The experiences of support work relationships within the ruling relations: An institutional ethnographic study on the relationships between personal budget holders with intellectual disabilities and their support workers in Germany and Australia

Author:
Lutz, Deborah Luise

The experiences of support work relationships within the ruling relations

An institutional ethnographic study on the relationships between personal budget holders with intellectual disabilities and their support workers in Germany and Australia

Deborah Luise Lutz

A thesis submitted in fulfilment of the requirements for the degree of
Doctor of Philosophy

UNSW
S Y D N E Y

Social Policy Research Centre
Faculty of Arts and Social Sciences
University of New South Wales

March 2019

Thesis/Dissertation Sheet

Surname/Family Name	:	**Lutz**
Given Name/s	:	**Deborah Luise**
Abbreviation for degree as give in the University calendar	:	**PhD**
Faculty	:	**Arts and Social Sciences**
School	:	**Social Policy Research Centre**
Thesis Title	:	**The experiences of support work relationships within the ruling relations: An institutional ethnographic study on the relationships between personal budget holders with intellectual disabilities and their support workers in Germany and Australia**

Abstract 350 words maximum: (PLEASE TYPE)

Many countries have introduced personal budgets for people with intellectual disabilities. A personal budget is a sum of money that allows people with intellectual disabilities to purchase their own support work. Support workers are people who assist budget holders to organise and do activities, such as household tasks and social activities in the community. This thesis uses care, Ethics of Care and disability studies literature to conceptualise support work relationships – the relationship between budget holders with intellectual disabilities and their support workers. It investigates two research questions: (1) How do people with intellectual disabilities in receipt of a personal budget and their support workers experience their relationships with each other? (2) How are the lived experiences of people with intellectual disabilities and their support workers in their relationship with each other influenced by personal budget policies organising support work? Through the methodology of Institutional Ethnography, the researcher explores both questions in Germany and Australia. This methodology states that people's everyday experiences are influenced by the 'ruling relations', which are policy processes and people's practices that organise social settings.

During one year of ethnographic field research in Germany and Australia, the researcher conducted participant observation and interviews with five people with intellectual disabilities and their support workers from each country. Additionally, the researcher conducted interviews with ten service professionals in each country and analysed disability policy documents from each country. By using the analytical framework of Institutional Ethnography, the study found that the constituents of the ruling relations included people's views and expectations about the support work relationship, the support work context and the policies of personal budgets. The policies of personal budgets were only one constituent of the ruling relations that operated within a wider social policy context. The interconnection between the three constituents influenced the ways in which the two people engaged in the emotional form of support work (the social interaction) and the practical form of support work (the support work activities) which affected their relationship. The study argues that disability research, policy and practice needs to be cognisant of all three constituents to improve the quality of support work relationships.

FOR OFFICE USE ONLY   Date of completion of requirements for Award:

ORIGINALITY STATEMENT

'I hereby declare that this submission is my own work and to the best of my knowledge it contains no materials previously published or written by another person, or substantial proportions of material which have been accepted for the award of any other degree or diploma at UNSW or any other educational institution, except where due acknowledgement is made in the thesis. Any contribution made to the research by others, with whom I have worked at UNSW or elsewhere, is explicitly acknowledged in the thesis. I also declare that the intellectual content of this thesis is the product of my own work, except to the extent that assistance from others in the project's design and conception or in style, presentation and linguistic expression is acknowledged.'

Signed   …………………………………………...............

Date   …………………………………………...............

INCLUSION OF PUBLICATIONS STATEMENT

UNSW is supportive of candidates publishing their research results during their candidature as detailed in the UNSW Thesis Examination Procedure.

Publications can be used in their thesis in lieu of a Chapter if:

- The student contributed greater than 50% of the content in the publication and is the "primary author", ie. the student was responsible primarily for the planning, execution and preparation of the work for publication
- The student has approval to include the publication in their thesis in lieu of a Chapter from their supervisor and Postgraduate Coordinator.
- The publication is not subject to any obligations or contractual agreements with a third party that would constrain its inclusion in the thesis

Please indicate whether this thesis contains published material or not.

☐   *This thesis contains no publications, either published or submitted for publication (if this box is checked, you may delete all the material on page 2)*

☒   *Some of the work described in this thesis has been published and it has been documented in the relevant Chapters with acknowledgement (if this box is checked, you may delete all the material on page 2)*

☐   *This thesis has publications (either published or submitted for publication) incorporated into it in lieu of a chapter and the details are presented below*

CANDIDATE'S DECLARATION

I declare that:

- I have complied with the Thesis Examination Procedure
- where I have used a publication in lieu of a Chapter, the listed publication(s) below meet(s) the requirements to be included in the thesis.

Name	Signature	Date (dd/mm/yy)

Postgraduate Coordinator's Declaration (to be filled in where publications are used in lieu of Chapters)

I declare that:

- the information below is accurate
- where listed publication(s) have been used in lieu of Chapter(s), their use complies with the Thesis Examination Procedure
- the minimum requirements for the format of the thesis have been met.

PGC's Name	PGC's Signature	Date (dd/mm/yy)

Acknowledgements

I am conscious that I would have not been able to complete this research project without certain relationships. The support I received - through those relationships – comes from very special people in my life whom I would like to acknowledge on the next two pages.

First and foremost, I would like to express my respect, gratitude and admiration to *all the people who took part in this research study*, especially the people with intellectual disabilities and their support workers. You opened up to me in such generous ways and made this research important and alive. I will never forget the time we shared together and hope that I have been able to present your experiences with fidelity and in a way that is meaningful to you. It is my hope that these experiences will contribute to a richer understanding of what it is like to be in a support work relationship.

I would like to thank my two teachers, from whom I have learned on a personal and professional level. Thank you to my supervisor *Professor Kelley Johnson* for her warmth, care, patience, sensitivity and wisdom. You have always made time for me and took a genuine interest in the lived experience of my research participants and my own. I also want to thank my supervisor *Professor Karen Fisher* for her humour, trust, focused mind and enormous confidence in me as a researcher and woman. Kelley and Karen have guided me very thoughtfully through this project – all the way to Cavafy's Ithaca. I thank them for being so committed to me during this journey and for never losing faith in me.

I further pay tribute to *Professor Thomas Meyer*, my German mentor and advisor, whom I have known since my undergraduate studies. You were the first person who showed me that research is fun and always encouraged me to not give up the discovery. I feel grateful for your generosity in sharing ideas, your ongoing interest in my work and your open heart and mind.

Over the last ten years, my uncle *Dr Paul Fairchild* from the USA has been a wonderful writing mentor to me. I am indebted to you for your kindness, wisdom and gentle guidance that supported me to write in the English language with more clarity and grace.

Thank you to *the people at UNSW Australia* whom I have learned from over many years, including *Professor Leanne Dowse* for giving critical and supportive feedback on my work along the way as the expert reader of my annual review panel. UNSW Australia and the Faculty of Arts and Social Sciences have generously provided scholarships to finance a very time-consuming ethnographic study in two countries. Thank you.

The limited pages of this section cannot capture the credit that *all my friends* deserve. It would be impossible to name them all individually, but my friends know who they are. Throughout this tough and challenging PhD journey, they have reminded me that life is about having fun and being kind, generous and forgiving. I thank them for listening, making me laugh and for showing me that distance, nationality and many other things mean so little when someone means so much.

Finally, I would like to thank *all my extended family* who supported me in so many different ways throughout this journey. Most important to me has been the care and love of my parents who are both experienced practitioners in the field of disability. My mother has been my foundation for the world of intellectual disability. Throughout my life, I have been very fortunate as I witnessed the deep friendship and generous love my parents share with each other. This PhD thesis is dedicated to my parents, *Andrea and Günter*, in recognition of their companionship and unconditional love for each other. It is an acknowledgement of my ongoing gratitude for nurturing my sister Sophia, my brother Jonathan and me with their relationship.

Publications arising from the writing of this thesis

Article

Lutz, D. L. (2015). Friend or worker? Understanding relationships between people with intellectual disabilities and their support workers through Institutional Ethnography, *Human Welfare*, 4, 27-33.

Conference presentations

Lutz, D. (2017). *What can Institutional Ethnography offer? Learning about the connections between the lived experiences of support work relationships and disability policies.* Paper presented at the 14th NNDR Conference in Örebro, Sweden.

Lutz, D. (2017). *Using participant observations to understand relationships between people with intellectual disabilities and their support workers: methodological insights and challenges.* Paper presented at the 14th NNDR Conference in Örebro, Sweden.

Abstract

Many countries have introduced personal budgets for people with intellectual disabilities. A personal budget is a sum of money that allows people with intellectual disabilities to purchase their own support work. Support workers are people who assist budget holders to organise and do activities, such as household tasks and social activities in the community. This thesis uses care, Ethics of Care and disability studies literature to conceptualise support work relationships – the relationship between budget holders with intellectual disabilities and their support workers. It investigates two research questions: (1) How do people with intellectual disabilities in receipt of a personal budget and their support workers experience their relationships with each other? (2) How are the lived experiences of people with intellectual disabilities and their support workers in their relationship with each other influenced by personal budget policies organising support work? Through the methodology of Institutional Ethnography, the researcher explores both questions in Germany and Australia. This methodology states that people's everyday experiences are influenced by the 'ruling relations', which are policy processes and people's practices that organise social settings.

During one year of ethnographic field research in Germany and Australia, the researcher conducted participant observation and interviews with five people with intellectual disabilities and their support workers from each country. Additionally, the researcher conducted interviews with ten service professionals in each country and analysed disability policy documents from each country. By using the analytical framework of Institutional Ethnography, the study found that the constituents of the ruling relations included people's views and expectations about the support work relationship, the support work context and the policies of personal budgets. The policies of personal budgets were only one constituent of the ruling relations that operated within a wider social policy context. The interconnection between the three constituents influenced the ways in which the two people engaged in the emotional form of support work (the social interaction) and the practical form of support work (the support work activities) which affected their relationship. The study argues that disability research, policy and practice needs to be cognisant of all three constituents to improve the quality of support work relationships.

Contents

The budget holders and their support workers

The people introduced here are the people with intellectual disabilities and their support workers who took part in this study. They are placed at the front of the thesis as they are the most important people in it. Their names are pseudonyms and all information about them is from the time of the ethnographic field research (Feb 2016 to Jan 2017).

The Australian pairs

Felix Adler was a 26-year old man who received the Supported Living Fund and the Community Participation funding at the time of this study. He lived with his family and was in the process of moving into a house with two flatmates.

Michael Madden was a 28-year old man and had worked with Felix for six years. He usually worked with Felix once a week. He covered additional support work shifts on weekends and during holidays.

Elsa Hale was in her early 30s and received Community Participation funding. Elsa lived in a group home with two women and attended a day program.

Elizabeth Sweeney was Elsa's key worker. She was in her late 60s at the time of this study. She had been in the role of a disability support worker for a year and worked in the group home on three to four days a week which sometimes included sleep over shifts.

Lachlan Doherty was a 46-year old man who lived with his friend Paul in a house. Lachlan received the Supported Living Fund. He and Paul had a primary support worker, called William. They received support from four other support workers.

William MacArthur was a 38-year-old support worker who had worked with Lachlan for five years. William worked with Lachlan and Paul on four days a week and supported other people with disabilities.

Jeff Hughes was a 19-year old man with intellectual disabilities who attended a day centre from Mondays to Thursdays. The attendance at the centre was financed through the Community Participation funding. Jeff had many support workers at the day centre who worked with him.

Linda Schneider was in her early 30s. She had worked at the day centre for three years, but had only recently started to work with Jeff. As Jeff's key worker, she took part in his person-centred planning meetings, but she did not work with him every week.

Jack Chesterman was a 40-year old man with a Supported Living Fund. He lived with his parents at the time of this study. Jack had several support workers from two different providers who assisted him with household tasks and social activities outside the home environment.

Samantha White was in her late 50s and worked with Jack one day a week. She supported him in writing a shopping list, buying groceries from the local shops and cooking a meal. Samantha had worked with Jack for two years.

The German pairs

Yelena Weigel was a woman in her mid-20s and lived in an apartment on her own. Yelena did not use much verbal speech, but other means of communication, such as writing words on a piece of paper, facial expressions, sounds and body movements. Yelena had a personal budget for 'supported living' and was supported by four to six support workers.

Maria Baumann was a 22-year old support worker who studied Social Work. She had worked with Yelena for almost six months. She usually supported Yelena two days per week, but covered additional support work shifts when her colleagues were not available.

Helene Gehm was a young woman in her late 20s with Down syndrome. She had six support workers and received a personal budget for 'supported living' and 'recreational activities'. She took a strong interest in theatre play and singing.

Emma Lange had been Helene's support worker for many years, but had known Helene before she started working with her. Emma was about thirty years older than Helene and supported her on two consecutive days each week.

Lisa-Estelle Kaufmann was in her late 20s. Her personal budget covered support work for 'recreational activities', such as going to the gym and swimming, as well as 'supported living activities', such as cooking and cleaning. Lisa lived with her parents at the time of the study, but had planned on moving into her own place with her boyfriend soon.

Lydia Kupfer was in her early 60s and Lisa's support worker in the area of 'supported living'. She did the support work activities 'cooking' and 'cleaning' with Lisa. Lydia supported Lisa once a week and had worked with Lisa for more than five years.

Thomas Eckerts was a young man in his mid-20s and lived in a flat with four other people with intellectual disabilities. Thomas had a personal budget for 'supported living' and for 'employment'. He enjoyed rides on the tram, watching German football and writing poetry.

Luke Nold was in his late 30s and the support worker of Thomas. He had known Thomas for many years and supported him and his flatmates with activities that happened inside and outside the flat. Four other support workers worked in the flat, but not on the days when Luke was there. Luke was the primary support worker of Thomas and his flatmates. He worked full-time in this role.

Anja Kaltschmidt was a 26-year old woman and lived in a large residential facility with eighteen people with disabilities. She was the only person in the facility with a personal budget. Anja liked playing the harp and socialising with friends who lived in the same facility.

Laura Feldmaus was the 'key worker' of Anja and three other people with disabilities who lived in the same facility as Anja. Laura was in her early 50s and had supported Anja since she first moved into the facility. Laura enjoyed working with Anja and spending time with her outside the residential facility.

Glossary of terms

Budget holder: A person with disabilities using a personal budget.

(Disability) service provider: A social service that provides a range of support options to people with intellectual disabilities, including those who receive support through their personal budget. The involvement of the service provider in the organisation, implementation and delivery of the support can vary depending on the type of personal budget and the ways support work is organised.

Institution: Policy processes that can create hierarchical structures within social organisations. These structures can subject people to the ruling relations.

Personal budget: A personal budget consists of a certain amount of money allocated to a person with disabilities based on an assessment of their needs. It is intended to empower the person by enabling choice and control about how their money for support is spent and how the support is delivered.

Policy processes: People's activities and their relationships with others based on policies. These policies can include specific procedures, regulations and rules that operate in a social setting.

Ruling relations: The ruling relations organise and structure social settings. They are part of people's everyday activities and influence people's experiences.

Service professional: A service professional is a person working for a disability service provider and involved in the coordination and/ or management of support work organised through personal budgets.

Social organisation: This term is used to describe that people are part of social settings. In these settings, people work together and are part of policy processes through which they produce social knowledge within organisations.

Support work: Support work is a social service that can be purchased through a personal budget. It is the personal, direct and regular support delivered to people with disabilities by a paid worker. In Germany, and many other countries, support work is often referred to as '(personal) assistance'.

Support worker: The support worker is a paid worker (not a familial caregiver) who delivers the support work. This person usually assists the budget holder with day-to-day tasks, such as cooking, cleaning, using public transport, personal care and social activities. Support workers work in the home environment and the local community of the budget holder. In Germany, and many other countries, support workers are often referred to as '(personal) assistants'.

Third parties: These are persons who inevitably became part of the ethnographic fieldwork. They include house mates/ friends/ family members of budget holders and other support workers/ staff (e.g. team leaders of a group of support workers).

Abbreviations

ADHC	Ageing, Disability and Homecare (part of the Department of Family and Community Services in New South Wales, Australia)
CP	Community Participation (Funding)
CR	Critical Reflexivity
CRPD	(United Nations) Convention on the Rights of Persons with Disabilities
EoC	Ethics of Care
HREA	Human Research Ethics Advisory (Panel)
HREC	Human Research Ethics Committee
IE	Institutional Ethnography
ILS	Independent Living Skill(s)
LGA	Local Government Area
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NSW	New South Wales
OT	Occupational Therapy
PB	Personal Budget
PCP	Person-centred Plan(ning)
PIS and CF	Participant Information Statement and Consent Form
SLF	Supported Living Fund
TA	Thematic Analysis
TAFE	Technical and Further Education
TIE	Transnational Institutional Ethnography
UNSW	University of New South Wales

List of tables and figures

CHAPTER I: Setting the scene – Introduction to the thesis

> The heart must be,
> at each new call for leaving,
> prepared to part
> and start without the tragic,
> without the grief –
> with courage to endeavour.
>
> (Hermann Hesse, 2017, p. 187)

This thesis is about the support work relationship – the relationship between a person with intellectual disabilities using a personal budget (PB) and their support worker. This introductory chapter sets the scene for this thesis. It starts by explaining the rationale for the study which includes the researcher's personal motivation to undertake a study about support work relationships, as well as the context and background to the research topic. The chapter then introduces the conceptual approach to support work relationships and the methodology of the study. It ends by discussing the role of language, clarifying important terms and giving an overview of how the thesis is structured.

Rationale for the study

My personal interest and intellectual curiosity in exploring support work relationships arose from my previous role as a disability support worker, which I commenced as a high school student in Germany and continued till after I had completed my Master's degree in Australia when I was in my mid-twenties[1]. In this role, I had worked with children, young people and adults with intellectual disabilities, physical disabilities, diverse communication support needs and other kinds of impairments. One of my great learning experiences as a disability support worker included one year of working with a young boy with intellectual disabilities and autism who did not use verbal speech to express himself. Throughout this time, we gradually formed a close rapport that enabled me to

---

[1] I completed an undergraduate degree in Social Work at the Cooperative State University in Stuttgart (2006-2009), Germany and a postgraduate degree in Special Education (2010-2011), which I obtained from the University of Sydney in Australia.

understand why he was laughing, clapping or buzzing at certain moments. I also found myself in situations in which I could not fully understand the needs, desires, interests or wants that the people with intellectual disabilities I supported expressed. Not being able to respond in a way that felt appropriate to them concerned me. This concern was a starting point in questioning why these situations were occurring. My personal experiences as a disability support worker led me to wonder about how other people with intellectual disabilities and their support workers experience their relationships and negotiate these.

This study took place in two countries – Germany and Australia. As a German citizen with permanent residency status in Australia, I had a connection to both countries. I was born and grew up in Germany, but lived in Australia for seven years. I was located in Sydney, in the Australian state of New South Wales (NSW) for the first two years (August 2014 – July 2016) of the study and in Heidelberg, in the German state of Baden-Württemberg for the remainder of the time (August 2016 – March 2019). Having worked as a disability support worker, social worker and disability researcher in both countries, I could see differences in how support work had been organised through PBs in both countries at that time. For example, I noticed that the local government authorities in Germany providing funds in form of PBs played a major role in terms of deciding whether people with intellectual disabilities were granted a PB or not. On the other side, I could see that support staff in Australia were quite concerned about documenting the support work regularly and thoroughly, which the government authorities seemed to monitor closely. These observations made me curious about understanding the background to these policy procedures and their implications for budget holders with intellectual disabilities and their support workers.

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) provides an international framework for the rights of people with disabilities, including people with intellectual disabilities (United Nations, 2006). This framework acknowledges that they have a right to support that assists them in living a meaningful life (Johnson & Walmsley, 2010). Support within this human rights framework aims to promote their social inclusion and the respect for their inherent dignity (Johnson, 2013; Kayess & French, 2008). This framework has implications for the support work relationship as the support worker is intended to provide support to the budget holder with intellectual disabilities in ways that can facilitate the realisation of these rights. Therefore,

it is important to understand how budget holders with intellectual disabilities and their support workers experience their relationship. This I explore in this study.

The CRPD was ratified by the German government in 2009 and by the Australian government in 2008. Through this ratification, both countries made an official commitment to support people with intellectual disabilities in exercising their rights. This international commitment to change in disability policy and practice has shaped the idea of personalising (paid) support for people with intellectual disabilities. According to Article 19 of the CRPD, 'Living independently and being included in the community' (United Nations, 2006), they have a right to receive personalised support that places them at the centre of decision-making about their lives and promote their self-determination and independence in terms of how they want to live (Christensen, Guldvik & Larsson, 2013; Glendinning et al., 2008; Jones et al., 2014). One of the support and funding models consistent with these rights is the PB. A PB consists of a certain amount of government funds that can be granted to a person with disabilities to pay for services that support them in realising some of their rights (e.g. Johnson, 2013; Laragy, Fisher, Purcal, & Jenkinson, 2015; Slasberg & Beresford, 2015). Depending on the type of PB and its associated goals and activities, a support worker can provide this service and assist the budget holder in their home or local environment to achieve some of these rights (Shakespeare, 2014a).

The policies of support work and the type of funding attached to it have been found to be influential as to how budget holders and their support workers experience working together in these environments (e.g. Christensen, 2010, 2012; Leece & Peace, 2010). Research studies found that policies specific to PBs have potential to affect budget holders and their support workers (e.g. Christensen, 2012; Guldvik, 2014; Kelly, 2016; Leece, 2010; Leece & Peace, 2010; Ungerson, 1999, 2003; Yamaki & Yamazaki, 2004), but what has remained largely 'un-investigated' is how people with intellectual disabilities and their support workers experience their relationship with each other in the context of support work organised through the policies of PBs. Understanding these relationship experiences in connection to this social policy context can provide new pathways to knowledge about support work relationships. In this study, I add to this understanding by investigating how, in the policy contexts of Germany and Australia, budget holders with intellectual disabilities and their support workers experience their relationships under the influence of PB policies that organise support work.

Conceptual approach

The conceptual approach to support work relationships builds on the researcher's ontological understanding of relationships as social constructions that develop through human interactions (Gergen, 2015). I understand relationships as dialogic and dynamic processes between people, through which they give meaning to their individual lives. This view can help to understand certain aspects about one person in consideration of the other (Shakespeare, 2014a), generate balanced perspectives on both people's experiences in relationships (Folkestad & Folkestad, 2008; Kröger, 2009; Leece, 2010) and acknowledge that a person's social experience is, by definition, produced in relationships to others (Smith, 1996). This relational view reminded me to pay equal attention to both people within the support work relationship.

In Chapter II, I build the conceptual approach to support work relationships by drawing on care literature (e.g. Christensen, 2009, 2010, 2012; Kelly, 2011, 2013, 2016; Ungerson 1983, 2003), Ethics of Care (EoC) literature (e.g. Kittay, 2001, 2002, 2009a, 2009b, 2011; Rogers 2012, 2016; Rogers & Weller, 2013; Slote, 2007) and disability studies literature (e.g. Rogers, 2007, 2009; Shakespeare, 2006a, 2006b, 2014a, 2014b; Shakespeare, Stöckl, & Porter, 2018; Vehmas, 2012; Vorhaus, 2007, 2013, 2014, 2015). While the care theory and the EoC conceptualise 'care' as a form of support for people with intellectual disabilities, both take complementary theoretical positions. For example, the EoC developed as a feminist ethical theory that theorises the ethics of care-giving and care-taking. The care literature offers conceptual and theoretical perspectives on people with disabilities and their support workers and strongly connects with the disability studies theory I use in this thesis. The disability studies literature (e.g. Shakespeare, 2014a; Shakespeare et al., 2018) helped me to do discuss support work as a paid and professional service that inevitably becomes a social and emotional relationship. The disability studies perspective assisted me to understand the support work relationship in the context of PBs.

By combining the care, EoC and disability studies literature, I build a conceptual approach to analyse the experiences of budget holders with intellectual disabilities and their support workers. This approach understands that support work relationships are embedded in social policy contexts that have the potential to influence the experiences of the two people in the relationship. I selected the social policy contexts of PBs in Germany and Australia due to their related, but different policies of PBs and their potential

influence on support work relationships. Research from both countries identified barriers for people with intellectual disabilities in utilising PBs, but they did not explore the depth of the experiences of support work relationship. Both countries offer suitable places for the empirical exploration of support work relationships in new contexts of support work that are organised through PBs.

Research methodology

This research study is grounded in the qualitative methodology of Institutional Ethnography (IE), a social theory and empirical method developed by the Canadian feminist sociologist Dorothy Smith (e.g. Griffith & Smith, 2014; Smith, 1987; 1990a; 1990b, 1992, 1996, 2005, 2006). Smith (2008, p. 3) explained that IE 'reaches beyond the scope of standard sociological ethnographies' by making 'visible the translocal ruling relations that are present in, organize, and are beyond people's everyday lives'. The ruling relations are policy processes that make up people's practices, as well as rules and regulations that affect people's everyday experience. They are created by social organisations (e.g. disability services, government bodies) consisting of people who produce polices and social knowledge. What IE adds to ethnographic methodologies is its aim in not only to understand what people experience in their everyday life, but to also discover how the concept of 'ruling relations' works and how the ruling relations influence people's experiences. This 'linking process' between the micro (lived experiences of the two people in the relationship) and macro-level (the ruling relations and their influence on the people) yields the analytical contribution of IE.

From Smith's perspective, the 'local people', whose experiences the ethnographer aims to explore, are subordinated to the ruling relations that run through social settings in which people come together and engage in policy processes. From the subordinated location of the people, the institutional ethnographer 'moves up' into the ruling relations to understand how they influence people's experiences (Smith, 2006). IE served me as a suitable methodology in learning about the relational experiences of people with intellectual disabilities receiving a PB and their support workers under the influence of the policies of PBs. This gradual learning occurred through participant observations of people's activities, during which I paid careful attention to how they related to each other, interviews with people in the field and an analysis of policy documents. These are the traditional methods used in IE studies.

The empirical research of this study consisted of two fieldwork stages. The first stage (January 2015 to November 2015) included ten interviews with service professionals (5 in each country) to gain a contextual understanding of support work relationships, the focus of my exploration. The second stage included twelve months of ethnographic field research (February 2016 to January 2017). As a participant observer, I explored the day-to-day lives of ten people with intellectual disabilities (5 in each country) in relation to their support workers (5 in each country) by taking part in their support work activities and by conducting single and joint interviews with the ten pairs of persons. In each of the ten ethnographic environments, I further conducted one interview with a service professional and collected disability policy documents for review and analysis. As I analysed the experiences of support work relationships, I understood what policies were relevant to each pair and each ethnographic environment. I could then move further up in my theoretical thinking to identify the ruling relations and their influence on the experiences of the people.

Language

Throughout the thesis, with few exceptions, I use the first person to signal my presence as an institutional ethnographer and to indicate that, in this role, I too was 'subject' to the research process (Johnson, 1998). There were other reasons why I considered the place of language in this thesis. As a critical qualitative researcher, I view language as 'the main mode by which the reality of our worlds is created' (Braun & Clarke, 2013, p. 25). What people consider 'truthful' depends on their agreements on how to use language (Burr, 1995; Gergen, 2015). I observed and understood the worlds of my research participants through the language they used. This did not always include words or sounds. Half of the research participants with intellectual disabilities had communication support needs. Non-verbal language (e.g. body language, facial expression) was tremendously important in understanding their experiences and formed part of the data included in field notes and interview transcripts. My voice in writing this ethnography was shaped by the language of the people who participated in it. My 'rules' on using language were influenced by their silent and spoken words.

Acknowledging language is also relevant in terms of doing research in two countries whose official languages are different. As a bilingual researcher, I had to translate many quotes and documents from German into English and had to ensure that

the translation reflected what the person meant and what the document revealed. In some chapters, I included the German words in brackets after the English translation as I felt that the English translation could not reflect the uniqueness of the semantics in the German context or person.

The focus of the study's exploration was the 'support work relationship'. Although I decided on this term in the early stages of the research process, the suggestion of the disability studies researcher Tom Shakespeare (2014b) – to conduct research that abandons the classification of support relationships by assigning them to a fixed set of categories and exploring the more nuanced and patterned differences among these relationships instead – was present in my mind throughout this project. While engaging in this inductive exploration, I had to set up some rules on the use of terminology revolving around 'support work relationships' to ensure a consistency of language to use in my academic voice. This thesis is written in English and the study was approved and supported by an Australian university. Therefore, I follow, with few exceptions, the Australian terms related to support work for people with intellectual disabilities.

'Support work' was the general term the Australian research participants used to describe the daily or weekly support a person with intellectual disabilities receives (whether the person receives a PB or not). I use the term 'support work relationship' to refer to the relationship between people with intellectual disabilities using a PB and their support workers. I also use the plural mode when referring to 'person with (intellectual) disabilities' as many research participants were labelled with more than one impairment. I use 'person-first' language to refer to 'person with disabilities' (Kulick & Rydström, 2015) which is consistent with the linguistic preference in Germany and Australia and with the language used by many international disability studies scholars.

As for the term 'intellectual disabilities', I should note that in the German Constitution, people with intellectual disabilities are called 'Menschen mit geistiger Behinderung' which translates to 'people with spiritual disabilities'. People with autism and Down syndrome, for example, fall under this legal category in Germany. These days, most German disability studies scholars add the word 'so-called' in front of 'spiritual disability' (Menschen mit sogenannter "geistiger Behinderung") and put the 'spiritual disability' in inverted commas, as they argue and believe that the spirit (der Geist) cannot be disabled and is free. It appears that the term and concept 'intellectual disabilities' is evolving and dependent on the cultural and political context in which people labelled with 'intellectual disabilities' live. With this in mind, I use the term 'intellectual disabilities'

to refer to the budget holders who took part in my study and whose primary disability was an intellectual disability.

The term 'support worker' best describes the person supporting the budget holder with intellectual disabilities. However, I sometimes use 'assistant' (Assistent) in place of 'support worker', or 'assistance' (Assistenz) instead of 'support work'. This usually occurs when I refer to the German context of support work or a German relationship pair, as it was the language used by research participants in three out of five German ethnographic environments and complies with the terminology used in the German national and state policy documents on PBs and support work (see Appendix G) and by German disability studies scholars.

Structure

The thesis consists of nine chapters. While Chapter I has 'set the scene' for this thesis, Chapter II builds the conceptual approach to analyse support work relationships within the context of PBs that organise support work. In Chapter II, I further describe the social policy contexts of PBs in Germany and Australia by reviewing empirical and policy literature from both countries. The conceptual approach to support work relationships and the descriptions of both national contexts of PBs are important in understanding the research questions of this thesis, introduced in Chapter II.

Chapter III introduces and discusses the methodology of IE. It gives detailed account of how research participants were selected and recruited for this study, describes the research methods (participant observations, interviews and document analysis), explains the study's analytical framework and creates an ethical awareness for the empirical exploration of support work relationships through IE.

Chapter IV, V, VI and VII are the four empirical findings chapters of the thesis. Chapter IV includes the findings from the first fieldwork stage, which served to 'get the lay of the land', a contextual understanding of support work relationships before I commenced the ethnographic field research. This contextual knowledge equipped me with an intellectual awareness and care to live, write and do the IE in two countries that were thousands of kilometres apart. In Chapters V and VI, I introduce the relationship pairs in each country, describe their environments, the support work activities and goals and explain how support work was organised in their environments. Chapter VII uses the descriptive and contextual knowledge produced in Chapters IV,V and VI to analyse more

deeply the lived experiences of support work relationships in connection to the concept of ruling relations. It uses the two research questions to identify the constituents of the ruling relations in the empirical data of this study and to link it to the conceptual theory on support work relationships. In Chapters IV, V and VI, I present the findings in a chronological fieldwork order that starts with the country in which I first collected the data. This structure does not apply to Chapter VII as it combines both data sets to identify the constituents of the ruling relations across both national contexts.

In Chapter VIII, I discuss the empirical findings of this study by addressing the two research questions through the constituents of the ruling relations that I identified in Chapter VII. Chapter IX discusses the new understandings of support work relationships that emerged through this study. It closes the thesis by discussing how the empirical findings of this study contributed to the literature on support work relationships. It further discusses the application of IE in Germany and Australia, the methodological limitations of the thesis, further research about support work relationship and the implications of the empirical findings for disability policy and practice.

On a final note, I sometimes placed a poem or quote at the start of a chapter. The poetry and writings in which these quotes appear are connected to the ethnographer's experience of living this research study and are not made reference to inside the text. They belong to my personal journey in living and doing the institutional ethnography I present in this thesis.

The purpose of this opening chapter was to 'set the scene' for the study I present in this thesis. This was done by giving an overview of how and why the study was conducted to explore the relationship between a budget holder with intellectual disabilities and their support worker, the support work relationship. This relationship is important to explore as support work organised through a PB is provided within this relationship. It is important to understand this relationship within different national contexts as the policies of PBs within these contexts can vary and are intended to assist people with intellectual disabilities in living a meaningful life.

Chapter II: Conceptualising support work relationships in the context of personal budgets

Introduction

In this chapter, I build the conceptual approach to analyse the support work relationship[2]. I draw on care, EoC and disability studies literature to build a conceptual understanding of the support work relationship and its position within the social policy context of support work organised through PBs. I use this approach as an ontological understanding of the experiences of people with intellectual disabilities in receipt of a PB and their support workers in relationship with each other and as a guide to empirically investigate support work relationships through the methodological framework of IE, which I introduce in Chapter III.

Chapter II consists of two parts. In the first part, I discuss support work as a relationship between the person receiving it and the person providing it before I analyse the concept of interdependence that the EoC theorises within the 'care relationship'. I then conceptualise the social context of the support work relationship and the relationship in the context of PBs to highlight how context can affect experiences of support work relationships. I do this by describing some of the international research that has been and is currently conducted on support work relationships. I close the first part of the chapter with a statement about the value of combining care, EoC and disability studies theory to build a conceptual approach to support work relationships.

In the second part of the chapter, I describe the development and implementation of PBs for disability support in Germany and Australia by drawing on empirical (e.g. evaluation studies about PBs) and policy literature. Based on the descriptions of the German and Australian social policy contexts of PBs, I explain why I selected the two countries as places to conduct empirical research on support work relationships. I close the chapter by introducing the research questions for this study.

---

[2] Some of the work in this chapter has been published in the following article:
Lutz, D. L. (2015). Friend or worker? Understanding relationships between people with intellectual disabilities and their support workers through Institutional Ethnography, *Human Welfare*, 4, 27-33.

Support work relationships and personal budgets

The first part of this chapter builds the conceptual approach used in this study to analyse support work relationships, based on care, EoC and disability studies literature. Through this approach, I seek to understand the meaning of support work in relation to the experiences of the relationships between people with intellectual disabilities using a PB and their support workers and to develop an ontological understanding of the support work relationship within the social policy context of PBs.

Support work as a relationship

Paid and professional support for people with disabilities is a specific kind of work that involves a social relationship between the person with disabilities and their support worker (Shakespeare, 2014a; Shakespeare et al., 2018). While both people in this relationship may provide and receive support to and from each other, it is only the person with disabilities who receives paid support while the support worker provides a professional support service. Thus, the support work relationship differentiates itself from other social relationships through the provision and receipt of paid and professional support work.

The disability studies theorist Tom Shakespeare (2014a) noted that the paid and professional aspect of the support work transforms it into a 'service'. Shakespeare drawing on his own experience of being a support service user explains that any support service between a person with disabilities and their support worker inevitably is a social relationship, in which feelings evolve (Shakespeare, 2014a). He also noted that these feelings 'may be positive – gratitude, affection, respect – or they may be negative – frustration, resentment, dislike' and argued that it is impossible to distinguish between professional tasks and emotions as emotions develop while the work is being carried out by the two people (Shakespeare, 2014a, p. 175). This means that paid and professional support is not only based on practical forms of labour, but also on social and emotional interaction between the person with disabilities and their support worker. While Shakespeare (2014a) explains that the emotional labour of support includes the support worker's encouragement, support and guidance of the person with disabilities, he does not discuss the relational aspects of the emotional work between them. For example, he does not analyse how the support receiver reciprocates the guidance, support and

encouragment of the worker or how both people experience their emotions in presence of the other. The care literature, however, elaborates on the emotional labour of support.

Care researchers draw on the concept of care to analyse paid and professional support for people with disabilities. Some distinguish between an emotional (caring about) and a practical (caring for) form of caring that both relate to care work or caring labour (e.g. Christensen, 2009; Hooyman & Gonyea, 1999; Rogers, 2012; Ungerson, 1983). The practical form of care includes the performance of the care work. It involves the organisation, planning and completion of the care work tasks. The emotional form includes mutual engagement and dialogue in which both people contribute to an emotional connection within their relationship (Christensen, 2009; Rogers, 2012). This aspect has also been depicted as 'love labouring' with reference to mothers caring for their daughters with intellectual disabilities out of love (e.g. Kittay, 2001, 2002, 2009a; Rogers, 2012). In the context of support work relationships, this can mean that both people inevitably engage in the emotional and practical forms of support work.

The Norwegian care and disability studies scholar Karen Christensen (2009), for example, explained that the practice of 'caring for' happens as both people socially interact with each other. Christensen's definition of care work indicates that a reciprocal dialogue is part of the 'caring about', that is the emotional labour within the relationship. This dialogue provides the opportunity for both people to participate in the relationship and practice some form of care by becoming involved in the other person's life. In this process, both people take active roles within the relationship which they express through feelings, the emotional form of support work. This interaction facilitates the personal relationship within the support work relationship.

This section discussed support work as a social relationship based on emotional and practical forms of labour that form part of a professional and paid type of support service. While the practical forms of labour include the organisation, planning and accomplishment of the practical tasks of support, the emotional forms of support include paying attention to feelings and mutual engagement through a reciprocal dialogue between the person with disabilities and their support worker. Both emotional and practical forms of support work are part of the support work relationship.

Interdependence within support work relationships

Disability studies and care theory argue that interdependence – the dependence of both people on each other – is core to social relationships (e.g. Christensen, 2009; Leece, 2010; Sevenhuijsen, 1998; Shakespeare, 2014a; Shakespeare et al., 2018). While both theories use the concept of interdependence to theorise the relational aspects of human life, the care literature does this in connection to the concept of care.

The concept of care has been criticized by disability rights scholars (e.g. Shakespeare, 2014a; Watson, McKie, Hughes, Hopkins, & Gregory, 2004) for positioning people with disabilities as needing to be cared-for. This criticism involves a concern that the care concept could portray and position people with disabilities in a way that expects them to be the more passive and dependent person in the support work relationship (Kelly, 2016). Disability studies literature argues that all people depend on care at some point in their life cycle (Shakespeare, 2006a; Vorhaus, 2007). This argument involves a consideration of each person's vulnerability and need for care, irrespective of whether the person has disabilities or not. It also considers the link between the human need for care and the human dependence on each other, the interdependence.

The EoC theorist, Eva Feder Kittay (2001, 2002, 2009a, 2009b, 2011), writes about interdependence within 'care relationships', as she calls the relationship when she refers to people with intellectual disabilities and their paid and unpaid carers. Kittay refers to the relationship with her daughter Sesha who has intellectual disabilities, communication support needs and other impairments when she describes Sesha's subsequent need for care: 'someone such as my daughter could not survive, much less thrive, without constant and vigilant attention, without someone performing for her nearly all the tasks of daily living, as well as providing for her' (Kittay, 2001, p. 566). Kittay acknowledges Sesha's capacity in forming interdependent relationships with people who support her in her everyday life, such as her mother and support worker. Despite her daughter's greater need for assistance and personal care in daily life, she depends on Sesha just as much as Sesha on her, and in certain moments of her life, she had even felt that she depended on Sesha more than the other way around, Kittay (2001) notes.

In these moments, when Kittay felt more dependent on Sesha than vice versa, it seems that Kittay's dependence comes from the emotional bond she has with her daughter. Her love (caring about) for her daughter was expressed through the daily care work (caring for) she carried out for her, the practical form of care work. Kittay's

observation shows that Sesha provides some form of support to Kittay that Kittay depends on. This form of support includes Sesha's emotional response to the support that she receives from her mother and her other carers. These acts of reciprocation that Kittay (2001, p. 567) calls 'small pleasures' include laughing and kissing, for example.

While Kittay does not distinguish between the paid and unpaid 'care relationship', she calls attention to the experiences of support work relationships by conceptualising the meaning of interdependence between the person with intellectual disabilities receiving the support work and the one providing it. Each person's experience of being in a relationship is dependent on the other person's experience and the two interdependent roles within the relationship influence how each role is experienced.

Context of the support work relationship

A conceptual approach to support work relationships includes consideration of the context in which these relationships occur. The context can influence how people experience support work relationships. Therefore, it is important to understand what this context includes. This is the focus of this section of the chapter.

The English care and disability studies scholar Chrissie Rogers took the conceptual distinction of emotional and practical care work further and engaged with three 'spheres of care work' (Rogers, 2012, p. 132). She pointed out that the support work relationship with its emotional and practical forms is part of a broader social policy context (Rogers, 2012; Rogers & Tuckwell, 2016). In this context, support work can be a form of solidarity work, be given via financial support and be a professional and paid social service, which is intended to deliver certain policy outcomes (Rogers, 2012; Winance, Damamme, & Fillion, 2015). These policy outcomes can become meaningful as they can be set as goals for the person with disabilities (e.g. Pearson, 2012; Tew et al., 2015). For example, through specific and regular activities, the support worker is intended to help the person with disabilities in developing independent living skills (ILS) which can be goals of support work. Developing these skills can occurr during activities in support areas, such as cooking, laundry, budgeting, exercising, community participation and leisure (Guldvik, 2014; Kelly, 2016). However, these support areas can also include personal care, during which the support worker can assist the person with disabilities in showering, using the toilet or getting dressed. The nature and context of these activities can affect how people experience support work relationships.

Support work activities usually occur in the person with disabilities' home and/ or local environment which is the support worker's place of work (Franz, 2015; Guldvik, 2014; Kelly, 2011; Shakespeare, 2014a; Ungerson, 2003). Being in a relationship, in which one person is at home and/ or in their local environment, but the other person is in their professional work environment can contribute to both people in the support work relationship experiencing it in different ways. Rogers (2009) reflected on her personal experience of being a live-in support worker to Sam, a man with intellectual disabilities, whom she supported with leisure activities, chores around the house, personal care issues and medication. She tried to understand an emotional misunderstanding between Sam and her within a specific social context, in which she felt that boundaries and emotions within the support work relationship had appeared to slide into one another. 'After a year ago… our relationship changed forever. I was … in the kitchen with Sam. The 6-foot man grabbed the waist-band of my trousers clear in his intention to undress me' (2009, p. 277). In this account, Rogers calls attention to the possibility that people in support work relationships can place their own meanings on their relationships. While the personal meanings of support work relationships are influenced by people's individual needs and desires, they are also connected to the environment in which people experience their relationships. The type of environment (e.g. home, work) shows potential to affect the experiences between Rogers and Sam, for example. Sam's experience of his relationship with Rogers seemed different to the experience that Rogers had of her relationship with Sam. While Rogers shows that differences in experiences are linked to both people's understanding and interpretation of their relationship and are shaped by the wider social context, in which both people are in relationship, she does not consider the type of Sam's support work funding and how this funding shapes the context that can influence his experience of the relationship with Rogers.

This section called attention to the fact that people in support work relationships can place their own meanings on the relationship. These meanings can be influenced by the third sphere of care work, which includes the broader social policy context. In this context, support work relationships can be influenced by the activities and goals, as well as the type of environment in which the two people work together.

Support work relationships in the context of personal budgets

Over the last few decades, the social policy context of support work has changed internationally. The changes include the introduction of PBs, which have influenced the allocation and administration of funds for the organisation of support work for people with disabilities. Due to this change in context, support work relationships might also be experienced in new and different ways. This section discusses support work in the context of PBs. It does this by including the empirical literature on PBs relevant to support work relationships.

Personal budgets and support work relationships

PBs are a set amount of government funds allocated to a person with disabilities based on an assessment of their personal needs (Leece & Leece, 2010; Needham & Dickinson, 2018; Pearson, 2012). The term 'personal' within the 'personal budget' refers to a 'personal support demand' that can be fulfilled through the financial service arrangement of the 'budget' (Meyer, 2011). This service arrangement intends to personalise support so that the individual needs of the budget holder, the person with disabilities, can be met and responded to in a way that involves them in the organisation of their support work (Christensen & Pilling, 2014; Dickinson, Needham, & Sullivan, 2014; Purcal, Fisher, & Laragy, 2014; Slasberg & Beresford, 2015; Slasberg, Beresford, & Schofield, 2012). The involvement in the organisation of support work is intended to happen through adequate supports, such as people in contact with the budget holder who assist them in accessing information about their support work and exercising some power over the organisation of support work (Beresford, 2008, 2014; Broady, 2014; Leece & Leece, 2006; Pearson, 2012; Tew et al., 2015).

The policies of PBs can influence roles within the support work relationship and the way power is shared. The Norwegian PB researcher, Ingrid Guldvik, argued that having a PB tends to mean 'in principle that the power relation between the service user and the care worker is turned upside down' (Guldvik, 2014, p. 147). Her argument is that the PB has potential to change underlying power imbalances within the support work relationship. This change might happen when the support work organised through a PB enables the person with disabilities to act in the role of the budget holder who experiences an increase in power by having choice and control over support work.

A number of international research studies focused on the policies of PBs and support work relationships (e.g. Christensen, 2012; Guldvik, 2014; Kelly, 2016; Leece, 2010; Leece & Peace, 2010; Ungerson, 1999, 2003; Yamaki & Yamazaki, 2004). For example, Christensen, Gulvik and colleagues conducted research on budget holders with physical disabilities and their support workers in the United Kingdom and Norway (e.g. Christensen, 2009, 2010, 2012; Christensen & Guldvik, 2014; Christensen, Guldvik, & Larsson, 2013; Christensen & Pilling, 2014). Their research, based on interviews and observations with both people in the relationship, provided evidence that the context of PBs affected the support work relationship in that it created three different types of relationships. The first, called 'professional friendship' stressed the professional boundaries to the relationship set by employment contracts and formal regulations; the second was a 'solidarity-based companionship' which focused on emotions; and the third was the care 'master-servant model', where the master (person with disabilities) had the power to get things done the way they wanted it (Christensen, 2012, pp. 405-408) . While these research studies considered the link between PBs and support work relationships, they did not consider the experiences of budget holders with intellectual disabilities, in particular, and they did not aim to understand the depth of these experiences.

A research study in England, called 'Personal assistance relationships: power, ethics and emotions' (e.g. Porter & Shakespeare, 2016; Shakespeare, Porter, & Stöckl, 2017; Shakespeare et al., 2018) used interviews with people with disabilities and support workers to explore the relationship involved in the support work (referred to as 'personal assistance' in England). One of the findings which has emerged from this study concerns boundaries within support work relationships. These boundaries are connected to the emotional attachment between both people which can easily develop as both people engage in intimate and often informal support work tasks, such as the worker supporting the person with disabilities to have a shower (Shakespeare et al., 2017). While the study gained insights into the experiences of the personal relationship within the support work relationship through interviews, it has not captured the experiences of people with intellectual disabilities who may also have communication support needs. This group of people can experience difficulties in taking part in interviews. The current study uses ethnographic methods, including participant observations, to gain deeper insights into experiences of this group of budget holders in relation to their workers.

The administration of personal budgets and support work relationships

Exercising power by enabling choice and control for budget holders is connected to the ways in which PBs are administered to organise the support. One way the funding can be administered is to allocate the money from the budget to a service provider that is the financial broker and employs the support worker (from their own service or another service) to provide the support work. In this case, the service provider usually has more involvement in the administration of PBs and the organisation of the support work. Support work in this model is still intended to be implemented in a way that enables budget holders to exercise choice and control over their support.

The PB can also be administered as a direct payment. In this model, the budget holder receives the PB as a cash payment directly from local authorities to pay for services (Pearson, 2012). Through this pathway of payment, budget holders should receive support in a way that shifts power and control to them, as they are meant to pay their support worker directly from their budget and act in the role of an employer with adequate supports (Guldvik, 2014; Kelly, 2016; Kotsch, 2012). The person with disabilities may still be the one in need of the support, but they may take control over their support arrangements and determine whom they employ as their support worker. In contrast, the worker may be dependent and vulnerable in terms of their financial security through this type of employment and its occupational status (Guldvik, 2014; Kittay, 2009a).

Janet Leece conducted research that focused on direct employment of workers through PBs for people with physical disabilities (e.g. Leece & Leece, 2006; Leece & Leece, 2010; Leace & Peace, 2010). She conducted thirty-two interviews with budget holders and their support worker to compare direct (employed by the budget holder) and non-direct employment of workers (employed by a service provider) in one English authority. While the aim of her study was to understand how cash payment policies affected the power dynamics within support work relationships, she found that direct employment through a PB could increase the power of the person with disabilities. This increase in power, for example, included the power to choose their worker and to set the terms and conditions of employment of their workers. Through this increase in power, they could influence the relationship by prioritising their own interests. The increase in power for the budget holder had disadvantages for the workers, such as poorer working conditions (e.g. lower payments, temporary work arrangements) than not directly employed workers.

The link between the pathway of organising support work through a PB and the experiences of support work relationships is a topic that the Canadian care, PB and disability studies scholar Christine Kelly discusses too (e.g. Kelly, 2011, 2013, 2016). She describes feelings of social awkwardness in her relationship with her friend Killian, a man with physical disabilities who uses a PB as a direct payment. Kelly occasionally provides support work to Killian, for which she gets paid from his PB. In this context, she explains: 'The first time I helped Killian eat I knew we were no longer simply friends, and it was at times awkward for both of us to negotiate our shifting roles' (Kelly, 2013, p. 785). By this, Kelly sheds light on the context in which the support work activities organised through a PB happen. The professional arrangement of her personal friendship with Killian, organised through his direct payment, influenced her experience of being in this support work relationship, as well as her perception of Killian's experience. There was an awareness of her personal friendship with Killian while she was engaging with him as if he were her client. While Kelly occasionally shares observations on Killian's understanding in her work, it remains ambiguous how much he knows about the professional arrangements of his support work and how he perceives the relationship. Kelly further does not focus on and explore the experiences of budget holders with intellectual disabilities in relation to their support workers, which the current study does.

This section argued that the context of PBs and the experiences of support work relationships are linked. While some research studies identified issues of power, boundaries and feelings within the relationship, they did not place a particular focus on budget holders with intellectual disabilities in relationship to their workers and did not explore these particular relational experiences under the influence of the policies of PBs.

The context of PBs needs to be considered in research that aims to understand the relationship experiences of budget holders with intellectual disabilities and their support workers as this context influences their experiences. In respect to this study, this raises the question, to what extent the social policy context of PBs influences the way budget holders with intellectual disabilities, in particular, and their support workers experience their relationships.

Summary

This part of the chapter built a conceptual approach to support work relationships by drawing on care, EoC and disability studies literature, combining conceptual approaches from these three theories and connecting them to recent empirical literature on support work relationships in the context of PBs.

Care literature provided a context for exploring the emotional (social interaction) and practical forms (support work activities) of support work within the paid relationship between people with intellectual disabilities and their support workers. Both forms of support work happen as people are in support work relationships.

Kittay's EoC provided a basis for understanding experiences of mutual dependence between people with intellectual disabilities and communication support needs and their paid and unpaid carers. While she does not distinguish between the paid and unpaid 'care relationship', her work explores the experiences of people with intellectual disabilities, communication support needs and other impairments who are part of this study.

Disability studies literature contributed to an understanding of support work as a social relationship between two people – one person who provides paid and professional support and one person who receives it. It stressed the relational aspects of support work. Disability studies literature also added to the way the support work relationship within the context of a PB can be understood from the viewpoint of the budget holder and the support worker.

By combining conceptual approaches from these three theories, I was able to develop an understanding of relationships between budget holders with intellectual disabilities and their support workers within the context of PBs, which is the focus of this research study. These three theoretical perspectives helped to build a conceptual approach that specifically focuses on paid support work for budget holders with intellectual disabilities, as well as on the relational experiences of these budget holders and their support workers. In the next part of this chapter, I describe the German and Australian contexts of PBs and explain why this study explored support work relationships in these two national contexts.

Personal budgets in Germany and Australia

This part of Chapter II introduces the social policy context of PBs in Germany and Australia in which the empirical research of this study was conducted. The conceptual approach to support work relationships that I built in the first part of this chapter is relevant to the two contexts as the approach indicates that the social policy context of PBs has potential to affect the experiences of budget holders with intellectual disabilities and their support workers in relationship with each other.

The reason for selecting two countries is connected to the differences in policy trajectories of PBs which can inform the empirical exploration of support work relationships. The reasons for selecting Germany and Australia as these places include the following: (1) the research about PBs for people with intellectual disabilities that has been conducted in these countries; (2) the specific policy trajectories of PBs in both countries at the time of the empirical field research of the current study.

The disability service sectors in both countries were transitioning to new laws and policies of PBs, which included the *National Participation Law 2016* in Germany and the *National Disability Insurance Scheme Act 2013* in Australia at the time of this study. The people with intellectual disabilities who took part in this study used PB programs under the laws and policies prior to these recent reforms in both countries. However, the new laws and policies of PBs had started to become part of their support processes. Some budget holders have had consultations and planning meetings for these transitions. These transition processes happened as I carried out the ethnographic field research.

I now describe the policy trajectories concerning PBs in both countries and start the descriptions with the policy development and implementation of PBs in Germany. *Policy development* relates to the times during which laws and policies were introduced to implement PBs. *Implementation* concerns the ways in which PBs have been administered to practically organise support work for people with intellectual disabilities.

German context of personal budgets

This section describes the policy development of PBs in Germany, the implementation of PBs and their implications for people with intellectual disabilities based on national evaluation research and research in the German state of Baden-Württemberg, in which the empirical field research of this study was conducted.

Policy development of PBs

The development of PBs in the Federal Republic of Germany began in the 1960s, when individualised planning for people in need of social support from the state was included in the German Constitution (Niediek, 2010). In 2001, the German Social Code Book IX – called 'Rehabilitation and Participation' – was introduced and declared that support for people with disabilities could be organised through a PB (Baumgartner et al., 2007; Biewald & Frings, 2012; Franz, 2015; Kastl & Meyer, 2007). At this time, PBs had not been a legal entitlement for people with disabilities, but the idea to personalise support through a PB as part of a legal framework had been formulated.

In 2008, the German government launched 'The Personal Budget' as a national act which meant that it became a legal entitlement for persons with disabilities (including people with mental health issues) and was documented in the national legislation of Germany (see Article 17, Social Code Book IX) (Biewald & Frings, 2012; Meyer, 2011; Wacker, Wansing, & Schäfers, 2009). However, the implementation of PB policies vary across the sixteen states in Germany and the local government areas (LGAs) within each state, which make their own rules about how to administer a PB (Schäfers, 2009). This meant that the introduction of the PB as a national act gave people with disabilities an official right, but it did not guarantee that they could access PBs in practice.

The PB policies in Germany were designed to offer support services through a cash payment rather than allocating a service to administer the funding. This payment pathway aimed to reconfigure the welfare system, so that people with disabilities were no longer seen as 'objects of care' receiving standardised services, and improve their self-determination and participation in society (Baumgartner et al., 2007; Kotsch, 2012; Wacker et al., 2009). This intention included that social welfare authorities and/ or agencies (e.g. care insurance, pension insurance, youth service, social service, employment agencies), which form part of the German rehabilitation system, contribute financially towards the budget, but only one provider administers the funding and organises the support plan with the budget holder, called the 'Cross-provider Personal Budget' (Trägerübergreifendes Persönliches Budget) (BMAS, 2014).

Political discussions about the potential impact of this PB were promising before its introduction. In 2010, a national take up of 14,193 PBs among almost 10 million people with disabilities was recorded, which was a rather disappointing number (Prognos, 2012). People with mental health issues were the largest group of budget holders (41%), followed by people with intellectual disabilities (31%) and people with physical

disabilities (19%). In 2012, a slight increase (to 34%) amongst people with intellectual disabilities was recorded (Prognos, 2012), but until today the take-up of PBs in Germany has remained low.

In order to access and utilise a PB, applicants have to undergo many assessments as part of support planning processes. This has been a frustrating experience for people with intellectual disabilities, in particular, who have relied heavily on support from others to find accessible information on PBs, manage the application process and be fully included in consultations (Meyer, 2011; Prognos, 2012). Support workers are meant to assist during these processes, but it remains unclear how their assistance to people with intellectual disabilities should happen in practice.

Many support workers in Germany hold professional qualifications. For example, ongoing direct support work that involves personal care is often carried out by educational care workers (Heilerziehungspfleger) who complete a professional apprenticeship to obtain this qualification. Short-term and casual support worker roles are often filled by volunteers or university students from discipline-related courses (e.g. Social Work, Special Education, Inclusive Education). However, it remains unclear what skills support workers need to best support people with intellectual disabilities to access and use a PB and be more included in the support processes.

Implementation of PBs

The implementation process of the cross-provider PB has been problematic. The national evaluation study of its pilot, conducted from 2004-2007, identified implementation barriers (Metzler, Meyer, Rauscher, Schäfers, & Wansing, 2007). The study comprised quantitative and qualitative methods. These methods included interviews and questionnaires with budget holders, questionnaires for their legal guardians and staff from service providers, interviews with staff from the local authorities administering the PBs and an analysis of documents (e.g. PB applications, goal agreements[3]) (Metzler et al., 2007). It found that only 5% of all budget holders in Germany used the cross-provider model as service providers felt reluctant to collaborate and share the costs for support (Metzler et al., 2007). Most budget holders ended up using other ways of organising their

---

[3] A goal agreement (Zielvereinbarung) is a document that serves as a contract between the budget holder and the government agency paying the funds. It can, for example, include information about the amount of funding granted, the goals and the activities of the support work and the people involved in the support process (e.g. budget holder, service provider, support workers, family members) (Wacker et al., 2009).

support through a PB, for example, as a direct payment. In Germany, this model is called 'Employer model' (Arbeitgebermodell) as budget holders are intended to recruit and employ their support workers directly, administer their salaries and organise their own support work activities (Metzler et al., 2007).

Budget holders with intellectual disabilities using this model reported a lack of support in utilising it, which discouraged many from using it. The lack of support led them to involve staff from a service provider to help them manage the funds (Bracke & Güttner-Scarfone, 2017; Prognos, 2012; Schäfers, 2009). An evaluation of the PB pilot in the state of Baden-Württemberg, conducted from 2011-2015, stressed this issue (Kastl & Metzler, 2005). It found that people's decision to apply for a PB was influenced by the policies of local government authorities, which included rules on how PBs were administered in specific support areas (e.g. supported living, supported employment) and their implications for the organisation of support work. The evaluation also stressed the difficulties of budget holders with intellectual disabilities in organising their support work, which included some of the administrative tasks they were expected to do, such as liaising with stakeholders from government agencies and service providers.

The national evaluation found that the actual implementation of PBs affected how support work was organised (Metzler et al., 2007). For example, the domain 'supported living' (e.g. drop-in support for people with disabilities living in their own homes, rather than service-driven accommodation settings) and 'social participation' (e.g. assistance to participate in cultural or social activities within the local community) were the most common domains of support financed via PBs. German PB scholars argued that this was due to how local welfare authorities prefer to implement the organisation of support through a PB rather than following the preferences of budget holders (e.g. Kastl & Meyer, 2007; Schäfers, 2009). Overall, people with disabilities reported that the PB had changed their lives in a positive way – only a few did not observe any positive changes (Metzler et al., 2007). While the final report of the national evaluation study indicated that joint interviews with people with disabilities and their support workers were conducted when the former experienced communication support needs, it did not include the views of support workers and people with intellectual disabilities on their experiences of being in a relationship organised through the policies of PBs. To understand support work relationships in the context of PBs for people with intellectual disabilities, research needs to explore the views of this group of people in relation to their support workers.

While political debates and research discussions about PBs in Germany have been quieter over the last ten years, a new law – the introduction of the 'National Participation Law' (Bundesteilhabegesetz) – raised discussion again. This reform was launched in 2018 and is planned to be implemented by 2023. It is expected to have implications for the implementation of PBs (e.g. Axmann, 2017; Bracke & Güttner-Scarfone, 2017). The law proposes that support work, called 'assistance services' in Germany, should be purchased via PBs and for specific areas of support which may increase the take up of PBs. New forms of support work might emerge through a PB. For example, a PB in the area of employment that aims to help people with disabilities to find and maintain employment outside institutionalised work place settings is now available (Axmann, 2017). Consultations with PB applicants, financed by the federal government rather than individual providers that deliver support work, are planned to be implemented to select assistance services. It remains unclear how these consultations will be delivered to people with intellectual disabilities and their workers so that they can voice their wishes and be included in the support process.

Germany has implemented PBs for people with disabilities for several decades, but the take up of PBs has remained low. One of the reasons for the low take up has been the way in which the administration of PBs across states and LGAs has been managed. German research identified that people with intellectual disabilities especially have experienced barriers to accessing and using PBs. However, the research has not explored how budget holders with intellectual disabilities and their support workers experience their relationships under the influence of the policies of PBs that organise support work.

Australian context of personal budgets

This section canvasses the policy development and implementation of PBs in Australia, especially in NSW, in which the empirical research of this study took place. It does this in view of the time during which this study was conducted.

Policy development of PBs

At the time of the empirical research of this study, Australian states (New South Wales, Queensland, South Australia, Tasmania, Victoria, Western Australia) and territories (Northern Territory, Australian Capital Territory) administered and funded services for

people with disabilities based on their own policies and laws and the *National Disability Agreement* (Australian Government, 2009). Each government tended to fund service organisations to provide support work to a number of people, referred to as 'block-funding', rather than administering PBs to fund support work (Laragy et al., 2015; Purcal et al., 2014). While some state and territory governments and block-funded disability services started to implement personalised support in the 1980s, it was still based mainly on a 'one-size-fits-all' service approach and did not fully respond to the diverse needs of people with disabilities. This made it difficult to implement support work in a way that made budget holders the centre of their support arrangements (Ramcharan, 2016).

In the 1980s, PBs became available to some people in Australia and the policies of PBs expanded over time (Fisher et al., 2010). For example, in 2006, the NSW Government, the Department of Ageing, Disability and Homecare (ADHC) in the Department of Family and Community Services, announced new policies, guided by *Stronger Together: A new direction for disability services in NSW 2006-2016* (Jones et al., 2015). These policies identified the need to improve outcomes for people with disabilities by delivering more person-centred support through the promotion of PBs for people with disabilities (Jones et al., 2015). Person-centred service delivery within the context of a PB in Australia individualised funding with the intention of placing people with disabilities at the centre of decision-making and recognising them as active agents who can exercise choice and control over support work (Beadle-Brown, Hutchinson, & Whelton, 2012; Broady, 2014).

ADHC offered a range of PB programs to people with disabilities. Each program focused on a different life area (e.g. accommodation, community participation, leisure activities in form of respite). For example, the Supported Living Fund (SLF) was a PB program that funded accommodation support for adults with disabilities to create living arrangements that assisted in transitioning to living in a home of their own with paid support services (Jones et al., 2015). Between 2012 and 2013, 381 SLF packages at an average cost of $50,000AUD per year were allocated across NSW (Jones et al., 2015). Budget holders usually worked with an ADHC-approved service provider that directly provided support work or charged a fee to manage the package on the budget holder's behalf (Jones et al., 2015). How support workers assisted budget holders in exercising power, choice and control during this process and what type of skills this required varied among providers. More than half of the Australian disability workforce was made up of direct support workers who did not necessarily hold a professional qualification (Bigby,

2013). Australian research has not clarified how they can best support budget holders to use a PB and whether workers need professional qualifications to do so.

The Productivity Commission, the Australian Government's principal review and advisory body on microeconomic policy and regulation undertook an inquiry into disability support and care in 2011. The Commission found that the state and territory-based disability support system gave people with disabilities little choice and control and no certainty of access to appropriate supports (Productivity Commission, 2011). In response to this, the national labour government launched the National Disability Insurance Scheme (NDIS) in July 2013 and made an official commitment to the provision of life-long and recurrent funding for people with permanent disabilities (Collings, Dew, & Dowse, 2019; Fawcett & Plath, 2014; Needham & Dickinson, 2018). In the same year, the NDIS trial began in specific regions and for specific age groups within some Australian states. An independent national authority called National Disability Insurance Agency (NDIA) was established under the national legislation to administer it (Bonyhady, 2014; Dickinson et al., 2014). By 2019, all state government-funded PBs across Australia are planned to be replaced by PBs administered under the NDIS (Fisher, 2016; Purcal et al., 2014).

Implementation of PBs

Since the introduction of PBs in Australia, research studies have been conducted on the effects of the implementation of these programs, which included their impact on the lives of people with disabilities and their families (e.g. Fisher & Campbell-MacLean, 2008; Laragy et al., 2015; Jones et al., 2015). Findings from an evaluation study of PB programs in NSW, called the 'SAEF study' (Supported Accommodation Evaluation Framework), investigated how PB programs for supported living affected the lives of people with disabilities and their families (Jones et al., 2015). The study used quantitative and qualitative research data from budget holders with disabilities, their families, support workers and stakeholders within the disability service system to report on the impact of PBs under Stronger Together. In regards to support work relationships, the study revealed that people with intellectual disabilities found the relationships to their workers positive and experienced significant improvements in quality of life if their workers incorporated respect, flexibility, structure and support into the ways they delivered the support work to them. However, the SAEF study did not explore the experiences of both people in relation to each other and how the relationship was influenced by the policies of PBs.

The study identified a need for better advice, planning and implementation of support work to assist budget holders in exercising choice and control. It also highlighted the difficulties for people with intellectual disabilities in realising this due to the ways in which support work was organised through their PB, which included the application processes to access a PB. This issue seems to not have changed for many budget holders, which the national evaluation study of the pilot roll-out of PBs under the NDIS corroborated (Mavromaras, Moskos, Mahuteau, & Isherwood, 2018). It found that people with intellectual disabilities and communication support needs, in particular, experienced barriers in accessing information about the policies of PBs and poorer choice and control over their support than before. What has remained unclear from Australian research studies on PBs, however, is how budget holders with intellectual disabilities and their support workers experience their relationships with each other within the context of support work organised through the policies of PBs.

With the transition to the NDIS, the state-government funded PBs are now transforming to budgets that their recipients can use to purchase support services from traditional disability services or from the open market (Laragy et al., 2015; Macdonald & Charlesworth, 2016; Whitburn, Moss, & O'Mara, 2017). This may create the risk of inequality, especially for people with intellectual disabilities and communication support needs, as 'those who do well in negotiating with providers are likely to be those who are advantaged by education, financial resources, transport, geographic locations, family supports and access to technology' (Fawcett & Plath, 2014, p. 754). People with disabilities need to be equipped with certain skills and resources in order to participate actively in this market as budget holders (Soldatic, van Toorn, Dowse, & Muir, 2014).

Over the last decades, Australian policies of PBs developed to gradually replace block-funded disability support. More recently, the policies of PBs have been moving towards a competitive and private market of disability support, which aims to make budget holders the focus of their support arrangements to enable choice and control. Some Australian research examined how people with intellectual disabilities, in particular, can be better supported by their workers in their roles as budget holders in this new context of support work. However, it did not explore how both people experience their relationship with each other under the influence of PBs that organise support work.

Summary

Germany and Australia are countries with related, but different policy developments, histories, timeframes and experiences in implementing PBs. New forms of support work in both countries have developed through their specific policy trajectories concerning PBs.

While the development of PBs in Germany began in the 1960s, the law and policy of PBs were not introduced until 2008. The country has had a slow take up of PBs and has put little research and policy emphasis on implementing support through PBs in recent years. The original implementation intention of PBs in Germany included that the funds be transferred to the person with disabilities directly who would then purchase support services from a cross-provider system and navigate them. However, power and control are mostly sitting with the local authorities administering the funding which makes it difficult for budget holders to choose how and in which areas of life they want to organise their support work. Evaluation studies on PBs (e.g. Kastl & Metzler, 2005; Metzler et al., 2007; Prognos, 2012) reported there was a lack of support for people with intellectual disabilities in managing their funding with adequate assistance to enable choice and control over support work organised through a PB.

In contrast, Australia has offered a range of state-government funded PBs in different areas of support for several decades. Each state government has implemented its own policies of PBs. Recent evaluation studies on PBs (e.g. Jones et al., 2015; Mavromaras et al., 2018) highlighted that people with intellectual disabilities have not been well supported in taking the role of the budget holder to exercise choice and control over their funding and support. The country is in the midst of a more recent disability support policy change. Through the introduction of the NDIS, most of the disability service system transforms into a contracted market. Budget holders and/ or the people advocating for them are expected to act in the role of the customer to participate in this market. This requires new arrangements for support work.

While research studies on PBs and its implications for people with disabilities and their support workers have been conducted in both countries, they have not captured the richness of how budget holders with intellectual disabilities, in particular, and their support workers experience their relationship with each other under the influence of the policies of PBs. Both countries offer two interesting and suitable contexts of PBs in which I empirically explore support work relationships in this study.

Research questions of the thesis

The first part of this chapter highlighted that the support work relationship is a specific kind of relationship between a person with disabilities and their (paid) worker. In the context of this study, it is the relationship between the person with intellectual disabilities who uses a PB and their paid support worker. This relationship is part of the policy context of PBs in which the support work is organised. This context has potential to influence how both people experience their relationship with each other.

The disability policy contexts in Germany and Australia offer two research sites in which I examine the experiences of support work relationships under the influence of the policies of PBs. The relationship of budget holders with intellectual disabilities and their support workers is particularly important to investigate as the implementation of PBs can affect how this group of people utilises their PBs in a way that supports them in living a meaningful life, envisaged in the CRPD (see Section 'Rationale for the study' in Chapter I).

To date, knowledge about the views and perceptions of people with intellectual disabilities and their support workers on their relationships, within a support work context that is organised through the policies of PBs, remains limited. This study aims to add to this knowledge by exploring the relationship experiences of budget holders with intellectual disabilities and their support workers in Germany and Australia and to discover how these are influenced by the policies of PBs. Therefore, the study asks the following two research questions:

- How do people with intellectual disabilities in receipt of a personal budget and their support workers experience their relationships with each other?
- How are the lived experiences of people with intellectual disabilities and their support workers in their relationship with each other influenced by personal budget policies organising support work?

Conclusion

In this chapter, I argued that a conceptual approach to support work relationships based on care, EoC and disability studies literature is suitable to explore support work relationships in the context of a PB. By combining perspectives of these three theories, the conceptual approach draws on an ontological understanding of support work as a relationship between the person with intellectual disabilities receiving paid and professional support and the support worker providing this support.

The approach emphasises the emotional (social interaction) and practical (support work activities) forms of support work which are part of the support work relationship. The approach further takes a relational viewpoint on the two people and understands their experiences through the concept of interdependence. It argues that the experiences of the two people in this relationship are interdependent and embedded in a broader context of support work that affects the relational experiences. Within this approach, the depth and richness of these relationship experiences can be explored by considering its links to the context of the policies of PBs that organise support work.

I use the social policy context of PBs in Germany and Australia to explore the depth of the experiences of support work relationships within each context and to understand the link between these relational experiences and the policies of PBs. Both countries offer two research contexts that have related, but different policy developments, histories, timeframes and experiences in implementing PBs. Therefore, I selected them as places to explore support work relationships. The selection was further based on the analysis of the empirical literature from both countries. While it identified that people with intellectual disabilities experience barriers in utilising PBs, it has not explored the richness of the experiences of support work relationships.

The two research questions aim to add to an understanding of how budget holders with intellectual disabilities and their support workers experience their relationships in the German and Australian contexts of PBs that organise support work and to what extent these relationships are affected or shaped by the policies of PBs.

CHAPTER III: Living the questions – Methodological approach to the study

> Have patience
> with everything that is unsolved in your heart,
> and to try to cherish the questions themselves,
> like closed rooms
> and like books written in a very strange tongue.
> Do not search now for the answers,
> which cannot be given you
> because you could not live them.
> It is a matter of living everything.
> Live the questions now.
> Perhaps you will then gradually,
> without noticing it,
> one distant day live right into the answer.
>
> (Rainer Maria Rilke, 2008, p. 21)

Introduction

In this chapter, I draw on IE as a qualitative methodology[4] and social theory developed by the Canadian feminist sociologist Dorothy Smith during the 1980s (e.g. Griffith & Smith, 2014; Smith, 1987, 1990a, 1990b, 1992, 1996, 2005, 2006). IE influenced the epistemological foundation of this study in that it offered a lens, through which I critically explored the two research questions (how do budget holders with intellectual disabilities and their support workers experience their relationships with each other? How are the lived experiences of people with intellectual disabilities and their support workers in their relationship with each other influenced by PB policies organising support work?).

---

[4] Some of the work in this chapter has been published in form of oral presentations. These presentations are the following:

Lutz, D. (2017). *What can Institutional Ethnography offer? Learning about the connections between the lived experiences of support work relationships and disability policies.* Paper presented at the 14th NNDR Conference in Örebro, Sweden.

Lutz, D. (2017). *Using participant observations to understand relationships between people with intellectual disabilities and their support workers: methodological insights and challenges.* Paper presented at the 14th NNDR Conference in Örebro, Sweden.

In this chapter, I describe how IE guided me in the execution of its qualitative methods (participant observations, interviews and policy document analysis) and how it influenced the ways I approached, collected, analysed and presented the data. In addition to IE, I discuss how Critical Reflexivity (CR) helped me to examine, question and manage my role and subjectivity in this research process. I then describe the selection and recruitment of research participants, review the aims of the research methods, critically describe their implementation and constraints, explain the data analysis and discuss the ethical considerations of the empirical research.

Institutional Ethnography

In this study, I used IE as a method guiding my empirical work and as a social theory. Both, method and theory, aim to understand 'how the everyday world of our experience is put together by relations that extend vastly beyond the everyday' (Smith, 2005, p. 1). In this section, I explain what kind of relations Smith refers to in this quote. I further explore how IE is different from other ethnographic approaches due to its theoretical and methodological emphases and discuss how using IE as a theory and method benefitted this study in exploring support work relationships.

Institutional Ethnography as a social theory

Ethnography, the study of culture, is one of the major approaches of cultural anthropology and sociology that expects ethnographers to live among the people they are studying for an extended period of time (Gergen, 2015; Hammersley & Atkinson, 2007; O'Reilly, 2012). The American ethnographer James Spradley (1979) argued that ethnographers do not study people, but rather seek to learn from them. Through their immersion within a culture from which they want to learn, ethnographers engage in a process of 'getting to know' the people who are part of this culture (Goodley, 1999, p. 28). The aspect of 'knowing' in the process of getting to know 'refers to an ongoing project of building a researcher subjectivity that learns from the experiences of people' in the ethnographic field (Goodley, 1999, p. 29).

IE as a social theory was inspired by this anthropological understanding of learning from people's experiences, but was influenced by a variety of other theories, including ethnomethodology (Wieder, 1974), feminist theories on gender inequality (Campbell, 2003), Karl Marx's theory on political economy (Marx, 1971, 1977) and phenomenology (Schutz, 1962). What IE shares with these theoretical frameworks is 'a commitment to begin and develop inquiry' in the same world people live in (Smith, 2005, p. 2). Smith was particularly interested in the lives of marginalised and oppressed women within a 'cultural and intellectual world created largely by men' (1990b, p. 1). She (1990b) saw their everyday experiences influenced by the personal and public relations of male power.

> At all class levels and among whatever racial differences, women remained marginal within the ruling relations, playing the subordinate roles, lacking agency, producing their work for men's appropriation (Smith, 2005, p. 20).

Smith's theory starts out from where she sees women located and that is 'below' within institutions (Smith, 1996). The institutional ethnographer starts her investigation from there to understand how 'the social' – the focus of exploration (which was the support work relationship in my study) – is 'put together', as Smith (2005, p. 1) calls it. The investigation starts by understanding the 'focus people' (i.e. the participants that the research focuses on) which serves to produce knowledge about the 'workings' of society (Rankin & Campbell, 2009; Smith, 1996; Widerberg, 2004).

The theory of IE states that the 'institution' is not an entity (e.g. government, administration, management, corporation, the media and academic discourses), but rather the work of several seemingly disconnected organisations or practices that form the 'ruling relations' (Griffith & Smith, 2014; Slade, 2010; Smith, 2005) which are moving through people's everyday activities (Rankin & Campbell, 2009). The term 'institution' stresses the contemporary capitalist power and the hierarchical structure of the ruling relations (Smith, 2001). In Smith's writings, she does not clearly distinguish between 'institution', 'organisation' and 'ruling relations', but explains that the ruling relations weld 'organization and institution as components of a complex of relations' (Smith, 2001, p. 161). Smith's conceptual use of these terms suggests that they cannot be rigidly separated, are interconnected and part of a relational system that people are subjected to. However, people create and shape the ruling relations as they form part of interacting organisations. The ruling relations are therefore social by nature.

In contemporary capitalist society, the everyday world is organised in powerful ways through the ruling relations that pass through and influence local settings and accomplish a social organisation in which knowledge is produced (Griffith & Smith, 2014; Smith, 2006). Smith explains that the ruling relations do not dominate, but rather influence the local experiences and consciousness of those who work and live in social settings (Smith, 1990a, 1990b). They are power relations, often not visible to people and located above the people who experience the 'everyday world'. This subordinates the lived actualities of people's experience to the discourse of ruling (Smith, 1990b). Therefore, institutional ethnographers always work, analyse and theorise from below, where people are located, to understand the ruling relations. Institutional ethnographers do not only seek to understand what the ruling relations are within their local research

context, but also examine the interconnection between the ruling relations and the people who live the experience. This process forms part of using IE as an empirical method.

Institutional Ethnography as a method of qualitative inquiry

Smith also understands IE as a method of inquiry, in which research is discovery rather than 'testing of hypotheses or the explication of theory as analysis of the empirical' (Smith, 2005, p. 2). This makes the research process an open-ended project of inquiry. Rankin and Campbell (2009, p. 1), who have used IE to study the work of nurses in Canadian hospitals, explain that 'the distinctive contribution of IE is in making links empirically – not theoretically – between the everyday life and its specific social organisation'. Through identifying and following the actualities of people's activities, the 'ruling relations' can be studied empirically (Rankin & Campbell, 2009). To do this, institutional ethnographers examine the 'local phenomena' first, as Smith calls the lived experiences, to understand how larger power relations shape them (Slade, 2010). This approach is related to Smith's thinking about women's positioning within a patriarchal society (their voices should be heard first before investigating how the ruling relations influence their supressed position) and the way she builds on two lines of inquiry.

> First, into what it means to explore the social from the site of women's experience and beginning therefore with an experiencing and embodied subject, and second, into the social organization of the objectified knowledges that are essential constituents of the relations of ruling of contemporary capitalism (Smith, 1990a, p. 1).

By applying these two lines of inquiry within its theoretical framework, I intended to find out (1) what the local phenomena (i.e. support work relationships) were in my study, (2) what the ruling relations were and (3) to what extent and how the former were shaped by the latter within social settings.

Institutional ethnographers traditionally work with three research methods: interviewing, participant observations and analysing texts. For example, interviews in IE 'are not just analysed to reveal subjective states, but to locate and trace the points of connection among individuals' within social settings (Smith, 2006, p. 18). All three data collection methods require the researcher's engagement with texts, termed 'text work' (Walby, 2005, 2012). Texts are data sources, such as interview transcripts, observation

notes or documents which help the ethnographer to understand and locate embodied human experiences within the ruling relations.

I collected data with the three research methods of IE in two national contexts. Smith stresses the potential and value of IE as a contemporary method supporting the investigation of translocal policy processes within diverse organisations that form the ruling relations (e.g. Griffith & Smith, 2014; Smith, 2005; Smith, 2006), but she does not elaborate on cross-national investigations. Using IE in the context of research crossing national borders has more recently been termed 'Transnational Institutional Ethnography' (TIE) by Grace (2013). He used TIE in the context of a study, in which he collected data in six countries across three continents for a research project in public health. He did not use the empirical data to compare a specific phenomenon among the countries, but rather to explore its diversity across institutional settings in these countries (Grace, 2013). Transnational research methods have been used in qualitative social research for some time (e.g. Christensen, 2012; Timonen, Convery, & Cahill, 2006; Ungerson, 2003). Transnational research revalued ethnographic approaches to social knowledge (Ungerson, 1996) and assisted in comparing and examining different political systems, cultures or social phenomena using the same research methods in selected countries (Hantrais, 2014; Hantrais & Mangen, 1996). The transnational approach of this study provided an avenue to a new understanding of support work relationships as it allowed me to use the context of support work organised through PBs in two different countries. This approach expands on the sociological approach of IE and explores 'transnational processes across diverse institutional settings' (Grace, 2013, p. 587).

To add knowledge to support work relationships in Germany and Australia, I drew on the language skills and the contextual knowledge I acquired while I was living, working and studying in both countries. TIE influenced the conduct of the empirical research in this study in that it helped me to make sense of the experiences of support work relationships in Germany and Australia under the influence of the policies of PBs.

Combining the theory and empirical method of Institutional Ethnography

This research study is grounded in the sociological and methodological framework of IE. As a social theory, it provided an account of the epistemological approach to knowledge production through its core concepts (the lived experiences and the ruling relations) and

their interconnection. The concepts of IE informed the ways through which I learned about support work relationships within their social settings.

As an empirical method of qualitative inquiry, IE can be used across several national contexts to explore the same phenomenon with the same research methods. I used IE to explore the relationship experiences of budget holders with intellectual disabilities and their support workers in each ethnographic setting. I then 'moved up' into the ruling relations to understand how the ruling relations were constituted across the German and Australian contexts of support work and to analyse how they shaped the experiences of the two people in the relationship.

Critical reflexivity

The theory and empirical method of IE not only influenced my understanding and interpretation of the experiences of my research participants. It also influenced my understanding of my own experience while learning from these people within their social contexts. The distinction between my own experience and my interpretation of the experiences of research participants required a reflexive act, which I discuss next.

Researcher reflexivity and Institutional Ethnography

Reflexive researchers highlight the importance of paying attention to the researcher's personal experience during the research process. While some researchers are critical about this and see a risk in revealing details of the researcher's privacy in their work, reflexive researchers see a risk in uncritically reproducing othering and masking the researcher's power by not recognising the researcher subjectivity (e.g. Krumer-Nevo & Sidi, 2012; Traustadóttir, 2001; Wilkinson & Kitzinger, 2013). The researcher can mitigate this risk by relating to the participant's accounts in the research (e.g. Ellis, 2007, 2011) and acknowledging the researcher's presence and subjectivity (Johnson, 1998).

Researcher subjectivity describes an aspect of research mainly incorporated and recognised in qualitative studies. For example, the process of 'memoing', in which the researcher documents their observations of the research phenomenon, is a central element in Grounded Theory research and based on reflexive thinking and writing (Dunne, 2010). Reflexivity has also been at the heart of feminist and ethnographic methodologies (Etherington, 2004; Malacrida, 2007) that add to knowledge by the researcher examining their own reactions to situations occurring in the research process and impacting on it (see 'Managing the researcher experience through critical reflexivity' in this chapter). Although IE was influenced by feminism, Dorothy Smith does not explicitly mention CR as a concept, practice or process integral to her work. Very rarely, she uses the word 'reflexive inquiry' in her writings. She does explain though that researchers are objects of inquiry immersed in their investigations who have to become aware of how they participate in the ruling relations (Smith, 1990b). She sees their position and insider knowledge as another way of exploring the ruling relations.

In the context of this study, it was important to reflect on my relational approach, the approach in understanding the experiences of the two people in relationship with each

other. Dorothy Smith has not elaborated on the researcher's relational approach to learning from the lived experiences of the local people, but in *Institutional Ethnography – a sociology for people*, she briefly touches on people's relationality.

> For institutional ethnography, the social as the focus for study is to be located in how people's activities or practices are coordinated. Individuals are there; they are in their bodies; they are active; and what they're doing is coordinated with the doings of others. The focus of research is never the individual, but the individual does not disappear, indeed, she or he is an essential presence. Her or his doings, however, are to be taken relationally (Smith, 2005, p. 59).

In this quote, Dorothy Smith, indicates that she considers the aspect of 'relationality' in understanding people's experiences. CR helped me to constantly check if I was taking the relationality of people within each research setting into account, especially of the two people within the support work relationship. It reminded me to understand each person's experience in relation to the other person's experience within the relationship. This approach was aimed at generating a deeper understanding of the experiences of support work relationships within the ruling relations.

Managing the researcher experience through critical reflexivity

When doing ethnography, it is important to acknowledge the researcher's personal ethnography too, as their self is an integral part of the culture they are learning from and understood through this medium. Although my foci were the experiences of each person in the support work relationship, I remained conscious of my own feelings about each relationship pair I encountered in the field. My personal values and experiences motivated me to enter this research process. They had to be questioned as the experience of my research participants were interpreted through my experience (Gergen, 2015; Goodley, 1999; Ulrich, 2006). This process of questioning is part of CR.

While I was immersed in the ethnographic field research with people with intellectual disabilities and their support workers, I also used CR to understand my personal attachments to them and to balance this with my commitments and my role as a participant observer (see Sections 'Ethical considerations' and 'Participant observation' in this chapter). CR formed an important part of my ethnographic approach. I had many assumptions about the experiences of my research participants, which had to be challenged and unpacked through *writing and talking about them*.

Writing about them happened with the help of Kim Etherington's work (e.g. 2004, 2007) that encouraged me to write about my own personal history and how it led me to become interested in the research topic. This included thoughts about my presuppositions, gender, social class and culture in relation to the research topic. I jotted these thoughts into a paper journal first and then wrote more detailed reflective accounts into an online journal[5]. Reflexive journaling (e.g. Malacrida, 2007) also assisted me in developing mindfulness and self-care by providing a 'safe space' in which I could explore my emotional reactions to certain situations, process and resolve them.

Talking about them was facilitated by Professor Kelley Johnson who constantly challenged my written reflections in supervisions. By sharpening the awareness of my own experiences, I was learning to 'leave them behind' and place the focus on the research participants' experiences which helped me to 'surrender' myself to the spaces in which I encountered them.

While CR has been core to qualitative methodologies in general (e.g. Dunne, 2010; Gergen, 2015), including ethnographic methodologies, the conceptual theory of IE did not offer much guidance on the management of my emotions and personal perceptions in the process of inquiry. The work of several reflexive researchers provided this guidance to me (e.g. Ellis, 2007, 2011; Etherington, 2004, 2007; Gergen, 2015; Goodley, 1999; Johnson, 1998; Malacride, 2007; Traustadóttir, 2001; Wilkinson & Kitzinger, 2013). CR further helped me in taking a relational and reflexive approach to explore support work relationships, which included balanced views on the experiences of both people in relation to each other (see also Section 'Conceptual approach' in Chapter I).

---

[5] Compared to the paper journal, the online journal was produced at the computer. Here, I converted the jottings from the paper journal into full reflective sentences saved in Word Documents. Each ethnographic fieldwork day was captured in a separate Word Document. The document included my observations with more descriptive detail, analytical thoughts and my emotional responses to these experienced observations.

Research participants and sites

In this section of the chapter, I introduce the three research participant groups (service professionals, budget holders with intellectual disabilities, support workers) and the research sites. I first explain how I selected the research participants and then explain how I recruited them. All three participant groups are listed in Table 1, which provides an overview of the number of people involved, how and when they were involved and from which country I recruited them.

Table 1 Research participants and method, fieldwork time frames and locations

Fieldwork stages	Time frame	Stakeholder group	Research locations
First fieldwork stage: interviews with service professionals	January 2015-March 2015	5 professionals from disability services	Baden-Württemberg (Germany)
	July 2015 – November 2015	5 professionals from disability services	Greater Sydney (Australia)
Second fieldwork stage: interviews and participant observations with people with intellectual disabilities and their support workers, interviews with service professionals	February 2016 - July 2016	5 people with intellectual disabilities and 5 support workers; 5 service professionals	Greater Sydney (Australia)
	August 2016-January 2017	5 people with intellectual disabilities and 5 support workers; 5 service professionals	Baden-Württemberg (Germany)

Selection of research participants

My research questions gave me an orientation during the selection of my research participants. I made sure that all budget holders and/ or a family member acknowledged that the budget holder had intellectual disabilities and used at least one PB. I did not place an intentional focus on the age, gender or cultural background of people, but made sure that budget holders and their support workers were over the age of eighteen. I describe next what other aspects I considered when I selected the three participant groups.

Service professionals

I interviewed ten service professionals in each country for this study. Service professionals were people who usually worked for a disability service provider and were involved in the coordination and/or management of support work organised through PBs. From January to March 2015, I conducted five interviews with service professionals in Germany. From August to November 2015, I conducted another set of five interviews with service professionals in Australia (see Table 1). These early interviews formed part of the first fieldwork stage.

Institutional ethnographers conduct interviews with 'text practitioners' (Walby, 2007, p. 1012), in this case service professionals, to explore how the experiences of the local people (budget holders and support workers) and disability policy documents fit into the wider context of the ruling relations. The service professionals I selected were familiar with organisational policy documents (see Appendix G) which they could refer to in the interviews. I selected them due to their expertise (on the policies of PBs and the support work for people with intellectual disabilities) and their different levels of involvement in the implementation of PBs. Some of them had previously worked as support workers which had influenced their understanding of support work.

I spoke to them in the early stages of the study to develop a contextual understanding of support work relationships (see Chapter IV). This knowledge allowed me to understand the current situation of PBs in both countries better and helped specifying the research questions. The analytical themes arising from this research facilitated the design of my research tools, such as the observation guide and the interview schedules (Appendices C, D, E and F), and made it easier to establish contacts with service staff who assisted in recruiting the pairs for the second fieldwork stage.

I selected another set of five service professionals in each country (one in each ethnographic setting) for interviews during the second fieldwork stage. These people were not the same as the ones who took part in the first fieldwork stage, but in similar roles. In both countries, these were often the direct supervisors of the support workers I was observing and in a team leader, coordinator or manager role. In one case, the person was a human resources manager involved in the development of service policies about support work. In another case, where the budget holder was not associated with a service provider, I spoke to a person from the local government agency overseeing the implementation of support work for the budget holder. Identifying the 'right service

professional' happened by learning about the organisation of support work in each setting as an ethnographer.

Budget holders and support workers

During the second fieldwork stage, I worked with ten pairs. I selected five people with intellectual disabilities in receipt of a PB and five support workers in Germany and Australia. The support workers in my sample assisted the budget holder on a daily or weekly basis. They were either employed by the budget holder directly or by a disability service provider that administered the PB. Working with five pairs from each country allowed me to explore the relationships of five pairs within their support work context organised through a PB (see Chapter V and VI) and to use data from the same number of pairs within two different national policy contexts of PBs.

In the selection process of the pair, I focused on people with intellectual disabilities and always tried to approach them first. I wanted to make sure that their preferences about their involvement in the study were heard and also had in mind that support workers might assist people with other types of disabilities. Finding out if the person had intellectual disabilities and a PB happened by meeting the person prior to conducting participant observations and by having conversations with their informal supporters (e.g. family member, friend) and/ or formal supporters (e.g. advocate, legal guardian, support staff) (see also Section 'Consent process' in this chapter). Since budget holders often had more than one worker, I spent at least one week in an ethnographic setting before I could decide which worker I was going to focus on.

Research sites

To avoid logistical challenges, I focused on specific areas within Germany and Australia. In Australia, I was based in Sydney, NSW where the state-government funded PB programs were available to people with intellectual disabilities at the time. I focused on the area of Greater Sydney (see Figure 1) for the empirical field research. In Germany, not every LGA and city district promoted PBs which limited my recruitment options (see Section 'German context of personal budgets' in Chapter II). I recruited research participants from the state of Baden-Württemberg (see Figure 2 and 3) and was based in Heidelberg, where I lived in the second half of the study (see Figure 2).

The ten German service professionals were from two LGAs (which included rural areas) and three city districts within the state of Baden-Württemberg. I recruited pairs from the same LGAs and city districts[6] as I had established relationships with some services prior to this study and during the first fieldwork stage and was aware that people were utilising PBs in those areas. This awareness arose during the first fieldwork stage (e.g. by interviewing service professionals and familiarising myself with local government policies). In Australia, I recruited pairs from the Greater Sydney Region only. One out of five people with intellectual disabilities lived close to the city centre. The others were based in suburban areas of Sydney.

Figure 1 Map of the Greater Sydney Region

---

[6] The names of the German LGAs and city districts in which I collected data cannot be revealed due to the protection of people's privacy and the confidentiality of data. Due to the smaller population of these places (compared to Greater Sydney), I refer to the German sites as the German state of Baden-Württemberg.

Figure 2 Map of the State of Baden-Württemberg

Figure 3 Map of the State of Baden-Württemberg within the whole of Germany

Recruitment of research participants

The recruitment of research participants occurred in accordance with the requirements of the Human Research Ethics Committee (HREC) at UNSW Australia. The HREC at UNSW Australia recommends recruiting through services ('arm's length recruitment')

rather than using direct approaches to participants. This recommendation is based on the belief that the initiation of contact through a trusted or familiar person can 'avoid real or perceived coercion' (UNSW Australia, 2015, p. 7). I now explain how and why I recruited my research participants through an arm's length approach with convenience and snowball sampling strategies.

Service professionals

For the recruitment of German service professionals in the first fieldwork stage, I liaised with my German advisor Professor Thomas Meyer. Two service professionals were recruited through his networks, two were recruited separately through two disability services I had previously worked for and one was recruited through active snowball sampling. Here, the colleague of one participant had passed my email onto another potential candidate who replied directly and took part in an interview. Since I was in Australia when I started recruiting German service professionals, I initiated contact via email or phone. The email included a personal introduction with information about the study and the Participant Information Statement and Consent Form (PIS and CF).

All Australian service professionals were based in Greater Sydney. My initial aim was to recruit service professionals involved with PB programs in NSW. I attended two service provider forums in July and August 2015 to get in contact with potential service professionals. At one of these forums, I connected with a manager from a disability service provider in Sydney. He referred me to a work colleague who I was able to interview. Although other potential participants indicated interest in taking part in an interview, it was hard for them to commit to a specific day and time. Professor Karen Fisher and a former work colleague then put me in touch with people I could interview for the first fieldwork stage.

In the second fieldwork stage, the identification of the 'right service professional' for the interviews happened either during the participant observations or during the recruitment of the pairs. In many instances, it was the service professional who helped me get in touch with the pair. I always knew who I needed to approach for this interview once I got to know each ethnographic setting better.

Budget holders and support workers

The recruitment process for the ethnographic work started in January 2016 when I was in Sydney. In both countries, I initiated contact with some of the services I approached for the first fieldwork stage. This facilitated an iterative recruitment process. I sent them a summary of the findings from the first fieldwork stage, in either English or German. However, services were not always comfortable or interested in being involved with the recruitment of the pairs. I then initiated contact with staff from other disability services within Greater Sydney. Two providers helped in recruiting pairs, but I found that using my own networks within the disability service sector in Sydney was more effective in approaching people as a trusted person had introduced me to them in an informal way. This recruitment strategy enabled me to approach two budget holders.

In five of the ten ethnographic environments, I was a participant observer in the home of the budget holder's parents. Some services and family members of budget holders mentioned that they found the participant observations 'too intrusive' and would need to give careful thought to whether they wanted the budget holder to take part in the study. People needed time to think about whether they wanted to be involved in the study and make this commitment. I had to approach them several weeks and sometimes months before the day I had planned to start the ethnographic work with them.

I used the same recruitment approaches for people with intellectual disabilities and their support workers located in Germany. Between March and June 2016, I initiated contact with several services and explained my research plans. The German recruitment process had progressed well so that two people with intellectual disabilities had already indicated interest before I left Australia. A smooth recruitment process continued throughout the ethnographic field research in Germany.

Overall, my selection and recruitment strategies proved to be appropriate and effective ways to select and get in contact with people and eventually gain their trust to take part in the research. I relied on convenience and snowball sampling strategies with an iterative arm's length approach due to the (perceived) invasive nature of the ethnographic fieldwork and the time constraints associated with the fieldwork taking place in two countries.

Research methods

Any ethnography is 'not a distinct stage of the research' as it begins in the pre-fieldwork phase, during which the researcher formulates the research questions and continues into the process of writing up (Hammersley & Atkinson, 1995, p. 205). In this study, data collection, analysis and theory-building happened simultaneously through an inductive and iterative process. The data collection started in the first six months and continued into the third year of the study (see Table 1 in Section 'Research participants and sites' of this chapter). A new understanding of support work relationships developed as I collected data through interviews, participant observation and document analysis. In this section, I describe these methods and explain how I applied them in this study.

Interviews

The ways in which I conducted interviews in this study were influenced by Smith's approach to interviewing that draws on the concept of 'work' (Smith, 2006). She (2006, p. 110) explains that through this concept institutional ethnographers can direct their 'analytic attention' to the work of people, which includes their practical activities. This process helps the institutional ethnographer to locate the people within the ruling relations as they conduct interviews.

The conduct of my interviews was further influenced by the work of Brinkmann and Kvale (e.g. 2005, 2015; Kvale, 2006) who value dialogue between researcher and participants in interviews. Creating space and time for dialogue in the interview helped me to tune into the 'life worlds' of my research participants (Smith, 2005) by giving them power and control in sharing what was meaningful to them. This approach helped in understanding more deeply what was important to them about support work relationships.

Interviews with service professionals

All ten interviews with service professionals during the first fieldwork stage were conducted as 'exploratory interviews', which differ from other types of interviews by focusing on questions covering broad, unknown and latent areas of expertise within the boundaries of the research topic (e.g. Honer, 1994; Honer, 2011). These interviews were guided by a semi-structured schedule (Appendix A) and usually took 45-60 minutes. Most

questions were open-ended with follow up questions to get interviewees to elaborate on their answers if this did not occur naturally.

During the second fieldwork stage, I conducted one focused (follow-up) interview (e.g. Merton & Kendall, 1946; Witzel, 2000) with a service professional in each ethnographic setting. These interviews were the same length as the interviews I conducted with service professionals during the first fieldwork stage. After at least two to three weeks of ethnographic fieldwork with the pairs, I tried to step back from the data that I had collected. I made time to reflect on what I absorbed, read through my field notes and edited them by making continual links between the lived experience data and the policy processes within the ethnographic environments. My field notes had often thrown up more questions. By speaking to one service professional towards the end of the ethnographic fieldwork in each setting, I could follow up on remaining questions. These interviews sometimes gave me access to specific policy documents, which I could not access through the support work pair.

Interviews with budget holders and support workers

Interviews with budget holders and their support workers were conducted as dyadic interviews, which can be conducted as joint and/or single interviews with both persons (Caldwell, 2014). This technique recognises interdependent relationships within pairs. Interviewing one person in the relationship can provide the opportunity to receive information that would otherwise not be shared with the researcher. Yet, joint interviewing can reveal information on how both people reflect upon their relationship and interact while part of this reflection occurs. The joint interviews were guided by a semi-structured interview schedule (Appendix F) and usually took 30-50 minutes.

The single interviews with budget holders and their support workers had similar length and were also guided by semi-structured interview schedules (see Appendix D and E). However, many budget holders used non-verbal ways of expressing their feelings and I could best understand them by working as a participant observer in their local environment rather than by interviewing them. However, in the ninth research setting, Thomas, a budget holder took part in an interview although he used very little verbal language. Together with his mother, I organised that a special educator who had worked with Thomas for many years, but who was not the support worker taking part in this study, assisted him in the interview. He supported Thomas by holding his wrist so that he was

able to type the answers to my questions into a Word Document on his laptop (see Section 'Thomas and Luke' in Chapter VI). This example shows that I had to be flexible and creative in conducting the field research and be sensitive to the communication support needs of the budget holders as well as to their relationships with trusted persons in their environment that could assist in better including them in the research process.

Participant observation

The observations in this study were conducted as participant observations. Through this method, the ethnographer can get access to the 'fluidity of others' lives' and see 'from the inside how people lead their lives, how they carry out their daily rounds of activities, what they find meaningful, and how they do so' (Emerson, Fretz, & Shaw, 2011, p. 3). This requires the ethnographer to immerse herself in the worlds of her research participants.

On each observation day, I took notes after I had finished the observation. The immediacy of doing this helped in remembering what I had observed. The method of participant observation was limited in that I strongly relied on my memory and the commitment to write up field notes shortly after each observation day. As a fieldworker doing research in my second language, I had to be careful that I did not miss what someone said due to possible difficulties in understanding specific words (Emerson et al., 2011). This could have been a limitation for the ethnographic field research in Australia and was particularly relevant when people used Australian slang. However, I rarely had the feeling that I did not understand what people were saying due to conducting research in my second language. If I did not understand specific words, I asked participants what they meant and why they were using specific terms or sayings. This was sometimes the case when one person in the relationship used a term directed at the other person (e.g. nick name, code word or a saying that both people had created within their relationship culture). I also captured my observations focusing on terminological use in my field notes.

I usually observed each pair for a period of three to four weeks. The days and hours within one week varied. This depended on the support work hours as well as the preferences of participants regarding the length of time they wanted to spend on taking part in the research. Fifty-two hours across a period of three and a half weeks was the longest I spent with research participants. Sixteen hours across a period of four weeks was the shortest (see Table 2). The observation time included the interviews.

Table 2 Participant observation periods, interviews and hours spent with budget holders with intellectual disabilities and support workers in each ethnographic setting

Participants in each setting[7]	Observation time	Observation period	Interviews
Greater Sydney, Australia			
1 budget holder and 3 support workers	52 hrs	26/02/2016 - 18/03/16	3 support worker interviews
1 budget holder and 1 support worker	30 hrs	29/03/16 - 14/04/16	2 interviews with the budget holder
1 budget holder and 1 support worker	39.5 hrs	27/04/16 - 17/05/16	1 budget holder interview, 1 support worker interview, 1 joint interview
1 budget holder and 2 support workers	28 hrs	01/16/16 – 16/06/16	2 support worker interviews
1 budget holder and 1 support worker	16 hrs	24/06/16 – 22/07/16	1 support worker interview, 1 budget holder interview, 1 joint interview
State of Baden-Württemberg, Germany			
1 budget holder and 2 support workers	24.5 hrs	09/08/16 – 02/09/16	2 support worker interviews 1 budget holder interview
1 budget holder and 1 support worker	16.5 hrs	13/09/16 – 11/10/16	1 support worker interview, 1 budget holder interview, 1 joint interview
1 budget holder and 1 support worker	31.5 hrs	17/10/16 – 14/11/16	1 budget holder interview, 1 support worker interview, 1 joint interview
1 budget holder and 1 support worker	36.5 hrs	30/11/16 – 22/12/16	1 budget holder interview, 1 support worker interview
1 budget holder and 1 support worker	35 hrs	29/12/16 – 19/01/17	1 budget holder interview, 1 support worker interview, 1 joint interview

Qualitative researchers often do not know how much data to gather in advance due to the exploratory nature of qualitative research (Baker, Edwards, & Doidge, 2012). The long

---

[7] The main research participants in each setting were always the pairs (see Chapter V and VI). This included one budget holder and one support worker. However, as I sometimes identified the focus support worker towards the middle or end of the field research, I conducted interviews and participant observations with more than one worker in some settings.

observation time and the number of support worker interviews in the first setting (see Table 2), for example, were related to the fact that I had just started the ethnographic fieldwork. I had to develop an understanding of when I had collected enough data to answer my research questions. This researcher understanding developed gradually throughout the ethnographic fieldwork.

The environments in which I observed people depended on the preferences of research participants and the support work activities. I spent most of the time in the budget holder's private home as well as in public spaces, such as parks, swimming pools, shopping malls, cafés and beaches. This was dependent on where the activities were carried out. With permission of participants, photographs were taken during the observations (see Section 'Consent process' in this chapter). Third parties who inevitably became part of the observations (and whose consent was sought prior to undertaking the research) included house mates, friends and/or family members of budget holders; and/or other support workers/ staff; and/or team leaders of a group of support workers.

Jotting, editing and presenting field notes

At the end of each observation day, I jotted field notes into my paper journal, which I wrote into an online journal immediately the day after. Jottings are defined as 'to-be-remembered observations' that are translated 'into writing on paper as quickly rendered scribbles about actions and dialogue' (Emerson et al., 2011, p. 29). The process of writing field notes requires an ethnographer to sit down and turn a piece of their lived experience into a written text (Emerson et al., 2011). The notes I wrote into my paper journal were often 'key words' – associated with certain situations I had witnessed – and sometimes a quote, but usually not full sentences. These were notes that facilitated the process of remembering what had happened in the field while I was participating. Jotting notes 'should evoke recall, not only of the details about what happened, but also of specific circumstances or context involved: who was present, what they said or did, what occurred immediately before and after, and so on' (Emerson et al., 2011, p. 33). Information about these circumstances and context formed part of my field notes.

I rarely took notes in front of participants. I was concerned that this would affect my relationships with them. However, in some circumstances, for example, when the budget holder was focused on an individual activity and the support worker was engaged in paper work, such as documentation, I felt it was appropriate to write notes into my

paper journal. At times, I said to research participants that I was now going to write some notes into my diary about the activities we had done so far. Focusing on the participation rather than on the documentation of observation helped me to relax into situations, become fully present, participate more in people's lives and see what it was like for both persons to spend time together.

The transfer of my field notes from the paper journal to the online journal facilitated a learning process, in which I could understand the difference between reflecting on what I saw and what I interpreted about what I had observed between people. When I started in my role as a participant observer, the latter included judgements, assumptions and criticism about the ethnographic setting and the participants, which got in the way of understanding more deeply what was happening in the support work relationships. I then wrote my judgements, assumptions and criticism, which were often part of emotional reactions, as footnotes into the online journal so I could separate them from the actual observation. This writing strategy quickly became part of my online journal writing practice and helped me in remembering to focus on 'descriptions that lead to empathetic understanding of the social worlds of others' rather than to follow my own 'evaluative impulses' (Emerson et al., 2011, p. 62).

Document and policy review: working with texts

The incorporation of documents as texts into ethnographic practice enables the researcher to understand how human actions are mediated by text (Grace, 2013; Smith, 2005). Smith describes the 'text as a constituent of social relations' (1990a, p. 125). This goes in hand with Goodley's (2014) critical approach to text which serves as a method to discover discourses of disability. He explains that all texts have a 'constitutive character to it: disability is constructed and created through the workings of the text' (Goodley, 2014, p. 17). In my study, I worked with disability policy documents as texts from ten different support work contexts within two national contexts. These included legislation, national government policies, state policies, policies of organisations employing support workers and policies produced by the local people themselves and/or meaningful to them (see Appendix G). The disability policy documents I reviewed helped to understand the policy processes that organised support work, which were enacted in human actions and relationships (e.g. Hudson & Lowe, 2009). They further helped to better understand how

the experiences of support work relationships were connected to and influenced by the ruling relations, which can further be studied through interview transcripts and field notes.

While I carried out the fieldwork and became familiar with each research setting, I developed my analytical framework for understanding the lived experiences of support work relationships and identified the types of policy documents. The analysis of these documents depended on the preliminary analysis of the lived experience data captured in the interview transcripts and ethnographic field notes, as the lived experience data organise 'the direction of the ethnographer's investigation' and the 'researcher's further steps' (Smith, 2005, p. 31). This is a necessary step during the analysis of the lived experience data, as the acquired researcher knowledge can be more specified by locating the lived experiences within the ruling relations (Smith, 2005, 2006). It helps the ethnographer to reach beyond the observable into the ruling relations (Grace, 2013; Smith, 2005).

Practical constraints of the data collection

Smith (2005) explains that there are no 'natural' boundaries to ethnographies other than those of the practicalities of the research. The practical constraints in my study were mostly related to accommodating the wishes of all research participants. For example, initially, I had planned to conduct single interviews, participant observation and joint interviews with each pair. However, after I started working with research participants and got to know them better, I realised that I sometimes relied on participant observation and single interviews due to budget holders expressing their views and perceptions in non-verbal ways, the limited availability of a trusted person assisting them in taking part in an interview or the limited availability of the support worker.

In one instance, the support worker reported feelings of discomfort about participating in a joint interview prior to it happening. Although this person had consented to take part in the joint interview, she was absent on the day we had scheduled it for. She often excused herself when I asked a question and seemed anxious about 'saying something wrong' or 'revealing too much information'. Although I tried to reassure her as much as I could, she seemed intimidated by my presence. I had to accept this as I wanted and had to give my participants power and choice about how to take part in this study. Respecting the preferences and wishes of the research participants was not only an ethical principle. It was also part of IE as a methodology and political commitment, which

is meant 'to serve those whose standpoint it undertakes as its starting point' (Smith, 2005, p. 42): the people with intellectual disabilities and their support workers.

Another practical constraint relates to the fact that the ethnographic fieldwork was very time-consuming. I spent several hours on one to three days a week with research participants. In both countries, I used public transport during field research, but it sometimes took up to two hours to travel to the sites. Due to 'gatekeeper issues' in the fourth ethnographic environment, I could only observe within a period of sixteen days. Although I had recruited through a disability service and participants had consented, the supervisor of the support worker in this setting was not accommodating of my work. This limited my time and made it difficult to organise fieldwork in this ethnographic setting.

The limited hours of participant observation in each setting were sometimes reflected in the limited hours of support work that a budget holder received. However, in this context, a practical constraint was that the pair or the people in contact with the pair, whose environments I had invaded, sometimes indicated that they wanted some privacy and 'less people around', which included my presence. I respected this and adjusted my fieldwork schedule to their preferences.

This section introduced and reviewed the three research methods that I applied in my study which are the traditional research methods used in institutional ethnographic research projects. Participant observation constituted the core method of how I made sense of support work relationships. However, I relied on policy documents and interviews also as they expanded 'the scope of the ethnographic method beyond the limits of observation' (Smith, 2001, p. 160). Documents and interviews provided additional insights into policies at different levels and new opportunities in gaining an understanding of each relationship within its national context of support work organised through a PB.

Analytical approach

The analytical approach in IE is hermeneutic as the researcher seeks to understand the data rather than to generalise from it (Kinsella, 2006; Smith, 2005). In the context of this study, the analytical process of 'understanding' meant that I stepped into the ongoing role of 'the learner'. I was learning from my research participants (see Section 'Institutional Ethnography as a social theory' in this chapter).

In this section, I explain the inductive, analytical framework of IE that guided the entire data analysis of this study and refer to the method of Thematic Analysis (TA) that helped me to practically conduct the analysis during both fieldwork stages.

Thematic Analysis based in the analytical framework of Institutional Ethnography

The research discovery and analysis process in IE always focuses on how the ruling relations are experienced by people from the 'bottom up' instead of from a bird's eye view experienced from the top (LaFrance & Nicolas, 2012). This inductive approach requires the institutional ethnographer to start understanding the micro-level perspective first and then relate it to the macro-level perspective (Grace, 2013). The micro-level in my study was the level from which I was able to understand the experiences of support work relationships as an ethnographer. The macro-level was the level from which I analysed how the ruling relations influenced the experiences of the two people in the support work relationship. This analytical procedure includes working out how 'inquiry passes from micro to macro' (Smith, 2005, p. 35) and understanding the connection between both levels of analysis (Norstedt & Breimo, 2016). These conceptual ideas were part of my analytical thinking process which operated throughout the data analysis of this study. However, I combined this thinking process with the method of TA.

TA is a recent analytic method which was developed by the psychologists Virginia Braun and Victoria Clarke in Australasia (e.g. Braun & Clarke, 2006, 2013, 2014; Clarke & Braun, 2013). They (2013, p. 178) stated that TA 'only provides a method for data analysis' and 'does not prescribe methods of data collection, theoretical positions, epistemological or ontological frameworks'. As a method, it contains systemic procedures aimed at identifying patterned responses or meanings within the data set in relation to the research questions (Braun & Clarke, 2006). This text engagement occurs

through a data dialogue between the institutional ethnographer and the data sources (Smith, 2005). I engaged in this data dialogue by immersing myself in the data sources (field notes, interview transcripts, policy documents), interpreting them and linking their contents to one another. This process helped me to generate themes in relation to my research questions. For example, after I gained a sense of what people experienced in their support work relationship, I identified the documents that were relevant in understanding the influence of policy processes on these experiences and used 'sequences of texts' (Walby, 2005, p. 158) to link them to the ways support work organised through PBs was carried out and affected the relational experiences. The analytical linking of data sources and themes happened as I explored the interconnection between the micro and macro-levels of the ruling relations. This analytical framework was part of the theoretical framework of IE and the TA operated within this framework.

Analysis of the interviews from the first fieldwork stage

In preparation for the TA, I taped all interviews in this study with a voice recorder and transcribed them verbatim. I converted the oral speech from the German interviews into written German text and the English interviews into written English. During the analysis of the German interviews, I simultaneously translated the quotes I used into English.

The analysis of the ten transcripts from the interviews with service professionals during the first fieldwork stage were conducted manually. In TA, the researcher actively engages with the interview transcripts, which means that 'themes do not just emerge' (Braun & Clarke, 2006). Themes and sub-themes are being actively identified, developed and analysed through the researcher's immersion into the interview data. Working inductively includes familiarising oneself with the data in a way that one can start observing individual patterns in the data set, make initial assumptions about them and control and evaluate them through a systematic observation of the entire data set.

I engaged with the German transcripts first and worked with the Australian transcripts afterwards. Between the first German and the last Australian interview was a ten-month period. During this time, I refined my research questions and acquired more contextual knowledge of support work relationships. I slightly amended the interview schedule (Appendix A) after I had transcribed the German interviews. My own thinking about the topic had changed and the development of my methodological framework was still in process at this time. This partially influenced the way I asked questions and

engaged in conversations with service professionals. After reading and coding the first three transcripts from each data set, I developed an inductive set of themes and sub-themes. With this in mind, I coded each transcript and assigned the codes to sub-themes and overarching themes until data saturation was reached. I refined the themes as I continued analysing the data and writing the analysis up. The themes from both interview data sets are presented in Chapter IV of this thesis, the first of the four findings chapters. They served me in gaining a contextual knowledge of support work relationships before entering the ethnographic field.

Analysis of the ethnographic data from the second fieldwork stage
The data from the second fieldwork stage included field notes from the participant observations, interview transcripts and policy documents. All field notes were written in English. I immediatly translated German quotes into English and often wrote the original German quote in brackets behind the English quote. I followed the same procedures from the first fieldwork stage to prepare the interview data from the second fieldwork stage. Reflections about interviews were part of my field notes.

At the start of the ethnographic fieldwork, I was overcome by my own impressions and observations, which I had to process as I became accustomed to my 'new role' as a participant observer. I felt overwhelmed by the pages of field notes and interview transcripts I accumulated. At the end of the ethnographic fieldwork, I had written 800 pages of field notes and had conducted 47 interviews. Each of the 47 interview transcripts had 20 to 40 pages, without mentioning the policy documents I had collected. After I had written the first field note set, I often included headings to structure the field notes. Some headings referred to the support work activities, others referred to conversations or meetings that were held and the topics discussed. This formed part of the initial open coding process, during which 'the ethnographer reads fieldnotes line-by-line to identify and formulate any and all ideas, themes, or issues they suggest, no matter how varied and disparate' (Emerson et al., 2011, p. 172). Analytical thoughts about the data were shared with my supervisors and included in field notes as 'code memos' (usually in footnotes).

Code memos are the researcher's ideas, concerns and insights that they bring to re-reading their field notes and 'grow out of reengaging the scenes and events described' in their notes (Emerson et al., 2011, p. 186). When I 'reengaged with the scenes' I was reliving certain situations as I remembered the feelings of research participants and my

emotional reactions to them. This 'emotional recap' also occurred when I started using the NVivo Software Package 11 by QRS International, which helped me to organise, manage and code all interview transcripts and field notes after I had written up my last set of field notes. While computer-assisted qualitative analysis programs have their limitations, such as shifting the ethnographer's attention away from creating new codes and categories (Emerson et al., 2011) and missing details and complex examples that do not fit into categories (Kelly, 2016), they 'aid the researcher in breaking down and classifying large amounts of information' (Kelly, 2016, p. 59).

While I agree with Emerson et al. (2011) and Kelly (2016) about these limitations, I found that NVivo 'does provide a starting point for the daunting process of sorting through large amounts of information' (Kelly, 2016, p. 59). The software supported me in structuring my data, getting an overview of it and facilitated data immersion, during which I 'soaked myself' in it. Through the software, I was able to develop a set of codes and categories that guided me in developing the descriptive findings chapters (Chapter V and VI). I used these descriptive findings to explore the lived experiences of the two people by linking them to the concept of ruling relations, which I present in the analytical findings chapter (Chapter VII).

The analytical approach in this study developed through the analytical framework of IE. For the systematic conduct of the analysis during both fieldwork stages, I used the method of TA. TA operated within the conceptual and empirical framework of IE to help me in identifying the themes and sub-themes in my data relevant to my research questions.

Ethical considerations

Guillemin & Gillan (2004) differentiate between two major dimensions of ethics in qualitative reflexive research: (a) *procedural ethics*, which include seeking approval from a relevant ethics committee to undertake research involving humans; and (b) *ethics in practice*, which are everyday ethical tensions (microethics) arising in the doing of the research. In this section, I explain the procedural ethics of this study, reflect on the ethics in fieldwork practice and discuss a third dimension of ethics in qualitative reflexive research, which I called 'relationships with research participants'. As the ethnographer of a study about support work relationships, it was highly important that I remained conscious of and reflective about the relationships I formed with my participants.

Procedural ethics

In November 2014, the Human Research Ethics Advisory (HREA) Panel at UNSW Australia granted ethics approval for the first fieldwork stage of the study and in December 2015, the HREC granted ethics approval for the second fieldwork stage. The conduct of social science research in Germany does not require an ethics approval from a German institution. This was confirmed via email by the Association of Medical Ethics Committees *(Arbeitskreis Medizinischer Ethikkommissionen in der Bundesrepublik)* and the German National Ethics Committee (*German Ethikrat*), which I attached to both ethics applications. Apart from obtaining formal approval of ethics committees, familiarising myself with their relevant policy documents and providing them with annual reports, there were ethical questions and tensions which suddenly arose in the field. These were the ethics in fieldwork practice.

Ethics in fieldwork practice

I now draw special attention to the process of obtaining consent from participants, learning from ethically important moments as an ethnographer during data collection and providing feedback to participants.

Consent process

Informed consent was obtained from all three research participant groups. However, the consent of other people in the ethnographic field had to be considered as well. I designed consent forms for support workers, service professionals, people signing on behalf of budget holders (e.g. legal guardian, advocate), third parties in observations and supporters[8] in an interview. I designed two types of consent forms for budget holders; one in an easy-read format with pictures from Photosymbols Ltd 2016 and the other in plain language only. A friend who works as a Special Education teacher with students with intellectual disabilities gave advice on the accessibility of the easy-read consent form (see Appendix B) as I designed it. I only used this form in the field research with participants with intellectual disabilities as it was their preferred form.

During recruitment, I inquired whether the persons with intellectual disabilities had legal guardians. If this was the case, I always obtained their written consent. Although more than half of the budgets holders had legal guardians, nine out of ten could provide written consent. All ten had the ability to express consent in verbal or non-verbal ways. In all cases, I obtained their verbal and/ or written consent with the support of a trusted person, such as a family member or support worker. I usually met research participants a few weeks prior to the fieldwork to introduce myself, obtained informed consent and talked to them about the research in a language which I thought would be best understood by them. I was sensitive to their body language and other signs of non-verbal expressions to observe how they felt about taking part in this study. The consent process was ongoing. I always inquired, for example, when I took a photograph during observations (see Section 'Feedback to participants' in this chapter), if they were comfortable with me doing that. This often required explaining again the purpose, use and confidentiality of taking photographs for the study.

It was not always possible to obtain verbal and written consent from support workers and budget holders at the same time. This was dependent on the recruitment and with whom I had to liaise to get in contact with both people. In eight settings, I was initially in contact with a professional from the service involved in the provision of the support work. In two settings, the mother of the budget holder introduced me to them and their worker/s. In five settings, I had joint meetings with the person with intellectual

---

[8] In this study, a supporter was a trusted person who helped the person with intellectual disabilities and communication needs to answer for themselves in an interview (Lutz, Fisher, & Robinson, 2016).

disabilities and the support worker to obtain written and verbal consent. Sometimes these meetings were also attended by family members of budget holders. However, these meetings were often arranged between the support worker and me or the budget holder's mother and me. Only one budget holder organised this meeting independently in consultation with me. This person was used to making her own decisions and had great organisational skills. Because I was not always able to obtain consent simultaneously from people, I was sometimes concerned that people might have consented to please someone else within the ethnographic environment. Once I got to know my research participants better, these concerns subsided as I could repeatedly check with them if they were fine with the ways I collected information.

Ethically important moments during ethnographic fieldwork

As an ethnographer, I encountered a variety of 'ethical challenges'. I needed to manage these 'on the spot'. However, the word 'challenge' can imply a negative connotation, especially on a microethical level where the ethnographer works closely with people. I adopted the term 'ethically important moments' by Guillemin & Gillam (2004) as I learned from these moments and I hope my participants did too.

These learnings, for example, included my responses to research participants when they asked me for feedback during and after observations. Sometimes, we reflected on some activities we did together and what it was like for them to have me joining in. When it was appropriate, I shared some of my impressions with them. However, these thoughts focused more on the activities and the ways support work was organised rather than on what I thought about their relationship experiences. In two instances, the supervisors of support workers asked me what I had observed about their employees and in two other instances, family members of budget holders were curious about what the support worker and service professional shared in the interview with me. I had to gently remind them that the information people shared with me was confidential. I always had to be cautious and careful that I would not disclose confidential information that had potential to fracture or break existing relationships within the research setting.

Sometimes I felt irritated when an ethically important moment occurred in the field. For example, the social advocate (not the legal guardian) of a budget holder who took part in this study was present on one single day. This person wanted to have a say about the budget holder's involvement in the study after the budget holder had already

given consent. Neither the budget holder who had full capacity to give verbal and written consent, nor the service mentioned that the former had an advocate when I inquired during recruitment. In this case, I apologised to the advocate, provided her with information about the study and explained that I had obtained consent from the budget holder.

My learnings about ethically important moments also happened when I sensed that I related to one person in the support work relationship more than to the other. This became evident in my field notes. Through regular supervision meetings, I could reflect on this and carefully modify my approach and behaviour. My aim was to build rapport with the person with intellectual disabilities first when I entered a research setting. Yet, this was not always possible. In some instances, where support workers were extroverted and chatty, but the budget holder was shyer, reserved and had limited verbal speech, I observed that I was sometimes more inclined to focus on the worker. In one instance, I had the feeling that the support worker tried to impress me. I felt that this worker changed and added activities to the support work activity schedule due to my presence. I gently reminded the worker that I would be joining them both in the activities that the budget holder likes to do and usually does. In another setting, the support worker spent very little time with the budget holder and was not much around, which led me to build a stronger rapport with the budget holder. In another case, a woman with intellectual disabilities took control over her support arrangements and was organising her support work quite independently – sometimes without consulting her support worker. I felt that I often related to the woman more than to her worker. Regular supervision debriefings helped in noticing when this happened. I could then modify my approach and balance it more. Although relating to one person more than to the other happened both ways, I overall sensed that when budget holders had communication support needs and I had difficulties understanding their needs, there was a risk of relating more to the worker.

I also witnessed interactions between some pairs that distressed me. This occurred, for example, when I felt that the budget holder was expressing a need or a desire, which remained unanswered[9]. I then had to hold back, be sensitive as to how both people were working together and question why this was happening as it was not my role to intervene in these situations.

---

[9] Before going into the field, I set up a protocol which helped me to grade the potential risk of witnessing abuse and/or neglect during fieldwork. I did not have to make use of this protocol. However, I found it important to have this in place, as it could have been helpful in identifying and grading the level of abuse and/or neglect and guiding me in my decisions about what action I would have needed to take in certain circumstances.

Feedback to participants

Feedback to participants was provided in various ways. For example, I sent a summary of the findings from the first fieldwork stage to the service professionals I interviewed. This summary was available in English and in German. I explained to all participants that once this thesis is published, I will provide written feedback about the research findings to all the people who took part in this study and indicated interest that they wanted to receive feedback. This information was also included in the PIS and CF forms.

With consent from participants, I took photographs of them during the ethnographic fieldwork. This was included in the PIS and CF forms. The photos were for the participants only. Dependent on their wishes, I either emailed the photos, copied them onto a CD or handed them to participants as hard paper copies. Overall, people seemed grateful about receiving these photos and noted that it was a nice memory for them.

Feedback was also provided in form of sharing the interview transcripts with the person who took part in the interview. This happened via email, via post or in person, depending on whether the person had the capacity to read the transcript and was interested in it. However, in one instance, a budget holder had shared the interview transcript with her parents after I had left her place. The next time I saw her, she spoke to me about the transcript and mentioned that her parents said that she should have not mentioned a topic she had brought up in the interview. I felt that this topic was very important to her since she raised it several times and was upset about it. We talked and debriefed together. I offered to remove this topic from the transcript, but she expressed that she was fine if it stayed there. While I was reassuring her, I was mindful of her relationship with her parents. This incident reminded me of the influence of other people on budget holders and raised the question about how much power budget holders have in exercising rights and making their own decisions. In the same research setting, the support worker made a critical comment about the person's parents in the joint interview. When I returned the transcript to the budget holder, I removed this comment as I was concerned that the person would share the transcript with her parents again. This might have had the power to fracture the relationship between the worker and the parents. I constantly had to be mindful of the relationships that budget holders and support workers had to third parties when I provided feedback to them.

While I shared interview transcripts, I did not share observation notes with my research participants. All field notes were written in English and would have not been

accessible to all research participants. Furthermore, the field notes included critical comments and information about my own emotional responses to situations. Some notes could have been hurtful for some participants and even jeopardised a support work relationship. I was not trying to hide my interpretations of the findings from them, but considered their wellbeing and that I was not disrupting any existing relationships.

Relationships with research participants

Although my relationships with research participants were not the focus of this study, I reflected on them. Critical reflections in supervision debriefings helped in managing my experience of being in relationships with participants, supported me in the process of 'joining' and 'withdrawing' from these relationships and drawing attention to how this influenced each pair.

Venturing into relationships with research participants

When I entered each research setting and ventured into relationships with research participants, 'empathetic immersion' supported me in building trust and rapport with participants. Empathetic immersion is a process that starts by writing field notes, where the ethnographer thinks about what is important to the research participants (Emerson et al., 2011). During this recall, I became responsive to what my participants were concerned about in their own terms and experienced what it is like for them to experience a particular situation (Emerson et al., 2011). I then transformed my experience about the observed experience and presented it in a written account. This process helped me in deepening my relationships with research participants as I could immerse myself better in their worlds and open up to their feelings towards each other. Writing and re-reading my critical reflections about the relationships I formed with participants (as part of taking field notes) helped in becoming sensitive towards the feelings of participants, anticipating their reactions and noticing their responses to each other, the environment and to me.

Venturing out of relationships with research participants

Building relationships with participants can break down barriers between the researcher-self and the 'others' (Traustadóttir, 2001; Walmsley & Johnson, 2003). After spending three to four weeks with a pair, I was not so much 'the stranger' anymore. This was

something that often became evident towards the end of the observation time. I then became more conscious that I had to venture out of the relationships with research participants shortly. This often made the research participants and me upset.

The research participants and I had shared personal concerns. Often they wanted to know why I had become interested in their lives. I felt that an honest and personal reflection engendered trust in me and the research process. Sharing personal stories became part of forming a trusting relationship and 'trust is also key in good research relationships' (Rogers & Tuckwell, 2016, p. 3). Rogers (2003) explains that through the exploration of 'common ground', which can occur when sharing personal stories, the researcher may be less inclined to other. Developing a more personal relationship helped in reducing the potential to form judgements and made me more interested and curious about understanding the experiences of the research participants.

In some instances, I continued staying in regular contact with participants after I stopped working with them. I noticed that I sometimes had become attached to third parties too. I never left the research setting abruptly. Instead, I reminded people gently in the second or third week of my involvement that the following week was going to be my last week of fieldwork. I usually brought a celebratory cake and thanked everyone for letting me learn from them. On my last day in one specific setting, a support worker asked me, "So, what do you think of us?". In another setting, a third person commented on my last observation day, "It's very different here, isn't it?" and another person asked, "How did you find it over there?". Leaving the research setting and venturing out of these research relationships created anxieties on both sides at times. Reassuring research participants that I would remain in contact and update them on the research findings was in some cases imperative to sustain trusting and ethical relationships with them.

This last section of Chapter III discussed some important ethical considerations that I had to make in my role as an ethnographer. The ethically important moments were learnings for which I could often not prepare as they arose 'on the spot'. Building trusting relationships with my research participants helped in managing these situations. This was a time-consuming process and involved my ongoing ability and commitment to empathetically immerse myself in the life worlds of my research participants.

Conclusion

In this chapter, I discussed IE as an empirical method and a social theory to show how the potential of combining method and theory and using them in more than one country helped me to add to an understanding of support work relationships. I explained why I grounded the methodological framework of IE in CR and how this hybrid approach helped in exploring the two research questions and in critically evaluating the knowledge I generated throughout the research process while I managed my subjectivity as an ethnographer.

The chapter introduced the three research participants groups and explained how they took part in the study. The same research methods (interview, participants observation, review of policy documents) were applied in both countries to understand the empirical links between the ruling relations and the experiences of support work relationships. I explained why the empirical research of this study started with interviews with service professionals – 'to get the lay of the land' in both countries and generate a contextual understanding of support work relationships (see Chapter IV).

I described that the analytical framework of IE, which works from below, where people are located within social settings drove the data analysis in this study. By understanding the experiences of people with intellectual disabilities and their support workers first, I connected them to the ruling relations (see Chapter VII), which are located 'above' the people that I learned from during the ethnographic field research. Although the analytical approach is grounded in IE, I used TA to conduct the analysis that helped me to structure and organise the new knowledge in form of themes. I placed an additional emphasis on the ethical dimensions of the research and on the importance of forging trusting relationships with research participants to highlight the sensitivity of the ethnographic field research in this study.

CHAPTER IV: 'Getting the lay of the land' – Generating a contextual understanding of support work relationships

Introduction

This chapter presents the empirical findings from the first fieldwork stage in 2015. This stage included five interviews with service professionals in Germany and five interviews with service professionals in Australia (see Table 1 in Chapter III). By speaking to these service professionals and analysing our conversations, I identified themes about support work relationships in the context of PBs.

The analytical themes are grouped under 'support work relationships' and 'support work and the policies of PBs' to first understand the relationship and then its wider policy context. In the first part of the chapter, I present the views of the service professionals in Germany and in the second part, I present the views of the service professionals in Australia. In both parts of the chapter, I share my reflections on the knowledge acquired by making analytical links between support work relationships and the wider policy context of PBs. The chapter ends by introducing the questions arising from the research and by summarising the knowledge produced throughout the chapter.

In Chapter III, I explained that institutional ethnographers usually explore the lived experiences of the local people first, in this case the budget holders with intellectual disabilities and their support workers (see Section 'Institutional Ethnography as a method of qualitative inquiry'). However, by interviewing service professionals in the first stage of the research, I sought to provide a contextual understanding of support work relationships in Germany and Australia and map 'the lay of the land' for the ethnographic field research. I specifically asked service professionals about the two people involved in a support relationship, but some of their accounts related to people with (intellectual) disabilities in general and were not specific to budget holders (with intellectual disabilities) and support workers assisting budget holder with intellectual disabilities. Therefore, I use the terms that service professionals used.

Interviews with service professionals in Germany

This part of the chapter presents the themes from the interviews with service professionals in Germany (Silke, Franziska, Paula, Nicole, Anette and Stephan[10]). Although I worked with five transcripts from each country, one transcript in the German data set included the perspectives of two service professionals, Anette and Stephan. They were colleagues working in the same service and expressed the wish to be interviewed jointly.

Support work relationships

I will now describe how service professionals viewed support work relationships. In the interviews, they focused on the roles within support work relationships, the involvement of the service provider in the development of the relationship, the qualities of support workers and the meaning of supervision for the relationship.

Is the customer king? Power, dependence and roles

This section includes the views of service professionals on the role of the 'customer', the term which they assigned to the budget holder. I analyse their views on this role in connection to the support worker and link this to the support work relationship.

Anette said the policy developments of PBs have been the impetus for the creation of a social market in Germany. She explained that this social market had never fully developed because many people with disabilities did not utilise PBs. She also noted that the budget holder becomes the centre of attention in this market as "the person with disabilities doesn't have to adjust to the service anymore".

Franziska explained why she was using the term 'customer' when she referred to a budget holder: "we are a service provider, and you can buy our services, and if you buy our services, then you are our customer". She associated this term with the purchase of services. Franziska and Nicole said that customers can gain power through PBs, which has potential to change roles within the support work relationship. Nicole elaborated on this aspect by giving a practice example:

> The customer is king... if the customer says, "No, I would rather go into town with you to McDonalds", well, the customer is king! This doesn't imply though, that the assistant should go to McDonalds all the time... it is necessary to make compromises. (Nicole)

---

[10] The names of these research participants, including all others in this thesis, are pseudonyms.

Nicole's account signalled the importance of budget holders and their workers making compromises. However, 'making compromises' seemed to contradict the role of the customer in some way as a customer role should entail that the person gives directions in the support work relationship and should be considered as 'king'. Nicole's account further indicated that there were two people participating in the support work relationship whose interests seemed relevant in deciding on and doing support work activities.

The term 'customer' is a marketised term that occurs frequently in the international literature about PBs. Franziska's and Nicole's views and perceptions seemed to be influenced by a marketised and economic discourse of PBs. It obscured the extent to which budget holders exercised power over their support in practice. The money they referred to when they spoke about PBs were government funds. This also signalled a certain dependence of budget holders on others. Franziska shared her view about why budget holders can gain power through their PBs:

> With a PB, one has a much more powerful role. All of a sudden, they (budget holders) know what their assistant costs. This transparency is much greater, which gives much more power to the customer… this is where many colleagues struggle, they think that they (budget holders) must be happy to have us. But this has changed… we are service providers and the person with disabilities is customer and the king who decides. (Franziska)

It seemed that Franziska assumed that the customer role was powerful because the budget holder had more transparency about the costs of the service and could make decisions based on this transparency. It remained unclear how this transparency empowered a budget holder in making decisions. Franziska's account also indicated that service staff felt reluctant to share decision-making power with 'customers', but it did not indicate where this reluctance came from or how and by whom it was experienced.

Most service professionals referred to the support worker as 'the assistant' who is meant to deliver the support service in the way the customer wants it. They stressed the powerful role of the customer, but none of them said that the customer takes an active role in developing the support work relationship. No one mentioned that budget holders could potentially show initiative in negotiating decisions with their assistants or how they contribute to the work both people do together, which challenged their statements on the powerful role of the customer.

Service involvement in the 'togetherness': setting up lasting relationships

The service professionals indicated that they wanted to be involved in support work relationships to some extent so they could make sure that the relationship lasts. In this context, some made reference to 'friendship' within the support work relationship. For example, Paula explained that some people with disabilities call their support workers 'friends' and see them that way. This, as she noted, is often a requirement for starting a support work relationship as "they (support workers) need to have a high capacity to form a personal bond". A couple of service professionals mentioned that 'bonding' can, for example, happen when the support worker engages in an activity that may not be related to a specific goal captured in the support plan, but may suit the interests of the person with disabilities. This statement signals the importance of the worker's focus on the person with disabilities rather than on a set of work principles.

Nicole described the support work relationship as "a different togetherness" and associated this with two people being equal in the relationship, but that this was hard to realise: "I wouldn't call it friendship, it is more from eyeball to eyeball, because when you're professional, it will always be the advisor… there will always be someone who helps". Nicole acknowledged that the budget holder may not always be in a powerful role due to the person with disabilities' support needs and the support worker's role as a professional advisor. This seemed to challenge her other statement about the relationship 'from eyeball to eyeball'. Franziska picked up on a similar aspect about support work relationships and spoke about the 'same eye level' within the relationship. In this context, she explained that the worker's professional background is secondary when a budget holder employs a support worker.

> There are certain areas, where it makes a lot of sense to employ someone with appropriate qualification to make sure a good relationship develops, but there are certain things where professionalism is secondary and both people meet on the same eye level. (Franziska)

Franziska's account contradicts the statements she and others made earlier about the customer being the king. It made me question whether one person is or should be the king in the relationship if two people are supposed to meet on the 'same eye level'.

Nicole said that although support workers are autonomous in the ways they develop a support work relationship and deliver support, the service still monitors the trajectory of each relationship and only "backs off" when "everything goes smoothly". She added that her service has the intention of facilitating a process in which personal

and sustainable relationships can develop and grow by giving both people space in forming these relationships independently. With this strategy, her service tries to avoid "a high fluctuation among assistants" and still oversees the development of the relationship, in case issues arise, she commented.

Several interviewees touched on the process of matching support workers and people with intellectual disabilities so that they can start taking some control over the support work relationship. Several interviewees indicated that age and gender are criteria for matching budget holders and support workers. Franziska noted that her service asks people with intellectual disabilities about their preferences prior to starting the service, which includes questions about the gender and age of their preferred workers. Nicole explained that "if I come along with my mid-50s…I try and keep up to date to see what is 'in'… but I won't be as authentic in the togetherness as someone who has the same age" as the person with disabilities. She added that younger ages of university students can be "very refreshing" and compared them with older permanent staff members who are less likely to try new things and experiment. Anette said that men with intellectual disabilities are more likely to see their male workers as "buddies", but she did not elaborate on why this was the case. It seemed that matching criteria included certain commonalities which could maintain the relationship.

The service professionals in Germany made clear that they wanted the support work relationship to be a lasting arrangement. They were able to explain the idea of a lasting relationship and why they thought this was beneficial for both people and the involved service providers. The idea of 'togetherness' within the support work relationship stood out in this context. It seemed to be something related to both people's experiences of support work relationships.

Understanding the self and the other through reflection: qualities of support workers

Another issue that service professionals in Germany focused on in the interviews were the qualities of support workers. These qualities were not associated with professional qualifications, but rather with personal traits and values. While they mentioned a range of qualities that make a good support worker, they did not elaborate on all and only described those which seemed important for the development of support work relationships. Anette emphasised that the ability to self-reflect was an important quality.

> People are needed, who are flexible, who can observe themselves… reflect on themselves and pursue different pathways of action… this is where people in the disability field need to be ready for. This is the inner pedagogy… reflect on what we believe and think. (Anette)

Anette's statement conveyed that good support workers engage in a process of self-reflection to assess their own behaviour towards the person they are supporting and to make necessary adjustments according to the needs of the latter. It seemed that Anette thought that a support worker should not only understand the needs of the person they support, but also their own needs. To gain this understanding and differentiate between the needs of the person and one's own needs, a support worker must be able to self-reflect. Nicole explained that appreciating the budget holder should be inherent to the worker's approach and entails the capacity to understand one's own judgements.

> This is hard to portray in the mission statement. The most important principle is actually not to judge.... this is not always easy, but it is very often part of our discussions in case reviews. Often when it isn't going so well, there is a misbalance around judgment. (Nicole)

Silke remarked that support workers need to be open to the interests and talents of the person with intellectual disabilities which includes being able to see and work with their potential "in a therapeutic way" as this is when the latter's personality can develop and grow. Paula raised the importance of openness which she defined as, "that one can meet the other with their joys and fears, where the other stands and not where I want to see them... and to support them with all their concerns and not my concerns". This form of acceptance includes to "leave someone with their oddities", Franziska commented and noted that respect is reflected in the worker's language and how they address the person. Paula added that respect grows through the worker's reliability and empathy. She stressed the importance of these qualities by referring to the home environment of the person with disabilities where support work may take place.

> These people (support workers) need to be equipped with mirror neurons, so that they can empathise. Empathy, yes and respect… there needs to be a certain type of trust, because… they are in the personal home… many people don't like that. (Paula)

While Paula mentioned the importance of the home environment in the context of the qualities of support workers, she did not explain the link to the budget holder. Neither Paula, nor any of the other interviewees in Germany made clear that the qualities they

were describing formed part of a professional approach, specific to a support worker assisting a budget holder. They spoke about useful, but random qualities that may help any type of support worker to build a relationship with any person that might have support needs. It further remained unclear why these qualities were only associated with support workers, but not with budget holders.

Supervision and the support work relationships

Service professionals raised the importance of supervision in the form of collegial support for support workers. Nicole mentioned that monthly team meetings and one-on-one debriefings between support workers and their supervisors were important for evaluating the worker's style and capacity of developing a support work relationship.

> I think that this is crucial in the relationship work… we try over and over again to clarify things in case reviews…we have a big team… we use the time to talk and exchange ideas… and these inputs from the outside, they are very helpful, because if you are involved all the time and you think and want to give your best, you may get stuck. (Nicole)

Franziska explained that 'collegial advice' (kollegiale Beratung) is a technique used to supervise support workers in her service. "We do supervision from colleague to colleague", she commented, which can happen when support work is delivered in private homes. While Franziska considered the necessity to provide supervisory support in the form of collegial support to support workers working in private homes of people with disabilities, she did not make reference to and elaborate on the meaning and implications of the home environment of the person with disabilities (which is the work environment of the support worker) for the experiences of the support work relationship.

Some service professionals implied that they understood collegial support as a form of supervision and professional advice for support workers, which focuses on the implementation of the support work, rather than on the approach of the worker towards the budget holder. Silke, for example, reflected on one support work relationship, in which a person with intellectual disabilities could not fulfil the expectations of their support worker. She explained that this person "made a huge effort to live up to the expectations of her assistant… but that was never good enough". Silke linked this issue to a lack of supervisory support and stressed the importance of learning from relationships that do not work out. She recommended regular supervision, in which the person with

intellectual disabilities takes part. In her view, a good support work relationship can only work out when it is "directed at the person" with disabilities, which requires the worker to be open to the person's interests, rather than imposing their own values and expectations upon them.

Reflections

Service professionals revealed their views about the roles of both people in the relationship. They stressed the support worker's responsibilities in managing the support work relationship, but none of them mentioned that both people may have to negotiate tasks and responsibilities in a relational manner. They also identified a 'customer' and an 'assistant' in this relationship, but did not explain the two roles in relation to the other. I found contradictions in some of their statements. For example, it seemed that they found that the 'customer' had (decision-making) power, but their statements indicated a strong dependency of budget holders on their workers. In the ethnographic work, I wanted to observe how the pairs show signs of interdependence and if there are certain situations where one of them relies more on the other.

Some service professionals were personally involved in setting up lasting relationships. However, the wishes and preferences of both people in this process seemed to play a minor role. No one mentioned the budget holder's possible say in the selection of their workers. However, budget holders should have some choice and control over their support work arrangements (see Section 'Support work relationships in the context of personal budgets' in Chapter II). Interviewees mentioned that the support worker could be considered a friend by the person with intellectual disabilities, but not vice versa. The idea of a 'togetherness' emerged from the data and signalled that both people could be equal or meet on the same eye level, but that this could be difficult as the support worker takes the role of a helper and advisor within the support work relationship. This led me to question what kind of roles budget holders take.

All service professionals discussed the qualities of support workers in the interviews. Many of them mentioned that self-reflection was an imperative quality that could facilitate the understanding of oneself in relation to the other. They did not expand on this type of understanding and how it could benefit the budget holder, but indicated that it had great potential for the support work relationship. Reflecting on this finding made me question how the desired support worker qualities could help a budget holder

with intellectual disabilities to enjoy their support work activities and whether this experience has potential to influence the support work relationship.

The service professionals discussed the value of regular supervision in the form of collegial advice and support for support workers. Only one person considered involving the person with intellectual disabilities in this process. Reflecting on this issue led me to consider the importance of both roles and how they are filled within the support work relationship. It made me question how budget holders get assistance from their workers in these processes.

Support work and the policies of personal budgets

This section of the chapter discusses the views of the five German service professionals in relation to the support work context and the policies of PBs. Most interviewees associated support work with the goals that they deemed as important for budget holders to achieve. They further discussed the role of support planning and budget assistance when they spoke about the policies of PBs.

The goals of support work

Service professionals raised the goals of support work in the context of PB policies. Stephan, for example, noted that the goals of support work can give people with disabilities an incentive to do support work activities. He said that setting goals "is a positive aspect of the personal budget" because "in the beginning one thinks who and what do I need in order to get there, and this sometimes means that they can only achieve this with the personal budget". He observed that the goals of support work can support people with disabilities and their workers in being committed to support work activities as an activity can be driven by a goal. Franziska pointed out that a goal implies the expectation that budget holders have to improve something. However, a goal could mean "that someone doesn't exacerbate" and maintains a stable life situation, she explained by referring to a budget holder's mental health state.

From the interviewees, I learned that support work practice mainly included the development of independent living skills (ILSs). In their views, the support worker was meant to teach people with disabilities ILSs so that they could achieve support work goals. These, for example, included cooking, cleaning, using public transport, budgeting

and decision-making. The service professionals identified 'increased independence' as an overarching goal and highlighted that a good support work relationship is, to some degree, measured by the achievement of ILSs, which are directed towards an overarching goal.

One of the central ILSs that service professionals discussed concerned the making of decisions. Service professionals acknowledged that people with disabilities are likely to face more decisions when using a PB and that support workers have to support them in making decisions, particularly when many options are available. Nicole explained that some people may feel overwhelmed by a variety of choices and this is where the support worker comes into play and can, for example, support by making information accessible to the person with disabilities and acting as their "door opener". She quoted the mission statement of her service when she said that being the 'door opener' is part of the support worker's professional approach. It included helping the person with disabilities to face challenging decisions and encouraging them to work through those challenges. The idea of providing information in an accessible way was connected to learning how to make decisions. Paula said that this learning could entail supporting someone to decide how and when to spend money – what to keep and what to throw away. While service professionals identified decision-making as an ILS and providing accessible information as a support work practice, they did not explain how information can be made accessible in a way so that budget holders could experience increased independence. It also remained unclear how the learning process was negotiated and experienced by both people in the relationship.

Support planning

In Chapter II, I explained that Germany had a low take up of PBs due to issues of accessing them (see Section 'German context of personal budgets'). From the service professionals, I learned that these issues (e.g. different laws and policies of individual service providers in the context of the cross-provider PB; decision-power about allocation of PBs in the hands of each government agency) were still the same. Most service professionals did not indicate whether they agreed or disagreed with these issues, but hinted that it could cause social inequity, as some people had better supports in place than others to access PBs and utilise them. This came up in the context of planning the support work of budget holders.

From conversations with service professionals, I learned that the intensity and frequency of planning meetings vary and that support workers become part of the planning and may sometimes even conduct some of the planning with budget holders. While they did not explain what planning conversations between support workers and people with intellectual disabilities could look like, they mentioned different planning types. For example, Silke and Paula spoke about person-centred planning (PCP). They brought this up in conjunction with a 'circle of support' (Unterstützerkreis) and said that support workers, families and friends are part of the circle of support and expected to come to the circle meetings. They are supposed to promote the collaboration between people involved in the budget holder's support process which should focus on the budget holder's future. From them, I also learned that support planning sessions – organised internally by service providers – form part of a monitoring process, whereas PCP sessions occur less frequently, are not necessarily financed through PBs and are often conducted at transition points (e.g. leaving school, starting a new job).

Support planning further came up in the context of quality management. This included the monitoring of the efficiency of services, which can start with an assessment of demand, Stephan explained.

> We come to an agreement - a certain scope of support is required, we must always check if it relates to the practical arrangement of everyday living or daily routines… and when we come to a result, we must agree with the person… how to design the support according to an amount… it isn't always easy, but eventually you will have a number. (Stephan)

The PB sum is listed in the goal agreement and gets determined through the assessment of demand. The PB sum then determines how support work gets organised to meet the personal needs of the budget holder, Stephan explained. Franziska said that support planning can start prior to the approval of the person's PB application. She explained that "informal conversations… happen when we're unsure if this can be funded through a PB and we have a good connection and phone the responsible case officer". In her service, internal support planning meetings usually occur twice a year with each 'customer' to evaluate all areas of support.

> There is a personal assessment, that comes from the customer, for example, how much assistance is needed when one goes shopping… then there is an assessment conducted by the assistant, to check how they rate it, and then there is an assessment by a third party, where we involve relatives, where we involve formal guardians. (Franziska)

She explained that these internal assessments form part of an ongoing support planning process, directed by the customer's needs. They are an opportunity to review the support process and stay in contact with the involved parties, she said. However, the support worker is responsible for some of this planning which includes the revision of the support plan with budget holders at least every two years and the completion of a monthly documentation and a biannual survey. This process is aimed at improving both people's understanding of how to best provide and implement support work.

Overall, it seemed that each service provider had their own policies on how to implement and conduct the planning of the support work for budget holders. Additionally, it seemed that few budget holders tended to use planning support external to the providers. It seemed that there were no set rules on who was supposed to take part in these meetings. Some interviewees mentioned that support workers are occasionally included in some internal planning meetings, but it remained unclear how budget holders were actively taking part and making decision about their goals and activities during the support planning.

Budget assistance

'Budget assistance' played an important part in relation to the policies of PBs. A few service professionals raised this topic when they spoke about the Employer Model as this model required the budget holder to manage their PB. To do so, they usually needed the support from a budget assistant.

Service professionals mentioned that the labour of the budget assistant is usually not considered in the PB sum and therefore family members or friends of people disabilities often take this role. However, Annette und Stephan referred to self-employed budget assistants. Their apprehension about PBs for people with intellectual disabilities, in particular, became clear to me in the interview when we started talking about budget assistance. Stephan explained that the service delivered by budget assistants has, so far, not improved the situation of people with disabilities according to his observations. Anette had the impression that they even exacerbated budget holders' situations as they have become "game balls".

> Where I participated in meetings, it was disadvantageous for people with intellectual disabilities, because they got caught in clutches of the budget assistants who ask to be paid for this consultation. There is not a set amount of money for this consultation… these so called budget assistants are not included, but they still want their payments. (Anette)

Anette and Stephan identified a lack of transparency about the role of budget assistants who were meant to advise on the management of the budget. They had mixed views about who was meant to take the role of the budget assistant, but spoke about different cases and that family members, legal guardians, self-employed qualified social workers or occupational therapists, as well as service and government staff had previously taken this role. These people "deduct the money for the consultation" from the PB, Anette explained. Franziska and Silke both indicated that it is part of the budget assistant's responsibility to support a person with intellectual disabilities in preparing a PB application. Franziska had professional experience of providing PB consultations herself and said that ensuring neutrality could be challenging for a budget assistant, as each service provider has an interest to sell their own services.

> Even myself, I am also not a 100% neutral… it is comparable with a car dealer, if I go to Peugeot and seek advice, then they will tell me something about their Peugeot cars and not about Suzuki, for example, these are the sticking points. (Franziska)

In this context, she mentioned that financial interests could influence the neutrality of budget consultations and whether someone makes use of a paid consultation or not. She explained that the government agencies provide the consultation for free, which may influence budget holders to use government services rather than private services. However, the government was not impartial either, Franziska cautioned, as they intend to save money also. It seemed that various people could take the role of the budget assistants which includes the provision of consultations on how to use the funding from the PB to budget holders. It seemed that the neutrality of budget assistants was not guaranteed, regardless of who took this role.

Reflections

Service professionals identified the increase in independence for the person with disabilities as the main goal of support work. They explained that it was the support worker's job to help the person with disabilities to acquire ILSs in order to increase their

independence. During the ethnographic fieldwork, I wanted to explore how important the goal 'increased independence' was to the support work relationship.

One of the central ILSs that the service professionals identified was the making of decisions about support work and that support work must include the provision of accessible information to make decisions independently. By reflecting on the findings, it remained unclear how support work in practice would assist the person with disabilities in learning how to make decisions. This made me question whether there was a mutual learning process happening in support work relationships. It further led me to consider the relevance of support work goals to the support work relationship.

The views of service professionals on the implementation policies of PBs were consistent with the literature discussed in Chapter II (see Section 'German context of personal budgets'). The service professionals corroborated that the control over access to PBs was still in the hands of others, such as local government authorities and disability service providers. Many people with intellectual disabilities rely on support from a budget assistant when it comes to the planning and management of funds. It remained unclear how support planning and budget assistance are related to each other. It further remained unclear how budget holders were included in support planning and budget consultations and how they benefitted from being included. This made me question if planning (and what type of planning) becomes part of the support worker's job. During the ethnographic fieldwork, I wanted to explore to what extent planning is part of the organisation of support work. I also wanted to explore if and how budget holders are involved in this process.

Interviews with service professionals in Australia

This second part of the chapter presents the themes from the interviews with service professionals in Australia (Moira, Rachel, James, Naomi and Hannah). It has the same structure as the first part of the chapter and starts with the views of service professionals on support work relationships before it discusses the themes in relation to support work and the policies of PBs.

Support work relationships

In this section, I analyse the views of service professionals on 'boundaries' within support work relationship, the matching process to sustain support work relationships, the qualities of support workers and the importance of finding meaning within the relationships.

Boundaries in support work relationships

Service professionals raised the issue of boundaries within the support work relationship. I learned more about boundaries when James explained how they could be overstepped. He noted that boundary crossing occurs when a support worker takes the person with disabilities to their personal home, but did not explain why this was a boundary crossing. He deemed this practice as 'unprofessional' and seemed to associate boundaries with the location of support work. To James, maintaining boundaries seemed to be associated with a professional work approach.

The importance of boundaries also came up in the context of physical contact between both people. For example, Rachel said that people with disabilities need a hug or "pat on the back" when they are upset or "starved of affection" and cautioned that policies can take away "the human side of support work". James said, "We steer away from the hugging" when he referred to how boundaries can be overstepped from the person with disabilities' side. He linked these 'rules' to his internal service policies, titled 'organisational orientation and induction' policies, but did not explain if both people knew about them and how they were informed about them.

Most service professionals brought the topic 'boundaries' up in connection with 'friendship' between support workers and budget holders and recommended not being friends. Hannah and Moira said that their services developed policies that discourage

support workers from becoming Facebook friends with people with disabilities, but did not go into detail as to why this was central to boundaries. Naomi was the only service professional providing a perspective from the person with disabilities by acknowledging that some people may feel uncomfortable having support workers in their private homes and that this feeling needs to be considered also in the context of boundaries.

Moira saw a more personal relationship between both people as a risk. She noted that support workers have "to be very careful because if…. I take her (person with disabilities) out to get out of the house, she then starts seeing me as her friend that she goes out for coffee with". She explained that the confusion about the relationship (and its professional value) could be due to the informal nature of the support work service. In contrast, Rachel found it natural to see the worker as a friend, particularly, if both people work closely together over an extended period. She said that this was "not a bad thing" as it shows that the person with disabilities sees their worker as a "confidante", which Naomi corroborated. She explained that she does not believe in "blanket rules" for services to set boundaries. In fact, she was supportive of a friendship between both people as the support worker is usually a person of trust "so it's natural for them (people with disabilities) to feel a strong connection." Naomi acknowledged that her view may differ from others, but reaffirmed that this is part of her service's values and personal beliefs.

James asserted that people with disabilities are usually people without social networks and they are more likely to see their workers as their friends. Moira made a similar statement and said that people with intellectual disabilities were more likely to feel socially isolated than support workers. In this context, she noted that it was important to remember that it was a paid relationship and 'a short-term arrangement'.

> We're very definite on people not being friends… at the end of the day we're paid to be in that person's life. So, for example, with one man… he was like ringing like 10 times a day… asked if he could be Facebook friends… but that was due to the fact that he had no one else in his life, and that's the most common person we work with. (Moira)

When Moira notices that the person with disabilities becomes too dependent on the support worker, she introduces a second worker due to "signs of dependency" in the relationship. Hannah uses a similar strategy to avoid dependency on one support worker: "One thing we try always to do is have at least three, because we don't want an attachment or dependency developing". It seemed that service professionals saw the person with

disabilities as much more dependent on the support worker than vice versa. This dependence seemed to include an emotional dependence on the worker.

Matching and sustaining support work relationships

Matching and sustaining support work relationships was another theme that arose from the analysis of the interviews with service professionals in Australia. The interviewees signalled compatibility issues when they spoke about the two people in the support work relationship and then discussed the importance of matching them in order to sustain relationships.

Similar to the German interviewees, they said that certain selection criteria (e.g. gender, age) should be used to match the two people. They mentioned the possible development of romantic tensions in the relationship, which may involve people with disabilities becoming sexually attracted to their worker. They seemed conscious of the worker's influence on the person they are supporting, but did not mention the implications of romantic tensions for both people in the relationship and the possibility of the worker feeling attracted to the person with disabilities.

The Australian interviewees identified that the past of a person must be considered when matching both people as it is the basis for a mutual understanding. For example, Hannah noted that sometimes she does not understand the reason why one relationship works out and the other does not: "We don't know what's in the person's history, we don't know, maybe the first one reminded them a bit much of somebody else". Rachel related to this comment and explained that "a real good historical background" of the person with disabilities was important in understanding of how to best support them. She explained that if they "are being handed over", it is necessary to make sure that the new worker has information about their past.

Some service professionals used profiles with information about the interests of both people to match them. James explained that his service tries to accommodate the wishes and preferences of people with disabilities and their families when they look for a suitable worker. He referred to the start of a support work relationship and pointed out that there needs to be a certain skill set on the worker's side to make it work.

> If we're recruiting specifically - a staff member to support someone, then obviously that individual has criteria that they want addressed… we have a staff skills database… so if

> someone wants a particular staff member to support them in a particular activity we can pull up that information and find someone who cooks or knits. (James)

James did not define this approach as 'matching' and specifically said "we don't match them", but rather considered it a process of identifying someone with a particular skill that a person with disabilities wants to develop. Hannah and Rachel corroborated this. Hannah explained that "there's no point in sending someone who doesn't play or hasn't got any interest in music" when the person with disabilities explicitly indicates that they want to learn the guitar. For her, matching interests and looking for specific skills seemed to be connected to the support work activities. It seemed that she saw this as a facilitator for both people's engagement in activities.

Hannah explained that she will check the worker's mindset before she matches them with a person with disabilities. She asks the worker questions in the form of a scenario that the worker has to think through. Through this process, she gets an impression of their mindset. She described this process as a "test". Potential support workers must pass this test. Rachel said that her service starts the matching process from the worker's perspective. "We look at the skill of the support worker and then we look at who would probably best match that", she commented. For her, matching was important so that both people could achieve progress in their work together.

All service professionals indicated that the involved service has control over the matching process and that service staff endeavours to accommodate the preferences of workers and budget holders. It remained unclear how much control budget holders have over the selection of their workers and how support workers get consulted in this process to express their wishes about with whom they are paired.

Support worker qualities and service values

Service professionals in Australia stressed certain qualities of support workers in the interviews. They explained that these qualities determined whether a worker was a good support worker and connected these qualities with the professional values of their services.

Most interviewees hinted that a combination of a professional apprenticeship in the disability field and personal life experiences can be beneficial for the support worker role, but that a good support worker must have certain qualities. They discussed a range

of qualities, but focused on trust, patience, empathy, interest and faith in the other. They discussed these desirable qualities by referring to their organisational service values.

For example, Hannah explained that the worker should be a "team person", able to "see people" and put them "at the centre of the equation". This requires the support worker to have faith in the person they support.

> That ability to make them feel like… they can do it… that they're not going to fail, because often people aren't confident because they've had lots of failure… sometimes it's a physical thing of breaking the steps down. Sometimes it's talking the talk. (Hannah)

The ability to impart the feeling to the budget holder that someone believes in them was an important support worker quality for Hannah. James mentioned that a support worker needs to have a "certain amount of drive" to support and empower a person with intellectual disabilities. He mentioned this in the context of integrity and trust which form part of his service's values. According to these values, his support workers should "encourage or empower people to perform a particular skill or to learn something new". Naomi mentioned that her clients develop trust in their support workers through the "key worker model", where the support work relationship is being set up in a way so that a person with intellectual disabilities and their family can work closely with one particular support worker. If "clients", as she called budget holders and their families, feel that the service trusts their worker, then they are more likely to trust the support worker too.

Rachel discussed 'patience' and 'empathy' a little more in the interview. She related the former to not giving up on people with disabilities who might have "been written off by everybody". When she defined empathy, she noted that this was an ethical value of her service and defined it as the attempt to 'put oneself in the shoes of the other'. She did not discuss these qualities by considering both people in the relationship and did not describe what kind of feelings these qualities may evoke in the two people.

Most Australian interviewees stated that being genuinely interested in the other is a prerequisite to understand, work and connect with the person with disabilities. From Naomi's view, good support workers are the ones "who have got that kind of interest", including the interest to learn the communication style of the person with intellectual disabilities. Hannah added that the support worker is "like a mentor" and this role entails "coaching". She explained that the needs of people with disabilities are "higher on

Maslow's hierarchy"[11] these days because most people are getting their basic needs met and explained that different support arrangements demand different support worker qualities. While all Australian service professionals spoke about the support worker qualities that were meaningful to them, some explicitly said that the qualities and service values are more important than the professional qualification and background of the worker.

Finding meaning in support work relationships

Service professionals in Australia put an emphasis on both people 'finding meaning' in the support work relationship. They made this clearer by discussing that the 'paid relationship' between both people can change once the element of 'payment' dissolves. For example, Moira noted that a 'paid relationship' is an 'uneven relationship' "because one person's getting paid" and that both people may find new meanings in their relationship once they stop working together. Naomi explained that support workers often remain "a part of the person's life" when the two persons do not get together on the basis of a paid arrangement anymore. Staying in contact and maintaining a relationship after the support work relationship dissolves was generally seen as a positive aspect by service professionals. Rachel associated this aspect with the achievement of goals and the emotional dependence a person with disabilities may still feel after they stop working with their support worker. She explained that they often feel grateful when they reached the point where the service 'exits them', as this usually means that they have achieved their goals and gained more independence. This gratitude connects them to their support worker which can be a reason for why they may want to stay in contact with them and find meaning in this relationship that goes beyond the paid and professional relationship between them.

James talked about the rewards of the relationship from the perspective of a support worker: "Some people I think really walk away and go, look, I've been part of making a difference or helping someone learn… some people don't really kind of get that". Also, James referred to the achievement of goals in the context of finding meaning. He explained that the achievement of goals determines whether a worker feels satisfied

---

[11] Abraham Maslow was an American psychologist who developed a theory about an hierarchical order of human needs. The needs are arranged within a pyramid, starting with the basic needs at the bottom (e.g. food, water, warmth), culminating in self-actualisation at the top of the pyramid (e.g. Maslow, 1971).

with what they have done and ideally this should be fed back by the person with intellectual disabilities. Moira took the point of the worker's satisfaction further by explaining its connection to the achievement of support work goals.

> I would feel some sort of satisfaction in knowing that they're going to have increased independence… one lady I worked with had been sexually abused… in the time I worked with her she ended up getting into a healthy relationship… you see them through some good milestones… and you've kind of helped them along that path. (Moira)

Hannah had a similar perspective to James and Moira. She acknowledged that some people do not achieve their goals, but others "are really achieving amazing things". In this context, she shared a story about a person with intellectual disabilities who made excellent progress through a relationship with a skilled worker.

> We had a girl who had such bad anxiety she wouldn't leave the house… we sent one support worker who's an exceptionally good support worker, and got her to the bottom of the stairs, and she'd have a conversation… all of a sudden it was like flicking a switch, it was just that personality thing and this person's got her out. (Hannah)

Overall, service professionals were able to recall 'success stories' in relation to developing meaningful support work relationships. In this context, they referred to skilled support workers and person with disabilities achieving goals. They all indicated that this kind of progress may help both people in finding meaning in their relationships.

Reflections

Australian interviewees stressed the importance of setting boundaries within the support work relationship. Many seemed to see a risk of developing a more personal and friendly support work relationship as the budget holder could then see 'more than a professional' in their support worker. They discussed this in the context of 'boundary crossing'. This issue seemed connected to the literature in Chapter II (see Section 'Context of the support work relationship') where I analysed how both people can interpret their relationship and their boundaries in different ways due to the context, in which their relationship develops. The views of the service professionals on boundaries and on the risk of boundary crossing led me to question how both people experience their boundaries and whether they perceive this as an issue within their relationships. This was an issue I wanted to explore during the ethnographic fieldwork.

When service professionals spoke about these boundaries, most of them referred to service policies and rules that they expected workers to follow. There was not much discussion about the person with intellectual disabilities' having to set or adhere to boundaries and their expectations of what these boundaries could mean for the support work relationship. This finding made me question how and if information about internal service policies on boundaries was shared and discussed with support workers and people with intellectual disabilities. It raised the issue about how both people express and negotiate their boundaries.

Another point that stood out in relation to boundaries included that most service professionals saw the person with disabilities as the one being more likely to overstep boundaries as they were more dependent on the worker. This dependence was seen in terms of them being in need of the worker's friendship or in need of a person they could trust. However, none of the interviewees suggested that the support worker could also depend on the person they are supporting. They did not seem to consider the possibility of an emotional interdependence within the support work relationship.

Service professionals seemed very interested in setting up lasting relationships through a matching process. Although they mentioned that both people's preferences were sometimes considered in the matching process, their statements clearly indicated that the service has major control over it. This finding led me to question how much choice and control both people had in the matching process and if being a budget holder made a difference with respect to exercising choice and control over the selection of workers. I wanted to explore these questions during the ethnographic fieldwork.

The qualities of support workers were meaningful to the service professionals in Australia, which they brought up in connection to internal service values. When they spoke of desirable qualities, they did not elaborate on how these could help budget holders to enjoy support work activities and how this enjoyment could possibly benefit the development of the relationship. This led me to question why there was a much stronger focus on the support worker than on the budget holder.

Service professionals also discussed how both people can find meaning in their relationships. They explained that 'finding meaning' could be a feeling of satisfaction and reward for the support worker, which could happen through the budget holder's achievement of goals. This raised issues about the place of both people's feelings within support work relationships. It made me question how both people's feelings are

influenced by each other and how they are connected to the completion of support work activities and the achievement of goals.

Support work and the policies of personal budgets

This section discusses the perspectives of the five Australian service professionals on support work and the policies of PBs. In this context, they concentrated on how support workers should implement support work to support budget holders in achieving their goals. They also discussed different PB models and their implications for the choice of budget holders, the planning of support work and training and supervision options for support workers.

The 'doing with' approach and the goals of support work

When service professionals spoke about support work, they referred to the approach of support workers in working with budget holders. This approach was connected to the achievement of support work goals.

As areas of support work, in which budget holders could achieve goals, service professionals identified the following: Travelling, moving out of home, finding a job and suitable accommodation, training in personal care, cooking, developing social relationships, being included in the local community, improving physical and mental health, arranging medical appointments and decision-making. Many Australian service professionals associated the overarching goal of support work with 'independence'. Rachel, for example, explained that this could be achieved through skill building in the budget holder's private home.

> We come in to provide support for some of the areas that… they haven't built their skills up on and those are the goals that we work with them to try and build up their skills in areas where they need skill building to be able to live more independently. (Rachel)

Living independently through skills that budget holders develop with the support of their workers seemed to be an important part of support work from Rachel's perspective. Naomi explained that this does not mean "to build dependence" on the service provider because support work is about "doing with" rather than "doing for" and this approach is aimed at increasing independence. She explained that 'doing with' is about making

oneself redundant during the support process: "I'm very much about doing with or in fact letting them do it. The less I do the better". From her, I learned that working with budget holders until they have reached a point where they may not depend on the support worker anymore should be part of the professional approach of support workers. Moira noted that 'doing for' is still very present among new staff as they tend to feel that they have to 'help' the person with disabilities. In her view, doing a task or an activity for someone rather than with someone seemed to be connected to 'helping' rather than 'supporting'. She did not elaborate on the differences between the two. Also, Naomi stressed that support workers are not there "to babysit", but rather to "help the person implement his plan and it's got to be through the lens of supporting him to be as independent as possible, not doing up his shoelaces or doing the banking for him". Naomi added that providing support in a way that intends to increase independence for budget holders can be quite difficult for some support workers. She acknowledged that this might have not been communicated well enough in the induction training that her service offers to support workers. None of the service professionals mentioned that training or information sessions about work approaches were offered to budget holders also.

Hannah noted that her service does not promote the 'doing for' approach: "Some people like to be lazy, so if someone wants to be the butler or mother or whatever, they'll let them. It's not something we encourage". Rachel noted that there were limits to providing support in becoming independent and explained that letting someone make more decisions, for example, can sometimes overwhelm them and make them feel in need of help.

It seemed that the 'doing with' approach included work on building ILSs to increase independence for budget holders. These were seen as the goals of support work. It seemed that the 'doing with' approach was not always an easy way of implementing the support work and occasionally introduced challenges to the support work relationship. Service professionals did not elaborate on these challenges.

Personal budgets and having choice

Service professionals used different terms for PBs and indicated that different types of PBs had different potential for budget holders to exercise choice over support work. For example, Moira spoke of "individualised funding" and James referred to 'individualised

packages' when he distinguished between PB models. For example, he mentioned 'centre based' and 'self-managed' options, but only elaborated on the latter.

> There's two ways you can do the self-managed model. They (budget holders) can choose us to administer that package and we may or may not provide support as well. Or they can choose a third party to administer those funds and then we would only provide the support… we have one gentleman who uses a self-managed model. The funds are held by another provider. That provider asks us… to join in a particular programme that he wants to join in, and his hours of engagement… we send them an invoice every month. (James)

In Chapter II, I explained that there are different ways, in which a PB can be administered to organise support work (see Section 'Support work relationships in the context of personal budgets'). I explained that, as a direct payment, budget holders should manage their funding as they are meant to pay their support worker directly from their budget and act in the role of an employer. James's account revealed how a self-managed PB can be implemented in practical ways by an Australian disability service provider. He discussed this in relation to the choices of budget holders. While he did not talk about the budget holder's position and role in this process, he did say that the 'self-manager' gets to choose support from different providers. In the context of the centre-based PB option, budget holders had less choice as they were not in their home environment during support work hours and usually received support work administered by one service provider only. Hannah clarified that this model was older than the self-managed PB model and did not necessarily increase choice for budget holders. She did not go into detail as to why it had not much potential to increase choice.

Moira stressed the need for decision-making support for budget holders when they are confronted with more choice. She did not explain how a support worker assists with 'decision-making', but suggested that budget holders are expected to make more complex decisions due to a range of choices. This was an issue that also came up in connection to the budget holder's role as a 'customer'. Hannah explained that her employer expects service delivery to be "customer driven" based on their service policies. She did not elaborate on these policies, but said that they imply that budget holders make their own choices.

Overall, service professionals indicated that having choice can support budget holders in being more involved and included in the support work, but they did not say how this happened in practice. The only thing that James and Rachel mentioned in relation to choice was that policy processes have been put in place for dealing with

criticism and complaints, such as 'feedback and complaint forms' (for budget holders) and that it was essential to offer regular supervision to support workers so that budget holders do not reach the point where they lodge a complaint about their worker or the service. It seemed that they had considered that budget holders could become more aware of their rights and entitlements by being more involved in the support work.

Support planning, supervision and training

The service professionals in Australia mentioned that support planning, supervision and training were important aspects of the policies of PBs. Moira said that people with intellectual disabilities often do not know that they can apply for a PB "unless they have a case manager". It is the case manager's job to support them with the PB application and not the role of the support worker, she stated. Some interviewees noted that support workers may carry out some of the tasks that case managers are meant to do, but no one clearly stated where these overlaps are and what the policies say about roles and tasks.

Rachel mentioned an 'individual (support) plan' and 'person-centred plan' and explained that the former consists of 'different lifestyle areas' which are areas of support (e.g. education, employment, social networking) that the service reviews with the budget holder. Rachel did not specifically link these plans to budget holders with intellectual disabilities and did not explain how they may facilitate a personalised style of support work. However, she said that support planning should include a risk management plan and profile if budget holders had "behaviour concerns". This planning referred to safety policies that can help the worker in identifying behavioural triggers and provide guidance in "how to best support" persons with disabilities and "what to do in cases of emergency". While this seemed important to Rachel, it remained unclear from speaking to her what a 'behaviour of concern' was. It seemed that managing a behaviour was more present in her mind than to understand why a behaviour could potentially be displayed and what this could mean for both people in the support work relationship.

Naomi stated that it is the worker's job to develop and implement the support plan and "make those goals happen". James agreed with this and added that support workers have to report on the actions they take to work on monthly goals with budget holders. The policies of his service indicate that a budget holder's participation in planning meetings is voluntary and part of an internal quality assurance regulation.

> From a management perspective, we really hold staff accountable for the actions resulting from those meetings… at a planning meeting they (budget holders) might say…"I want to do some literacy classes." That might be a stated goal at his planning meeting, but staff after that meeting don't execute or follow through... now we've got a system where those things are identified and staff held accountable to make sure those things happen. (James)

Most service professionals mentioned the importance of training and supervision for support workers. In the context of training, they identified several areas, in which their services provided training for workers, such as trauma-informed care, service induction, duty of care, person-centred support and planning, (mental health) first aid, safety and cultural awareness. They also referred to the 'Employee Assistance Program' that workers can access any time if they needed to talk to a professional counsellor. It seemed that service professionals saw support work as something that could possibly be experienced as a demanding labour for support workers.

In the context of supervision, they mentioned one-on-one supervision meetings for support workers. Moira explained that she supervises seven support workers, meets "older staff" on a monthly basis, but "newer staff"on a fortnightly basis. She uses self-reflection cards, which are work principles and service values that facilitate reflective discussions about people with disabilities in those meetings. While service professionals considered supervision options for their employees, they neither discussed how these worked for their staff, nor did they talk about the benefits these processes may bring for budget holders or the support work relationship. They did not talk about the possibility of including budget holders in supervision and training.

Reflections

From the Australian interviewees, I learned that they distinguished between a 'doing with' and a 'doing for'. When they spoke about the 'doing with' approach, they identified 'independence' as the overarching support work goal. Independence can gradually be achieved by learning ILSs in the home environment of the budget holder. It seemed that service professionals were well aware of the budget holder's need in becoming less dependent on their worker. In this context, they did not seem to consider the possibility of an interdependence within the support work relationship. This led me to question whether this consideration could change their focus on the two people in the relationship.

Service professionals said that there were different PB models which could influence how and if budget holders exercised choice. For example, the self-managed

model seemed to have strong potential to promote choice for budget holders, but it remained unclear how this model was implemented in practice and what this meant for both people in the support work relationship.

The service professionals mentioned that the implementation of the support plan was the support worker's responsibility. While service professionals mentioned that the planning process was monitored by the service, they did not talk about the kind of support provided to each person in the support work relationship during the process of working towards goals. It remained unclear how these planning types were connected to people with intellectual disabilities receiving support work through a PB.

The interviewees discussed supervision and training options for support workers, but did not include the budget holder's role in these processes. It remained unclear why support workers could engage in supervision and training, but not budget holders. This led me to question who had made the decisions about the worker's training needs and what training types could be helpful in becoming a good support worker and developing good relationships with budget holders. This led me to consider both people's knowledge and understanding of these policy processes as well as their rights and entitlements. In the ethnographic field research, I intended to learn more about people's knowledge and interpretation of their rights and entitlements.

Questions for the ethnographic field research

The knowledge gained from the interviews with service professionals emerged in form of the reflections which I shared throughout this chapter. It threw up questions that motivated me to undertake the IE with budget holders with intellectual disabilities and their support workers. Some of these questions were:

- What are the feelings and expectations of budget holders and their support workers in their relationships with each other? How do they express these?

- What are the roles of both people in the relationship and how do they negotiate these? How are these roles shaped by the policies of PBs?

- What knowledge do budget holders and their support workers have about policies, including the policies of PBs that organise support work?

- What do policy documents say about support work and the roles of both people? Are these policies accessible to them?

- How do the goals of support work influence the ways both people experience their relationship with each other?

- How does the environment, in which the support work takes place, influence support work relationships? How do the people in this environment (e.g. family member of budget holder, other support staff) influence these relationships?

- What are the rights and entitlements of budget holders with intellectual disabilities? How does the support worker assist the former in exercising these?

- How (if at all) are budget holders and their support workers involved in the organisation of support work? How are decisions about the organisation of support work made?

I did not assign these questions to the two research questions of my thesis, but they gave me an incentive to explore the experiences of support work relationships more deeply during the ethnographic fieldwork stage. In the following findings chapters (Chapter V, VI and VII), I use the knowledge from the first fieldwork stage in the process of producing 'new knowledge' about support work relationships during the ethnographic field research.

Conclusion

This chapter presented the analytical themes from the first fieldwork stage in Germany and Australia. The service professionals in both countries shared interesting insights into support work relationships, support work practices and the policies of PBs. By analysing both data sets, it became evident that most statements and accounts did not reflect mutual dependence within support work relationships that I conceptualised in Chapter II (see Section 'Interdependence within support work relationships'). Service professionals either focused on the person with disabilities or the support worker in their discussions. They put a stronger focus on one person in the relationship, which was usually the support worker. They did not seem to consider that a support work relationship involved two people who could equally depend on and influence each other. Appreciating both people within the support work relationship and understanding their roles was something I wanted to explore more thoroughly through the ethnographic fieldwork.

I found that service professionals in both countries connected their personal views and perceptions to the policies of the services they worked for. They named specific documents when they referred to policies that affected the support work relationship or one of the two roles within that relationship. They seemed well aware of the contents of these documents and often used first person plural (we) in their statements when they described a procedure connected to PBs. It seemed that they identified with the policies of their services to some extent. The analysis in this chapter, however, did not reveal who or what exactly was behind the 'we' and whether support workers and people with disabilities knew anything about these procedures.

I used the knowledge presented in this chapter as a starting point for the IE. It helped me to generate a preliminary and contextual understanding of support work relationships and gave me confidence as an institutional ethnographer. Acquiring this knowledge prior to the ethnographic work was an important epistemological step, as I now had specific knowledge about support work relationships in the 'back of my mind', which I could take into the ethnographic field and use to make sense of my prospective experience as an institutional ethnographer.

Chapter V: The Australian pairs and their support work context

Introduction

Chapter V is the first of two chapters that focus on the ethnographic descriptions of the budget holders with intellectual disabilities and their support workers within the specific context of support work. The descriptive accounts of the people and their environments in this chapter and in Chapter VI present the diversity and particularity of the ten relationships within their context and follow a chronological fieldwork order (see also Section 'Structure' in Chapter I). I use these descriptions for the in-depth analysis of the lived experiences of support work relationships by linking them to the concept of ruling relations that I present in Chapter VII (see also Section 'Analysis of the ethnographic data from the second fieldwork stage' in Chapter III).

Chapter V presents the ethnographic descriptions of the five support work relationships in Australia. I conducted the ethnographic fieldwork in Australia from February to July 2016. The findings in each descriptive account are grouped under three themes that emerged from the analysis: (1) 'the people and the environment', (2) 'support work activities and goals' and (3) 'organisation of support work'.

The first theme includes the introduction and descriptions of budget holders, their support workers and other people in contact with the pair, as well as the descriptions of the environment, in which each relationship developed. While I often observed more than one support worker in a setting and introduce them (see Table 2 in Chapter III), I describe only the support worker whom I focused on in each setting.

In the second theme, I describe some of the support work activities that I witnessed as an ethnographer and the goals of the support work that I could identify. I found that the support work relationships were strongly embedded in the wider social context of support work (see also Section 'Context of the support work relationship' in Chapter II). Therefore, I draw analytical links between the activities and goals, while I share observations of the two people experiencing their support work relationship as they interact and work with each other.

The place of the relationship within the wider social context made it difficult to separate the ethnographic descriptions of the 'support work activities and goals' from the ethnographic descriptions of the 'organisation of support work', the third theme. How

support work was organised in each place became clearer as I analysed the activities in relation to the goals and learned about the two people and their relationship as I participated in the support work activities with them.

In the third theme, I describe how the organisation of support work via the PB occurred in each environment. This includes descriptions of who was involved in the organisation of the budget holder's support work and/ or the administration of the funding and how these people were involved. The chapter ends with concluding reflections.

Felix and Michael

The people and the environment

Felix was a young man in his mid-20s who was living with his parents, Margaret and Victor, and a sister at the time I met him. Felix had autism and in my field notes, I described his physical appearance as 'about 175 centimetres, thin, with brown eyes'. Felix generally used one or two words to communicate with people. He mostly engaged in non-verbal ways of communicating. For example, when he greeted someone he liked or knew, he touched their hand gently and looked at them, maintaining a focused eye contact. After Felix got to know people better and trusted them, he occasionally gave them "blessings", as his support workers called them. A blessing was a gentle kiss on the forehead. My first encounter with Felix was at his home.

> Felix's home is a white-painted townhouse. There are many frames with family photos in the dining and living area of the house. Felix and his sisters are depicted in most of them. The living room leads onto an outside veranda. The house has two storeys. Upstairs are the bedrooms. Felix has his own bedroom and shares a bathroom with his parents. (Field notes)

Inside the living room was a computer on a desk, which was in a corner close to the veranda. Throughout the field research, I often saw Felix spending time at the computer and watching music videos on YouTube, such as songs from 'Sesame Street' or 'Bananas in Pyjamas'. Felix returned to this corner of the room and listened to songs when he needed time and space to himself. The songs were calming him.

Felix had six workers: Charlotte, Elke, Imogen (team leader), Michael, Geoff and Roland. They were all near Felix's age and were with Felix on different days each week. *Michael* had known Felix the longest. He was a strongly-built man in his late 20s. His hair was blond, short and usually styled with gel. Michael had worked with Felix for six years and referred to him as "family". "I'd want to keep working with him (Felix) for the reason that I love him – I love working with him", Michael once noted. Felix was also fond of Michael. On my first fieldwork day, Charlotte asked Felix, "Who is your best friend?" and Felix responded "Michael". Felix was always looking forward to seeing Michael. He did not hide his excitement when Michael arrived.

> I arrived with Michael at Felix's house. The front door was closed. Michael knocked and said, "Knocki, knocki, knocki". He always says this when he arrives at Felix's place and then Charlotte usually says to him "Who's coming?", "Who's that?" or "Is that your friend

Michael?" Felix opened the door and gave Michael a long hug. Felix looked at us. His eyes were open wide and focused on Michael. His smile was bright and cheerful. (Field notes)

Support work activities and goals

Felix's support work consisted of outdoor activities (e.g. swimming, having lunch at the park/beach) and indoor activities (e.g. fixing a sandwich, washing clothes). These activities were part of Felix's weekly schedule that Margaret handed to me at the start of the field research. For example, on one of the days, he worked as a volunteer and distributed leaflets with Charlotte at Centennial Park. Before they drove to the park, Felix usually had one hour of speech therapy with a therapist named Melanie. Melanie used a range of tools, such as puzzles and iPad programs, to facilitate Felix's verbal expression and teach him how to speak in full sentences. One time, Melanie advised Felix to stop repeatedly pressing an icon on his iPad and explained that this type of behaviour was "non-communicative". Felix sometimes became fixated on a word or a particular movement, which he then said or did over and over again. When Felix pressed an icon repetitively that produced a sound on his iPad, his workers usually tried to distract him to shift his focus on something else. Sometimes I had the feeling that Felix had fun engaging in these repetitions. Occasionally, I had the impression that he was bored. In other situations, for example, when Felix repeatedly jumped up and down inside a café or supermarket, he seemed agitated and anxious.

I never saw a support plan for Felix, nor did anyone mention such a document when I inquired. However, there was a white folder somewhere near Felix's computer. I saw the support workers using it towards the end of a support work shift. The folder had sheets with printed tables on them that helped the workers to document how Felix had worked towards a goal during an activity. The sheets were called 'Felix's daily routine'. Each activity had 'skills/ goals' assigned to them and required the worker to tick if Felix had done the activity in the following ways: 'independent, non-verbal prompt, verbal prompt, dependent, N/A'. One of the columns asked the worker to circle specific behaviours 'that occurred today'. These for example were 'jumping, hands in back or front of pants, head banging, running away, and spinning'. I frequently witnessed Felix engaging in some of these behaviours. When this happened, Michael tried to stop these behaviours by distracting Felix. Michael also supported Felix with showering, toileting and getting changed. One afternoon, Michael was shaving Felix at home.

> Michael got an electric shaver out of the bathroom cupboard and asked Felix to take off his shirt. Felix stood in front of the sink and looked into the mirror – he could see Michael and me. Michael stood behind Felix and I stood next to Felix. Then Michael said to Felix, "You're vain" and laughed. He told Felix that he was going to switch the shaver on, which would make a noise. Felix watched, but didn't say anything. Michael turned the shaver on. Felix was still and continued watching how Michael shaved him. (Field notes)

I could see that Felix felt comfortable being shaved by Michael and being part of this intimate process. He was quiet, calm and observant. He looked at himself facing the mirror and did not move – he just watched the process of being shaved. It seemed that Felix trusted Michael and knew that he was not going to hurt him.

I could see that Felix and Michael enjoyed each other's company. I often witnessed this when they did not plan an activity, but rather did something spontaneously. For example, one afternoon, I saw them both singing together inside Felix's house.

> Michael sang the musical scale and asked Felix to join him. Both men got physically close while they sang and touched each other's forehead. When their forehead's touched, Felix and Michael looked into each other's eyes for a long time. (Field notes)

In this moment, the two men were connected. This connection occurred when they did not focus on a goal or an activity.

Felix expressed his physical affection and his liking for Michael in a way different from what he showed Charlotte and Elke, for example. There was much more physical contact between the men. The physical contact sometimes looked like a soft 'wrestling', which involved hugging. The following situation describes this physical banter:

> When Michael arrived, Felix moved away from the computer. He was suddenly focused on Michael. Felix laughed and giggled and followed Michael around. Michael widened his arms, reached them out and said "I am going to eat you". Felix got excited and laughed. Michael lifted him up. They jumped onto the sofa and grappled. (Field notes)

This banter had become part of their routine. Felix's weekly schedule said that Michael supported Felix with 'outings and exercising' on Fridays. Michael, Felix and I often went swimming in a pool at Sydney harbour. From Felix's parents and workers, I learned that 'swimming' was his favourite activity, but I sometimes got the impression that Felix felt bored when he stayed in the water for too long.

> Michael explained to me that it is good if one of us goes into the water first so we can stop Felix from swimming to the beach as the goal is to stay in the water for as long as possible.

> Felix jumped in the water. He dived under and swam around. I approached him and explained that we were now waiting for Michael to jump in. Michael and Felix were in eye contact. Michael spoke to Felix while he was preparing for the jump. After Michael jumped in, I said "Let's swim to the isle" and pointed at one of them. We all got onto the isle. We jumped in together by counting to three. Then we swam to the shallower part of the water, closer to the beach. Michael was holding Felix in his arms. Sometimes he tried to lift him and throw him further into the water. Felix giggled and laughed. Then Michael tried to teach Felix how to float. He said to him "Put your feet up" and supported Felix's back from below the water. Many years ago, Felix wouldn't stay in the water, he would jump in and go back to the showers immediately – now he stays in for longer which is great, Michael noted. Felix tried to get back to the beach, but we kept distracting him. Felix said "showers" several times indicating that he wanted to leave. (Field notes)

In Felix's daily routine sheet, 'swimming' was assigned to a column in a table titled 'exercises'. The sheet asked for the 'duration' of this exercise. To Michael, it was important that Felix stayed in the water for as long as possible. However, from Felix's standpoint, it seemed odd that this was an objective, as he did not seem comfortable staying in the water for long.

Organisation of support work

Felix's support work was funded through two 'self-managed' PBs, the Supported Living Fund (SLF) and the Community Participation (CP) funding. As a participant observer, I could see that Felix was engaged in activities intended to facilitate his community participation (e.g. distributing leaflets at Centennial Park, swimming in public areas), as well as to support him to live more independently (e.g. buying groceries, cooking a meal).

Margaret and Victor were overseeing the administration of the funds. Together with Imogen, they set up the support schedule. Imogen and Margaret were occasionally in contact with the service provider paying the salaries of Felix's workers, but the workers told me that they hardly had any contact with someone from the service. I also learned that none of the workers were recruited through the provider – they had recruited each other. For example, Charlotte and Michael had been good friends before Charlotte started working with Felix. Michael had told Charlotte about the job vacancy and introduced her to Felix and his family. Michael explained that through his and Imogen's circle of friends, they recruited almost all the support workers, which proved to be an effective strategy. Before recruiting that way, Felix often had workers interested in short-term work who "just didn't care basically", Michael asserted.

I further learned that Felix's parents' interests played a crucial role in Felix's everyday life. The workers were guided by their advice and instructions to some extent.

However, Michael mentioned that he would tell Felix's parents if he disagreed with their views on Felix's support. He explained that he had earned Victor and Margaret's respect and trust over time and now feels that he can share his opinion honestly with them – something they take into consideration, when deciding about things in relation to Felix.

When the workers arrived at Felix's place, Margaret had already decided on the activities they were meant to do with Felix. Sometimes, she had written them onto a whiteboard next to the kitchen door. In the mornings, there was a 'hand over' between Margaret and a worker; and in the afternoons, if neither Victor nor Margaret were around, there was a 'hand over talk' between the workers. Felix was usually present while these chats occurred. Sometimes he was included in them, for example, when Michael asked him a closed-ended question about how his day had been. Then Felix and Michael held hands and looked at each other.

I once had the privilege of taking part in the monthly team meeting and observing it. The workers met to talk about the work they were doing with Felix. These meetings included debriefings amongst the workers, but also discussions on how the workers saw Felix's behaviours listed in Felix's daily routine sheet and how these behaviours affected Felix's concentration on doing activities. I learned that Felix and his family attended every second team meeting, as it was hard for Felix to focus on the discussions. This imposed a limitation as to how to involve Felix in decisions about his life. His parents usually spoke to his workers when they made decisions about his support, Michael explained. I never saw Felix involved in the formal arrangements of his support, which included how his activities with Michael were set up. It seemed that the views and expectations of other people within Felix's support environment influenced how his support work was organised in practice.

Elsa and Elizabeth

The people and the environment

Elsa was a young woman in her early 30s. At the time I met her, she had been living in a group home with two women, Rosa and Gwen, for some years. Elsa had short hair and usually wore a hair band. In my field notes, I described her as 'friendly, polite and gentle'. Elsa attended a day centre during the day, which was close to the group home. She told me that she had no contact with her family, due to a history of family violence and abuse. One of the first people she mentioned to me was her boyfriend Andrew. Elsa sadly narrated that Andrew and she wanted to get married, but he died a few years ago. She had a photo of Andrew inside her bedroom.

> Elsa's bedroom is small. It has self-painted pictures attached to the door and many pink and purple-coloured items. It contains a double bed, a wardrobe, a cabinet and a window. Elsa has a key to her room. She locks the door whenever she leaves her bedroom.
> Her room is located behind the communal kitchen, which is a separate room inside the living room area. You can see the interior of the kitchen from being inside the living room. You access the living room area by walking along the corridor that starts at the front door of the group home. The ceilings are very high. The first room to the left is the staff room, followed by the storage room, laundry and the communal bathroom. (Field notes)

I asked Elsa why she locked her room and she commented with resignation in her voice, "because of behaviours". At this point, I did not know what Elsa meant by 'behaviours' – it just felt as if people were locked away in their own homes. The staff room and the communal kitchen (including kitchen cupboards and fridge) were locked, just like the front door of the group home. Only support staff had keys to unlock these facilities.

During my time with Elsa, I also got to know Gwen and Rosa, both near Elsa's age. They were curious about my visits and spent time with Elsa and me inside the living room area. Gwen had her own apartment which included a living room, a bedroom, a bathroom and an outdoor terrace and formed part of the group home. She spent most of her time there. Gwen had short hair, was strongly-built and always up for a joke. Rosa had a small bedroom and shared a bathroom with Elsa. She had long hair and was more outgoing than Elsa. She used little verbal speech to communicate, repeatedly expressed the wish to hug Elsa or me and often said 'I love you' to one of us. Rosa was always nearby and it felt as if she was desperate for attention.

At the time I met *Elizabeth*, she had worked at the group home for a year. She was an older lady with long blond hair put up in a ponytail. A couple of months before, she

had become Elsa's "key worker", as she called her role. All three women had their own key workers who were on a permanent work contract. Elizabeth was 'shy and not overly talkative', as I captured in my field notes. When she spoke to Elsa and the other women, she did this in a prompt and directive way, using the imperative voice. When she prompted Elsa to do something, she often added the words "darl" or "love" to the instruction. I experienced Elizabeth as brief and blunt and did not observe much conversation between her and Elsa, but in the interview, she said, "we're pretty close" and said she related to Elsa as "a little sister". She noted that her affection towards Elsa did not involve much physical contact, but occasionally a side hug, encouragement and praise.

Molly was the team leader of the group home and worked inside the staff room during the day. I occasionally saw three casual workers. Elsa knew some of their faces, but not always their names. They were 'filling in' whenever permanent workers were unavailable.

Support work activities and goals

When Elsa came home from the day program, she usually spent the afternoon with Rosa in the living room area. Both women mostly spent the time together – without staff. On a few occasions, a casual worker was with them. Elizabeth spent most time inside the staff room. When I saw her, she often excused herself saying, "I gotta do so much paper work". It was usually around 6pm when Elizabeth left the staff room and came into the living room area where Elsa, Rosa, I and sometimes Gwen were socialising. The women often drew in their colouring books. The TV was usually switched on, but neither Elsa nor Rosa paid much attention to it. Elizabeth unlocked the kitchen cupboards first and then assisted Elsa preparing dinner. Between 6 and 7pm was the usual time I witnessed conversation between Elizabeth and Elsa. This was the time when the women had dinner at the dining table in the living room. After 7pm, the women had showers and got ready for bed. Elizabeth did not have dinner with the women, but sat with them at the table, like I did. When she sat down and talked to Elsa, I had the feeling that she enjoyed the chat. But generally the communication between Elizabeth and Elsa focused on chores, such as cooking a meal or having a shower. I never witnessed that Elizabeth was trying to find out what Elsa desired or wanted, but I often saw Elsa trying to get into conversation with Elizabeth to tell her about her day. Elizabeth hardly ever took this conversation further.

117

Opening up and talking to Elizabeth about her feelings and moods had been part of a broader goal, called 'health and wellbeing', which was listed in Elsa's 'person-centred case plan' (as the document was titled) and included two other broad goals, 'community inclusion' and 'social relationships'. From Elsa, I learned that she was struggling with anxious and depressed feelings. Improving her mental health included gaining "confidence with talking and talking to staff members", she explained. Part of achieving this goal was to talk to Elizabeth and to her psychologist about her "complicated feelings", as she called them. Elsa explained that she sees the psychologist once a month, which helps her to develop strategies to cope with "bad memories" about her past family issues. These memories hit her sometimes "without warning", she told me. I never saw Elsa and Elizabeth talking about Elsa's feelings or anxieties. In fact, the scarce communication between them was one of the first things that had caught my attention. I asked Elsa about this one time. She acknowledged that there was not much communication between the women and staff, but that she was not sure herself why this was happening. When I asked Elsa what she knew about Elizabeth's life outside the group home, she responded, "I don't know nothing about Elizabeth's life" and explained that Elizabeth does not disclose much about her private life. She recognised Elizabeth's need for her support as Elizabeth was relatively new to the job: "I am helping them (staff) out. Yes, with other chores they tell me to do". Elsa explained that she was teaching Elizabeth, which to her meant that she showed Elizabeth how she did things in her everyday life, such as budgeting her pocket money. Elsa saw a teaching purpose in her role within the relationship she had with Elizabeth.

Elizabeth and Elsa both expressed the wish to spend more "one-on-one time" together, as they called it, which was time they dedicated to only one another. It was the time that only involved the key worker and the person. Elizabeth's role as a key worker entailed taking Elsa out and doing activities together in the community, which happened once a month if at all. In the interviews, both women told me about a recent day they spent together outside the group home. Elsa lit up and smiled when she talked about this day. She noted that she would like "more one-on-ones" with Elizabeth, but that "she (Elizabeth) looks after the other two girls too", which makes it difficult to spend more time together. Elizabeth shared similar feelings.

> We do go out on activities on a Saturday. Elsa has just started a TAFE course, so I took her shopping, 'cause I never had a chance to have that one-on-one. We're always here (group

home) and I've got the other girls, so I made a point of NO, it's me and you on Saturday, so we're just gonna spend time out and buy you an outfit. (Elizabeth)

Spending time outside the usual work and home environment together made Elsa and Elizabeth look at their relationship differently. However, I never witnessed Elizabeth inquiring whether Elsa wanted to do activities with her in or outside the group home. The decisions had already been made before I got there. Yet, Elsa was in receipt of the CP funding. One of its objectives included to expand friendships and networks within the local community of the budget holder, which seemed related to the other two broad goals in Elsa's case plan.

Apart from doing activities outside the group home together, the 'key worker' role also entailed the discussion of goals. "I have one-on-one with her (Elizabeth) when we talk about stuff, like goals and self-centred things", Elsa explained to me. She engaged in a 15 minute "one-on-one" chat with Elizabeth each week to talk about her person-centred case plan which included her goals and the steps on how to achieve them. Elizabeth said that the purpose of this chat was to "sit down and talk about things that she (Elsa) wants to strive for and the time frame that she wants to do it in". On the days I was present, I never saw both women having this 15-minute chat about Elsa's goals.

Organisation of support work

In the interviews with Elizabeth and Molly, I learned that they were unsure what type of funding Elsa received and what activities and goals her PB pursued. Molly referred to the funding as "state funding" and noted, "I am still getting my head around it". When I spoke to Elsa, she indicated that she heard of the funding type in the context of her day program.

> *Debbie:* I was told that you've got a community participation package. That's the name of that money. Have you heard of that?
> *Elsa:* Yes, I have. Only in that sort of day services… we go out swimming, bowling…

No one at the group home I spoke to knew if Elsa's funding package was shared between the day centre and the group home. I did not witness much contact between the day centre and the group home and never witnessed Elsa and Elizabeth discussing options of how to do activities in the community or with people outside the group home.

During my time in this setting, I witnessed two types of meetings, a staff and a house meeting. Only the house meeting included the women. It was meant to happen

every Monday. One time, I was present at a house meeting, when they discussed twelve 'house rules' (respect one another; be patient; be considerate; respect one another's privacy; be nice to one another; no running inside; knock before entering; no going into the pantry; respect one another's personal space; no swearing; no throwing things; one person in the kitchen at a time), which were also attached to Elsa's bedroom wall.

> Molly asked Elsa to pick one of the house rules. Elsa picked 'to respect one another'. Molly asked Elsa what this means to her. Elsa said that this means that other clients respect her belongings and don't take them or break them. Molly agreed. She asked, "How does it make you feel?" when that happens. Elsa said that she gets upset about it. Molly explained that we should not take the belongings of others and respect them otherwise we hurt that person and they may be upset with us for many days. Elizabeth stressed that Gwen needs to follow this rule and be more considerate of Elsa's feelings. (Field notes)

Elizabeth did not say much during the entire meeting, but advocated for Elsa when she remembered that Gwen had taken Elsa's belongings in the past. Elizabeth showed concern and care for Elsa. To Molly, it was very important that the three women living in the group home understood and followed the rules stated in the meeting. Not following these rules could lead to 'behaviours', she explained.

When I asked Elizabeth and other staff about the meaning of 'behaviours', they explained that they could not speak about this as it was confidential. From Elsa, I learned that 'behaviours' were not so much related to her, but rather to Gwen and Rosa. It seemed that the internal house rules had been set up to prevent these behaviours happening.

Lachlan and William

The people and the environment

Lachlan was a man in his mid-40s who lived with his friend Paul in a house. *William* was the primary support worker of Lachlan and Paul. He had been working with both men for five years. On the day I first met Lachlan and William, Lachlan's mother Catherine picked me up at a train station and drove me to Lachlan's place to introduce me to them.

> Catherine parked her car in the driveway of a small white house surrounded by a green area. I then realised that Lachlan was living in a house and not in an apartment block. There were other houses close by. Lachlan stood in the garden – in front of the main entrance of the house. I could see that he had Down syndrome. He moved slowly and gently, looking at his mum and me. (Field notes)

Before we stepped out of the car, Catherine explained that she and her husband bought the house for Lachlan. Because Paul and Lachlan had been long-term friends, they had asked Paul and his parents if he wanted to move in with Lachlan, she said. Catherine narrated that Lachlan used to live in a group home, but did not feel comfortable there. He had to remove photos in his room, as it made others living in the group home jealous, she explained. After we got out of the car, Catherine introduced me to her son. Lachlan had short, brown hair and smiled at me when I said that I was Debbie. I walked up the stairs onto the veranda, which led into the house.

> It is a one-storey house with a garden in the back. Lachlan and Paul have their own bedrooms, but share the bathroom, kitchen and living and dining area. There is a spare room, adjacent to Paul's bedroom. It has a desk and a bed inside, but was smaller than the other two bedrooms. It was a homely environment with personal items revealing something about the characters of the people living there. The first thing I saw was the living room with a tea table, two couches and a pool table. I could see a shirt from the 'Parramatta Eels' (an Australian Rugby Team) and a Beatles poster attached to the walls. (Field notes)

William was tall, had blond hair, blue eyes and was in his late 30s. William gave me a firm handshake and was jokey from the moment I met him. He had a dry and sarcastic humour. Throughout my time with William and Lachlan, I learned that Lachlan sometimes relied on William to be heard by others. This became clearer when I became aware of my own dependence on William to understand Lachlan. Lachlan spoke quietly, not in full sentences and stuttered sometimes. William interpreted his speech for me, asked follow-up questions and provided contextual information, so I could find out more about Lachlan.

I met Paul the same day as I met William and Lachlan. He arrived a little later – after he got home from work. Paul and Lachlan worked part-time in restaurants. Paul was shorter than Lachlan. His hair was dark and he wore glasses. Throughout my time in this setting, I never witnessed disagreements between Lachlan and Paul. I did not hear them conversing much either. I occasionally saw them hugging or smiling at each other. They negotiated things, such as sharing household tasks, in silent and non-verbal ways.

Support work activities and goals

Paul and Lachlan both received the SLF. The Individual Funding Handbook from the NSW State Government indicates that the SLF 'enables greater flexibility and choice to sustain and realise a person's supported living arrangements'. I learned that Lachlan's choices in creating his living arrangements were rather limited. William explained that activities, such as bushwalking or going to the gym, had been set by Catherine. He commented that Lachlan does not want to be active all the time and enjoys a bit of 'downtime', but "Catherine wants him to get moving". He explained how he interprets Lachlan's reaction when he suggests bushwalking to him.

> *William:* So for example, bushwalking, that's a very big part of their life…
> *Debbie:* The family's life?
> *William:* Yes.
> *Debbie:* Ah really.
> *William:* Yeah. And they like to engage Lachlan in it, but everyone that has worked with Lachlan sees a total lack of enthusiasm when it comes to bushwalking. He doesn't like it, unless there is an energy there beside him that can create something worthwhile. Because otherwise he will just go 'what the heck', he will show you with the body language, it will just go (exhales)…
> *Debbie:* So you go bushwalking with him?
> *William:* Yes.

From William's standpoint, the 'energy beside Lachlan', as he called it, was William himself. He identified as the 'energy' that Lachlan relied on to do activities. I had noticed that Lachlan was often quiet, seemed disengaged and moved slowly. I never saw them bushwalking or talking about it. I joined them when they went fishing, exercising at the gym, buying groceries or playing pool. However, 'bushwalking' was listed in Lachlan's 'support plan' under 'what is important to me' and in his 'support profile' under 'what I enjoy'. When Lachlan showed me these documents, I learned from him that his family had produced them. William corroborated this and noted that Catherine had produced

Lachlan's support plan and monthly support schedule, which includes the weekly activities he is expected to do with Lachlan.

Lachlan was introverted and William told me that this had irritated him initially. It had led him to think that he had done something wrong. However, Catherine assured him that this was just the way Lachlan was, William said. I saw William inquiring what Lachlan wanted to do, but there was always an expectation that something needed to be done within the time they had together. I did not witness many moments, in which William just sat with Lachlan and waited till something came from Lachlan. However, Lachlan had the capacity to initiate conversations. For example, he occasionally offered me a cup of coffee by saying "coffee?" and looking at me. As a participant observer, I saw Lachlan at his happiest when he played pool with William and Paul.

> Lachlan had a big smile on his face and focused on the balls. Paul had put on music. We played in teams. It was either Lachlan and I against William and Paul or William and Lachlan against Paul and me. Lachlan sometimes did a winner pose by lifting his arms to show his muscles. Lachlan was alive and happy. William was loud and jokey. (Field notes)

It seemed that playing pool and exercising at the gym were activities that Lachlan really enjoyed. Lachlan went to the gym several times each week with William and Paul.

> Lachlan, William and I used the treadmill to warm up. After, we walked into the back studio where the weight machines were for the upper body. Modern pop music was playing on TV. William told Lachlan and me that we were going to take turns at the machines. First, we did exercises for arms, chest and back. I was on one machine and Lachlan on another. William was putting weights onto the machines. Lachlan was focused on the weight-lifting. Often William counted for Lachlan. We usually counted to 10. There were 3 repeats at each machine. Lachlan smiled when he managed to lift weight and William praised him. He sometimes gave him a pat on the back or a hug from the side. (Field notes)

During the activities, I experienced William as an 'entertainer'. For example, when I asked Lachlan in the joint interview if he enjoyed fishing and whether he knew how to fish before he met William, he responded "yeah". William elaborated on that answer, when Lachlan turned quiet and added "It's all about the energy and the company. If someone's got more than what I have, that helps". William often made these jokes in Lachlan's presence. I often wondered what Lachlan was thinking in these moments. One morning when William, Lachlan and I went fishing, William said to me "I make a lot more theatre when you're not here". He was saying this while Lachlan was holding the

fishing pole overlooking the water. I was unsure whether Lachlan heard this comment and what he thought about it.

Organisation of support work

In Lachlan's support schedule I saw that Lachlan and Paul received support work from Mondays to Saturdays. William worked four days a week with Lachlan and covered about twenty-six hours of support – some he spent with both men. There were four other casual workers supporting both men. I only met one of them. He came to Lachlan's house on Tuesdays to do an activity with Paul, while William worked with Lachlan. William explained that the purpose of having a secondary worker is "to bring in another male energy" and to consider Lachlan's preferences about the activities.

> The idea behind it was to separate the guys so that they can focus on an activity that they like… Paul, 9 times out of 10, used to go tenpin bowling, whereas Lachlan doesn't like it. Lachlan would choose to do something outside or go to the movies, but Paul doesn't like it so much. And if the person that he goes with isn't fully engaged or receptive to their needs or understands what they want, then they'll have a poor poor time. So that's where they brought in another person… and both guys for one or two days out of the week aren't sort of giving up for the other. (William)

From Grace, the manager of the service that paid William's salary, I learned that "depending on the person's goals and budget around their individualised funding", they can employ their own workers. William once mentioned that he follows the wishes of Lachlan's parents, whom he sees as his employers, but considers Lachlan's interests when he plans activities.

> *Debbie:* You said the parents hired you. Was it not the service provider (says name of the provider) that hired you? Whom do you see as your employer? Do you see the service as your employer? Or do you see Lachlan as your employer or do you see his parents as your employer?
> *William:* It's both. Not the fellas, but they certainly have a lot to do with it, because if they said "No", that was the end of it. Well they might be okay, let's give it a go, but generally the decision comes down to the parent if it's family governed, because they are taking it into their own hands. And the service provider is just the vessel.
> *Debbie:* So the money comes from the service provider?
> *William:* Yes.

William explained that Lachlan's support work was "family governed". This meant that Lachlan's parents made the final decisions about what he did with Lachlan. He made this

point clear by explaining that Lachlan's parents hired him, as "they didn't want someone who was trained in disabilities" and had an "institution mentality".

> I had that nutritional background. I had that physical exercise background. I had that personal skills and management skills... the next step was basically oh, well he ticked all the boxes, he comes across quite well, let's see how he goes. Before that it was like, well, how do you feel about the fellas. And how do the fellas think about you. (William)

After each support work shift, towards the afternoon or evening, William disappeared into the spare room. He then excused himself saying that he needed to write "progress notes", as he called them. Lachlan could physically access these notes, but not read them. I never got to see the progress notes to understand what was being progressed, but learned from William and Grace that the notes were never discussed with Lachlan. Grace did not think that Lachlan was aware of the content or function of these notes and said that these are "probably not the right words to use – they're more like documentation... because what are they progressing?" When I spoke to William, he confirmed that he neither talks to Lachlan about the notes, nor does he show them to him. They "are kept out of their eyes" he stated and hinted that they could potentially upset the men. William told me that they were confidential and that he handed them to his supervisor and the families of both men. I never saw William talking to Lachlan about the documentation of their activities and the goals that Lachlan was expected to achieve. I only witnessed occasional chats between them, during which William explained what they were going to do throughout the day. Many activities had already been planned.

Jeff and Linda

The people and the environment

I met *Jeff* at a day centre for adults with disabilities. Jeff was 19, had recently graduated from high school and lived with his parents and his brother. He had dark, short hair and usually wore a shirt, jogging trousers and glasses. He did not have much verbal speech, but his voice went up when he tried expressing himself. He used vowels, which he pronounced firmly and loudly. I sometimes recognised the words he was trying to say, such as "Nooh" (No) and "Nana" (Banana). When Jeff made those sounds, he sometimes looked at a person around him. It seemed he was trying to get a reaction from them. The workers in the centre often perceived these sounds as shouts and responded with "Soft voice, Jeff" or "Inside voice, Jeff". Jeff also used facial expression and gestures to express his moods. For example, when he was interested and engaged, he showed this by smiling and being curious about things and people. He explored them by scrutinizing, watching and touching them. However, 'touching people' was a 'behaviour' the workers were trying to prevent Jeff and the other "day program participants", as staff called them, from doing. The participants were divided into three groups, consisting of four to six people. Brad, Mitchell, Howard, Rhia and Jason were part of Jeff's group. They were all young adults and travelled in a van together when they left the centre.

> The day centre was surrounded by a fence. I had to sign my name and the time into a visitor's book when I arrived and left the centre. It was part of a larger building which included offices for administration and management staff, as well as a supported employment area, in which some of the participants worked. The staff room was accessible via a digit code. All other rooms were accessible via a token that workers had attached to their clothes. Most rooms and spaces had open doors and participants could move from one room to another. There was one spacious communal area with three large tables and an open kitchen space with a kitchen bench that had a sink. A laminated sheet called the 'healthy eating pyramid' was attached to the kitchen wall. There was a music room (music was played loudly on a screen inside), a sensory room (it was locked), a craft room and a TV & Computer room. Inside the communal area was a big communication board with visuals. It had today's date, activities, the name of the day and the group with photos of people who were on leave on it. (Field notes).

Linda was Jeff's key worker and the key worker of five more people. She was in her early 30s and had a European accent. She had brown hair and tattoos. Throughout my time in this setting, I learned that each participant had a key worker who was a permanent worker, but neither the workers nor the participants had choice about with whom they were paired.

Bridget was the team leader of the day centre. She spent most of her time inside the staff room, which was a room inside the day centre facility. I saw her in the mornings, when I arrived and in the afternoons, when I left. One of the first things she said to me was, "We have guys with behaviours" and explained that I needed to be cautious around the participants, especially the men. She advised that if they approached me physically, I would have to step back and tell them firmly that they should not come closer.

Support work activities and goals

The day program started around 9am and finished between 3 and 3.30pm. It usually began with morning tea. The participants brought their own food to the centre. Staff wore blue gloves when they assisted some people in eating their food. Staff were usually standing behind the participants while the latter were eating. This created a distance between the workers and the people with disabilities. It looked like the workers were trying to make sure that all participants were eating their food instead of "playing up" and "showing behaviours", which were words staff frequently used. This distance also felt like some workers feared being physically approached or 'invaded' by participants.

Jeff paid for the day program with the CP funding. The state policies on the CP indicated that support is meant to focus on skill development and the person's participation within their community. Each day, one of the groups left the day centre with a van and travelled somewhere to do an activity (e.g. cinema, gym, lunch at a park, swimming). We usually travelled long distances. Sometimes we spent up to three hours in the van. The workers sat in the front of the van and the participants and I sat in the back – either on single seats or two-seaters. Jeff had to sit on a separate, single seat inside the van due to his 'behaviours'.

> Jeff sat next to me. Linda saw this as she came into the back of the van to make sure that everyone was buckled up. She then said "No darling, Jeff sits there" and pointed at the single seat closer to the front of the van. When we drove off, Jeff shouted out. Linda's response was "Yes, I'll turn the radio on", and she did. (Field notes)

Jeff did not have a choice about where to sit. I could see that he often asked his workers to sit on a two-seater and found his request rejected. Over time, I learned that 'behaviours' were actions that staff deemed as unacceptable. They included touching staff or running away from the group without letting the workers know. In Jeff's case, 'behaviours' also included kissing others.

127

I saw Linda using Makaton signs and 'touch chat'; a communication program on the iPad, to find out what Jeff was interested in doing. She explained that she recognises when Jeff is in a good mood because then "there's lots of laughing, smiling, singing". When he feels upset or frustrated, he may throw something, scream or "he would push through you", she commented. This can happen when Jeff feels misunderstood. Linda explained that "if you don't have the iPad there, and he wants something… you say, 'okay, get up now, take my hand and bring me, what is it you want, what you need? You show me'". Linda used strategies to find out what Jeff desired, but found it challenging to really understand him. On my first visit with Jeff, I spoke to his father who collected Jeff at the centre. "We tried everything to support Jeff in talking, he now goes to speech therapy on Wednesdays – it's so frustrating", he sighed. There was resignation and disappointment in his voice. He remarked that his wife and he tried a range of communication facilitators, but nothing worked. He noted that when Jeff, for example, sees a girl that he likes, he cannot speak to her and does not know how to approach her.

The atmosphere inside the centre was hectic and the workers were stressed. When I tried making conversation with them, they were usually short with me. I experienced the shortage of staff and its related pressure on Linda and her colleagues by being asked to take on responsibilities that workers (and not I) were meant to do. I witnessed Linda's difficulty in attending to Jeff. It felt as if she did not have the capacity and time to respond to his individual needs. There was a situation when Jeff's group was at a park where Linda's feelings of being overwhelmed became very obvious to me.

> Jeff finished his lunch and started to chase pigeons which were close by. Howard sat next to me. Richard (student) and Linda were with the others at the table next to us. Rhia was crying. Jeff had become more and more unsettled. He walked further away from us and approached the playground, which was inside the park. Linda repeatedly asked Jeff to come back, but he didn't. Linda ran after him and said, "C'mon Jeff, back to the group, you know the rules, enough silliness for today, I can't split myself into ten pieces". (Field notes)

Linda felt distressed about not being able to attend to each person. She felt as if she needed "to split herself" to make sure she was still in control of the situation. However, Jeff often seemed bored when he had to wait for the others. He had a strong urge to move and usually finished his lunch before they did. I also witnessed situations in which Linda took time to inquire about Jeff's interests – when she tried finding out more about him. For example, one time I observed the following interchange when we had just left the gym.

> We got back on the van. Linda assisted Jeff in buckling up. Her face was close to Jeff's. She looked at him. They both kept eye contact. She asked him if he enjoyed the gym. He smiled at her. She asked "Come back next week?". Jeff smiled at her again. (Field notes)

There were moments when a brief connection between Jeff and Linda occurred. However, when Linda was overwhelmed by the number of people she had to supervise or the tasks she was expected to take on, she could not fully respond to Jeff's needs.

From Linda and other staff, I learned that the key worker's role entailed the involvement in their participant's person-centred plan (PCP), which was the only difference compared to being a support worker. This meant that she had to attend the annual PCP meeting and work (like the other workers) on the goals captured in Jeff's PCP, which was inside his 'client file' stored inside the staff room. His goals in the plan were 'cooking' and using 'touch chat'. The touch chat was a means of communication, but neither the documents nor Linda defined what 'communication' meant in Jeff's support work context. I could clearly see that it was important that Jeff was learning to stop engaging in 'behaviours' as part of this goal. The Disability Rights Standards structured his PCP. Jeff's progress was measured against the standards. They, for example, included rights; participation, integration and inclusion; individual outcomes; feedback and complaints; and service access. Two of the things mentioned in the standards were, 'I have been given choice in my life' and 'I was given the opportunity to participate in a range of service activities'. The plan looked like a tool of how staff were making themselves accountable, as behind each standard was a statement about how Jeff had achieved the standard, for example, by being involved in preparing his PCP meeting. However, I never witnessed Jeff choosing from a range of activities, especially not when he left the day centre with his group.

Organisation of support work

Throughout my time in this research setting, I learned that five permanent support workers (excluding the team leader) were working at the day centre. Casual workers and 'work experience students' supported permanent staff. The workers rotated weekly across the three groups. This meant that Jeff worked with different workers each week[12]. I once asked Linda about the purpose of this 'rotation practice':

---

[12] The rotation of support workers imposed a methodological challenge as I initially had difficulties identifying a focus support worker in this ethnographic setting.

Debbie: How often do you spend time with him (Jeff) per month?
Linda: … we have a roster on, that we all share groups, like everybody has a turn with a group so they don't get too attached to us and we don't get too attached to them.
Debbie: Like emotionally attached?
Linda: Yeah. Then it's all, yeah, also, we have a slow group, we have a medium group and we have a faster group. Jeff's always in the faster one…
Debbie: Do you feel you'd get attached sometimes to the clients?
Linda: Yes, for sure you would. The ones you work with longer, I think you always will get a bit attached to them. That's yeah, that's human nature. I think we're not robots. Even we're maybe expected to be on the one hand, when you look at the policies. But no, it's not possible, not to be attached a little bit. Like if any of them died today, I would cry for sure.

The 'rotation policy' had been implemented to prevent support workers and program participants from becoming too attached to each other. Linda, and all other support workers, had to work with more than one person at a time. When I spoke to the Human Resources manager, Misty, I inquired about the 'rotation practice', and she commented:

Rotating helps with a bit of flexibility for the people with a disability to have the opportunity to get used to working with someone different and it's human nature to always prefer someone over another person. But it's also good for our staff to get to know exactly who our clients are and keep them on the ball and help them with their flexibility and adjusting… so I see it as not just being for the person with a disability. I see it as a big benefit for our staff as well… I'm just not quite sure who implemented that. (Misty)

While Misty explained that organising support in this way aimed to achieve greater flexibility for the day program users and their support workers, I could see that the rotation practice made it difficult for Jeff to be heard and understood as he needed to adjust to new workers each week. It also had implications for Linda as it took her longer to familiarise herself with Jeff's way of communicating. This affected their relationship.

Jack and Samantha

The people and the environment

Jack was about forty years of age and was living with his parents, Tom and Karla. He was a friendly man with blond hair and freckles. He used verbal language to express himself and a walking stick to walk longer distances. Jack had several support workers doing different activities with him. 'Cooking' was the activity he did with Samantha on Friday afternoons for three hours. Jack and Samantha had been working together for two years.

   Samantha was an older, friendly lady with brown curly hair at shoulder length. She felt passionate about cooking, as she emphasised many times. When she worked with Jack, she used a couple of common phrases, short prompts and questions. For example, when she wanted Jack to work faster, she usually said "Step it out"; and when she was concerned or anxious about him, she often gave him an instruction using the imperative voice and added the sentence, "That's the mother in me". Samantha provided support through prompting and modelling (e.g. showing Jack a 'chopping-up' technique). She also provided suggestions on recipes and cooking techniques (e.g. preparing dough). Samantha and Jack used Karla's kitchen for the cooking activity, which was an open space next to a dining area.

Support work activities and goals

When Samantha arrived at Jack's place, they first wrote a shopping list, then left for the local supermarket to buy groceries and prepared the cooking. Samantha did not have dinner with Jack and his parents after the cooking. She left once they had cooked the meal. When I arrived at Jack's place, his parents were usually around. They left the house during the afternoon and returned towards the end of the cooking activity.

   Jack had a 12-week cooking plan, which included recipes for specific dishes he intended to cook with Samantha. Samantha explained that she had set up the schedule together with Jack at the start of the 12-week period. I sometimes heard them talking about potential meals before or during cooking. Samantha often provided suggestions on what to cook in future, and Jack decided for or against a cooking item due to the consideration of his parents' food likes. He would then say, "Mum doesn't like it" or "Dad loves it". Perhaps cooking for someone gave Jack an incentive to learn the recipes and do the cooking. Samantha and Jack both stressed that repeating the recipes regularly

was important as Jack would forget them quickly. They were using a specific type of cooking book to record the recipes. In my field notes, I described it as 'a white folder that included laminated papers with pictures depicting utensils and food items – it had some basic instructions next to the pictures'. Jack said that he appreciated that these recipes were written in a way so that he understood the individual cooking steps. When Samantha spoke about the 'easy-read recipes' and 'simplified cooking methods', she referred to them as "Jack-friendly". "He doesn't have to make short crust pastry to make an apple pie, he can buy the packet stuff which makes it more achievable for him", she explained. Samantha acknowledged Jack's capacity due to his intellectual disabilities, which imposed certain limitations on the work she did with him:

> You want them to reach their goals... but I need to understand that there is a limitation… because I've worked with him for two years… in the back of my mind I know I could work with him for the rest of time and he'll never be able to cook a three course dinner for 20 people. Like it's just not within his capabilities. (Samantha)

Cooking a three course dinner for twenty people might have been an achievement for Samantha, but I never got the impression that Jack felt so enthusiastic about cooking that he would aim for this, regardless of whether he had disabilities or not. While Jack was not overly excited about cooking, he was pleased when he saw the outcome and tasted the dish.

When Samantha and Jack went to the local shops, Samantha supported Jack in finding the ingredients for the planned meal. Jack looked at the shopping list and once he placed the item into the trolley, Samantha said "Scribble it out" and Jack struck through the name of the item on the list. He sometimes forgot the location of certain cooking items "because with the disability is short-term memory loss", he explained to me. Samantha always walked ahead of him and showed him where he could find the items.

Throughout my time in this setting, I learned that Jack's long-term goal was to move into supported accommodation, which he called "Independent Living". Samantha explained that support work "is about independence". To her this meant that "I (Samantha) try to get him back on track that he needs to look at the recipe and then he'll go to say 'I'll do this now' and I'll know that's not what's next on the recipe because I wrote these recipes". To Samantha, independence meant to focus on the recipe; to not get "distracted", as she stressed many times; and to learn how to cook. She supported this by repeating instructions, reminding Jack of the next steps and making sure that he was

staying "on-task". Samantha's knowledge about cooking gave her the power to provide instructions and Jack was the one learning the cooking based on these instructions. However, Samantha acknowledged that she was learning from Jack also.

> I'm learning every day from Jack as simple as when he put his hand on the stove… when you first start you go into it not having any idea what it is to work with somebody with a disability… I'd make honey chicken at home and not give it a thought but I'm watching Jack do it and seeing that it's spitting in his face and thinking, 'Yeah I can get a little burned', but you wouldn't set a person up with a disability to get burnt. So I'm changing my thinking all the time… I'm learning all the time to modify things. (Samantha)

In her statements, Samantha put a strong focus on Jack's limitations in progressing with cooking skills. She considered the risks of the cooking activity, which she ascribed to Jack's intellectual disabilities.

Jack's and Samantha's relationship was marked by an ongoing verbal banter. In their conversations, I often witnessed Jack calling Samantha 'teacher' or 'mum'. I once asked Jack why he was nick-naming Samantha. He responded jokingly, „I was just being smart". It seemed as if Jack himself was not sure why he referred to Samantha as 'teacher' sometimes.

> They had placed the groceries onto the kitchen bench. Samantha said "What do we gotta do first? Read the recipe!". Jack said "Yes, Mum" and read out the recipe. Throughout the afternoon, she asked him to focus on the work and checked the timing. She reminded him that she wanted to leave on time and asked him to talk less. She said "We're concentrating now, Jack". He responded "Yes, Mum". Samantha asked "How would you soften the butter?". Jack responded "Put it for a few seconds into the microwave". Samantha commented "Excellent" and advised to put the butter in for 15 seconds. (Field notes)

This banter was part of the common conversation between them and their role-taking. Samantha gave orders and Jack executed what Samantha told him. This was happening while they were teasing each other. For example, Samantha would ask "Do you want me to hold the bowl?". Jack would then laugh and respond "No, it's called independence". Jack was being sarcastic and about "learning to become independent", as he noted many times. One time, inside the supermarket, I asked Jack if he needed a hand with placing the items onto the check-out counter. He responded jokingly, "No, thanks, I need to get independent". From Jack, I learned that this banter had developed from when they started working together. He noted that he liked Samantha because she "can be fun" and "light-

hearted". Throughout my time with both, Jack referred to his disability and goal (becoming independent) in this banter.

> Jack was talking to me. Samantha interrupted him and asked "Where is your knife? We've gotta get those pizzas moving". Jack responded "Yes, step by step". In the meantime, Jack had chopped up onions for the pizza layer and made the dough for the cookies. Samantha had put little pieces of the dough onto the trays which she placed inside the oven. Samantha became pushy and asked Jack to cut up the capsicum. He explained that he was still busy preparing the onions. Samantha said "Well, step it out". Jack replied "I'll take the trump card". I asked Jack what he meant. He started laughing and said "I've got a disability! It's an excuse for being slow". (Field notes)

There was this ongoing teasing between them, but at times, I experienced a derogatory undertone when these 'jokes' were made – more so in Samantha than in Jack. For example, Jack cut his finger once, when he prepared garlic bread. In that moment, I experienced Samantha as dogmatic and patronising. The first thing she said when this happened was, "Why did you think that happened?" Jack said "I don't know" and Samantha asked "Were you not concentrating?" Jack responded in a firm tone, "Oh, yes, I did concentrate". Samantha helped Jack to treat the wound, but commented, "That's the smallest cut I've ever seen in my entire life".

Samantha and Jack hardly ever did a cooking task jointly. Samantha usually sat or stood next to Jack at the kitchen bench and was giving instructions while Jack was completing the task. It was only when Jack was behind the time schedule that Samantha sometimes got a chopping board out and chopped up vegetables together with Jack. This separation of tasks demarcated their roles and the distribution of power between them. When Samantha and Jack were doing the same task together, and Samantha was not standing next to Jack observing how and if he was following her instructions, it was somehow equalising their relationship. Samantha then did the activity with Jack instead of teaching him how to do it. I also noticed this in my role as a participant observer. When I fully participated in activities and stepped out of the role of the conscious observer, I felt I could mitigate the power imbalance between research participants and me to some degree.

Organisation of support work

Jack's support work was financed through the SLF. From Jack, I learned that one of his future goals was to move out of his parents' place. He mentioned that learning to cook could help him live in his own place one day. I did not witness conversations between

people discussing Jack's future move, nor was Jack aware of his funding type when I asked him. However, supporting people with disabilities to move into their own homes was one of the key objectives of the SLF.

I once witnessed a conversation between Samantha and Jack's parents about the funding and goal planning. Samantha asked Tom if Jack had had his NDIS planning meeting yet. Jack was close by when this chat occurred, but not involved in it. From Jack, I learned that Tom had produced his support plan. He once showed me the plan, titled 'pre-planning support plan'. The proposed plan had been made for the funding Jack was going to receive under the NDIS. A goal listed in the plan was 'to live independently with the support of a drop-in service or in a shared accommodation with people who support and understand me'. Ava, the service coordinator of the service that administered Jack's SLF, explained that Jack's PB was a self-managed PB, but that Jack was not self-managing his funding in practice:

> Self-management is when I guess the money is sitting with the person or the family and they sort of control all the invoicing… that doesn't happen with Jack. It (the money) does sit with us, and he has myself as his coordinator who oversees what he wants to do, paying for the invoices, helping him with the planning and the budgeting. (Ava)

I also learned that Ava's service commissioned another service that employed Samantha to provide support to Jack. Ava's service was the financial provider and Samantha's service acted as the support provider. This was how Jack's PB was administered.

Neither Jack nor Samantha had much contact with Ava or other service staff. However, there was an 'evaluation form' they completed at the end of each shift, which Samantha returned to her service provider, but not to Ava's service.

> I'm supposed to be filling it out and say what I think went well. But every week I say to Jack, "What do you think went well today?" and then in my report, I've got 'Jack says' and then I put underneath 'And I say this' and Jack will say things, "Learning something new" … "making an apple pie for dad" and some weeks he'll say nothing. (Samantha)

In general, I got the impression that Samantha kept repeating the recipes with Jack. It sometimes looked like she provided social company to Jack and the cooking activity was just part of a weekly routine. The goal of moving into his own accommodation seemed like an uncertain plan for the future, but to Jack and Samantha it seemed to be the reason that Jack had to learn how to cook.

Reflections

The findings in this chapter revealed how the pairs experienced the emotional (social interaction) and practical (the activities and tasks) forms of support work, which resonates with the literature (e.g. Christensen, 2009; Hooyman & Gonyea, 1999; Rogers, 2012: Ungerson, 1983) I analysed in Chapter II (see Section 'Support work as a relationship'). Both forms of support work, for example, came to the surface when the two people engaged in a banter or showed certain feelings in response to the other (emotional form) as they carried out the activities (practical form).

Both people's experiences were influenced by their involvement in the organisation of support work. Budget holders' involvement was affected by their communication support needs and by third parties in the environment (e.g. family members, flatmates or other support staff). It was influenced by the worker's relationship to these people and what the latter expected of the former. Most pairs seemed to experience limited involvement in this process, which included their say in the planning and implementation of activities and the administration of the funds from the PB. This seemed connected to their knowledge of the policies of PBs and the support work goals. How the activity was organised influenced its implementation which affected whether budget holders enjoyed it and how the worker dedicated themselves to budget holders during activities. It affected the emotional and practical forms of support work.

The findings also revealed that the support work goals were usually listed in documents, such as a support plan. The goals in the documents were often different to what I saw both people working towards when they were doing activities in practice. Most pairs seemed uncertain about why they were doing the activities they were doing, what the goals of the activities were and who had set them. The connection between the activities and the goals was often unclear. This might have been related to the fact that the goals captured in documents were not always consistent with the goals that the two people worked on in practice.

Each environment was demarcated by certain rules and practices (e.g. having a key worker or team leader in a setting) that influenced the implementation of the activities and goals, but I could not always understand how and if these rules and practices were linked to the PB. They seemed to be part of the wider support work context.

Chapter VI: The German pairs and their support work context

<div align="right">

Get up Abel

if only you′d get up

and take back

that first wrong answer

to the only question

that matters

get up

so that Cain says

so that he can say

I am your keeper

brother

(Hilde Domin, 1979, p. 49)

</div>

Introduction

This chapter presents the ethnographic descriptions of the five support work relationships in Germany. The ethnographic fieldwork in Germany happened after I completed the ethnographic fieldwork in Australia. It started in August 2016 and finished in January 2017.

The five descriptive accounts in this chapter are structured according to the same themes used in Chapter V. The chapter ends with reflections on the knowledge gathered through the descriptions of the five support work relationships and their support work context in Germany.

Yelena and Maria

The people and the environment

Yelena was a young woman in her mid-20s with intellectual and physical disabilities. After my first encounter with her, I wrote the following notes about her physical appearance in my field diary: 'Yelena had blond and curly hair. She was wearing black leggings and a singlet. Her legs were thin and her arms were very strong'. Yelena used a few words, basic signing and sometimes wrote a text on her iPhone or paper notebook to communicate with others. Due to the spasm in her arms and legs, she tended to move them in rough, fast and abrupt ways. At the time I met Yelena, she had been dating Max for two months. They met through a supported employment program. Max used a wheelchair and verbal language to express himself. He was about the same age as Yelena.

Yelena got 'assistance' from four to six 'assistants', as they were called. Two of them coordinated her support. I spoke with one of them. Her name was Barbara and her office was walking distance away from Yelena's apartment. Yelena lived by herself. She used a lift to access her apartment and a bus service to travel to places.

> Yelena's apartment has a spacious bedroom, bathroom and a small kitchen. I perceived the kitchen as 'inaccessible'. The stove and sink, for example, were not adjusted to someone with Yelena's disabilities. The kitchen had a little foldable table attached to the wall, located below a window, opposite side of the kitchen bench. The bathroom was spacious. It had a sliding door adjacent to a long corridor that led from the kitchen to the bedroom. Justin Bieber posters were attached to the walls inside the corridor. There was a working desk, a wardrobe, a bed and a chest of drawers inside the bedroom. (Field notes)

Maria was one of Yelena's assistants. Barbara was her supervisor. Maria was doing a full-time student placement with the service providing assistance to Yelena. Her role as an assistant was part of this internship. She was aged 22 at the time I met her and had worked with Yelena for almost six months. Maria supported Yelena two days per week.

Support work activities and goals

During my time in this setting, I witnessed Yelena doing a range of activities with Maria, such as grocery shopping, banking, eating and drinking and going for walks. When Yelena came home from work in the afternoons, she and Maria usually made a plan for the rest of the day or week. This planning activity was the most common activity I observed in this setting and it sometimes seemed that the planning itself was a support work activity. It included scheduling upcoming services (e.g. therapy, assistance, travel).

Yelena and Maria always did the planning first, and then Yelena ate something and left the apartment. During the planning, Maria sat at the desk inside Yelena's bedroom and Yelena sat in her wheelchair beside Maria.

> Yelena indicated by holding her thumb up that she wanted to organise the transport first. This was her 'yes/ correct response' to a closed-ended question of Maria. Maria said, "Tomorrow you have occupational therapy (OT)". Max then said "What? But she's on holidays". Maria responded, "Well, she can still go to OT, unless she doesn't want it, then we can cancel it". Maria asked Yelena whether she would like to cancel OT. Yelena confirmed by opening her mouth and smiling. When Yelena smiles, opens her mouth widely, keeps eye contact and makes sounds, then she expresses joy. This happens, for example, when she feels understood and someone interprets her answer correctly. Maria looked at some documents on the work desk and figured out that it was a specific taxi service that was taking Yelena to OT tomorrow. She looked at Yelena and asked whether she should cancel the taxi. Yelena nodded and Maria looked for the phone number of the taxi service. Maria called the occupational therapist and said, "She would like to spend the time with her boyfriend". After Maria said this, Yelena started laughing out loud. The OT understood and Maria passed on what the OT had told her in a joking way: "I hope she has fun and behaves herself". Max and Yelena laughed. Maria asked the OT whether she had the number of the taxi service and she passed on the number to Maria. She asked Yelena "Do you want to do the weekly planner tomorrow?". Yelena firmly indicated "Yes". Maria asked what else she wanted to do today and Yelena made a movement with her hands (moving pointer and middle finger forward and backward, but in opposite side direction and holding them downwards) indicating that she wanted to go for a walk. (Field notes)

Yelena was in love and she wanted to spend as much time with Max as she possibly could. She relied on Maria to schedule her therapy appointments and adjust them to the dates she had planned with Max. I could see that communicating Yelena's preferences was often challenging for both her and Maria.

The planning activity often took up to an hour. Occasionally, Yelena had done some pre-planning before Maria arrived. She was conscious of the limited time and the activities she wanted to complete within that time. One time, Yelena had prepared a shopping list so there was time to pick up rings at the jeweller for Max and her. Picking up these rings seemed an important activity to Yelena. She had ordered them before I started researching with her. The jeweller was located in the city centre and Yelena kept asking Maria when they could collect them. Maria repeatedly mentioned that they would not have time to travel there and pick up the rings. After some time, I assumed that 'picking up rings' might have been an activity that was not meant to be done during 'assistance', but from Barbara I learned that Yelena could do such activities during 'assistance'. By the end of the fieldwork, Yelena still did not have the rings.

The communication challenges were part of the everyday work Maria and Yelena did together. It was frustrating for Yelena to express her desires when Maria was struggling to work out what she wanted. One time, I was taken aback by the way Maria spoke to Yelena. Maria seemed frustrated about not being able to answer Yelena's questions.

> Maria, Yelena and I were outside as Yelena wanted go for a stroll. Yelena was writing into her phone. After about twenty minutes, Yelena held up her phone. Maria read the message and stopped pushing the wheelchair. She walked around and looked at Yelena. She raised her voice and said, "Are you trying to shit me?" I became a little anxious and wondered whether Yelena had said something insulting. Maria looked at her and said "I don't know who's gonna come to work tomorrow midday". She looked very frustrated and explained that she can't contact anyone from the office anymore as they had all left. Yelena's body was calm. Her back was turned towards me. I couldn't see her face. (Field notes)

On several occasions, I witnessed a condescending tone in Maria's voice when she spoke to Yelena. Sometimes, she looked tired and annoyed when Yelena demanded things that she was unable to provide. However, one of the things that Maria admired about Yelena was that she "had a mind of her own", as Maria put it. She was inspired by Yelena's self-determination in trying to take control over her life.

> I like that she knows what she wants and that you do not have to make all the suggestions… She knows … what needs to be done, and then she does it… she does not let others decide for her… of course some things… need to be decided for her… by her family. (Maria)

Maria appreciated that Yelena was "super open for new things, because there is a regular turn-over of assistants", but also shared feelings of sadness and explained that it was hard to see Yelena's restrictions in her everyday life, which I also witnessed as an ethnographer.

> Yelena tried to put pasta onto her spoon, using one hand. She couldn't hold the hand still and was shaking. Some pasta went onto the table. Yelena wiped off the table with her hand and the pasta fell onto her lap which was covered by the plastic apron. I couldn't understand why she wasn't eating with the fork, but then realised that the fork could hurt her when putting food inside her mouth. She repeated this procedure. Whenever she was able to get food onto the spoon and into her mouth, she placed the food with her right hand just below her palate and used her other hand to close her mouth – to make sure that the food wouldn't fall out. However, it never all stayed inside her mouth. Half of it usually fell out. At times, she had already chewed some and it dropped out with more saliva. Most fell onto her lap and some fell onto the floor. In between, she drank some milk, but it took a while till she had the straw in a position where she could suck and get the milk into her mouth. Some of the milk went onto her shoulder and dropped down between her arm pits. (Field notes)

Yelena usually ate and drank without Maria's support. On very few occasions, Maria fed Yelena. This only happened when Yelena was extremely tired. I learned that eating and drinking by herself was part of 'living independently', which was the overarching goal that Yelena's funding pursued. 'Eating and drinking' was one of her sub-goals, which formed part of a broader goal, called 'personal care'. Yelena's sub-goals and goals were documented and part of the organisation of her assistance, which I explain next.

Organisation of support work

From the service manager and supervisor of Barbara, Matilda, I learned that Yelena's PB covered twelve and a half hours of assistance a week and aimed to help Yelena live independently. It included a sum of almost €4000EUR per month. From Matilda, I learned that 'customers', like Yelena who received individual assistance, participated in an assistance planning process. The 'demand for support' (Unterstützungsbedarf) got documented through an inquiry sheet that the service used internally. She gave me a copy of this form and I could see that they had investigated the support demand through six 'life domains' (personal care, household, medical care, lifestyle and occupation, public authorities, special assistance) that included sub domains/ sub-goals. Each sub domain was linked to a broader support goal.

However, Yelena told me that her future goal was to move in with Max and start a family. As an observer, I could see that it was always a priority for her to spend time with Max. This was not captured in the form, which was last updated in November 2015. Yelena had met Max after this date, but I had learned from Barbara that 'dating' had been on Yelena's mind for the last few years. Barbara explained that her role as an 'assistance-coordinator' entailed the provision of assistance, but also its planning and administration. This, for example, included facilitating team meetings and inductions for assistants and organising prescriptions from doctors for OT, speech therapy and physiotherapy. However, the organisation of the assistance involved Yelena's mother and sister.

> Yelena needs to wash her clothes at 60 degrees, well underwear and stuff like that… then I said to Yelena, "Well, we gotta do washing". And we did so, but she did not want to wash it at 60 degrees, it ended up being different washing, sweaters and things like that, where I said, „Yelena… that's too hot". I then try to talk to her and persuade her, but in the end, she does what she wants, and that's a good thing. (Maria)

Maria said that the instructions often came from Yelena's sister who wanted to have a say in how the activities were done. Maria's impression was that Yelena feared telling her sister when she disagreed. Maria then felt caught between Yelena's and the sister's preferences. However, it was unclear to me whether Yelena always knew what was expected of her. For example, Maria had completed her internship by the end of my time with her, but Yelena had not been fully aware of how her relationship with Maria was going to continue.

> *Debbie:* Okay, and Maria stopped working here, right?
> *Yelena:* Affirms this question with a sound that I interpret as 'yes'.
> *Debbie:* I got to know her in the last few weeks. Do you think you will see her again?
> *Yelena:* Ah-Ah. (Indicating a negative)
> *Debbie:* Never again? Or you just don't know.
> *Yelena:* Makes a sound, which I interpret as "I don't know".
> *Debbie:* Would you like to see her again, one day?
> *Yelena:* Affirms this question by nodding.
> *Debbie:* Well, it has been fun working with both of you.
> *Barbara:* May I say something? (Barbara was documenting work at Yelena's desk)
> *Debbie:* Yes, sure.
> *Barbara:* Well, Maria is starting to work for us on a casual basis, did she not say that? (looks at Yelena and me)
> *Yelena:* Makes a sound indicating a negative.

Until that moment, Yelena had not been aware that Maria was going to continue working with the service in a different capacity. On the second last fieldwork day, I had witnessed Maria saying goodbye to Yelena and telling her that it was her last day with her. Had this been enough notice for Yelena? People involved in Yelena's organisation of assistance might have not always considered whether important information was shared with her.

Helene and Emma

The people and the environment

Helene was a young woman aged 28. She lived with her mother Kerstin who was her legal guardian. Helene had six 'assistants', as she called them, and was interested in theatre and singing, which she practised occasionally. From Helene, I learned that she was about to start a job as a receptionist in Kerstin's business.

Emma had been Helene's assistant for many years. They met eleven years ago when Helene attended the same school as Emma's children. Emma supported Helene on two consecutive days each week. On my first day with them, Helene opened the apartment door to welcome me.

> Helene's apartment was inside an apartment block. Helene stood at the door when I had walked up the stairs. She had Down syndrome, dark hair and was wearing a trendy head scarf. She walked into the corridor to hug me. She was warm and approachable. She asked me to come in. Once I walked into the flat, I could smell food and realised that someone was cooking inside the kitchen. It was Emma. I said "This smells lovely". Emma came out and smiled at me. We shook hands. She said "Yes, Helene loves food". I said "Me too". We laughed. Emma wore an apron. She was probably in her late 50s. Her grey hair was chin-length. (Field notes)

While I was researching with Helene and Emma, I saw more of the apartment.

> I could see two larger posters with writings and graphs attached to the wall inside the dining room. One was about a new assistant that Helene wanted to hire to help her with the new job. The poster indicated that she was looking for a non-smoker. A week planner with an erasable ball-point pen was attached to the wall. It had the names of each day on top of the column. The apartment had three bedrooms. Helene showed them to me. Her room was behind the dining room. It was colourful and light. It had a sofa and a tea table close to a window. It also had a work desk, bed and wardrobe. The bed covers had yellow stars on them. There was a baby's changing table next to the bed. I spotted two dolls and said something like "I used to have a doll like that". I asked "What are their names?". Helene replied "This is Emily and this is Laure – they're my children". (Field notes)

Support work activities and goals

When Emma worked with Helene, she stayed overnight. She once showed me her time sheet. She always put in three hours of support work for Mondays and six hours of support work for Tuesdays. I always came on Tuesdays mornings and had breakfast with them. After breakfast, Helene usually washed clothes; then we drove to Biomarkt, an organic food store, where Helene and Emma bought food for lunch; and then they started cooking. This routine was captured in the time sheet that Emma submitted to Kerstin at the end of

each month. After lunch, Helene usually had time to herself, which she sometimes spent at the computer. Emma called this time Helene's 'protective space' (Schonraum).

Helene's goal agreement said that she had a PB of €1015EUR per month for 'Participation in Community Life' and 'Independent Living Training in the Family Home'. The document was from December 2015 and included five goals: independence in the home environment, conflict resolution and becoming independent from mother, developing a day structure and a healthy living style, coping with tensions and unease, participation in community life (e.g. fostering and developing friendships with people with disabilities, attending cultural events). The document did not indicate which assistant was meant to pursue which goal or whether all assistants were meant to work on all goals. However, the document indicated that Emma, Helene, Kerstin and a support planner from the government attended the meeting at which the goals had been set and agreed on. While each goal had sub-goals, the goal agreement did not indicate how Helene and her assistants would know if the goals had been achieved. With an awareness of these goals, I, as a participant observer, never saw Emma joining Helene in community activities with others. I never saw Helene cooking, but saw that she and Emma bought vegetables and fruits at Biomarkt, which might have been related to the goal 'healthy living style'. Emma always cooked lunch after they got back from the food store. I could also see that Emma tried teaching Helene things that she wanted her to eventually do on her own.

> We approached the check-out inside Biomarkt and Emma realised that she was still carrying the deposit bottles. She walked to the recycling machine. She asked Helene to come with her. Helene stood next to me, close to the toiletries and chocolate products. Helene said to Emma that she doesn't want to come. Emma asked, "Do you know how it works?". Helene snappishly said "Yes, I know how it works". Emma returned the bottles and came back to us with a receipt. (Field notes)

Emma was trying to show Helene how to return deposit bottles, which Helene was not interested in doing. She was annoyed about Emma's comments and questions. On another occasion, when we had just left Biomarkt to travel to Helene's place, Emma answered a question, which I directed at Helene. I could sense Helene's anger in this situation.

> I asked Helene "Do you know how I get to the big shopping centre by street car? I want to go there later this afternoon". Emma immediately answered, "You have to change at Market Square". Helene said the same, but a few seconds later. Emma then said to Helene "Did you see, Helene, the new staff at Biomarkt were learning the ropes". Helene snippily responded "I know, I saw that, I am not stupid". Emma turned quiet. (Field notes)

On several occasions, I asked Helene a question, but Emma answered for her. In the joint interview, Helene got upset and seemed to feel misunderstood and not heard.

Emma: I am in ongoing contact with Kerstin, I perhaps know a little better how to handle her (Helene). You understand 'handle'? (uses the word in English, no translation was required)
Debbie: Yes, I understand the word 'handle'…
Helene: I don't want Kerstin to always talk to Emma, because…
Emma: Does she do that? She doesn't do that!
Helene: Yes, she does. Sometimes.
Emma: When I'm not here?
Helene: I don't know, but when I am sure that I want to do something with Emma alone, then my mother gets involved, most of the times.
Emma: That's a different story, Helene. You sometimes go on about this (language gets unclear as Emma is leaving the room for a minute).
Helene: (raises her voice and gets angry) It's true, Emma!
Emma: Yes, you are right! (shouts from the room next door).
Debbie: Does she get involved, your mum?
Helene: Yes. And I want to do things with Emma on my own, together with her, with the assistants.

Emma was about the same age as Kerstin. They had known each other for many years. I was unsure about the depth of their friendship, but sometimes had the impression that Helene might have had the feeling that Emma allied with Kerstin. In the single interview with Helene, she did not talk much about Emma, although I specifically asked questions about her. Instead, she repeatedly mentioned Tina, another assistant who was about her age, and referred to Tina as her best friend.

Debbie: Well, you said something interesting just before. You said that Tina has become your very best friend. Would you also say that Emma is a friend or would you rather say that she is your assistant?
Helene: Well, Emma is not really a friend, she is assistance.

After this statement, Helene continued talking about Tina, but did not elaborate on the distinction she had made between friendship and assistance. Tina was the only assistant that Helene referred to as her friend.

Several times, throughout the field research, Emma mentioned that she learns from Helene. She gave an example of how Helene teaches her to enjoy and stay in the moment.

When it comes to eating. She sits at the table and says, "I am hungry". Then we put food on our plates, and she does this and that, and then she starts eating and by that time, I have

already finished half of the plate and then she always says, "You are eating so fast" (Emma laughs). And then I always say, "When I am around you, I learn to enjoy". (Emma)

Emma added that she takes a more relaxed approach to the activities with Helene. "Well, if you look at it, one may say 'well, they are not getting that much work done in the morning' or so… but it would not be Kerstin's wish anyway", she explained. Emma mentioned that Helene feels easily overwhelmed if she confronts her with too many tasks. "She does not react well to pressure", Emma commented and acknowledged that she needed to learn patience when she started working with Helene. For Emma, the most essential thing she was learning from Helene was that she was slowing her down as she had to adjust to Helene's pace. "Helene is spontaneous, she can be enthused, she is never unforgiving, she is happy and she is slowing down my life. You must concentrate on one single activity with her", Emma commented. Helene taught Emma something that Emma found useful to incorporate into her life. There was some kind of teaching and learning in the relationship between the two women, but the learning that Emma experienced through the relationship with Helene seemed unintended compared to Helene's learning which was organised through the PB.

Organisation of support work

Helene's PB was a self-managed budget, but it was in Kerstin's hands. Kerstin and Helene said that they had recruited all workers, but Helene's actual involvement in this process stayed unclear to me. None of the assistants were recruited through a third party, such as an agency or a service provider. I had my first insights into the support work arrangements, when I started organising the field research. I sometimes spoke to Helene on the phone, when I called to confirm the fieldwork times. Helene was often unsure and handed the phone to Emma, when Kerstin was not present. Although I inquired about Helene's preferences, it was Emma who told me when to come, after she had checked with Kerstin. And it did not seem that Helene herself felt that she was much involved in the decisions that affected her life.

> *Helene:* Well, Emma also stayed a few times longer here when I was by myself, when Kerstin was gone and that was fun. I could then watch TV with her in the evenings and then we do what I want.
> *Debbie:* Do you have the feeling that you do what you want… or what she wants?
> *Helene:* What Emma wants.
> *Debbie:* You often have the feeling that you do what Emma wants?
> *Helene:* Yes!

Debbie: And who is making the decisions?
Helene: My mother.
Debbie: Okay, she is making the decisions, what you both do?
Helene: Correct.
Debbie: And you do not get to have a say in that?
Helene: Well, when I'm allowed to say something (laughs as she is being sarcastic).
Debbie: And when are you allowed to say something?
Helene: Ahh, I don't really know.
Debbie: But you do say at times what you want to do, don't you?
Helene: Of course.
Debbie: Not everything gets decided for you?
Helene: No, if I want to go to bed in the evenings, then I know when I should go to bed.

Helene used the word 'allowed' when she spoke about her involvement in the organisation of support. From her, I learned that Kerstin set up her support schedule. Emma saw Kerstin as her commissioner and employer. She organised Emma's payment, which came out of Helene's PB. In the interview with Emma, she explained that Kerstin has a big say in Helene's support process. "To me it is important, because I am in Kerstin's space, well in her apartment, I have to check with her and consult her", Emma explained and noted that Helene partially gets involved in conversations about planning. Helene "adds something to the discussion sometimes", but it takes longer for Helene to process the information… it's the same with children", Emma said.

It seemed that Werner, a service professional from the government agency granting and overseeing Helene's PB, was more appreciative of Helene's situation.

I will use the word 'power'. The power of the parents, especially the mothers is extreme in these situations… you can't blame them, because they have been in this dependent relationship their entire life. And to say something against the opinion of your mother, well that is something you have to learn. If I don't learn it, if I don't adjust, because I rely on their help... I would be getting into a conflict with my parents, my mother, and in the next moment I'll ask her "Can you get something out of my wheelchair please?" And I am in an argument with my mother, my assistant, the trade union… I really wish that Helene will eventually move out of her mum's house. (Werner)

Werner was considerate of Helene's dependency on her mother and the implications this had for her role as a self-manager. Kerstin's involvement in the organisation of the support work had influenced Emma's and Helene's relationship to a great extent as Emma often had to check with Kerstin when decisions about the support work were made.

Lisa and Lydia

The people and the environment

I met *Lisa* when she was 28. Lisa had brown, curly hair and wore glasses. Lisa had Down syndrome, but I barely noticed her restrictions or impairments as I researched with her. I experienced Lisa as an exuberant woman who spoke with excitement and enthusiasm, when she talked about her activities. Lisa had many interests, such as playing cello, ten-pin bowling, swimming, going to parties and cooking. I also experienced Lisa as very organised and structured. She not only enjoyed planning activities, but also took pleasure organising some of the fieldwork days with me. At the time I worked with her, she had been in a relationship with Sebastian for two years. I never met Lisa's boyfriend, but she often mentioned him.

Lisa lived with her parents, Jürgen and Bettina. She was planning on moving into her own place with Sebastian sometime in the future. Lisa worked in a café during the day. After work, she sometimes received assistance for 'leisure' or 'supported living'. The former focused on physical exercises, such as going to the gym, swimming and running; the latter included cooking and cleaning. During the time I worked with Lisa; her leisure assistant named Norah was unavailable. A requirement of Lisa's assistance was that the worker had to provide their own car for some activities and Norah's car had recently broken down. Norah was replaced by three other assistants. One of them was Lilly, the service manager I interviewed. Another assistant was Lydia.

Lydia was in her early 60s and had been Lisa's 'assistant' for four years. She worked part-time and had a permanent contract with the service that employed Lisa's assistants. Lydia was tall and had grey hair, which was a bit longer than shoulder length. Lydia supported Lisa with cooking or cleaning once a week. The cleaning took place at Lisa's place and the cooking took place inside a large spacious kitchen that belonged to the service, which was a fifteen minutes' drive away from Lisa's place. Lisa's place was a spacious apartment on a ground level inside a two storey house. Bettina, Jürgen and Lisa were living there.

Support work activities and goals

Lisa always had a fixed plan of what she wanted to get done during the time Lydia was present. When she made a plan about an activity, she wanted to stick to the plan.

Lisa asked if I ate fish. I said, "Of course". She said, "Good, cause next Monday, we will cook tuna pizza". Lydia said that this was not 100% sure yet and they needed to talk about it again. I was aware that Lydia couldn't tell Lisa that her father had wanted to surprise Lisa and take her out to dinner. Lisa insisted and said to Lydia that they had decided on tuna pizza a while ago and she wanted to do the pizza. Lydia came up with excuses about not having enough time to do the pizza next Monday, but Lisa did not give in. (Field notes)

Lisa was very persistent when she wanted something, but this did not mean that Lisa was not open to Lydia's suggestions on how to go about the activities. It appeared that making plans about her activities gave Lisa an incentive to engage in them. This incentive had something to do with her future goal, which was moving into her own place with Sebastian.

Debbie: And what have you learned so far? What are the things that Lydia taught you?
Lisa: Well, that I can also cook pasta dishes now. I have cooked many pasta dishes, also different variations. And there is pizza. I will continue doing that, but with a different topping. But as long as my mum buys the tuna for me, we will eat tuna. And then we will do something else.
Debbie: Okay, you now try a recipe at a time, and…
Lisa: Yes, I only practice one recipe at a time.
Debbie: Over several weeks or does it change?
Lisa: No, not weeks. Months.
Debbie: That means that every fortnight you will have tuna pizza?
Lisa: Well, when the tuna is all used up, then we won't do tuna pizza anymore. Then we will cook other pizzas with different toppings… with olives and artichokes. Otherwise my boyfriend will complain one day and will say "When will we have pizza?" and I can't cook pizza for him.

When I spoke to Lilly, I asked about Lisa's future living options. She explained that the service provided accommodation options for couples with disabilities. She noted that she could imagine Lisa and Sebastian moving into one of these apartments at some point.

Before the cooking activity, Lydia and Lisa usually went to the shops to buy the ingredients for pizza. I watched Lydia supporting Lisa by reminding her subtly of the cooking steps while Lisa was selecting the groceries.

We walked into the shopping mall. Lisa held a hand-written paper note in her hands. She had prepared a shopping list. It said tomato paste, olives, salmon, spinach and a few other things. When we got inside the supermarket of the shopping centre, Lisa discussed with Lydia whether she needed to buy frozen or raw spinach. Lydia advised Lisa on how they could prepare the topping for the pizzas and explained that frozen spinach should be fine. Lydia helped Lisa to imagine how she would prepare the topping. For example, when Lisa was looking at the spinach on the shelf, Lydia advised to braise the spinach lightly with onions later on when they cook. She suggested adding olive water from the jar. Lisa then thought about what Lydia had said and decided on the type of spinach. (Field notes)

Lydia provided Lisa with a space and time that helped Lisa to envisage the upcoming task and its procedures. By asking these types of questions, Lydia supported Lisa in using her own capabilities and making decisions. This was the same when the two women cleaned together, but the activity was sometimes accompanied by an ongoing tease between them.

> The first thing that Lisa and Lydia did together was changing the bed sheets, blankets and pillows. They chatted about the weather and that it was time to get the blanket with the downy feathers out as it got colder. The bedding was in one of the top parts of the wardrobe. "This is where I come into effect", Lydia noted and looked at me when she reached up to the top level of the wardrobe shelf. Lydia was much taller than Lisa and I. She pulled out the bedding equipment and handed it to Lisa who had taken off the old sheets and bed covers. Then Lisa and Lydia were dusting off the furniture. Lydia helped her cleaning the shelf and furniture located at a higher level. When Lydia prompted Lisa to do something, Lisa occasionally said "I love you too, Lydia". She said this in a teasing way. For example, Lydia would pose a question related to a work task. Lisa then replied, "I love you too" in a cheeky way. One time that evening, Lisa left the bedroom and walked outside the house. Her bedroom door was open and the shutters were closed. But Lydia and I could hear Lisa from outside. I believe that she had put the rubbish bags into the containers. Lisa said, "Trick or Treat". Lydia asked her to come back inside as it was cold out there. Lisa responded, "I love you too" and laughed. There was a happiness and joy in her tone of voice. Lydia responded, "I love you too". (Field notes)

When I interviewed Lydia alone, I asked her about the banter between her and Lisa. I was curious about Lydia's interpretation of the sentence "I love you".

> If I say something to her, which might include criticism, she says "Yes, I love you too". That's our banter. And when she says something critical to me, I say "Yes, Lisa, I love you so much". We've been doing this, well I don't know for how many years. (Lydia)

I could see that both women were fond of each other and used each other's strengths to work with one another. The mutual fondness was expressed as the activities occurred. In the joint interview, I inquired about future support work activities.

> *Debbie:* Well, do you think the cooking and cleaning on Mondays will stop at some point…? And you will then do a different activity?
> *Lydia:* Yes, we do have to learn how to iron for example.
> *Lisa:* Yes.
> *Lydia:* Washing and ironing. Theoretically we have done the washing, but we have not done it yet in practice. We have to talk to Lisa's mother about how we are going to organise this. It might be an activity she can do once she has her own place.

It seemed that the activities both women could do together were dependent on the spaces or facilities they were able to use, which involved discussions with Lisa's parents.

Organisation of support work

Although Lisa was autonomous in planning her activities, Bettina and Jürgen had a voice in the organisation of the support work too. I also learned about this when Lisa and Lydia explained why they had stopped cooking at Lisa's place.

> *Debbie:* If you are alone with Lydia here (referring to the kitchen of the service provider) ... are there differences compared to home? If you are at home and you cook.... Is it better here or there?
> *Lisa:* Well, that was the wish of my parents that we moved here.
> *Debbie:* Yes, you told me in the first interview.
> *Lisa:* Exactly.
> *Debbie:* It was the wish of your parents. And what was Lydia's reaction?
> *Lisa:* She said 'Okay, I'll do it'.
> *Lydia:* Was fine.
> *Lisa:* Well, she has to do it the way she is being told. (Lisa turns to Lydia and looks at her). I am sorry, I put that so bluntly. I had to say it that way.
> *Lydia:* That's okay.
> *...*
> *Debbie:* You have more space here. The kitchen at home is smaller.
> *Lisa:* It is not that small.
> *Lydia:* It's got nothing to do with that. At Lisa's place, I cannot operate the stove properly.
> *Lisa:* She can't do it, but I can, because I know the ropes.
> *Lydia:* You do, but when I put something on the stove, it indicates something… that's too much for me. And besides, we must be super tidy at Lisa's place (starts whispering). We must clean everything up right away, don't we? (looks at Lisa to seek reassurance) …

Lisa was not using her own kitchen for the cooking activity. This did not fit with her parents' ideas on how space was used in their apartment. The ways in which both women implemented support work was dependent on Bettina's and Jürgen's expectations. This seemed to influence Lisa's learning of cooking independently.

From Lydia, I learned that Lisa was scheduling the support work activities and did most of the planning, but in consultation with Lydia and Lisa's parents. "Her father checks the schedule, he skims over the dates, as Lisa tends to plan things that the parents are not aware of", Lydia remarked. Bettina corroborated Lydia's observation and indicated that Lisa was not always telling her if she had made plans regarding her support.

> I walked into the kitchen. Bettina was sitting on the kitchen bench. Lisa was hugging me from the side. I asked if I could get a copy of the goal agreement and explained why I was interested in the document. Bettina and Lisa agreed straight away. We spoke about the sum of the PB. Lisa had a small budget – it was €500EUR per month. Bettina noted that the budget used to be smaller, but one time when they met with the government official monitoring the support process, the government official asked if there was something that needed to be changed. Lisa bluntly said "Yes, the money is not enough", Bettina explained. She noted that she was surprised about Lisa saying this so suddenly. Lisa had not told her beforehand that she was going to complain. Bettina said that she was happy that Lisa got

something in the first place. After Lisa complained, the government increased Lisa's budget. (Field notes)

Bettina's account resonated with my impressions of Lisa. I had experienced Lisa as a confident and determined young woman who would not let others easily walk over her. Over time, I could understand that part of her confidence as a budget holder was influenced by the knowledge she had about her budget. Lisa was the only budget holder in this study who knew the hourly rate of her assistants. I once witnessed a situation, in which Lisa told Lydia, when Lydia completed the time sheet, that Lydia should bump up to the full hour. They had finished about quarter to the full hour and Lisa needed to sign the time sheet.

While I witnessed Lisa taking control and responsibility over the organisation of her support, I also got to know her 'soft side' when I worked with her. She once explained to me that the frequent turnover of workers had saddened her. She stated that she had let workers into her heart and then they deserted her from one day to the next. There was resentment and disappointment in her voice when she reported this. From Lisa and Lilly, I learned that Lisa had a partial say in the selection of her workers, but that her choice in this process was limited due to the limited number of available support workers. Despite Lisa's self-determination and confidence in expressing her preferences concerning the support work, she was still dependent on many other people and policy procedures within her environment.

Thomas and Luke

The people and the environment

Thomas was a young man who lived in a flat with four other people with disabilities named Moritz, Tanja, Steffi and Sandra. Thomas enjoyed rides on the tram, watching German football, and visiting his parents and siblings who lived close by. Thomas had a PB for 'supported living', which involved the support he needed to live in the flat, and a budget for a day program that he visited. Each budget sat with a separate service provider.

Luke was a permanent full-time support worker of the service that helped Thomas in the area of 'supported living'. From Luke, I learned that there were four other workers working with Thomas and his flatmates. Luke was in his late 30s and had known Thomas for ten years. He supported him in moving into the flat six years ago. Luke helped Thomas and his flatmates with independent living tasks, such as cooking, shopping and cleaning. I first met both men in person when I visited them in Thomas' flat to talk about the study.

> Thomas' apartment was on the first level inside a big apartment block. Luke opened the apartment door and welcomed me in. Thomas was sitting behind him on a sofa. Later that evening, I learned that Luke was staying overnight and was sleeping on that sofa. It was located inside the communal area that had a TV and dining table with chairs. A large board with a table that looked like a weekly schedule was attached to the wall. The names of the weekdays were on top of each column. In the Sunday evening column, it said my name and the time they expected me to visit. I learned that every tenant had their own bedroom. Luke had fair hair. He was cheery and a little restless. Thomas was quiet and calm. He had blond, short hair. Luke noted that Thomas' flatmates were still out on a trip and were coming back this evening. Thomas got up from the sofa, came closer and smiled at me. Luke asked, "Would you like a coffee or water, I am going to fix myself a cup of coffee". I thanked him and said, "I'd like both". Until then, Thomas had not said anything. But I then heard him saying "Tuesday". Luke said that it was Thomas' birthday on Tuesday. He was turning 26. (Field notes)

Throughout my time as an ethnographer in this environment, I learned more about Thomas' ways of communicating. Thomas had autism. He did not use much spoken language to tell others what was going on for him. From Thomas' mother, Gerda, I learned that Thomas worked with a communication facilitator named Robert. Robert assisted Thomas in putting his thoughts and feelings into writing, also in the form of poems. Robert and Thomas used a laptop for the writing. At the end of the ethnographic work with Thomas, I had the privilege to witness how Robert and Thomas worked together. Robert held Thomas' wrist so that Thomas could type his views, about my questions, into a Word Document. In this interview, I asked Thomas about his poetry.

153

Debbie: I read your poem 'From Me'. You have written this poem… I was very touched by this poem. I thought it was beautiful. And I wanted to ask you what you mean when you use the words 'All Alone' (Mutterseelenallein) in this poem. That is what you are writing. 'All alone' – that is how you are starting this poem. Do you mean that you are feeling alone?
Thomas: (Grinds his teeth and then starts typing while Robert encourages him to do so).
Debbie: (After a few minutes, Debbie starts reading). Okay, you wrote 'By god, of course, I am all alone with myself, very alone'.

Support work activities and goals

Thomas had shared his feelings of loneliness with me. As an observer, I had always seen him surrounded by Luke and/ or his flatmates. For example, I saw them all taking the street car into town to go to cafes, going to the local food store to buy groceries, cooking or watching TV together. These were some of the support work activities I witnessed. Thomas and Luke never did them together alone. Moritz, Steffi and Sandra were usually with them. Support work always occurred within a group and never solely between Luke and Thomas. However, Thomas still felt 'alone with himself' as he expressed in his poem. As a participant observer, I could see that Thomas might have felt misunderstood at times.

I sat at the dining table. Thomas and his flatmates were getting ready. I learned that we were waiting for Steffi - then we would head off to the Christmas markets. Luke looked at me and said, "The forms". He was referring to the consent forms. Luke was walking around, checking his folders. He pulled out a couple of folders and files until he found them. I stood up and walked over to Luke to check with him if they were the right ones. Thomas suddenly grabbed me firmly from behind and pulled me onto his body. Luke stepped between him and me and said "Stop". He held Thomas' hands down and moved them closer to Thomas' body. It was a firm, but cautious movement. He looked at Thomas and said, "You cannot touch Debbie like this". Luke looked Thomas in the eyes. Thomas reciprocated the eye contact. Initially, he smiled, but then Luke asked "Do you understand? You can't grab Debbie from behind, this is not okay". Thomas said "Yes" after Luke asked him another time if he understood. Moritz didn't say anything and watched. Thomas then disappeared into his room. (Field notes)

I did not witness a conversation between Luke and Thomas following this incident. I asked Thomas in the interview why he sometimes hugged people abruptly. Thomas wrote 'my muscle tone fluctuates and when I am joyful it increases and is uncontrollable'. I then delved a little further into the meaning of the hugging.

Debbie: One time, you did that with me, you hugged me and then you said 'love', and I saw you doing that with Steffi. And perhaps you also do that with Anastacia (another support worker) … What does the hugging mean? What does a firm hug mean when you say 'love'? and just before, you took my hand and kissed it and said 'love'...
Thomas: (is thinking for a while and then starts typing while he is grinding his teeth) …
Debbie: Well, you answered the question 'What does the hug and the word 'love' mean

when you hug someone?'. 'Love means that I feel a trusting emotion, and the hug is an expression of this feeling', you are saying.

The act of 'hugging' meant something different to Thomas than how Luke interpreted it. These differences in meaning sometimes seemed to cause misunderstandings between Thomas and Luke as they carried out the activities. For example, there were several situations during the field research, where Thomas behaved in ways that annoyed and irritated Luke and Thomas' flatmates. One time, we were about to head back to Thomas' flat after we had spent some hours in town.

> We bumped into two women. One of them sat in a wheelchair; the other one was pushing it. Moritz, Steffi, and Luke chatted to them. After a few minutes, Luke realised that Thomas had disappeared. Luke got anxious and walked a little further away to try and find Thomas. I looked around to see where Thomas had gone and spotted him. He was in front of the book store close by. I called Luke and showed him where Thomas was. He walked over to Thomas who had just taken a magazine off the rack. Thomas grinned at Luke. Luke faced him. Luke had a strict tone in his voice. He took the magazine off him, placed it back onto the rack and said "You can't do that Thomas". We then said goodbye to the two women. Thomas and Luke held hands when we walked back to the street car station. (Field notes)

I could sense Luke's feelings of anger when Thomas left without letting him know. I saw it happening on a few occasions. Luke became worried in those moments. I asked Thomas in the interview why he sometimes disappeared without telling someone. As a response, he typed 'I enjoy teasing people'. Sometimes, especially when Luke was attending to Moritz, Sandra or Steffi, Thomas stood in front of the window inside the dining area. He looked outside, was still and watched people passing. He was calm in those moments.

Although Thomas had limited verbal speech, he was able to initiate conversation. I witnessed this many times.

> Thomas walked over to me and said "Help". He pulled his jacket closer to me. The zipper hadn't properly opened at the bottom of the jacket. He looked at me and I knew that he wanted me to help him to open the zipper. (Field notes)

Luke supported Thomas with personal care (e.g. showering, dressing), but Thomas did not share his 'gentle thoughts' with him. 'Gentle thoughts' was the name of one of his poems. In the interview, I asked Thomas what 'gentle thoughts' meant. 'Gentle thoughts are very confidential, even intimate; thoughts one does not share with everyone', he explained.

> *Debbie:* Thomas, with whom do you share your gentle thoughts? Is there someone you can share them with? Anyone? For example, Robert or mum? With whom?
> *Robert:* I will write up the question.
> *Debbie:* Okay. With whom can you share gentle thoughts?
> *Thomas:* (is typing and then suddenly stops).
> *Debbie:* With whom?
> *Robert:* With whom? Do you have an idea? (Says this to Thomas).
> *Thomas:* (is typing).
> *Debbie:* (Debbie is reading the response) Mother and sister are feeling… 'practically, it is only possible with Robert, but mother and sister are feeling the most with me.'

In the continuation of this chat, I asked Thomas if there was someone in the flat with whom he could share his 'gentle thoughts'. Thomas then wrote 'with Anastacia it works the best'. However, Thomas did not do the computer writing exercise with Anastacia. He was only doing it with Robert and occasionally with Gerda.

Organisation of support work

From Luke, I learned that he did the planning for support work in Thomas' home environment, but not for the day program. He noted that his service does not receive additional funds for the planning component. I also learned that Thomas refuses to take part in the annual 'budget conversations' (Budgetgespräche), as Luke called them. Luke explained that he and Gerda met with government staff and spoke on Thomas' behalf.

> Thomas does not want to participate. He explicitly said this. He commissioned his mother to talk on his behalf. Thomas does not like it and it distresses him. He does not want to sit there, because he cannot… avoid that we talk about him and avoid that they pose certain questions… to sit there and not be able to express himself. What would he say? He would probably like to say something in that moment, but he does not have options. (Luke)

Throughout my time in this setting, I did not observe whether Gerda, Luke, Robert or someone else sought Thomas' views about his preferences in preparation for these planning meetings. From Luke's perspective, Thomas had the capacity to understand what was happening around him, but the budget conversations were not set up in a way that included Thomas in questions concerning his support. Luke elaborated on Thomas' communication problems:

> The input is working, but not the output... everything goes inside, he can process it… he can understand it, but the adaptive behaviour or adaptive responses or talking… that is the problem… he has no issues comprehending… the information gets to him… when he voted… he told me who he voted for, he doesn't make a secret out of it… at six o'clock we gathered and watched the outcome of the election, the first predictions. And when he

could see that the party that he voted for was leading, no one had to say "Hey, that's the party you voted for, they had a great outcome". He saw it, understood it, and was happy about it... there is no limitation… But it is difficult with Thomas. (Luke)

One of the goals captured in Thomas' support plan and goal agreement was 'To sustain the communication options within the environment'. The local government staff had set up a goal agreement with Gerda and Luke, which stated that Thomas was entitled to communication options and tools around him. However, Thomas could not participate in the support planning sessions due to the way they had been organised. On several occasions, Luke stressed that Thomas would have not been able to receive a PB in the first place if Gerda had not fought for it: "I am aware that his mother certainly is his best advocate". When I spoke to Luke's supervisor, Bahar, who was also the CEO of the disability service that provided Thomas' living support, she explained that Gerda keeps asking for more individual support. Bahar said that individual support included that Thomas spent time with only one worker and practise typing on his laptop, which their service cannot afford.

> Gerda wanted us to include 'communication' as part of the living support… that's where I needed to put a boundary in place… we do not offer it in the context of supported living… we are not going to cover that, which is part of the day program… documented in the goal agreement… Luke keeps trying to work on it (communication)… but Thomas is very clear that he does not want to practise with Luke. He wants to do it with Robert. (Bahar)

It seemed that Gerda and Bahar were clear about their goals for Thomas' support work. However, the discussions about the organisation of Thomas' support work arrangements, including his goals and activities, were not set up in a way that always allowed Thomas to express his ideas and wishes.

Anja and Laura

The people and the environment

Anja was a 26-year old woman with physical and intellectual disabilities. She lived in a residential facility, named 'Living Together', which started as a parent-led initiative many years ago. The facility accommodated twenty people with disabilities in small apartment studios. At the time I researched with Anja, almost all apartments were occupied.

Anja had dark, short hair and usually a bright smile on her face. She enjoyed wheelchair dancing and playing the harp. She had regular contact with Vera, her legal guardian who had supported her to move out of the previous housing facility and into 'Living Together' about a year ago. Vera had also helped Anja to apply for a PB, which funded the support in her 'new home'. Anja was the only person at 'Living Together' who utilised a PB.

> The building was in a side street and surrounded by a fence. It was three to four levels high and consisted of separate apartments with balconies. Mostly town houses were in the area. You had to pass through two gates and walk along a hallway to get to the main entrance. On the left hand side of the hallway was a large dining hall. The door of the main entrance, like most doors inside the facility, opened and closed automatically. The staff room was on the right hand side straight after the main entrance. People could not enter from outside unless they had a key to it.
> Anja's room was on the second floor. It was spacious and had an en suite bathroom. Her bed had a frame around it. I think Anja could elevate it electronically. There was a shelf next to the bed and a table in the middle of the room next to a sink, which was not part of a kitchenette. It reminded me of a former hospital room. Stuffed animal toys were arranged on a wardrobe next to her bed. Through a large window inside the room, I could see the street I had walked along earlier that day. In front of the window, in the right hand corner of the room was a hoist. (Field notes)

Laura was the 'key worker' (Bezugsbetreuer) of five residents, including Anja. I experienced her as friendly and warm. 'She never seemed rushed', I described her in my field notes. Laura had long, auburn hair and a slim figure. She stressed that Anja was still getting used to the 'new home' as she had more support hours in the previous accommodation. "The challenge sometimes is that I have to teach her that she is responsible for herself – that she needs to look after her own things", she explained. Both women told me that they did not choose to work together, but enjoyed it.

> It was like this straight from the start… when I started working here, my boss Ella (service manager) was here and a male colleague. And I had capacity. That's how it was. My colleague already had enough people he supported and Ella too. And then it was clear that

she (Anja) was going to work with me… also the male colleague was focusing on the male residents. (Laura)

Support work activities and goals

Anja used services from several providers. She had a physiotherapist and an occupational therapist. They came into the facility to work with her. During the week, Anja attended a supported employment program in the same city she was living in. She once explained to me what she was doing there, "I work with cardboard… I fold it together and pile it up until fourteen… because I can count till fourteen". Nursing staff dropped into the facility at least twice a day to assist Anja with toileting, showering and other personal care needs. The nurses sometimes came when Anja was eating inside the dining hall with fellow residents and support staff.

> The nurses came into the dining hall at 6.15pm. It was a woman and a man in their late 20s or early 30s. They were wearing a uniform. The woman said, "May I abduct Anja?" Anja had finished her pizza, but couldn't stay longer and chat after dinner like the others did. It felt as if Anja had been 'pulled out' of the group gatherings very suddenly. (Field notes)

When Anja was picked up by the nurses, she usually smiled and said goodbye to everyone, especially when she knew that she was not going to come back afterwards. However, Anja was sometimes frustrated about certain limitations of the support inside the facility.

> *Debbie:* When do you usually go to bed?
> *Anja*: Well in the evening, after dinner usually. Because sometimes they wake me so early…although I have said before that I do not want to get woken so early.
> *Debbie:* But then they still wake you?
> *Anja:* Yes.
> *Debbie:* Because of breakfast or what are the reasons?
> *Anja*: No, it's just like that.
> *Debbie*: Just like that. Because of the nursing care service?
> *Anja*: Yes.
> *Debbie:* The nursing care service comes at a particular time and then you have to get up?
> *Anja:* Yes.
> *Debbie:* Although you want to continue sleeping?
> *Anja:* Yes, also because it's weekend… on public holidays, I have to get up early too, even though I don't want to.

Laura was aware of Anja's frustration and anger, and elaborated on this organisational issue by connecting it to the different services involved in Anja's life.

> When nursing care comes in, then she has to be inside her room. They are rushing through the whole house and are looking for her. And that is not good. And now I designed a tag and attached it to her bedroom door so that she can just insert the name of the person that she is visiting right now, so that they (nursing service) know where to look for her. (Laura)

From Laura, I learned that Anja had been so frustrated about being woken by the nurses that one morning she threw her breakfast at them. "The problem was that she wanted to chat on the phone and the guy said after twenty minutes waiting that she needs to stop… and she didn't like that... then she threw the cheese bread roll", Laura told me.

Anja had to comply with certain service schedules and set procedures of the service providers involved in her life, which were not always compatible with her preferences and wishes. For example, I found out that Anja was not included in the planning for cooking. The facility had a kitchen service that set up a cooking plan each week. The plan was attached to a bulletin board inside the dining hall. Anja mentioned some of her favourite dishes that kitchen service prepared at times, but stressed that she does not like the Friday meals, as they always include fish. I asked what happened when she does not like a meal and she commented, "Then I just leave it on the plate… and fix myself a sandwich".

I observed several different situations, in which Anja was able to choose from options that Laura offered her during activities; for example, when they went shopping at a supermarket, close to 'Living Together'.

> When we got to the toiletry section, Laura asked Anja what brand she wanted. Anja said "Dove". Laura grabbed three different types of Dove shower gels from the shelf. Anja wouldn't have been able to reach as the Dove shower gels were on the top level of the shelf and Anja was in her wheelchair. Laura opened the lid and handed Anja one at a time, so that she could smell them. Then Anja told Laura which ones she wanted. (Field notes)

Laura had limited the choice to three so that there was a smaller range to choose from. She waited for Anja's reaction by stepping back and giving Anja time to decide what she wanted. I witnessed this another time inside a chemist.

> Laura and I stood next to Anja. Anja was facing the chemist - an older man. Laura stepped to the side and looked at Anja as if she was encouraging her to speak for herself. The chemist spoke to Anja directly and looked at her. He asked how he could help. Anja responded, "Do you have something for a scar?". He asked what scar it was and how old it was. Laura gradually joined the conversation and provided further information about the creams they had in mind. She explained to the pharmacist that the scar was causing pain and it would be ideal to have something that Anja could rub onto her skin. The pharmacist introduced three to four products. He maintained eye contact with Anja while he spoke to

her. More people came into the pharmacy. The queue behind us was getting longer. This did not bother the chemist. He continued giving advice to Anja, speaking in a calm and relaxed way. (Field notes)

In this situation, Laura made space for Anja to talk to the chemist by stepping away and holding back. She gave her an opportunity to speak for herself and engage with someone whom she had not met before. Laura only got involved when the chemist needed more information that Anja could not provide. However, Laura's way of working also included a teaching component.

> We stopped in front of a clothing container. Anja had a plastic bag with clothing items on her lap. Laura helped Anja to tie a slip knot in the plastic bag. She stood beside Anja. Laura asked Anja to pull down the handle of the container. Anja stretched her body. Once she reached the handle and pulled it down, Laura said to her "Now you put your clothing up there". Laura encouraged Anja to push the handle back up. It took some time until Anja had reached the handle to push it up. "Now, it plopped", Laura said after we heard the sound of the plastic bag falling on top of the other bags in inside the container. (Field notes)

Laura provided Anja with a learning space to do things herself. She encouraged her by reassuring her that she had the ability to put the bag inside the container herself.

I saw some of these support work activities reflected in Anja's goals. Her goal agreement had listed four goals. Each goal included an action for its achievement: (1) acquisition of skills relating to the practical arrangements of everyday living/ learning the basics of housekeeping; (2) improving independence through the prevention of hindering her development; (3) participation in community life through the contacts she has with fellow residents and recreational activities within 'Living Together', (4) personal care and support work through the collaboration between nursing staff and staff from 'Living Together'. I witnessed activities and conversations between Anja and Laura, which I associated with Goal 3 and 4. However, the first and second goal were unclear to me. I did not fully understand what 'housekeeping' in the first goal involved, nor did I understand what Anja's 'development' in the second goal included. Laura once explained the following about Anja's development in the context of household activities:

> These are little things... she collects her dirty clothes… she has to bring it downstairs into the laundry. Otherwise no one will wash it. And after one year, she still does not understand… we practise it every week… and I have to continue saying "It is your job, you have to remember it"… she does not do it until someone reminds her. (Laura)

161

It seemed that Laura had been working with Anja towards the goal 'household activities', but Anja seemed to experience difficulties in achieving this goal which frustrated Laura.

Organisation of support work

At 'Living Together', there were five permanent part-time support workers assisting the residents throughout the week. They did not always work on the same days. During the week, they usually started work at midday or in the afternoon and finished around 8pm. However, I saw that staff also worked on weekends. Overnight, there was an on-call service that the residents could call if there was an emergency. Anja's goal agreement indicated that she received twenty-nine professional hours of support and seventeen hours of support within the group. Ella noted that these support hours are meant to cover all 'life domains'. She named the life domains in the interview I conducted with her, but I also saw the 'basic matrix of life domains', as Ella had called it, inside the organisational conception, which was a document I received from her. The domains included 'living, household, budgeting, correspondence with public authorities, employment, leisure, cultural participation, health, social contacts, day structure, mobility, diet, and personal care and hygiene'. I saw Laura, for example, helping Anja with budgeting, picking up medicine at the pharmacy, and going shopping. However, due to the responsibilities of being a key worker to five people, Laura's time was limited in spending it only with Anja, which she also explained in the interview.

> It (being a key worker) means that… you follow up on the funding procedures… that you make doctor's appointments and attend them… talk to the legal guardian... Sometimes we talk about purchasing clothes… transportation… having food etc. we do for everyone... I do not just provide to the people assigned to me. Cause not all key workers are here at the same time. So altogether, I'd say it is more about the administrative affairs. (Laura)

Laura told me that Anja attended the budget planning sessions with her, Vera and government staff, but "we don't really talk about the money. I say to her (Anja), 'we are having a talk again about how you are doing and if you like it here'. It actually hasn't got anything to do with money". When I asked Anja about these planning sessions, she said that she never heard of them and never participated in one. I did not have the impression that Anja was aware of her goals and their meaning for her activities.

Reflections

The findings in this chapter revealed how the German pairs experienced their relationships through the emotional and practical forms of support work. The interactions and feelings expressed within the relationship were influenced by the activities and goals in each setting, which affected how both people participated in the support work relationship. The planning, organisation and doing of the activities were part of the practical form of support work and sometimes influenced the emotional form of support work (e.g. Maria and Yelena experiencing communication struggles during the informal planning activities making them feel frustrated, Thomas withdrawing from activities as he and Luke experience misunderstandings).

The findings also revealed that each budget holder in Germany had a goal agreement that had been set up between people within the environment (but not always the budget holder) and staff from the local government authorities overseeing the spending of the money. This resonates with the literature (e.g. Wacker et al., 2009) and the findings in Chapter IV (see Section 'Support planning'). However, it did not seem that these documented, formal arrangements of support work contributed to both people developing a better understanding of the goals and activities they were expected to do. It was often unclear how these policies were linked to the budget holder's PB (e.g. Laura being Anja's key worker, but also the key worker to other people with disabilities who were not budget holders). This might have been connected to both people's limited involvement in the organisation of support work.

The organisation was usually in the hands of other people (e.g. family members, support staff, flatmates) who had expectations of what the support work should look like. This shaped how both people worked together, the practical form of support work. It sometimes remained unclear if third parties in the environment inquired and asked budget holders about their preferences and interests and whether this was considered during the organisation of the support work. However, in one setting, the budget holder (Lisa) was strongly involved in the organisation of their support work. Lisa did not self-manage her PB, but seemed to take much control over the planning, organisation and implementation of her activities. This seemed related to her own expectations of her relationship with Lydia, but also to the wider support work context, in which she was supported by other people in taking control and accessing information about her PB.

Chapter VII: The experiences of support work relationships within the ruling relations

Introduction

This chapter presents the analysis of how the ten pairs experienced their support work relationships within the ruling relations. It is the last findings chapter of this thesis and builds on the contextual knowledge about support work relationships in Chapter IV and the ethnographic descriptions of the ten relationships in Chapter V and VI.

The analysis presented in this chapter was guided by the research questions and was based in the analytical framework of IE. I first explored the experiences of each person in relation to the other and then connected these relational experiences to the concept of the ruling relation (see Section 'Institutional Ethnography as a social theory' in Chapter III). During this process, I identified that the policies of PBs – that I aimed to identify and unpack through my research questions – are one of three constituents of the ruling relations that can assist in understanding support work relationships. These constituents are the themes that emerged from the analysis. They include the views and expectations of people about the support work relationship, the support work context and the policies of PBs. Each constituent consists of two components which I introduce and explain in this chapter.

As described in Chapter III, transnational institutional ethnographers do not use empirical data to compare a specific phenomenon between countries. They explore diversity across social settings in different countries to gain new insights into people's experiences which was my aim (see Section 'Institutional Ethnography as a method of qualitative inquiry').Working as an institutional ethnographer with the ten pairs helped me to understand the particularity and depth of the relational experiences of support work relationships under the influence of the ruling relations. By analysing each constituent and its components, I present the experiences of the people in support work relationships in Germany and Australia within the ruling relations.

Following the analysis, I combined the data from both countries in the way this chapter is structured, as I found that the constituents of the ruling relations were similar in both national contexts. This understanding evolved as I identified similar sub-themes across both data sets. These sub-themes (language and communication, behaviours, feelings, policies, boundaries and closeness, power and control, attention, interpersonal

164

discovery, time, roles, history and length of time of the relationship, fixed views) emerged as I analysed the three constituents of the ruling relations and their components. They demonstrated the interconnection among people's experiences, the support work context and the policies of PBs and in unravelling the ruling relations across the German and Australian contexts of support work. The theme of power within the support work relationship stood out and became apparent in connection to the role of the ruling relations. The ruling relations in my data were hierarchical and social structures enacted in people's practices, relationships and the policy processes in each setting.

The constituents of the ruling relations: People's experiences, the support work context and the policies of personal budgets

Institutional ethnographers not only seek to understand what the ruling relations are within their local research context and how they influence the experiences of local people, they also examine the interconnection within the ruling relations (e.g. Grace, 2013; Smith, 2001, 2005). The analysis revealed three major constituents of the ruling relations that were interconnected and influenced people's experiences of support work relationships.

Constituent 1: People's views and expectations about the support work relationship

The first constituent was the views and expectations about the two people in the relationship and the views and expectations about the support work relationship that other people in contact with the pair had. In Chapter III, I explained that the institutional ethnographer aims to locate and trace the points of connection among individuals within social settings that are constituted through the hierarchical structure of the ruling relations (see Section 'Institutional Ethnography as a method of qualitative inquiry'). Understanding each pair's relational experiences through the first constituent of the ruling relations helped to identify these points of connection. It added to an understanding of people's positions and roles within their relationships and of how they influenced each other through their relationships.

Views and expectations of the two people within the support work relationship

The first component of the first constituent of the ruling relations emerged by observing and analysing both people's relational behaviours, the language they used when they communicated with each other and the feelings they expressed for the other which seemed to underlie their behaviours and communication. This observational method revealed both people's views and expectations within their relationship and helped me to understand their relationship experiences.

The language both people used in reference to the other and their relationship revealed their views and expectations within the support work relationship. The ten pairs did not use verbal language to classify their relationships as positive or negative, but

described the other, their role or the relationship in the following ways: "different type of relationship" (Jack about his relationship with Samantha), "he is my substitute mother and my day-to-day manager" (Thomas about Luke), "Emma is assistance" (Helene about Emma), "he is a good mate" (William about Lachlan), "he is a good friend and dear to me" (Luke about Thomas), "professional relationship with a bit of fun" (Samantha about her relationship with Jack) or "I try to be a friend" (Maria about her role as Yelena's assistant). These descriptions revealed a range of variations and similarities in people's views and expectations of the other within the support work relationship. The views and expectations of budget holders who did not use verbal language are described later in this section.

The language both people chose also revealed how each person understood the other and how they saw their role within the relationship. For example, Jack often used a teasing tone and language when he worked with Samantha and often referred to her as 'mum' or 'teacher', both authority figures of sorts (see Chapter V). It seemed that he was rebelling against the expectations that Samantha had of him and the tasks he was expected to do with her support. His comments revealed his view of himself and Samantha indicating that he saw himself being placed in a subordinate role in relation to her. Samantha's passion for cooking and her proficiency in this area had influenced her expectations of how her relationship to Jack should work during the cooking activity. Part of this expectation came from Samantha's view of herself as the teacher, which ascribed the role of the learner to Jack. The language they used in these relational views and expectations shaped how both people experienced their relationship with each other.

Language also included withdrawals from interactions. For example, Lachlan sometimes communicated his views and expectations of his relationship with William by withdrawing from conversations and activities with him. I found that Lachlan did not hold or have much of an expectation of William in terms of William involving him in the organisation of support work activities (see Chapter V). 'Not having an expectation' seemed to be some kind of expectation of passivity. Lachlan was introverted and quiet. He never said much, and if he did say something, he only said a few words. This behaviour revealed Lachlan's view and expectation about his relationship to William, which was that William organised and suggested activities and that Lachlan sometimes agreed or disagreed with these suggestions when William asked him about his preferences.

I observed other forms of withdrawal when I researched with Thomas and Jeff, two budget holders with communication support needs. Both men sometimes challenged their workers by walking away from their groups when they were in public places and not 'obeying' certain rules specific to their support work contexts (e.g. not asking people for permission before hugging them) (see Chapter V and VI). While I could see that they sometimes displayed these behaviours because they seemed to dislike an activity or were not overly interested in it, I also observed that budget holders with communication support needs in both countries sometimes seemed to use this action as a way to communicate with their worker. In these moments, when budget holders withdrew from the activity, it initially looked as if they were also withdrawing from the relationship with their worker. However, as a participant observer, I could see that their underlying expectation included a desire to be in contact with their worker, for example, by being acknowledged or recognised through evoking an expression of anger, worry or of being upset – feelings workers expressed when they noticed that the budget holder had separated from the group (see Linda's and Luke's reactions in Chapter V and VI).

In Lachlan and William's relationship, gendered language was used to describe their relational experiences and the feelings involved in these experiences. This language revealed their views and expectations of each other. In Chapter V, I explained that I rarely saw Lachlan and William hugging, but that it occasionally happened when Lachlan completed a support work activity, such as lifting weights inside the gym. Sometimes, it seemed that Lachlan sought this type of physical affection which William reciprocated. In this instance, the affection occurred in response to the practical form of support work – the fulfillment of the tasks related to the support work activity. I also witnessed moments, in which William initiated the expression of emotions through physical contact. This expression seemed connected to his image and interpretation of 'mateship' (invoking an Australian concept of friendship between men) which his language revealed.

Debbie: What would you do if Lachlan, for example, said to you 'I love you'. Would you then say, 'I love you' back? Or how would you react?
William: Probably 'That's nice mate, but I am a man', you know.
Debbie: Ah okay. But the hugging was fine?
William: Yes, that's acceptable, because I cleared that with the family. And I said, 'Look, where do I stand with this?'
Debbie: So you asked them for advice?
William: Yes, I said, look, it's different and you probably know yourself when there is that real strong emotional need for contact. It's different here, it's more like a gentle 'Thank you' through that contact… we would have a group hug, but it's manly. There is not really

much sensitivity or anything like that. It's that male bonding.

William held a specific view about how two men should be and act in a support work relationship, which was sometimes reflected in his Australian slang. His interpretation of how 'mates' should ideally express affection for one another influenced the experiences of the support work relationship. Anette, a service professional in Germany, had pointed out that male support workers might be seen as a 'buddies' by men with intellectual disabilities, but she did not explain why (see Section 'Service involvement in the 'togetherness'' in Chapter IV). The ethnographic fieldwork with Lachlan and William revealed that language was connected to a cultural representation of 'mateship'. It affected how two men, Lachlan and William, expressed affection in their relationship within the Australian context of support work.

Both people in the support work relationship expressed their feelings through language in the context of empathy which happened when they were capable of tuning into the other's emotional states. When this happened, it seemed that they imparted the feeling to the other that they understood what was going on for them. It seemed like a form of recognition and acknowledgement. For example, Felix used non-verbal communication cues showing that he empathised with Michael (e.g. giving him a kiss on the forehead and engaging in a close, long eye contact) (see Chapter V). In turn, Michael told me that he acknowledged and reciprocated Felix's concern and regard for his wellbeing.

> Years ago I broke up with my girlfriend and I was really, really upset and he (Felix) knew. Straight away he was saying her name and looking at me and hugging me more. I had always talked to him about the things I was going through with her. And when I got in the car I was very sad and had some tears in my eyes and said, "We broke up". He really knows what's going on. I think that is something I really like about him. (Michael)

Through this experience, Michael learned about Felix's capability of being an empathetic person. This influenced his view of Felix – a person with intellectual disabilities showing empathy who did not rely on verbal language to express this feeling of care for him. A similar experience became apparent during the fieldwork in Germany. Luke recalled a situation when he was receptive to the comfort that Thomas gave him.

> He wears his heart on his sleeve. I value that. He is capable of being empathetic… I was once going through a rough stage where my family was unwell... and he was great. Thomas wasn't so well either at the time… but I perceived him as very understanding during that

time. He understood where I was coming from. I really appreciated that. (Luke)

Thomas was able to share feelings when Luke was open to Thomas' way of communicating and had made the time and effort to understand him. It required both person's openness toward each other's feelings to experience empathy.

The different forms of how people – especially people with communication support needs – emotionally communicated in the relationship provided insights into the interdependence of the views and expectations that the two people had of each other. For example, Yelena's dependency on Maria and the vulnerability she expressed seemed to be influenced by her disabilities and the policies affecting her support work. Yelena had intellectual disabilities, but experienced additional disabilities, such as physical restrictions and complex communication needs. Yelena relied on Maria's support in very intimate areas of her everyday life (e.g. when she ate and drank or needed to use the bathroom) which made her dependent on Maria. However, Yelena was used to having a range of different assistants around who helped her in intimate areas. I could not observe that Yelena felt uncomfortable receiving this support. She made it clear that she wanted to get through her activities as soon as possible so that she could spend more time with her boyfriend (see Chapter VI). The practical form of support work, the performance and responsibility to accomplish the activities, often seemed to drive Yelena's actions. In this context, Maria told me that Yelena was busy with the organisation of her life and seemed self-absorbed which Maria appreciated. However, Maria did reveal a subtle disappointment about Yelena seeing her mainly as an assistant rather than a true friend. In turn, Yelena did not seem to expect Maria to be her friend due to the support work she was providing. This relationship example shows that friendship was not a necessary condition for a workable support relationship.

The views and expectations that the two people had of each other were formed and revealed by the language they used in their interactions, the emotional form of support work. However, it seemed that these interactions were also influenced by other factors, such as their personal interpretation of the relationship or their reciprocal feelings.

Views and expectations of the people in contact with the pair
The first constituent of the ruling relations further included the views and expectations of third parties. Third parties were the parents or flat-mates of budget holders, as well as

specific support staff (e.g. speech therapist, support worker's supervisor) who were in contact with the pair. Third parties held certain views and expectations which were shaped by the policies that were 'running' through each support work setting and that affected the experiences of the two people in the relationship.

The data showed that there was a flow in how expectations of third parties were imposed upon the two people in the relationship. Expectations usually came from people at a higher hierarchical level within the setting and were passed down to the people located below them within the hierarchical order. This flow seemed related to the policies that third parties embodied. For example, the supervisor of the support worker within a group setting had embodied policy expectations which had been passed to them by their supervisor. For example, Bridget was Linda's supervisor and the team leader of Jeff's day centre (see Chapter V). She held certain expectations about the relationship between Jeff and Linda, which sometimes led her to monitor it.

> Linda asked Jeff whether he wanted to use the iPad. He confirmed. They got the iPad from the staff room. Linda explained that the speech therapist suggested to Jeff's mum that he should use 'touch chat' on the iPad. Jeff touched a couple of icons on the App, then withdrew from the activity and watched 'Bananas in Pyjamas'. Bridget came into the TV room and said "You should be watching the trains, Jeff". She continued asking him to use the 'train app'. Jeff said "Noooh". His voice was loud and firm. (Field notes)

The situation described in these field notes shows that Linda was expected to do an activity with Jeff which was directed towards Jeff's goal of using 'touch chat' to improve his communication, as listed in his PCP (see Chapter V). This is how Bridget saw the relationship between Jeff and Linda in this moment. Her presence imposed the expectation that they should be doing something specific, which was related to the practical form of support work. However, this expectation had also been created by Linda, Jeff's mother and his speech therapist. This affected Linda's relationship with Jeff as she was expected to engage him in specific activities related to his goals. Linda's focus on Bridget's expectations made her less able to respond to the needs and interests that Jeff expressed. This example shows that the supervision process involved Bridget and Linda, but had an effect on the relationship between Jeff and Linda.

In Chapter IV, the service professionals in Germany discussed supervision with reference to support workers – budget holders did not seem included in these processes (see Section 'Supervision and the support work relationship'). The analysis revealed that support workers were more involved in discussions about these expectations than budget

holders. The Australian context of support work, in which Jeff's and Linda's relationship developed served in understanding that. Supervision as a policy process was linked to certain expectations about how and what type of support work goals were supposed to be achieved by the two people within the given time and the policy expectations specific to the support setting.

The hierarchical flow (from the top down to the bottom) of policy processes was part of the aspect of 'ruling' within the ruling relations. This aspect was a dominant force that came from the top and affected the experiences of people. Due to this element, the ruling relations had run through people's everyday activities (Smith, 1987; 1996) and often seemed to rush support workers and affected how they allocated their time to budget holders. This rush influenced both people's experiences within their relationship in powerful ways. This force had certain implications for budget holders and their workers. It subordinated them to the expectations of people who were in more powerful positions and located at a higher level within the hierarchical and dominating structure of the ruling relations.

This structure formed part of how the places, in which the pairs worked, were organised. It made budget holders, in particular, adjust to the rules and regulations within their local support systems, as raised in previous research (e.g. Fisher, Lutz, Gadow, Robinson, & Gendera, 2015; Trescher, 2017). However, one of the central goals of the PB is to use the money in a way that personalises support to enable choice, increase independence for budget holders and empower them in exercising control over their support arrangements (see Section 'Support work relationships in the context of personal budgets' in Chapter II), which did not seem to have a strong influence on third parties' views and expectations of the support work relationship. They were much more influenced by their own agendas and the policies operating within the specific support work setting of the budget holder. This became evident in the relationship between Lachlan and William. As mentioned earlier, William's image of his relationship to Lachlan determined, to some extent, what the relationship was and how it was experienced. However, his views on mateship and how two mates should work together was influenced by Catherine's (Lachlan's mum) views of support work and her expectations of William in the relationship to her son and his role as Lachlan's support worker. Catherine drove the ruling relations in this setting, to a large extent, and William viewed her as his 'employer', not Lachlan (see Chapter V). The support worker's focus

on the parent rather than the budget holder was evident in the German and Australian contexts of support work.

In Germany, for example, I observed the worker's strong focus on the parent in the relationship between Helene and Emma. Their relationship was shaped by Kerstin's (Helene's mum) view and expectations. Helene held the expectation of being able to make her own decisions and to be treated like an adult instead of a child. "The adults always know it better" Emma once said when she explained that she thinks that this is how Helene sees her and Kerstin. Each time, Helene experienced that Emma did not view her as an adult, she expressed her reaction by showing feelings of anger, frustration, sadness and disappointment (see Chapter VI). Emma's view of what support work was meant to look like in practice was strongly influenced by Kerstin's expectations of how Emma was meant to work with Helene. Kerstin had planned the activities that Emma and Helene did together. Emma usually followed Kerstin's instructions rather than Helene's wishes concerning the support work and then made decisions for Helene. That people with intellectual disabilities experience difficulties in making decisions about their support work due to other people in their local environments making decisions for them has been discussed in the literature (e.g. Beadle-Brown, 2015; Bigby, Douglas, & Carney et al., 2017; Bigby, Whiteside, & Douglas, 2017; Rood, Kanter, & Causton, 2015). However, Helene wanted to feel empowered and be in charge of the organisation of her activities which did not happen. That she felt frustrated about this was due to the expectations that Kerstin had imposed on Emma and Emma imposed on her. Emma and Kerstin governed how Helene's support work was implemented in practice and the extent to which this made her feel like being a budget holder who was viewed as a woman with agency and the capacity to exercise power or not. This example brings the tension between the expectations of being a budget holder and the powerful influence of the views of third parties to the surface. It demonstrates the implications for the relationship between Helene and Emma, which included the tension between them caused by the fact that Kerstin held a specific view of how both women were meant to be in relationship with each other.

While recognising that expectations were usually transferred through the hierarchical order of the ruling relations, I also found exceptions to this structure. The relationship between Maria and Yelena, for example, showed that Yelena had a strong desire to pick up the rings for her boyfriend and her (see Chapter VI). Many times she inquired whether this could be done during the assistance time she had with Maria. Maria

said that she was not supposed to do this activity with Yelena during her work hours. However, by speaking to Barbara (Maria's supervisor), I learned that this was certainly an activity that Maria could have done with Yelena. Yelena's desire about the rings remained unanswered during the time I spent with the two women. In this case, the views and expectations of Barbara were not imposed upon Maria – they were not transported through the ruling relations. Maria had stopped the hierarchical flow of the ruling relations and changed it based on her interests which were related to her views and expectations of Yelena and her own role within this relationship. In this case, the worker used their power to follow their personal preferences.

In Chapter IV, I discussed that some German service professionals referred to the budget holder as 'customer' and associated this term with a marketised disability service sector, which was also raised in the Section 'Australian context of personal budgets' in Chapter II. The German service professionals had stressed the powerful role of the customer, but none of them said that this was an active role, in which power was exercised, for example, by taking the initiative to negotiate and make decisions about the planning of activities (see Section 'Is the customer king? Power, dependence and roles' in Chapter IV). They did not consider the budget holder as an initiator and active negotiator in the context of making decisions about their support, which is a consideration that the PB should promote. The rhetoric of service professionals disguised how the budget holder's role was filled within the relationship and what this meant for the support worker's role. For example, on several occasions, I heard Molly, the team leader of the group home in which Elsa lived, referring to Elsa and her house mates as 'clients' and 'customers' in their presence and to the support workers as 'staff'. In the interview, she referred to the support work service as 'a bargain', which connected Elsa and Elizabeth. She stressed the necessity of boundaries in the context of this bargain and predicted that Elizabeth was not doing her job well and Elsa was "not keeping up the end of her bargain" if these boundaries were not maintained.

Molly's language revealed that the dichotomy between 'staff' and 'client' was part of a larger policy discourse specific to this group home that influenced how Elsa and Elizabeth were supposed to see, refer to and work with each other. I noticed that Molly's verbally stated policies were sometimes adopted by Elsa and Elizabeth. Elsa, for example, referred to herself as 'client' and to Elizabeth as 'carer'. She explained that she prefers the term 'carer' and rejects the term 'support worker' because the word 'carer' is

"professional talk". Elsa was clear that Elizabeth was not her friend, but said that Rosa and Gwen (Elsa's house mates) were her friends. While Elizabeth did not say much, I observed that she referred to Elsa and her house mates as 'girls', but not 'women'. The language in this group home was shaping the picture that Elsa and Elizabeth had of themselves and the relational other. Molly's views partially influenced how Elsa and Elisabeth experienced their relationship.

The second component of the first constituent of the ruling relations showed that the views and expectations of third parties about the support work relationship had strong potential to influence both people's relationship experiences. The ways in which they were influenced was related to how support work was set up in the German and Australian contexts of support work. This influence came from the hierarchical flow and structure that transported expectations across people in a setting and affected the realisation of the person with intellectual disabilities' rights as a budget holder, which included exercising control over their support work arrangements.

Constituent 2: The support work context

The conditions and set up of support work within each context had a strong influence on the way people experienced their relationship. This 'set up' often seemed connected to the policies and practices specific to the support work context, in which the pair worked. It included whether support work was a group arrangement or based on one-on-one support and it also involved specific rules and regulations in each setting.

Group arrangement and one-on-one support

The educational and moral philosopher John Vorhaus (2015) discussed the causes for a lack of respect for the dignity of people with intellectual disabilities. He saw them coming from other people's lack of attention and care towards people with intellectual disabilities, but also from living environments 'characterised by the imposition of routines found to be mundane and uncongenial' (Vorhaus, 2015, p. 474). This study provides support for Vorhaus' argument as the worker's care and attention for the budget holder were influenced by the way support work had been set up in each ethnographic environment. It influenced the development of the emotional and practical forms of support work. Each support setting was a specific context with its own support work rules and practices that

impacted on situations in which the relationship could evolve. It was often the living environment of budget holders, but the work environment of workers and the arrangements of support work within these environments affected both person's lived experiences (see Section 'Context of the support work relationship' in Chapter II). While the service professionals in Germany had touched on some interesting issues in reference to these environments when they spoke about one of the two people in the relationship (e.g. the support worker has to be particularly respectful and sensitive when they work in someone's private home) (see Section 'Understanding the self and the other through reflection: qualities of support workers' in Chapter IV), they did not specify what these environments mean for the experiences of both people in the relationship.

The service professionals in Australia stated that the 'centre-based models' of PBs promoted support work within group arrangements. They explained that this practice does not necessarily increase choice for budget holders as support work organised through this model is less personalised (see Section 'PBs and having choice' in Chapter IV). By researching with Jeff and Linda, I learned that the worker's attention for the budget holder was at risk of being compromised when the budget holder had to 'share' their worker with others. In group settings, such as shared accommodation or day programs, the time both people had together was often compromised by the number of people, with whom the support worker was expected to work. This sometimes led to situations in which the support worker could not respond to the budget holder's expressed need in an appropriate way. Many times, I saw Linda and Jeff in these situations.

> Before we (Jeff, his group members, Linda, another support worker and I) left the shop, Jeff grabbed a package of sausages and showed them to Linda. He held them up and wanted to put them inside the shopping basket that Linda carried. She briefly looked at Jeff and said "No, not today Jeff – pumpkin soup". (Field notes)

Linda's response in this situation seemed related to her experiencing difficulties in attending to several program participants at the same time inside the shop. She then sometimes imposed her own expectations upon Jeff rather than trying to understand and open up to his expectation which was connected to the first component of the first constituent of the ruling relations, views and expectations of the two people. When Jeff and Linda left the day centre, Jeff's group members always came too. Attending to several people at the same time was described by Linda as a feeling of 'splitting herself into ten pieces' (see Chapter V). These expectations came from work conditions specific to Jeff's

day program where people experienced staffing issues. These issues within the support work context limited Linda's capacity to attend to Jeff, tune into his emotional states and understand what was going on for him in specific moments. This capacity facilitated the emotional interactions between the two and was influenced by support work being delivered as part of a group arrangement.

In Germany, group arrangements also introduced a risk of not considering the overarching goals of PBs (e.g. the budget holder exercises control over support work activities that they wish to do), for example, by not involving the person with intellectual disabilities in the organisation, planning and implementation of support work. It created a risk of excluding the budget holder from decisions about their support, which often occurred when the budget holder had communication support needs. In order to address the needs of the budget holder and to hear them, the worker needed to make time and only dedicate their attention to the budget holder – time which they rarely had, especially when they worked in group settings. The quality of time involved the time each person only dedicated to the other – the 'one-on-one', as Elsa had called it (see Chapter V). The quality of time was compromised by regulations specific to the support work context which included group or one-on-one support arrangements. For example, Laura expressed that she had limited time with Anja as she was often expected to work with other clients at the same time she worked with Anja inside the housing facility.

> When you're alone with someone, you have more time for that person. You can be more dedicated to the person, compared to being around five people. And so here in the house (refers to facility) this sometimes gets lost, because all the others want something too. And then you have to back off and go into the residential apartments and close the door. (Laura)

Laura associated 'time' with her capability of dedicating herself to Anja. Anja shared similar observations of their relationship. She said that "when she (Laura) is at the computer, she has no time" due to "work stress" which meant that Laura was inside the staff room and could then not be physically close to Anja. Throughout the time I spent with Anja, she never said that it bothered her when she and Laura were surrounded by other people. However, if Anja had never experienced this any other way, then this might have led her to accept the situation as it was.

I observed that both women focused on each other when they had time together, which was occasionally when they were alone together in Anja's apartment or when they

had left the residential facility in which Anja lived. Sometimes, this also happened during afternoon tea when the other residents were present.

> Anja ate cookies. She was holding hands with Laura. Laura sat next to her at the dining table. It wasn't a firm, but rather a gentle and affectionate type of hand-holding. Laura and Anja sat closely next to each other until afternoon tea was over. (Field notes)

Working within this group arrangement did not prevent Anja and Laura from occasionally spending time together and showing affection for each other. However, Anja as a budget holder was not privileged over her fellow residents (who did not use PBs) in the way her support work was delivered. I could not find a significant difference in how her support work was set up compared to the other residents or see this difference impacting on how Laura and Anja worked together. However, budget holders in group settings were often available to engage with their workers, but not vice versa.

The issue revolving around one-on-one support had potential to facilitate the emotional and practical forms of support work (i.e. how both people related to each other as they engaged in the activity). I observed this in the relationship between Yelena and Maria, for example. When they spent one-on-one time together, they usually had more opportunities to focus on and engage with each other during an activity.

> Maria sat down next to Yelena on a little stool. She looked her in the eyes and smiled at her. It was a focused, lasting look. Yelena burped. Maria laughed. She looked at her gently. Yelena engaged in the eye contact. She was still and focused on Maria's face. (Field notes)

In these field notes, Yelena sensitively acknowledged Maria's presence through long, intimate eye contact. I witnessed several non-verbal interchanges like these between both women. When they occurred, both women had a subtle smile on their face. It looked like a mindful and gentle gesture, during which they gave recognition to each other and non-verbally exchanged a form of appreciation of the other's company. The fact that Yelena received one-on-one support through Maria in a one-on-one setting seemed to facilitate the fact that both women could occasionally share these intimate moments.

Communication required more time when a budget holder did not use much verbal language to express what they desired. Here, both people had to be willing and open to work through misunderstandings to get to know each other better, which Maria and Yelena did. This was sometimes an opportunity for an 'interpersonal discovery'.

> Yelena was eating very fast. Maria asked her, "Are you rushing because you want to go for a walk?". Yelena smiled at her. Maria then told me that Yelena did not want to eat one day in the past, but was terribly hungry by the time they got back from the walk. Maria said that she then realised that Yelena did not eat because she was concerned that there was less time for a stroll. (Field notes)

Through reflection on this misunderstanding, Maria was able to learn more about Yelena's interests. She learned that Yelena enjoyed spending time outside more than inside. The initial challenge of not knowing what Yelena wanted was important in finding out more about Yelena. Both women had to occasionally deal with frustrated and helpless feelings, but these 'struggles' provided an avenue for further exploration and negotiations, for example, by resolving them. Working through misunderstandings was part of the two women experiencing each other. It was part of creating a history of their relationship, which helped each of them understand the other person's situation. This was facilitated by the condition that Yelena received one-on-one support from Maria and that Maria took the time to work through misunderstandings with Yelena as her support worker.

Reflections on misunderstandings served as interpersonal discoveries that helped both people in becoming familiar with and learning about each other. Although this occasionally created tensions in their relationships, it gave both people the opportunity to get to know each other on a more intimate level. This could happen when both people took time to open up to each other which was influenced by whether they worked within group arrangement or had one-on-one time together.

Rules and regulations specific to the setting

The rules and regulations in each environment were shown in the practices of its local people and how the pair engaged in support work activities. It was not always clear who set the rules and regulations specific to the setting and where they had come from, but they were usually based on organisational policies (see Appendix G), such as the 'person-centred policies' in Jeff's setting (see Chapter V). Every day program participant had a PCP, including the ones who did not have a PB. What was special about the rules at Jeff's day program was that they influenced Jeff's and Linda's relationship to a great extent. These rules incorporated the 'rotation policies' (i.e. support workers rotate across the day program participant groups) and the 'no-touching policies' (i.e. support workers and day program participants should not touch each other). The 'rotation policies', for example,

were aimed at increasing people's flexibility to adjust to working with different people and to stop people from becoming too attached to and dependent on each other (see Chapter V). This was also a point that Moira, an Australian service professional, had raised who explained that introducing new workers to people with disabilities on a regular basis helped to avoid mutual dependency, but especially the person with intellectual disabilities' dependency on their worker (see Section 'Boundaries in support work relationships' in Chapter IV). This had an effect on how Jeff and Linda physically and emotionally expressed their experiences within the relationship. This expression seemed controlled by the worker due to Linda's awareness of how much physical closeness she was allowed to admit. "The policy says basically, no touching at all… but if you would work like that, then you would not show any heart, I don't think anybody would like that either", Linda explained to me in the interview. How these 'no-touching policies' were translated into practice became more apparent in a situation, in which Jeff hugged me in Bridget's presence, the supervisor of Linda.

> Jeff and I stood next to each other. Bridget stood close by. Jeff walked over and hugged Bridget. Bridget didn't seem to mind the hug. After a few seconds, she said "No". It was a delayed response. Then Jeff hugged me briefly. Bridget said to me "Don't let him hug you". I asked her what I was meant to do. She said "You need to step back and say 'personal space'". I said "Ah, ok, this was the first time he did it". Bridget responded "Yeah, it's weird, he is very happy today". She had an irritated look on her face. (Field notes)

In this situation, it felt wrong not to reciprocate Jeff's hug, to step back and follow the procedure that Bridget had recommended. Jeff seemed happy and not as if he were trying to hurt me. Bridget was watching how Linda was socialising with Jeff and this influenced their relationship. It influenced the fact that Jeff's request to make contact with Linda was often dismissed. Linda's awareness of policies concerning physical closeness had been shaped by third parties monitoring the relationship. While these 'restrictions' seemed relevant in terms of protecting the support worker's (rather than the budget holder's) personal boundaries, they sometimes limited opportunities for budget holders to express their feelings for their workers physically, which was particularly important when they experienced communication support needs.

By connecting this finding to the 'ruling relations' that are based on power and hierarchical structures within social settings (Smith, 2001), it becomes clearer that the ruling relations had the effect of surveillance on the people who worked and lived in each support work setting (Walby, 2005). It seemed that the ruling relations were what was

behind the 'we' that the service professionals from both countries identified with when they spoke in first person plural about the policy procedures of their services (see Section 'Conclusion' in Chapter IV). The ruling relations determined the specific rules and regulations within each setting and formed part of the policies specific to the support work context rather than to policies that were connected to the PB that operated in a setting.

The literature highlighted that 'boundary crossing' can happen on both sides when one's dependency on the other comes to the surface and one's own vulnerabilities are exposed (e.g. Franz, 2015; Guldvik, 2014; Kelly, 2011; Rogers, 2009; Shakespeare, 2014a, 2018), such as in moments, in which people rely on support in very intimate areas of their lives. The Australian service professionals in Chapter IV gave examples of what 'boundary crossing' is in practice (e.g. being Facebook friends, the worker taking the person with disabilities to the former's private home). They cautioned that by crossing these boundaries both people could potentially build an affectionate rapport or a closer friendship. Yet, the EoC, which theorises and analyses the rewards that both people receive through an interdependent and caring relationship (e.g. Kittay, 2001, 2002, 2009a, 2009b, 2011), indicates that policy procedures aimed at preventing boundary crossing and the development of mutual dependence can be challenged, as interdependence also has potential to facilitate caring relationships based on empathy (Slote, 2007; Walmsley, 1993). It seems that the expressed caution of service professionals was related to a concern that the practical form of support work could be compromised if both people developed a strong emotional connection. While this concern indicated potential to protect people's boundaries, it needs to be balanced with the emotional form of support work, as the analysis showed that being engaged with the other also affected the engagement in and the completion of the support work activities, the practical form of support work.

The functions and implications of boundaries have more often been discussed in the context of support relationships that include persons with physical disabilities (Kelly, 2013, 2016; Kulick & Rydström, 2015) rather than intellectual disabilities. This study's findings showed that the 'interpersonal discoveries', in which both people get insights into the dependency on the other and into each other's vulnerabilities and capabilities, is also dependent on the budget holder's impairments and needs related to their disabilities. However, the rules and regulations specific to the environment sometimes prevented these 'interpersonal discoveries' from evolving. I could see this in the relationship

between Linda and Jeff and the relationship between Yelena and Maria, for example, where the two support workers worked with budget holders who mostly relied on non-verbal ways of communication. Getting to know the other in the relationship happened over time, by resolving misunderstandings and finding out about the other person's overall interests, which included other areas of life, outside support work. However, the 'rotation policies' in Jeff's day centre – which were specific to the Australian context of support work – affected the relationship between him and Linda in that it stopped the two from developing this deeper and broader understanding of each other.

In Chapter IV, the service professionals in both countries raised the issue that 'increased independence' through the acquisition of ILS was a major goal of support work (see Sections 'The goals of support work' and 'The 'doing with' approach and the goals of support work'). This included 'becoming independent' from the worker. Increased independence, however, did not appear to be the central idea behind the rules and regulations specific to the support work settings, in which I worked as an ethnographer. The findings do not corroborate the importance of ILS to the support work relationships in the context of a PB. While I could sometimes see that the worker's approach facilitated that the budget holder engaged in activities more independently (e.g. when Lydia supported Lisa in finding the right ingredients for the pizza inside the supermarket, see Chapter VI), the development of ILS did not seem to be the goal of support work. It often seemed more important that the budget holder had someone on their side when they did the activity. Yet, the rules and regulations specific to each setting influenced whether the support worker adopted an approach that allowed them to share or shift at least some power to the budget holder. Occasionally, this encouraged levels of decision-making for the budget holder and contributed to their independence.

The analysis of the second constituent of the ruling relations revealed that the support work environment set certain conditions that shaped the relationship experiences in terms of the closeness people could develop. These conditions included the rules and regulations specific to the environment and whether budget holders received support as part of a group arrangement or through a one-on-one approach. These conditions specific to the environment came from the policy practices and processes that set a certain direction and guideline for how to behave in a support work relationship.

Constituent 3: The policies of personal budgets

The analysis revealed that the third constituent of the ruling relations was the policies of PBs. The first component of the third constituent concerned the aspect of 'self-management' within the policies of PBs. This component seemed important in understanding support work relationships as it related to how power was shared between people, including the people in contact with the pair. How power was shared and accessed was linked to the level of understanding both people had about support work organised through the PB, as well as the activities and goals associated with the type of funding. Exercising power and control through an awareness of the policies of PBs constituted the second component of the third constituent of the ruling relations.

The aspect of 'self-management' within the policies of personal budgets

In Chapter II, I explained that a PB can be self-managed when it is administered as a direct payment (see Section 'Support work relationships in the context of personal budgets'). In this arrangement, budget holders should have power and control over the management of the PB as they can pay their support worker directly from their budget and employ them which implies that the budget holder should have some understanding about how the money from their PB is used (see also the Employer Model in Section 'German context of personal budgets' in Chapter II). This understanding for budget holders with intellectual disabilities, in particular, is intended to be facilitated by support from support workers or third parties.

   In this study, a service provider involved in the delivery of the support work, third parties or even the support worker usually had more control over the organisation of the support work than the budget holder, if the PB was not administered as a self-managed PB. If the 'self-management' aspect applied, then most budget holders in Germany and Australia were not fully in control of the management of their PBs either. Many conversations about support work were not held with the budget holders, but rather about them with others (see Chapter V and VI). Parents, for example, often managed the PB for their daughter/ son if the aspect of 'self-management' applied. While I observed that they considered their daughter's/ son's preferences and acted on them as they organised the support work, most conversations about the organisation of support work were not inclusive of budget holders, particularly not of those with communication support needs. I became especially sensitive to this issue during the ethnographic fieldwork in Germany.

For example, Helene received a 'self-managed' PB, but the informal planning conversations about it occurred between Emma and Kerstin. From Emma's perspective, this was partly due to Helene not being able to follow the conversations between her and Kerstin. Helene's goal – becoming independent from mother (as stated in her goal agreement, see Chapter VI) – organised through her PB was even harder for her to achieve if Emma and Kerstin did not shift some control to her by letting her decide about her activities. Helene's limited involvement in conversations about her support work seemed connected to the views and expectations that Emma and Kerstin had of Helene as a budget holder with intellectual disabilities.

Not participating in planning conversations applied to people who did not have a self-managed PB as well as to people who had one. For example, in Chapter VI, Luke pointed out that Thomas did not want to take part in the annual budget planning meetings because he could not respond to the questions that he was being asked. These meetings had not been set up in a manner that considered Thomas' communication needs. However, Luke explicitly stated that Thomas understands everything. Thomas' disability did not imply that he could not comprehend what other people said about him (e.g. Thomas' vote in the election stressed that Thomas had a very good understanding of the things happening around him, see Chapter VI). This resonated with my experience of Thomas. In the interview with Thomas, I adjusted to his communication needs and opened up to his way of communicating, for example, by taking time and talking to him about his poems. While doing this, I witnessed that Thomas had a profound understanding of what other people said, but that he did not respond in a way others were accustomed to. This point relates to the first constituent of the ruling relations as staff from the local authority granting the funds of Thomas' PB had an expectation of Thomas which he could not fulfil due to his impairments caused by his intellectual disabilities. Luke was aware that this upset Thomas, but he was not able to change this policy procedure related to how Thomas' PB was governed. While Luke or Gerda might have advocated for Thomas in these formal meetings and considered his preferences, Thomas' agency as a budget holder was sometimes compromised when it came to decisions regarding his support work.

Although Thomas' PB was not self-managed, it did intend – according to his goal agreement – to support him in living a life with more independence by providing him with communication options in his everyday life (see Chapter VI). This example demonstrates that the ruling relations (which the local authority regulating and granting

Thomas' PB was part of) had an expectation of what the support work relationship was supposed to achieve through the policies specific to Thomas' PB, but at the same time prevented the two men from making this happen. It sometimes took the opportunity from Thomas to experience moments with Luke in which his dignity was respected by being able to express how he wished his support to be organised through his PB.

The data showed that budget holders who received one-on-one support (i.e. the support worker did not work with several people at the same time as they did with the budget holder) were usually the ones who were part of a setting in which a 'self-managed' PB operated. However, the decisions on how activities were implemented and what goals the person was supposed to pursue with their support workers were usually made by others. These were family members of budget holders who sometimes consulted the support worker, but not always the budget holder. For example, Felix had two self-managed PBs which were managed by his mother (see Chapter V). She influenced how and what kind of activities Michael did with Felix. I witnessed Felix quickly disengaging in the activities he did with Michael. I could see that Michael put in much effort to get Felix's attention back to the activity when this happened. He was focused on the goals and often told me about the progress he had achieved with Felix. 'Progress' for Michael meant keeping Felix engaged in an activity for as long as possible: "When he was able to swim… two laps of the pool, that feeling of coming home to Margaret and Victor (Felix's parents) and saying he swam two laps… we were so happy". He often referred to the expectations of Felix's parents when he spoke about Felix's goals and achievements, which relates to the first constituent of the ruling relations. To Michael, it was important that they were met, but it remained unclear whether Felix perceived the achievement of goals as success. To Felix, it mattered whether he had fun with the person he was doing the activity with. When Felix experienced this joy with Michael, he was able to show him that he valued his presence, for example, by giving him a kiss on the forehead (see Chapter V).

This example shows that people who had a self-managed PB were sometimes viewed as people lacking capacity to be fully involved in the management of their funding with adequate supports. However, this was also the case among budget holders who did not receive a self-managed PB. Since there was a limitation of time to each support work relationship in nurturing itself through moments of mutual attention and enjoyment, the policies of PBs provided limited opportunities to explore when and how budget holders

could develop the capacity to manage their own PB with adequate supports and act in the role of a self-manager. This point relates to the issues raised about the German and Australian disability service systems in not adequately responding to the individual needs of budget holders with intellectual disabilities in Chapter II (see Sections 'German context of personal budgets' and 'Australian context of personal budgets'). This study showed that each support setting, which was part of a larger disability service system, rarely facilitated a style of support that provided opportunities for budget holders to develop this capacity. However, the PB showed potential to either constrain or facilitate the time that the two people in the support work relationship shared and this was influenced by whether they received a self-managed PB or not.

The analysis further revealed that it was important that the worker understood the budget holder's priorities and how they wanted to spend their time during support work. This was part of the support giver role and supposed to help the person with intellectual disabilities to become a 'budget holder' or 'budget owner' instead of taking the role of a 'passive budget recipient'. The analysis revealed that budget holders were expected to be understanding towards their worker if their own wishes were not answered by their worker (e.g. Yelena having to accept that Maria did not collect the rings with her, see Chapter VI). Although the support work organised through a PB should be set up in a way that responds to the personal needs and wishes of budget holders, it was the relationship itself that helped both people in working together. This expected budget holders to consider the priorities of their workers also and applied to budget holders in self-managed as well as in not self-managed settings.

Kelly's (2016) observations coming from her research on direct payment and care work in Canada seem relevant in discussing the complexity of being a self-manager. She found that people with intellectual and physical disabilities using direct payments (self-managers) were active recipients of support because they cared about their support workers through their 'empathetic interpersonal skills' (Kelly, 2016, p. 85). In my study, budget holders (including the ones with high communication support needs) from both countries were capable of showing concern, regard and care for their workers. Across the ten settings, I continued to witness moments, in which they were sensitive towards their worker, especially when they felt that their worker was unwell. However, only one budget holder (Lisa) in this study acted in the role of a 'self-manager' in that she took control over the planning of her support work, but she did not identify as a self-manager. It

seemed that Lisa's sensitivity towards Lydia was sometimes compromised due to Lisa's strong initiative in trying to direct her support work (see Chapter VI). Lisa's experience of taking this initiative required Lydia to understand Lisa's role as a budget holder and her own role as Lisa's assistant, which did not always seem to be an easy experience for Lydia. Lydia was very critical of her relationship to Lisa.

> I am convinced that all people with disabilities are selfish... and that they have to be because they have a limitation. And this comes through with all of them. And it is very difficult to teach them empathy… I can see that with Lisa very clearly. When I tell her something… it does not interest her. Her own persona is the centre of attention. (Lydia)

Over the time I researched with Lydia and Lisa, I gradually learned that Lydia perceived Lisa as a person who was very focused on her own needs and interests. I had experienced Lisa as confident and blunt, but I also witnessed that Lisa showed Lydia that she was fond of her (see Chapter VI). Lisa could articulate her wishes and seemed more likely to complain about a worker if she was unhappy with their service. She was informed about her rights and entitlements and took control over the organisation of the activities. Lydia did not have much say in that. Lisa gave Lydia instructions on how she wanted her to take part in the activities and Lydia adjusted to that. Lisa was not a 'self-manager' in that she employed her workers and paid them directly from her PB. A disability service provider was involved to do so. However, she had been involved in the selection of her workers. Being a self-manager did not inevitably mean that people with intellectual disabilities held power over their PB and it did not mean that they were less capable to reciprocate affection and care within the support work relationship. This was dependent on both people's sensitive understanding of their roles due to one person being in receipt of a PB.

In contrast to Kelly's (2016) research, my study also showed that reciprocating the relationship with kindness and empathy was influenced by the history of each relationship and the length of time both people had known each other. For example, some of the Australian pairs demonstrated that having a history of shared experience helped in picking up each other's communication signs much faster than pairs who had worked with each other for a shorter period of time. Michael made this point very clear by stating, "I guess just from history. You watch him (Felix) for so long and you kind of know… if something is wrong he gets a very particular look in his eye".

In the German ethnographic data set, however, I found that a long experience of working with the same person as support giver and support receiver could contribute to

developing 'fixed views' of each other, which had been touched on in the literature but not explored (e.g. Antaki, Finlay, & Walton, 2007). For example, Helene and Emma seemed to have developed specific views of the other during the eleven years they had worked together. Helene had a self-managed PB, but this did not stop Emma from patronising Helene, and Helene getting angry with Emma when she noticed that she was being patronised. While a long history of working together sometimes gave people the opportunity to get to know each other well, it also influenced the relationship sometimes in that it did not 'flow'. The two people then seemed to have created 'fixed views' of the other. In these cases, I could not observe that receiving a PB through a 'self-managed' way of organising the funding had an effect on their relational experiences. I could then not observe that this aspect influenced the relational experience in privileging the person with intellectual disabilities to be an active decision-maker who exercised control over their support work.

People experienced their support work relationships according to how power and control over support arrangements were shared in a setting which was connected to the aspect of 'self-management' within the policies of PBs. In settings, where a self-managed PB operated, third parties had some influence on the budget holder's involvement in the organisation of support work in that it sometimes limited the latter's power and control. While this often led support workers focus on the interests of third parties, it did not hinder both people in developing a rich and sensitive understanding of each other, which influenced the experiences of their relationships.

Exercising power and control through an awareness of the policies of personal budgets

How both people experienced their relationship and if the budget holder with intellectual disabilities exercised power and control over their support work had something to do with both person's awareness and knowledge about the budget holder's specific PB. To Smith, 'knowledge' has a social nature as it is created through people's relationships (Smith, 1990b; Smith, 2006). In Chapter IV, Silke, a service professional from Germany, had touched on the importance of learning from relationships through regular supervisions including both people in the relationship (see Section 'Supervision and the support work relationship'). This learning requires the worker to be open to what the budget holder offers, rather than imposing their own values and expectations upon them. As an

ethnographer, I could see that both people had created knowledge in form of an awareness about their own role in relation to the other and about the other person's role in relation to their own role. This affected how both people experienced their relationship with each other. When I researched in Germany, I learned that Maria dealt with ambivalent feelings in relation to Yelena. This ambivalence had something to do with her role as a support giver of a budget holder who experienced severe restrictions in everyday life.

> Maria explained that she used to think that people with disabilities get born with their disability and had it their entire lives, but Yelena acquired her disability only three to four years ago. "It was brutal and awful to watch, I nearly started crying", Maria commented when she explained that she once saw Yelena ram the toothbrush into her mouth due to her spasm. She also said that she was inspired by Yelena's will to live, which changed the way she thinks about people with disabilities. (Field notes)

For Yelena, this meant that she had someone around her who admired her perseverance on the one hand; but felt sorry for her on the other hand, when they, for example, noticed her limitations during simple day-to-day tasks, such as brushing teeth or having food. It was unclear whether Yelena perceived Maria's emotional ambivalence and inner struggles when they worked together. Yelena has had support from many different assistants in the past. She had a long history as a support receiver and perhaps Maria was not the first assistant who had shown ambivalent feelings towards her. The service involved in Yelena's life managed her PB for her and paid Maria. It had arranged that Yelena receive assistance from different workers each day. These policies expected Yelena to adjust to a different worker each day. However, Yelena's awareness about these procedures gave her a certain control to be involved in the organisation of her support work (see Chapter VI).

Lisa was the only budget holder in this study who had substantial knowledge about her PB and the organisation of support work associated with her PB. This knowledge empowered her in that she was aware of her entitlements and rights as a budget holder and could insist in realising them. Lisa said that her parents let her view the financial reports about her PB that came from the local authority. They did not block her from accessing these. This knowledge sometimes gave her the power to oppose the views and ideas of other people, including those of Lydia and her parents.

> Bettina (Lisa's mother) told me that she went with Lisa to the guardianship authority to extend her and her husband's guardianship for Lisa. The staff there asked them how things

were going and Lisa responded, "One guardian is enough". Bettina said that she had no idea that Lisa was going to say this as Lisa had not mentioned anything to her. (Field notes)

Lisa's understanding about her support work organised through her PB often helped her to control its organisation. It enabled her to actively take part in the ruling relations and influence them rather than being influenced by them. Gaining knowledge through access to information about PBs is an emancipatory practice that support work organised through PBs in Germany – as well as Australia – should promote (see Section 'Personal budgets in Germany and Australia' in Chapter II). Nine out of ten budget holders in this study did not know how the funds from their PBs were used and therefore fewer opportunities to make changes. This was also connected to the support worker's limited awareness of how the PBs were used. However, acquiring this knowledge and sharing it with budget holders in accessible ways was important for both people in opposing, accepting or questioning the ruling relations. This understanding seems powerful in that it has potential to empower budget holders in influencing the dynamics of the ruling relations. This resonates with Smith's view that 'real policy changes' happen when they are initiated by the people located below within social settings as they are subject to them (Smith, 2004) and that political activism develops through people's knowledge about the workings of society (Campbell, 2003).

As an institutional ethnographer, I reviewed, for example, support plans or goal agreements and could see that a specific support needed to be in place so that budget holders could achieve their goals (e.g. Samantha providing an easy-read recipe with pictures to support Jack in learning how to cook, see Chapter V). However, I observed that not all budget holders were aware of their goals, let alone that there was a document that entitled them to receive support in a particular area that empowered them to be in charge of their support work. Not having this awareness meant that they were less likely to take the role of the budget holder. Being a budget recipient instead of a budget holder sometimes led to a style of support that was much more driven by the views and expectations of the support worker than by the person with intellectual disabilities. This meant that the support worker was more likely to be in control of the organisation of support work. This became evident in the relationship between Jack and Samantha. Jack experienced a support worker who determined how he did the activities and who expected him to concentrate and do the activities related to cooking in a fast and thorough manner. The way power was shared in this relationship was linked to what both people were

expected to achieve within the hours of support that Jack's PB covered. This had an effect on how both people experienced their relationship.

Some of the support workers seemed to experience resistance when they felt that the budget holder exercised control over the organisation of their support work or attempted to do so (see Chapter VI). It seemed that this reminded them of their role as an 'assistant' in contrast to the role of the 'budget owner' or 'budget holder'. I found that this resistance was related to some support workers feeling apprehensive about giving up some of their power in their role as a support worker and shifting this to the budget owner instead. The analysis in Chapter IV indicated that the disability service providers that the service professionals worked for wanted to hold some power over the support work relationship, for example, by matching people to set up lasting relationships (see Sections 'Service involvement in the 'togetherness': setting up lasting relationships' and 'Matching and sustaining support work relationships'). The findings in Chapter IV indicated that disability service providers were part of the ruling relations, which the ethnographic analysis confirmed. The expectations within the ethnographic settings were passed down in an hierarchical order. This flow of power usually reached the support worker first. They were then in a position where they were expected to regulate the boundaries between themselves and the budget holder.

However, according to the policies of PBs, the person with intellectual disabilities was supposed to be empowered in their role as a budget holder with the help of their worker and other supporters (see Section 'Support work relationships in the context of personal budgets' in Chapter II). If the budget holder managed to use some of their power, then it sometimes seemed to leave the worker with the feeling of being 'replaceable' or 'not so important' which seemed dissatisfying to some of them. This issue was connected to the first component of the first constituent of the ruling relations, views and expectations of the two people within the support work relationship. For example, in Chapter VI, I described that Helene referred to her assistant Tina, when she spoke about friendship, and to Emma when she spoke about 'assistance'. In the interview with Emma, she appeared disappointed about Helene's view of her and noted, "This also happened to other workers, well, everyone thinks that they are someone special, but we are nothing special. We are one of many".

I observed that the people with intellectual disabilities sometimes encountered obstacles in exercising power and control over their PBs due to the worker's feelings of

disappointment or frustration. In these instances, the PB did not enable them to actively take part in the ruling relations. It seemed hard for both people to change these power dynamics within settings, but even harder for the budget holders. It seemed that a change of the flow of procedures (directions coming from the top) caused fear and insecurity for some workers. It also seemed that this issue had potential to occasionally create an experience of 'confusion' for budget holders in relation to their workers (if the budget holder had an awareness of the policies of PBs). This confusion seemed to come from one of the overarching goals of PBs which seemed paradoxical to me: to shift power to budget holders by letting them take control over support work (see Section 'Support work relationships in the context of personal budgets' in Chapter II) and seeing that other people, including support workers, often remained in control. This somehow showed the daily possibilities for people with intellectual disabilities to be subject to the misuse of power by their worker (e.g. Kelly, 2016, 2017a; Kelly & Chapman, 2015).

In this study, I witnessed moments of trust, enjoyment and intimacy between both people, but I also witnessed a misuse of power in many instances (e.g. Elsa waiting for Elizabeth to come out of the staff room to unlock certain doors and facilities in the group home; Maria raising her voice at Yelena due to the communication challenges she experienced in her relationship with Yelena, see Chapter V and VI). This misuse of power created moments of vulnerability between the two people in the relationship. Often the budget holder had less power in the relationship. Their 'vulnerable side' showed itself, for example, by expressing a need, but not being responded to in a way that answered this need or by not demanding to be allowed their entitlements. While this seemed connected to how budget holders were viewed based on their intellectual disabilities, the latter point (not demanding to be allowed their entitlements) also seemed connected to their lack of information about their entitlements in relation to their funding and how the money from the PB was used. This issue had caused a lack of understanding about how their support was supposed to work under their specific PB scheme. This information was supposed to be provided by their support workers and others in their support environment (Hamilton et al., 2016), but I rarely saw this happening. It also seemed that the behaviour of being 'not demanding' was related to people with intellectual disabilities being used to other people making decisions for them, which was connected to the lack of agency people with intellectual disabilities experience in their everyday lives (e.g. Christensen et al., 2013; Morris, 2001; Vorhaus, 2013).

Connecting the issue of having agency to the ruling relations through the awareness of support work, it becomes clear that the knowledge about the PBs influenced whether people with intellectual disabilities exercised control over their support work and whether support workers assisted them in doing so. This area of knowledge determined how power was shared between the two and vulnerabilities in response to the other were shown and exposed in support work relationships. It encompassed an awareness and understanding of the complexity of support processes associated with a PB, the role and rights of budget holders and its implications for the role and support style of support workers.

Both people's experiences of their relationships were influenced by their awareness of policy processes that operated within their individual environments, which incorporated their understanding of people's functions within the environment. Some processes were specific to the person's PB; others were specific to the individual environment, but their understanding about the former was usually very limited, which resonates with the findings in Chapter V and VI. This influenced how both people participated in the ruling relations and affected whether budget holders exercised power and control and how support workers provided support to them.

The interconnection between the constituents of the ruling relations

The three constituents of the ruling relations and their components emerged by drawing on the ethnographic data collected in both countries and connecting them to the contextual findings (see Chapter IV) and the descriptive findings (see Chapter V and VI). I used the concept of ruling relations through the analytical lens of IE and built on the conceptual approach to support work relationships in Chapter II, which helped me to understand the knowledge production of the entire research study.

As I identified and unpacked the three constituents of the ruling relations – people's views and expectations, the support work context and the policies of PBs, I learned about their influence on the experiences of support work relationships. This influence happened through the interconnection of the constituents which was powerful in that it affected how the person with intellectual disabilities acted in the role of the budget holder and how the worker took an approach that facilitated this role-taking. The ways in which the two people filled their roles in the relationship shaped their experiences of being in the relationship.

The analysis of the interconnection in the ruling relations demonstrated that the policies of PBs were only one constituent that affected the lived experiences of both people in the support work relationship. The other two constituents worked in conjunction with the policies of PBs and organised the support work which shaped the relational experiences. The people and policies in each setting drove the ruling relations and determined from where the influence on the lived experiences of the two people in relationship came from. The people and policies determined how it shaped the relational experiences as the two people engaged in the emotional and practical forms of support work.

Conclusion

This chapter critically analysed the lived experiences of support work relationships by identifying and unpacking the three constituents of the ruling relations and their components across five support work contexts in each country. Through this analytical exploration, the interconnection between the constituents and each constituent's function within the ruling relations emerged. Each constituent and its components was informed by the other two constituents and they demonstrated, that together, they had an influence on the experiences of support work relationships.

Both research aims (to add to an understanding of how budget holders with intellectual disabilities and their support workers experience their relationships and how these experiences were influenced by PB policies that organise support work in Germany and Australia) were achieved by understanding that the policies of PBs were only one of three constituents that formed the ruling relations which organised the support work and influenced the experiences of these relationships.

In Chapter IV, V and VI, I presented the findings separately, but in this last findings chapter, I combined both data sets to draw the links across the findings and to the conceptual theory of this thesis. The combined presentation and analysis of the ethnographic data from Germany and Australia not only helped to find that the ruling relations were made of three constituents in both national contexts. Through this approach, I identified variations and similarities in the support work contexts that played into the ruling relations which affected the experiences of support work relationships. The contexts in both countries helped to understand what the components of the three constituents were and how they related and added to the conceptual approach of support work relationships in this thesis.

Chapter VIII: Adding to an understanding of support work relationships

Answers close off the question;
sometimes –
in the spiritual life and,
indeed, in personal relationships –
it's better to stay with the question.
Why pretend to know the unknowable?

(Hugh Mackay, 2016, p. 9)

Introduction

This chapter discusses how the findings added to an understanding of the experiences of support work relationships within the ruling relations. It does not address how the empirical investigation in both countries added to an understanding of support work relationships based on the literature used in this thesis. This will be discussed in Chapter IX.

This chapter more specifically discusses the findings in light of the research aims. The aims were to add to an understanding of the relationship experiences of budget holders with intellectual disabilities and their support workers and to add to an understanding of how the experiences of the two people within the relationship were influenced by the policies of PBs that organised support work in Germany and Australia.

The achievement of both research aims is important as support work organised through a PB is given and received within the support work relationship and is intended to assist people with intellectual disabilities in living a meaningful life (Christensen, 2009; Johnson, 2013; Johnson & Walmsley, 2010; Shakespeare 2014a; United Nations, 2006). Both research aims are reflected in the two research questions of this thesis, namely:

- How do budget holders with intellectual disabilities and their support workers experience their relationships with each other?

- How are the lived experiences of people with intellectual disabilities and their support workers in their relationship with each other influenced by PB policies organising support work?

To address these questions, I used the three constituents of the ruling relations and their components, which were the core findings of the analysis, presented in Chapter VII:

Constituent 1: People's views and expectations about the support work relationship

Views and expectations of the two people within the support work relationship

Views and expectations of the people in contact with the pair

Constituent 2: The support work context

Group arrangement and one-on-one support

Rules and regulations specific to the setting

Constituent 3: The policies of PBs

The aspect of 'self-management' within the policies of PBs

Exercising power and control through an awareness of the policies of PBs

In this chapter, I explore each research question by discussing it in relation to each component of each constituent of the ruling relations, by considering the German and Australian contexts of PBs and by drawing on the emotional and practical forms of support work. This approach helped to explore the influence of the three constituents of the ruling relations on the support work relationship and the variations of experiences among budget holders with intellectual disabilities and their support workers in relation to each other. Through this exploration, I found that the three constituents of the ruling relations affected how the two forms of support work were experienced by the two people within the relationships and that the first two constituents often had stronger influence than the policies of PBs.

The research questions

This study found that people experienced their relationships through their engagement in the emotional and practical forms of support work. The three constituents of the ruling relations influenced how the two forms of support work were played out within the relationship. This had effects on the experiences of the two people in relation to each other. Before I address both research questions through the three constituents of the ruling relations, I will briefly explain what the emotional and practical forms of support work were in the context of my study.

Emotional and practical forms of support work

In Chapter II, I conceptualised support work as a professional service arrangement and a social relationship that inevitably involves feelings between a paid support worker and a person with intellectual disabilities (Shakespeare, 2014a; Shakespeare et al., 2018). In this context, I discussed the emotional (caring about) and the practical (caring for) forms of care work (e.g. Christensen, 2009; Hooyman & Gonyea, 1999; Rogers, 2012; Ungerson, 1983), which I referred to as the emotional and practical forms of support work throughout this thesis. Both forms of support work were embedded in the social policy context of support work in which the policies of PBs operated.

The emotional form of support work includes the mutual engagement and dialogue in which both people in the support work relationship contribute to an emotional connection (Christensen, 2009; Rogers, 2012). In my data, the emotional form of support work was the social and emotional interaction between both people, which included the non-verbal and verbal language that both people used in response to the other. The interaction consisted of reciprocal and interdependent gestures within the relationship (see Chapter VII), which were based on positive and negative emotions (Shakespeare, 2014a). In my data, the expression of positive emotions, for example, happened when one person showed concern and regard for the other or acknowledged the other through a physical expression, such as long and intimate eye contact, a pat on the back, a hug, a smile or a verbal gesture. The expression of negative emotions, for example, happened when people experienced misunderstandings. This sometimes led them to feel frustration or disappointment, feelings they expressed through various actions. For example, they disengaged in conversations with the other or raised their voice at the other person.

This study showed that the emotional form of support work occurred as the pairs engaged in the practical form of support work. The practical form relates to the organisation, planning and accomplishment of the practical labour of support which involves the support work activities and goals (Christensen, 2009; Rogers, 2012; Ungerson, 1983). In the context of this study, the practical form of support work included the actual engagement in the support work activities, as well as the organisation and planning of the tasks related to the activities. These activities were often driven by people's views and expectations which were sometimes reflected in the support work goals. However, the goal and its connection to specific activities that the pair carried out were often unclear to the two people in the relationship – and sometimes also to the people in contact with the pair.

Both forms of support work occurred as the two people experienced their relationship. However, the interconnection between the three constituents of the ruling relations affected which form of support dominated at any particular moment within the relationship. This kind of influence of the ruling relations shaped the relationship experiences of budget holders with intellectual disabilities and their support workers.

Research question 1: How do budget holders with intellectual disabilities and their support workers experience their relationships with each other?

This part of the chapter addresses the first research question by drawing on each component of each of the three constituents of the ruling relations. I discuss how each component contributed to an understanding of how budget holders with intellectual disabilities and their support workers in both countries experienced their relationships as they engaged in the emotional and practical forms of support work.

Experiences within the first constituent of the ruling relations – People's views and expectations about the support work relationship

The analysis revealed that both people's experiences in relationship to each other were influenced by the views and expectations of the two people within the relationship, the first component of the first constituent of the ruling relations. Each person's view of themselves, the other and their relationship came from the expectations they held towards

each other (see Section 'Views and expectations of the two people within the support work relationship' in Chapter VII).

Their views and expectations were evident from paying attention to people's language and the history of their relationship. This was consistent in both data sets. For example, in Australia, I found that people's language revealed how they saw each other and how they experienced their support work relationship (e.g. Elsa referred to Elizabeth as 'carer', William used the terms 'mates' and 'mateship' when he spoke about his relationship to Lachlan, Jack called Samantha 'teacher' and/or 'mum', see Chapter V and VI). This analytical observation showed that the two people experienced their relationship through the views and expectations they had of each other, which was influenced by other factors (e.g. their degree of empathy and care towards each other, see Chapter VII). Elsa's view of Elizabeth as her 'carer' and her view of their relationship as being a 'professional' one affected how the emotional form of support work in the relationship was played out. The women did not spend much time together and emphasised that they needed more time, which they could dedicate only to their relationship, the one-on-one time. When Elizabeth left the staff room, she usually came out to check if Elsa was engaged in an activity (e.g. preparing food, drawing in a colouring book, see Chapter V). Elizabeth placed her focus on the practical form of support work, a focus which was influenced by her view of Elsa, as a 'girl' that she had to supervise in order to make sure that Elsa completed her activities. This view was connected to Elizabeth's experience of being a support worker to a woman with intellectual disabilities.

While the history of relationships and the levels of familiarisation between the two people created opportunities for them to get to know each other, they also had potential to create 'fixed views' (see Section 'The aspect of 'self-management' within the policies of personal budgets' in Chapter VII). 'Fixed views' were set expectations that the two people had of each other which seemed less flexible and dynamic. These types of views influenced the extent to which the two people allowed their relationship to become something different over time. It influenced the experiences of both people in that their roles and associated tasks were, in fact, more set. In Germany, these views were also reflected in people's language (e.g. Yelena seeing in Maria an assistant and Maria seeing in Yelena someone who she is trying to befriend; Emma seeing Kerstin as her employer and Helene as a 'child' and Helene seeing in Emma only an 'assistant', but in other

assistants a 'friend'; Thomas seeing in Luke a 'day-to-day manager' and Luke seeing in Thomas a friend who is very dear to him, see Chapter VI and VII).

The length of time people had known each other played a role in both data sets and was connected to how they saw each other. For example, Michael thought he could tell how Felix felt as he understood Felix's non-verbal ways of communicating due to the six years they had worked with each other (see Section 'The aspect of 'self-management' within the policies of personal budgets' in Chapter VII). The history of their relationship supported both men in becoming familiar with each other. This familiarity helped their relationship in that they could better understand how the other person felt. In other words, it helped them in becoming empathetic towards each other. In the German data set, this also became apparent in the relationship between Thomas and Luke who had worked with each other for ten years. Luke was familiar with Thomas' non-verbal communication and both men had a profound understanding of how the other person felt (see Chapter VI and VII). However, they had created a specific and sometimes fixed view of the other which also seemed to have potential to lower their expectations of the other (e.g. Luke feeling frustrated about Thomas' attempts to express a need that Luke did not immediately understand, see Chapter VI). Thomas' communication needs were connected to his intellectual disabilities. Luke's frustration in response to them was part of his experience of being a support worker to a person with intellectual disabilities whose communication support needs seemed to challenge him. This part of the emotional form of support work was influenced by the views and expectations both people had of each other, which were shaped by the history of their relationship.

The two people in relationship with each other were also affected by the second component of the first constituent, the views and expectations of the people in contact with the pair. These people, for example, were parents of 'self-managers' (e.g. Margarete and Victor, Catherine, Kerstin, Bettina and Jürgen). In Germany and Australia, they appeared quite dominant within support settings and took control over the organisation of their daughter's/ son's support work. While these parents made it possible for their daughter/ son to receive a self-managed PB, they often made it difficult for them to become involved in the organisation of support work and take control over their activities, the practical form of support work. The views and expectations of third parties, which also included other support staff or the supervisor of a support worker, were often focused on the practical form of support work. They were concerned about the organisation of

support work in terms of its practical arrangements and the progress budget holders were expected to make, which sometimes compromised the emotional side of the work. This happened when they imposed their ideas on the pair about what kind of activity they should be doing and how the activity should be implemented (e.g. Kerstin expecting Helene to eat particular foods at particular times, see Chapter VI). This idea was shaped by their expectation of what the activities were supposed to achieve for their daughter/ son (e.g. improving or maintaining their health). However, their focus on the practical form of support work did not exclude their consideration of the emotional form of support work. For example, parents gave serious consideration to their daughter's/ son's feelings of like or dislike towards a worker when they selected and recruited them. This was particularly so in one-on-one support settings across both data sets.

In both data sets, the expectations of third parties were usually expressed to the support worker first, who then followed the wishes of third parties and sometimes engaged the budget holder in activities that they were not interested in. This was influenced by the hierarchical flow of the ruling relations, which seemed common among the five settings in both countries and not specific to the policies of PBs. The flow usually reached the support worker first, who then imposed their expectations on the budget holder (see Chapter VII).

Experiences within the second constituent of the ruling relations – The support work context

The first component of the second constituent – group arrangements and one-on-one support – affected how much attention the two people paid to the emotional form of support work within their relationship. Group arrangements were flat shares (Lachlan and William, Thomas and Luke), housing facilities (Anja and Laura), group homes (Elsa and Elizabeth) or day centres (Jeff and Linda). One-on-one support occurred in settings in which budget holders received support at their parents' place (Felix and Michael, Jack and Samantha, Helene and Emma, Lisa and Lydia) or lived by themselves (Yelena and Maria). Both group and one-on-one arrangements existed in both countries, but there was only one budget holder in Australia who visited a day program (Jeff) and only one budget holder in Germany who lived by themselves (Yelena). When support workers provided support to budget holders in group arrangements, they often had to focus on several people at the same time. This happened in both countries and sometimes compromised

the worker's dedication to the budget holder and affected the emotional form of support work. However, people did not necessarily dedicate or contribute more to the emotional form of support work when they spent one-on-one time in one-on-one support settings either (e.g. Samantha rushing Jack through the cooking activity while she provides one-on-one support to Jack; Emma asking Helene to focus on the tasks inside the organic food store although Helene seems interested in something else, see Chapter V and VI). This issue sometimes seemed connected to the limited hours of support work that the PB funded and the support worker's focus on the achievement of goals through the activities, the practical form of support work.

In both national support work contexts, group arrangements and one-on-one support sometimes affected the ways in which the emotional form of support work showed itself within the relationship (e.g. Felix providing support to Michael when Michael broke up with his girlfriend; Thomas being empathetic towards Luke when Luke was unwell; Lydia following the instructions from Lisa as she feels that Lisa wants to be in charge of her activities, see Chapter VII). The development of this sensitivity was sometimes facilitated by the time that the pairs spent only with each other, which they also did in group arrangements. In Australia, for example, I observed situations in which Linda took time to inquire about Jeff's interest (e.g. she asked Jeff while they were on the van with the other day program participants if he enjoyed the activity at the gym and whether he wanted to do the activity again next week, see Chapter V). In this moment, Linda was not feeling overwhelmed by the number of people she was supervising. However, when Linda felt like she was 'splitting herself into ten pieces', she could not fully address Jeff's needs which sometimes led Jeff to withdraw from the interaction with Linda, the emotional form of support work, and disengage in the activity, the practical form of support work. Linda's experience of being overwhelmed and Jeff's response to this was sometimes influenced by the fact that Jeff was supported in a group arrangement. It further seemed influenced by the ways in which Jeff expressed his needs non-verbally (e.g. running away from the group, kissing people) which were related to his intellectual disabilities and Linda's response to the expression of his needs.

One-on-one support sometimes gave both people the opportunity to get to know each other better, and this included their experiences of having misunderstandings and disagreements and working out how they could resolve them together. The study showed that these misunderstandings sometimes served as interpersonal discoveries and were a

chance for both people to become familiar with the needs, priorities, wishes, desires and dislikes of the other person. This became very clear in understanding how Maria and Yelena experienced their relationship with each other, which occurred in a one-on-one support setting. I often witnessed the frustration of both women due to misunderstandings within their interactions, the emotional form of support work. Yelena used non-verbal ways of communicating with Maria and Maria often struggled in finding out what Yelena was trying to say (see Chapter VI). These interactions were about the practical form of support work – scheduling and planning the weekly support work activities. By working through misunderstandings, Maria learned that Yelena preferred going out for walks instead of being inside her apartment (see Section 'Group arrangement and one-on-one support' in Chapter VII). In turn, Yelena learned that by working through communication struggles she would eventually be heard by Maria.

The ruling relations regulated the emotional form of support work through the rules and regulations specific to a support work setting, the second component of the second constituent. For example, in Germany, I found that Maria's ambivalent feelings evolved in her role as a support giver with someone who had perseverance, but experienced severe restrictions (e.g. intellectual and physical disabilities, high communication support needs) in their everyday life (see Section 'Exercising power and control through an awareness of the policies of personal budgets' in Chapter VII). The ways in which Yelena's PB organised the support work via the disability service provider that employed Maria contributed to how both women adjusted to the service rules that helped them to schedule and plan activities at the start of each shift, the practical form of support work. These regulations sometimes contributed to the communication struggles both women experienced within their relationship.

The rules specific to the support work setting influenced both forms of support work. For example, the 'rotation policies' in Jeff's setting had the power to prevent him and Linda from spending one-on-one time together. This policy regulated how the emotional and practical forms of support work were played out in the support work relationship. In this instance, the focus on the practical form of support work in Jeff's day centre was meant to protect both people's boundaries within the support work relationship. However, the analysis suggested that this needed to be balanced with the emotional form of support work (see Section 'Rules and regulations specific to the setting' in Chapter VII), as the emotional form affected both people's engagement in and

their completion of the support work activities (e.g. Samantha talks to Jack about her weekend activities as Jack engages in the cooking activity; Emma tells Helene about her family as she has breakfast or lunch with Helene). These rituals were part of the rules and regulations specific to a support work setting and affected how the two people experienced their relationship with each other.

The second constituent of the ruling relations had potential to create conditions that facilitated moments, in which the two people placed their focus on either the emotional or practical forms of support work. In both countries, this happened in group arrangements as well as in one-on-one settings. However, the quality of one-on-one time was marked by the mutual dedication and focus that the two people shared which was observable in one-on-one support settings as well as in group arrangements.

Experiences within the third constituent of the ruling relations – The policies of personal budgets

The first component of the third constituent of the ruling relations, the aspect of 'self-management' within the policies of PBs, helped in understanding the roles of budget holders who received self-managed PBs. A budget holder who self-manages their PB receives the money from their PB as a direct payment which is intended to shift power and control to budget holders as they can select, employ and pay their support worker directly from their budget (Guldvik, 2014; Kelly, 2016; Kotsch, 2012; Pearson, 2012). This study found that being a self-manager did not inevitably mean that people with intellectual disabilities held power over the management of their PBs. If they held some power was dependent on whether third parties within the support work context made room for the person with intellectual disabilities to take this role and whether budget holders had the interest and adequate supports in place, including the support of their worker, to be in this role. This was observable in both countries.

In those settings, in which a self-managed PB formally operated (e.g. Felix's, Lachlan's and Helene's setting), I found that parents of budget holders, especially mothers, took on the role of the PB manager and organised the support work. This was related to the fact that budget holders in this study had intellectual disabilities and that third parties, and often the support workers as well, did not view them as people who could potentially develop the capacity to self-manage their budget with adequate supports in place. The people managing the PBs for them sometimes seemed apprehensive about

shifting power and responsibility about support work to budget holders (see Section 'Exercising power through an awareness of the policies of PBs' in Chapter VII). Felix had two self-managed PBs, but he did not act as a self-manager. His parents advised Michael on how they wanted the activities to be implemented. In Germany, Helene received a self-managed PB and its administration was organised as an Employer Model (see the Employer Model in Section 'German context of personal budgets' in Chapter II). She was the only German budget holder who formally received her PB as a direct payment, but she had very little involvement in the organisation of this payment as her mother had supported her in the role of the self-manager. Her involvement in the support work was connected to how Emma and her mother viewed her as a woman with intellectual disabilities and to how power was distributed within these relationships. Helene's experience of her limited involvement in support work led to tensions and arguments between her and Emma (e.g. see situation in joint interview when Helene indicates that she does not get as much involved in the organisation of support work as her mother makes decisions about her support work which upsets Helene, see Chapter VI). Both women often expressed frustration and disappointment due to these issues. Their feelings were part of the emotional form of support work and showed that they were affected by the ways in which 'self-managed' PBs were implemented.

The policies of PBs are intended to promote the role of the budget holder so budget holders can exercise greater control over the organisation of support work and have more power within the support work relationship (Beresford, 2008, 2014; Broady, 2014; Guldvik, 2014; Leece & Leece, 2006; Pearson, 2012; Tew et al., 2015). Taking on this role was facilitated by the support worker's style of support which seemed to be part of the emotional form of support work. For example, a style of support that included a 'stepping or holding back' often helped the budget holder to exercise some power and control through an awareness of policies, the second component of the third constituent of the ruling relations. By adopting this style of support, the support worker sometimes made space and time for the budget holder to express a wish or need in relation to an activity. Having this space was particularly important for budget holders with communication support needs. This became evident in the relationship between Anja and Laura, for example (see Chapter VI). On the day we had gone to the pharmacy, Laura explained certain policy procedures to Anja before they did the activity. Laura gave Anja space and time to speak to the chemist and buy the crème that she wanted. Laura gave

Anja the opportunity to take control over her activity and create an awareness of the procedures of the activity. In this instance, the emotional form of support work helped Anja in accomplishing the activity by Laura's willingness to share or shift power to Anja. This style of support focused on what Anja desired in her role as a budget holder. In situations in which budget holders experienced limited opportunities to have this type of ownership, there was distance between the two people and the emotional form of support work was compromised. This happened in both countries (e.g. Jeff running away inside the park after he finished his lunch and no one conversed with him, see Chapter V; Thomas running away in town after not being asked what he wanted to do there, see Chapter VI). In these instances, the connection within the support work relationship seemed interrupted which was partially linked to people's limited awareness of the policies of PBs.

The third constituent of the ruling relations showed that the role of the self-manager for people with intellectual disabilities and the worker's style of support were relevant to understanding how budget holders and their support workers experienced their relationships. These roles affected the ways in which power and control were distributed and exercised within the relationship.

Research question 2: How are the lived experiences of budget holders with intellectual disabilities and their support workers in their relationship with each other influenced by personal budget policies organising support work?

In response to the second question, I found that the policies of PBs were only one constituent of the ruling relations. The policies of PBs were interconnected with the first and second constituent, the views and expectations of people about the support work relationship and the support work context. The first two constituents often seemed to have stronger influence on the relationship experiences than the policies of PBs.

Influence of the policies of personal budgets within the first constituent of the ruling relations – People's views and expectations about the support work relationship

The data revealed that the influence of the policies of PBs on the experiences of support work relationships was linked to the roles that the two people took in the relationship and their involvement in the support work. This was observable in both countries.

The roles were influenced by both people's views and expectations of each other, the first component of the first constituent of the ruling relations. These views and expectations shaped how the two people took and filled their roles within the relationship. For example, in Australia, the policies of PBs did not always influence the budget holder in filling their role as someone who had control over the organisation of their support work. In the joint interview with Samantha and Jack, I observed that Samantha defined her relationship with Jack first and she did not ask Jack if he saw things differently. His options were to agree or to disagree with her statements. She regulated the emotional (e.g. she held the power about defining and explaining what their relationship was) and the practical forms of support work (e.g. she was 'in charge' of the cooking activity) within the relationship. In this instance, the PB policies did not seem to increase Jack's control over the activity or influence Samantha in a way so that she filled her role as a support worker who assisted Jack in directing his activities.

Support work organised through a PB is intended to facilitate the budget holder's involvement in the organisation of their support work so they can fill the role of the budget holder (Christensen & Pilling, 2014; Dickinson et al., 2014; Purcal et al., 2014; Slasberg & Beresford, 2015; Slasberg et al., 2012). In this study, the involvement of budget holders in the organisation of support work was limited as conversations about support work were usually not accessible to them (e.g. Yelena not being aware of Maria finishing her role as her assistant, see Chapter VI). The structure of these conversations did not accommodate the communication support needs of a person experiencing intellectual disabilities. This issue was present in both national contexts of support work.

The accessibility of these conversations was further influenced by the ways in which support work was administered and set up in a setting, which sometimes excluded the support worker from conversations about the organisation of support work too. This seemed to limit the awareness of the pairs about policy procedures operating in their settings, including the policies of PBs. However, having this awareness had potential to support them in controlling the practical form of support work. The limited involvement

of budget holders with intellectual disabilities in conversations was related to how other people, including support workers, saw these budget holders. This issue relates to both components of the first constituent of the ruling relations. In most settings, third parties and sometimes support workers did not see the person with intellectual disabilities as a person with the capacity to take more control over the organisation of their support work with adequate supports. This view affected the emotional form of support work as some support workers did not expect budget holders to be able to make certain decisions about the organisation of their support work (e.g. on what days to do what kind of activities, to prepare the activities in advance so they could be better implemented within the given time). This sometimes led some of the support workers to miss opportunities to inquire what the budget holder desired in relation to the practical form of support work (e.g. what kind of activities they wanted to do, how they wanted to do the activities, in what order they wanted to do the activities). These inquiries were important for the relationship as they helped both people to get to know each other better, be empathetic towards each other and connect on an emotional level. This kind of emotional form of support work sometimes helped the worker to adopt a style of support that gave the budget holder the opportunity to take control and be involved in support work (e.g. Michael having trust in Felix that he would sit still during the shaving, see Chapter V).

Through the second component of the first constituent of the ruling relations – views and expectations of the people in contact with the pair, I found that the specific views of third parties on what the relationship was supposed to achieve (e.g. Catherine expecting William to go bushwalking with Lachlan; Linda following the advice of Jeff's mother, speech therapist and Bridget when she uses the iPad to improve Jeff's communication skills, see Chapter V and VII) often seemed to have a stronger influence on the relationship experiences than the policies of PBs. While these people were part of the support process, their idea of 'achievement' with its focus on the practical form of support work sometimes hindered both people in nurturing the emotional form of support work, which included the recognition and acknowledgement of the other person (see Chapter VII). When the support worker expected the budget holder to engage in an activity associated with a specific goal to achieve, the budget holder sometimes withdrew from the relationship and from their worker. This compromised both forms of support work. For example, in Chapter V, I described that the support work organised through Felix's PB expected Felix and Michael to do the swimming activity together as it was

part of Felix's 'daily routine' plan. Felix did not seem to enjoy the swimming activity when Michael expected him to stay in the water for a long time. Felix's disengagement in the activity led him to focus on getting out of the water and withdraw from the interaction with Michael. Michael's focus on the completion of the activity was an expectation imposed onto him by Felix's parents. This was one way in which the second component of the first constituent of the ruling relations, views and expectations of the people in contact with the pair, dominated the policies of PBs. The example of Felix and Michael also shows how the second component of the first constituent influenced the first component of the first constituent, views and expectations of the two people within the support work relationship. The expectations of third parties (Felix's parents) had been imposed on the support worker (Michael) which the support worker usually wanted to meet. This influenced the interplay between the emotional and practical forms of support work and this interplay affected the experiences of support work relationships at the same time.

People's views and expectations about the support work relationships usually dominated the influence of the policies of PBs on the relational experiences. This happened in both countries. The ways in which budget holders with intellectual disabilities, especially those with communication support needs, were seen in their settings influenced how they took the role of the budget holder and often limited their involvement in the organisation of their support work. The kind of involvement regulated how both forms of support work were experienced within the relationship.

Influence of the policies of personal budgets within the second constituent of the ruling relations – The support work context

The analysis revealed that the first component of the second constituent of the ruling relations – group and one-on-one support arrangements affected the ways in which the policies of PBs could influence the experiences of support work relationships. For example, the time pressure within each ethnographic setting revealed that the ruling relations did not only 'run', but also 'rushed' through people's everyday activities. The 'day-to-day rush', as Kelly (2017b) called this phenomenon in relation to the work pressure that support workers are exposed to, did not only compromise the support worker's capacity to attend to the person with intellectual disabilities in mindful ways. It

sometimes affected the budget holder's emotional responses to their support worker also. It affected the emotional form of support work.

The influence of time constraints and certain expectations in relation to the completion of activities within a specific time frame had implications for the experiences of the two people. The felt time pressure created work conditions that limited opportunities for both people to fully open up to the interests and feelings of the other and reciprocate them in a way which made the other person feel valued and recognised. This occurred in both countries and particularly became apparent in relationships that developed in group arrangements (e.g. Elsa and Elizabeth, Jeff and Linda, Thomas and Luke, Anja and Laura). However, the time pressure was also present in one-on-one support settings (e.g. Emma asking Helene to stay focused on the activities so they were completed by the time Kerstin came home for lunch). The 'rush' affected how the emotional form of support work was experienced in terms of whether the pairs had the time to open up to each other. The policies of PBs sometimes seemed to provide the funds to receive support within group or one-on-one settings and therefore had an influence on the experiences of people within these arrangements (e.g. Thomas' PB was used to finance Luke's support in form of living assistance in a flat with four other people with disabilities which shaped how Thomas and Luke experienced each other, see Chapter VI). However, the arrangement itself seemed to be a 'set up' specific to the support work context (e.g. receiving a self-managed PB in a family home, receiving a PB to pay for a day program). This became clear to me by working with the data sets from both national contexts.

By using the second component of the second constituent, the rules and regulations specific to the setting, the data revealed that the 'no-touching policies' operated in both national data sets (e.g. in Jeff's and in Thomas' setting) and did not seem to be related to the policies of PBs. However, the 'rotation policies' (i.e. working with a different group of people with disabilities each week) only operated in an Australian environment (Jeff's setting). These rules and regulations were part of organisational policies (in Jeff's setting) and part of informal policies that did not seem produced by a disability service provider involved (in Thomas' setting).

In both countries, the 'no-touching policies' had special implications for budget holders with communication support needs. Jeff and Thomas were both men who expressed themselves physically, but were sometimes restricted in expressing certain

feelings. While these policies were intended to protect people's boundaries within the relationship (see Chapter IV and VII), they constrained the emotional form of support work within the relationship in that both men were sometimes limited in physically expressing an emotion towards their worker. The support workers had to be sensitive in picking up on subtle and often non-verbal signs of communication. However, in Felix's setting, where 'touching the support worker' through a kiss on the forehead, a hand clap or a hug was allowed, both people could nurture the emotional form of support work which led to feelings of enjoyment (see Chapter V).

In both countries, the rules and regulations specific to the setting sometimes constrained the experiences in that both people could not nurture the emotional form of support work. When this form of support work received less attention, then the practical form of support work was also compromised (e.g. Jeff withdrawing from the conversation with Linda when he is being asked to use the 'train App' which was an activity connected to his support work goal 'communication', see Chapter VII). It affected how the support work activities were carried out by the pair. In order for the policies of PBs to be in action and have an influence on the experiences, the pair needed to pay attention to both forms of support work. They needed to create some kind of balance between the emotional and practical forms of support work. If this balance was achieved, then the support work activity could be implemented in a way in which the budget holder could voice their personal needs and the support worker could respond to them directly. When this happened, the policies of PBs had some influence on the experiences of support work relationships in that the budget holder exercised some power and control over the organisation of support work, which the policies of PBs are intended to do (e.g. Christensen & Pilling, 2014; Guldvik, 2014; Purcal et al., 2014; Slasberg & Beresford, 2015; Slasberg et al., 2012).

The support work context in the five settings in each country provided certain set-ups (group or one-on-one arrangements) and rules and regulations that often seemed to dominate the influence of the policies of PBs on the relational experiences. They created certain situations in which the policies of PBs did not have much influence and the emotional form of support work seemed constrained. If both people balanced their attention towards the emotional and practical forms of support work, then this usually helped their relationship in that both people stayed connected.

Influence of the policies of personal budgets within the third constituent of the ruling relations – The policies of personal budgets

The policies of PBs had an influence on the experiences of support work relationships through both components of the policies of PBs, the aspect of 'self-management' within the policies of PBs and exercising power and control through an awareness of these policies. While the other two constituents of the ruling relations seemed to have stronger influence on the relational experiences, the policies of PBs occasionally influenced support work relationships too in that they created differences in experiences between people in self-managed and in not self-managed support settings across both countries.

A PB can be self-managed when it is administered as a direct payment. In this context, the budget holder has power and control over the management of the PB, pays their support worker directly from their budget and employs them (Guldvik, 2014; Kelly, 2016; Kotsch, 2012; Pearson, 2012). This study found that budget holders experienced difficulties in taking the role of the self-manager. This was connected to how they were supported in their roles as self-managers and how the support worker and others provided information to them about their rights. It was further linked to the individual person (e.g. Lisa taking initiative to select and recruit support workers and being confident to demand her entitlements to be realised) and their understanding of their rights and entitlements as budget holders in their roles as self-managers (e.g. Lisa's understanding of goals, activities, recruitment of workers, financial statements, implications of guardianship arrangements although she did not formally receive a self-managed PB).

The limited access to information about these rights and entitlements seemed to contribute to the fact that both people sometimes influenced the ruling relations in limited ways and were more likely to be influenced by them. However, taking the role of the budget holder and self-manager more actively helped in participating in the ruling relations. This active role-taking led to a style of support that was much more driven by the views and expectations of the budget holder than the support worker. This sometimes changed the hierarchical flow of the ruling relations and influenced the emotional form of support work (e.g. Yelena being persistent in asking Maria about tomorrow's assistance shift which led Maria to raise her voice and become frustrated; Helene snapping at Emma and not following her advice in some situations which caused tensions within their relationship, see Chapter VI).

It seemed easier for budget holders to influence the ruling relations in a way so that their own views and expectations were more present when they had adequate supports in place that enabled choice and control. Particularly the budget holders with communication support needs (e.g. Felix, Lachlan, Jeff, Yelena, Thomas, Andrea) experienced difficulties in following set policy procedures and demanding their rights. In moments, when they did not follow set policies, it seemed that they were trying to get in contact with their support worker (see Section 'Views and expectations of the two people within the support work relationship' in Chapter VII). Budget holders in group settings often seemed available and open to engage with their workers, but not vice versa (e.g. Elsa has to wait until Elizabeth comes out of the staff room, see Chapter V). In these moments, the first two constituents of the ruling relations – the views and expectations of people about the support work relationship and the support work context – dominated the third constituent, the policies of PBs. The policies of PBs were then of less priority.

The policies of PBs were partially intended to promote the personalisation of support work and facilitate the process of privileging the wishes of budget holders (e.g. Beresford, 2008, 2014; Christensen et. al., 2013; Christensen & Pilling, 2014; Leece & Leece, 2010; Slasberg et al., 2012). However, the policies in the support work context often included other priorities, such as doing activities and working towards goals that third parties expected them to do. The interconnection of the three constituents often created expectations within each support environment that constrained possibilities for budget holders to exercise power and control over the organisation of their support work. This was due to many support environments not being inclusive and responsive to the support needs of budget holders. Overall, it seemed that most pairs in a support setting followed the rules and regulations they were aware of, used to and expected to comply with. It sometimes appeared like an unthinking following of policy and procedures that were specific to the support setting and had placed a focus on the practical form of support work. This meant that some support workers could not respond to or inquire about the needs, desires and interests of budget holders. An implication of this issue was that budget holders could not experience their own expression of how they wished their support work to be organised through their PB, which included their decision about how the support worker was supposed to work with them, the support style.

Overall, the policies of PBs did not sufficiently support the people with intellectual disabilities in taking the role of the budget holder so they could exercise power

over the organisation of their support work. This was due to the fact that the policies of PBs were usually dominated by the first two constituents that had much stronger influence on the relationship experiences. However, the policies of PBs occasionally contributed to the creation of certain roles, in which budget holders were sometimes more likely to take some control over the organisation of support work and actively nurture the relationship through the emotional form of support work.

Conclusion

The discussion in this chapter addressed the two research questions through the three constituents of the ruling relations. The exploration of both research questions revealed similarities and differences within the experiences of the ten support work relationships. This was due to the ways in which the ruling relations were constituted and interconnected which affected how support work was organised in a setting, irrespective of the country.

The five settings in each country helped to understand the hierarchical structure and the dynamics of the ruling relations which were similar in both national contexts of PBs. While the policies of PBs were part of the constituents of the ruling relations, they were not the most powerful element to influence people's experiences of their support work relationship. The study found that the first two constituents – people's views and expectations about the support work relationship and the support work context – often seemed to have a stronger influence on the relationship experiences than the policies of PBs. People's views and expectations and the implementation of the policies specific to the support work context were shaped by the fact that one person in the relationship had intellectual disabilities and sometimes communication support needs, as well as by the fact that one person received support while the other person provided it. This applied to the German and Australian settings.

The interconnection between the three constituents of the ruling relations affected the experiences of support work relationships in that they had the power to constrain the emotional form and place the focus on the practical form of support work. Both people experienced their relationships as they engaged in both forms of support work. The emotional form was integrated in the ways in which the pairs performed the practical form of support work. However, the emotional form needed to be balanced with the practical form of support work as the emotional form nurtured the support work relationship in that both people could do activities together. The ruling relations often tended to hinder both people in nurturing the emotional form of support work as the force of the ruling relations shifted the focus on the practical form of support work. This often caused a tension or an emotional disconnection between the two people.

Chapter IX: New understandings of support work relationships

> Learn to think with your heart,
> and learn to feel with your mind.
>
> (Theodor Fontane, 1898, p. 27)

In this chapter, I close the thesis by exploring the contribution of this study, the new understandings of support work relationships. I discuss the contribution of the empirical findings to the conceptual approach to support work relationships, the application of IE in Germany and Australia, the methodological limitations of the thesis, further research about support work relationship and the implications of the findings for disability policy and practice.

Contribution to the conceptual approach to support work relationships

This study revealed the nuanced variations within the experiences of support work relationships across ten settings and two national support work contexts. The significant findings from this study were the identification of the three constituents of the ruling relations and their influence on support work relationships. The three constituents were the views and expectations of people about the support work relationship – including those of the pairs, the support work context and the policies of PBs. Further findings included how the three constituents were interconnected and how they shaped the emotional and practical forms of support work which influenced the experiences of the people in support work relationships. These findings add some important contributions to the conceptual approach to understanding how support work relationships are experienced, discussed in Chapter II.

This study confirmed the value of using conceptual approaches from care, EoC and disability literature to inform theoretical understandings of relationships between people with intellectual disabilities (using PBs) and their support workers. By drawing on disability studies literature (e.g. Christensen, 2012; Shakespeare, 2014a; Shakespeare et al., 2018), I was able to build from an understanding of support work as a social

relationship, in which the person with disabilities receives paid support while the support worker provides a professional support service and a relationship, in which both people inevitably have positive and negative feelings in response to the other (Shakespeare, 2014a). With the addition of care literature (e.g. Christensen, 2009; Hooyman & Gonyea, 1999; Rogers, 2012; Ungerson, 1983), I made use of the concepts of 'caring about' (emotional form) and 'caring for' (practical form) to conceptualise both forms of support work within the support work relationship (see Section 'Support work as a relationship' in Chapter II). The conceptual ideas of both forms of support work added nuance to the analysis in that they helped me to unpack the experiences of the two people in relationship with each other and to interpret them (see Chapter VIII). I used the concept of the emotional form of support work to understand the experiences through the social interaction and the concept of the practical form to understand the experiences as both people engaged in activities. Both forms of support work interacted with the three constituents of the ruling relations, which further helped me to understand the emotional and practical forms of support work as part of the experiences of support work relationships in connection to each component of the three constituents (see Chapter VIII). In this context, I found that people's experiences of both forms varied as the ruling relations often tended to hinder the emotional form of support work and shifted the focus on the practical form of support work.

In Chapter II, I further discussed interdependence within support work relationships – the dependence of both people on each other – by drawing on the EoC theorist Eva Feder Kittay (see Section 'Interdependence within support work relationships'). Following Kittay, I argued that each person's experience of being in a relationship is dependent on the other person's relationship experience. During the empirical analysis, the concept of interdependence helped me to understand both people's views and expectations of each other (see Section 'Views and expectations of the two people within the support work relationship' in Chapter VII). One's own dependency on the other was experienced as both persons interacted and completed activities. Both people experienced that they needed each other to engage in the emotional and practical forms of support work. This corroborates Kittay's (e.g. 2001, 2002, 2009a, 2009b, 2011) argument about the relationships between people with intellectual disabilities and their paid and unpaid carers. Both people in this relationship are dependent on each other, irrespective of the fact that one person has intellectual disabilities. However, the empirical

findings indicated that some policies specific to the paid support work context (e.g. rotation policies) were aimed at restricting the development of interdependence within support work relationships (see Section 'Rules and regulations specific to the setting' in Chapter VII). These policies were aimed at maintaining boundaries within the support work relationship and seemed to influence some of the views and expectations that third parties in the ethnographic settings had, such as service professionals or support staff (see Chapter IV, VII and VIII). Some of these people did not necessarily see interdependence as a facilitator for a relationship based on empathy and care, as some EoC theorists argued (e.g. Slote, 2007; Walmsley, 1993). The analysis of the views and expectations of third parties showed that they sometimes associated interdependence with a concern that the practical form of support work could be compromised if both people developed a strong emotional relationship and depended too much on each other.

In Chapter II, I explained that one of the central goals of the policies of PBs is to provide 'adequate supports' to enable budget holders with intellectual disabilities to exercise power over the organisation of support work by having choice and control (see Section 'Support work relationships in the context of personal budgets'). Exercising choice and control over support work is consistent with the right of people with intellectual disabilities to live a meaningful life, envisaged in the CRPD (United Nations, 2006). In Chapter II, I also explained the options of using a PB as a direct payment or via a service provider who assists with the administration of the funds. These arrangements within the wider social policy context of support work in which budget holders with intellectual disabilities and their support workers develop their relationships can influence both people's experiences with each other (e.g. Guldvik, 2014; Rogers, 2009, 2012; Kelly 2011, 2013, 2016). This study confirmed that the arrangements within the wider social policy context influence support work relationships, but also found that the social policy context of support work organised through PBs was only one of three constituents and was not necessarily effective in increasing budget holder's power over the organisation of their support work.

In nearly all the ten settings, budget holders experienced situations in which they had limited power over the planning, organising and doing of their support work activities (the practical form of support work) as they were often not included in conversations about their support work (see Chapter V, VI and VII). This finding suggests that the idea of 'adequate supports' to enable power, choice and control for budget holders with

intellectual disabilities needs to be revisited and that the roles of the support worker and the person with intellectual disabilities in this context need to be clarified. It further suggests that the interactive processes within a support work context that may or may not facilitate the involvement of budget holders in conversations about their support work need to be explored and theorised further. Particular attention needs to be drawn to budget holders with intellectual disabilities and communication support needs as the study showed that this group of budget holders was at risk of being excluded from such conversations.

Using Institutional Ethnography in Germany and Australia

In Chapter III, I explained that institutional ethnographic research projects are open-ended projects of inquiry (see Section 'Institutional Ethnography as a method of qualitative inquiry'), where 'the researcher does not know in advance where her or his investigation will go' (Smith, 2005, p. 68). Given that the theory of IE argues that the ruling relations govern people's local and everyday experience, the lived experiences of people become the hermeneutic starting point for the institutional ethnographer. From this point of departure, I 'worked my way up' – on an analytical level – to the constituents of the ruling relations, 'traced their interconnections' and analysed how they affected the experiences of support work relationships. This analytical 'pathway' was influenced by working with the data I collected during the first fieldwork stage which stimulated the start of an inductive and iterative knowledge production process. 'Getting the lay of the land' meant that I gained a contextual understanding of support work relationships (Chapter IV) across both research contexts as I developed my research questions and my conceptual approach to support work relationships (Chapter II).

According to the literature on IE (e.g. Smith, 1987, 1992, 2005, 2006), the institutional ethnographer starts their research by understanding the experiences of the local people, which were the budget holders and support workers in my study. However, this literature does not discuss the application of IE in two countries. Conducting and analysing the interviews with service professionals during the first fieldwork stage were important steps in scoping the ethnographic field in Germany and Australia and preparing the transnational field research, the second fieldwork stage. This empirical step contributed to the theory about IE studies as the contextual knowledge that emerged in form of questions and reflections raised in Chapter IV demonstrated that it informed the

preparation of the second fieldwork stage and contributed to the overall knowledge production process of this thesis.

In Chapter II, I provided a rationale for doing research in two countries (see second part of Chapter II). I explained that I was using two social policy contexts to better understand the empirical links between the policies of PBs and the experiences of support work relationships as social policy contexts have potential to influence the experiences. I further explained that I was focusing on the German and Australian contexts of PBs due to their specific developments and implementations of PBs at the time of the empirical research of this study. The literature on transnational research studies in qualitative social research (e.g. Christensen, 2012; Timonen & Convery, & Cahill, 2006; Ungerson, 2003) stressed the value of using more than one country to generate social knowledge (see Section 'Institutional Ethnography as a method of qualitative inquiry' in Chapter III). I found that doing IE in Germany and Australia helped in looking at the diversity of my data through the concept of ruling relations by using each component of each constituent to understand the lived experiences within support work relationships (see Chapter VII). In contrast to the comparative social science researchers Linda Haintrais and Stephen Mangen (Hantrais, 2014; Hantrais & Mangen, 1996), I did not use both contexts to compare social phenomena (e.g. support work relationships and their environments) or to make generalisations from the influence of the ruling relations in one setting to how support work through a PB was set up in a whole country. This goes beyond the potential of applying IE in two countries with the two research questions I worked with. I used data from both countries to add nuance to my understanding of how two different support work contexts organised through PBs affected how people experienced support work relationships.

Kulick & Rydström (2015) used ethnographic methods in their research in Denmark and Sweden to explore the sexual lives of people with disabilities in group homes. Similar to their work, I found that the application of IE in two countries served me in learning about how the ruling relations were constituted through the policies and lived experiences in Germany and Australia. Identifying and unpacking the ruling relations and understanding how they worked together happened by using both contexts as empirical territories. They shaped and created the conditions for the structure of the three constituents of the ruling relations through the analysis of the data that I collected there. However, this structure was not different in both countries. The five ethnographic

settings in each country helped me to understand this structure through which I found and explored variations and similarities of the relationship experiences affected by the ways in which support work was organised, irrespective of the country.

In Chapter III, I also noted that institutional ethnographers analyse the translocal character of the ruling relations that can cross national borders which has more recently been termed TIE (Grace, 2013; Smith, 2001). By doing this study in two countries, I extended the translocal space of the ruling relations through which I analysed support work relationships. Grace (2013) explained that this 'may inform other investigations of cross-border organizational processes in diverse institutional settings', but does not support the development of a comparative framework for a research investigation (Grace, 2013, p. 602). I share a similar experience with Grace. IE accommodated my interest in exploring support work relationships in two countries to uncover translocal policy processes in ten ethnographic environments. The fact that five of the ten settings were located in one state of Germany and the other five in one Australian state provided rich data to identify and analyse the experiences of support work relationships within the ruling relations. I was able to access a range of policy documents (see Appendix G) from both countries which created interesting and new opportunities in seeing how policies influenced people's lived experiences. However, the transnational context of the study yielded its potential in that it enabled me to identify the three particular types of constituents and their components which were common to both contexts and to understand that the first two constituents had greater influence on the experiences of support work relationships than the policies of PBs.

Methodological limitations of the thesis

The context of research for this PhD thesis involved methodological limitations. These included the number of the pairs involved in this study, the research sites (the state of Baden-Württemberg in Germany and the Greater Sydney Region in Australia), and the qualitative nature of the research and my subjectivity and role in it.

I explored the relational experiences of five support work pairs in each country which represents a sufficient qualitative sample. This number was influenced by the qualitative methodology I used and the time and costs available to conduct this study. My aim was to collect rich data about the depth of the experiences of the two people in the relationship which is reflected in the number of the people with intellectual disabilities

and their support workers recruited for this study. From this sample, I was able to work with data that provided insights into what it is like to be in a support work relationship, but I was not able to make generalisations about support work relationships across large populations. However, this study was not designed to make these generalisations. It was designed to understand how people experience their support work relationships under the influence of the policies of PBs.

In reference to the locations of the empirical research, the thesis is limited to the LGAs in each country. In the German state of Baden-Württemberg, I focused on LGAs that made PBs available to people with disabilities. The government agencies approving the PB funds within each LGA made their own rules about the administration of PBs (Schäfers, 2009). This can influence how support work is organised by a budget holder with intellectual disabilities (see Section 'German context of personal budgets in Chapter II). If I had recruited research participants from other LGAs, I might have received different insights into the organisation of support work through a PB. The same applies to the Greater Sydney Region that I selected as my Australian research site. The disability policies that operated in this region provided insights into how support work was organised in practice. However, these insights were limited in that they were shaped by the policies specific to the region I researched in. If I had recruited pairs from other locations within NSW or outside of NSW, I would have analysed different policies. These policies might have given me a broader view of how one context of support work was organised through the policies of PBs.

In Chapter III, I introduced the research methods (participant observations, interviews and policy document analysis) and acknowledged their limitations (e.g. relying on my memory and my commitment to write up field notes after each observation day). I further discussed the practical constraints of the data collection process (e.g. limited availability of research participants to take part in interviews) (see Section 'Practical constraints of the data collection'). The qualitative methodology of this study emphasised my subjectivity in this research process which relates to my role as an institutional ethnographer and disability researcher. While researcher subjectivity can mitigate risks, such as reproducing othering and masking the researcher's power (e.g. Krumer-Nevo & Sidi, 2012; Traustadóttir, 2001; Wilkinson & Kitzinger, 2013), it can also introduce boundaries to a study (e.g. difficulties in separating the ethnographer's experiences from those of the research participants). In this study, I used CR to support

me in managing my subjectivity in this role (see Section 'Critical reflexivity' in Chapter III). My role as an institutional ethnographer was strongly influenced by my experiences of living, working and researching in Germany and Australia for many years and by my professional and academic background in the area of support work for people with intellectual disabilities. My research was shaped by certain values and ideas, which changed throughout the study. Understanding the influence of these changing values and ideas required me to engage in ongoing critical reflections, which was guided by the work of several reflexive researchers (e.g. Ellis, 2007, 2011; Etherington, 2004, 2007; Gergen, 2015; Goodley, 1999). Their work supported me in using my subjectivity as a tool to separate my experiences in the ethnographic field from the people who lived the experiences, the research participants.

Further research on support work relationships

The findings from this study suggest implications for future research on support work relationships. The first implication relates to further research on the quality of support work and its influence on support work relationships. While this study provided insights into how the style of support work affected the emotional and practical forms of support work relationships, it did not focus on and explore the quality of support work and how it affected these relationships. The quality of support work could have been explored by focusing on specific aspects, such as whether the style of support work was respectful or caring. The quality of support work could be investigated further through more structured participant observations which could aim to understand how the behaviours and interactions between both people reveal information about specific aspects of support work and their connection to the experiences of support work relationships.

The second implication relates to the stronger involvement of third parties in research about support work relationships. The first constituent of the ruling relations highlighted that the views and expectations of third parties influenced the experiences of support work relationships. They partially governed how support work was implemented in practice and how the person with intellectual disabilities took the role of the budget holder. While the study found that the views and expectations of third parties affected the two people in the relationship, it did not capture their in-depth perspectives on the support work relationship. The aim of the study was to focus on the experiences of the two people in the relationship. However, I did find that the views of third parties had a strong

influence on whether and how people with intellectual disabilities took the role of the budget holder, what activities they engaged in and how the two people worked together, for example. Their perceptions could be investigated in-depth in future research on support work relationships – by including them as a research participant group in future studies rather than 'third parties in observations'.

A consideration for further research on support work relationships relates to the involvement of people with intellectual disabilities and communication support needs in the fieldwork. I was sometimes limited in my understanding of support work relationships in that I did not always understand the communication support needs of some research participants with intellectual disabilities. Neither IE nor the research methods captured the lived experience of the person with communication needs in the same ways it did for the support worker. In understanding the former's lived experience, I relied much more on my own interpretations of what they experienced and on second hand information (e.g. through support workers or third parties)[13]. While disability studies literature acknowledged the ethical value and importance of such relationships in qualitative research (e.g. Kelly 2016, Lutz et al., 2016; Rogers, 2003; Rogers & Tuckwell, 2016) it needs to further explore how trusting relationships between researchers and participants with intellectual disabilities and communication support needs can develop. Learning about the interests of research participants may help the researcher to develop these trusting relationships. I learned about Thomas' passion for poetry writing and talking to him about this in the interview, which helped me to understand his experience in relation to Luke (see Chapter VI). To better include the individual voice of the person through a first-hand inquiry, further research needs to consider the time necessary for a participant observer to forge sensitive relationships with research participants based on trust and to learn about their interests.

Another consideration for further research on support work relationships relates to the use and analysis of disability policy documents. The ruling relations affected people's relationships, were part of people's language and were included in written texts which were the documents that had been produced by people or service providers. The observations 'on the ground' and the written accounts captured in policy documents, field

---

[13] This does not exclude the possibility that support workers might have had similar experiences in certain situations during the ethnographic fieldwork. I sometimes received information from others about them too, especially during the recruitment stages. However, the person with intellectual disabilities and communication needs deserves my focus in this section as I more often witnessed their struggles in trying to express a wish or need.

notes and interview transcripts were important in understanding the relational 'everyday experience' within policy frameworks of PBs. This type of 'text work' (see Section 'Institutional Ethnography as a method of qualitative inquiry' in Chapter III) helped me in thinking beyond the observable and checking the relevance of texts in relation to people's observable actions, which included their verbal accounts (Grace, 2013; Smith, 2005). However, the study mainly drew on personal (e.g. support plan) and organisational (e.g. mission statement) disability policy documents (see Appendix G) to identify the goals of the support work activities. Personal and organisational policies played a central role in constituting the ruling relations. However, the goals on the personal and organisational level had overarching goals specific to PBs, which were sometimes captured in the national and international legislation and policy (e.g. the 'National Disability Strategy 2010-2020' from the Australian Government, 'The Personal Budget' by the Federal Ministry of Labour and Social Affairs in Germany). It was generally hard to identify the policies at a state, national and international level, which seemed relevant to each support work relationship. While this study drew some links to these upper layers of policies, further research could aim to connect the local experiences of people more directly to the national and international legislation and policy relevant to PBs. Here, it could consider the national and state policies of different countries to continue exploring the influence of PB policies on the people using them and those involved in their support.

Another implication for further research relates to the comparison between people with intellectual disabilities using a PB and those who do not use PBs, as well as the comparison between people with different types of PBs (e.g. PBs for supported living or community participation). Through this study, I gained rich insights into the experiences of support work relationships in group arrangements and one-on-one support settings. I identified differences in influences of policy processes on the budget holder's realisation of rights according to their PBs by considering other people with disabilities in the setting who did not hold PBs, but I did not explore this particular difference between people with and without PBs. The same applies to such differences based on the types of PBs that people with intellectual disabilities used. While comparing these aspects (e.g. realisation of rights based on PB types and/ or support work organised via a PB or not) was not the study's aim, further research could build on these comparative aspects. Further ethnographic research could add to an understanding of what kind of support

environments may facilitate a support style that support workers can adopt to help budget holders in realising their rights.

The last implication relates to research drawing on care, EoC and disability studies literature. While the thesis acknowledged the value of combining theoretical viewpoints from this literature to conceptualise support work relationships, it has, so far, not acknowledged the limitations of these theories in analysing the experiences of budget holders with intellectual disabilities and communication support needs and its implications for further research.

While disability studies literature (e.g. Christensen, 2012; Guldvik, 2014; Kelly, 2016; Leece, 2010; Leece & Peace, 2010; Porter & Shakespeare, 2016; Shakespeare et al., 2017; Shakespeare et al., 2018) revealed the link between the policies of PBs and its influence on support work relationships, it did not explore the in-depth experiences of people with intellectual disabilities and communication support needs and their support workers in relation with each other under the influence of the policies of PBs. Eva Feder Kittay (e.g. 2001, 2002, 2009a, 2099b, 2011) portrayed the experiences of people with intellectual disabilities and communication support needs in her work, but she did not make a link between PBs and the experiences of these people. Care and disability studies research, for example, started to explore the experiences of people with intellectual disabilities and their workers (e.g. Rogers, 2009) and the experiences of people with physical disabilities using direct payments and their workers (e.g. Kelly, 2001, 2013, 2016). However, these theoretical approaches did not explore the link between PBs and the relationship experiences of people with intellectual disabilities and communication support needs and their support workers. The communication support needs have to be considered in the support process to facilitate budget holders' involvement in it, which the findings of this study stressed. Similar to this study, further research needs to continue exploring what it is like for budget holders with intellectual disabilities and communication support needs to be in a support work relationship. It needs to understand what it means for support workers to provide support work to a person with intellectual disabilities and communication support needs in ways so that they can experience having some power over the organisation of their support work organised through a PB. It is important for this group of people to experience this power over support work as it can help them in living a meaningful life (Johnson & Walmsley, 2010).

227

Implications for disability policy and practice

The empirical findings also suggest implications for disability policy and practice that may improve the quality of support work organised through PBs for people with intellectual disabilities. One implication relates to the role of budget holders and the function of PBs. In Chapter II, I acknowledged that PB researchers in Germany (e.g. Kastl & Metzler, 2005; Metzler et al., 2007; Schäfers, 2009; Prognos, 2012) and Australia (e.g. Fisher et al., 2010; Jones et. al., 2015; Laragy, 2015; Ramcharan, 2016) stressed that budget holders with intellectual disabilities still experience limited power over the organisation of their support work (see Section 'Personal budgets in Germany and Australia'). I also noted that one of the goals of PBs is to increase power for budget holders by enabling choice and control in the process of organising support work (see Section 'Support work relationships in the context of personal budgets' in Chapter II). The empirical findings of this study corroborated what the Australian and German PB researchers found in terms of budget holders exercising limited power over support work. This became evident during conversations that addressed the organisation of support work. Budget holders, especially those with communication support needs (Felix, Lachlan, Jeff, Yelena and Thomas), were often not included in such conversations and experienced a lack of 'adequate supports' to participate in them. The development and implementation of further policy procedures need to allow budget holders to be included in these conversations and have a voice to represent their wishes about how they would like their support work to be delivered. Making these conversations more accessible and adjusting them to the individual communication needs of budget holders would be one way of doing this, which has insufficiently been discussed in the international disability studies literature on PBs for people with disabilities (e.g. Beresford, 2008, 2014; Fisher et al, 2010; Hamilton et al., 2016). However, the process of adjusting these conversations to the individual communication needs of budget holders with intellectual disabilities requires additional time which needs to be considered in the budget sum. In this context, the element of time within the support work relationship needs to be paid more attention to in the process of developing and implementing policies that address the rights of budget holders.

The findings of this study further stressed the relevance of the quality of one-on-one time within the support work relationship. One-on-time was important for the two people in the relationship to build trust and get to know each other properly as it

sometimes provided them with opportunities to focus on each other, get to know each other better and develop a deeper and more intimate relationship with each other (see Section 'Experiences within the second constituent of the ruling relations – The support work context' in Chapter VIII). An implication of this finding is that the support work relationship itself could facilitate the involvement of budget holders with intellectual disabilities in conversations about their PBs. The support worker may have a better understanding of the interests of budget holders, including their wishes of how they would like to express themselves. This understanding could be used to increase their participation options which may result in an experience of having more control about their support work. However, this process needs to be guided with care so that both people feel supported. Further disability policies need to consider the implementation of support work based on this 'careful guidance' by the support worker and others involved in the budget holder's support process.

The findings further emphasised the importance of the worker's support style and the provision of 'adequate supports' to enable power through choice and control over support work activities. The findings showed that a particular style of support (e.g. holding back and giving the budget holder space and time to figure out how they wanted to do an activity) facilitated that budget holders could sometimes exercise choice and control during activities by having more time and a better space to explore how they wanted to do activities. This time and space for personal exploration and its link to the worker's support style is an important implication that new policies concerning support work practice for people with intellectual disabilities need to consider.

Furthermore, the study demonstrated that support workers were often influenced by family members of budget holders in how to involve budget holders in decisions about their support work, which previous literature indicated (e.g. Beadle-Brown, 2015; Bigby, Douglas, & Carney et al., 2017; Bigby, Whiteside, & Douglas, 2017; Rood et al., 2015). This was related to their views of budget holders and their views of the family members of budget holders. In many instances, they saw the parent rather than the budget holder as their employer which sometimes created tensions within the support work relationships. These tensions often came to the surface when arrangements were made about the practical form of support work, the support work activities. Family members often had an expectation about the activities which did not always comply with the expectations of the budget holder. The support worker was usually inclined to meet the

expectations of the family member first. This often hindered budget holders from experiencing that their wishes were heard and realised. However, the empirical findings also revealed that the people in the support work relationship had capacity to understand and respond to the other person's interests and needs, which formed part of the emotional form of support work. Further disability policy and practice could build on this capacity. Both people's knowledge of each other and their relationship could be used to better understand how budget holders with intellectual disabilities can experience greater involvement in the organisation of their support work.

New understandings about support work relationships emerged through this study. This study stressed that the wider social policy context, that encompasses all three constituents of the ruling relations, needs to be taken into account when learning from and about support work relationships. The policies of PBs operate within this wider context and are connected to other policies and practices. Future disability research, policy and practice need to give greater attention to the support work relationship within this wider context as the interconnection of the constituents of the ruling relations within the wider context affect how budget holders with intellectual disabilities and their support workers experience their relationships with each other.

The study demonstrated that using two countries to identify the constituents of the ruling relations through the analytical framework of IE can assist in exploring the wider social policy context that shapes the emotional and practical forms of support work. The ways in which budget holders with intellectual disabilities and their support workers engage in these two forms of support work can influence how they experience their relationship. Understanding the experiences of both people in relationship with each other is important as the support work relationship can serve as a facilitator to involve budget holders with intellectual disabilities in the organisation of their support work. The experience of being involved in the organisation of support work can help budget holders to exercise some power over support work. Exercising this power can support them in living a meaningful life.

Bibliography

Ageing, Disability and Home Care. (2010). *Stronger together: A new direction for disability services in NSW. The second phase (2011-2016).* Sydney, Australia: NSW Department of Family and Community Services.

Antaki, C., Finlay, W. M. L., & Walton, C. (2007). The staff are your friends: Intellectually disabled identities in official discourse and interactional practice. *British Journal of Social Psychology, 46*(1), 1-18.

Axmann, J. (2017). BTHG und Co. - was verändert sich bei Teilhabe und Pflege? Die wichtigsten Neuerungen in der Übersicht. (The New Participation Law and Co. - what changes are made in participation and care? The most important reforms in an overview). *Teilhabe, 2017*(2), 82-88.

Baden-Württemberg. [Map]. (2014). Map of the State of Baden-Württemberg. Retrieved March 18, 2017, from https://commons.wikimedia.org/wiki/File:Baden-Wuerttemberg_travel_map_EN.png

Baden-Württemberg. [Map]. (2017). Map of the State of Baden-Württemberg within the whole of Germany. Retrieved March 18, 2017, from http://ontheworldmap.com/germany/state/baden-wurttemberg/baden-wurttemberg-location-on-the-germany-map.html

Baker, S. E., Edwards, R., & Doidge, M. (2012). *How many qualitative interviews is enough? Expert voices and early career reflections on sampling and cases in qualitative research. Discussion Paper.* Southampton, England: National Centre for Research Methods.

Baumgartner, E., Wacker, E., Castelli, F., Klemenz, R., Oberholzer, D., Schäfers, M., & Wansing, G. (2007). *Assistenzmodelle im internationalen Vergleich: Leistungen und Maßnahmen zur Unterstützung selbstbestimmten und eigenverantwortlichen Lebens in ausgewählten Ländern - Evaluation „Pilotversuch Assistenzbudget". Beiträge zur Sozialen Sicherheit. Research Report (11/07).* (Assistance models in an international comparison: Support services for a self-determined and self-responsible life in selected countries). Bern, Switzerland: Federal Social Insurance Office.

Beadle-Brown, J. (2015). Supported decision-making in the United Kingdom: Lessons for future success. *Research and Practice in Intellectual and Developmental Disabilities, 2*(1), 17-28.

Beadle-Brown, J., Hutchinson, A., & Whelton, B. (2012). Person-Centred Active Support - Increasing Choice, Promoting Independence and Reducing Challenging Behaviour. *Journal of Applied Research in Intellectual Disabilities, 25*(4), 291-307.

Beresford, P. (2008). Time to get Real about Personalisation. *Journal of Integrated Care, 16*(2), 2-4.

Beresford, P. (2014). *Personalisation*. Bristol, England: The Policy Press.

Biewald, M., & Frings, S. (2012). Auf die Plätze, fertig, los!? An die Arbeit - mit Persönlichem Budget! (Ready, Set, Go!? Do the Work - with a Direct Payment!). *Teilhabe, 2012*(1), 37-42.

Bigby, C. (2013). A National Disability Insurance Scheme - Challenges for Social Work. *Australian Social Work, 66*(1), 1-6.

Bigby, C., Douglas, J., Carney, T., Then, S. N., Wiesel, I., & Smith, E. (2017). Delivering decision making support to people with cognitive disability – What has been learned from pilot programs in Australia from 2010 to 2015. *Australian Journal of Social Issues, 52*(3), 222-240.

Bigby, C., Whiteside, M., & Douglas, J. (2017). Providing support for decision making to adults with intellectual disability: Perspectives of family members and workers in disability support services. *Journal of Intellectual & Developmental Disability*, 1-14. DOI: 10.3109/13668250.2017.1378873

Bundesministerium für Arbeit und Soziales (BMAS). (2014). *Das trägerübergreifende Persönliche Budget. (The cross-provider personal budget)*. Bonn, Germany: German Government Department of Labour and Social Affairs.

Bonyhady, B. (2014). National Disability Insurance Scheme: Tides of change – the NDIS and its journey to transform disability support. *The Australian Journal on Psychosocial Rehabilitation*, summer 2014, 6-9.

Bracke, J., & Güttner-Scarfone, C. (2017). Einfach teilhaben! Das (trägerübergreifende) Persönliche Budget in der Praxis. (Easy participation? - The cross-provider personal budget in practice). *Teilhabe, 2017*(1), 30-33.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. London, England: Sage.

Braun, V., & Clarke, V. (2014). What can ''thematic analysis" offer health and wellbeing researchers?. *International journal of qualitative studies on health and well-being, 9*, 1-2.

Brinkmann, S., & Kvale, S. (2005). Confronting the ethics of qualitative research. *Journal of Constructivist Psychology, 18*(2), 157-181.

Brinkmann, S., & Kvale, S. (2015). *InterViews. Learning the craft of qualitative interviewing.* (3rd ed.). Thousand Oaks, USA: Sage.

Broady, T. (2014). What is a person-centred approach?: Familiarity and understanding of individualised funding amongst carers in New South Wales. *Australian Journal of Social Issues, 49*(3), 285-307.

Burr, V. (1995). Does language affect the way we think? In V. Burr, *An introduction to social constructionism* (pp. 32-45). London, England: Routledge.

Caldwell, K. (2014). Dyadic interviewing: A technique valuing interdependence in interviews with individuals with intellectual disabilities. *Qualitative Research, 14*(4), 488-507.

Campbell, M. (2003). Dorothy Smith and knowing the world we live in. *The Journal of Sociology & Social Welfare, 30*(1), 2-22.

Christensen, K. (2009). In(ter)dependent lives. *Scandinavian Journal of Disability Research, 11*(2), 117-130.

Christensen, K. (2010). Caring about independent lives. *Disability & Society, 25*(2), 241-252.

Christensen, K. (2012). Towards sustainable hybrid relationships in cash-for-care systems. *Disability & Society, 27*(3), 399-412.

Christensen, K., & Guldvik, I. (2014). *Migrant Care Workers: Searching for New Horizons*: Surrey, England: Ashgate Publishing Ltd.

Christensen, K., Guldvik, I., & Larsson, M. (2013). Active social citizenship: The case of disabled peoples' rights to personal assistance. *Scandinavian Journal of Disability Research, 16*(sup1), 19-33.

Christensen, K., & Pilling, D. (2014). Policies of Personalisation in Norway and England: On the Impact of Political Context. *Journal of Social Policy, 43*(03), 479-496.

Christensen, K., & Pilling, D. (Eds.). (2018). *The Routledge Handbook of Social Care Work Around the World*. London, England: Routledge.

Clarke, V., & Braun, V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The Psychologist, 26*(2), 120-123.

Collings, S., Dew, A., & Dowse, L. (2019). "They need to be able to have walked in our shoes": What people with intellectual disability say about National Disability Insurance Scheme planning. *Journal of Intellectual & Developmental Disability*, *44*(1), 1-12.

Council of Australian Government. (2009). *National Disability Agreement. Intergovernmental Agreement on Federal Financial Relations*. Australian Government.

Dickinson, H., Needham, C., & Sullivan, H. (2014). Individual Funding for Disability Support: What are the Implications for Accountability? *Australian Journal of Public Administration, 73*(4), 417-425.

Domin, H. (1979). *Abel steh auf. Gedichte Prosa, Theorie*. (Get up Abel. Poems, Prose, Theory). Stuttgart, Germany: Reclam.

Dunne, C. (2010). The place of the literature review in grounded theory research. *International Journal of Social Research Methodology, 14*(2), 111-124.

Ellis, C. (2007). Telling secrets, revealing lives: Relational ethics in research with intimate others. *Qualitative Inquiry, 13*(1), 3-29.

Ellis, C., Adams, T. E., & Bochner, A. P. (2011). Autoethnography: An Overview. *Forum: Qualitative Social Research, 12*(1), (no page numbers).

Emerson, R. M., Fretz, R. I., & Shaw, L. L. (2011). *Writing ethnographic fieldnotes* (2nd ed.). Chicago, USA: University of Chicago Press.

Etherington, K. (2004). *Becoming a Reflexive Researcher: Using Our Selves in Research*. London, England: Jessica Kingsley Publishers.

Etherington, K. (2007). Ethical Research in Reflexive Relationships. *Qualitative Inquiry, 13*(5), 599-616.

Fawcett, B., & Plath, D. (2014). A National Disability Insurance Scheme: What Social Work Has to Offer. *British Journal of Social Work, 44*(3), 747-762.

Fisher, K. R. (2016). *Understanding the NDIS: Many eligible people with disabilities are likely to miss out*. Retrieved June 26, 2018, from https://theconversation.com/understanding-the-ndis-many-eligible-people-with-disabilities-are-likely-to-miss-out-61016

Fisher, K.R., & Campbell-McLean, C. (2008). *Attendant Care Program Direct Funding Pilot Evaluation, SPRC Report 11/08. Final report*. Sydney, Australia: NSW Department of Ageing, Disability and Home Care.

Fisher, K. R., Edwards, R., Gleeson, R., Purcal, C., Sitek, T., Dinning, B., . . . Thompson, D. (2010). *Effectiveness of individual funding approaches for disability support. Occasional*

paper no. 29. Canberra, Australia: Australien Government Department of Families, Housing, Community Services and Indigenous Affairs.

Fisher, K. R., Lutz, D., Gadow, F., Robinson, S., & Gendera, S. (2015). A Transformative Framework for Deinstitutionalisation. *Research and Practice in Intellectual and Developmental Disabilities, 2*(1), 60-72.

Folkestad, H., & Folkestad, L. (2008). The sociology of acceptance revisited: "There must have been something because I grieve so!". *Intellectual and developmental disabilities, 46*(6), 427-435.

Fontane, T. (1898). *Poems. Edition 1898.* Berlin, Germany: Contumax-Verlag.

Franz, D. (2015). *Anforderungen an MitarbeiterInnen in wohnbezogenen Diensten der Behindertenhilfe: Veränderungen des professionellen Handelns im Wandel von der institutionellen zur personalen Orientierung.* (The work conditions of support staff in disability accommodation services: changes of professional actions at the transition from institutional to personalised orientation). Marburg, Germany: Lebenshilfe-Verlag.

Gergen, K. J. (2015). *An invitation to social construction* (3rd ed.). London, England: Sage.

Glendinning, C., Challis, D., Fernandez, J., Jacobs, S., Jones, K., Knapp, M., . . . Stevens, M. (2008). *Evaluation of the individual budgets pilot programme. Final Report.* York, England: Social Policy Research Unit, University of York.

Goodley, D. (1999). Disability Research and the "Researcher Template": Reflections on Grounded Subjectivity in Ethnographic Research. *Qualitative Inquiry, 5*(1), 24-46.

Goodley, D. (2014). *Dis/ability studies: Theorising disablism and ableism.* New York, USA: Routledge.

Grace, D. (2013). Transnational institutional ethnography: Tracing text and talk beyond state boundaries. *International Journal of Qualitative Methods, 12*(1), 587-605.

Griffith, A. I., & Smith, D. E. (2014). *Under new public management: Institutional ethnographies of changing front-line work.* Toronto, Canada: University of Toronto Press.

Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and "ethically important moments" in research. *Qualitative Inquiry, 10*(2), 261-280.

Guldvik, I. (2014). Facing Challenging Intimate Relationships. In K. Christensen & I. Guldvik (Eds.), *Migrant care workers: searching for new horizons* (pp. 147-172). Surrey, England: Ashgate Publishing Ltd.

Hamilton, S., Tew, J., Szymczynska, P., Clewett, N., Manthorpe, J., Larsen, J., & Pinfold, V. (2016). Power, choice and control: How do personal budgets affect the experiences of people with mental health problems and their relationships with social workers and other practitioners? *The British Journal of Social Work, 46*(3), 719-736.

Hammersley, M., & Atkinson, P. (1995). *Ethnography: Principles in practice.* (2nd ed.). New York, USA: Routledge.

Hammersley, M., & Atkinson, P. (2007). *Ethnography: Principles in practice.* (3rd ed.). New York, USA: Routledge.

Hantrais, L. (2014). Methodological pluralism in international comparative research. *International Journal of Social Research Methodology, 17*(2), 133-145.

Hantrais, L., & Mangen, S. P. (1996). *Cross National Research Methods*: London, England: Bloomsbury Publishing.

Hesse, H. (2017). *Stufen. Ausgewählte Gedichte 1895 bis 1941. (Steps. Selected poems 1895 to 1941).* Frankfurt am Main, Germany: Suhrkamp.

Honer, A. (1994). Das explorative Interview: Zur Rekonstruktion der Relevanzen von Expertinnen und anderen Leuten. (The exploratory interview: On the reconstruction of the relevance of experts and other people). *Swiss Journal of Sociology, 20*(3), 623-640.

Honer, A. (2011). Das explorative Interview (The exploratory interview). In Honer, A., *Kleine Leiblichkeiten: Erkundungen in Lebenswelten (Little corporealities: exploring life worlds)* (pp. 41-58). Wiesbaden, Germany: VS Verlag für Sozialwissenschaften.

Hooyman, N. R., & Gonyea, J. G. (1999). A feminist model of family care: Practice and policy directions. *Journal of Women & aging, 11*(2-3), 149-169.

Hudson, J., & Lowe, S. (2009). *Understanding the policy process: Analysing welfare policy and practice.* Bristol, England: The Policy Press.

Jacobs, S., Abell, J., Stevens, M., Wilberforce, M., Challis, D., Manthorpe, J., . . . Netten, A. (2013). The personalization of care services and the early impact on staff activity patterns. *Journal of Social Work, 13*(2), 141-163.

Johnson, K. (1998). *Deinstitutionalising women: An ethnographic study of institutional closure.* Cambridge, England: Cambridge University Press.

Johnson, K., & Walmsley, J. (2010). *People with intellectual disabilities: Towards a good life?.* Bristol, England: Policy Press.

Johnson, K. (2013). The UN Convention on the Rights of Persons with Disabilities: A Framework for Ethical and Inclusive Practice? *Ethics and Social Welfare, 7*(3), 218-231.

Jones, K., Netten, A., Rabiee, P., Glendinning, C., Arksey, H., & Moran, N. (2014). Can individual budgets have an impact on carers and the caring role? *Ageing and Society, 34*(01), 157-175.

Jones, A., Purcal, C., Meltzer, A., Lutz, D., Fisher, K. R., Robinson, S., . . . Kayess, R. (2015). *Supported Accommodation Evaluation Framework (SAEF). Individual Packages.* Sydney, Australia: Social Policy Research Centre, UNSW Australia.

Kastl, J.M., & Metzler, H. (2005). *Modellprojekt Persönliches Budget für Menschen mit Behinderung in Baden-Württemberg (The pilot of personal budgets for people with disabilities in Baden-Württemberg). Final Report.* Stuttgart, Germany: State Government of Labour and Social Affairs Baden-Württemberg.

Kastl, J. M., & Meyer, T. (2007). Deinstitutionalisierung durch Persönliche Budgets? Am Beispiel der Situation von Menschen mit psychischen Behinderungen. (Deinstitutionalisation through personal budgets? The example of the situation of of people with mental health issues). Retrieved from http://www.zslschweiz.ch/z_alteseite/Archiv/PDF/Deinstitutionalisierung%20durch%20 Persoenliche%20Budgets.pdf

Kayess, R., & French, P. (2008). Out of darkness into light? Introducing the Convention on the Rights of Persons with Disabilities. *Human rights law review, 8*(1), 1-34.

Kelly, C. (2011). Making 'care' accessible: Personal assistance for disabled people and the politics of language. *Critical Social Policy, 31*(4), 562-582.

Kelly, C. (2013). Building Bridges with Accessible Care: Disability Studies, Feminist Care Scholarship, and Beyond. *Hypatia, 28*(4), 784-800.

Kelly, C. (2016). *Disability Politics and Care: The Challenge of Direct Funding.* Vancouver, Canada: UBC Press.

Kelly, C. (2017a). Care and violence through the lens of personal support workers. *International Journal of Care and Caring, 1*(1), 97-113.

Kelly, C. (2017b). Exploring experiences of Personal Support Worker education in Ontario, Canada. *Health & Social Care in the Community, 25*(4), 1-9.

Kelly, C., & Chapman, C. (2015). Adversarial Allies: Care, Harm, and Resistance in the Helping Professions. *Journal of Progressive Human Services, 26*(1), 46-66.

Kinsella, E. A. (2006). Hermeneutics and Critical Hermeneutics: Exploring Possibilities within the Art of Interpretation. *Forum: Qualitative Social Research, 7*(3), (no page numbers).

Kittay, E. F. (2001). When caring is just and justice is caring: Justice and mental retardation. *Public Culture, 13*(3), 557-579.

Kittay, E. F. (2002). Loves Labor Revisited. *Hypatia, 17*(3), 237-250.

Kittay, E. F. (2009a). The Moral Harm of Migrant Carework. *Philosophical Topics, 37*(2), 53-73.

Kittay, E. F. (2009b). The Personal is Philosophical is Political: A philosopher and mother of a cognitively disabled person sends notes from the battlefield. *Metaphilosophy, 40*(3/4), 606-627.

Kittay, E. F. (2011). The Ethics of Care, Dependence, and Disability. *Ratio Juris, 24*(1), 49-58.

Kotsch, L. (2012). *Assistenzinteraktionen: Zur Interaktionsordnung in der persönlichen Assistenz körperbehinderter Menschen. (Assistance-interactions: About the organisation of interactions within personal assistance for people with physical disabilities)*. Wiesbaden, Germany: Springer.

Krumer-Nevo, M., & Sidi, M. (2012). Writing Against Othering. *Qualitative Inquiry, 18*(4), 299-309.

Kröger, T. (2009). Care research and disability studies: Nothing in common? *Critical Social Policy, 29*(3), 398-420.

Kulick, D., & Rydström, J. (2015). *Loneliness and its opposite: Sex, disability, and the ethics of engagement*. London, England: Duke University Press.

Kvale, S. (2006). Dominance Through Interviews and Dialogues. *Qualitative Inquiry, 12*(3), 480-500.

LaFrance, M., & Nicolas, M. (2012). Institutional Ethnography as Materialist Framework for Writing Program Research and the Faculty-Staff Work Standpoints Project. *College Composition and Communication, 64*(1), 130.

Laragy, C., Fisher, K. R., Purcal, C., & Jenkinson, S. (2015). Australia's Individualised Disability Funding Packages: When Do They Provide Greater Choice and Opportunity?. *Asian Social Work and Policy Review, 9*(3), 1-11.

Leece, D., & Leece, J. (2006). Direct payments: Creating a two-tiered system in social care?. *British Journal of Social Work, 36*(8), 1379-1393.

Leece, J. (2010). Paying the Piper and Calling the Tune: Power and the Direct Payment Relationship. *British Journal of Social Work, 40*(1), 188-206.

Leece, J., & Leece, D. (2010). Personalisation: Perceptions of the role of social work in a world of brokers and budgets. *British Journal of Social Work, 41*(2), 204-223.

Leece, J., & Peace, S. (2010). Developing New Understandings of Independence and Autonomy in the Personalised Relationship. *British Journal of Social Work, 40*(6), 1847-1865.

Lutz, D., Fisher, K. R., & Robinson, S. (2016). Sharing the focus: Engaging with support workers to include people with communication needs in research. *British Journal of Learning Disabilities*, *44*(2), 138-145.

Macdonald, F., & Charlesworth, S. (2016). Cash for care under the NDIS: Shaping care workers' working conditions?. *Journal of Industrial Relations*, *58*(5), 627-646.

Mackay, H. (2016: *Beyond belief. How we find meaning, with or without religion.* Sydney, Australia: Pan Macmillian Australia.

Malacrida, C. (2007). Reflexive journaling on emotional research topics: Ethical issues for team researchers. *Qualitative Health Research, 17*(10), 1329-1339.

Maslow, A. H. (1971). *The farther reaches of human nature.* New York, USA: The Viking Press.

Marx, K. (1971). *A contribution to the critique of political economy*. London, England: Lawrence & Wishart.

Marx, K. (1977). *Capital: A critique of political economy. Volume 1*. New York, USA: Vintage Books.

Mavromaras, K., Moskos, M., Mahuteau, S., & Isherwood, L. (2018). *Evaluation of the NDIS. Final Report*. Adelaide, Australia: National Institute of Labour Studies, Flinders University.

Merton, R. K., & Kendall, P. L. (1946). The Focused Interview. *American Journal of Sociology, 51*(6), 541-557.

Metzler, H., Meyer, T., Rauscher, C., Schäfers, M., & Wansing, G. (2007). *Begleitung und Auswertung der Erprobung trägerübergreifender Persönlicher Budgets (Evaluation of the personal budget pilots in Germany)*. Final report. Berlin, Germany: German Government Department of Labour and Social Affairs.

Meyer, T. (2011). *Potenzial und Praxis des persönlichen Budgets (The potential and implementation of personal budgets)*. Wiesbaden, Germany: Springer.

Morris, J. (2001). Impairment and Disability: Constructing an Ethics of Care That Promotes Human Rights. *Hypatia, 16*(4), 1-16.

National Disability Insurance Scheme Act. (2013). *No. 20.* Retrieved February 8, 2019, from: https://www.legislation.gov.au/Details/C2013A00020

National Participation Law (2016). Gesetz zur Stärkung der Teilhabe und Selbstbestimmung von Menschen mit Behinderungen – Bundesteilhabegesetz). (Law about the improvement of

participation and self-determination for people with disabilities – National Participation Law). Retrieved February 8, 2019, from: https://www.bmas.de/SharedDocs/Downloads/DE/PDF-Meldungen/2016/bundesteilhabegesetz.pdf?__blob=publicationFile&v=7

Needham, C., & Dickinson, H. (2018). 'Any one of us could be among that number': Comparing the Policy Narratives for Individualized Disability Funding in Australia and England. *Social Policy & Administration, 52*(3), 731-749.

Niediek, I. (2010). *Das Subjekt im Hilfesystem. (The subject within the support system)*. Wiesbaden, Germany: Springer.

Norstedt, M., & Breimo, J. P. (2016). Moving Beyond Everyday Life in Institutional Ethnographies: Methodological Challenges and Ethical Dilemmas. *Forum: Qualitative Social Research, 17*(2), (no page numbers).

O'Reilly, K. (2012). *Ethnographic methods*. New York, USA: Routledge.

Porter, T., & Shakespeare, T. (2016). 'Imposed unknowns': a qualitative study into the impact of Independent Living Fund closure on users. *Disability & Society*, *31*(7), 884-896.

Pearson, C. (2012). Independent living. In N. Watson, A. Roulstone, & C. Thomas (Eds.), *Routledge Handbook of Disability Studies* (pp. 240-252). New York, USA: Routledge.

Productivity Commission. (2011). *Disability care and support. Inquiry report no. 54*. Melbourne, Australia: Australian Government.

Prognos. (2012). *Forschungsbericht 433. Umsetzung und Akzeptanz des Persönlichen Budgets. (Research Report 433. Implementation and Responsiveness of Personal Budgets)*. Berlin, Germany: German Government Department of Labour and Social Affairs.

Purcal, C., Fisher, K. R., & Laragy, C. (2014). Analysing choice in Australian individual funding disability policies. *Australian Journal of Public Administration, 73*(1), 88-102.

Ramcharan, P. (2016). *Understanding the NDIS: A history of disability welfare from 'deserving poor' to consumers in control*. Retrieved June 26, 2018, from https://theconversation.com/understanding-the-ndis-a-history-of-disability-welfare-from-deserving-poor-to-consumers-in-control-58069

Rankin, J., & Campbell, M. (2009). Institutional Ethnography (IE), Nursing Work and Hospital Reform: IE's Cautionary Analysis. *Forum: Qualitative Social Research, 10*(2), (no page numbers).

Rilke, R. M. (2008). *Letters to a young poet*. New York, USA: BN Publishing.

Rogers, C. (2003). The mother/researcher in blurred boundaries of a reflexive research process. *Auto/Biography, 11*(1&2), 47-54.

Rogers, C. (2007). Disabling a family? Emotional dilemmas experienced in becoming a parent of a child with learning disabilities. *British Journal of Special Education, 34*(3), 136-143.

Rogers, C. (2009). (S)excerpts from a life told: Sex, gender and learning disability. *Sexualities, 12*(3), 270-288.

Rogers, C. (2012). Intellectual disability and mothering: An engagement with ethics of care and emotional work. In C. Rogers & S. Weller (Eds.), *Critical approaches to care: Understanding caring relations, identities and cultures.* (pp. 132-143). London, England: Routledge.

Rogers, C. (2016). *Intellectual Disability and Being Human: A Care Ethics Model.* London, England: Routledge.

Rogers, C., & Tuckwell, S. (2016). Co-constructed caring research and intellectual disability: An exploration of friendship and intimacy in being human. *Sexualities, 19*(5&6), 623-640.

Rogers, C., & Weller, S. (Eds.). (2013). Critical Approaches to Care: understanding caring relations, identities and cultures. New York, USA: Routledge.

Rood, C. E., Kanter, A., & Causton, J. (2014). Presumption of incompetence: The systematic assignment of guardianship within the transition process. *Research and Practice for Persons with Severe Disabilities,* 39(4), 319-328.

Schutz, A. (1962). *Collected papers. Volume 1: The problem of social reality.* The Hague, The Netherlands: Martinus Nijhoff.

Schäfers, M. (2009). Wie man aus einem Persönlichen Budget eine verdeckte Sachleistung macht. (How to transform a personal budget into a concealed in-kind benefit). *Teilhabe, 2009*(4), 176-183.

Sevenhuijsen, S. (1998). *Citizenship and the ethics of care: Feminist considerations on justice, morality, and politics.* New York, USA: Routledge.

Shakespeare, T. (2006a). Care, support and assistance. In T. Shakespeare, *Disability Rights and Wrongs* (pp. 135-152). London, England: Routledge.

Shakespeare, T. (2006b). Disability Rights and Wrongs. London, England: Routledge.

Shakespeare, T. (2014a). Personal assistance as a relationship. In T. Shakespeare, *Disability rights and wrongs revisited* (2nd ed., pp. 173-187). New York: Routledge.

Shakespeare, T. (2014b). *Disability rights and wrongs revisited* (2nd ed.). New York, USA: Routledge.

Shakespeare, T., Porter, T., & Stöckl, A. (2017). *Personal assistance relationships: power, ethics and emotions. Report on ESRC project.* Norwich, England: University of East Anglia.

Shakespeare, T., Stöckl, A., & Porter, T. (2018). Metaphors to work by: The meaning of personal assistance in England. International Journal of Care and Caring, 2(2), 165-179.

Slade, B. (2010). Institutional ethnography. In A. J. Mills, G. Durepos, & E. Wiebe (Eds.), *Encyclopedia of Case Study Research* (pp. 462-465). Thousand Oaks, USA: Sage.

Slasberg, C., & Beresford, P. (2015). Building on the original strengths of direct payments to create a better future for social care. *Disability & Society, 30*(3), 479-483.

Slasberg, C., Beresford, P., & Schofield, P. (2012). How self-directed support is failing to deliver personal budgets and personalisation. *Research, Policy and Planning, 29*(3), 161-177.

Slote, M. (2007). *The Ethics of Care and Empathy* (1st ed.). New York, USA: Taylor and Francis.

Smith, D. E. (1987). *The everyday world as problematic: A feminist sociology*. Toronto, Canada: University of Toronto Press.

Smith, D. E. (1990a). *Texts, facts, and femininity: Exploring the relations of ruling*. New York, USA: Routledge.

Smith, D. E. (1990b). *The conceptual practices of power: A feminist sociology of knowledge*. Toronto, Canada: University of Toronto Press.

Smith, D. E. (1992). Sociology from Women's Experience: A Reaffirmation. *Sociological Theory, 10*(1), 88-98.

Smith, D. E. (1996). The relations of ruling: A feminist inquiry. *Studies in Cultures, Organizations and Societies, 2*(2), 171-190.

Smith, D. E. (2001). Texts and the ontology of organizations and institutions. *Studies in Cultures, Organizations and Societies, 7*(2), 159-198.

Smith, D. E. (2004). Ideology, Science and Social Relations: A Reinterpretation of Marx's Epistemology. *European Journal of Social Theory, 7*(4), 445-462.

Smith, D. E. (2005). *Institutional ethnography: A sociology for people*. Toronto, Canada: Rowman Altamira.

Smith, D. E. (2006). *Institutional ethnography as practice*. Oxford, England: Rowman & Littlefield Publishers.

Smith, D. E. (2008). Institutional Ethnography. In Lisa M. Given (Ed.), *The Sage Encyclopedia of Qualitative Research Methods* (pp. 433-436). Thousand Oaks, USA: Sage.

Soldatic, K., van Toorn, G., Dowse, L., & Muir, K. (2014). Intellectual Disability and Complex Intersections: Marginalisation under the National Disability Insurance Scheme. *Research and Practice in Intellectual and Developmental Disabilities, 1*(1), 6-16.

Spradley, J. P. (1979). *The ethnographic interview*. Long Grove, USA: Waveland Press.

Sydney [Map]. (2015). Greater Sydney Region. Retrieved March, 18, 2017, from https://commons.wikimedia.org/wiki/File:Greater_Sydney_map.svg

Tew, J., Larsen, J., Hamilton, S., Manthorpe, J., Clewett, N., Pinfold, V., & Szymczynska, P. (2015). 'And the Stuff that I'm Able to Achieve Now Is Really Amazing': The Potential of Personal Budgets as a Mechanism for Supporting Recovery in Mental Health. *British Journal of Social Work, 45*(suppl_1), i79-i97.

Timonen, V., Convery, J., & Cahill, S. (2006). Care revolutions in the making? A comparison of cash-for-care programmes in four European countries. *Ageing & Society, 26*(3), 455-474.

Traustadóttir, R. (2001). Research with others: Reflections on representation, difference and othering. *Scandinavian Journal of Disability Research, 3*(2), 9-28.

Trescher, H. (2017). Behinderung, Fluchtmigration, Kommunikation (Disability, forced migration, communication). *Teilhabe, 2017*(4), 150-155.

Ulrich, W. (2006). Rethinking critically reflective research practice: Beyond Popper's critical rationalism. *Journal of Research Practice, 2*(2), 1-18.

Ungerson, C. (1983). Why do women care? In J. Finch & D. Groves (Eds.), *A labour of love: Women, work and caring* (pp. 31-49). London, England: Routledge.

Ungerson, C. (1996). Part two: Qualitative methods. In L. Hantrais & S. Mangen (Eds.), *Cross-national research methods in the social sciences*, (pp. 63-65). London, England: Pinter.

Ungerson, C. (1999). Personal assistants and disabled people: An examination of a hybrid form of work and care. *Work, Employment and Society, 13*(04), 583-600.

Ungerson, C. (2003). Commodified care work in European labour markets. *European Societies, 5*(4), 377-396.

United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. Retrieved February 6, 2019, from: https://www.un.org/development/desa/disabilities/

UNSW Australia. (2015). *UNSW Human Research Ethics. Risk Assessment and Application Form*. Sydney, Australia: UNSW Australia.

Vehmas, S. (2012). What can philosophy tell us about disability? In N. Watson, A. Roulstone, & C. Thomas (Eds.), *Routledge handbook of disability studies* (pp. 298-309). New York, USA: Routledge.

Vorhaus, J. S. (2007). Disability, Dependency and Indebtedness? *Journal of Philosophy of Education, 41*(1), 29-44.

Vorhaus, J. S. (2013). Capability, freedom and profound disability. *Disability & Society, 28*(8), 1047-1058.

Vorhaus, J. S. (2014). Philosophy and profound disability: Learning from experience. *Disability & Society, 29*(4), 611-623.

Vorhaus, J. S. (2015). Dignity, Capability, and Profound Disability. *Metaphilosophy, 46*(3), 462-478.

Wacker, E., Wansing, G., & Schäfers, M. (2009). *Personenbezogene Unterstützung und Lebensqualität: Teilhabe mit einem persönlichen Budget (Person-centred support and quality of Life: participation with a personal budget)*. Wiesbaden, Germany: Springer.

Walby, K. (2005). Institutional ethnography and surveillance studies: An outline for inquiry. *Surveillance & Society, 3*(2/3), 158-172.

Walby, K. (2007). On the Social Relations of Research: A Critical Assessment of Institutional Ethnography. *Qualitative Inquiry, 13*(7), 1008-1030.

Walby, K. (2012). Institutional ethnography and data analysis: Making sense of data dialogues. *International Journal of Social Research Methodology, 16*(2), 141-154.

Walmsley, J. (1993). Contradictions in Caring: Reciprocity and Interdependence. *Disability, Handicap & Society, 8*(2), 129-141.

Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present, and futures*. London, England: Jessica Kingsley Publishers.

Watson, N., McKie, L., Hughes, B., Hopkins, D., & Gregory, S. (2004). (Inter)Dependence, Needs and Care: The Potential for Disability and Feminist Theorists to Develop an Emancipatory Model. *Sociology, 38*(2), 331-350.

Whitburn, B., Moss, J., & O'Mara, J. (2017). The policy problem: The National Disability Insurance Scheme (NDIS) and implications for access to education. *Journal of Education Policy, 32*(4), 467-479.

Widerberg, K. (2004). Institutional ethnography – towards a productive sociology. An interview with Dorothy E. Smith. *Sosiologisk tidskrift, 12*, 179-184.

Wieder, D. L. (1974). *Language and social reality: The case of telling the convict code. Volume 10*. The Hague, The Netherlands: Mouton & Co.

Wilkinson, S., & Kitzinger, C. (2013). Representing Our Own Experience: Issues in "Insider" Research. *Psychology of Women Quarterly, 37*(2), 251-255.

Winance, M., Damamme, A., & Fillion, E. (2015). Thinking the aid and care relationship from the standpoint of disability: Stakes and ambiguities. *ALTER - European Journal of Disability Research, 9*(3), 163-168.

Witzel, A. (2000). The Problem-centered Interview. *Forum: Qualitative Social Research, 1*(1), (no page numbers).

Yamaki, C., & Yamazaki, Y. (2004). 'Instruments','employees','companions','social assets': Understanding relationships between persons with disabilities and their assistants in Japan. *Disability & Society, 19*(1), 31-46.

Appendices

Appendix A: Semi-structured interview schedule for service professionals in the first fieldwork stage (English version)

(see pages below)

Interview questions (service professionals)

Background

First, I'd like to get some background information on your organisation and your role.

1. Can you please describe your role within the organisation?

2. How long have you worked here?

3. What type of support work (or personal assistance) does your organisation deliver to people with intellectual disabilities?

Personal budget policies and implementation

Over the years, there have been changes in policy and practice concerning the ways support is designed and delivered to better meet the needs of people with intellectual disabilities. For example, personal budgets have been introduced in many countries to allow them to purchase the support services that they really want. With this money, they are meant to buy support work (or personal assistance) and organise it in a way so it suits their needs. I'd like to hear about your views on those changes within your organisation.

4. How is your organisation dealing with those changes?
   - What are the values within your organisation that underpin those changes?
   - What values within your organisation shape support work organised through a personal budget?

5. How does your organisation use policy guidelines and principles to support the relationships between support workers and people with intellectual disabilities?
   - Can you tell me about these principles and explain how your organisation integrates them into service delivery?
   - How well does this process work?

Support work context

Through personal budgets, people with intellectual disabilities and their support workers often spend more time together on their own. They can become very friendly with each other and it may be hard at times to maintain professional boundaries.

6. How do you think and feel about this?
   - Can you think of potential benefits or challenges for the relationship between support workers and people with intellectual disabilities?

7. What professional qualifications (if at all) do support workers within your organisation hold?
   - Can you tell me about the training that support workers receive in your organisation to carry out their work?

8. How (if at all) are people with intellectual disabilities included and consulted during the support process?
   - What choice do people with intellectual disabilities have about selecting a support worker? How does this selection process work? Who selects them?

9. How does your organisation support and encourage the support worker and the person with intellectual disabilities to work together? (prompt for training, education, professional development, supervision, workshops)?

10. What do you think makes a good support worker?
    - Can you describe the professional approach they take towards people with intellectual disabilities?
    - How do people with intellectual disabilities react to this approach?

Relationships

My PhD study aims to better understand how support workers and people with intellectual disabilities in receipt of a personal budget experience their relationships together. One of the purposes of personal budgets is to support people with intellectual disabilities in gaining independence. However, achieving more independence means that the budget holder may be less dependent on their support worker.

11. How do you think about this?

12. Can you please tell me a little about how support workers and people with intellectual disabilities work together?
    - What are your own observations of these support relationships?
    - How are people with intellectual disabilities in your organisation assisted in their everyday lives by their support workers?

13. What do you think could be the challenges people with intellectual disabilities and their support workers face in their relationships together?

14. How well are these relationships recognised and supported by your organisation?

15. What qualities help support workers and people with intellectual disabilities in your organisation to work well together?

- What do you think both people get out of this relationship?

16. What other things do you think influences the development of this relationship? (prompt for geographical location, age, gender)

Final question and comment

We are now at the end of the interview. I have one final question for you.

What are the main rights and responsibilities of both people in the support relationship from your point of view?

I am wondering if there is anything we haven't talked about today that you'd like to share with me. Do you have any questions for me? You can also provide material in writing if you like.

Would you be willing to talk to me again after this interview? I might have some follow-up questions for you at a later stage of this research study.

Thank you for your participation in the interview.

Appendix B: Consent form with pictures for people with intellectual disabilities (English version)

(see pages below)

PARTICIPANT INFORMATION STATEMENT AND CONSENT FORM

My name is Debbie Lutz. I am a researcher from the University of New South Wales. I would like to invite you to take part in my study as I am interested in learning about your experiences of working with a support worker. This form tells you about the study and what it means to take part in it.	
I will spend about 3 weeks with you and your support worker. During this time, I would like to join you and your support worker in some of the activities you do together and take notes. I will also have a photo camera on me and may take photos of you if you agree. Or you may decide to take some photos yourself.	
These photos will NOT be made public. They may go into a booklet with a summary of the study. This booklet will only be for you and your support worker.	

I will also talk to you and your support worker about what it's like to work together. You can answer whatever questions YOU like. I will record the interview if you agree.	
Taking part in the study is your choice. It is okay say NO or YES. If you decide to take part then you sign page 4 and tick the boxes. You then allow me to use information about you for this study. But I won't let anyone know who you are.	
You will get a $30 gift voucher for your time and costs. You can use the voucher at any Westfield Shopping Centre.	
Sometimes people get upset after taking part in a research activity. This doesn't happen often. If it does, you can tell me about it. Or you can contact the Mental Health Line on 1800 011 511.	
You can leave the study during the time we work together. You just need to sign the last page. Or you can ring +61410922218 or email d.lutz@unsw.edu.au me. Once we have finished working together, you cannot leave the study anymore. You can also phone my teacher Kelley Johnson (9385 7802) or email her (kelley.johnson@unsw.edu.au) if you don't want to talk to me.	

I will also be spending some time in Germany during this study and will be working with support workers and people with intellectual disabilities there. I would like to give you my German contact details so you can talk to me while I am away. My German phone number is +4915754113491 and my email address is d.lutz@unsw.edu.au.

You can also contact my German teacher Thomas Meyer via email (Thomas.Meyer@dhbw-stuttgart.de) or phone him on +497111849654 if you don't want to talk to me.

If you have complaints, you can email (humanethics@unsw.edu.au) or ring (9385 6222) the Human Research Ethics Coordinator and give them this number: HC15738.

Yes – I want to take part in the study

I have read this form/ someone explained it to me;

I understand what it means to take part;

Photos of me can be taken;

I understand that I can only leave the study during the time I am working with Debbie

_____

Printed name of participant

_____

Signature of participant

_____

Date

Declaration by Researcher*

I have given a verbal explanation of the research study, its study activities and risks and I believe that the participant has understood that explanation.

_____

Name of Researcher

_____

Researcher Signature*

_____

Date

[+]An appropriately qualified member of the research team must provide the explanation of, and information concerning the research study. All parties signing the consent section must date their own signature.

I changed my mind – I don't want to take part anymore

I wish to **LEAVE** the research study and understand that this **WILL NOT** change my relationship with the university or the researcher/s.

_____
Printed name of participant

_____
Signature of participant

_____
Date

This signed form should go to:

Professor Kelley Johnson

Social Policy Research Centre

University of New South Wales

John Goodsell Building (F20), Level 2, Room 320

Kensington NSW 2052

Email: Kelley.johnson@unsw.edu.au

Phone: 02 9385 7802

Appendix C: Observation guide for the ethnographic field research

Guide for participant observation

<u>**Research Questions**</u>

1. **How do people with intellectual disabilities in receipt of a personal budget and their support workers experience their relationships with each other?**

2. **How are the lived experiences of people with intellectual disabilities and their support workers in their relationship with each other influenced by personal budget policies organising support work?**

<u>**General impressions**</u>

Finding out about the lives of participants

- What did I observe about their lives today?
- What did I observe about their feelings today?
- What did I observe about them being in a relationship with each other? How much time did they actually spend together on the day I observed them?
- What did I experience about myself (e.g. my gender, my cultural background, my use of language etc.) when I observed them today? (in footnotes)

<u>**Relationship between support worker and budget holder**</u>

Development of the support work relationship

- Did I observe any challenges? What did I observe about these challenges (e.g. the type of challenge)? How were they resolved?
- Were there any boundaries (e.g. personal space) to the relationship? If yes, how were they negotiated?
- What did I observe about their communication (e.g. verbal, physical affection, telepathy etc.)?
- What role does physical affection play within the support work relationship? Are there policies on this?

Possible factors influencing the support work relationships

- What did I observe about intellectual disability, gender, age, sexuality and possible cultural differences within the support work relationship (if at all)?

- What did I observe about the characteristics and behaviours both people displayed when they worked together? How did it influence their engagement? Was there a particular characteristic (e.g. humour) that stood out?
- What other factors (e.g. third parties, such as flatmates or family members) did I observe that influenced the relationship?
  (the last three questions are more process-related and it may be easier to answer them after a few days of observing people)

Support work and personal budget policies

Support work

- What did I observe about both people relating each other?
- What activities were parts of today's support work practice? Did the support worker need support or care (e.g. reassurance) from the person with intellectual disabilities at all?
- How were these activities related to independent living skill development? How were they related to a particular support goal?
- Did I observe a connection between the support work activity and disability? If yes, describe this observation.
- What role does planning play within daily support work practice?

Personal budget policies

- How were power (e.g. power-sharing, power-imbalances), choice and control about decision-making within the support work relationship negotiated today? What other relationships are of importance to the support work relationship? Are there other power forces?
- How might issues of power and its negotiation *(consider the Employer Model)* be linked to the personal budget arrangement and its policies?
- How were behaviours and actions of both persons influenced by the policies (*IE framework*) of the support organisations involved in the support process? Do people make their own rules and policies when they work together? How do they develop their own relationship culture?
- Do they know about these policies? What is their understanding of these policies? If yes, did I observe that both people translate the organisational policies into practice?

Reflections on the researcher's experience and perception of herself

(this can be captured in footnotes)

Feelings of the researcher

- What did I feel during today's observations?
- What were my difficult emotions that arose in the observational experience and how did I manage them?
- Which enjoyable emotions did I feel today and how did they arise?

The researcher role

- What did I observe about the role that I took today?
- How did it come to be that I took this role?
- What was it like being in this role?
- How did I negotiate the role of the *observer* and *participant* today?
- Were there other significant roles that I took (e.g. my role as a woman)?
- What could I have done differently?
- How did I feel about this role?

Shared/similar experience

- What experience did I share with participants today?
- What did I experience that I felt was similar to the ones of participants? (sometimes this comes up as a memory)
- How did I bond with participants (if at all)? What was this process like?

Being in relationships with participants

- How did I get to know the participants a bit better today?
- How (if at all) did I build rapport with the person with intellectual disabilities today?
- How (if at all) did I build rapport with the support worker today?
- What might have made it difficult to build rapport with one of them?

Appendix D: Interview schedule for people with intellectual disabilities (English version)

Interview questions - person with intellectual disabilities

Background questions

- Can you tell me a little about yourself and your life? What do you enjoy doing? What are the most important things in your life?
- How many support workers do you have? (Alternative question: Does anyone else work with you the way ___ does?)
- How do you choose your support worker/s? How do you meet your support worker?
- Can you describe what it was like to start working with your support worker/s?
- What do you know about your support worker? How old is/are your support worker/s?

Support work relationship – feelings about each other

You spend _____ hours together each week. This must lead at times to different feelings about working with your support worker. (abstract thinking)

- How do you feel about working with the support worker? (prompt for feelings about gender, age, sexuality, boundaries, possible cultural differences, professional background of support worker)
- What are the things you like about your support worker the most?
- What are the things you talk to your support worker about?
- When do you know when your support worker is having a good day or bad day?
- When does your support worker know when you're having a good day or bad day?

Spending time together

- Where do you and your support worker spend time together?
- What are the places you visit together?
- What do you think about other people being at these places? (if applicable)
- Can you explain what it is like to spend time together in public spaces?
- Can you explain what it is like to spend time with your support worker in your own home?
- Are there any meetings that you and the support worker and other people attend together to discuss how to best support you? Can you explain what you do in those meetings?

Working together and learning from each other

- Can you please tell me a little about how you both work together? What are the things your support worker helps you with?
- Can you explain what it's like on the days when your support worker isn't around (maybe ask this question if the person has more than one support worker)?
- When you and your support worker have disagreements, how do you solve them?
- What has been the best thing so far that you and your support worker did together? What made it 'the best thing'?
- What does working well together mean to you?
- What do you learn from your support worker? What does your support worker learn from you?
- When do you have a lot of fun with your support worker?

Policies of personal budgets

I heard that you receive a personal budget (use the term for 'personal budget' that the budget holder is familiar with) to buy your supports. What does it mean to you to have a personal budget?

- What is it like to have your own money for support? How do you use it?
- Can you describe what changed by using your own money for support?
- What is this new way of working with a support worker like?
- What support do you get with the management of the budget and the planning for it? Can you describe what the support worker supports you with?

Closing questions

- Can you describe what changed in your life since you started working with your support worker? (abstract question) What would you like to change?
- How would you see your relationship with the support worker in future if you stopped working together one day? (abstract question)
- How did any of your past relationships with support workers develop after you stopped working with them? (abstract question)

Appendix E: Interview schedule for support workers (English version)

Interview questions - support worker

Background questions

- How many people with disabilities do you support?
- When did you start working as a support worker?
- How old is/are the person/s you're supporting?
- When did you meet the person you are supporting? When did you start working with him/her?

Support work relationship – feelings about each other

You spend _____ hours together each week. This must lead at times to different feelings about your work.

- How do you feel about working with the person you're supporting? (prompt for feelings about gender, age, intellectual disability, sexuality, possible cultural differences)
- What are the things you like about the person the most?
- What are the things you talk about with the person you are supporting?
- What do you do when the person is having a good or bad day?
- What do you do when you are having a good or bad day?

Support work

- How do other people within your organisation assist you in supporting a person with intellectual disabilities (prompt for training, supervision, personal development, reflexive practice)?
- Where do you and the person spend time together? What are the places you visit together?
- What do you do there?
- What do you think about other people being at these places?
- What is it like to spend time together in public spaces? What is it like to spend time in the person's home?
- What do 'professional boundaries' mean to you? What do you think could be boundaries for the person with intellectual disabilities? How comfortable are you with these boundaries? What (if anything) would you like to change about them?

Support work relationship – working together

- Can you please tell me a little about what you do together? What are the things you help the person with? How (if at all) does the person with intellectual disabilities support you?

- When you and the person have disagreements, how do you solve them?
- What has been the best thing so far that you both did together? What made it 'the best thing'?
- How do you learn things from the person with intellectual disabilities?
- What does working well together mean to you?
- How do you have fun with the person?
- What do you think the person you're supporting likes about you the most? What do you like about them?

Policies of personal budgets

The person you are supporting receives a personal budget. Can you please tell me a little about this type of support arrangement?

- How is it different to working with people who do not use a personal budget? How has it changed the way you feel about your role as a support worker?
- People say that personal budgets are meant to give people with intellectual disabilities more choice and control. What do you think about this? Does it matter to you and the person you are supporting?
- How (if at all) is the person with intellectual disabilities being supported with the management of the budget and planning for it? How (if at all) do you support him/her with any of this?

Closing questions

- What has changed in your life since you started working with the person?
- Is this the kind of work you'd like to keep doing in future? (abstract question)
- How would you see your relationship with the person in future if you stopped working together one day? (abstract question)
- How did any of your past support work relationships develop after you stopped working with the persons you were supporting? (abstract question)

Appendix F: Questions for joint interview (English version)

Topics for joint interviews

Support work relationship – feelings about each other

- What do you both do to enjoy spending time together?
- What are the things you like about each other the most?
- What are the things you like about working together and what would you like to change?
- What do you do when you both have disagreements? Can you describe what you do to solve them?
- How do you both feel about your relationship?

Support work relationship – working together

- What is it like when you work together?
- What are the things you discuss when you work together? What are the most important things you discuss together?
- What do you do to support each other?
- What has been the best thing so far that you both did together?
- What does 'working well together' mean to you? What do other people do to help you both in working well together?
- What do you both learn from each other?
- What are the things you most value about each other?
- What do you do to have a good relationship?

Support work context

- How do you plan for and remember the work you do together?
- Can you explain what you both do to stay in contact with the organisation/s that helped you to work together?
- Can you explain what the organisation does to support both of you in working together? What do you think about the organisation being involved?
- What are the activities you do together? Do you decide on these activities or someone else?
- Do you both meet with anyone from the organisation? Can you describe what these meetings are like?
- Where do you both enjoy spending time together?
- What do you enjoy about spending time there?
- What do you feel about other people being there when you spend time together? (if applicable)

Closing questions

- Over the last three weeks we all spend time together. What was it like for you that I was there too when you worked together? (abstract question)
- Is there anything that you wish that would have been different during the time we worked together? If yes, how? (abstract question)

Final comment

We are now at the end of the interview.

- I am wondering if there is anything we haven't talked about today that you'd like to share with me. Do you have any questions for me? You can also provide material in writing if something comes up later.
- Would you be willing to talk to me again after this interview? I might have some follow-up questions for you at a later stage.
- What is the best way to keep in touch with you?

Thank you for your participation in the interview.

Appendix G: Selection of policy documents according to policy levels

Name of document	Country and policy level
United Nations (2006). *Convention on the Rights of People with Disabilities and Optional Protocol.*	International
Australia	
Department of Social Services. (2013). *National Standards for Disability Services.*	National
National Disability Insurance Scheme Act. (2013). *No 20.* Canberra, Australia.	
Commonwealth of Australia. (2011). *National Disability Strategy 2010-2020.*	
Australian Government. (2009). *National Disability Agreement. Intergovernmental Agreement on Federal Financial Relations.*	
NSW Department of Family and Community Services. (2015). *Individual Funding Handbook.* NSW Department of Family and Community Services. (2015). *Individual Funding Packages Guidance for Intermediaries. A Companion Guide to the Individual Funding Handbook.* NSW Department of Family and Community Services. (2015). *Choosing an Intermediary for Individual Funding.*	State
NSW Government. (2015). *National Disability Inclusion Plan.*	
NSW Government. (2015). *Disability Inclusion Action Planning. Guidelines.*	
NSW Department of Family and Community Services. (2013). *Ready Together: a better future for people with disability in NSW.* NSW Government. (2010). *Stronger Together. A new direction for disability services in NSW 2006-2016. The second phase 2011-2016.*	
NSW Department of Family and Community Services. (2014). *Abuse and Neglect. Policy Procedures.*	
NSW Department of Family and Community Services. (2012). *Decision making and consent. Policy and procedures.*	
NSW Department of Family and Community Services. (2016). *Supporting Sexuality. Practice guide for practitioners who support people with disability.*	
NSW Department of Family and Community Services. (2012). *Behaviour Support Policy.*	
NSW Department of Family and Community Services. (2015). *Accommodation support service provider guidelines.*	
NSW Disability Service Standards (1993). *Disability Services Act 1993.*	
NSW Disability Inclusion Act (2014). *No 41.*	
NSW Government (2014). *My Choice matters. NSW Consumer Development Fund. Get more skills. Thinking about a good life. My needs and dreams: Workbook 1.*	
An induction package for support workers from a disability service provider (this power point document included mission and vision of service, boundary policies, duty of care, dignity of risk, cultural awareness, anti-discrimination, incident reporting, compliments and complaints, OH&S, manual handling, abuse & neglect, bullying, medication, PCP, timesheets, reimbursement forms, role descriptions)	Organisational
Organisational charts, daily routine sheets, medication sheets	
Weekly schedule (of support work), support work roster	Personal

House rules of a group home, profile of a budget holder	
Person-centred plan, support plan, preplanning support plan for the NDIS	
Germany	
Federal Ministry of Labour and Social Affairs (Bundesministerium für Arbeit und Soziales). (2016). *Federal government report on participation with regard to circumstances of persons with impairments. (Teilhabebericht über die Lebenslagen von Menschen mit Beeinträchtigungen).* Federal Ministry of Labour and Social Affairs. (2015). *National Report on Participation* (Arbeitsgruppe Bundesteilhabebericht – Arbeitsgruppe A&B)	National
Federal Ministry of Labour and Social Affairs. (2016). *Social security: Basic insurance in age and disability (Sozialhilfe: Grundsicherung im Alter und bei Erwerbsminderung).*	
Federal Ministry of Labour and Social Affairs. (2014). *The personal budget (Das persönliche Budget).* Federal Ministry of Labour and Social Affairs. (2013). *The Personal Budget for people with disabilities – best practice examples (Das persönliche Budget für Menschen mit Behinderungen – gute Beispiele aus der Praxis).*	
Federal Ministry of Labour and Social Affairs. (2011). *National Action Plan: Our path to an inclusive society. (Nationaler Aktionsplan: Unser Weg in eine inklusive Gesellschaft)*	
Federal Ministry of Labour and Social Affairs. (2016). *National Participation Law (Das Bundesteilhabegesetz).*	
Needs Assessment Guide (Metzler Bogen)	State
Service flyers, program brochures	Organisational
Organisational chart (Organigram), service value statements (Wertekatalog)	
Service profile and mission statement (Konzeption, Organisationsprofil, Leitbild)	
Role description of assistants and their time sheets	
Support planning tools (e.g. monthly documentation, survey protocol)	
Individual support plans (with goal agreements), weekly support work schedules	Personal