



**“You really need to hold back, you
are only the surrogate eye.”
Personal assistance in Austria**

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About ETHOS

ETHOS - Towards a European Theory Of Justice and fairness is a European Commission Horizon 2020 research project that seeks to provide building blocks for the development of an empirically informed European theory of justice and fairness. The project seeks to do so by:

- a) refining and deepening knowledge on the European foundations of justice - both historically based and contemporarily envisaged;
- b) enhancing awareness of mechanisms that impede the realisation of justice ideals as they are lived in contemporary Europe;
- c) advancing the understanding of the process of drawing and re-drawing of the boundaries of justice (fault lines); and
- d) providing guidance to politicians, policy makers, activists and other stakeholders on how to design and implement policies to reverse inequalities and prevent injustice.

ETHOS does not only understand justice as an abstract moral ideal that is universal and worth striving for but also as a re-enacted and re-constructed 'lived' experience. This experience is embedded in legal, political, moral, social, economic and cultural institutions that claim to be geared toward giving members of society their due.

In the ETHOS project, justice is studied as an interdependent relationship between the ideal of justice and its manifestation – as set out in the complex institutions of contemporary European societies. The relationship between the normative and practical, the formal and informal, is acknowledged and critically assessed through a multi-disciplinary approach.

To enhance the formulation of an empirically based theory of justice and fairness, ETHOS will explore the normative (ideal) underpinnings of justice and its practical realisation in four heuristically defined domains of justice - social justice, economic justice, political justice, and civil and symbolic justice. These domains are revealed in several spheres:

- a) philosophical and political tradition;
- b) legal framework;
- c) daily (bureaucratic) practice;
- d) current public debates; and
- e) the accounts of vulnerable populations in six European countries (Austria, Hungary, the Netherlands, Portugal, Turkey and the UK).

The question of drawing boundaries and redrawing the fault-lines of justice permeates the entire investigation.

Utrecht University in the Netherlands coordinates the project, and works together with five other research institutions. These are based in Austria (European Training and Research Centre for Human Rights and Democracy), Hungary (Central European University), Portugal (Centre for Social Studies), Turkey (Boğaziçi University), and the UK (University of Bristol). The research project lasts from January 2017 to December 2019.

EXECUTIVE SUMMARY

Work package 5 is concerned with justice as lived experience. It examines the subjective experiences of those vulnerable to injustice in three spheres of justice: political, economic and social, and has a particular focus on people's lived experiences as vulnerable categories in the welfare state such as disabled adults and care workers. We are interested in the conflicts, tensions and contradictions between different justice claims of vulnerable groups and how these are negotiated in day to day situations. D5.3 explores the accommodation of justice claims in the lives of adult physically disabled care users and people who are paid to provide care in private households. We are interested in everyday practices of recognition and redistribution and how daily conflicts of justice claims are understood and managed (or not). Analysis will draw on a capability approach, considering people's capacity to achieve the kinds of lives that they value, and the achievements themselves.

In Austria, adult physically disabled people do not use care, but paid personal assistance. The concept of personal assistance follows the capability approach. Personal assistance is assistance in self-care and not care. Thus, the mini-ethnography for the Austrian case study was carried out in the private households of users of personal assistance. Thereby, a researcher was present during service hours, observed the service encounters without interfering or participating and took notes. Some occasional questions were asked. The visits and the notes were based on an analytical grid containing all aspects to be observed during the visits. Interviews with the observed users and providers of personal assistance supplement the data on justice claims, conflicts and negotiations.

Findings highlight the justice claims, negotiations, conflicts and tools for the case of personal assistance in Styria (AT). Personal assistance in self-care is an important distinction from care. Users of personal assistance define the kind and amount of services needed and they define how they are to be carried out. Service users receive a personal budget to hire, instruct and pay personal assistants. Findings indicate that the concept and practice of personal assistance basically facilitate a self-determined life for people with physical/sensory disabilities. Personal assistance is basically in line with their justice claims, because people with disabilities themselves select the assistants, employ and hire them, decide what they will do and how they will do it and – last but not least – pay them. Conflicts are due to misunderstandings regarding tasks and the way they are performed. Furthermore, conflicts are due to incompatible flexibility requirements between user and provider. Finally, conflicts are due to inconsistent roles and role conflicts. Relevant tools to deal with conflicts and negotiation are: written rules, clear and consistent roles (employer, assistant), leadership competence and giving feedback.

The findings have the following policy implications. Personal assistance is usually paid with service vouchers. The model of service vouchers provides assistants with insurance against work accidents, but not against sickness, unemployment and pension. Personal assistants are not entitled to paid vacation. Personal assistants are denied the general means of worker protection. At the same time, personal assistance has central features of employment, assistants are bound by instructions, to a very large extent not free to decide on working times, they do not use their own tools. Thus, there is a contradiction between employment and self-employment in personal assistance. Another policy implication is related to the allocation of service hours and the assessment. The process of allocation is not transparent for beneficiaries. Social workers and carers for people with disabilities assign these hours. But personal assistance is not care.

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1. INTRODUCTION

The case study at hand has a clear focus on personal assistance for people with physical/sensory disabilities. Unlike care services, which are available for people with mental or psycho-gerontological illnesses or children, personal assistance has been designed specifically for people with physical or sensory disabilities. Personal assistance is designed to assist people in living their self-determined life. Thereby the service user defines the kind and amount of services and selects the assistant. Thus, it is an important instrument to achieve independence for people with disabilities.

Personal assistance is significantly different to “care”, as it aims at facilitating a *self-determined* life. The competence herein lies with the persons with disabilities, who are the contractors, i.e. employers. The person with disability freely chooses the personal assistant and decides on a timetable. Personal assistants usually do not have any formal qualifications as is usually the case for professional care workers. Personal assistance is conceptualised as laymen-work without required qualifications. The instruction competence is with the service user, who instructs and trains the assistant. Service users are competent when it comes to assessing their own needs, the person who should cater for these needs (staff competence/management and organisation competence), in what manner (instruction competence) and in which space (spatial competence).

The state provides the money for “personal assistance” directly to the affected persons (i.e. it equips them with a “personal budget”) to finance the services they need (financial competence).

1.1. NATIONAL CONTEXT

The national action plan on disability states that “in the area of housing a wide-ranging programme of de-institutionalisation in all provinces is necessary.” Large institutions have to be reduced and aid for persons with high care needs have to be provided to facilitate their independent living.¹

The rights of persons with disabilities mainly lie within the competences of the nine Austrian provinces. Only the care allowance is a federal competence. The personal budget and the personal assistance are also in provincial competence. Structural parameters (personnel key, size of institutions, equipment), quality assurance, availability of services and costs and tariffs are within provincial competence too. The personal budget and assistance are differently implemented in the provinces or not at all implemented in some provinces. The provinces declared to work towards greater harmonisation of services and quality thereof if they are cost-neutral. Services are granted for each province separately. Main residence in the province of application is the requirement for almost all support services. If a person wishes to move to another province the entitlement remains unaffected but the question of carriage of costs has to be clarified in advance, since different authorities are in charge then. If a person moves within a province, no new application is needed.

¹ Austria, *Nationaler Aktionsplan Behinderung 2012-2020*, available at: https://www.sozialministerium.at/site/Service_Medien/Infomaterial/Downloads/Nationaler_Aktionsplan_Behinderung_2012_2020, p. 86.

Generally speaking, there are no legal restrictions for persons with disabilities to choose where and with whom they live. In practice however persons with severe physical disabilities and those with learning disabilities do not have a chance to decide freely where and with whom they live. Particularly in case of lacking financial support, accommodation in care homes is often the only possibility.

In its care provision report 2016 (*Pflegevorsorgebericht 2016*) the Federal Ministry for Labour, Social Affairs and Consumer Protection stated that the provinces altogether received 349.931.620,00€ through the Care Funds (*Pflegefonds*). The Care Funds support community based services, such as mobile care, stationary care, short-term care, case- and care management, alternative housing forms, quality assurance measures and innovative projects. 52,5% of care allowance receivers are taken care of by relatives, 25% receive care through mobile services, 5% receive care by 24 hours carers and 17,5% are taken care of in care home (Rudda et al 2008).²

The subject of the present ethnography is people with physical and sensory disabilities. Thus, the following explanations on the legal and policy framework will focus on benefits for people with physical and sensory disabilities. Furthermore, due to the different legal provisions at provincial level, the focus will lie on the geographical region of Styria as the ethnography is carried out there.

1.1.1. LEGAL AND POLICY FRAMEWORK ON BENEFITS FOR PERSONS WITH DISABILITIES

The care allowance is the core of the benefits for people with disabilities. It is a universal monetary beneficiary for persons depending on their care needs. The care needs are assessed individually by a doctor and a nurse and the money is provided independently from property and income. In addition, the province of Styria offers personal budget to persons with physical disabilities or disabilities of the senses. The personal budget puts them in a position to hire personal assistants, who assist them in their daily life. Additionally, some “in-kind” contributions are in place. These are mainly mobile care services, which are organised and offered by agencies. Agencies are NGOs commissioned by the provinces for providing these services. Furthermore, 24 hours care workers provide live-in care services to persons with severe physical disabilities or the elderly. They are mostly self-employed and migrants. Inpatient services consist of daycare centres and care homes, but these services are off topic here.

The care allowance and the personal budget are the core benefits for persons with physical and sensory disabilities. The governmental competence for personal assistance lies at provincial level. Thus, personal assistance is not implemented similarly in all Austrian provinces. Furthermore, rules and funding for this assistance varies from province to province.

² FORBA (2017), *Erwerbstätige pflegende Angehörige in Österreich: Herausforderungen im Alltag und für die Politik*, available at: https://www.forba.at/wp-content/uploads/2018/11/1234-FB_01_2017.pdf, p. 6.

1.1.2. CARE ALLOWANCE

In 1991, Austria introduced the care allowance (*Pflegegeld*)³ aiming to bring people in care needs into a position to organise and pay for the care services they need. Persons with permanent care needs of at least 65 hours per month, which are due to disabilities and which are expected to entail care needs for at least six months, are entitled to care allowance. Permanent residence in Austria is another requirement for the care allowance.

The concrete amount of care allowance is determined by a medical examination and it is granted in six levels, depending on care needs. The amounts of care allowance are €157,30 monthly payment from lowest level 1 (care needs for more than 65 hours a month) to €1.688,90 for the highest level 7. Care needs in level 7 are more than 180 hours, where the person is bedridden or has similar impairments.⁴

The care allowance is paid directly to the care receiver or their guardian in case of mental disabilities. The care allowance can be used to pay family members, professional care services or laymen carers. Quality checks of private care settings are foreseen in the form of random and unannounced visits in care receivers' households. However, evidence shows that these house visits are only carried out in case abuse is reported by family members, neighbours or others. In December 2016, 450.967 persons received the care allowance: 116.970 in level 1, 110.103 level 2, 80.673 level 3, 64.766 level 4, 49.230 level 5, 19.778 level 6 and 9.447 level 7. In December 2015, 451.753 persons received care allowance (*Pflegegeld*), almost 2/3 female.

1.1.3. PERSONAL BUDGET

Personal budget was introduced in Austria following the ratification of the UN Disability Convention. Personal budget is money for persons with mainly physical or sensory disabilities, paid out in addition to the care allowance. Personal budget is paid for tasks which are not covered by the care allowance, for instance leisure time assistance. Inclusion and maximal self-determination of the lives of persons with disabilities are meant to be achieved through the personal budget, which is used for personal assistance and exists in 5 out of 9 Provinces. Personal budget in Styria can be applied for by:⁵ Persons with sensory impairment or considerable impairment of movement and Austrian or EEA citizenship or residence permit whose main residence is in Styria, the persons need help for certain or all tasks of their daily life. Personal budget is granted as a yearly allotment of hours with the maximum amount of 1600 hours and payments of €25,51 per hour. The personal budget is paid four times per year in

³ Austria, *Bundesgesetz, mit dem ein Pflegegeld eingeführt wird* (Bundespflegegeldgesetz — BPGG), available at: <https://www.ris.bka.gv.at/GeltendeFassung.wxe?Abfrage=Bundesnormen&Gesetzesnummer=10008859>.

⁴ Austria, Federal Ministry for Labour, Social Affairs, Health and Consumer Protection (*Bundesministerium für Arbeit, Soziales, Gesundheit und Konsumentenschutz, BMAŠK*), *Pflegegeld*, available at: https://www.sozialministerium.at/site/Pension_Pflege/Pflege_und_Betreuung/Hilfe_Finanzielle_Unterstuetzung/Pflegegeld/#intertitle-1.

⁵ Austria, Province of Styria, Styrian Disability Act, Art. 22a (*Steiermärkisches Behindertengesetz*), available at: <https://www.ris.bka.gv.at/GeltendeFassung.wxe?Abfrage=LrStmk&Gesetzesnummer=20000434>.

advance.⁶ It can be used for services in household, personal hygiene, keeping up health and mobility, communication and leisure time. Persons with disabilities decide freely whom to take for personal assistance and how much to pay for it. Relatives living together with the person cannot be taken as personal assistants in Styria due to the subsidiary principle. The subsidiary principle means that the state provides services and payments subsidiary to the capacities of families. Thus, unpaid family care must be used before state services are provided.

An application for personal budget has to be filed at the municipality of residence. Based on this, a clearing talk at the local authority takes place and the amount of needs for personal assistance is assessed by a group of experts. The personal budget is either paid directly to the service user or to the agency in charge of the placement of personal assistants.

Personal assistants are mostly employed as freelancers (*Freie Dienstnehmer*), paid per hours and without holiday pay, sick leave or Christmas bonus.⁷ In case an agency is involved, they recruit the assistants, guide the services, coordinate care services if relevant and are contact points for users and providers of personal assistance. Furthermore, it intermediates in case of conflicts. The Upper Austrian agency “Persönliche Assistenz GmbH” also has implemented a workers council for assistants.⁸

Persons with disabilities initiated the ‘independent living movement’ to defend themselves against professionals who talk over them and in this way define their lives. The service “personal assistance” derives from this movement (see Breitfuß 2012, 4). Personal assistance is significantly different to “care” as it facilitates a self-determined life. Competence is with the person with disabilities, who is the contractor, i.e. employer. Personal assistants usually do not have any formal qualifications, such as professional care workers. This is because it is assumed that the user of personal assistance themselves know best what services they need.

Based on scientific work and the independent living movement, a concept of competencies of users of personal assistance has been developed. The following competencies are drawn out there:

- *Staff competence*: users of personal assistance choose their staff, the size of the team of assistants and it is their responsibility to hire and dismiss staff. However, this can also be carried out by an agency.
- *Instruction competence*: users of personal assistance instruct their assistants for the services needed and define the amount and explain the kind of support and also how it has to be carried out.
- *Management/organization competence*: service users develop duty rosters of their assistants and they are team leaders.

⁶ Austria, Province of Styria, Personal Budget (*Persönliches Budget*), available at: <http://www.soziales.steiermark.at/cms/beitrag/11843358/439/>.

⁷Persönliche Assistenz GmbH, *Dienstverhältnisse*, available at: <https://www.persoeliche-assistenz.at/dienstverhaeltnis.html>.

⁸ Persönliche Assistenz GmbH (2012), *Persönliche Assistenz, Broschüre*, available at: <https://www.persoeliche-assistenz.at/downloads.html>, p. 5.

- *Space and place competence*: users of personal assistance define the place of service.
- *Financial competence*: provincial funding is paid directly to service users (and not assistants). However, there are also different ways of dealing with this, they can also be paid to the assistants and then an agency is involved. This agency then receives the funds and pays the assistants, whereby the care users do not.⁹

The following table points out the roles and requirements on service users.¹⁰

TABLE 1: Roles and requirements on service users

Personal capacities	Qualification / characteristics	Knowledge
Self-consciousness	Leadership	Search strategies
Engagement in self-representation	Guidance and instructions	Legal framework of working contracts
Patience	Organisation	Financing

There are no formal qualification requirements for personal assistants. The assistant needs to be clear that the employer has the only instruction competence. This means that the assistant is strongly bound by instructions and the service user decides on what to do and when.¹¹ Thus, clear rules in the working contract in terms of tasks to be performed as well as communication get a strong relevance. They act as backup in case of conflicts resulting from different points of view on tasks, responsibilities and self-determination. Table 2 provides an overview on the requirements on personal assistants.¹²

⁹ Persönliche Assistenz GmbH, Persönliche Assistenz, Broschüre (Linz 2012) available at: <https://www.persoeliche-assistenz.at/downloads.html>, p. 5.

¹⁰ Esterer Theresa, *Nähe und Distanz in der Persönlichen Assistenz*, Diploma Thesis, University Vienna, Department for Pedagogics (Vienna 2012), p. 23, available at: <https://core.ac.uk/download/pdf/16427833.pdf>.

¹¹ Esterer Theresa, *Nähe und Distanz in der Persönlichen Assistenz*, Diploma Thesis, University Vienna, Department for Pedagogics (Vienna 2012), p. 24, available at: <https://core.ac.uk/download/pdf/16427833.pdf>.

¹² Esterer Theresa, *Nähe und Distanz in der Persönlichen Assistenz*, Diploma Thesis, University Vienna, Department for Pedagogics (Vienna 2012), p. 26, available at: <https://core.ac.uk/download/pdf/16427833.pdf>.

TABLE 2: Roles and requirements on personal assistants

Personal characteristics	Qualifications	Knowledge
Ability to listen, regard	Physical capacities	Drivers licence
Tolerance towards existing differences	Being on time	Basic knowledge in housework
Ability to keep themselves in background	Reliability	Knowledge in dealing with wheel chairs and other tools for persons with disabilities
Serenity	Ability to deal with conflicts	Basic knowledge in care
Responsibility	Respect, loyalty	Basic knowledge related to certain disabilities (i.e. disabilities of the senses)
Security in actions	Openness, honesty	Knowledge in sign language
No fear of physical contact	Adaptability	
Respect of privacy	Knowing one's emotional and physical limits	
Ability to separate between friendship and work	Being aware on the own motives to take this work	
Acceptance of people with disabilities as employers	Flexibility	

According to Rehfeld, the challenge of personal assistance is dealing with conflicting requirements. The personal assistant is required to be the substitute of a disabled body part (e.g. the eyes, the legs of the care user), which somehow demands a neglect of the assistant's personality. At the same time, the assistant should remain authentic and empathic in service provision.¹³ Research shows that such conflicting requirements are a main source of conflicts in service encounters.¹⁴

¹³ Rehfeld Silke, *Das Spektrum von Persönlicher Assistenz*. In: Mobile – Selbstbestimmt Leben Behinderter e.V. Zentrum für selbstbestimmtes Leben Köln (Eds.): *Handbuch Selbstbestimmt Leben mit persönlicher Assistenz. Ein Schulungskonzept für persönliche AssistentInnen*, Band B. (AG Spak Dortmund 2001), p. 58ff.

¹⁴ Koch Marita, *Untersuchungen über eine Qualifikation zum Assistenten für Menschen mit Behinderung* (Volkshochschule Köln 1995), p. 24.

1.1.4. SERVICE VOUCHER

The service voucher enables the payment of simple services in private households (e.g. cleaning, gardening, baby sitting). The assistants are accident-insured, but not insured against sickness, pension or unemployment. Prorated special bonus payments are included into the hourly wages. The service voucher applies to short-term working contracts of one month at maximum. The same persons may be contracted repeatedly. The monthly income must not exceed the amount of € 600,07 in 2018. The process with service vouchers works as follows. The assistant and service users have to register at the public insurance company. The service user buys the service voucher either online or at the tobacco or postal service shop. The service user has to pay a 2% tax on the voucher-value because of administrative costs and the share for the accident insurance. Then the service takes place. Afterwards, the service user and the assistant fill in the service voucher. Then, the service user gives the voucher to the assistant, who submits it to the pension insurance company – either online, by post or in person. Service vouchers have to be submitted after service provision and at the latest by the end of the following month. Then the service users receive the money into their bank accounts.¹⁵

1.2. LITERATURE REVIEW

There are several scientific contributions on personal assistance in the German speaking area, based on conceptual as well as empirical studies. Conceptual studies deal with the concept of personal assistance in opposition to care and ask which aspects of personal assistance enable a self-determined life.¹⁶ Empirical studies address a certain group of service users, i.e. women with disabilities or people with mental disabilities.¹⁷ Other empirical studies compare the situation in Austria with other countries, e.g. Germany and Sweden.¹⁸ However, the majority of empirical contributions put the relationship between service user and assistant at the centre of analysis. These studies explore conflicts, expectations, satisfaction, social roles, proximity and distance and interactions.¹⁹

¹⁵ Austria, Austrian Government, Government agency help site, Service Vouchers, available at: <https://www.help.gv.at/Portal.Node/hlpd/public/content/207/Seite.2070004.html>.

¹⁶ Rehfeld Silke, *Das Spektrum von Persönlicher Assistenz*. In: Mobile – Selbstbestimmt Leben Behinderter e.V. Zentrum für selbstbestimmtes Leben Köln (Eds.): *Handbuch Selbstbestimmt Leben mit persönlicher Assistenz. Ein Schulungskonzept für persönliche AssistentInnen*, Band B. (AG Spak Dortmund 2001), see also Müller Conny, *Persönliche Assistenz. Kompendium von der Praxis für die Praxis* (Diplomica Hamburg 2011).

¹⁷ Franz Alexandra, *Selbstbestimmt Leben mit persönlicher Assistenz. Eine alternative Lebensform behinderter Frauen* (AG Spak Dortmund 2002).

¹⁸ Thaller Tina, *Persönliche Assistenz in Österreich, Deutschland und Schweden. Für Menschen mit intellektueller, körperlicher, psychischer Beeinträchtigung oder Sinnesbehinderung in Österreich* (Dr. Müller Saarbrücken 2010).

¹⁹ Thielking Verena, *Persönliche Assistenz bei körperlich behinderten Menschen im Modell der 24-Stunden Assistenz aus der Sicht der Assistenten* (Grin Verlag, Köln 2010); Esterer Theresa, *Nähe und Distanz in der Persönlichen Assistenz*, Diploma Thesis, University Vienna, Department for Pedagogics (Vienna 2012), p. 26, available at: http://othes.univie.ac.at/22945/1/2012-09-08_9626643.pdf; see also Kotsch Lakshmi, *Assistenzinteraktionen: Zur Interaktionsordnung in der persönlichen Assistenz körperbehinderter Menschen*, Doctoral Thesis (Springer VS Wiesbaden 2012); Fritzer Carina, *Persönliche Assistenz und Selbstbestimmung. Dynamiken, Konfliktfelder, Einflussfaktoren und Lösungsstrategien innerhalb von Assistenzverhältnissen – Fallstudie aus der Sicht der Sozialen Arbeit* (Dr. Müller Saarbrücken 2011); Bacher Johann et al., *Persönliche*

Furthermore, there are several diploma theses available in Austria, which deal with the issue of personal assistance. These are often written by persons who carried out personal assistance when they were students.²⁰

Findings indicate that the concept of personal assistance is related to a significant change in the perspective on care relationships in disability work: persons with disabilities turn away from the role of “the person with care needs” towards the role of a self-determined employer. They turn from a “heteronomous object to subjects of their own actions.”²¹ The crucial point of this relationship is the fact that the service user is an expert for his/her own needs. The specific concept of personal assistance marks a significant shift in the power relationship between assistant and service user. Some relevant findings of these studies on personal assistance will be discussed in this section.

1.2.1. PERSONAL CHARACTERISTICS OF SERVICE USERS AND PROVIDERS

The main reasons for using personal assistance are: self-determination (99%), independence/autonomy (96%), flexibility of working hours (95%), relieve the burden on family and friends (95%), self-determined organisation of services provided (92%) and diversity of services provided (89%).²²

97% of all service users state that they live a self-determined life, 97% highly appreciate the self-determined arrangement of services and 94% state that they know to whom to turn in case of problems or conflicts. 88% state that they highly appreciate the fact that personal assistance is provided by laymen and not by professionals of social work or care. The concept of personal assistance, developed by the independent living movement, underlies the fact that users of personal assistance

Assistenz in Oberösterreich Final Report, available at: http://www.persoelliche-assistenz.at/downloads/Persoelliche_Assistenz_Oberoesterreich.pdf accessed on 26 June 2018; and Brandstetter Helga et al. *PAZ Persönliche Assistenz Zufriedenheit*. Final Report, Johannes Kepler University, Department for Sociology, p. 18, available at: <https://www.persoelliche-assistenz.at/downloads.html>, accessed on 26 June 2018.

²⁰ Esterer Theresa, *Nähe und Distanz in der Persönlichen Assistenz*, Diploma Thesis, University Vienna, Department for Pedagogics (Vienna 2012), p. 26, available at: http://othes.univie.ac.at/22945/1/2012-09-08_9626643.pdf; Thielking Verena, *Persönliche Assistenz bei körperlich behinderten Menschen im Modell der 24-Stunden Assistenz aus der Sicht der Assistenten* (Grin Verlag, Köln 2010); Woitzik Thomas, *Der Assistent sagt >nein<. Ein unwirkliches Gedankenexperiment* In: *Orientierung* 3/2006, p. 7.

²¹ Steiner 2004, quoted in Esterer 2012, Esterer Theresa, *Nähe und Distanz in der Persönlichen Assistenz*, Diploma Thesis, University Vienna, Department for Pedagogics (Vienna 2012), p. 3, available at: http://othes.univie.ac.at/22945/1/2012-09-08_9626643.pdf.

²² Esterer 2012, Esterer Theresa, *Nähe und Distanz in der Persönlichen Assistenz*, Diploma Thesis, University Vienna, Department for Pedagogics (Vienna 2012), p. 30, available at: http://othes.univie.ac.at/22945/1/2012-09-08_9626643.pdf.

are experts for themselves and do not need professionals. The layman character of personal assistance conceptually underlies the self-determination of service users.²³

Findings on the characteristics of assistants show that their main motives for service provision are: working in the social area (99%), helping other people (98%), flexibility of working hours (96%), additional income (87%), reconciliation of work and family (86%), no qualification/training needed (73%).²⁴

The majority of personal assistants interviewed work under a free service contract for one service user. Assistants name the same preconditions for a successful work relationship as service users. Assistants rate service users' level of self-determination lower than service users themselves: 97% of service users state that they live a self-determined life, while only 60% of assistants fully agree that their service users do so.²⁵ The main burdens for assistants are: small income due to reduced service demand, time pressure due to reduced service hours funded, heavy physical work, burdens resulting from the personal situation of the service user and short-notice cancellation of arranged service hours.²⁶ The insecure life situation of personal assistants is another negative factor of this work. Half of respondents perceive the reputation of personal assistance as good.²⁷

The survey shows that the main sources of conflict are related to tensions between autonomy and organisation. The lay character of these services may facilitate an open and sometimes even affective definition of roles and responsibilities. The open and unclear roles in the work relationship create risks of strong involvement and even burnout among personal assistants.²⁸ There are contradicting findings on whether the low-skilled character of assistance fosters or hinders the self-determination of service users. Some studies discuss unqualified assistance as a risk for self-determination (i.e. manipulation of service users by assistants, burnout of assistants).²⁹ Others

²³ Esterer 2012, Esterer Theresa, *Nähe und Distanz in der Persönlichen Assistenz*, Diploma Thesis, University Vienna, Department for Pedagogics (Vienna 2012), pp. 35-40, available at: http://othes.univie.ac.at/22945/1/2012-09-08_9626643.pdf.

²⁴ Esterer 2012, Esterer Theresa, *Nähe und Distanz in der Persönlichen Assistenz*, Diploma Thesis, University Vienna, Department for Pedagogics (Vienna 2012), p. 71, available at: http://othes.univie.ac.at/22945/1/2012-09-08_9626643.pdf.

²⁵ Esterer 2012, Esterer Theresa, *Nähe und Distanz in der Persönlichen Assistenz*, Diploma Thesis, University Vienna, Department for Pedagogics (Vienna 2012), p. 83, available at: http://othes.univie.ac.at/22945/1/2012-09-08_9626643.pdf.

²⁶ Esterer 2012, Esterer Theresa, *Nähe und Distanz in der Persönlichen Assistenz*, Diploma Thesis, University Vienna, Department for Pedagogics (Vienna 2012), p. 91, available at: http://othes.univie.ac.at/22945/1/2012-09-08_9626643.pdf.

²⁷ Esterer 2012, Esterer Theresa, *Nähe und Distanz in der Persönlichen Assistenz*, Diploma Thesis, University Vienna, Department for Pedagogics (Vienna 2012), p. 91, available at: http://othes.univie.ac.at/22945/1/2012-09-08_9626643.pdf.

²⁸ Rock Kerstin, *Sonderpädagogische Professionalität unter Leitidee der Selbstbestimmung* (Klinkhardt, Bad Heilbrunn 2001).

²⁹ Rock Kerstin, *Sonderpädagogische Professionalität unter Leitidee der Selbstbestimmung* (Klinkhardt, Bad Heilbrunn 2001).

perceive layman services in personal assistance as conceptually relevant to enable the self-determination of service users.³⁰

1.2.2. WORK RELATIONSHIPS

The factual realisation of a self-determined life is strongly interlinked with processes of negotiation and thus realised through interactions. Research findings indicate the following **areas of tension** when it comes to personal assistance:³¹

- closeness/proximity and distance

Encounters in service provision are per se close. Assistants accompany service users in intimate life. A distant work relationship focuses on the tasks to be performed, i.e. being the substitute of the feet and hands or eyes. Service users are clear that the reduction of service encounters/service provision to these instrumental parts is neither realistic nor desirable.³²

- Work relationship and friendship

This area of tension is related to the proximity of service provision. Service provision takes place under a working contract. However, due to the intimate and laymen service, friendship may develop or be desired. The power inequality of the employer-employee relationship stands in contradiction with the equal relation of a friendship.³³

- Dealing with conflicts

The work relationship and the tasks to be performed are closely related to the kind of disability. Service users reflect about conflicts and problematic work relationships already in the phase of recruiting. They also think about their expectations. Findings show that preliminary reflection is an important way of preventing conflicts. Persons with mental disabilities more seldom reflect about these aspects in advance. While they are able to adapt their behaviour in case of conflicts, they are less able to develop

³⁰ Steiner Gusti, *Einführung: Selbstbestimmung und Persönliche Assistenz*. In: Mobile – Selbstbestimmt Leben Behinderter e.V. Zentrum für selbstbestimmtes Leben Köln (Ed.), *Handbuch Selbstbestimmt Leben mit persönlicher Assistenz. Ein Schulungskonzept für persönliche AssistentInnen* Band B (AG Spak Dortmund 2001), pp. 25-46.

³¹ Esterer 2012, Esterer Theresa, *Nähe und Distanz in der Persönlichen Assistenz*, Diploma Thesis, University Vienna, Department for Pedagogics (Vienna 2012), p. 27ff, available at: http://othes.univie.ac.at/22945/1/2012-09-08_9626643.pdf.

³² Esterer 2012, Esterer Theresa, *Nähe und Distanz in der Persönlichen Assistenz*, Diploma Thesis, University Vienna, Department for Pedagogics (Vienna 2012), p. 80, available at: http://othes.univie.ac.at/22945/1/2012-09-08_9626643.pdf.

³³ Esterer 2012, Esterer Theresa, *Nähe und Distanz in der Persönlichen Assistenz*, Diploma Thesis, University Vienna, Department for Pedagogics (Vienna 2012), p. 33, available at: http://othes.univie.ac.at/22945/1/2012-09-08_9626643.pdf.

solutions. Research findings highlight the need for supervision in personal assistance and the establishment of clear rules.³⁴

The majority of academic research (particularly diploma theses) is pedagogics and educational sciences. Sociological approaches on personal assistance are more promising, because service users are not dealt with as “cases” like in pedagogics.³⁵

2. METHODOLOGY

The methodology underlying this research is a combination of mini-ethnographies and semi-structured interviews with users and providers of personal assistance. Service users were interviewed twice: at the beginning of the mini-ethnographies and several times after the visits. Both semi-structured interviews as well as field visits followed the guidelines developed by the project coordinators. These guidelines were translated into the national language and slightly adapted along the specific context and subject of personal assistance – which is understood in opposition to ‘care work’. Thus, personal assistance per concept implies self-determination (see section II on national context). Also the level of detail in the guidelines was adapted to the national context.

2.1. ETHICS

An application for ethical approval was requested from the University of Graz before fieldwork started. The application followed the standardised procedure implemented by the University of Graz, containing the following information: title of the research project, persons responsible, research disciplines, funding. A description of the research project, focusing on content of research, aims and objectives, interviewees, methods of recruiting and information on personal data gathered was added based on the research guidelines. Information on specific ethical issues included that there are no conflicts of interest for scientists involved and that there are neither advantages nor disadvantages for all research participants. It was clearly described that participation in the research was voluntary and could be withdrawn at any time until the report was published. The informed consent information letter and form were attached to the application. As this research project involves persons with disabilities, information was provided on how to obtain consent barrier free, i.e. reading it out and audiotaping verbal consent in the case of blind persons. Finally, information on the protection of personal data was provided. The ethics committee approved this research project within a few weeks (application submitted on 26 March, approval obtained on 19 April).

³⁴ Esterer 2012, Esterer Theresa, *Nähe und Distanz in der Persönlichen Assistenz*, Diploma Thesis, University Vienna, Department for Pedagogics (Vienna 2012), p. 79, available at: http://othes.univie.ac.at/22945/1/2012-09-08_9626643.pdf.

³⁵ Esterer 2012, Esterer Theresa, *Nähe und Distanz in der Persönlichen Assistenz*, Diploma Thesis, University Vienna, Department for Pedagogics (Vienna 2012), pp. 82-83, available at: http://othes.univie.ac.at/22945/1/2012-09-08_9626643.pdf.

2.2. ACCESS TO THE FIELD

The following strategies were applied to get access to the field. First of all we contacted individuals who published job announcements for personal assistants. This strategy proved unsuccessful. Later on, the Styrian Association “*Selbstbestimmt Leben*” was asked for support in accessing the field. This association is an umbrella organisation of users of personal assistance. It was founded in 2012 for the purpose of representing the interests of persons with disabilities, particularly in the fields of inclusion and participation in society. The main tasks of this association are representing the interests of persons with disabilities before politics, public administration and the general public and supporting people with disabilities in applying for funds and services. Furthermore, they cooperate with the province of Styria on implementing the action plan on the CRPD.³⁶

The executive board of this organisation was informed about the project, its embeddedness into the ETHOS project and Horizon 2020. Moreover they were informed about the methods of data gathering, data evaluation and data protection. The board circulated the request for participation among their members. Many users expressed their interest in participating in the survey – the readiness was significantly higher than expected. The centre for integrated studies (*Zentrum integriert Studieren*) at the University of Graz was another successful channel for recruiting cases. A member of this centre received the call for participation via the association *Selbstbestimmt Leben* and distributed it among their students. In the end, more people than needed expressed their readiness to participate in the survey. Interestingly, the majority of these persons were blind. All these persons highly valued the study and research. One blind person expressed interest in participating in the study, but did not give consent to the visits in her home. She only wanted to share her views in the framework of an interview. However, unfortunately, this person and others had to be refused. Criteria for refusal were: order of consent for participation, location (persons living in too remote areas were excluded) and heterogeneity of the sample (the aim was to include people with different kinds of disabilities and experiences with service provision).

The researchers were fully aware about the rights of care workers and people with disabilities³⁷ before going into the field. The report on law and policy on care and private households in Austria has been written prior to the fieldwork.

2.3. SAMPLE AND DATA ANALYSIS

The sample consists of four users of personal assistance and five assistants. Three service users are blind, two are fully blind and one is partly blind. The fourth service user is spastic and uses an electric wheel chair. One partly blind person and one fully blind person included in the sample live together and have three children, who are not disabled. The other two live alone. Three out of four service users

³⁶ Selbstbestimmt Leben Steiermark, available at: <https://www.sl-stmk.at/>.

³⁷ Including labour rights of professional care workers and care workers paid by cash-for-care schemes, the rights of disabled people to care, labour rights in private households and, if migration is an important source of care labour, how migrants (including au pairs in some cases) fit into this picture.

are female. All service users are aged between 25 and 35 and are employed part-time. Three out of four have obtained a University degree.

3. ETHNOGRAPHY

3.1. SERVICE RELATIONSHIPS

This section briefly discusses the central characteristics of each service relationship, drawing on needs, capabilities, circumstances and special features of each case. This is the relevant background information to understand the findings highlighted in the section on reflections and comparisons. Furthermore, this section provides information about the sample.

3.1.1. CASE 1

3.1.1.1. CAPABILITIES

The service user in case 1 is female, around 30 years old and blind from birth on. Sandra³⁸ lives alone in a barrier-free accessible apartment. She mostly spends her days at home. Sandra has a huge circle of friends and a boyfriend. She often gets visited during the evening and she likes to go out in the evening too. She currently receives unemployment benefits. She is looking for a job. She would like to work as a child carer, but faces difficulties in finding work. She traces these difficulties back to her blindness – mothers do not trust her to bring their children to her custody.

Sandra uses personal assistance, starting in 2006 with assistance in living. Her previous living assistance services applied a pedagogical approach during service provision. The staffs were pedagogues too. As Sandra is neither mentally disabled nor has a need for pedagogic support, she perceived these approaches as inappropriate. Sandra points out that she does not need a pedagogue, who recommends her not to buy alcohol or industrial food. She needs an assistant who finds the goods for her in the supermarket and does not comment on what she buys. Thus she applied for personal assistance as soon as the personal budget was implemented in Styria. Sandra's central motive to apply for personal assistance was to get away from the "paternalistic" agencies which provided the living assistance to her. She wanted to organise her assistance for herself and independently from an organisation. Selecting her staff herself is of great importance for her.

Sandra is able to orientate herself in her apartment. The apartment is accessible barrier-free and she has a strict order of her things. Every piece has its place, so she is able to find it quickly. It is important not to leave things unattended in her flat to avoid the risk of stumbling over it.

Sandra needs personal assistance for shopping, household tasks (except for cooking) and particularly for mobility. She does not need assistance with these basic physical necessities. She does the toilet for herself and also cooks for herself – she likes cooking a lot. She is able to basically clean

³⁸ All names in the case studies are pseudonyms.

up and remove her objects. She is able to put out the garbage. Separating white glass from coloured glass is the only thing she cannot do – there is no possibility to find out colours through touching.

3.1.1.2. SERVICE PROVISION

Sandra has four personal assistants, two male and two female. Three are students and one is unemployed. All personal assistants appreciate the flexibility of working hours and the possibility to earn a little additional money. The personal assistants work for her during a few months up to half a year. Three out of four assistants do not have any former experience with people with disabilities. Only one assistant used to carry out his civic service in a facility for people with disabilities.

Three are personal assistants in the narrow sense and one is mainly a household help. During the week, each assistant has his/her fixed service days in order to allow planning for both Sandra and assistants. She has personal assistance every weekday for two hours on average, depending on the concrete activities to be carried out. In case Sandra plans some activities for the weekend, she asks all personal assistants for their availability to accompany and assist her. The person who responds first will get the job. She receives personal budget from the province of Styria for 400 service hours per year, which is about eight hours per week. Sandra does not receive family care and is happy about this.

The assistants were employed as freelancers before. This entailed a lot of effort for Sandra when it comes to administering the personnel, exchanging data with the public health insurance and so on. In the meantime, she organises her assistance services via the service vouchers. Sandra greatly prefers this over the employment as freelancers, as it entails no administrative efforts. For the personal assistants it is the same as freelancing. Sandra pays 14€ per service hour and then buys vouchers for e.g. 28€ and gives them to the assistant, who works for her for 2 hours. The assistant has to be registered on the system of service vouchers and then organises the money transfer to the bank account online. Sandra pays 2 percent more than the value of the voucher to cover administrative costs. According to Sandra, this is easy for both Sandra and assistant.

Sandra overtakes the coordination of service hours. There is no need for assistants to coordinate among each other. Each assistant is aware of the others, but they do not meet each other. Each provides services separately and independently from others. In case of personnel shortages or sickness, Sandra finds substitutes. Assistants are freelancers, thus there is no duty to work. They may refuse the service hours offered, but as soon as they confirm an appointment for service hours, it is binding. All assistants in this case do not have other caring or assistance obligations.

3.1.1.3. DAILY LIFE

Sandra is able to leave the home with a white stick. She has no guide dog. She is able to cycle with a tandem-bike. However, she feels insecure when leaving the home alone. This is due to lacking orientation and the fact that the public sphere is not equally accessible for blind persons. Thus, she prefers leaving the home with assistants. Together with her assistants, she moves across the city either in a rented car or on a tandem bike. The assistant opens the car doors and she herself takes the seat. They do not use public transport. When walking, she uses the white stick and the arms of her assistant

to orientate herself. It is not difficult for the assistants to assist Sandra in mobility as long as they are mobile themselves, i.e. have driver's licence and practice and are able to cycle with tandem. Both mobility requirements are of utmost importance for Sandra.

Communication with her works like with everybody else. The only difference is the impossibility to show her something. You either need to verbally describe it for her or you need to facilitate touching (either by bringing it to her or by assisting her to reach it herself).

Sandra is able to move about the house, which is due to the fact that she is used to being blind and also used to the flat. She uses a braille line and a screen reader for communication. She also has a braille printer. During a service encounter, Sandra's post needed to be dealt with. Sandra prepared some letters at the table and the assistant searched in the whole living room for other envelopes. During this search, the assistant shows a good mood and has a lot of fun. She appears very motivated. Suddenly, she finds a plastic bag and looks what is inside. She finds a rotten apple and says: "Oh, there is a rotten apple inside, it needs to be thrown away, you will not like to eat it anymore, I think." The assistant knows exactly where to dispose of the apple; she does not need to ask. Then, she takes all envelopes and postmails and asks to Sandra: "Should we go to your office and proceed?" Assistant, Sandra and observer move to Sandra's office. Sandra sits at her desk in front of her computer, the assistant sits on the floor with the envelopes and the observer takes place on the couch. Sandra turns on the computer in order to register the mail electronically. The assistant finds an old and dirty cup of coffee. She immediately disposes it. When she comes back, she sits down on the floor again and starts reading the letters. The assistant asks Sandra if she has a separate folder for letters from the public insurance company. Sandra responds that she has already scanned this letter and the assistant may dispose of it. The assistant then tears the letter into pieces and takes the next one. She initially has a look on what it is and then starts reading again. She does not read every word, but rather summarises the content. Sandra then says that she will need to keep this letter and explains to the assistant where to store it. The assistant then says: "Ok, but I may dispose the envelope, right?" The assistant tears all disposable letters into small pieces. The next letter is a utility bill. The assistant asks Sandra if she keeps such utility bills. Sandra asks for the date and searches for the scan in her computer. The assistant then says she likes to keep these things in a printed version too. This way, she is always able to check the bills later on. Sandra then responds that she cannot check the printed version later on (because she is blind) and thus, she checks the electronic version on the computer (through the reading software). The assistant then asks Sandra how the scan works. Sandra shows it to her. The assistant informs Sandra that the letter is printed on both sides. As soon as the letter is scanned, the assistant tears them into pieces and takes the next letter. Both have a lot of fun, they laugh a lot and it becomes noticeable that they understand each other. Then, Sandra says to the assistant: now I need the folder, which is placed on the left side. The assistant finds a salary statement of Sandra and Sandra requests her to dispose of it. The next letter is a bill and Sandra requests the assistant to read out the bank account of the issuer. The assistant reads it out and Sandra enters it into her computer. The assistant makes a joke and says: you will forget to transfer the money. The whole pile of post is dealt with by the assistant reading out and Sandra entering the data into her computer. As the pile is finished, the assistant points to a registered letter and asks Sandra if she wants to proceed with it. Sandra does not appear motivated to proceed with it. She already said that she does not like this administrative work. Sandra says that they cannot go out anyway, because of the rainy weather. The assistant motivates Sandra to proceed with the mail by saying: now we have already done a lot. The next letters contain account statements and

the assistant asks Sandra if she should open the envelopes or not. Sandra requests her to open the envelopes. There is no issue with the personal data of the account statements. The assistant and Sandra proceed with the account statements. The assistant offers Sandra to buy something she initially wanted to buy, together with her boyfriend, because he has a car. Sandra refuses. The assistant finds a postcard from a holiday island, which is shaped like Holiday Island. The assistant describes the picture to Sandra and asks her if she should read out the letter. Sandra refuses but wants to hang out the postcard in the living room. Sandra stores the letters in a transparent cover, which is lettered in braille. The assistant asks Sandra to explain the device to letter transparent covers to her. Sandra explains it and the assistant thanks her for explanation. At the end of the service provision, the assistant tells Sandra that she found a midwife – she is pregnant. They talk a bit about the pregnancy and the midwife, while proceeding with the mail.

The ethnography was carried out three times during a week: day 1: 4pm to 6pm, day 2: 11am to 1pm, day three: 4pm to 6pm.

3.1.2. CASE 2

3.1.2.1. CAPABILITIES

In case 2, the service users are a family consisting of a completely blind mother (Diana), a partly blind father (Carl) and three not disabled children, aged between half a year and seven. Carl is additionally handicapped on one hand and one foot. They live together in a flat, which is accessible for them. Carl has a full-time job at the University and Diana works at the University too. Diana mainly cares for the children.

They have used assistance since 2000. As soon as the personal budget was implemented in Styria, they applied for it. Their central motive was to get away from the agencies (which provided the living assistance to her) and to organise the assistance services independently and to select the staff themselves. Their previous assistance in living also had a pedagogical approach and was carried out by pedagogues. Similarly to case one, also Diana and Carl perceived the pedagogic approach inappropriate, as they are not mentally disabled and do not need pedagogical support. Diana tells about the pedagogical services and points out that she coincidentally became aware that case conferences took place about them, without them. She is a psychologist herself and perceived this as inappropriate. Similarly to case one, in case an assistant is sick, organising an appropriate substitute was difficult. Diana says that one time during Christmas they had no services due to vacancies and sickness.

Diana and Carl are able to be unaccompanied in their apartment. Similarly to case one, every piece has its place and they adopt strategies to orient themselves in their apartment. They do not need any assistance in basic physical necessities: e.g. washing, getting in and out of bed, eating, toileting, moving about the house.

Diana and Carl need assistants for mobility, shopping, in household tasks and in childcare. However, it is important for them that the assistant does not care for the children themselves, they assist them in caring. There are no caring relatives. Diana is able to move across the city with a white

stick. Carl is able to walk around without white stick, he is partly visually impaired. Carl is unable to use one of his hands. However, he is able to move his arm.

Diana and Carl receive a personal budget of 400 service hours per year. Different from case one, their service needs are rather unpredictable. They cannot say in advance how many hours they will need per day. They pay their assistants to be on standby the whole day and to act when needed. This is a strongly needs-based service provision, whereby the assistants have to remain very flexible. They get paid for the whole stand-by services.

3.1.2.2. SERVICE PROVISION

They have seven personal assistants and each of them has one day of (stand-by) duty. The duty encompasses assisting the service users in child care, but does not encompass providing child care services. Diana and Carl put a lot of emphasis on differentiating between this. It is important for them that they themselves care for their children and not the assistants. They also pay their personal assistants via the service voucher and overtake the coordination of assistants. The assistants do not know each other well. Diana and Carl take a lot of care that the assistants do not build up relations among each other and exchange service hours. Diana and Carl rather want to have the control about who comes when. They arrange an event for all assistants once a year. They perceive this as acknowledgment of the performance of the assistants and to keep them motivated. This is part of their leadership style.

Diana and Carl draw a lot of attention to not mix up private life, friendship and personal assistance. They draw a strict line between work and private life. They adopt a rather strict leadership style and set of about 52 written rules, which they submit to all personal assistants at the beginning of every month. In case a rule is violated, the violator will receive a verbal rule-reminder. If a rule is not obeyed because it was formulated in a misleading manner, the rule will be revised and submitted to all assistants again. The set of rules is permanently updated based on experiences with the assistants. There are different types of rules:

1) rules on the style of service provision, such as:

- a) when shopping: in case the requested amount is not available, round it up
- b) in case the requested good is not available in the suggested shop, do NOT go to another shop without authorisation
- c) please avoid unrequested counselling, like "If I were you, I would"
- d) in case you come for assistance and we have visitors: please do not communicate with the visitors
- e) please only wash the dishes upon request by us.

2) rules on duties and tasks, such as:

- a) no (verbal) disciplinary measures against the children, e.g. in case you feel they are too loud

- b) no confirmation of our communication with the children, e.g. if we request [Son] to do something, please do not confirm this
- c) please only describe what you see (e.g. son eats sand) and do not comment what we will do with this information
- d) do not take private phone calls while you are working, this is permitted only in emergency cases and after pre-approval
- e) please do not derive requests for action out of our questions, e.g. if we ask where our son's shoes are, only answer the question and do not get the shoes.

3) *rules dealing with "common sense", such as:*

- a) full bags of the waste basket need to be replaced with empty ones

4) *rules motivated by legal necessity, such as:*

- b) in case you need knives for your work, never leave them but store them safely for the children
- c) in case you are on your way alone, please be available for our phone calls
- d) in case you drive the car and get a phone call, stop at the next safe place and call back. Safety first, but make sure that you hear the phone.

These rules equally apply to the services provided for Carl and Diana. Some of these rules apply more strongly to assisting Diana, while others apply more strongly to assisting Carl, but they are collected and submitted to the assistants collectively. Carl explains the success of this system:

Usually it's the case, if we send such a reminder of rules, usually the next day a mail reply comes, yes, I forgot, I will pay attention to it, or I understood the rule in the way that (...) and the person has to, we have to adjust the rule because maybe we didn't phrase it clearly, I don't know. I am not even excluding that. Just everyone then immediately knows. So that's the vital- / so it's a kind of, a, a, a, a bit (...) kind of staff management which is necessary (AT_SU_03_C2).³⁹

Diana and Carl perceive this setting up of rules as a very good working tool for the negotiation of justice claims as it provides transparency in expectations on how the work has to be carried out. Furthermore, these rules secure transparency and equal treatment of all assistants. They perceive this as particularly important because children are involved in the service encounters. The children are no direct service

³⁹ Meistens ist dann so, wenn wir so eine Regelerinnerung verschicken, kommt meistens dann am nächsten Tag eine Mail zurück, ja, hab ich vergessen, werde ich beherzigen, oder, ich hab die Regel so verstanden, dass [...] Und der muss, müssen wir halt die Regel nachjustieren, weil vielleicht haben wir es auch schlecht ausgedrückt, weiß ich nicht. Das schließ ich gar nicht aus. Nur wissen es dann gleich alle. Das ist der spring-, also es ist ein bisschen ein, bisschen ein, ein, ein, ein bisschen ein, ein (...) Art von Personalführung. Die notwendig ist. (AT_SU_03_C2)

users, but the services also target them indirectly (Diana and Carl are assisted in carrying out their childcare obligations).

3.1.2.3. DAILY LIFE

One assistant was encountered during the ethnography. She works for Diana and Carl for four years. It is her first job as personal assistant and she has no other service users. She is a student and she has no experiences in providing household services or working with persons with disabilities. She is aware about the other assistants, but does not see them or meet them. Each of them provides their services separately and independently from each other.

The ethnography took place on one day from 8am to 7pm. Carl and the baby child were at home, Diana was at work and the two other children were in school. The assistant was expected to arrive one hour later to go shopping together. However, the baby child still sleeps and Carl cannot go shopping with the assistant in this case. This is why Carl will occupy the assistant with housework until the baby child wakes up. Carl says that the needs for assistants are unforeseen – just because of the children. The baby phone signals that the baby child wakes up. Carl and the observer go together into the sleeping room and Carl changes the baby's diapers. Then the assistant arrives. They previously negotiated about their tasks for the day. Carl instructs the assistant to empty the washing machine and to hang up the clothes while he changes the baby's diapers. Then Carl informs the assistant that he needs a spare part for the grill and asks the assistant how to get there. The assistant suggests going there by bus and Carl refuses, saying he prefers to walk. On the way, the assistant and Carl talk friendly about several issues. It appears that they have known each other for several times. They talk about good and bad neighbourhoods. Carl is quite self-determined, the assistant is quite passive. Carl orders the spare part and talks with the seller. Only in one moment, when the seller needs to know the dimensions of the spare part, Carl requests the assistant to read them out. Other than that, the assistant stands passively. As this task was done, Carl wants to go to the farmers market and asks the assistant how to go there. They drive with the bus and talk about electric cars. The assistant remains passive at the farmers market too. Carl strongly interacts with the researcher and informs her about personal assistance as a concept. The assistant remains silent. The atmosphere is nice and comfortable. Back home, the assistant behaves a little submissively and asks Carl if she may go to the toilet and if she should put off her shoes. The assistant then does some household tasks and Carl prepares the lunch. Then, the interview with the assistant takes place and Carl asks if he is allowed to be present. The interviewer refuses the presence and Carl leaves the room. However, during the interview, Carl repeatedly enters the room or stays in front of the door, where he is able to hear everything. In the afternoon, Diana enters the flat together with the two other children. The interview with Diana is disturbed by the children. The children run around the flat and want to interact with their mother. The baby needs to breastfed. Carl remains passive and does not occupy the children to allow a calm interview with Diana. Carl is present during the interview with Diana and adds some comments on personal assistance. Upon Diana's request, Carl leaves the room with the children. Then, Carl plays cards with the children.

3.1.3. CASE 3

3.1.3.1. CAPABILITIES

The service user in case three is called Mary. She is about thirty years old and she works at a church 25 hours a week. She has spastic paralysis from birth on and uses personal assistance since 2006, when she started her studies. Previously, she lived with her family and her parents (mainly her mother) assisted her. During her studies, she lived in a shared flat and her flat mates assisted her.

Mary needs assistance with basic physical necessities, like washing, getting in and out of bed, eating, and toileting and dressing up. She needs assistance in the morning, for bodily care, for work, for mobility-services, for eating, household – for many tasks in daily life. She uses an electric wheel chair, which is necessary for her mobility. As soon as she is in the wheel chair or in bed, she may be left in the house unaccompanied. However, she is physically safe only for a short time, as she needs assistance in toileting. She is able to leave the home and use public transport with her electric wheel chair. However, she needs a barrier-free accessible surrounding.

Mary is very kind. Communication with her works like with persons without disabilities. She reports that sometimes service users made a lot of emotional demands on her. However, this is ok for her, as she is a socially-oriented person. Sometimes she also purposefully selects assistants in a challenging life situation or with emotional problems to give them a chance for employment.

Mary receives 30 weekly hours of personal assistance related to work and additionally 35 weekly hours personal assistance at home (1.789 hours per year). She receives personal budget from the province for the personal assistance at home. Work assistance is provided for an additional 30 hours and publicly paid by the province. Work assistance is carried out by an agency.

3.1.3.2. SERVICE PROVISION

She has six assistants for personal assistance and three assistants for work assistance. Two assistants are both work assistants and personal assistants. Some of them are employed by her as freelancers and the others are self-employed personal assistants. Mary prefers the model of self-employment as it entails fewer administrative efforts for her. There are no friends and family involved in the personal assistance. Mary had family assistance until she started her studies. During her studies, she received assistance from her roommates in the shared flat. Mary's family lives somewhere else.

Mary has ordered a tax counsellor for the administrative work related to the personal assistance. She very much likes the fact that she decides on the personnel and the tasks to be carried out. She appreciates that the personal assistance allows her to shape her daily life the way she wants. Due to her disabilities, the (amount of) assistance needed cannot be planned in advance. This entails the challenge to secure the availability of assistants at short notice.

During the ethnographic study, one personal assistant was encountered. She is female and approximately the age of Mary. She has worked for the service user for 2,5 years as personal assistant and only works for her. She works for up to 30 hours per week, including household services, re-mobility assistance and bodily care. In the framework of another contract with an agency, she provides

work assistance for the same service user. She coordinates with the other assistants by using a WhatsApp group, including all assistants and Mary. The assistant is strongly bound by these assistance services. Often service times are extended at the expense of her leisure time or the time with her boyfriend. She does not like this, but accepts it. In case she wants to go on holiday, she posts it into the group and looks for replacements in advance. In case nobody is found to replace her hours, she will waive her leisure plans and take on the assistance. The assistant reports challenges in reconciling her work as a personal assistant and a work assistant for Mary. She is employed by an agency for the work assistance and she is a freelancer for the personal assistance. She would have to take vacation in the job as work assistant in order to perform extended personal assistance, e.g. in case she accompanies Mary during therapy weeks abroad. In case Mary is on vacation and consequently no work assistance is needed, the agency dismisses her and re-hires her as soon as Mary's vacation time is over. Also sometimes Mary's mother takes over assistance services, but this is carried out rather irregularly.

The assistant has a brother with disabilities and used to care for him when they were children. Now and then she still does it; however, there is no need to combine these responsibilities as the responsibilities towards her brother are really small.

3.1.3.3. DAILY LIFE

The ethnography was carried out for one day (arrival at 10am, departure at 5pm). The assistant arrives at 10am and clears out the dishwasher. She tests whether the plants need some water. In the meantime, Mary is lying on the floor in her sleeping room and receives physiotherapeutic treatment from somebody else. Later on, the assistant goes into the sleeping room and starts with intimate care. Mary offers the researcher to go out in case observing the intimate care is embarrassing for her. The observer refuses this offer and says she prefers to remain in the room in case it is ok for Mary and her assistant. Mary allows the researcher to take place on her bed. The assistant routinely performs the intimate care and dresses Mary up. Mary wears a support corset under her clothes, which is very tight. During the care work, the assistant and Mary talk about a festival in the church. The assistant baked a cake for the festival. Mary's flat is full with crucifixes and other religious symbols. It becomes apparent that Mary is religious. The interactions between Mary and her assistant are very friendly and informal. They exchange about personal issues and experiences and a new person cannot follow the conversations – you need to be an insider. Later on, they talk about shopping in the supermarket. The assistant checks the refrigerator and assesses which food is needed. Furthermore, they talk about what to cook this day. Mary informs the assistant that they will have to use the tomato sauce for cooking, because otherwise it will get bad.

Mary has a mobile phone with speech recognition. She enters the shopping list into the phone. The assistant recommends Mary to use a jacket because it is cold outside and it is likely to rain. The assistant assists her with putting on the coat. Mary wants to wear a scarf too – the yellow one. The observer accompanies Mary on her way to work by bus, while the assistant drives by car. On the way, Mary informs the observer about her work and her life. As the bus arrives, Mary signals the driver that she will need the mobile handicap ramp. The bus driver gets out of the bus and prepares it for her and asks her at which stop she will leave the bus. Another wheel-chair user is in the bus. Mary positions

her next to him and they talk about wheelchairs. The two know each other from bus driving. The wheelchair works quite fast, it is difficult to follow in walking. Mary says that she herself is sometimes surprised about the speed of the electric wheelchair.

The assistant already arrived at the church and they negotiate about the preparations for the church event and the lunch cooking. The assistant prepares the lunch and Mary does some desk work. She uses a laptop with speech recognition and is able to type slowly with her fingers. During lunchtime, the assistant rolls up Mary's sleeves. Mary eats alone until she is almost ready. Then she needs assistance to grasp the last pieces of food on her fork. She is fed by the assistant. During the feeding, the assistant scolds her by taking on the role of a mother and says: you soiled your shirt. Both start laughing, the atmosphere is very warm and jokes are allowed. After lunch, the assistant prepares the event and serves coffee and her cake. The women come and in the meantime the assistant and the observer do an interview. After the interview, the assistant says: I feel that Mary needs me, let us go inside. Mary is a bit tired and needs a break. The assistant does some remobilisation exercises with her in the park in front of the church. It appears that they have a lot of fun with it. Later on, some children come to church and they need to be cared for. The assistant does the majority of work with the children and Mary sits next. It appears that she is a bit tired, but she tries to talk to the children.

When the children have left, the assistant tells the observer, that the service hours were extended. She initially wanted to have dinner with her boyfriend and then go to Mary's to prepare her for bed. However, as the service hours were extended, it is not worth it for her to go to dinner. Thus she will remain with Mary until she is in bed.

3.2. REFLECTIONS AND COMPARISONS

The service users are living the life they want. All of them are highly educated; three out of four have obtained University degrees and all of them are employed part-time. When asked about good or bad aspects of their days, answers do not differ from those that persons without disabilities would provide. Service users mention different sources of pleasure in their everyday lives, such as meeting friends or family, parties, children, civic engagement, the church or engagement for the rights of people with disabilities, music, arts and so on. The evidence from this mini-ethnography in no way indicates any differences between people with disabilities and people without disabilities in this regard.

Service encounters in case 1 are full of friendliness and mutual interest. In the beginning, all assistants say hello, kiss each other on the cheeks and then the assistants ask: what will we be doing today? Sandra informs them about the plan of the day and their tasks. This conversation is accompanied by some stories and exchange on private issues. It appears that particularly assistant 1 and assistant 3 made friends with Sandra – they share similar interests and leisure activities. They talk a lot about personal experiences and working appears to be a lot of fun. However, the encounters with assistant 2 are also friendly. Assistant 2 is a bit older than Sandra and the other two assistants. They do not share many leisure activities. However, assistant 2 and Sandra have in common that they like cats a lot. All assistants are well acquainted with the household. They know where everything is and care a lot that they put everything back where they took it. This is important for Sandra's orientation and safety. When they go shopping, Sandra has a list and the assistants tell her about everything they see. Sandra then decides what to do. She pays herself.

Compared to the other case studies, the working relationship in case 2 is rather hierarchically organised. The service users highlight their role as employers and as team leaders – they clearly say that they are the supervisors of the assistants and they have to lead them. They do not appreciate being friends or coming closer to their assistants. This kind of leadership is important because of their children. Carl and Diana do not want their children to get used to a certain assistant who then quits the job. Service provision has a clearly instrumental component: assistants are the substitute for the disabled body part. They have written rules on the behaviour of personal assistants and also on the way they have to carry out their tasks. These rules are permanently adapted along “mistakes” and failures of assistants, or if they are not pointed out clearly enough and there are misunderstandings. In case an assistant makes a mistake, he/she receives a written and oral rule-reminder (see section 3.1.2.2). It appears that the assistant obeys these rules but sometimes wishes to be more present as a person during service provision. The service encounters are not accompanied by friendship as they are in cases 1 and 3. The assistant remains rather passive and focussed on carrying out household tasks. Still, the interactions between assistant and Carl are friendly and kindly.

The service encounter in case 3 was a particularly friendly one. The assistant has a lot of experience and knowledge in personal assistance and household work. She came in and took care of everything in the household. She works in a very self-determined manner, but not over the head of Mary. Furthermore, as a physical therapist she has qualifications in bodily care and re-mobilisation services. During the observation, it became apparent that these two are a really good team. They treat each other with a lot of respect and appreciation and humor is not lacking too. Mary is a religious person and the assistant is not. However, the assistant accepts the religious aspect and is also curious about it. Mary does not request a religious belief from assistants but requests respect for her religiosity.

3.2.1. JUSTICE CLAIMS OF SERVICE USERS

The justice claims of the service users emerge in their description of preconditions for a good working relationship. As the literature already shows (see section 1.2), the work of personal assistants has the main purpose of substituting a concrete barrier due to the disability and enabling the user to live an independent and self-determined life. Apart from the concrete working tasks (i.e. household, accompaniment when shopping, working, etc.), specific features emerged of the observations and interviews. A service user names the preconditions for being a good personal assistant: calm, shy, intelligent, common sense and a driver’s licence (AT_SU_03_C2).

3.2.1.1. INSTRUCTION COMPETENCE

Findings indicate that personal assistance is assistance in the narrow sense – this means that service users and their needs are at the core of service provision. Personal assistants are requested to hold back their opinion, e.g. if they believe that a certain cheese is better than the one the service user wants to buy. The service user has the instruction competence and defines the services to be carried out. Even if the need for cleaning a certain room becomes evident, it must not be cleaned if the service user does not want it to be cleaned. For some assistants, it is difficult to hold back their opinions. This

difficulty may be due to the fact that assistance is carried out in daily life activities and everybody has their own experiences and competencies in daily live activities. However, in personal assistance, they must not be shared. A service user says:

And that's what's in the foreground, what I would like to have. When I say we are now going to [discount supermarket] but the assistant doesn't like that supermarket, then I don't really care. He has to get over it. But yes, at the moment I don't have that, but I also had it that people interfere more than I would like.⁴⁰ (AT_SU_01_C1)

The instruction competence and the silence of assistants in decision-making is an important justice claim for all service users. However, findings indicate that the intensity and importance of this claim differs. In its highest intensity, personal assistance is reduced to instrumental aspects, i.e. being a substitute for the disabled body part (i.e. the eye, the arm, the leg). One of the observed relationships shows this high-level instruction competence. Assistants are requested in writing not to share their opinions and participate in decisions when they carry out the work. Carl brings an example of how he perceives his assistants:

If I am in some meeting, I always do it the same way when I introduce myself: "And to my left Miss X is sitting, you don't need to pay attention to her much, she only needs some air to breathe." (AT_SU_02_C2)⁴¹

This quote clearly shows the role of the assistant: s/he is a means to compensate the blind eye, she only needs "air to breathe", but other than that she must not be noticed. Carl notices that others perceive this approach as provocative, particularly social workers and pedagogues. He explains how he responds in such cases:

Among the pedagogues there tends to be a discussion that's starting about the valuing and not-valuing of the assistant. And from me it will always be the same response. Do you also thank your eyes for their existence every day? No. But also it doesn't mean I need to treat them like dirt. (AT_SU_02_C2)⁴²

Carl argues that people without disabilities also do not perceive their arms as body parts with a personality. They rather have an instrumental view of these body parts, and so does this service user with his assistants. He states that if it was possible, he would like to replace assistants with a machine:

⁴⁰ Und es ist das im Vordergrund, was ich gern hätte. Wenn ich sage, wir gehen zum Hofer einkaufen und der Assistent mag den Hofer aber nicht, dann ist mir das ziemlich wurscht. Da muss er durch. Aber ja, jetzt momentan habe ich das nicht, aber habe ich eben auch schon gehabt, dass Leute sich dann eben mehr einmischen, als mir recht ist oder, ja. (AT_SU_01_C1)

⁴¹ Wenn ich bei irgendeiner Besprechung sitze, ich mach's immer gleich, wenn ich mich vorstelle sage ich: „Und links von mir sitzt die Frau X, die brauchen sie nicht weiter zu beachten, sie braucht nur ein bisschen eine Luft zum Atmen“. (AT_SU_02_C2)

⁴² Unter den Pädagogen beginnt tendenziell eine Diskussion darüber, über die Wert und Nicht-Wertschätzung der Assistentin. Und da kommt von mir immer das Gleiche. Dankst du deinen Augen auch jeden Tag für deren Sein? Nein. Heißt jetzt aber nicht, dass ich sie behandeln muss wie einen Dreck. (AT_SU_02_C2)

Exactly that, for me that's, that's an instrument. So for me that's an instrument and if one day it is technically possible to replace the assistant, I will do that. (AT_SU_02_C2)⁴³

Assistants are expected to hold back their opinion, but also to hold back in communication. They are expected to retreat and to remain silent when they are not needed and when communication between service users and third persons take place. Diana, Carl's wife, says:

What shouldn't be the case is that the people then get involved in communication and act as if they were part of (...) of what's happening, so like I said, usually they retreat and do something by themselves and don't sit there and take part in social interaction, rather they are simply here if we need them and not here if we don't need them. It's also not their duty, but those (...) are *my social interactions* not their social interactions. (AT_SU_02_C2)⁴⁴

Restraint as part of justice claims is of importance for this couple, also because they have children. They do not want the assistants to intervene in their role as parents – not even in the sense of supporting them in this role. The quote of Diana clearly shows this justice claim. She talks about the attributes of a good personal assistant:

And also what's very important in our case (...) is that the people don't act like educators and child carers (...). No one is responsible for our kids, in principle. And (...) also, for example, that they hold back with enforcing what we say to our children, like: "but your mum said so", and such things, so we simply don't want that, because that's our educational duty. So basically what falls under holding back. (AT_SU_C2)⁴⁵

An assistant in this case confesses that it is sometimes a bit difficult for her to not intervene in conversations. This is one of the negative aspects of her work:

What's not so [laughs] not so good is, is, you need to be able to hold back, to hold yourself back very well, and in many issues that's/ so, if they discuss something and you don't interfere, then it's clear of course. But if it's sometimes difficult/ or with children, who are

⁴³ Genau da, das ist, für mich ist das ein Instrument. Also für mich ist das ein Instrument und wenn es eines Tages technisch möglich ist die Assistentin zu ersetzen, werde ich das tun. (AT_SU_02_C2)

⁴⁴ Was nicht sein sollte ist, dass die Leute sich dann in, in die Kommunikation einbringen und da irgendwie so tun als wären sie Teil des (...) Geschehens, also, wie gesagt, in der Regel ziehen sie sich zurück und machen irgendwas für sich und sitzen nicht dabei und beteiligen sich an der sozialen Interaktion, sondern sind einfach da wenn wir sie brauchen und nicht da wenn wir sie nicht brauchen. Das ist auch nicht deren Aufgabe, sondern das (...) sind dann halt meine sozialen Interaktionen aber nicht deren soziale Interaktionen. (AT_SU_02_C2)

⁴⁵ Und eben bei uns auch ganz wichtig ist (...), dass die Leute nicht Erziehung spielen.... niemand zuständig im Prinzip für unsere Kinder. Und (...) auch zum Beispiel, dass es unterlassen wird, dass, dass verstärkt wird, wenn wir etwas sagen, dass dann gesagt wird, „deine Mama hat aber gesagt“ und solche Dinge, also das wollen wir einfach nicht, weil das ist eben unsere Erziehungsaufgabe. Also was ja im Grunde auch unter Zurückhaltung fällt. (AT_SU_C2)

there and you need to hold back saying something, so that's difficult sometimes, but I mean, it's just a part of that. (AT_SP_04_C3)⁴⁶

When asked about the requirements of a good personal assistant, this assistant mentions the dominance of the instrumental aspects of work, i.e. to be the substitute for the disabled body part:

So I know from stories and so on, and definitely common sense is required here. And I don't think more than that. So that you basically hold yourself back and are really only the substitute, like it's here, the substitute for the eyes and maybe the hand, but not more, and that it's also/that one is aware of that, that you are not more than that. (AT_SP_04_C3)⁴⁷

Service users in cases 1 (Sandra) and 3 (Mary) do not set such high-level requirements on distancing and holding back. However, they also do not have children. Mary is able to bear and tolerate mood swings in personal assistants when she is at home. However, during work she does not tolerate these mood swings. She works at a church, where she is in close contact with others. She says:

And that's very important to me, that the work assistants are people who themselves are somewhat stable and can take it, also if they are in the background themselves sometimes, and I don't acknowledge them at all, and they still look after me in the background and maybe give me something to drink, but are able to hold themselves back. At home it's very often the case that I talk to them a lot and am in contact, and we talk about many private things, and that often doesn't work at the workplace, there it's more, the things have to work the way they have to work right now. (AT_SU_04_C3)⁴⁸

Unlike Sandra, Carl and Diana, Mary needs personal assistance in bodily care, moving her body, eating, and going to the toilet. It appears that she does not so much share the focus on instrumental service provision as the other service users. Albeit this instrumental part of personal assistance is also an important aspect of the job, it should be accompanied by personal exchange and good communication. Mary does not perceive personal assistance solely as a substitute for disabled body parts. Her assistant also emphasises the good working relationship and the good communication they have. The good relationship is a central motivator for her. Mary's assistant indeed could perform her work in this solely

⁴⁶ Was eher nicht so [lacht], nicht so gut ist, ist, man muss sich voll gut zurückhalten können, und das ist in voll vielen Sachen halt/ also, wenn sie diskutieren und man mischt sich halt nicht ein, das ist eh klar. Aber es ist halt teilweise schwierig/ oder halt mit Kindern, wenn die dann mit dabei sind und man muss sich da so zurückhalten, irgendetwas zu sagen, also das ist teilweise schwierig, aber ich meine, das gehört halt dazu. (AT_SP_04_C3)

⁴⁷ Also ich weiß von Erzählungen oder so, dass auf jeden Fall Hausverstand einfach gefragt ist. Und ich glaube mehr auch nicht. Also, dass man halt sich halt eben einfach zurücknimmt und wirklich eben nur der Ersatz ist, wie es da ist, Ersatz ist für Augen und halt Hand vielleicht, aber mehr nicht, und das halt auch/ sich dessen bewusst ist, dass man nicht mehr ist als das. (AT_SP_04_C3)

⁴⁸ Dann ist mir ganz wichtig, dass das Leute sind, die da selber irgendwie stabil sind und das aushalten, auch wenn sie selber mal im Hintergrund sind und ich sie grad gar nicht beachte und sie aber trotzdem im Hintergrund auf mich schauen und mir mal was zum Trinken geben aber sich selber im Hintergrund halten können. Daheim ist es aber ganz viel so, dass ich halt ganz viel mit ihnen rede und schon in Kontakt bin und wir auch ganz viel private Dinge reden und das geht halt in der Arbeit oft nicht, da ist mehr das, dass halt die Dinge funktionieren wie sie grad funktionieren müssen. (AT_SU_04_C3)

instrumental style and completely hold herself back. However, in these cases, she would only see her work as a job for money. She states:

Because I do know many of her friends and of course I am always there as an assistant, and they always somehow include me and it's a lot nicer than if you are basically just sitting there and nobody talks to you, everyone ignores you and you are thinking to yourself: "What I am doing here now, and at home I would have to do a lot, and I miss my people" and so on, so then you always wish you were somewhere else and really only do it as a job, and then it will probably annoy you. But if you are also included, then you are also LIVING there. (AT_SP_05_C3)⁴⁹

When asked if role conflicts result from this close relationship, Mary's assistant answers negatively. She explains this saying that despite their good working relationship, she still knows what her job is in the end. She says:

No, such conflicts do not arise, because it is clear to me that I am her hands, I am her feet, her – how should I say – I am simply her assistant. I assist her and this is my task and I am well aware on this and thus it is logical, it is so clear and thus, we never had any problems, at least in my view (laughs) (AT_SP_05_C3).⁵⁰

Moreover, working times define the role: as soon as she is on duty, she is the assistant. However, they also meet each other off the job.

Mary's instruction competence is limited, as she does not see what is to be done in the household. Assistants do not only need to identify the household tasks themselves (compensate for the lacking instruction competence), but should rather have communication skills to follow the priorities of the service user.

So I have one, I find that very charming, she asks "[name], what do you still plan on doing today, and what is your list of priorities, so what is the most important to you?" Because often we don't manage to do everything I planned for myself, and I really like that in her, because she recognizes my priorities and for me often things are important that are not that important to others. [...] Indeed, on the one hand see what is important to me, but on the other hand also some kind of self-responsibility, namely a form of prudence, that they still do things that I maybe don't have my eye on that much, or that they at least alert me to that. Not every stroke of the hand needs to be discussed with me, but I like it when

⁴⁹ Weil ich kenne halt auch schon viele von ihren Freundinnen und bin natürlich immer dabei als Assistentin und die beziehen mich immer irgendwie mit ein und es ist viel schöner als wenn du quasi daneben sitzt und keiner redet mit dir, alle ignorieren dich und du denkst dir: was mache ich jetzt und zu Hause und meine Leute und so, also dann wünschst du dich immer irgendwo anders hin und machst es halt wirklich nur als Job und es nervt dich halt wahrscheinlich. Aber wenn du halt auch miteinbezogen wirst, dann LEBST du halt auch dort. (AT_SP_05_C3).

⁵⁰ Nein, solche Konflikte entstehen nicht, weil für mich ist es klar, dass ich ihre Hände bin, ich ihre Füße bin, ihre – how should I say – ihre Assistentin einfach bin. Ich assistiere ihr und das ist meine Aufgabe und dessen bin ich mir sehr bewusst und dadurch ist es so logisch, es ist so klar und deshalb hat es da noch nie irgendwelche Probleme gegeben, also aus meiner Sicht (lacht) (AT_SP_05_C3).

I am included in the doings, and for some it's very obvious, and others feel monitored too much. (AT_SU_04_C3)⁵¹

Communication skills are needed to give Mary a feeling of autonomy, control and self-determination. Her assistant says that one of her greatest conflicts in service provision is accepting Mary's limits. As therapist, the assistant knows exactly about the importance of re-mobilisation:

How far can I go, because she is cognitively completely healthy, but still every person has their inner weaker self and their habits. And sometimes it is quite difficult, because I know how much she can do, and then she is too lazy, or not too lazy, maybe she simply doesn't have the energy anymore or patience or importance, next to all the other things she has to do, to tell every single person: "hey, I can put on my glasses by myself, I can sit back in my wheelchair by myself". Actually that's my biggest conflict in relation to her, where I think: "You could do so much alone, but you don't refuse help offered by the others". (AT_SP_05_C3)⁵²

3.2.1.2. MONETARY COMPETENCE

Moreover, findings clearly show that (unpaid) assistance carried out by family members or friends is in conflict with service users' justice claims. Service users perceive their payments for the services as security or leverage that services will actually be performed. This is of importance for their self-determination. Thus, service users prefer a distinct role of paid personal assistants, rather than having friends or family perform these tasks. Some of them already had this experience and state that unpaid assistance keeps them in dependency. This is because service is performed for good will and not for money. A blind service user talks about family assistance:

Because I don't want it, for example, if my brother is angry at me and he leaves me standing somewhere. Because he is allowed to be angry at me, because he is my brother,

⁵¹ Also eine hab ich, das find ich immer ganz nett, die fragt: „[Name] was hast heute noch alles vor und was ist deine Prioritätenliste, also was ist dir das wichtigste?“ Weil oft schaffen wir ja gar nicht alles, was ich mir so vorgenommen hab und das mag ich voll an ihr, weil sie einfach meine Prioritäten wahrnimmt und mir sind oft Dinge wichtig die für Andere gar nicht so wichtig wären. [...] schon einerseits auf das schauen, was mir wichtig ist, aber auch so eine Eigenverantwortung und zwar so eine Umsichtigkeit, dass sie die Dinge trotzdem machen, die ich vielleicht gar nicht so im Blick habe, oder dass sie mich zumindest darauf hinweisen. Es muss nicht jeder Handgriff immer mit mir abgeklärt sein, aber ich mag es wenn ich miteinbezogen werde in das tun und für manche ist das ganz selbstverständlich und manche fühlen sich da sehr beobachtet. (AT_SU_04_C3)

⁵² Wie weit darf ich gehen, weil sie ja kognitiv völlig gesund ist, aber dennoch hat jeder Mensch seinen Schweinehund und seine Gewohnheiten und jetzt geht es in den Therapiewochen darum, die maximale Leistung von dieser Person zu verlangen und das in den Alltag zu integrieren und dem Menschen zu helfen, völlig selbständig zu sein. Und das ist manchmal schon schwierig, weil ich weiß wieviel sie kann und sie ist dann halt quasi zu faul oder nicht zu faul, sie hat einfach nicht die Kraft mehr oder die Geduld oder die Wichtigkeit neben allen den anderen Dingen, die sie machen muss, jetzt jedem einzelnen zu sagen: Hey, ich kann mir die Brille alleine aufsetzen, ich kann mich im Rollstuhl alleine zurücksetzen. Das ist eigentlich mein größter Konflikt in mir mit ihr, wo ich mir denke: es ginge noch so viel und du sagst es den anderen nicht. (AT_SP_05_C3).

or something, but as employee he isn't allowed to be angry at me, because I am feeding the account. That (...) then, personal issues should be left aside. (AT_SU_02_C2)⁵³

A quote from Sandra similarly shows the importance of paid work for the freedom, independency and security of service users:

But it's a liberty, where I say I don't always need to plead and beg for someone to help me, but I can also really remunerate them and don't need to have a guilty conscience afterwards. But mostly with friends it's the case that they do it [for free] anyway, but at least you have the opportunity to make them an offer. (AT_SU_01_C1)⁵⁴

The following quote of Sandra shows how the financial competence is interconnected with the instruction competence:

For example I can go to the shop when I want to and not when the friend has time. The friend goes to the [supermarket] tomorrow morning and says: "Yes, of course you can join." But what if I want to go to the supermarket today and what if I want to go to another supermarket? And with the assistant I decide when and where we go, and that's great, and that's actually the case in all areas: you can decide yourself how things should work. (AT_SU_01_C1)⁵⁵

Payments for service provision furthermore allow drawing clear borders between service hours and leisure time, i.e. the services are clearly limited by the payments. The importance of paid services rather than unpaid family services is confirmed by all service users. Unpaid service provision by relatives would give service users a feeling of dependency and the need for being grateful or a bad conscience for needing assistance. Mary clearly points out that she would feel like a burden for her family members in case they provided assistance. Family members are "forced" to carry out this work because of family roles, while paid assistants do it because of a work contract. Her assistant, whose brother has disabilities, compares her role as sister with her role as personal assistant. She says:

As sister I am a lot less inhibited, you always deal with siblings differently. For example in this vein, I never paid consideration to my brother, we also fought just like that, or something, and that's something I wouldn't do at work (laughs). [...] Maybe I would try a

⁵³ Weil ich will nicht, als Beispiel, wenn mein Bruder angefressen auf mich ist und der lasst mich halt irgendwo stehen. Weil er ja auch auf mich beleidigt sein darf, wenn er mein Bruder ist, oder so aber als Arbeitnehmer hat er nicht beleidigt zu sein auf mich, weil ich sein Konto füttere. Das, (...) dann, da muss man dann persönliche Dinge sein lassen. (AT_SU_02_C2)

⁵⁴ Aber es ist halt eine Freiheit, wo ich sage, ich muss nicht immer nur bitten und betteln, dass mir wer hilft, sondern ich kann den dann auch wirklich entlohnen und muss nicht ein schlechtes Gewissen dann haben oder so. Aber meistens bei Freunden ist es eh so, dass sie es so [gratis] machen, aber man hat zumindest die Möglichkeit, dass man ihnen das Angebot macht. (AT_SU_01_C1)

⁵⁵ Ich kann zum Beispiel dann einkaufen gehen wann ich will und nicht dann wenn der Freund Zeit hat. Die Freundin geht morgen früh zum Billa einkaufen und sagt: ja sicher kannst du mit und ich würde aber lieber heute zum Hofer einkaufen gehen. Und mit der Assistentin entscheide ich wann und wo wir hingehen und das ist super und das ist eigentlich in allen Bereichen so: du kannst selbst entscheiden wann und wie das ganze abzulaufen hat. (AT_SU_01_C1)

bit harder [...] when the brother says: Yes, I am thirsty or hungry, I say: Yes, wait for a moment, or in her case I also make sure that something is already there [for her to eat], or when the brother comes and says he needs something, that I go get it for him, I will say: Yes, I will finish that first, and then I will come. And in her case I know: I am there for that, and I am also paid for being here, so I can't take forever to do it. (AT_SP_05_C3)⁵⁶

In case assistants are not satisfied with their working conditions, they are free to leave the work relationship. The same is valid for service users. The monetary competence ensures this freedom for service users. It stands in contrast to other care arrangements and it is an important justice claim for them. Mary says:

The difference for me is that in the case of the assistants, I know they decided out of their own free will, they could also do another job [...]. In turn, with the family, there it's often the case that among siblings for example, "mah, now I need to do that too", and I mean, they do it anyway, they grew up with it, but it was often already the case, and that was not nice for me when I notice, they are now doing that because they have to, but they are not happy with it [...]. It's difficult, if you have the feeling, yes, you become somebody's burden or something, yes, I don't like that at all. (AT_SU_04_C3)⁵⁷

On the other hand, this service user sometimes indeed enjoys the assistance provided by her mother. According to her, her mother knows her best and, in turn, she would not like personal assistants who only work for money. She requests an intrinsic motivation for this work too. Findings clearly show that there are pros and cons when it comes to the 'ideal' assistants. However, the financial competence has an important role as a justice claim, which fosters self-determination and independence and ensures the instruction competence. Also assistants note that (unpaid) family assistance would limit the instruction competence. An assistant says:

And I think that with family members this plays more of a role, the issue: "I do know, basically, what they want; I don't need to ask them anyway." And that interferes with a person's independence, right? And if the personal assistant does that, it's always based

⁵⁶ Als Schwester bin ich halt viel ungenierter, mit Geschwistern geht man immer anders um. Beispielsweise habe ich in der Hinsicht nie auf meinen Bruder Rücksicht genommen, wir haben genauso gerauft oder was und das würde ich vielleicht in der Arbeit doch nicht tun (lacht). [...] Vielleicht gebe ich mir ein bisschen mehr Mühe (lacht), wenn der Bruder sagt: Ja, ich habe Durst oder Hunger, sage ich: ja, wart halt einmal einen Moment und bei ihr schau ich halt schon dass etwas da ist oder wenn der Bruder sagt er braucht etwas, dass ich es ihm hole, sage ich: ja, ich mach erst das fertig und dann komme ich. Und bei ihr weiß ich: ich bin dafür da und ich werde auch für das bezahlt, dass ich da bin, ich kann auch nicht ewig brauchen für das. (AT_SP_05_C3)

⁵⁷ Der Unterschied ist der für mich, dass ich bei den Assistentinnen weiß, sie haben sich freiwillig entschieden, sie können auch einen anderen Job machen. (...) Das wiederum ist bei der Familie, da ist es halt oft so, dass bei den Geschwistern jetzt zum Beispiel, „mah jetzt muss ich das auch noch machen“ und ich mein, ja, sie machen es eh, sie sind damit aufgewachsen, aber war halt schon öfter mal so, dass das nicht so schön war für mich, wenn ich merke, die tun das jetzt, weil sie es halt müssen, aber freuen tut es sie grade nicht (...) es ist halt schwer, wenn man das Gefühl hat, ja, man fällt jemanden zur Last oder so, ja, das mag ich gar nicht. (AT_SU_04_C3)

on the fact that they are made to do things in that way. So I do think it makes a difference.
(AT_SP_04_C2)⁵⁸

Furthermore assistants draw attention to how unpaid family assistance services might aggravate internal family conflicts.

3.2.2. JUSTICE CLAIMS OF ASSISTANTS

Not only service users, but also assistants have their justice claims. These are mainly related to their working conditions and work atmosphere. However, assistants also discussed the fact that they work with persons with disabilities, as in almost all cases, the respective job is their first in this area. Assistants are at the same time curious and insecure when it comes to working with persons with disabilities. They are curious about the daily life of a person with physical or sensory disabilities, and at the same time they are unsure about service performance. This might be due to the fact that personal assistance is constructed as laymen job, which does not have any requirements in terms of qualification or knowledge. Assistants deal with this insecurity by adapting normalisation strategies and through communication. An assistant interviewed in case 1 says:

And I thought to myself, yes, I mean I haven't had any experience with blind persons until now. My god, for me it was clear from the beginning that she is a completely normal person to me and masters her life very well. [...] And I thought to myself I will simply ask her for everything how she wants it and all of that, and then it was actually fine. [...] It also seems to me in particular what's very important is to accept the personality, how she is, and to see the person as a complete human being. Not with the approach: "Oh, that person is so deprived or something", but really think: yes, that's a person like any other, and also has their good and bad days sometimes, so, yes. (AT_SP_02_C1)⁵⁹

Another assistant in the same case perceives it similarly and also emphasises the importance of the service relationship to be based on an equal footing. She says:

But I also think a good form of being down to earth, so not over-complicating things but seeing your opposite as equal, as bad as that sounds now that I have to say it, but simply

⁵⁸ Und ich glaube, dass bei Familienmitgliedern immer mehr mitschwingt, von wegen: ich weiß ja eh, so auf die Art, was der will, ich brauche ihn eh nicht fragen. Und das viel mehr dann eingreift in der Person ihr Selbstständigkeit, oder? Und wenn die persönliche Assistentin das macht, ist es halt immer aufgrund dessen, weil sie halt angeleitet wird, dass sie Sachen so erledigt. Also ich glaube schon, dass das einen Unterschied macht. (AT_SP_04_C2)

⁵⁹ Und ich habe mir gedacht, ja, ich meine ich habe jetzt mit blinden Menschen keine Erfahrung noch gehabt. Mein Gott na, für mich war das von Anfang an klar, dass sie ein ganz normaler Mensch für mich ist und ihr Leben super meistert. [...] Und ich habe mir gedacht, ich werde sie dann halt bei allem fragen, was sie will und so und das alles und dann hat es eigentlich gepasst. [...] vor allem auch kommt mir vor, sehr wichtig ist, dem seine Persönlichkeit akzeptieren, wie sie ist und ihn als vollwertigen Menschen sehen. Nicht irgendwie so mit der Einstellung: ach der ist ja so viel arm, oder so, sondern wirklich denken, ja, ist ein Mensch wie jeder andere und hat auch seinen guten oder seinen schlechten Tag einmal, so, ja. (AT_SP_02_C1)

not acting as though you had a child you need to take care of, but simply meeting someone on eye-level. (AT_SP_03_C1)⁶⁰

Another assistant confirms that she does not talk about equality in terms of good service encounters, she presupposes this. She talks about good service relationships in terms of joking. She says:

When we go to therapy week and pack up the things, then we often make jokes and say: haha, what are we packing now, we even make jokes about the spasticity, when the finger goes up and she instructs me, then I copy her and [raises the finger and re-enacts a spastic paralysis] as though drunk, and then say: of course. So there is simply a large form of ease, we were also never angry at each other. When people see us from the outside, maybe they would say: "My god, how tragic, you can't say that", but between us such jokes about disability are normal, every now and then, you shouldn't take the disability too seriously, because if you forget the disability, that's what it's about: as soon as you recognize the person behind the disability, you really forget it. (AT_SP_05_C3)⁶¹

She says that she forgets about the disability in the course of these funny service encounters. Forgetting about the disability sometimes leads her to overestimate the capacities of her service user. She knows exactly from her work what the service user can and cannot do. However, this "forgetting" about the disabilities and capabilities is in her view the precondition for a good service encounter and a relationship on an equal footing, as the person becomes more important than the (dis-)ability. She says: "For me that's the determining question: have I also got to know the person behind the disability, or do I only see the disability?" (AT_SP_05_C3)⁶² This assistant has a disabled brother and thus has experience on this issue. She explains that her brother hates nothing more than people who feel pity for him. This makes him feel like a child: not taken seriously, not recognised for what he is and reduced to his disability and the things he cannot do.

The assistant in case two adopts a more instrumental point of view on her work. When asked for the reasons why she works as a personal assistant, she says: "Honestly, I just needed a job as a student." When asked about her relationship with the service users, she responds after a moment of thinking:

⁶⁰ Ich glaub aber auch eine gute Bodenständigkeit, also Dinge nicht zu verkomplizieren, sondern sein Gegenüber als gleichwertig zu sehen, so schlimm das jetzt klingt, dass ich das jetzt sagen muss, aber einfach nicht so zu tun als hätte man jetzt ein Kind um das man sich kümmern muss, sondern einfach jemanden auf Augenhöhe zu begegnen. (AT_SP_03_C1)

⁶¹ Wenn wir auf Therapiewoche fahren und zusammenpacken, dann machen wir oft so Scherze und sagen: hahaa was packen wir jetzt ein oder selbst über die Spastik machen wir Witze, wenn dann der Finger so raufgeht und sie mir etwas anschafft, dann mache ich sie so nach und so [hebt den Finger und macht eine spastische Lähmung nach] wie betrunken und sage dann: natürlich. Also es ist einfach so eine große Leichtigkeit dabei, wir waren auch nie böse aufeinander und wenn uns Leute von außen sehen, würden sie vielleicht sagen: oh Gott, wie schlimm, das kann man ja nicht sagen, aber zwischen uns sind so Scherze über die Behinderung normal auch wieder, man soll die Behinderung nicht so ernst nehmen, weil man eben die Behinderung vergisst, darum geht es: sobald du den Menschen erkennst hinter der Behinderung, vergisst du es wirklich. (AT_SP_05_C3).

⁶² Das ist für mich so der Prüfpunkt dann: habe ich den Menschen hinter der Behinderung auch kennengelernt oder sehe ich nur die Behinderung? (AT_SP_05_C3)

I do not know, well, comfortable [laughs]. But always with a little distance, but this [distance] is part of the job, this is part of the job requirements. Well, we do conversations indeed, but I would not say that it [the relationship with the service users] became closer or so, but we got to know one another better, simply because you have conversations while working. (AT_SP_04_C2)⁶³

This assistant did not refer to any specificities of her work as social assistant. It is a job like every other job and she mainly does it because of the money. However, on the other hand it is important for her to do a good job and to satisfy the service users. But she could not imagine any blurred boundaries between work and friendship.

3.2.2.1. COMMUNICATIVE WORK WITH IMMEDIATE RESULTS

Personal assistance – compared to other services in private households or cleaning in an office – is targeted toward an individual’s needs. Unlike care, personal assistance is provided to a self-determined person who has punctual impairments that need to be compensated. Thus, by nature it allows deep insights into the daily life of another person, her housing situation, her social contacts, her work, her household, her clothes, her bathroom, her bank accounts, etc. At the same time, it is an unskilled form of work that is based on daily life routines and needs. It still requires flexibility from the assistant.

Assistants derive a lot of motivation and satisfaction from the fact that their work is useful and needs-based. The needs-based and person-centred character of personal assistance allows a visible work impact. The immediacy of work results is one of the most positive aspects of the work for the personal assistants. This is shown by a quote:

That means, I want to channel my manpower into something I can directly see, that actually makes a difference and that helps someone, on a level that has nothing to do with money or things. So I like to work with people and simply seeing results. I like to get involved. (AT_SP_01_C1)⁶⁴

The immediacy of work results motivates assistants – they see that their work “makes sense”. Assistants differentiate the personal assistance (even if it is housework) from more anonymous household work or office cleaning. Office cleaning or housework without the presence of the service user is perceived as anonymous and not satisfying for the assistants. Furthermore, it is perceived as

⁶³ Ich weiß nicht, also gemütlich [lacht]. Aber halt immer ein bisschen Distanz, aber was halt dazugehört, eben weil beruflich halt einfach das gegeben ist. Naja, es ist schon/ also, man unterhält sich halt, und dadurch/ also es ist jetzt/ ich würde nicht sagen, es ist näher oder so geworden, aber man lernt sich halt besser kennen, halt einfach dadurch, dass man sich halt unterhält, während man arbeitet und so, ja. (AT_SP_04_C2)

⁶⁴ Das heißt, ich will meine Arbeitskraft wo einsetzen, wo ich direkt sehe, dass es einen Unterschied macht und das Jemanden damit geholfen ist, auf einer Ebene die jetzt nichts mit Geld oder Dingen zu tun hat. Also ich arbeite gerne mit Menschen und sehe da einfach gern Ergebnisse. Ich bringe mich einfach gern ein. (AT_SP_01_C1)

monotonous to repeat the same tasks, while personal assistance provides for a variety. The following quote underlies this point of view:

In the case of a cleaning job that you have regardless, then you also have the responsibility to be somewhere at a certain time and to do that, regardless of whether it's necessary or not. I think that's the crucial point. If I go to [name] and help in the household or Hoover, then I know that it's time again, that it's necessary, and that it's not only done because it says so somewhere on a piece of paper. For me that's very positive, yes of course, because there is simply no lost manpower. (AT_SP_01_C1)⁶⁵

This aspect is related to the instruction competence of the service users: service provision is targeted along the concrete needs and accompanied by communication about these needs. Another service provider in the same case also points out the importance of the communicative aspect of instrumental work. She says:

Actually also cleaning is easier, somehow, when it's for a particular person and because we always chat a bit in between. Yes, that's a lot more fun, somehow. [...] It's a bit different than if I worked for a company, so completely different, yes, I would say the personal contact makes it different, that you have it. [...] Because otherwise, I mean, in an empty flat or a flat where nobody is at home, it doesn't matter whether or not I clean. (AT_SP_02_C1)⁶⁶

The importance of meaningful work with immediate results, which is accompanied by communication, is also pointed out by the third assistant in this case:

Yes, there is a difference. So I mean, because I also have personal contact with her. It's not just about the cleaning now. There is a big difference; it's a lot more personal. You really, so I hardly think that you can get a more personal impression of someone than when you are really at someone's home and the task is simply also, going through the other person's letters and looking through them, which is something very private. (AT_SP_03_C1)⁶⁷

⁶⁵ Bei so einem Reinigungsjob, den man ohnehin hat, da hat man ja die Verpflichtung zu einer fixen Uhrzeit wo zu sein und das zu machen, unabhängig davon ob es jetzt nötig ist oder nicht. Ich glaub das ist der Knackpunkt. Wenn ich zur [Name] gehe und dort im Haushalt helfe oder Staubsauger, dann weiß ich, dass es wieder an der Zeit ist, dass es nötig ist, dass das jetzt nicht nur gemacht wird, weil es einfach irgendwo auf einem Papier steht. Das ist für mich sehr positiv, ja natürlich, weil es einfach keine verschwendete Arbeitskraft ist. (AT_SP_01_C1)

⁶⁶ Dass eigentlich dann auch das Putzen leichter fällt, irgendwie, wenn es für eine bestimmte Person ist. Und weil wir halt dazwischen immer tratschen ein bisschen. Ja, das macht viel mehr Spaß irgendwie. [...]es ist ein bisschen anders, als wie wenn ich jetzt in einer Firma arbeite, also total anders irgendwie, ja, der persönliche Kontakt tät ich mal sagen, macht es anders. Dass man den doch hat. [...] Weil sonst, ich meine, in einer leeren Wohnung, oder wo keiner daheim ist, ist es wurscht, ob ich putze oder nicht. (AT_SP_02_C1)

⁶⁷ Ja, das ist schon ein Unterschied. Also, ich meine, weil ich da halt auch persönlichen Kontakt mit ihr habe. Es geht ja nicht nur um das Putzen da jetzt. Das ist schon ein krasser Unterschied, dass es viel persönlicher ist. Man kriegt ja wirklich, also ich glaub kaum, viel mehr persönlichen Eindruck kann man von jemanden gar nicht kriegen,

The diversity of tasks is another positive feature of personal assistance, according to the assistants. The concrete tasks are often arranged directly at the beginning of the service hours and thus, they are unforeseen for the assistants. The assistant says:

That it's a lot more varied, because every week we do something completely different and it's always so exciting because it's like this: the first thing I ask when I arrive is: "What are we going to do today?" and then there is information like: "We are going to try shoes now." So it's really something completely new every week, something I'm actually never prepared for. That's also what makes it very exciting, that it's so varied. (AT_SP_03_C1)⁶⁸

Another assistant perceives it similarly. She also points out the aspect of communication and the variety in service provision as a positive aspect of her work, which is different to "ordinary household services":

It's definitely more varied, because when I arrive early, I don't know what's waiting for me. Which sometimes/ so of course it also has disadvantages, because you can't prepare for anything, but it's always varied. So that's great too, you also learn through the fact that as an assistant, you join for something and get to know other things, or you go somewhere where you normally wouldn't go, and so on. Yes. (AT_SP_04_C3)⁶⁹

An assistant notes that in the beginning she had difficulties cleaning the flat properly, because Sandra is blind. The assistant assumed that Sandra would not be able to recognise the output of service provision anyway. She says:

I mean, at the beginning I really had difficulties, because she is blind. Well, I thought to myself: you don't need to [clean] that precisely, you know, so the thought did come up in the beginning, she can't see it anyway, right? Stupid, right? And then I told myself immediately: no, you will clean here as though you lived here yourself, that you could also feel well yourself and would do so, and then it immediately worked for me [laughs]. Yes, so at the beginning it was, well, what should I clean more for, she can't see it anyway, right? (AT_SP_02_C1)⁷⁰

als wenn man bei dem wirklich zu Hause ist und die Tätigkeit einfach auch ist, die Briefe des Anderen zu lesen und durchzuschauen, was schon etwas sehr privates ist. (AT_SP_03_C1)

⁶⁸ Dass es viel abwechslungsreicher ist, weil wir wirklich jede Woche etwas komplett anderes machen und es ist immer so spannend, weil es so: das erste was ich frage wenn ich komm ist „was mach ma denn heute?“ und dann kommen wieder so Infos wie: „wir gehen jetzt Schuhe probieren“. Also es ist wirklich jede Woche etwas absolut Neues, auf das ich eigentlich nie vorbereitet bin. Das macht es auch irrsinnig spannend, dass es so abwechslungsreich ist. (AT_SP_03_C1)

⁶⁹ Es ist abwechslungsreicher auf jeden Fall, weil, wenn ich halt in Früh komme, weiß ich nicht, was mich erwartet. Was teil/ also es hat natürlich auch Nachteile, weil man kann sich auf nichts einstellen, aber es halt immer eine Abwechslung. Also das ist auch super, und man lernt dann auch, dadurch, dass halt man als Assistentin irgendwo halt mitgeht auch andere Sachen kennen, oder geht wo hin wo man normal nicht hingehet und so, ja. (AT_SP_04_C3)

⁷⁰ Ich meine, am Anfang habe ich echt Schwierigkeiten gehabt, weil sie ja blind ist. Na, da habe ich mir gedacht: brauchst eh nicht so genau [putzen], weißt eh, so der Gedanke ist am Anfang gekommen, sie sieht es eh nicht,

The way this person presents the issue here is important – she talks about difficulties and not about simplifications: her work would not become easier because of Sandra’s blindness. She perceived Sandra’s blindness as a factor that reduces her work motivation or performance, as her employer would not be able to assess the performance.

Communication is requested in terms of the instruction competence and in terms of acknowledgement of a good service provision or constructive feedback on how to do it better. This means, the assistants claim professional leadership from the service users.

3.2.2.2. DEMARCATED SERVICE HOURS AND TASKS

When it comes to the justice claims of assistants, the limitation of services in terms of working times and tasks plays an important role. Assistants have clear ideas about which tasks they can perform and which tasks they cannot. It appears that justice claims in personal assistants are connected to a demarcation of tasks and responsibilities. In other words, fair working conditions in personal assistance or more generally – offering services to persons with disabilities – are not only related to how the work is to be performed, but also to a clear scope of work. Bodily care, mobilisation and physical services are to a large extent outside the scope of work for the assistants in the case studies. Assistants justify their lacking readiness to perform these services by referring to their lacking qualification. Moreover, assistants cannot bear the intimacy or closeness that is connected with this kind of service. An assistant says:

I already once applied to someone who was in a wheelchair or something, but then we also never ended up meeting, [...] I then I thought to myself, I don’t know. I also then I didn’t look closely, because they really wouldn’t have/ that really would have been this personal assistance, also with physical care and all of that, but no, not so much that. Because I mean, she did write that you don’t need a qualification or anything, you will be taught by her. But I would have a few difficulties I think, because it’s a completely unknown person, I don’t know. (AT_SP_02_C1)⁷¹

Another assistant similarly explains the limitations of his scope of work and explains them referring to the qualification:

nicht, so? Blöd, nicht? Und dann habe ich mir aber sofort gesagt: nein, du putzt jetzt da, als tätest du da selber wohnen, dass du dich selber auch wohl fühlen könntest oder würdest, und das hat dann gleich hingehauen bei mir [lacht]. Ja, das war halt am Anfang schon, naja, für was soll ich mehr putzen, sie sieht es ja eh nicht, nicht? (AT_SP_02_C1)

⁷¹ Ich habe ja schon einmal bei einer beworben, die ist im Rollstuhl oder was, aber da haben wir uns dann auch nie getroffen, [...] ich habe mir dann gedacht, ich weiß nicht. Ich habe mich dann auch nicht ganz hinausgesehen, und weil das wäre wirklich nicht/ das wäre wirklich so persönliche Assistenz gewesen, auch mit Körperpflege und mit allem, aber, nein, das weniger. Weil ich meine, sie hat da zwar geschrieben, du brauchst keine Ausbildung, gar nichts, du wirst angelernt von ihr. Aber da hätte ich schon Schwierigkeiten glaube ich ein bisschen, weil es doch ein total fremder Mensch ist, ich weiß nicht. (AT_SP_02_C1)

In principle it wouldn't matter which tasks I do for her, it's just in my case, as I said, that I don't have a qualification in the area and hence wouldn't trust myself to do certain things. Well for example, if [name] needed more support, for example in physical care, such things. (AT_SP_01_C1)⁷²

The limited scope of work as justice claim is also related to working times. The assistants are ready to offer their services within the frame of punctual visits and accompaniment. In this regard, the assistants want predictable service hours and flexibility related to other demands in their life, such as studies or holidays. Assistants point out that service provision during punctual visits is in line with their justice claims, but they could not live together with the service users. Distancing themselves from the service user in terms of time and tasks constitutes an important part of their justice claims.

So I think it's very important, in general, if you have something to do with people in private, that you still always maintain a bit of distance, you need to care that enough distance is there. So I find that important. And I can imagine that it, if it runs through an institution, perhaps gets lost if it's communicated wrongly. (AT_SP_04_C2)⁷³

In this quote, personal assistance is differentiated from care work offered via an institution. Personal assistance, offered under a service contract, offers assistants possibilities to distance themselves from the service users and their life. Assistants cannot imagine that live-in care work or care work offered via an institution would provide them the same distance.

An assistant also discusses the gender component in this regard and points that live-in care work or cleaning might make them vulnerable to sexual harassment. This person already had the experience of being sexually harassed by a male client. The limited character of service provision in personal assistance is seen as an instrument to prevent vulnerabilities in terms of sexual harassment:

No, not really. I think you need to draw boundaries for yourself and/ I mean in the case of 24-hour care you are there really day and night, that's really something completely different. In personal assistance, you may be only going there for a few hours and that's that. I think I wouldn't want that. (AT_SP_02_C1)⁷⁴

Personal assistance is perceived in opposition to live-in care work and care work offered via an institution. Personal assistance is accompanied by clearly arranged service hours and clearly arranged tasks. Thus, it gives the assistant distance and prevents vulnerability to sexual harassment or

⁷² Es wär im Prinzip egal, welche Arbeiten ich für sie mache, es ist jetzt nur bei mir, wie gesagt, dass ich eben keine Ausbildung habe in dem Bereich und mir dadurch gewisse Sachen jetzt natürlich nicht zutrauen würde. Naja zum Beispiel wenn die [Name] jetzt mehr Unterstützung bräuchte, zum Beispiel bei der Körperpflege, solche Sachen. (AT_SP_01_C1)

⁷³ Also ich finde, das ist ganz wichtig, überhaupt, wenn man eben privat mit den Leuten zu tun hat, dass man da trotzdem immer ein bisschen Abstand bewahrt, also die Distanz da ist. Also ich finde, dass das wichtig ist. Und ich kann mir schon vorstellen, dass das, wenn das über eine Institution läuft, vielleicht eher verloren geht, wenn das falsch kommuniziert wird. (AT_SP_04_C2)

⁷⁴ Nein, nicht wirklich, ich glaube, da muss man sich schon abgrenzen und/ ich meine bei der 24-Stunden-Pflege ist man ja Tag und Nacht dort, das ist schon etwas ganz etwas anderes. Als persönliche Assistenz, da geht vielleicht nur ein paar Stunden hin und das ist es. Ich glaube, das täte ich nicht wollen. (AT_SP_02_C1)

dependency on service users' needs. Care work on the other hand is associated with dependencies on both sides. Thus it is not in line with the justice claims of assistants and this is why it could not be offered by the assistants.

3.2.2.3. LEARNING SOMETHING NEW

Curiosity is a central motivating factor for taking the job as a personal assistant. Curiosity is related to the self-determined lives of persons with disabilities. Assistants derive personal development from the fact that they get insights into the daily life of persons with disabilities through their work. The following quote shows an example of this:

There I said yes, good that sounds very exciting, I would really like to know how her daily routine looks and how she deals with it. I find it very exciting, because such small things, where I learn how it works with describing things. As a blind person, how do you describe the sheets or your documents, and how does that work, there are so many new impressions that I didn't know anything about beforehand, because I have nobody in my environment who is blind. I simply really wanted to know that, because I find it very exciting and because of course somebody else is helped by that, then it's somehow this win-win situation and that's why I found it so exciting and I really like it, and I very much like doing it. (AT_SP_3_C1)⁷⁵

In terms of justice, this quote shows how assumed inequalities are balanced: the assistant supports the service user and gets something back: interesting insights into another life and the chance to further develop their personalities. Assistants expect to benefit in terms of personality from their work with persons with disabilities. Another quote of the same assistant underlies this further:

[...] Yes, that she, that she more, so based on the fact that it's all new for me, actually, and also this contact to someone who is blind, I notice many small things that are normal for those who see, in daily life, so things that need to be expressed differently, need to be described differently. So these are completely new thought processes that you get, how do I now describe the path to go somewhere, or what could she orient herself on if we go somewhere and she has never been there, or how can she remember that, and indeed

⁷⁵ Da hab ich gesagt ja, gut, das klingt total spannend, ich würd wirklich gern wissen, wie eigentlich ihr Alltag dann ausschaut und wie sie den Alltag einfach bestreitet. Ich find es total spannend, weil so Kleinigkeiten, wo ich dann wieder erfahr, wie funktioniert das mit dem Beschreiben. Wie beschreibt man als blinder Mensch dann die Blätter oder seine Dokumente und wie funktioniert das, das sind so viele neue Einblicke, von denen ich vorher überhaupt keine Ahnung gehabt hab, weil ich niemanden in meinem Umfeld hab, der blind ist. Ich wollt das einfach unbedingt wissen, weil ich das total spannend find und wenn natürlich jemanden anders auch noch dabei geholfen wird, dann ist das irgendwie so eine Win-Win-Situation und deswegen hab ich das so spannend gefunden und es gefällt mir total gut und ich mach das echt gern. (AT_SP_3_C1)

that is something that initiates thought processes and I find that curious, yes.
(AT_SP_3_C1)⁷⁶

They expect to obtain central communicative skills. Moreover, assistants somehow admire service users for the fact that they are able to manage their daily lives, which people without disabilities could not. The following quote shows an example:

For example, I really admire [name] for the fact that she is so well-versed in technology, and I can really learn something by watching her, because I think: there are no excuses for not doing something, because for example I am not well-versed in technology. I have a hard time with those things. I think to myself she is the one who should have a much harder time, actually, but she loves dealing with these things and she is so good at them and I simply find that very progressive, very innovative and good. (AT_SP_3_C1)⁷⁷

Learning something new is not only related to the disability of the service users, it is also related to accompanying persons with a different lifestyle, with different hobbies, different tasks and households. The job as a personal assistant brings new impressions and inspirations.

3.3. TOOLS TO NEGOTIATE CONFLICTING JUSTICE CLAIMS

Findings indicate that conflicting justice claims are related to how services are performed. Thus, conflicts are related to ineffective communication related to the instruction competence of service users or lacking acceptance of the instruction competence by service providers. Service relations, whereby assistants do not respect the instruction competence of service users, are accompanied by conflicts. Lacking respect of the instruction competence is not necessarily intended by the assistants but has to do with the character of work: it is laymen work, which is located in the private household and daily life. Assistants have their own households and do similar tasks for themselves. Thus, they may face difficulties in drawing the line between their own household tasks – where the definition competence lies with them– and doing the same work for somebody else and thereby accepting their definition competence. This is illustrated by a remark of a service user regarding which kind of assistants she does not like:

⁷⁶ (...) Ja, dass sie, dass sie mehr, dadurch dass das für mich ganz neu ist eigentlich und auch dieser Kontakt jetzt zu jemandem der blind ist, fallen mir so viele Kleinigkeiten auf, die für jemanden Sehenden im Alltag ganz normal sind, also die natürlich dann anders ausgedrückt, anders beschrieben werden müssen. Das sind halt ganz neue Gedankengänge, die man da kriegt, wie beschreib ich jetzt einen Weg dorthin, oder woran könnte sie sich jetzt orientieren, wenn wir irgendwo hingehen und sie war dort noch nie, oder wie kann sie sich das jetzt merken und das ist halt schon immer wieder etwas, was dann zum Überlegen anregt und das find ich spannend, ja. (AT_SP_3_C1)

⁷⁷ Ich bewundere die [Name] zum Beispiel dafür, dass sie so voll technikaffin ist und da kann ich mir jedes Mal etwas anschauen, wenn ich mir denk: es gibt keine Ausreden dafür etwas nicht zu tun, weil ich bin zum Beispiel nicht technikaffin. Ich tu mir mit sowas schwer. Ich denk mir und sie der es noch viel schwerer fallen müsste eigentlich, befasst sich so gern damit und ist so gut darin und das find ich einfach voll fortschrittlich, voll innovativ und gut. (AT_SP_3_C1)

In the case of cooking, if for some recipe only the egg yolk is needed from the whole egg, and not the egg white, and for her it was completely clear that you simply throw it away, and for me that was not clear at all, because I am used to it from back home that you are not wasteful with food. And the assistant didn't take that seriously at all and laughed at me, how granny-like I am and said "I shouldn't have told you, if you don't know [that I dispose of it] you won't be annoyed." That in turn really annoyed me, because under no circumstances do I want things to happen behind my back. I like that if something concerns me, things are done in the way that I find them correct, also ethically correct, something like that. (AT_SU_04_C3)⁷⁸

The conflict here is based not only on the assistant's ignorance of the instruction competence but also on the fact that the assistant would counteract it behind her back. In this case, the assistant performs the household work in a way she would do in her home for herself, but not the way expected by her employer. Another example of assistants violating the instruction competence of service users, is related to speaking for the service user in interactions with third persons. Carl names an example:

Sadly language is a traitor because if a wheelchair user comes, so if a friend of ours, a wheelchair user, comes and I ask my friend: do you want to drink something else, and the assistant says: "No, we don't want another drink", then I know what is going on. (AT_SU_03_C2)⁷⁹

Another source of such conflicts is different perceptions on how the working relationship is shaped. This source of conflicts is related to the management and staff competence of the service user. The different concepts of helping a friend, free contracting and employment seem to be a source of such conflicts. This is shown by a quote of Mary addressing the concept of free contracting in opposition to being employed:

I mean, in my opinion you did have to separate that: I am now a flat mate and can do what I like, and now I am at work and when we arrange Tuesday at five is the time when you go to the toilet with me, then that's your worktime. Also as it takes place in the flat, you need to be there at that time. And it emerged already in the first weeks that it didn't work at all with her, and then we said it's better she is just the flat mate and I know that I can't rely on her when it comes to assistance services. I think she wasn't aware of that, that for

⁷⁸ Beim Kochen: wenn für irgendein Rezept nur der Dotter vom Ei gebraucht wird und das Eiklar nicht und für sie war klar, das schüttet man weg und für mich ist das überhaupt nicht klar, weil ich bin das so gewohnt, auch von daheim, dass man das in ein Behältnis tut und dass man aus dem dann noch irgendwas anderes macht und dass man halt nicht so verschwenderisch mit Lebensmitteln umgeht. Dann hat sie das halt überhaupt nicht ernst genommen und mich ausgelacht wie omahaft ich bin und hat gemeint, „ich hätts dir nicht sagen soll, was du nicht weißt macht dich nicht heiß“ und das wiederum hat mich erst recht heiß gemacht, weil ich mag auf gar keinen Fall, dass hinter meinem Rücken dann Dinge passieren, sondern ich mag halt, dass das was mich betrifft, so gemacht wird wie ich es für richtig halte, also auch ethisch korrekt halte, so irgendwie. (AT_SU_04_C3)

⁷⁹ Und da ist die Sprache leider so ein verräterischeres Luder weil wenn halt eine Assistentin, also wenn eine Freundin von uns, eine Rollstuhlfahrerin, kommt und ich sag zur Freundin: willst du noch was trinken und die Assistentin antwortet, „Nein, wir wollen nix mehr trinken“, dann weiß ich was los ist. (AT_SU_03_C2).

me it's really existential and not "yes, if I am here I am here and if not, then not".
(AT_SU_04_C3)⁸⁰

In the end, the only solution is ending the service relationship. The tools to negotiate conflicting justice claims must be understood as tools to prevent conflicting justice claims. Findings indicate that it is too late when the conflict is already taking place.

3.3.1. CLEAR FEEDBACK

Open communication about expectations and clear feedback in case of failure to obtain the instruction competence, are important tools for the prevention of conflicts. Sandra for example explains that her assistant (a free contractor) informed her about her sickness and cancelled appointed service hours. Later on, the assistant never contacted her again. Two weeks later, Sandra called her assistant and asked if she had got better in the meantime. The assistant told her that she had recovered. Sandra then clearly told her assistant that she expected her to inform in case of recovery and to inform her of how long she approximately would be ill. She says:

And then I said, hey you, it doesn't work like that, if you are ill you can't not respond for two weeks, especially if you only have a bit of a cold or something, I do expect you to say at some point, yes, I am okay, or maybe I need another week and after that week we see how it goes for me, or something. But not hearing anything, I can't prepare for that and also can't tell the others: you need to jump in for a week or two or three, right. So in that simple manner, when communication is lacking. (AT_SU_01_C1)⁸¹

However, it can also be the case that needs and expectations are communicated clearly, and assistants do not obey them or make "false promises". Sandra highlights an example for such a situation, which also shows that unclear communication might lead to conflicts. Sandra requires her personal assistants to be ready to cycle with a tandem bike. She expressed this recruiting requirement in her job vacancy. An applicant said this is not problem for her. However, later on, the assistant found excuses for not cycling. Sandra said:

⁸⁰ Ich mein, also da hat man das schon meiner Meinung nach trennen müssen: jetzt bin ich Mitbewohnerin und darf tun was ich will und jetzt bin ich grad im Dienst und wenn wir ausmachen am Dienstag um Fünf ist deine Zeit wo du mit mir aufs Klo gehst, dann ist das deine Arbeitszeit. Auch wenn es in der Wohnung ist und dann musst du da sein zu der Zeit und das hat sich dann gleich in den ersten Wochen rausgestellt, dass das mit ihr gar nicht geht und dann haben wir gesagt, es ist gescheiter sie ist einfach nur Mitbewohnerin und ich weiß, dass ich nicht auf sie zurückgreifen kann was Assistenzdienste betrifft. Ich glaub ihr war das auch nicht so bewusst, dass das wirklich für mich existentiell ist und nicht so: „Ja, wenn ich da bin, bin ich da und wenn nicht, halt nicht“ (AT_SU_04_C3)

⁸¹ Und dann habe ich gesagt, du, das geht so nicht, du kannst nicht, wenn du krank bist, dann zwei Wochen nichts hören lassen, vor allem wenn du nur so, ja, bisschen grippig oder so bist, ja, erwarte ich dann schon, dass du irgendwann wieder sagst, ja, jetzt geht es wieder oder vielleicht brauche ich die Woche noch, und nach der Woche schauen wir dann weiter, wie es mir geht oder so. Aber so gar nichts, da kann ich dann gar nicht mich einstellen drauf oder auch den anderen nicht sagen, du musst jetzt eine Woche einspringen oder zwei oder drei oder. Also so einfach, wenn die Kommunikation fehlt. (AT_SU_01_C1)

At some point I said: hey, does the thing with the cycling annoy you? Then she said: yes, she doesn't feel so well when she does it. Then I said, yes, I would have preferred if she had honestly told me that in advance, because always these excuses, then that's a bit [...] yes, and then I said but if it doesn't work at all for you, we need to find another solution or then I can't keep it up because for me it's important and I need the exercise, and that was the case from the beginning, it also says so in the call [for service provision] and I always mention that in the conversation with the person, that it's important to me. Yes, she also understood that, but she wasn't too happy about it but then, it wasn't possible in any other way. (AT_SU_01_C1)⁸²

Conflicts may arise in case needs and qualifications are not communicated clearly and openly. In another example, requirements were communicated clearly too. However, the assistant failed to obey them. Diana and Carl were invited to a wedding and went there together with a personal assistant. This personal assistant met a friend of hers at this wedding and started talking with the friend and thereby neglected her assistance duties. Carl says:

So I would never say "you, do your job", but I would narrow it down to the task level and say "now you do this, now you do that, now you do that", that means I don't give her the space for her to talk (...) around. And that's that. And in her case it happened that she got a rule reminder, and she then apologized anyway. So she was aware of what was happening. (AT_SU_02_C2)⁸³

When it comes to dealing with such conflicts, Carl and Diana point out the importance of adopting a clear leadership. A clear leadership is associated with transparent rules and an equal treatment of all assistants in a team. Diana says:

And I think we have a very predictable way of leading, so we don't say one thing today, another tomorrow, and then another the day after. And I think that's very important, this, this steadfastness and also the consistency in both directions. I can't demand consistency from the assistant and at the same time behave like the biggest donkey, that, that's not

⁸² Irgendwann habe ich gesagt: du, zipft dich das an mit dem Radfahren? Dann hat sie gesagt, ja, es ist ihr nicht so wohl dabei. Dann habe ich gesagt, ja, wäre mir lieber gewesen wenn sie es gleich ehrlich gesagt hätte, weil so immer die Ausflüchte, das ist dann ein bisschen. Ja und dann habe ich gesagt, aber wenn das für dich gar nicht geht, müssen wir eine andere Lösung finden oder dann kann ich das nicht aufrechterhalten, weil mir das halt wichtig ist und ich die Bewegung auch brauche, und das war von vornherein, eben das steht auch in der Ausschreibung und sage ich halt auch beim Gespräch immer dazu, dass mir das wichtig ist. Ja, hat sie auch verstanden, aber die war nicht so glücklich dann darüber, aber es ist halt dann, war nicht wirklich anders möglich (AT_SU_01_C1).

⁸³ Also ich würd nie sagen „Du, jetzt geh deinem Job nach“, sondern ich drehe es einfach auf die Aufgabenebene runter und sag, „Jetzt tust du das, jetzt tust du das, jetzt tust du das“, das heißt ich lass ihr die Luft gar nicht, dass sie da groß (...) redet. Und damit wars das. Und bei der wars dann so, die hat dann eine Regelerinnerung gekriegt und die hat sich dann eh entschuldigt. Also ihr war bewusst was Sache war. (AT_SU_03_C2)

possible. And on the other hand it of course also doesn't work, and sadly that's my observation in the community of people with disabilities: soft leading. (AT_SU_03_C2)⁸⁴

It appears that a soft leadership culture in personal assistance may lead to a blurring of boundaries between work and friendship and may bring the assistants not to take their work seriously. Soft leadership and blurred boundaries between work relation and personal relation cause problems in case of dismissal.

Findings also indicate that the leadership-ability of service users becomes better over time. Bad experiences with not serious assistants bring service users to adopt a more clear leadership role. It seems to be a learning process for the service users. Carl observes that personal assistance is not too far away from other work relationships. Thus, a clear leadership role is important:

In my assessment it's that you communicate clearly. So you really concretely say what you want, what you don't want (...) mostly also don't stray from this path because if you act like this today, is like that with every employer anyway, it only leads to the development of misunderstandings. And difficult working conditions and conflicts as well, ultimately. Fair treatment, so (...) still, employees should be treated in such a manner. (AT_SU_02_C2)⁸⁵

Service users are expected to provide clear instructions on how to perform the tasks. At the same time, a good service user is also ready for fair and justifiable compromises. Personal assistants perceive clear instructions and an open way of communication also as important tools to prevent conflicts. An assistant says:

That (...) communication works, so that also for the employer it's important to evaluate: how much can I put on the personal assistant? Where does he maybe have the need to catch up, or whatever? So simply that such an open conversation is possible. (AT_SP_01_C1)⁸⁶

Assistants request that open communication also includes the disability and the capabilities of the service users. The disability must not be tabooed in a service relationship. Assistants argue that – especially because of the laymen character of personal assistance – clear communication about

⁸⁴ Und wir haben glaube ich eine sehr berechenbare Art zu führen, also wir sagen nicht heute so, morgen so, und übermorgen wieder anders. Und das ist, glaube ich, sehr wichtig, diese, diese Standhaftigkeit und auch diese Konsequenz in beiden Richtungen. Ich kann nicht nur Konsequenz von den Assistenten fordern und mich selber aufführen wie der größte Esel, das das funktioniert nicht. Und umgekehrt funktioniert es natürlich auch nicht, und das ist leider meine Beobachtung in der Behindertenszene: nur weich zu führen. (AT_SU_03_C1).

⁸⁵ Meines Erachtens, das man klar kommuniziert. Also wirklich konkret sagt was man will, was man nicht will. (...) Diesen Pfad möglichst auch nicht verlässt, weil wenn man heute so tut und morgen so, das ist eh bei jedem Arbeitgeber so, da entstehen nur Missverständnisse. Und schwierige Arbeitsverhältnisse und Konflikte letzten Endes auch. Ein fairer Umgang, also (...) es sind ja dennoch Arbeitnehmerinnen und als solche auch zu behandeln (AT_SU_02_C2)

⁸⁶ Dass (...) die Kommunikation einfach stimmt, dass auch für die Arbeitgeberin abschätzbar ist, was kann ich dem persönlichen Assistenten zumuten. Wo hat der vielleicht Aufholpotenzial, oder wie auch immer. Also die Kommunikation ist einfach so ein, dass ein offenes Gespräch möglich ist. (AT_SP_01_C1)

disabilities and capacities is of importance. Personal assistants neither have qualifications nor experiences in working with people with disabilities. Personal assistants are not always aware of the capabilities of their service users. Sometimes they also neglect limitations and barriers due to the disability and a barrier-full environment. Also here, clear communication about of utmost importance for service provision:

Also when it comes to disability: communication, openness. So in the case of [name] I do ask directly how it is in certain daily situations, if I should help her or if I am coming on too strongly, and what she wants to do by herself, and I find that very positive in her case (...) and now concretely with [name] because I haven't made any other experiences. (AT_SP_01_C1)⁸⁷

Clear communication also helped another assistant in the same case dealing with her initial insecurities about how service should be provided. She says:

When I went shopping with her for the first time, I was very scared beforehand. I thought by myself oh god, how should that work, I have never done that before and then I simply told her, you need to tell me what I can help you with. And then she said, yes, let me hook my arm into yours and then we walked. And it wasn't a problem at all, everything worked really well. Only for me that was completely new, and everything was a new experience, right. (AT_SP_02_C1)⁸⁸

Personal assistants point out that clear instructions are part of respectful dealing with them. Constructive criticism and feedback is not only important for successful and effective service provision but also for a good working relationship in terms of preventing conflicts arising from conflicting justice claims.

3.3.2. PROFESSIONALISM

Findings indicate the importance of clear roles between service user (employer) and assistant (employee). Clear roles are important in person-centred services that are carried out by laymen. Concrete perceptions on clear roles differ among service users and assistants – they depend on the work relationships. Thus, the management and staff competence of service users is an important tool

⁸⁷ Auch über die Beeinträchtigung. Kommunikation, Offenheit. Also bei der [Name] frag ich einfach ganz direkt wie das einfach ist, in gewissen Alltagssituationen, ob ich ihr da helfen soll, oder ob ich mich da zu viel aufdränge und was sie alleine machen will und das find ich sehr positiv bei ihr (.....) und jetzt im konkreten Fall mit der [Name], weil ich ja keine andere Erfahrung hab. (AT_SP_01_C1)

⁸⁸ Spannend war ja, wie ich das erste Mal mit ihr, also ich war ja nur einmal mit ihr einkaufen, da habe ich voll Angst gehabt vorher, da hab mich mir gedacht, mein Gott, na, wie soll das gehen und ich habe das noch nie gemacht, und dann habe ich halt einfach zu ihr gesagt, du musst mir sagen, was auch immer ich dir helfen kann. Und dann hat sie gesagt, ja, lass mich einhängen bei dir und dann sind wir gegangen. Und es war überhaupt kein Problem, hat super hingehaut alles. Nur für mich war das halt total neu und eine neue Erfahrung und alles, gell. (AT_SP_02_C1)

to establish a respectful work relationship and prevent conflicts. The following quote shows the consequences in case the management and staff competence is not used clearly:

In practice it's the case that for people who have a personal budget within the employer's model, it's very difficult to dismiss someone, and on the other hand people let others (...) way too close to themselves. And that's a reciprocal effect. With that day, when I let someone too close to my, ideally without rules, I logically will have a hard time [dismissing them]. On the other hand I can't say "You are my best friend", and then in the next sentence: "You, I can't work with you." That's schizophrenic, it doesn't work like that. (AT_SU_03_C2)⁸⁹

This perspective draws on a professional, hierarchical relationship: the service user pays for service provision and this is not reconcilable with friendship, which should be based on an equal relationship.

Another service user also addresses this issue. However, she would allow a higher degree of closeness, as she perceives closeness as a feature of successful service relationships. Still, she is also aware of limitations in this regard: even if they make friends, there must be a boundary between the friendship itself and the service provision:

It also always depends on the person. Because actually I haven't had anyone who could have come on too strongly in private, or anything like that. Or if I, as a service user, come on too strongly in private. So I work with someone, yes, she does her things and then we don't actually have any contact other than that, it's only related to work. And others who say, yes, I don't know, I am at a [festival] today, do you want to come, or something. (AT_SU_01_C1)⁹⁰

Carl argues that conflicts and problems arise when the roles are not clearly defined and consequently there is a lack of leadership. He refers to the example of 24-hour live-in care work, in which leadership in service encounters is sometimes missing, because placement agencies take the leadership competence away from the service users:

24-hour carers surely have these problems in reality, because there is nobody who manages staff. These agencies, in reality they take away staff competences from you. The competence to make [financial] settlements – they take that away. The competence to guide [instruction competence] and interpersonal competence – nobody ever takes them

⁸⁹ In der Praxis ist es so, dass die Menschen, die persönliches Budget haben im Arbeitgebermodell massiv schwer tun zu kündigen. Also ich, ich beobachte zwei Dinge. Einerseits tun sie sich irrsinnig schwer zu kündigen, und andererseits lassen sie die Leute viel zu (...) nah zu sich. Und das ist eine Wechselwirkung. Mit dem Tag, wo ich den Leuten viel zu nah zu mir lasse, möglicherweise möglichst regelfrei, tu ich mir logischerweise schwer. Auf der einen Seite kann ich nicht sagen, „Du bist der beste Freund“ und im nächsten Atemzug: „Du, mit dir kann ich nicht zusammenarbeiten“. Das ist, das ist schizoid, das geht nicht. (AT_SU_03_C1)

⁹⁰ Es kommt immer auch auf die Person an. Weil eigentlich habe ich jetzt niemanden gehabt, der dann privat aufdringlich gewesen wäre oder so. Oder wenn ich jetzt als Assistenznehmerin privat dann zu aufdringlich werde. Also ich arbeite auch mit einer, ja, die macht halt ihre Sachen und dann haben wir eigentlich sonst keinen Kontakt, das ist nur auf die Arbeit bezogen. Und andere wieder, die sagen, ja, ich weiß nicht, ich bin heute am [Fest], schaust du auch vorbei oder so. (AT_SU_01_C1)

from you. And that's what it's really about. And in the case of 24-hour carers, relatives, they don't have time for staff management, for reflections or something like that. No time. And I think that's the, that's the crux. (AT_SU_03_C2)⁹¹

Placement agencies take over the staff and management competence, but they do not take over the instruction competence from service users and their relatives. Also in family care, the instruction competence is to a certain degree taken on by relatives. Thus, leadership is mentioned as an important tool to prevent conflicts and as central characteristic of personal assistance in opposition to care. A vague definition of roles may lead to a blurring of boundaries between work and friendship at the expense of effective service provision. Mary recounts her experiences with this vague boundary between friendship and work relationship. A quote from her clearly shows possible consequences of undefined leadership roles in a service relationship:

So I do think it gets very mixed, where I often realise it and am not completely sure: is it nice, that the person feels so close to me, or is it too much if of course, they borrow my socks, or of course they sit on my bed and study there, then I think it does overstep boundaries a little. But on the other hand I think: actually it is nice that she feels so close to me, that she has the feeling she is allowed to do that, so those are the tipping points, where I sometimes don't know exactly, where I sometimes do have the feeling that boundaries are overstepped or something, but on the other hand, yes, I do like it if there is more of a friendly relationship, and not a relationship related only to work. (AT_SU_04_C3)⁹²

Mary faces some difficulties in adopting a clear leadership role. She explains it by referring to the importance of friendship or at least sympathy when it comes to service provision. If her assistants perceived their work solely as a job and do it mainly for the money, she would perceive herself as a "suppliant" – just like in case of (unpaid) family care. However, this perception entails the consequence of an insecure leadership and instruction competence.

I often say, I don't want to hurt people and often don't say anything if I am not happy with something and just let it happen, but actually the most annoying thing is that even with the loveliest assistance, so sadly this also occurs, some are closer to me and in those cases

⁹¹ Die 24 Stunden Pflege hat genau diese Probleme sicher real, weil die niemand ist, der das Personal führt. Diese Agenturen, im persönlichen Assistenzbereich würde man sagen, Personalkompetenz nehmen sie dir in der Wirklichkeit. Verrechnungskompetenz, nehmen sie dir. Die Anleitungskompetenz und die zwischenmenschliche Kompetenz, die nimmt dir nie wer ab. Und um die geht's eigentlich. Und jetzt in 24 Stunden Pflege, Angehörige, die haben ja keine Zeit für Personalführung, für Reflexionen oder was auch immer. Keine Zeit. Und ich glaube das ist der, das ist die Krux (AT_SU_03_C2).

⁹² Also ich glaube es vermischt schon sehr, wo ich es dann oft merke und mir jetzt nicht ganz sicher bin: ist es jetzt schön, dass sich die Person so mir nahe fühlt, oder ist das jetzt zu arg wenn selbstverständlich meine Socken ausgeborgt werden, oder wenn selbstverständlich in mein Bett sitzt und dort lernt, dann denk ich mir, das ist ein bisschen grenzüberschreitend. Aber andererseits denk ich mir: eigentlich eh schön, wenn sie sich mir so nahe fühlt, dass sie das Gefühl hat, das darf sie, also eben, das sind so Knackpunkte, wo ich manchmal nicht genau weiß, wo ich manchmal schon so das Gefühl hab, dass meine Grenzen überschritten werden, oder so, aber andererseits, ja mag ich es schon wenn es eher so ein freundschaftliches und nicht nur arbeitsbezogenes Verhältnis ist. (AT_SU_04_C3)

I do say it very clearly, because with them I dare to and they need to deal with experiencing me like that. And those with whom I am not as trusting, I don't say anything and it's often very annoying, because it's exactly those who actually always do everything really well, they immediately get [the negative consequences] if something isn't right, and those where I often feel that something isn't right, with those I simply don't say anything. (AT_SU_04_C3)⁹³

It appears that it is easier for her to adopt her leadership competence if a friendship relation between her and the assistant exists. The importance of friendship in this case may be due to the fact that Mary needs extensive assistance, also in bodily care, targeting the very personal and intimate sphere. Carl and Diana, who adopt a hierarchical leadership role, do not need that body-centred assistance. They are blind and a little impaired in moving. Carl says that he would prefer a robot over a person as personal assistant. In case children are involved in the service relationship, a clear leadership role is important to protect the children.

Also in service relationships which are accompanied by friendship, it is important to draw a consistent line between working time and leisure time spent together as friends. Friendship also developed out of service relationships in case 1. No conflict emerged between friendship and work during scheduled service hours in this case. This is mainly due to the fact that the services are foreseen and thus, service hours can be arranged in a binding mode. There are no or very few unexpected services or spontaneously extended services. Keeping a sharp differentiation between friendship and work relationship is more difficult if service needs are rather unexpected or if service hours need to be unexpectedly extended. Particularly in case friendship grows out of the working relationship, service time and leisure time need to be defined in every encounter. An assistant points out:

Recently there was a flea market, [name] took part, so did I, and then there was the situation that I added some things [to the selling table]. I helped her with her story. Exactly. And then we tried to sell that and I was there the whole day, present, and for me personally it wasn't entirely clear how she sees that now, so if this is time as a personal assistant, this whole day, or if she sees it in a way that I can add all my things and that for me, that I basically also have some gain from that because I can sell things. (AT_SP_01_C1)⁹⁴

⁹³ And ich bin oft so, dass ich sag, ich will halt die Leute nicht verletzen und ich schluck oft Dinge und sag nicht wenn mir irgendwas nicht so passt und lass es halt so über mich ergehen und am allergeinsten ist es aber eigentlich, dass ich bei den allerliebsten Assistentinnen, also es gibt leider auch sowas, manche stehen mir halt näher und manche nicht und die mir am vertrautesten sind, bei denen sag ich das schon ganz klar, weil bei denen trau ich mich es und die müssen das dann aushalten mich so zu erleben und denen die mir nicht so vertraut sind, da sag ich dann nichts und das ist dann oft gemein, weil ausgerechnet die, die eigentlich eh immer alles super gut machen, die kriegen es dann gleich wenn irgendwas nicht passt und die wo mir eigentlich öfter mal was nicht passt, da sag ich halt einfach nix. (AT_SU_04_C3)⁹³

⁹⁴ Es war vor kurzem ein Flohmarkt, da hat die [Name] teilgenommen und ich auch und dann war die Situation so, dass ich ein paar Sachen [auf den Verkaufstisch] dazu gestellt habe. Ich hab ihr geholfen bei ihrer Geschichte. Genau und wir haben versucht das zu verkaufen und ich war eben den ganzen Tag da anwesend und mir persönlich war nicht ganz klar wie sie das jetzt sieht, also ob das jetzt eine persönliche Assistenzzeit ist, dieser

Waiting and seeing was the strategy applied by this assistant to find a way out of this conflict or insecurity about roles. The assistant explains:

For me that wasn't entirely clear. I then decided for myself to simply see how it develops, what she does to also see a little bit how she values me, how she sees it, how she treats it without ever having talked about it, and ultimately I also got the day paid for. So, we didn't talk about it a lot, it simply happened and thankfully it solved itself just like that, because we both saw it very similarly and if it had happened differently, then I would have asked her how she saw it back then, and that it was probably a misunderstanding and that maybe you mutually settle on an amount [of payment] that's somewhere in the middle. (AT_SP_01_C1)⁹⁵

In case Sandra had not paid for flea market attendance, the assistant would have felt a missing acknowledgement of his work and a lacking appreciation of him as a friend. In case Sandra had remunerated attendance, he would have informed her about the way he perceives it.

Thus, findings indicate that clear roles of employer and employee and adopting a clear and consistent leadership style are important tools to prevent conflicts and to have a serious work relationship. However, findings also show that not all service users aim to stick to the rules of a work relationship without any alternatives. The justice claims of service users rather include a certain degree of friendship or personal contact during service provision. Especially for these types of service users – the ones who adopt a soft leadership role – clear demarcation between service hours/work relationship and leisure time/friendship are important to prevent conflicts.

3.4. THE ROLE OF THE STATE AND THE LEGAL FRAMEWORK

Service users comment on how the state shapes working relationships through the personal budget. Basically, service users appreciate the personal budget for personal assistance and the way it is organised. The main reason for this appreciation is that it enables their self-determination. However, service users and their assistants discuss some problems.

While the legal framework of personal assistance enables a realisation of the justice claims of people with disabilities, the allocation of service hours is a bit non-transparent for them. Furthermore, the wages of personal assistants are unclearly regulated and consequently not always fair for some assistants. Personal assistants of people who are severely disabled and need assistance in bodily care

ganze Tag, oder ob sie das so sieht, dass ich meine Sachen dazu stellen kann und dass das quasi für mich eh, dass ich ja eh auch was davon hab weil ich ja Sachen verkaufen kann. (AT_SP_01_C1)

⁹⁵ Das war mir nicht ganz klar. Ich hab dann für mich beschlossen einfach zu schauen wie sich das entwickelt, was sie macht, auch um ein bisschen zu sehen, wie ihre Wertschätzung mir gegenüber ist, wie sie das sieht, wie sie das ohne darüber gesprochen zu haben behandelt und ich hab dann im Endeffekt den Tag auch bezahlt bekommen. Also, wir haben da nicht viel darüber geredet, das ist einfach passiert und es hat sich zum Glück einfach so gelöst, weil wir das beide sehr ähnlich gesehen haben und wenn das jetzt anders gekommen wäre, dann hätte ich sie schon gefragt, wie sie das damals gesehen hat und dass da wahrscheinlich ein Missverständnis war und dass man da sich auf irgendeinen Betrag vielleicht einigt, der irgendwo in der Mitte liegt. (AT_SP_01_C1)

and bodily mobility are underpaid. Although both personal assistants and service users point out that no training or qualification is required for assisting mentally healthy people in body care and body mobility, this hard work entails physical wear for assistants. This physical wear and the medical treatment it may entail are not remunerated.

The assistants enjoy the flexibility of the system of service vouchers and free service contracts. At the same time, they criticise lacking worker protection, i.e. no security in case of sickness, unforeseen workloads, no entitlements to paid vacancies. Moreover, assistants are only insured against accidents, but not against unemployment and service hours are not awarded for pension insurance. Findings indicate that the job as a personal assistant is assumed to be attractive mainly for students – it is a student job. It is not sufficient to earn a living, it is hardly reconcilable with caring obligations and it is low qualified work. In short, assistants enjoy the benefits of a free contract, but miss the benefits of employment.

Personal budget is paid directly to service users to enable them to hire personal assistants. This is highly appreciated by them. The fact that they themselves select the staff and instruct their staff – thereby being able to define the kind and amount of tasks performed – ensures their self-determination, which they highly appreciate. The management and organisation competence, i.e. developing the duty rosters of their team and the administrative efforts are not so appreciated, but accepted as part of self-determination. In short, service users enjoy the benefits of having the leadership and instruction competence but do not like the organisation competence and the administrative tasks it entails.

Sandra prefers the model of service vouchers because she does not have to pay for her assistants' sick leave. Moreover, in case she is sick and thus does not need personal assistance, she may just cancel the arranged service hours and does not need to pay. At the same time, she has no entitlement to a substitute in case her assistants are sick at short notice. She will have to organise the substitute herself. She says that she has no idea on how to make the situation more just without increased efforts for both parties.

Mary reports about the positive aspects of personal assistance:

So in general I am very, very thankful that that exists, because, so in my youth I didn't know anything about that and I actually assumed that I would have to spend my life in assisted living, and I am extremely grateful that I don't have to do that, and that I can live in this freedom and am allowed to shape my daily life in the way I like it, and that I can choose the people who work with me, because yes, they simply spend a lot of time with me and actually notice a lot about me and my daily life, and if that's not a good fit, then it's just exhausting and not nice, that's why I am very thankful that exists.
(AT_SU_04_C3)⁹⁶

⁹⁶ Also grundsätzlich bin ich einmal sehr, sehr dankbar, dass es das gibt, weil, also in meiner Jugendzeit, da hab ich noch gar nichts davon gewusst und hab eigentlich damit gerechnet, dass ich mein Leben in einem betreuten Wohnen verbringen muss und bin sowas von dankbar, dass ich das nicht muss und dass ich in dieser Freiheit leben darf und eben meinen Alltag so gestalten darf wie es mir halt gefällt und dass ich mir die Menschen selber

The system of personal assistance allows for self-determination and freedom for service users, it enables them independent living. However, it is also attended by administrative tasks, no entitlement to services – even in case of a work contract – and organisation. For service users, personal assistance offers low-threshold access to part-time work, which is reconcilable with their other duties. They are free to arrange working hours, there is no duty to work, but there is also no income in case of missing work or sickness. The system of personal assistance has both benefits and disadvantages for both sides.

However, some critical points relating to personal assistance came up during fieldwork. These will be addressed in the following sections.

3.4.1. ASSESSMENT OF ASSISTANCE NEEDS

The allocation of personal budget is based on diagnosis and an assessment of needs. The use of the personal budget is predefined and pre-assessed. This assessment is carried out via the Association on counselling, supporting and accompaniment of authorities in assessing the individual assistance needs of people with disabilities (*Verein zur Beratung, Unterstützung und Begleitung von Behörden zur Ermittlung des individuellen Hilfebedarfs von Menschen mit Behinderung, IHB*). This is a private association and there is no legal obligation to an expert assessment or the inclusion of people with disabilities into this assessment. Moreover, the inclusion of medical expertise into this assessment of needs is not foreseen. In practice, the assessment for the provision of personal budget works as follows: applicants turn to the IHB and discuss with social workers and pedagogues their personal circumstances and what tasks they need assistance for. Based on this, the IHB issues a recommendation on the amount of personal budget to the province of Styria. According to the experience of service users, the authority usually follows this recommendation. Service users criticise the scarce participation of peers, i.e. people with disabilities, in this assessment. Those who decide on the service provision are mainly social workers. They do not have specific expertise on the needs of, for instance, blind persons in terms of braille, usage of IKT and digital barrier freedom.

Thus, service users argue for the participation of persons with disabilities in assessing the amount of personal budget:

I think it would help immensely if those who are affected were be a part of that procedure, and not those people who believe that they know in an expert manner what is needed and what isn't. The inclusion of peers in the assessment would be better, where you simply know from practice what you are talking about and not based on supposed theory. [...] Because I have been living with my disability for more than ten years. [...] it would make sense to really underpin that together with those who are affected, and not with

aussuchen darf, die mit mir arbeiten, weil ja, die verbringen einfach ganz viel Zeit mit mir und kriegen eigentlich ganz viel von mir und meinem Alltag mit und wenn das nicht gut passt, dann ist das einfach anstrengend und nicht schön, darum bin ich da sehr dankbar, dass es das gibt. (AT_SU_04_C3)

those who think they have an expert qualification. Because you can't get an expert qualification on me. (AT_SU_02_C2)⁹⁷

A critical point for families such as those in case 2 is that the personal assistance is not available for their childcare. The service users perceive this as unjust because they have the right and the duty to parental custody. However, the provision of personal budget is oriented toward the service user's needs and the need for assistance in child care is hardly included under the service user's needs. The authority perceives assistance for childcare as direct support for children and thus denies financing it for disabled adults. Service users perceive it as assistance for them, as they themselves have parental responsibility.

Sandra's funded service hours were reduced from 500 to 200 from one year to the next without any justification by the authority. Sandra provided evidence that she actually used all these 500 service hours the year before. Still, the personal budget was reduced. She reports about the consequences of this reduction:

If you immediately have 60% less help, then a lot of liberty falls away. Then I need to think about what I do with the four hours left in the week: do I go and shop for food, or would I rather want to do something related to free time? And I fell into quite a depression because I didn't get out much during that time. (AT_SU_01_C1)⁹⁸

She highlights another example:

They also say: "Yes, you don't need to go to the shop with your assistant, you can order online anyway." Or: "Such tandem excursions with the bicycle or any trips: you don't need to take these trips." Then it's clear: if I don't need to do anything, there will be less hours. (AT_SU_01_C1)⁹⁹

During the observation, she also explains that the lady at the authority recommended her to register at an online-dating service to find somebody, to assist her in cycling and other leisure activities. Sandra responded: "And how should I pay for this assistance – with sex?" Then the lady at the authority

⁹⁷ Ich glaube es würde schon enorm helfen, wenn bei diesen Verfahren Betroffene mitwirken würden und nicht Leute die meinen facheinschlägig zu wissen, was gebraucht wird und was nicht, sondern besser wär das in Form von peers, wo man halt einfach weiß wovon man spricht, aus der Praxis und nicht aus der vermeintlichen Theorie heraus. [...] Weil ich lebe mit meiner Behinderung, mehr als zehn Jahre. Es ist (...) es wäre sinnvoll das wirklich mit Betroffenen gemeinsam zu untermauern und nicht mit Menschen die glauben eine facheinschlägige Ausbildung zu haben. Weil zu mir kann man keine facheinschlägige Ausbildung machen (AT_SU_02_C2)

⁹⁸ Und wenn man dann gleich einmal um 60% weniger Hilfe hat, dann fällt viel weg an Freiheit. Da muss ich mir dann überlegen mit den vier Stunden, die bleiben in der Woche: gehe ich Lebensmitteln einkaufen oder möchte ich doch etwas Freizeitmäßiges machen? Ich bin dann auch in eine ziemliche Depression geschlittert, weil ich wenig rausgekommen bin zu der Zeit. (AT_SU_01_C1)

⁹⁹ Die sagen dann ja auch: ja, Sie müssen eh nicht mit einem Assistenten einkaufen gehen, Sie können ja eh online bestellen. Oder eben: so Tandem-Ausflüge mit dem Rad oder irgendwelche Ausflüge: müssen Sie ja eh nicht machen, diese Ausflüge. Da ist es dann klar: wenn ich nichts muss, dass dann weniger Stunden rauskommen. (AT_SU_01_C1)

alluded to the fact that she likes to play guitar and has other artist hobbies. She responded that she would be creative enough to find solutions for these issues.

This massive shortage of service hours brought Sandra to depression and an in-patient stay in hospital. She applied together with her psychiatrist for an increase of paid service hours. The psychiatrist confirmed that this service user suffered from depression due to the lacking mobility and possibility to exercise her hobbies. In response to this application supported by the psychiatrist, the authority immediately arranged an appointment with her. There, she complained about the reduced service hours again and said that she is indeed aware of other persons with similar disabilities who have been granted 900 service hours and the like. She criticised this arbitrariness and expressed her readiness to inform the media. She then immediately got granted her needed amount of personal budget.

3.4.2. WAGE COMPENSATION AND WORK CONTRACTS

The personal assistants in the sample are freelancers, although they work in private households and are strongly determined by the instructions of their contractors. Work in private households is subject to the law on household services, which provides for employment. Work in private households as employment brings sick leave, paid vacancies and 14 instead of 12 monthly salaries, they are entitled to further education measures amounting to four days.

According to a service user, the Public Health Insurance Company noticed that work contracts as freelancers and work in private households are not reconcilable. Worker protection measures do not apply to freelancers. Freelancers receive payments only when they work, they are not entitled to paid holiday and in case they are sick, they simply earn no money. A personal assistant comments on this:

Because it really is like that, I come to work because I am ill / so if I am a bit ill, I still want to earn money. And that's the way it is, yes, no, I am not feeling fine, I can / I can call in sick and so on. But the thing is, it is / so that was always a reason where I thought I really need to look out for a different form of work, because there is no holiday money. I once got hurt on the hand and I think I was unable to work for two months or so. And I did realise why full employment would have been better. But as I said, as student it was perfect the way it was. (AT_SP_04_C2)¹⁰⁰

In order to solve this problem, the law on vouchers for household services was created. The law on vouchers for household services allows freelancing in private households without employment related

¹⁰⁰ Weil so ist es wirklich, ich komme halt zur Arbeit, weil ich krank/ also weil ich halt angeschlagen bin, aber ich will ja auch ein Geld verdienen. Und so ist es halt, ja, nein, geht mir nicht gut, ich habe eh/ also ich kann eh in Krankenstand gehen und so. Das Ding ist, es ist schon/ also das war schon auch immer ein Grund, wo ich mir gedacht habe, ich muss dann einmal unbedingt wegen einer anderen Arbeit schauen, eben weil kein Urlaubsgeld. Ich habe mir einmal weh getan bei der Hand und ich war glaube ich zwei Monate oder so bin ich ausgefallen komplett, und dann habe ich auch kein Geld gekriegt. Und ich habe es dann schon gemerkt, warum eine Anstellung besser wäre. Aber eben, als Studentin war das so perfekt wie es war. (AT_SP_04_C2)

entitlements. However, the thirteenth and fourteenth wages are compensated by a higher hourly salary.

Although in the case of the voucher for household services, that's not entirely true, because in the so-called minimum wages, this is included in aliquots, the holiday- and Christmas thing [13th and 14th wage in Austria]. So in general it's not entirely true, but what is true is that if they are ill, they don't get anything. That's the only thing that's right, so to say, because the rest, when it comes to holiday- and Christmas money, it's only half true, because in the minimum wages that's included in aliquots. (AT_SU_03_C2)¹⁰¹

There is no trade union or worker's representative organisation for personal assistants. Only a minimum wage is defined by the law on the vouchers for household services. According to a service user, trade unions are not needed in personal assistance, as the law on vouchers for household services is strong enough to protect workers' rights. In his view, assistants would lose out in stronger regularised systems. However, he could not argue more comprehensively why exactly assistants would be the losers of trade unions or having worker rights. For him, the service voucher model is best as it entails a higher hourly salary for assistants but not administrative efforts for service users. Somehow, he ignores that the model of service vouchers offers no protection of workers' rights.

Service users as well as assistants perceive the wage compensation of personal assistance as not just. Service users say that they have no influence on this, as the wages are pre-defined either by the collective agreement for social workers or by the law on service vouchers for household work. However, the law on service vouchers for (laymen) household work does not differentiate between tasks. A service user says:

It becomes unjust when someone works for me and, let's take a lady who is sitting in a wheelchair, and gets the same amount of money for that. That's unjust. Why? Because in the case of supporting the person in the wheelchair, he will end up ruining his body sooner or later. That's simply the case, there is a lot of lifting to do. It's almost exclusively lifting, laying down, bathing, so you call it a care service. And to say that you would apply the same scale of measurement, that would make it unjust. (AT_SU_03_C2)¹⁰²

According to the law on vouchers for household services, personal assistants, who also carry out bodily care, are entitled to a minimum wage of €16,20, while personal assistants, who do not, receive a minimum wage of €13,97 per hour. The requirement of carrying heavy weight in the long run has consequences for the health condition of assistants. The hourly payment of an additional two euros

¹⁰¹ Wobei das stimmt beim Dienstleistungsscheck nicht ganz, weil nämlich in den sogenannten Mindestlöhnen aliquotiert mitgerechnet wird, der Urlaubs- und der Weihnachtsgeld. Also im Prinzip das stimmt nicht ganz, aber was stimmt, wenn sie krank sind, kriegen sie nichts. Das ist das einzige sozusagen was stimmt, weil der Rest, mit Urlaub und Weihnachtsgeld, das stimmt nur jein, weil es wird dort gleich in den Mindestlöhnen wird das gleich mitaliquotiert abgerechnet. (AT_SU_03_C2)

¹⁰² Ungerecht wird's dann, wenn jemand für mich arbeitet und für eine, nehmen wir eine Dame her, die im Rollstuhl sitzt und dafür gleich viel bezahlt bekommt. Das ist ungerecht. Warum? Weil im Falle der Unterstützung einer Rollstuhlfahrerin ruiniert er sich früher oder später den Körper. Das ist einfach so, das ist einfach viel zum Heben. Das ist fast ausschließlich zum Heben, zum Legen, zum Baden, als, pflegerische Tätigkeit nennt man sie. Und da zu sagen: da setze ich dieselben Maßstäbe an, da wird's dann eher ungerecht werden. (AT_SU_03_C2)

cannot compensate for the physical wear caused by this kind of assistance, i.e. the need for physical therapy. This is confirmed by the personal assistant of a person with severe mobility impairments (case 3):

Because for example if you have people in wheelchairs who are extremely overweight – as an assistant you simply need physical therapy yourself, otherwise you would ruin your body. You mostly work uni-laterally, because some things only work that way. The person always lays in bed in the same direction. That means you always dress them with the same movements. I myself had physical therapy for example and I noticed over time that my spine has become worse and I asked my physical therapist whether it can be the case that my spine changes because of work, and then she said she would confirm that for 100%. And if I don't want to have extreme pains at some point, also the physical therapy should be paid for and I would find it nice if that was included in the remuneration. (AT_SP_05_C3)¹⁰³

Mary recognises that the model of employment offers assistants more protection, particularly in case of pregnancy. She additionally recognises the lacking protection of freelancers in terms of worker rights and fairness:

So if you are a student, then I think you are happy to earn a little extra, but if you do it for your whole life then in that sense, it's unjust. They are all registered as free employees and have all the pension insurances and all, and on the long run that whole thing is bad for them, on the other hand I don't have enough personal budgets to fully employ them, like full employment would be. (AT_SU_04_C3)¹⁰⁴

Her personal assistant confirms this point of view. She will complete her studies soon and then she will quit personal assistance. She says that payments for social assistance and also the way it is shaped do not allow people to build something up in their life or to have children. Payments are simply too low. Thus, she will be forced to search for a better-paid job. She indeed understands that no academic qualification is needed for personal assistance. Still, some service users are academics themselves and prefer assistants who have high education too:

¹⁰³ Weil beispielsweise wenn man Menschen im Rollstuhl hat, die sehr übergewichtig sind – als Assistentin braucht man dann einfach selbst Physiotherapie, weil man sich den Körper sonst einfach verhaut. Man arbeitet meistens einseitig, weil gewisse Dinge nur einseitig gehen. Die Person liegt immer in der gleichen Richtung im Bett, das heißt, du ziehst sie immer mit den gleichen Bewegungen an. Und ich selbst habe Physiotherapie genommen beispielsweise und ich habe auch im Verlauf der Zeit gemerkt, dass sich meine Wirbelsäule verschlechtert hat und dann meine Physiotherapeutin gefragt, ob das sein kann, dass sich meine Wirbelsäule verändert durch die Arbeit und dann hat sie mir gesagt, das wird sie mir 100 prozentig unterschreiben. Und wenn man nicht irgendwann einmal starke Schmerzen haben will, dann gehört die Physiotherapie auch bezahlt. Ich fände es schön, wenn das mit einbezogen wird, in die Entlohnung. (AT_SP_05_C3).

¹⁰⁴ Also wenn man jetzt Studentin ist, dann ist man glaub ich froh, wenn man ein bisschen was dazu verdient, aber wenn man das für sein Leben lang macht, dann ist es in dem Sinne ungerecht. Sie sind ja jetzt alle eben als freie Dienstnehmer gemeldet und haben diese ganzen Pensionsversicherungen und das Ganze und das ist natürlich auf Dauer gesehen blöd für sie, andererseits, hab ich nicht genug persönliches Budget, dass ich sie wirklich voll anstellen kann, wie es jetzt eine richtige Anstellung wäre. (AT_SU_04_C3)

Of course she [service user] would love to have an educated person as an assistant or someone she knows from her private environment. But that doesn't work, because as soon as people start looking out for her money, they think: "Ok, having a family, building a house – I need to earn more, I can't do the job anymore." And at the same time she has to give up on people she would like to take, because we are only paid on level 4 [of the collective wage agreement] and normally I would be on level 7 or 8. And I know, if I find a workplace where I am remunerated better, I need to take that because otherwise I can't live the way I would like to on the long run. During my studies fine, but not after that. It does really impede liberty [of service users] a lot, which kind of assistants is available to them [as shaped by the state and legal framework]. (AT_SP_05_C3)¹⁰⁵

Mary furthermore notes that working times in her case are not reconcilable with childcare. She points out that she needs assistance at exactly those times when a baby or a child needs care too. This is in the morning to get up and receive bodily care, at noon to eat, and in the evening when going to bed. She explains that she indeed had an assistant with a baby who brought the baby with her. However, she is aware that this is an exceptional case. Generally, personal assistance – at least for her – and a baby are difficult to reconcile.

Almost all assistants in the case studies are students and can reconcile their work with their other obligations. They perceive the fact that no qualifications are required for personal assistance as positive, although the status of personal assistance is low.

Personal assistance combines elements of self-employment with elements of employment. For instance, assistants are bound by the instructions of service users, the work is carried out in private households and assistants usually do not own their work materials. These are typical elements of employment. On the other hand, assistants define the amount of service provision and also may refuse service inventions without consequences. They may work for different service users – there is no prohibition of competition – and they only earn money if they actually work. These are elements of self-employment.

Wages for this unqualified service are too low to keep academics in these jobs. Thus, these services are mainly attractive for students, but not for academics who perhaps want to start a family and expect a higher standard of living. Consequently, the (limited) wages in these services, limit the personnel competence of the service users.

To sum up, personal assistance it is an unqualified and punctual service. The punctual character of the service has consequences for the social security and rights of the assistants. On the

¹⁰⁵ Sicher hätte sie gerne gebildete Menschen als Assistenten oder solche, die sie aus ihrem privaten Umfeld kennt. Geht aber nicht, weil sobald die Leute anfangen auf ihr Geld zu schauen, denken sie: ok, Familiengründung, Hausbau – ich muss mehr verdienen, ich kann den Job nicht mehr machen. Und sie muss gleichzeitig auf die Leute verzichten, die sie gerne nehmen würde, weil wir halt nur auf Stufe 4 (des Kollektivvertrages) entlohnt werden und normalerweise bin ich halt auf Stufe 7 oder 8. Und ich weiß, wenn ich eine Arbeitsstelle finde wo ich besser entlohnt werde, muss ich das annehmen, weil ich sonst selbst nicht so leben kann, wie ich es langfristig gerne möchte. Das ist während dem Studium ok, aber danach nicht mehr. Das schränkt die Freiheit halt schon sehr ein: welche Assistentin steht mir zur Verfügung. (AT_SP_05_C3)

one hand, it is an ideal and typical student job, as it provides for / and requires flexibility and offers a low-threshold accessible extra income. On the other hand, it does not provide any worker protection (i.e. protection against unemployment, sickness or pension). The laymen character of this work impacts earnings and wages.

4. CONCLUSION

It has to be concluded that the concept of personal assistance is in line with the justice claims of people with physical/sensory disabilities. Personal assistance supports them in their independence and it enables a self-determined life. Personal assistants' work is related to substituting the disabled body part when service users live their daily lives and perform their self-care. The fact that the person with a disability hires and pays the assistants significantly reduces their vulnerability and balances their situation by offering a work relationship, which is on an equal footing. All decision-making lies with the person with disability, which is important when it comes to the ability to live a self-determined life. The competence and power to hire and pay assistants keeps persons with disabilities independent from the "good will" of their families and friends. Moreover, it keeps the persons with disabilities independent from the "paternalistic" care of pedagogic professionals in agencies. The staff and budget competence acts as a safeguard for service delivery. Thus, personal assistance as it is conceptualised is suitable to compensate vulnerabilities of persons with disabilities and – if certain requirements are met – to prevent conflicts in service encounters. There is no mutual dependency between service user and assistant – both are free to end the work relationship at any time in case they are not satisfied with the working conditions or the work performed. The obligations of assistants are directly related to the service user.

The findings of the interviews and the insights into the daily life of people with disabilities from the observations highlight that persons with physical disabilities are experts for themselves and thus know best what they want. There is no need for care, counselling or social work – people with disabilities care for themselves.

Findings provide no evidence for a special relevance of the factor "private household" when it comes to negotiation of justice claims. Several reasons can be found for the lacking relevance of the private household. Firstly, personal assistance is not reduced to the private household: it takes place wherever the service user requests. Secondly, the services are person-related in the first place and the space relation of services only comes later on. The private household plays only an indirect role on an instrumental level, when it comes to household work. For instance, conflicts may result from different perceptions on wasting food, clean homes or supermarkets. However, these are more issues of lifestyle, which are negotiated at the household level. These are no household issues in the narrow sense. Thirdly, personal assistance is carried out in a rather punctual manner; these are no live-in care relationships.

Selecting the assistant and defining the services needed, as well as the way they are carried out, are important justice claims to a self-determined life. This becomes apparent when considering the findings on the justice claims of service users as showed in the report. Conflicts are related to a lacking or insequent leadership competence and an ineffective communication and unclear

instructions. Moreover, conflicts result from assistants who exceed their competences (e.g. sharing their opinions) or who do not perform well (e.g. in household tasks). Thus, clear communication about requirements and rules for service provision and also a clear (and consistent) adherence to the roles of employer and employee are important to prevent conflicts.

The following justice claims of assistants can be found: visible work impact and acknowledgements expressed through feedback. Moreover, clear limitations of service provision in terms of time and tasks constitute an important share of the assistants' justice claims. However, findings related to the role of the state and the legal framework also indicate that personal assistance is in line with justice claims of students or those who seek temporary employment and additional money. Personal assistance as a job is not so attractive for qualified persons or those who need to live from work.

Basically, these conclusions can be drawn out of all cases similarly. The cases differ when it comes to the leadership style and the definition of roles. In case two, a strong emphasis is put on leadership and working roles. An important reason for this strict leadership style and the clear roles is the involvement of children. Case three represents an opposing leadership style. In case three, the boundaries between work and friendship are blurred to a large extent – the work relationships are completely different from those in case two. Assistants are friends and friends are assistants. A reason for this is the intense and body-centred needs of the service user. Case one is a mix between the other two: no children are involved, but also no intense assistance in body care is demanded. In case one, some service relationships are accompanied by friendship, while others are not.

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