dir überlassen, ob du das..., ob du die Gelder direkt an den Betreiber fließen lässt von der Versicherungskasse, kannst du dann unterschreiben, die sollen es zum Betreiber geben und dann verwalten die das Geld. Natürlich, wenn du es verlangst, sind sie schon verpflichtet dir sofort zu sagen, wie es steht. Aber dann..., und das machen wahrscheinlich sehr viele weil auf die Weise ist es bequemer (S2: 98-103).*

There might be municipalities, which do not allocate the money to the assistance user but services in kind

(o)

### 1.5. The funding has the purpose of paying for any assistance required

The funding can be sufficient to pay for any assistance needed. Assistance users with multiple disabilities can get a 12% higher flat rate. The flat rate per hour is evaluated as sufficient, but in many cases the amount of granted hours is not sufficient especially if the assistance is granted by the municipality.

*"Just". Und dann gibt's natürlich die Regel, dass du nochmal einen erhöhten Stundensatz kriegst mit 12 Prozent und wenn das dann reicht dann ist ja gut, aber wenn das nicht reicht, fehlt es eben. Das war jetzt die Frage der Kosten per Stunde. Dann ist natürlich langt die Stundenanzahl als solche und das ist wieder ein ganz anderes Kapitel. Und da muss man schon davon ausgehen, dass das in vielen Fällen nicht reicht (S2: 146-150).*

The interview partners mentioned situations, which might not be covered by the funding. The funding might not be sufficient to pay higher salaries to qualified assistants and to have substitute assistants in the case an assistant gets sick. It is difficult to pay for the assistant's company on many trips. So disabled people cannot have jobs where they have to travel a lot.

*One time I was politically engaged in Sweden, I didn't have the money to stay politically engaged because I had to take that out of my private, out of my budget and my budget only went so far. So it became too expensive to have a political, a political, how do you call it, a political "uppdrag"... [...] engagement. In Sweden it wasn't easy (S1: 48-55).*

Another problem is that inactive times of assistance are not taken into account.

*The difference is coming from where this inactive and active hours. Where my assistant does go in the car with me because I can't ask one assistant to put me in the car at home and then another assistant to take me out. So that half an hour gets eaten up somewhere. It's not counted as assistance hour, but they get paid for it anyway (S1: 259-263).*

(X)



1.6. The funding is based on an individual needs assessment

The Funding is based on an individual needs assessment. The assessment might be repeated within less than every two years. There is a manual with intimate questions to assess the needs of a disabled person.

*I mean they use a manual and they ask everything very detailed as you heard from many people now probably. So you have to be prepared for any question that you, you know..., I remember 2010 they ask me how long it took for taking a shower and I said 15 minutes. And she said: only 15 minutes? I was like: oh shit, I should have said 30 minutes. I was so scared, you know. So I mean they go to much into details. But it's difficult (S3: 78-82).*

(✓)

1.7. The funding is based on the individual life circumstances

The funding might not take into account the individual life circumstances if this leads to extra costs like a job where one has to travel a lot.

*S1 42-44 I mean I'm not going to get more money than somebody else who just lives in Sweden and doesn't travel. They're not going to give me more because I travel internationally. It's based on the hours of assistance I need and that's what it's going to give that amount.*

(o)

1.8. Individualized services must not result in reduced budget or higher personal payment for assistance

There is no personal contribution of assistance users to the costs of their personal assistance. In general the personal assistance allowance is smaller than the costs of the home services but bigger than the personal contribution to the home service

*S1 95-96 For example the home help, when you take the costs of the home help, that hour costs more than personal assistance hours. So it is more expensive.*

*S2 79-82 Aber was man von der Versicherung kriegt ist ja vom Einkommen unabhängig und da brauche ich auch nichts dazu zu zahlen, kein "cofunding", Ei-*

*genbetrag. Und der Betrag ist 291 und da kriegt man, das ist auf jeden Fall mehr als der Eigenbetrag für den Heimdienst wäre.*

(✓)

2. Service controlled by the person with disability

2.1. The person with disability can contract the service from a variety of providers

The experts agreed that there is the possibility to contract the services from a variety of providers. Assistance user can choose different organizational models. They can receive services through the municipality, private companies, cooperatives, an own company or act as an employer.

*In Sweden you have four choices. You have the choice of having your personal assistance administrated by the city which you can choose if you want to do that. And some people, in the beginning most people did that. It took years before that pattern changed to the other three possibilities which are either employing a company, doing it yourself or being, as I myself, being a member of a cooperative (S1: 115-119).*

However, private companies service providers can deny assistance user as customers.

*Dass Assistenznehmer von bestimmten Firmen vielleicht nicht genommen werden als Kunden weil die Firmen finden, das ist zu aufwendig, vielleicht von der Verwaltung oder vielleicht auch vom Abstand (S2: 265-267).*

An expert stated that new regulations and bureaucracy make it harder to choose a self-organized assistance model. The budget, for example, is paid retrospectively after two months.

*Which changed a little in the recent past, in the most recent past is that is becoming so complicated with some rules on regulation and having, being, what do you call it, being assessed, being able to be the provider of personal assistance plus the cost. For example before you were paid in advance for two months, say two months forward you get your money. So even as a person, as a private person you would have the money in the bank to be able to pay the salary. Now you get the money two months after. So I mean I would have to take my own personal budget and pay those personal assistants. So I don't think there is probably any newcomers doing personal assistance as an individ-*

*ual unless they're very rich. So that more or less with all the bureaucracy that's..., the changes in bureaucracy they are more or less taking away that freedom that was there before (S1: 119-129).*

(o)

## 2.2. The person with disability can act as an employer

There is the possibility to act as an employer and assistance users even have the possibility to found their own assistance company.

*Like I said to you, there is four possibilities: having the city, having your own company, choosing a company or choosing a cooperative (S1: 207-208).*

But the interview partners mentioned that disabled people might feel discouraged to organize assistance as an employer because of the high efforts and new regulations.

*I think or I believe that because of the new regulations or new rules the hard talking, you know, the hard style from "försäkringskassan" is also scaring some users to be employers because it's lot of..., you know, attacking and, you know, people who have disabilities, some... I met many people who asked me because I taught them and show how I organize it. And I understand by talking to them that they..., first they are very interested, but when you're saying that you're a employer 24 hours, you get no rest, you're fucked. You have to be alert and work and to fix every problem. Then they go: ah no, I go to a company and they help me (S3: 256-263)*

Another problem they see is that it is difficult to find enough assistants to act as an employer and have a functioning assistance.

*Ja. Aber das ist natürlich vom System her nicht zu garantieren, dass die Leute überall, wo sie auch wohnen, dann diese Wahlfreiheit haben weil eben nicht, vielleicht nicht genügend Arbeitskräfte da sind (S2: 243-245).*

(o)

## 2.3. Persons with disabilities have the option to custom-design their own service: decide by whom, how, when, where and in what way the service is delivered

Assistance user can decide by whom, how, when, where and in what way the assistance is delivered. An expert stated that very precisely in the following quote.

*Where with personal assistance you can control who's coming when, where they coming, are you going to get the service in the home or outside of the home, are you going to and how, what time of the day you want to clean your house (S1: 100-103).*

But there can be restrictions from the unions or the providers of what an assistant is allowed to do.

*Yeah. There is one thing that starting to become a little bit more popular happening where the cities deciding that for example in Gotland, Gotland has decided that a personal assistant is not allowed to do any gardening. Which means the person can't live... You have to pay for this gardening in another way, you can't use your personal assistance to do that. So you can't be a gardener yourself and do your gardening. They are restricting it. (S1: 238-249)*

Furthermore, an interview partner stated that assistance users might not be able to decide who is assisting if the assistance is provided by a company and some assistants are sick.

(o)

#### 2.4. The person with disability can instruct and direct service providers

An expert has the opinion that there are service providers where assistance users cannot influence the service design. It might depend on the service provider if it is possible or not.

*Das heißt ich war noch nie bei einer anderen Firma, wo die Leute eben gesagt bekommen so machen wir's, das ist das was wir anbieten können, „take it or leave it“. So was habe ich noch nicht gehabt. Aber ich bin sicher, dass das zum großen Teil auch hier, dass das auch hier viel mitspielt was die Firma für Betriebsklima hat und wie weit die ihre Assistenten da ausbilden und unterstützen in der Hinsicht (S2: 584-589).*

(o)

### 3. One-to-one relationship

#### 3.1. Personal assistants must be recruited, trained and supervised by the person granted personal assistance

The interview partners agreed that in Sweden assistance users can recruit, train and supervise their assistants. But all of them mentioned difficulties finding assistants. The following quote is an example.

*Und es gibt zu wenig, es hängt wieder von der Konjunktur ab. Geht die Konjunktur gut dann wird es für uns immer schwieriger Leute zu kriegen (S2: 324-326).*

According to the experts in Sweden it is possible to recruit family members as assistants. There are service providers offering help with recruiting assistants. But there might be providers that train their assistants, which influences their behavior and openness towards the training from the assistance user.

*Und wie das ist bei Leuten, die große Firmen haben, da kriegen die Assistenten erst eine Ausbildung. Und inwieweit diese Ausbildung die Leute jetzt, Assistenten, auf ein Modell, eine Haltung oder auch praktische Details steuert im Gegensatz zu ganz offen, dass man im Assistenznehmer das überlässt, das weiß ich nicht, das hängt sicher von Firmen, variiert sicher mit den Firmen (S2: 281-286).*

S2 also said that it can be difficult to supervise assistants, who might be influenced by other experiences. Assistants who worked in the care sector before might not be used seeing the assistance user as a boss. Another expert mentioned that he discusses the instructions with his assistants.

(✓)

#### 3.2. Personal assistants should not be 'shared' without the full and free consent of the person granted personal assistance

Assistants can work for several assistance users. When they are employed by a provider they might even have to work for several persons. An expert criticizes that because he has to share assistants indirectly with others.

*Das heißt, das ist ein Nachteil und dadurch, dass sie eben woanders arbeitet, bin ich indirekt gezwungen die Assistentin mit jemand anders zu teilen (S2: 342-344).*

Another interview partner does not see that as problematic.

*No. We can compare it with other jobs. I mean, [name assistant 1], he's here, he works as a bus driver. I mean, you can compare it with that. Is he more a bus driver than an...? Or [name assistant 2] who works here, who's also doing, is working in a restaurant kitchen. But you know it doesn't take away anything. We try to solve everything. So, and ya... (S3: 307-311).*

An interview partner explained that she sometimes decides to share assistants with friends when she has no assistants available. But assistants do not work for several assistance users at the same time.

(✓)

#### 4. Self-management of service delivery

##### 4.1. The assistance user can freely choose their degree of personal control over service delivery according to their life circumstances and preferences

Assistance users can choose between different models to organize the assistance, which give the user different degrees of control. They can also have different models at the same time and change their organizational model.

*Yeah. Because they're not satisfied with one company, they move to another or they move to a cooperative or they move to doing it by themselves and they mix because they see that ah administration is too difficult. So I buy the administration and they change again, go to a company because the company is stealing your money or whatever. So I heard many stories that people switch a lot between everything. So I mean it seems to me quite easy (S3: 397-402).*

Municipalities, companies and cooperatives can take over responsibilities and as an employer the assistance user can outsource tasks.

*I heard different solutions. That company can help you with assistants and you don't need to choose, they serve you with assistants. But the law says that you should choose. But, I mean everyone is not capable of choosing. [...] Because they are kids or you got brain damage or whatever (S3: 327-333)*

An interview partner stated that the degree of control cannot be changed immediately, but it depends on the service provider. If the assistance user is temporarily not able to have the full control over the service delivery, assistants or family members can take over the control.

(o)

4.2. Even if the responsibilities of 'the employer' are contracted out, the person with disability always remains at the center of the decisions concerning the assistance

If assistants are employed by a provider or a cooperative, the assistance user can still be the working leader and instruct the assistants.

*Yeah, they have some kind of arrangement there that the user is employer but just in words. So, I mean the real employer is the company (S3: 242-243).*

An expert said that it can depend on the service provider how much control the assistance user has over the service delivery.

(o)

4.3. The assistance user must be enquired about and respected upon individual preferences

The assistance user instructs the assistants to make sure that the assistance is provided according to the individual preferences. But assistance users might have to agree to receive assistance according to their individual preferences.

*So I mean you might have people who take their own initiative then. There's funny stories of people remodeling the apartment while you're someplace. But I mean my assistants know if they don't, then they probably have a short time with me, that they should do what I want them to do, when I want them to do and how I want them to do. And how is usually always a problem because they say, but I do it this way. So I say, yeah but I do it this way. (S1: 380-385).*

(o)

#### 4.4. The control of personal assistance can be through supported decision-making

The interview partners mentioned different ways of how persons with mental disabilities can control personal assistance. At the cooperative STIL, assistance users can get a vice working leader, who organizes the assistance for them.

*So this person would then take on the responsibility of doing the time, doing the schedule for all the..., and this person would get paid. If this person is an assistant, would get paid to be an assistant, but also get paid some sort of administration fee to be doing this administrative work (S1: 335-338).*

It is possible to control the assistance through supported decision making in the so called JAG model through a guarantee person, who is trained to know what the assistance user prefers and how the assistance should be. The guarantee person makes sure that there is always personal assistance for the assistance user.

*Which in Sweden we have [supported decision making]. We usually use what we call the JAG model is an example where people with multiple disabilities who can't take their own decisions maybe don't even have a communication possibility are still having personal assistance and living in their own apartment. And it's through a what they call a guarantee person (S1: 394-397).*

A so called 'god man' can also help to control the assistance. A 'god man' is a mentor and a representative who can help to implement the assistance user's interests. The interview partners did not question the models to be either supported or substituted decision making.

(✓)

### 7.3 Discussion

The results of the evaluation are discussed by comparing the practical implementation of personal assistance in Germany and Sweden. Furthermore, the results of the theoretical and practical evaluation are compared. Finally, the results are interpreted.



### 7.3.1 The Practical Implementation

Table 6 summarizes the results of the evaluation of the practical implementation of personal assistance according to the experts' experiences and opinions in Germany and Sweden.

Table 6: *Results of the evaluation of the practical implementation of personal assistance in Germany and Sweden.*

<b>Criteria (practical evaluation)</b>		<b>Germany</b>	<b>Sweden</b>
<b>1</b>	<b>Funding for personal assistance</b>		
1.1	The funding is provided on basis of personalized criteria	(X)	(o)
1.2	The funding takes into account human rights standards for decent employment	(o)	(o)
1.3	The funding is controlled by the person with disability	(✓)	(o)
1.4	The funding is allocated to the person with disability	(✓)	(o)
1.5	The funding has the purpose of paying for any assistance required	(X)	(X)
1.6	The funding is based on an individual needs assessment	(o)	(✓)
1.7	The funding is based on the individual life circumstances	(X)	(o)
1.8	Individualized services must not result in reduced budget or higher personal payment for assistance	(o)	(✓)
<b>2.</b>	<b>Service controlled by the person with disability</b>		
2.1	The person with disability can contract the service from a variety of providers	(o)	(o)
2.2	The person with disability can act as an employer	(o)	(o)
2.3	Persons with disabilities have the option to custom-design their own service: decide by whom, how, when, where and in what way the service is delivered	(o)	(o)
2.4	The person with disability can instruct and direct service providers	(o)	(o)

<b>3. One-to-one relationship</b>		
3.1	Personal assistants must be recruited, trained and supervised by the person granted personal assistance	(o) (✓)
3.2	Personal assistants should not be 'shared' without the full and free consent of the person granted personal assistance	(✓) (✓)
<b>4. Self-management of service delivery</b>		
4.1	The assistance user can freely choose their degree of personal control over service delivery according to their life circumstances and preferences	(✓) (o)
4.2	Even if the responsibilities of 'the employer' are contracted out, the person with disability always remains at the center of the decisions concerning the assistance	(o) (o)
4.3	The assistance user must be enquired about and respected upon individual preferences	(o) (o)
4.4	The control of personal assistance can be through supported decision-making	(✓) (✓)

The opinions and experiences of the experts show that neither Germany nor Sweden fulfill all requirements of personal assistance according to the General Comment. According to the evaluation, the Swedish system of personal assistance does not fulfill the criteria in the practical implementation more than the German system does. Both countries have problems to fulfill the requirements concerning the funding of personal assistance. In Germany, the funding is not only based on personalized criteria. The funding also depends on the responsible authority, the region the assistance user is living in and whether the costs are interpreted to be reasonable. According to the experts in Germany, the funding is not based on the individual life circumstances. For example, circumstances of hospitalization are not covered by the personal assistance allowance except for assistance users in the employer model. In Germany and Sweden, the funding does not have the purpose of paying for any assistance required. German assistance users normally have to contribute to the costs of their personal assistance depending on their income and assets. In Sweden, the amount of funding per assistance hour might be appropriate, but the amount of granted hours and, therefore, the total amount of funding is often not sufficient. According to the interview partners' experi-

ences, there are some more differences in the practical implementation between Germany and Sweden. While in Germany the funding is allocated to and controlled by the assistance user, in Sweden, there might be municipalities, which do not allocate money to the disabled person but services in kind. Furthermore, there can be rules from cooperatives or opinions of municipalities that might restrict the person's control. The German interview partners pointed out that German assistance users often have to fight for a sufficient funding. In comparison to Sweden where personal assistance does not lead to a reduced budget, German benefits of the care insurance are lower than the coupons for services in kind. The experts stated that, in Germany, it depends on the service provider if assistance users can recruit, train and supervise their assistants. In Sweden, the possibility to freely choose the degree of personal control over service delivery can depend on the service provider.

### **7.3.2 Comparison of the Theoretical and Practical Implementation**

The evaluation of the practical implementation of personal assistance according to the experts' experiences and opinions shows different results than the theoretical evaluation. While in theory the personal assistance in Sweden is better than in Germany, the practical evaluation does not show a country that is better than the other. In comparison to the theoretical evaluation, the evaluation of the practical implementation does not find as many criteria to be fulfilled. The interview partners had more things to criticize than the theoretical evaluation could find. None of the criteria were assessed to be better in practical experience than in theory. However, the differences between theoretical and practical evaluation are not significant. Criteria, which were assessed to be fulfilled in theory were not assessed to be not fulfilled in the practical experience. Only two criteria were assessed as fulfilled in theory and in practice in both countries. In Sweden and Germany, personal assistants are not 'shared' without the full and free consent of the person granted personal assistance. Personal assistants do not work for several assistance users at the same time. Furthermore, in both countries disabled persons can control personal assistance through supported decision-making. To which extent the described models can be seen in all its aspects as supported decision making and not as substituted decision making was not discussed in the evaluations.

The differences between the results of the theoretical and practical evaluation are more significant in the Swedish assessment than in the German one. In Sweden, eleven criteria of the practical evaluation were found to be not as good as in theory. In compari-

son, only six criteria concerning the German system reached other results in practice than in theory. There are five criteria that in both countries were evaluated worse than in the theoretical evaluation. In theory, funding in Sweden and Germany is sufficient for a decent employment of assistants. The experiences of the assistance users show that this criterion is only partly fulfilled in practice. For example, in Germany, the funding is often not sufficient to employ assistants who are subject to social insurances, and in Sweden, the funding does not increase in relation to the wage rates and inflation. Further, in both countries, the funding is rather less based on the individual life circumstances than it was analyzed in theory. In Germany, there are some life circumstances that are not taken into account by the funding, and in Sweden, circumstances where one has to travel a lot are not covered. The criterion, which applies to the possibility to act as an employer, was theoretically evaluated to be fulfilled in both countries. But the experts mentioned aspects that restrict this possibility. Besides the fact that it is difficult to find enough assistants in both countries, in Sweden, assistance users might feel discouraged by new regulations. In Germany, the funding might not be enough to organize personal assistance in the employer model. In theory, there is also the possibility to custom-design the personal assistance service in both countries. But the practical evaluation came to the conclusion that, both in Sweden and Germany, it depends on the providers. The individual preferences are enquired about and respected in theory in Germany and Sweden. According to the experts' experiences, assistance users might have to defend their preferences in both countries.

In contrast to Sweden, the criterion concerning the individual needs assessment is evaluated to be only partly fulfilled in the practical implementation in Germany. Assistance users in Germany might have to negotiate and fight for appropriate funding. In Sweden, there are more criteria, which were evaluated to be fulfilled in theory but were only partly fulfilled in the practical implementation. In Sweden, some municipalities might allocate services in kind instead of a direct payment to the disabled person. Furthermore, the person's control over the funding might be restricted by the municipality or the cooperative. The possibility to contract services from a variety of providers might be restricted in Sweden because service providers might deny assistance users as customers and new regulations make it harder to choose a self-organized assistance model. The experts also mentioned that it depends on the provider whether the assistance users can instruct their assistants. It also depends on the provider whether disabled people can choose their degree of control over the service delivery. The criterion concerning the adequacy of the funding (criterion 1.5) was evaluated to be only partly

fulfilled in theory but was evaluated to be not fulfilled in the practice. The experts mentioned more cases than the theoretical evaluation found in which the funding is not sufficient to pay the required assistance. Table 7 shows the comparison of the results of the practical and theoretical evaluation.

Table 7: *Comparison of the results of the practical and theoretical evaluation of the personal assistance systems in Germany and Sweden.*

	Practical Evaluation		Theoretical Evaluation	
	Germany	Sweden	Germany	Sweden
<b>1. Funding</b>				
1.1 The funding is provided on basis of personalized criteria	(X)	(o)	(X)	(o)
1.2 The funding takes into account human rights standards for decent employment	(o)	(o)	(✓)	(✓)
1.3 The funding is controlled by the person with disability	(✓)	(o)	(✓)	(✓)
1.4 The funding is allocated to the person with disability	(✓)	(o)	(✓)	(✓)
1.5 The funding has the purpose of paying for any assistance required	(X)	(X)	(X)	(o)
1.6 The funding is based on an individual needs assessment	(o)	(✓)	(✓)	(✓)
1.7 The funding is based on the individual life circumstances	(X)	(o)	(o)	(✓)
1.8 Individualized services must not result in reduced budget or higher personal payment for assistance	(o)	(✓)	(o)	(✓)
<b>2. Service controlled by the person with disability</b>				
2.1 The person with disability can contract the service from a variety of providers	(o)	(o)	(o)	(✓)
2.2 The person with disability can act as an employer	(o)	(o)	(✓)	(✓)
2.3 Persons with disabilities have the option to custom-design their own service: decide by whom, how, when, where and in what way the service is delivered	(o)	(o)	(✓)	(✓)
2.4 The person with disability can "instruct and direct service providers"	(o)	(o)	(o)	(✓)

<b>3. One-to-one relationship</b>				
3.1 Personal assistants must be recruited, trained and supervised by the person granted personal assistance	(o)	(✓)	(o)	(✓)
3.2 Personal assistants should not be 'shared' without the full and free consent of the person granted personal assistance	(✓)	(✓)	(✓)	(✓)
<b>4. Self-management of service delivery</b>				
4.1 The assistance user can freely choose their degree of personal control over service delivery according to their life circumstances and preferences	(✓)	(o)	(✓)	(✓)
4.2 Even if the responsibilities of 'the employer' are contracted out, the person with disability always remains at the center of the decisions concerning the assistance	(o)	(o)	(o)	(o)
4.3 The assistance user must be enquired about and respected upon individual preferences	(o)	(o)	(✓)	(✓)
4.4 The control of personal assistance can be through supported decision-making	(✓)	(✓)	(✓)	(✓)

The personal assistance systems in Sweden and Germany fulfill the requirements of the General Comment neither in theory nor in the practical implementation according to the interviewed experts. The systems seem to be better in theory compared to how the assistance users experience them in their practical implementation. Especially some criteria concerning the funding of personal assistance do not fulfill the requirements. Many criteria were assessed as partly fulfilled because the compliance depends on the personal assistance provider. Therefore, in both countries, the employer model is the best way to ensure personal assistance as a person-directed and user-led support according to the General Comment.

### 7.3.3 Interpretation of the Results

The results of the evaluations can be discussed critically. There might be several reasons for the differences between the theory and practical implementation of personal assistance in Sweden and Germany. The interview partners described the systems based on their individual experiences and cases they heard of. The data collected in the interviews is not representative. The evaluation does not include all personal cases, but the interviews provide an insight into the practical implementation of personal assistance and the existing opinions on it. More opinions and experiences could have been included by interviewing more assistance users. The theoretical evaluation does not take individual cases into account. It is also possible that the research did not include all sources. Most of the interview partners were glad that someone is interested in their opinion and that they had the chance to tell someone what is going wrong in the system of personal assistance. The differences between theory and practical implementation in Germany were not as significant as in Sweden. This could be the result of a better research on the German system or because the practical implementation in Germany complies more with the theory than it does in Sweden. The differences between Germany and Sweden in general could also be influenced by the individual experts and their cultural background. It seemed that the interview partners in Sweden were less willing to agree that a requirement is fulfilled. They often found examples, which showed that there are exceptions.

A question to discuss is what these results of the evaluation of personal assistance mean for the disabled people in Germany and Sweden. Especially the results that are not or only partly fulfilled are interesting to look at.

In Germany disabled people might get a lower budget when they move to another city. The costs of personal assistance have to be reasonable to be paid by the responsible authority. People with disabilities are not as free as others to choose their place of residence (according to Art. 19 a CRPD) because they might not get a sufficient budget to organize personal assistance in another region. The funding depends on the authority, which leads to inequalities. People who got their disability through an accident might get paid more assistance or rather have to pay less by themselves (criterion 1.1). The personal contribution of disabled people to their personal assistance is the main reason why the funding is not purposed to pay for any assistance needed. Because the funding is (still) means-tested, disabled people might feel demotivated to work or accept a better work position. More income might lead to a higher personal contribution. Disa-

bled people are not treated as equal members of society who have the same chances to save money to invest in a personal dream. Families with a disabled person might have less money and a higher risk of living at poverty level. If the funding for personal assistance does not cover all areas of life, like voluntary engagement, disabled people cannot participate in the community equally to others (criterion 1.5). Disabled people rather have to fight for sufficient funding to be able to live independently rather than the state ensuring the exercise of this right (criterion 1.6). The funding might be based on individual life circumstances but does not take into account all circumstances of life, like e.g. in the case of hospitalization. Of course, they receive care in a hospital, but depending on the kind of disability, disabled people might not be able to move or express themselves to their liking without personal assistance (criterion 1.7). The salary that can be paid with the personal budget is not violating human rights, but the profession of a personal assistant is not well paid. Often it is a part time job or a marginal employment without social insurances, which might lead to high fluctuation of assistants (criterion 1.2). Sometimes the authorities might even restrict the recruitment to assistants who are not subject to social insurances (criterion 3.1). This and the fact that the availability of assistants depends highly on the economic situation and employment market might lead to an unstable situation for assistance users in the employer model (criterion 2.2). Another reason why disabled people might feel discouraged to act as employers for their assistants is that the budget can be lower than the costs of services in kind (criterion 1.8). So the possibility to act as an employer and, thereby, the possibility to fully control and direct the personal assistance is indirectly restricted.

But the alternative, which is to buy services from a provider, is restricted too. A problem in Germany is that there are only conventional care providers in some regions and no big variety of providers (criterion 2.1). This restricts the possibility to live independently and self-determined when one is not able to organize the assistance as an employer. So it depends highly on the provider whether assistance users can control the service delivery if the responsibility of the employer is contracted out (criterion 4.2). It might not be possible to custom design services and instruct the provider. If disabled people do not have the possibility to decide who is assisting them how, when and where, self-determination is highly restricted. It might even violate the human dignity if one has to accept assistance from anybody. Furthermore, it restricts the freedom of movement if the assistance is only given at home (criteria 2.3, 2.4). Also the training and supervision of assistance is linked to the possibility to custom-design the service. Without supervising the assistants, disabled people cannot decide how the assistance is delivered,



which can lead to violations of the user's dignity (criterion 3.1). In such cases, the preferences of the assistance user are not respected. 'Carers' employed by providers might not even have to respect the preferences of their clients because they are not employed by the disabled person.

In Sweden, the funding can vary between the municipality and the social insurance. Municipalities do not have to follow the guidelines of the social insurance. Like in Germany, this might lead to inequality and restrict the freedom of movement (criterion 1.1). If the flat rate per assistance hour does not increase in relation to the wage rates and the inflation, this does not mean that the human rights standards of decent employment are violated. Assistance users can still pay decent salaries, but there might be less money left over to pay for other assistance related costs, like for example for the assistant's companionship on trips (criterion 1.2). The funding might be based on the individual life circumstances but does not take all circumstances into account. Higher costs, which are not directly related to the disability, are not covered by the allowance. Disabled people cannot have jobs or voluntary engagements where they have to travel a lot. This means disabled people do not have equal opportunities to others (criterion 1.7). Irrespective of the amount of funding per hour the amount of granted assistance hours is often not enough to cover all assistance needed. People might not get the assistance they need to participate in society equal to others. Reinterpretations of the basic needs are the major reason why disabled people lose their state funded assistance and get less assistance hours granted. Since 2015, the number of persons receiving personal assistance allowances has been decreasing (1.5) (Assistansköll n.d.c). From 2016 to 2017, the number of assistance users acting as employers decreased by around half. New regulations might be the reason for this. Each month assistance users in the employer model have to pay back the money that was not spent on assistance. Therefore, they do not have the possibility to save money for times when they might need more money, for example for the assistant's companionship on summer holiday. This might discourage people to organize assistance as an employer. Furthermore, it is difficult to find enough assistants to act as an employer. In Sweden, there is a variety of personal assistance providers one can choose from. Assistance providers that are private companies can deny customers (criterion 2.1). However, there is still the municipality, which has to provide assistance if there are no other providers. But there might be municipalities, which do not allocate the money but services in kind to the assistance user. This would limit the self-determination of disabled people to decide how the assistance is organized. Providers and collective agreements can

restrict the assistance user's control over the funding (criterion 1.3). There are restrictions on what an assistant is allowed to do and, thereby, the assistance users' freedom to do whatever they want to do is limited (criterion 2.3). But these rules might be trade-offs to ensure the safety of the assistants. As a customer of a service provider, the assistance user might not be able to influence who provides the assistance when assistants are sick (criterion 2.3). Disabled people might have to accept assistance from persons they did not choose. But in comparison to assistance users in the employer model, the provision of assistance is ensured. The amount of control the assistance user has over the service might depend on the provider (criterion 4.2). It is not guaranteed that assistance users can take all decisions concerning the assistance and that they can change their degree of control according to their life circumstances and preferences (criteria 4.1, 4.2). Depending on how the control is limited by the provider, this can lead to restrictions of self-determination of the disabled person. Furthermore, individual preferences might have to be defended (criterion 4.3). Disabled people often experience that others want to decide over their daily lives.

The evaluation results of the Swedish personal assistance system must be seen in the context of its preconditions. Personal assistance is not available for all disabled people in the need of assistance. Only certain groups of persons with particular needs are eligible for personal assistance allowance (§ 1 LSS). Even if the practical implementation of personal assistance is better in Sweden than in Germany (according to the interview partners), the access to personal assistance services is restricted in Sweden to a certain group of persons and, therefore, criticized by the interview partners.

*Ah also in Swedish legislation you have three categories of people who can have personal assistance. So someone who's deaf blind doesn't have access to personal assistance and I think that's wrong. Because I think you put disabilities against one another, organizations against one another. I think that's wrong. (S1: 492-496)*

Whether someone is eligible for personal assistance does not depend on the need of assistance but on a bunch of other criteria, which have to be fulfilled. An expert claims that anybody with the need of assistance, irrespective of the age and reason for the need, should have the right to personal assistance.

*Naja es ist dann eben das ganze System hat auch den Nachteil, dass es also nicht vom Bedarf ausgeht, sondern von einer Anzahl von Kriterien, die teilweise geschichtlich begründet sind (S2: 738-740).*

*Das ist genau verdreht. Man müsste die Kriterien haben: jemanden, der ganz gleich aus welchem Grund, ganz gleich welchen Alters, diesen Bedarf hat an dieser Art von Unterstützung, die darauf hinausgeht, dass der einzelne dieses Eins-zu-eins Verhältnis hat, die ihm eher die Fortsetzung des bisherigen Lebens oder wenn es neugeboren ist ermöglicht. So rum (S2: 751-755).*

The eligibility also depends on the age. An interview partner criticized that after the age of 65 a person is not seen as disabled anymore but old. A disabled person cannot apply for personal assistance after the 65th birthday.

*Was schlecht ist, das erlebe ich jetzt am eigenen Leib, das ist die Altersdiskriminierung. Und da ist es meistens bei, es ist in vielen Ländern so, da ist mit 65 Schluss. Da ist irgendwie passiert da was in den Köpfen der Leute, die sagen mit 65 da brauchen wir das einfach nicht mehr, da ist man bloß noch alt, vorher war's behindert... (S2: 695-699).*

When asking the experts about their general opinion on the Swedish system of personal assistance, they did not only criticize the eligibility criteria. Another aspect, which was criticized, is the 'shared' responsibility between social insurance agency and the municipalities.

*I think that there's a disadvantage that it's a legislation with the division between the city and the state rather having everything at the state level. Because when it, because of the division of the city and the state you can become a ping pong ball with the back you back and forward thing, who's going to actually take the responsibility? (S1: 478-482).*

Furthermore, the responsibility of the municipality keeps the disabled people from freely moving where they want to. They would have to go through the whole process with the risk of getting less hours of assistance granted. Another interview partner mentioned the changed atmosphere. The social insurance agency has been cutting personal assistance allowances and there is less transparency and participation of disabled people.

*And also this, from the beginning the government said that because of this with the UN Convention and everything, they say people with disabilities should be around the table when we talk about people. We should not talk about them. Ok, that worked many years, but in the last years something changed. So government, "försäkringskassan", almost everyone is cutting details. And they are*

*not talking with us anymore. So it's been chillier, colder and we got frustrated because they don't listen to us, they don't want to answer. When we are asking for meetings they don't say... It's just quiet. So and that a lot around "personlig assistans" nowadays. So that's the problem, I think, that they are not talking with us. So from going to be a good country with a lot of innovative solutions to be restrictive and being a real Big Brother (S3: 643-653).*

This leads to a feeling of insecurity and fear of losing personal assistance hours.

*But I still have my "personlig assistans" as I want it, but I'm scared, I'm very scared to lose it. But I'm preparing my mind for times when it can go worse. So I'm not alone, we are many who are very scared. But I'm a fighter so I never give up. So I, you know, I have not so much to fight about, but this is important for me (S3: 653-657).*

The German interview partners were also asked which aspects of the German personal assistance system they criticize the most. A negative aspect for many is the personal contribution to the personal assistance service depending on their income and assets. An expert criticized that in Germany a disability means that one has to live at the poverty line.

*Davon ausnehmen möchte ich allerdings, dass auch diese Behörden immer voraussetzen, dass man an der Armutsgrenze lebt. Also Behinderung ist in Deutschland auch immer eine Armutsgrenze, was ja eigentlich auch wieder eine Diskriminierung ist und was wieder Grenzen schafft irgendwie (G2: 780-783).*

An expert said that German politics do not see the potential of personal assistance as a solution for the state of emergency in the care profession. Families with a relative in need of care can often not handle the responsibility and workload. Elderly people are put in institutions or are cared by illegal employed carers at home because the regulations on wage accounting are so complicated. Families need support and trainings in recruiting, supervising and accounting.

*Worauf ich hinauswill ist, diese..., was völlig verkannt wird ist, dass dieses System mit relativ wenig Aufwand den Pflegenotstand und auch die Assistenz oder Pflege in einem ganz großen Umfang sichern und stabilisieren könnte. Derzeit ist es so, wenn jemand, gerade die alten Leute, wenn da Pflegebedürftigkeit dazu kommt, es bleibt fast nur immer diese Heimunterbringung, ne. [...] Die*

*Angehörigen sind überfordert, werden psychisch krank oder überhaupt krank und können das nicht leisten, ne. [...] Also die Lohnbuchhaltung ist sowas von kompliziert, dass sie in Deutschland eigentlich zur Illegalität..., die Leute sind gezwungen illegal zu beschäftigen (G1: 860-875).*

In general the interview partners in Germany criticized the misunderstanding and missing implementation of the CRPD. An expert stated that the change to a social model of disability has not yet been done. Interview partner G2 mentioned that Germany has not yet understood that participation is a human right.

*Und ich denke, wir haben viel erreicht und die UN-Konvention war sicher ein Schritt in die richtige Richtung, aber Deutschland tut sich total schwer oder will es auch nicht umsetzen. [...] Also man hat in Deutschland überhaupt nicht begriffen, was Teilhabe bedeutet und dass es ein Menschenrecht ist, das versteht man hier nicht (G2: 800-812).*

The interview partners also mentioned good aspects in the German system of personal assistance. A new law introduced the so called complementary and independent participation counseling (ergänzende unabhängige Teilhabeberatung) where disabled people support and advice other disabled people on questions about support services. This is seen as good progress.

*Aber es gibt tatsächlich ein Punkt im Bundesteilhabegesetz, über den wir, auch als Beraterinnen, sehr, sehr glücklich sind, dass zum 1.1.18 die ergänzende unabhängige Teilhabeberatung in Deutschland eingeführt wurde, wo Vereine, wo Menschen mit Behinderung arbeiten, sich drauf bewerben konnten, Zusage auch bekommen haben und Menschen mit Behinderung auf dem ersten Arbeitsmarkt eine Anstellung, Vollzeit, Teilzeit etc. bekommen konnten. Das ist erst mal ein Punkt, über den wir sehr zufrieden sind in Deutschland (G3: 561-567).*

Furthermore, an expert stated that it is possible to live almost like others if a disabled person can express his or her interests and has the energy to deal with authorities.

*Also loben möchte ich, wenn man in der Lage ist als Mensch mit Behinderung seine Interessen selber zu formulieren und wenn man auch die Kraft und Energie hat sich mit Behörden auseinanderzusetzen, dann ist einiges möglich. Und dann ist es auch möglich, also nahezu, fast nahezu ein Leben zu leben, was dem einer nicht behinderten Person gleicht (G2: 776-780).*

In Sweden, the experts praised the fact that personal assistance services are not means-tested and that there is no personal contribution for the user in contrast to Germany. Furthermore, it is seen as a good aspect that assistance users can choose their organizational model and between different service providers.

*Was ich am meisten lobe ist im Gegensatz zu den Alternativen anderswo, das ist, dass es einkommensunabhängig ist, vermögensunabhängig ist, von dir selbst und von den Verwandten bis zum dritten Grad und so weiter im Gegensatz zu Deutschland. Das ist das eine was gut ist. Das andere was gut ist, dass keine Selbstbeteiligung dabei ist. Also ich war doch kürzlich in Taiwan, da zahlst du 30 Prozent der Kosten selbst. [...] Ja. Ja und das nenne ich "tax on disability". Wer kann sich das leisten, kannst dir ja nicht leisten. Das ist das schöne hier. Ja. Dann hast du im auf dem Papier aber meistens auch den Betreiber selbst wählen kannst, die verschiedenen Formen auch selbst: Genossenschaft, Gemeinde, private Firma und so weiter. Das finde ich auch stark, das ist oft nicht gegeben (S2: 658-672).*

The interview partners in Sweden mentioned that the personal assistance system allow them to live like others and have control over their lives.

*So I'm not going to change it because I like it to have a control and just be easy. [...] Decide my life and it's only me and the assistants, I mean no one between us. We can talk to each other and I mean it's so easy (S3: 268- 275).*

*[...] but I mean the things that are good is when you have a personal assistance which functions which my personal assistance in Sweden has, I've been able to live a life, I've gone to the university and did PhD studies, worked internationally at the EU level. I am quite active, I've been able to be a mother, a friend and have relations. That you can do the things you organize and have a good free time, hobby time as well (S1: 502-506).*

## 8 Conclusion

Article 19 of the CRPD includes the right to personal assistance for disabled people as a tool for Independent Living. Among other countries, Germany and Sweden ratified the Convention and are obliged to ensure this right. However, General Comment Number 5 on Article 19 of the CRPD criticized the inadequacy of personal assistance systems. In state reports the Committee on the Rights of Persons with Disability criticized the implementation of personal assistance in Germany and Sweden. The General Comment recognizes the national differences in the implementation of this right and gives clear criteria, which define personal assistance and which have to be fulfilled in order to call a service 'personal assistance'.

The presented thesis analyzed the theoretical and practical implementation of personal assistance in Germany and Sweden. The research question asked how the practical implementation of the personal assistance systems in Germany and Sweden fulfill the requirements of the criteria defining personal assistance according to the General Comment on Article 19 of the CRPD in comparison to their theoretical implementation. The work focused on the analysis of the existing personal assistance systems rather than on the availability and access to these services. To answer the research question three main steps were conducted. First, the personal assistance systems in Germany and Sweden were described and compared. The second step was the theoretical evaluation. It was evaluated how the systems fulfill the criteria of the General Comment in theory. As a last step, the practical implementation was evaluated in interviews with experts and compared with the results of the theoretical evaluation.

The comparison of the German and Swedish system illustrated the differences between both systems. While in Germany, in principle all disabled people are eligible for personal assistance services, in Sweden, there are specific eligibility criteria and an age limit. In Sweden, there are only two authorities, which can be responsible to grant personal assistance. In Germany, there are many possible authorities depending on how one got a disability and for what the assistance is needed for. Another big difference is that personal assistance services in Germany are mostly means-tested. Personal assistance users pay a personal contribution depending on their income and assets.

In the theoretical evaluation, it was assessed how the described systems of personal assistance fulfill the criteria of the General Comment theoretically. This evaluation was based on the specific law texts and other textual sources about personal assistance.

The evaluation showed that Sweden fulfills more criteria of the General Comment than Germany does. But neither Germany nor Sweden fulfill all criteria defining personal assistance according to the General Comment. There is a lack of compliance especially in the criteria concerning the funding. In both countries, the funding is rather not based on personalized criteria and is rather not sufficient to cover any assistance needed.

The practical implementation of personal assistance in both countries was evaluated by a qualitative research. In semi-structured interviews, assistance users campaigning for Independent Living assessed the personal assistance systems in Germany and Sweden. This practical evaluation showed that only a few criteria of the General Comment are fulfilled in practice. The results showed that less criteria were fulfilled in the practical implementation in comparison to the theoretical one. Comparable to the theoretical evaluation, most problems were seen in the compliance of the criteria concerning the funding.

The main difficulties in the implementation of personal assistance are different in Sweden and Germany. In Germany, the main problem is that most of the times personal assistance is a means-tested allowance. Even if the income limits were increased by the new law disabled people still might have to pay a personal contribution depending on their income and assets. Having a disability in Germany still means that the person might be forced to live in a so called 'adequate living standard'. Further, there are many different authorities, which can be responsible to grant personal assistance. The authorities vary between the federal states and have their own regulations. A main problem in Germany is that there is no variety of service providers, which provide 'real' personal assistance where users can decide who assists when, where and how. Especially in rural areas, there are often only conventional care providers. The employer model is often the only way to live a self-determined life. In comparison to Germany, personal assistance is well known in Sweden and there is a variety of providers offering 'real' personal assistance services. But the main problem in Sweden lies in the preconditions for personal assistance. Personal assistance is not available to all disabled people in need of assistance. Through reinterpretations of the eligibility criteria 'basic needs', many disabled people experienced sharp cutbacks in their personal assistance.

The presented thesis shows that there is a need for improvement in the Swedish and the German systems of personal assistance. The Committee on the Rights of Persons with Disability criticized the inadequate implementation of Article 19 already in its state



reports. The results of the evaluations correspond with the state reports of the Committee. The Committee expressed its concerns about the reinterpretations of the law and the cutbacks in state funded personal assistance in Sweden (Committee on the Rights of Persons with Disabilities 2014, p. 6). In Germany, the Committee criticized the means-testing of services (Committee on the Rights of Persons with Disabilities 2015, p. 7). The research conducted in this thesis revealed the specific deficits by evaluating the particular criteria of the General Comment. Thereby, not only the lacks but also the compliance of the system with the CRPD could be shown. Countries can learn from each other by giving good examples of implementations. This thesis is a contribution to promote a fact based discussion on personal assistance. The results of this work might be used as a basis for a political discussion to improve personal assistance in accordance with the CRPD.

The presented work could be criticized because of the small group of interview partners who evaluated the practical implementation of personal assistance. The data gained through the interviews is not representative and might not reflect a complete range of opinions and experiences. However, it can provide a general picture of the practical implementation of personal assistance in Germany and Sweden. Maybe a greater lack of compliance would have been revealed by interviewing more experts. Therefore, further research is needed. In future work on this topic, the results could be more detailed by operationalizing the criteria to get clear and comprehensive indicators, which have to be fulfilled in order to call a service personal assistance in the sense of the CRPD. Furthermore, the personal assistance systems of other countries, which ratified the convention could be evaluated according to their compliance with the requirements of the General Comment. These efforts could advance the discussion about personal assistance. The work in general would have a higher relevance if the General Comment itself was a legally binding document. However, the General Comment is an authoritative text, which gives guidelines to interpret the provisions stated in the CRPD.

In general, there should be more awareness about the CRPD. The CRPD is not about special rights for disabled people but ensuring the human rights for disabled people. More research and lobbying is necessary to reveal the gap between the current state of human rights for disabled people in particular countries of this world and the required target status according to the CRPD. This work has shown the gaps between a right stated in the CRPD and the current situation in Germany and Sweden. Further research could deepen the understanding of the availability of services discussed in the thesis. Independent Living is to some extent materialized in Germany and Sweden.

However, the states have a long way to go to fully implement the rights, which they are bound to implement by public international law (CRPD). General Comment Number 5 on Article 19 should be wider known and used as a guideline to implement the right to live independently and being included in the community. To live independently and to have the choice equal to others to decide with whom, where and how one wants to live is a human right and is made possible for disabled people through personal assistance.

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## **Appendix**

The appendix contains the interview guides in German and English and the coding guide for the qualitative content analysis.

### **I. Interview Guides**

#### **a. Interview Guide in German**

### **Interviewleitfaden**

#### **1. Begrüßung und Einführung**

- Begrüßung und Bedankung, Überprüfung der Technik
- Information zum Datenschutz
  - o Einverständniserklärung zur Aufzeichnung des Interviews und Bearbeitung im Rahmen der Masterarbeit, Anonymisierung der Transkription des Interviews
- Vorstellung Masterarbeit:
  - o Masterarbeit an der Katholischen Hochschule Freiburg für und in Kooperation mit dem Independent Living Institute in Stockholm
  - o Forschungsfrage: Inwieweit entsprechen die Systeme der Persönlichen Assistenz in Deutschland und Schweden den Anforderungen des General Comment on Article 19 (GC) der UN-Behindertenrechtskonvention?
- Ziel und Aufbau des Interviews
  - o Einschätzung und Erfahrungen von Assistenznutzern bezogen auf die Anforderung des GC an die Persönliche Assistenz.
  - o Interview orientiert sich an den 18 Anforderung des GC, unterteilt in vier Gruppen

#### **2. Hauptfragen**

##### **2.1 Finanzausstattung**

- Von welchen Kriterien hängt die Höhe des Persönlichen Budgets ab, mit dem die Persönliche Assistenz finanziert werden soll. Der GC fordert, dass die Finanzausstattung nur von individuellen und personenbezogenen Kriterien abhängt.
  - o Beruht die Finanzausstattung auf personenbezogenen Kriterien?

- Basieren die Geldmittel auf einer individuellen Bedarfsermittlung?
- Basieren die Geldmittel auf den individuellen Lebensumständen?
- Können die individualisierten Leistungen zu einem geringeren Budget oder einer höheren Eigenbeteiligung führen? (z.B. Kann das Persönliche Budget geringer sein als die Kosten einer standardisierten Leistung?)
- Nach dem GC müssen die Geldmittel für Assistenz dem Assistenznutzer zugewiesen und von diesem kontrolliert werden können. Wird dieses Kriterium Ihrer Meinung nach erfüllt?
  - Hat der Mensch mit Behinderung die Kontrolle über die Geldmittel?
  - Werden die Geldmittel dem Menschen mit Behinderung zugewiesen?
- Der GC fordert außerdem, dass die Geldmittel den Zweck haben sollen jede notwendige Assistenz bezahlen zu können. Ist das so und wird dieser Zweck erreicht, also reicht das Geld aus?
  - Werden bei der Finanzausstattung menschenrechtliche Standards für eine ordentliche Beschäftigung berücksichtigt?
  - Hat die Finanzausstattung den Zweck jede notwendige Assistenz bezahlen zu können? Wird der Zweck erreicht oder muss der Rest selbst gezahlt werden?

## **2.2 Leistung gesteuert von der Person mit Behinderung**

- Nach dem GC sollen Menschen mit Behinderung verschiedene Möglichkeiten haben ihre Assistenz beziehen oder organisieren zu können, z.B. sollen sie aus einer Auswahl von Anbietern wählen oder selbst als Arbeitgeber agieren können. Ist das Ihrer Meinung nach gegeben?
  - Gibt es die Möglichkeit Leistungen von einer Auswahl an Anbietern zu beziehen?
  - Gibt es die Möglichkeit als Arbeitgeber zu agieren?
- Der Assistenznutzer soll entscheiden können von wem, wie, wann und in welcher Weise die Leistung erbracht wird und soll die Möglichkeit haben seine Assistenten selbst anzuleiten. Inwieweit trifft das Ihrer Meinung nach zu?
  - Gibt es die Option maßgeschneiderter Leistungen: zu entscheiden von wem, wie, wann und in welcher Weise die Leistung erbracht wird?
  - Gibt es die Möglichkeit den Leistungserbringer (Persönlichen Assistenten) zu führen und anzuleiten?

### **2.3 Eins-zu-eins Beziehung**

- Der GC definiert die Persönliche Assistenz als Eins-zu-eins Beziehung, in der ein Assistent nicht geteilt werden muss, d.h. nicht gleichzeitig für mehrere Assistenznutzer zuständig ist und der Assistenznutzer die Assistenten rekrutiert, ausbildet und anleitet. Wird dies Ihrer Meinung erfüllt?
  - o Werden Persönliche Assistenten vom Assistenznutzer rekrutiert, ausgebildet und angeleitet?
  - o Müssen die Persönlichen Assistenten ohne Einverständnis der Assistenznutzer mit anderen geteilt werden? (Ist ein Assistent gleichzeitig für mehrere Assistenznutzer zuständig?)

### **2.4 Selbstverwaltung der Leistungserbringung**

- Nach dem GC sollen Assistenznutzer frei entscheiden können, wieviel Kontrolle sie über die Leistungserbringung haben aber stets im Zentrum der Entscheidungen bleiben. Wie schätzen Sie dies in Deutschland ein?
  - o Können Personen mit Behinderung gemäß ihrer Lebensumstände und Präferenzen frei darüber entscheiden wie viel Kontrolle sie über die Leistungserbringung haben?
  - o Bleibt die Person mit Behinderung immer im Zentrum der Entscheidungen, auch wenn die Arbeitgeberverantwortung abgegeben wurde?
  - o Werden die individuellen Präferenzen erfragt und respektiert?
  - o Kann die Persönliche Assistenz durch unterstützte Entscheidungsfindung gesteuert werden?

### **3. Abschließende Fragen**

- Welche Aspekte finden Sie besonders gut und welche Punkte kritisieren Sie am meisten am deutschen System der Persönlichen Assistenz?
- Gibt es von Ihrer Seite noch weitere Punkte, die Sie bezüglich der Persönlichen Assistenz ansprechen möchten?

### **4. Abschluss**

- Bedankung, Verabschiedung

## **b. Interview Guide in English**

### **Interview Guide**

#### **1. Welcome and introduction**

- Welcome and thanks, (check if the technical equipment works)
- Information about protection of data privacy
  - o Declaration of agreement to record the interview und analyze the gathered data in the context of the Master's thesis, transliteration will be anonymized
- Introduction of the Master's thesis
  - o Master's thesis at the Catholic University for Applied Sciences Freiburg (Germany) for and in cooperation with the Independent Living Institute in Stockholm
  - o Research question: How do the systems of personal assistance for disabled people in Germany and Sweden fulfill the requirements of the General Comment (GC) on Article 19 of the CRPD?
- Aim and Structure of the Interview
  - o How do assistance users see and experience personal assistance in their country? Does the system fulfill to the requirements of the GC in their opinion?
  - o The structure of the interview follows the 18 requirements of the GC, subdivided in four groups.

#### **2. Main Questions**

##### **2.1 Funding**

- What determines the amount of personal assistance allowance in Sweden? The GC states that the amount of the personal assistance allowance should only be based on individual and personalized criteria.
  - o Is the funding based on personalized criteria?
  - o Is the funding based on an individual needs assessment?
  - o Is the funding based on individual life circumstances?
  - o Do individualized services result in reduced budget or higher personal payment for assistance?



- According to the GC the funding should be allocated and controlled by the person with disability. Do you think the Swedish system fulfills this criterion?
  - Is the funding controlled by the person with disability?
  - Is the funding allocated to the person with disability?
- The GC claims that the funding should be purposed to pay for any assistance required. Is the amount of allowance sufficient to pay for the assistance required?
  - Does the funding take into account human rights standards for decent employment?
  - Is the funding purposed to pay for any assistance required? Does it achieve this purpose or do you have to pay the rest by yourself?

### **2.2 Service controlled by the person with disability**

- According to the GC the person with disability should have different possibilities to organize the assistance, for example the possibility to choose from a variety of providers or to act as an employer. Is this true for Sweden?
  - Is there the possibility to contract the service from a variety of providers?
  - Is there the possibility to act as an employer?
- The assistance user should be able to decide by whom, how, when, where and in what way the service is delivered and he or she should also have the possibility to direct his or her personal assistants. How would you evaluate this criterion?
  - Is there the option to custom-design the service: decide by whom, how, when, where and in what way the service is delivered?
  - Is there the possibility to instruct and direct service providers (personal assistant)?

### **2.3 One-to-one relationship**

- The GC defines Personal Assistance as a one-to-one relationship, which means that assistants do not have to be shared and that they can be recruited, trained and supervised by the assistance user. Does Sweden fulfill this criterion in your opinion?
  - Can personal assistants be recruited, trained and supervised by the person with disability?
  - Must personal assistants be shared without full and free consent by the person with disability?

## **2.4 Self-management of service delivery**

- According to the GC assistance user should be able to freely choose their degree of personal control over the service delivery and still remain in the center of the decisions. In which extent do you think Sweden fulfills this criterion?
  - o Can persons with disability freely choose their degree of personal control over the service delivery according to their life circumstances and preferences?
  - o Does the person with disability always remain at the center of the decisions concerning the assistance even if the responsibility of the employer is contracted out?
  - o Is the person with disability enquired about and respected upon individual preferences?
  - o Can the personal assistance be controlled through supported decision-making?

## **3. Concluding questions**

- Which good aspects do you recognize and which aspects do you criticize most in the Swedish system of personal assistance?
- Are there further arguments or points of view, which you would like to bring up in this interview?

## **4. Conclusion**

- Thanks and goodbye

## II. Coding Guide

Category	Definition	Key Example	Coding Rule
<b>1. Funding for personal assistance</b>			
1.1 The funding is “provided on basis of personalized criteria”	The amount of allowance for personal assistance depends only on facts, which are constituted in the individual person.	<b>G2 403-407</b> Das kommt, wie gesagt, auch auf die Gegend an, wo man lebt. Also ich sage jetzt mal vom Bedarf her, in München bekomme ich 24 Stunden und wenn ich jetzt in Augsburg wohne, das sind ungefähr 60 km weiter weg oder 50, da kriege ich keine 24 Stunden mehr. Ja weil die Behörde oder weil die Kommune einfach nicht so viel Geld hat und das einfach nicht zulässt von vorne rein.	Only comments on how the funding is based on personalized criteria
1.2 The funding takes “into account human rights standards for decent employment”	The amount of allowance for personal assistance is sufficient to pay the assistants a decent salary. A decent salary is at least the minimum wage plus insurances.	<b>S1 9-14</b> So, I mean it covers... the funding will cover first to pay the salary and the salary increases if it's hours used the evening or hours used on the weekend or hours at Christmas are more expensive than an hour on a Monday or Tuesday. So this has to cover that, has to cover vacation, has to cover insurances and the normal costs that you have around the profession what it should cost.	Only comments on the sufficiency of the funding to pay the assistants

1.3 The funding is “controlled by [...] the person with disability”	The assistance user has the control over the funding and decides how it is spent.	<b>S3 135-137</b> Yeah, and I'm not allowed to take the money and do what I want with it. I must use it for assistance. So everything, every "krona" has to go to "assistans". And that's correct. Very good.	Only comments on the control over the funding
1.4 The funding is “allocated to the person with disability”	The personal assistance allowance is a direct payment, which is allocated to the assistance user, e.g. on his or her bank account.	<b>G3 124-128</b> Genau. Also wer ein Persönliches Budget beantragt, bekommt das auf ein extra Konto, was auf den eigenen Namen läuft, überwiesen und dann muss man da natürlich Verwendungsnachweise einreichen. Also wir haben das nicht frei zur Verfügung und können dann mit der Summe handhaben, sondern es muss schon nachgewiesen werden.	Only comments on the allocation of the funding
1.5 The funding has “the purpose of paying for any assistance required”	The amount of allowance for personal assistance is sufficient to pay for any assistance required, which includes all aspects of life and no contribution from the assistance user.	<b>G3 141-143</b> Naja, also wenn ich jetzt aus meiner Perspektive ausgehe, ich habe einen 24 Stunden Assistenzbedarf und die 24 Stunden bekomme ich auch also genehmigt und meine Assistenten auch bezahlt, also ja, ist gedeckelt, alles in Ordnung.	Only comments on the sufficiency of the funding to pay for the assistance

1.6 The funding “is based on an individual needs assessment”	The amount of allowance for personal assistance is based on the individual needs of the assistance user, which are assessed in an individual needs assessment.	<b>G3 10-16</b> Ja. Also wir haben in Deutschland auf jeden Fall auch gerade ab diesem Jahr mit den ganzen Teilhabeplänen und so weiter eine individuell, also es wird individuell geguckt, welchen Bedarf hat der Mensch mit Behinderung, der ein Persönliches Budget beantragt. Und das kann von einer Stunde täglich bis zu 24 Stunden pro Tag sein und danach richtet sich natürlich dann auch die Summe, die wir bekommen. Wobei die Summe für eine Assistenzstunde genauso hoch ist, also der Bruttolohn sozusagen, wie für 24 Stunden für die Assistenten.	Only comments on the needs assessment
1.7 The funding is based on “the individual life circumstances”	The amount of allowance for personal assistance takes into account the individual life circumstances, like social roles or changing capacities.	<b>S1 42-44</b> I mean I'm not going to get more money than somebody else who just lives in Sweden and doesn't travel. They're not going to give me more because I travel internationally. It's based on the hours of assistance I need and that's what it's going to give that amount.	Only comments on how the funding is based on the individual life circumstances
1.8 “Individualized services must not result in reduced budget or higher personal payment for assistance”	The assistance user does not get less money and does not have to pay more by him or herself because he or she uses personal assistance.	<b>G3 100-102</b> Naja, also da wir ja davon ausgehen müssen, dass das Persönliche Budget keine Extraleistung ist, sondern das Persönliche Budget einfach nur eine Form ist Leistungen in Anspruch zu nehmen, darf es natürlich nicht niedriger sein von der Logik her.	Only comments on the amount of funding in relation to other services

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## 2. Service controlled by the person with disability

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2.1 The person with disability can “contract the service from a variety of providers”	The assistance user can obtain personal assistance from different providers and there is variety of service providers, which one can choose from.	<b>G3 192-197</b> Also es gibt natürlich Region auch wieder in Deutschland, wo es gar keine Assistenzdienste gibt, wo die Menschen natürlich dann schon eher überlegen Arbeitgeber zu werden, um überhaupt selbstbestimmt leben zu können, aber da gibt es, Gott sei Dank, ja auch die Möglichkeit sich von gemeinnützigen Vereinen ein bisschen unterstützen zu lassen, so wie wir das ja bei [Name Organisation] auch teilweise machen.	Only comments on the possibility to buy services and the availability of providers.
2.2 The person with disability can “act as an employer”	The assistance user can choose to be an employer and employ his or her own personal assistants.	<b>G3 190-192</b> Ja! Definitiv. Also wir sind da sehr frei, ob wir jetzt Arbeitgeberinnen werden oder halt einen Dienst wählen, das kann man wirklich individuell für sich überlegen und gestalten, also einfach was für einen auch besser passt.	Only comments on the possibility to act as an employer
2.3 “Persons with disabilities have the option to custom-design their own service [...]: decide by whom, how, when, where and in what way the service is delivered”	The assistance user decides how the service is designed: the assisting person, the place, the time and the way the service is delivered.	<b>S1 100-103</b> Where with personal assistance you can control who's coming when, where they coming, are you going to get the service in the home or outside of the home, are you going to and how, what time of the day you want to clean your house.	Only comments on the possibility to custom design the service

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2.4 The person with disability can “instruct and direct service providers”	The assistance user can instruct and direct the provider by deciding how the service is designed and the personal assistant as the practical provider of personal assistance.	<b>G1 535-544</b> Es ist natürlich bei Leistungserbringern und Diensten nicht juristisch so machbar. Es gibt zwar Verträge dann durchaus, das nennt sich..., also die Pflegeversicherung nennt das Pflegeverträge. Manche ambulante Dienste nennen das Assistenzverträge. Da kann man solche Sachen dann auch reinschreiben: die behinderte Person ist verantwortlich für die Personalsuche und sucht es selbst aus, ne. Es muss dann immer noch juristisch der Organisation vorgeschlagen werden dieses Personal und die Organisation..., mittlerweile muss sie sogar polizeiliche Führungszeugnis einholen, kann dann immer noch entscheiden, ob sie diese Person wirklich beschäftigen will oder nicht, ne. Also das wird sehr selten praktiziert und ehrlich in Reinstform habe ich das noch nie so richtig gesehen, dass es so läuft.	Only comments on the possibility to instruct and direct service providers
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### 3. One-to-one relationship

3.1 “Personal assistants must be recruited, trained and supervised by the person granted personal assistance”	The assistance user recruits, trains and supervises the personal assistants.	<b>G3 288-292</b> Möglich. Ja. Also im Arbeitgebermodell ist es natürlich logisch, dass wir nur die Leute anstellen, anlernen und so weiter und so fort. Bei Assistenzdiensten in Deutschland, es ist zum Teil möglich, dass die Leute sich das aussuchen können und die Anleitung machen, aber ich behaupte und ich weiß es eigentlich auch, dass es nicht bei allen möglich ist.	Only comments on the possibility to recruit, train and supervise personal assistants
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3.2 “Personal assistants should not be ‘shared’ without the full and free consent of the person granted personal assistance”	A personal assistant assists only one person at the same time.	<b>G3 251-254</b> Also im Arbeitgebermodell natürlich, weil da bin ich die Arbeitgeberin, ich habe meine Assistentinnen und Assistenten, die bei mir arbeiten und in der Zeit können die ja gar nicht woanders arbeiten und wenn sie noch einen anderen Job annehmen, müssen sie natürlich mich als Arbeitgeberin fragen. Also da ist es gegeben.	Only comments on the probability of sharing assistants
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#### 4. Self-management of service delivery

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4.1 The assistance user “can freely choose their degree of personal control over service delivery according to their life circumstances and preferences”	The assistance user can choose how much control he or she wants to have over the service delivery and can decide to have more or less control depending on the life circumstances and preferences by changing the model or transferring tasks to the provider or the assistants.	<b>S3 327-333</b> I heard different solutions. That company can help you with assistants and you don't need to choose, they serve you with assistants. But the law says that you should choose. But, I mean everyone is not capable of choosing. [...] Because they are kids or you got brain damage or whatever.	Only comments on the possibility to choose the degree of personal control over the service delivery
4.2 “Even if the responsibilities of ‘the employer’ are contracted out, the person with disability always remains at the center of the decisions concerning the assistance”	The assistance user takes all decisions concerning the service delivery even if he or she is not the employer of the assistants.	<b>S3 242-243</b> Yeah, they have some kind of arrangement there that the user is employer but just in words. So, I mean the real employer is the company.	Only comments on the control over the service delivery if the assistance user is not the employer of the assistants

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<p>4.3 The assistance user “must be enquired about and respected upon individual preferences”</p>	<p>The individual preferences of the assistance user must be enquired and respected by the assistants.</p>	<p><b>G2 321-324</b> Ich meine es gibt auch so Leute, habe ich auch in einem Team, die irgendwie meinen, sie wissen alles besser was für mich gut ist. Und das führt natürlich dann zu Konflikten, das will ja keiner von uns.</p>	<p>Only comments on the enquiry and respect of the assistance users preferences</p>
<p>4.4 “The control of personal assistance can be through supported decision-making”</p>	<p>The assistance user can control personal assistance through supported decision-making. The disabled person can choose one or several persons who support him or her in taking decisions. The disabled person participates actively in the decision making process and is supported by the realization of his or her will.</p>	<p><b>S1 394-397</b> Which in Sweden we have [supported decision making]. We usually use what we call the JAG model is an example where people with multiple disabilities who can't take their own decisions maybe don't even have a communication possibility are still having personal assistance and living in their own apartment. And it's through a what they call a guarantee person.</p>	<p>Only comments on the control of personal assistance through supported decision-making</p>



## **Declaration of Authorship**

I hereby declare that the thesis submitted is my own unaided work. I have not used sources other than the ones indicated (including electronic and online sources). All direct and indirect sources used are acknowledged clearly as references. I have not applied any structures of other sources directly or analogously. I am aware that an attempt to deceive will result in failing the exam. Furthermore, I know that in the case of multiple or severe attempts to deceive, I can be excluded from exams and expelled from university.

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Selina Griesser