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Life in the Hands of Welfare Bureaucracy: The Impact of Austerity on Disabled People in Sweden

Ida Maria Josefine Norberg

MA Hons (SocSci); MRes

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School of Social and Political Sciences, College of Social Sciences

University of Glasgow

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Abstract

Sweden has often been seen as the epitome of a social democratic welfare state. These accounts, however, often fail to take into consideration the development of neoliberal thought in Sweden and the expansion of austerity. Reflections regarding Sweden's welfare state also often neglect to include disabled people. This is partly to do with the fact that the Swedish welfare state conflates illness and disability, which is rarely explored in Swedish disability research. This thesis will address these lacunas by investigating how disabled people in Sweden have been impacted by austerity. By looking at a range of areas, such as the social consequences of being a disabled person, bureaucracy, the representation of disabled people in economic theory, and employment, it offers a holistic approach to understand the development of Sweden into a neoliberal country and how disabled people have been affected by this change.

The data for this thesis was gathered by interviewing 24 disabled people, eight welfare professionals, and eight disability organisation representatives. Using thematic data analysis, it became clear that disabled people experience stigma and discrimination in Sweden and that welfare bureaucracy has significant an impact on their lives. This was particularly the case for those whom cannot access resources on the 'free market'. The thesis argues that the decreased provision of welfare resources for disabled people require a broader reflection upon the normative nature of economic theory and the social position of disabled people in Sweden.

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Author's Declaration

I declare that, except where explicit reference is made to the contribution of others, that this thesis is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Ida Norberg

21st of January 2019

List of Abbreviations

Table 1: List of Abbreviations

DHR	*Delaktighet Handlingskraft Rörelsefrihet* (Participation Decisiveness Freedom of Movement)
HSO	*Handikappförbunden* (The Handicap Federations)
ICF	The International Classification of Functioning, Disability and Health
LSS	*Lagen om stöd och service till vissa funktionshindrade* (The Act Concerning Support and Service for Persons with Certain Functional Impairments)
NPM	New Public Management
OECD	The Organisation for Economic Co-operation and Development
SAP	*Sveriges socialdemokratiska arbetareparti* (Swedish Social Democratic Party)
SoL	*Socialtjänstlagen* (The Social Services Act)
STIL	*Stiftarna av Independent Living i Sverige* (Independent Living Sweden)
UK	The United Kingdom
UN	The United Nations
UNCRPD	The Convention on the Rights of Persons with Disabilities
US	The United States of America
WHO	World Health Organisation

1. Introduction

Sweden has frequently been hailed as the epitome of a generous, progressive welfare state (Esping-Andersen, 1996; Hassan, 2007). This has not just been the case in academic literature but its aspirational and utopian quality is also embedded in popular consciousness. Sweden was often invoked as a potential blueprint that Scotland could adopt during the 2014 Independence Referendum, its positive aspects often emphasised (Cairney, 2013). When US Congresswoman Alexandria Ocasio-Cortez suggested 70% marginal tax rate, Sweden was offered by magazine *Jacobin* as an example for its feasibility, saying that “Sweden is not perfect but it’s a successful high-income country where ordinary people have a higher standard of living than their US peers” (Brueing, 2019). Even conservative sources admire Sweden (though maybe for different reasons), with *The Economist* arguing that “… ever more countries should look to the Nordics” (The Economist, 2013). Late night comedian James Corden once exclaimed on American television in 2016, “Sweden is *amazing*, it’s incredible […] nothing bad ever happens there. The worst thing to ever happen to that entire country is when the band ABBA broke up. That’s it! That’s all there is” (The Late Late Show with James Corden, 2016).

This view of Sweden remains dominant despite rapidly increasing levels of inequality (OECD, 2015), especially after the 1990s (Copeland et al, 2015:8), significantly changing social policies (SOU 2010:04a) and recommodification within the welfare state (Svalfors, 2007: 6). There have also been political changes, most particularly the expansion of neoliberalism (an ambiguous concept that is explored further in chapter 3), that have only been explored in a limited capacity. Some have noted the turn towards neoliberalism within Sweden (Harvey, 2005; Östberg, 2012) but it has largely remained the province of political journalists (Carlén et al., 2014; Eztler, 2013; Persson et al., 2010). Consequently, there is a pressing academic need to explore this and its implications further.

The reluctance to address the expansion of Swedish neoliberalism and austerity is puzzling, especially in light of its thorough exploration in other countries –

most notably the UK. The UK is often highlighted as one of the most prominent examples of neoliberal governance (for some examples see Bauman, 2007a; Birch and Myknenko, 2010a; Harvey, 2005; Hassan, 2007) and equally British austerity has been significantly explored in austerity literature (Blyth, 2013; Bramall, 2013; Clarke and Newman, 2012; Clarke and Newman, 2012; Cross, 2013; Goodley et al., 2014; O'Hara, 2014). With British austerity, there are reports and evidence that suggest that disabled people are the most affected group (BBC, 2016; Butler, 2017; Kentish, 2017). The OECD (2010:10) argued that spending on disability-related welfare resources was a hindrance to economic growth. Thus, concern over disability expenditure has not been limited to the UK. Concern over disability welfare provision has been frequently expressed in Sweden and criticism over sick leave and exemption from the labour market has dominated Swedish political debate with the intensification of austerity (Johnson, 2010). While the concern over welfare 'costs' have been rampant, there has been no investigation into the human consequences of austerity in Sweden.

The problematisation of welfare provision for disabled people alongside the intensification of austerity prompts important questions about how disabled people have been impacted by austerity and affords an opportunity to revisit the idea of Sweden as the epitome of a social democratic welfare state. A government report (Barron et al., 2000: 166) highlighted that there is a need to explore how disabled people have been affected by changes in the welfare state. In this thesis, I will explore the impact of austerity on disabled people in Sweden. To explore the impact of austerity on this group, it is necessary to define the disability-related welfare resources and support that are available to disabled people. Consequently, it is important to define what services and support is available to disabled people in Sweden in order to show how they have changed.

1.1 Disability-related welfare support and services

To explore how disabled people have been affected by austerity, it is important to denote what welfare services and support are available to disabled people within the Swedish welfare state. This also helps frame the type of welfare support that will form the primary focus of this thesis. It enables conceptual clarity throughout the thesis as it is the services and support that I outline below that I refer to when I write about 'disability-related welfare services and support', unless otherwise specified. Because illness and disability are conflated within the welfare state, services such as sick leave is also related to disability-related support. This, however, will be accounted for more closely in chapter 2 and 8.

The most prolific and significant welfare provision for disabled people in Sweden is LSS (*Lagen om stöd och service till vissa funktionshindrade*). LSS stands for The Act Concerning Support and Service for Persons with Certain Functional Impairments. It signifies the provision of services for welfare services and support for three groups of people: (1) people with a learning disability, autism or autism-like conditions, (2) people with "significant and lasting developmental disability or brain injury at adult age because of external violence or bodily illness", or (3) people with "other lasting physical or psychological impairments that evidently is not due to normal aging, if they are great and cause significant difficulties in daily life and therefore constitute a significant need of support or service"[1] (Riksdagsförvaltningen, 2018). Services covered by LSS are personal assistance, guidance, contact person, assisted living, and daily activity. As is clear, however, the legislation does not provide for *all* disabled people (and this has been exacerbated with the expansion of austerity, as chapter 3 will outline).

Disabled people who are not covered under LSS may seek assistance from the Social Services Act or, for example, apply for sick leave. Sick leave is defined in law as the "work ability having become completely or partially decreased as a result of illness, injury or other decrease in function" (Johnson, 2010: 23). This means, importantly, that "sick leave is therefore not equivalent to illness"

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[1] It should also be noted, more broadly, that all translations from Swedish to English throughout the thesis are done by me. This is the case both for literature and fieldwork data.

(Johnson, 2010: 23). For this reason, I categorise sick leave as part of disability-related welfare resources, even though they traditionally tend to be separated. Within this broad church of measures, you can get activity compensation if you are “between 19 and 29 years old and have an illness or a decrease in function that means that you cannot work for at least a year. While you have activity compensation, you can get support and help to be able to start working” (Försäkringskassan, 2018a) or alternatively sick compensation, “if you are between 19 and 64 years old and have an illness or a decrease in function that means that you will never be able to work, not now or in the future” (Försäkringskassan, 2018d).

You can also get handicap compensation if you have “a decrease in function or illness that means that you need help in everyday life or have additional costs” (Försäkringskassan, 2018c) or housing support, which gives you “money in addition to your activity compensation or sick compensation if you have costs for your housing” (Försäkringskassan, 2018b). You can also be given aids, wage subsides, or work in protected employment forms, most notably Samhall (Swedish Public Employment Service, 2018b). Samhall’s task is to “through work develop” disabled people and is something that a disabled person can get if “you have a decrease in function that affects your ability to work and need a job that is adjusted according to your needs” (Swedish Public Employment Service, 2018a). These are the broad contours of the welfare support specifically targeted to disabled people. In Sweden, actual levels of compensation are generally determined by a combination of factors, such as the formal level of compensation, the cap on income eligibility, the duration of the compensation, and qualifying days (SOU, 2010:04a). This means that while the formal level of financial welfare support may formally rest on 80%, the actual level of compensation would be around 55% of an average industrial worker’s pay (SOU, 2010:04a). This means that welfare support is heavily individualised and difficult to calculate.

1.2 Research aims

Due to the limited research that has been conducted into how changes in welfare impact disabled people in Sweden, this thesis will need to adopt a multi-layered approach to investigate this issue. This is particularly significant because, as I will expand on in chapter 3, Swedish austerity has been implemented in a way where it especially impacts 'weaker' social groups (Lindbom, 2011: 33). Further, because there tends to be multiple perspectives on the 'problem of disability' (Stone, 1984), utilising multiple perspectives on how disabled people have been impacted can help to elucidate the relationship between disabled people and the welfare state in Sweden. With these reflections in mind, this thesis has three key research aims:

1. To understand how disabled people, disability organisations, and welfare professionals understand the changes in the Swedish welfare state
2. To see how disabled people in Sweden have been affected by austerity measures
3. To see what, if any, impact the welfare state has on the experience of being a disabled person in Sweden today

These broad, open-ended concerns enables the thesis to be guided by the fieldwork data. To achieve these aims, I utilise semi-structured interviews with disabled people, disability organisations, and welfare professionals. More aspects of the methodology will be outlined in chapter 4. In the case of austerity, I will articulate the relationship between neoliberalism and austerity more clearly in chapter 3 but, in short, I argue that in the Swedish context, austerity and neoliberalism are historically linked as austerity was facilitated and promoted by the neoliberalisation of Sweden. For this reason, any exploration into Swedish austerity also require discussions of neoliberalism.

1.3 Outline of thesis

This thesis contains two literature review chapters, one methodology chapter, four data chapters, and a concluding chapter. The general contours of these chapters are outlined below.

Chapter 2 outlines disability terminologies and concepts. Investigating this in detail is particularly important because the English word 'disability' does not have a Swedish equivalent (Thomas, 2004: 25). It explores the key academic models in which disability is understood and how disability is understood within the Swedish state. The so-called relational model of disability, dominant in Scandinavia, and the social model, prominent in the UK, are particularly explored. In this chapter, I show how I position myself with regards to disability terminology.

Chapter 3 is a theoretical and policy review chapter. Firstly, it outlines debates around neoliberalism and how I have positioned myself and my understanding of neoliberalism in light of these debates. I then go on to explore how I understand the welfare state and how it has been affected by neoliberalism. Thirdly, I outline the nature of austerity and how Swedish neoliberal austerity has been enacted. This is done in two parts. Initially, I explore the political conditions that were necessary for the emergence of neoliberalism in Sweden. The second aspect necessary to answer this question is the policy and economic decisions that caused the move away from Keynesianism.

Chapter 4 outlines my methodology and the methodological choices that were made during the fieldwork. I explore my ontological and epistemological position by discussing emancipatory research methods, power imbalances in research, and reflexivity in particular. This chapter also explores the practical elements of my research. These include how I positioned myself regarding translation, who I interviewed and where, as well as ethical moments that arose during the research.

Chapter 5 is the first of four chapters that present my research findings. This chapter chiefly explores what my disabled participants said about what it was like to be a disabled person in Sweden. It addresses issues around stigma and feeling isolated. It also explores how disabled people felt the effects of austerity and bureaucracy in their everyday lives. It also, crucially, demonstrates how my participants 'managed' under austerity.

Chapter 6 is the second data chapter. It explores the austerity-justifying discourse of 'costs'. It addresses how welfare professionals positioned themselves in relation to this discourse and how disabled people are impacted by it. It also addresses issues around psycho-emotional disablism (Thomas, 1999) and what implications 'cutting costs' have.

Chapter 7 explores the impact of bureaucracy on disabled people and the view of welfare professionals. It also accounts for the different stages of welfare bureaucracy that disabled people have to engage with when applying for welfare services and support. It then demonstrates how welfare professionals have been impacted by the changes in the welfare state and the uncertainty they feel as a result of the changes to, in particular, LSS provision. This opens up questions as to how uncertainty and 'un-knowledge' operates in within the bureaucratic system and this is something the chapter will explore.

Chapter 8 is the final data chapter and it focuses on employment. Employment was something that all participants related to in my research and it is also one of the few things that the state still regards as an 'investment'. The chapter begins by exploring the government and disability organisational perspective on employment. It then highlights how my disabled participants related to employment. It became clear that it was not just about resources but work as also served as a moral indicator. For those that were unable to participate in the labour market, however, employment pressures were viewed as a discipline.

Chapter 9 is the conclusion to the thesis. First, the main findings of the thesis are outlined as well as contextual aspects to my data. As a result, I highlight four key themes that emerged from my data. These are class, bureaucratic power, invisibility and the role of economics in marginalisation. I discuss the implications of each of these themes in relation to my research and point to the need for future scholarship as a result of my research findings.

2. Disability terminology and models

There are many ways of referring to, describing and discussing disability and none of these are self-evident. For any thesis exploring issues related to disability, addressing one's perspective on disability is of central importance. This is because any view on disability also carries methodological and theoretical consequences (Grönvik, 2002: 52). The issue of terminology is also heightened in this research as there is considerable difference between how disability is denoted in English and in Swedish. This is not just a difference deriving from different academic positions but also one that is embedded in language. The term 'disability' has no direct Swedish equivalent (Traustadottir, 2009: 13–14). These differences carry implications for how disability/impairment is understood and for different academic models seeking to understand disability. This chapter will primarily focus on disability terminologies but also encompass the main disability models that are prominent in Sweden and in the UK. The primary model utilised in Sweden is the (Scandinavian) relational model of disability and the dominant British model is the social model of disability (Oliver, 1990).

The relational model and the social model are part of the same "family of ideas" (Tøssebro, 2004: 3–4) but with the Swedish approach constituting a weak 'relational' perspective and the British being a strong relational perspective in its understanding of disability. The social model derived from activism from disabled people themselves (UPIAS 1976) whereas the Swedish 'relational' model emerged from a combination of political ambitions, disability organisations demanding more research and academics striving for more funding (Hjelmquist, 2005: 21). Despite these differences, comparing these two models are essential for this research. The dominant reason is that while the traditional articulation of the social model has been criticised for negating the relational aspect of disability (Thomas, 2004b), this chapter will demonstrate that the Swedish 'relational' model fails to account for discrimination/oppression, which is central to the social model, and the extent to which the Swedish academic model is relational is debatable. As this thesis is more concerned with the social elements of disability and particularly the potential occurrence of discrimination, the contrast is necessary.

Terminologies and academic models are, however, not the only relevant perspectives on disability. As a significant part of this thesis is about exploring disabled people's relationship to the welfare state, some reflection on how disability is understood by the welfare state is needed. This will show that the way that the Swedish state regards disability is by conflating it with illness and by using highly medicalised understandings of disability. As chapter 3 will show, medicalisation of disability has increased with the expansion of neoliberal austerity.

First, this chapter will outline the terminology and models present in Sweden. It will begin by highlighting the state perspective on disability, before accounting for the relational model of disability. Secondly, this chapter will explore the social model and how it corresponds to some of the weaknesses of the Swedish relational model. It will briefly go into some of the critiques that the social model has received and explore the position I have taken to amend these criticisms. It will also introduce a central concept for this thesis, psycho-emotional disablism.

In this chapter, I will argue that while the British social model has many warranted critiques, the Swedish 'relational' model is considerably more problematic in the context of this research. I will argue that it is not as able to include social elements due to its bias for individualised, medical perspectives. The relational model does highlight the need to not overemphasise disability in every context and that has been taken into consideration. The limited way in which the social aspects of disability are incorporated in the academic model, however, is a problem as it can then not sufficiently challenge the state perspective on disability, which is conflating disability with illness. Being able to address issues of discrimination and oppression is central to understand how disabled people have been affected by austerity. By incorporating important theoretical improvements from authors such as Hughes and Paterson (1997), Reeve (2004), and Thomas (1999), the social model provides a more useful framework to unpack the data. A direct application, however, remains difficult because of the linguistic difference in Sweden. Instead, the approach that I adopted in this thesis can be described as inspired by the social model but with continuous sensitivity to the linguistic difference in the Swedish context.

2.1 Swedish understandings of ‘disability’

Swedish terminologies and disability models have only been theoretically explored in a limited way. Consequently, this investigation will form part of this thesis’ original contribution to knowledge. This section will first highlight the state perspective on disability. The second section will explore the dominant academic models present in Sweden at the time of the research and the emergence of functional-focused terminologies. This will give a brief overview of the state of disability theory and conceptualisations in Sweden.

2.1.1 Swedish state understandings of disability

This section will explore the relationship between disability and the state. The state has not only been important for disability research but also for disability organisations. Most of them are given government support and they are seen as being engaged in a “societal conversation” (Sellerberg, 2009: 92). While Sweden has having a cooperative model between the state and third sector organisations, the relationship between the state and disability organisations has changed. It is now more akin to a lobbying system (Sellerberg, 2009: 88). This section will first explore some key historical context before exploring the concept of ‘work ability’ and the importance of medical criteria.

Before delving into the specifics of the state perspective on disability, it is important to acknowledge key historical background and influences. The medical perspective has been dominant prism through which disability is understood. The eugenics movement that emerged in the interwar period was very prominent in Sweden. Eugenic thinking had two parallel tendencies – one progressive and one oppressive. The progressive tendency suggested promoting societal good through the improvement of collective services, as was the case in the UK (Renwick, 2017) and Sweden, where this led to the creation of the welfare state. The oppressive element of eugenic thinking was simultaneously enacted in Sweden on minorities (the most notable example for this thesis is disabled people) and is evident by the fact that Sweden was the second largest enforcer of forced sterilisations after Nazi Germany (Lindberg, 2011: 41; Grunewald, 2008: 78). This oppressive element was more concerned with limiting ‘contamination’ and limiting ‘genetic degradation in the general population’. Sweden was also key in promoting Social Darwinist and white supremacist ideas and policies by, for example, establishing of the Swedish State Institute for Race Biology (Kjellman, 2013) and trying to pass off these ideas as scientific. The rationalisation of eugenic thinking and particularly the emphasis on medical understandings with regards to disability has a long-standing history in Sweden (as elsewhere).

Forced sterilisation remained a policy in Sweden between 1935 to 1975 and within that timeframe, over 62,888 sterilisations were performed (Spektorowski and Mizrachi, 2004: 333). It should, however, be noted that trans people were subjected to forced sterilisations until 2013 if they wanted their gender identity legally recognised (RFSL, 2016). Forced sterilisations were justified on the basis that its enforcers represented a ‘natural aristocracy’ (Björkman and Widmalm, 2010: 380). At the time, forced sterilisation was viewed as a more ‘humane’ effort than internment and was viewed as a key method of bringing down social and medical costs “associated with low genetic quality […] and the caring for the unfit [*sic*]” (Björkman and Widmalm, 2010: 383). The key element in relation to this thesis is that this policy endowed the state and medical establishment tremendous power over disabled people’s lives. This history is important to incorporate to understand the development of disability conceptualisations. In particular because of the centrality of the state in these measures, the eugenic influence is especially important to contend with in relation to the state. It should be noted that there are also positive instances, such as disability being included as a protected characteristic and the right to have accessible television screenings in the Swedish constitution (Sweden, 1974).

Another influencing factor on the state perspective on disability was the normalisation principle. This principle was outlined by Nirje (1994: 19) as “making available to the mentally retarded [*sic*] patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society”. This principle, however, retains the same individualised focus as the relational model and the state perspective. The principle focuses on giving disabled people – most notably people with learning disabilities – as equal a standard of living as non-disabled people. That normal immediately implies non-disabled is not explored and while attitudes are noted as important to take into consideration (Nirje, 1994: 20), even here issues of structural discrimination and oppression remain remarkably absent. The key legacy of this perspective, however, is in the LSS legislation where the stated goal is to enable disabled people to 'live like others'; an aspiration, however formidable, which remains from a policy perspective notoriously vague and open to multiple interpretations (Stone, 2002).

Stone (1984) noted that the disability category occupied a central position within the welfare state and is utilised to attempt to solve the issue of redistributive justice. In Sweden, the concept of work ability (*arbetsförmåga*) is central to discern disability within a welfare context. For example, as outlined in the chapter 1, the concept of work ability is central to services such as sick leave and supported employment. Work ability is a concept that is riddled with ambiguity and even the government recognise that it is "a difficult concept to define and judge. It exists in interaction between a person's ability and the demands in a job" (SOU 2008:66). This is a concept that is not merely applied to disabled people but something that is theoretically applied to all citizens. Administrators are thus placed in the position of "not only distinguish[ing] between sick and well but also on work inability and work ability" (SOU 2008:66, p14). Thus, there is an expectation that everyone should and can work. Those that are deemed unable to work thus within the Swedish state get characterised as 'ill'. Thus, the concept is similar to Stone's (1984) and Parson's (1951) perspectives in that 'illness' is medically defined and measured and an event. Consequently, work ability is therefore one of the most central concepts within the welfare state and it is also key for several disability-related welfare resources and services. Despite this centrality for disability-related resources, it is surprising how little space is devoted to disability in a government report on the concept (SOU 2008:66). There is an acknowledgement of conditions that not do adhere to the illness and injury paradigm in a footnote which states that "there are also those who are born with an illness or injury. In such cases there is a comparison not between before and after but with others in a corresponding age" (SOU 2008:66, p18). The 'others' is implicitly understood to be non-disabled people and thus the concept of work ability highlights the overt conflation of illness and disability.

As this footnote makes clear, state views on ‘illness’ is conceptualised as an ‘event’ where there is a ‘before healthy you’ and an ‘after ill you’ (SOU 2008:66) and the disparity between these is what constitutes ‘injury’ or ‘deficit’ in relation to the insurance. The report on work ability (SOU 2008:66) argued that there are many who are ill and working, people who have symptoms that do not necessarily affect the ability to work, others have symptoms that cause impairments where “the ability to carry out or participate in everyday activities is impacted” and within this group there are “people with impact on work ability. The impairments [*funktionsnedsättningarna*] are then of such a nature that they have a negative impact on the person’s ability to carry out different tasks. The ability to work is then decreased”. In determining the ‘condition of function’ – that is to say the extent to which impairments impact ability to carry out tasks – the WHO scheme is a key reference point (SOU 2008:66). The WHO scheme has been criticised for its individualistic approach to understanding disability (Barnes and Mercer, 2003: 14) and has since then been replaced by a different classifying scheme, ICF. What the WHO and the ICF share is a focus on disability as a “restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being” (Barnes and Mercer, 2003: 13) or, in the words of the ICF, ‘levels of functioning’ (Üstün et al., 2010). The focus is very much on the carrying out of tasks.

Work ability is also a highly normative concept, in that while a report (SOU 2008:66) argues that it is important to focus on the ‘ability’ and not the ‘loss’, and there is an open-ended interpretation of what “is enough, what is the normal?”. This normalcy is implicitly understood to mean a non-disabled person through the idea of a 100% work ability present within the welfare state. Granted, this is an idealised construction as there is ample recognition that even for non-disabled people, work ability varies over time – not just over one’s life but throughout the day (Paulsen, 2014). Problematising the concept of 100% work ability and the normative framework this concept provides remains absent despite it being a central lynchpin in the welfare state. The relationship between the state’s conflation of disability and illness, work ability, and the ‘administrative concept of disability’ (Stone, 1984) will be elaborated upon in chapter 8.

While it may play homage to more relational perspectives, as the next section will demonstrate, the infrastructure of the welfare state remains focused on medical aspects. This is visible in relation to disability organisations. The majority of Swedish disability organisations are “being formed, each specific to a disability, disorder or diagnosis, each articulating its own problems” (Sellerberg, 2009: 87). Medical professionals and a medicalising of impairment as ‘illness’ serve a key role in determining work ability and this role has intensified as a result of expanding austerity measures, as chapter 3 will demonstrate.

Medical certifications have become even more vital in ‘proving’ the presence of impairments and there has also been an increasing utilisation of insurance doctors, who work for the Social Insurance Agency, who are medical doctors but merely determine the ‘reliability’ of medical evidence provided in an application. They work in an advisory capacity and the decision on applications remain with the caseworker. Despite the seemingly closer cooperation between medical professionals and the Social Insurance Agency, the agency has received mounting criticism that they disregard certificates that doctors write and that due to the amount of time that certificates take, doctors struggle to manage the paperwork alongside treating patients (Lallerstedt, 2018; Suni, 2017). What it indicates is that medical understandings are being operationalised in a way that does not necessitate the cooperation of medical professionals. Medical doctors do not become arbitrators of access to welfare resources – that privilege remains with the Social Insurance Agency.

It is also important to note that medicalisation of disability has been heavily criticised (UPIAS, 1976). For example, medical sociology tended to denote isolation as a consequence of acquiring an impairment (Bury, 2001:176; Charmaz, 1983) instead of recognising that the resulting isolation was a by-product of social forces rather and a result of social oppression. Rendering social aspects invisible by placing primacy on impairments meant the socially created consequences of having an impairment were naturalised (Thomas, 2004a; de Wolfe, 2002; Shakespeare, 2014). For this reason, it has been important for disability theorists and activists to separate disability from impairment in order to break with the ‘tragedy’ model offered by the medical model (Barnes and Mercer, 2003). Like other oppressed groups, medical ‘knowledge’ has been historically cited as reasons for their inferior social position but, while other oppressed groups have managed to move away from that understanding, Barnes and Mercer (2003:20) argue that this has not been the case for how society views disabled people. This will be explored in more detail later in this chapter.

2.1.2 The Swedish ‘relational’ model of disability

This chapter has so far explored the Swedish state’s understanding of disability. While the state conflates illness and disability, this is not quite the case within Swedish academia. The so-called Scandinavian relational model is prominently cited as the key disability model in Swedish research (Thomas, 2004a; Tøssebro, 2004). Unlike the social model, which this chapter will explore later, Swedish disability research emerged from the state (Larsson and Magdalenić, 2015; Roulstone 2003; Söder, 2013). This section will also explore functional perspectives on disability that are emerging as frequent utilised terms to denote disability in Sweden. Theoretical explorations in Swedish disability research have been notably poor (Roulstone, 2013; Söder, 2013: 104). This is especially the case in relation to the emerging functional terminology. Swedish disability terms remain a very underexplored area of academic research and is therefore influenced by my reading of the limited available material.

As mentioned earlier in the chapter, the Scandinavian understanding of disability must be regarded as a weak relational perspective within the various ‘relational’ disability models that currently exist (Tøssebro, 2004: 3–4). Writing about Swedish conceptualisations of disability, Söder (2005: 15) offered a relative definition where “handicap [*sic*] is something that emerge in the meeting between a human with a disability [*funktionshinder*] and the environment”. Scandinavian understandings of disability are not just relational in the interaction between the individual and the environment but also situational, as Tøssebro (2004: 4) explains:

> Disability is thus a relationship, and it is relative to the environment. It is also situational rather than an always present essence of the person: A blind person is not disabled when speaking on the telephone, and is exceptionally able when the lights have gone out.

The benefit of this, Grönvik (2005: 46) argued, is that ‘handicap’ does not become a personal quality but it arises first “in relation to an inaccessible environment. A handicap is therefore […] neither […] a signifier for an environment, but a description of the meeting between a person with a disability and a lacking environment”. Thus, an individual can be ‘handicapped’ in some situations but not necessarily in another (Grönvik, 2005: 46-7).

When it comes to the actual terms used to denote disability or impairments in research that utilise this model, Söder (2013) noted that most research ends up relying on medicalised understandings of disability, such as medical diagnoses. Roulstone (2003: 2) highlighted that historically Scandinavian “disability research imperatives have had a distinctly medical orientation or have not been based on the views of disabled people”. Grönvik (2005: 44) recognised the problem that medical diagnoses often have connotations of the individual being the ‘problem of disability’ but did not expand on any potential issues deriving from the prominence of medical categorisation despite being a seemingly ‘relational’ model. Due to the definitional power of medical categorisations in relation to impairments, disability has a tendency within Swedish disability research to be reduced to medical diagnoses despite claiming to include a social constructionist perspective (Söder, 2013: 102). Thus, it seems based on my reading of this undertheorised model that the relational model has a tendency to resign the body to medical knowledge in the same vein as classic iterations of the social model (Hughes and Paterson, 1997). Further, the preoccupation with the functional elements of impairments neglect the fact that impairments may affect disabled people culturally and socially, even in situations where their impairment is functionally irrelevant. For example, any reflection on discrimination and oppression is surprisingly absent, especially given Sweden’s eugenic history.

These absences are critical for this thesis. Particularly as the research aims of this thesis are primarily concerned with the influence of social and structural aspects on the lives of disabled people. Secondly, these absences also temper the praise given the Scandinavian relational model as being notably ‘intersectional’ (Roulstone, 2013: 2). Particularly as Roulstone (2013: 3) argues that “intersectionality is profoundly concerned with social structure”. The absence of key elements of social structures and accounts of discrimination and oppression that arise as a result of hostile social structures and values is not, in my view, given adequate space to be deemed sufficiently ‘relational’. Instead, its propensity to surrender the body to medical sciences and reduce the meeting of the individual and the environment to be about accessibility limit the way that other important elements can be incorporated. This is in keeping with the government perspective on disability as well, which recognises the importance of accessible television programming in its constitution in 1974 but did not recognise inaccessibility as grounds for discrimination until 2015 (Sweden, 1974; Diskrimineringsombudsmannen, 2018). Further, while the relational model is concerned with the meeting between the individual and the environment, it is still a deeply individual meeting and how disabled people as a collective group are treated by non-disabled people remains unexplored in this model. Instead, the so-called Scandinavian ‘relational’ model seems to maintain the same kind of attention on functional ability (i.e. the carrying out of tasks) as the state perspective on disability but with a heightened contextual awareness.

2.1.3 Functional terminology

Indeed, the proclivity towards a functional focus is shared by many sectors of Swedish society. This preoccupation with functionality has birthed several terminologies to denote disability that are rapidly growing in popularity in Sweden. These can be seen as a response to the absence of a Swedish equivalent to ‘disability’ in Swedish (Traustadottir, 2009: 13–14). This is a section where there is no academic literature and, as such, will contain translations and explanations of frequently used disability-related terminology. Exploring these terms is part of this thesis’ original contribution to knowledge, as Swedish disability terminologies have been even less explored than Swedish disability models. A rare example of this functional terminology is present in Bhaskar and Danermark (2006: 284) where they recognise function as “the manifestation of impairment in daily life” and view disability as the “implications of the reduction in a person’s functions in social life, including the normative handicaps imposed by, and the psychological, psycho-social and other social effects of, for example, the process of stigmatization and other effects that normally follow (in our societies) from an impairment”. In this way, function is largely focused on ability to perform a movement or activity and this carries with it bodily or mental associations.

A majority of these terms remain prolific within activist and academic circles but are gaining more widespread use. One of the most common terms is *funktionshindrad*, which translates to ‘hindered to function’. The word could be likened to a ‘barriers’ approach akin to that of British disability studies (Barnes and Mercer, 2003; Oliver, 1990), but there has been growing concern that the term has too many negative connotations. In its wake, there have been a variety of words that have emerged to attempt to rectify the supposed shortcoming of *funktionshindrad*. Overall, the most frequently used at the time of writing is *funktionsnedsättning*, which translates as ‘a decrease in function’. This is a term that has also been adopted in a limited way by the state, wherein they renamed the budget related to disability, ‘economic security in illness and *funktionsnedsättning*’ (Betänkande 2017/18:SfU1) instead of using handicap (*handikapp*).

Building on that, *funktionsvariation* has also become an increasingly popular way of defining disability. *Funktionsvariation* means ‘a variation in function’. One of the participants talked about *normbrytande funktionalitet*, which translates as norm-defying functionality. The terms indicate a move towards a more embodied understanding of disability, but they maintain important differences. *Funktionsnedsättning* acknowledges the functional limitations that disability sometimes entails. *Funktionsvariation* acknowledges the universality in functional variations among the population. The ideal of an ‘able-bodied’ working individual that capitalist ideology promotes is a caricature that few – if any – people can actually fulfil. Ability to work – or in general to perform activities – not only varies across the life course but also over the course of a day (Paulsen, 2014). The extent to which *funktionsvariation* can acknowledge that there is sometimes a particular ‘variation in function’ that is inherent with some impairments remains to be seen. *Normbrytande funktionalitet* highlights that disability is often a functionality that is seen to defy the capitalist normative assumptions surrounding functionality.

While these terms are more embodied, the extent that they manage to address structural concerns – which *funktionshindrad* attempted to do – remains negotiable. While these terms acknowledge a more embodied way of describing disability, the external barriers that prevent disabled people from achieving equality and full participation are only addressed in a limited capacity. While these functional perspectives might be deemed as entirely separate from the medicalised notions of disability prominent in policy, as the previous sections of this chapter have demonstrated, there is a common denominator between the two models and these terms in that they are all concerned with functionality to various degrees. The focus on functionality, however, does not challenge the conflation of disability and illness in policy nor does it address the absence of discrimination or oppression that disabled people might face, with the exception of perhaps *normbrytande funktionalitet*.

What this exploration of frequently used terminology has demonstrated are two aspects: firstly, that the focus on functionality is spread across both the state and academia and it is influencing emerging terminology, and, secondly, that social aspects of disability are only partially addressed. This means that the terminology and the state and academic model contain an inclination towards focusing on individualised aspects that have to do with carrying out tasks and impairments. This combined with the fact that impairments are defined by medical categorisations mean that the Swedish relational model and alternative models and terminologies remain ill-equipped to incorporate broader societal issues such as discrimination and oppression, which I argue are central to include when assessing the impact of welfare reform on disabled people's lives.

2.2 The social model of disability

This chapter has so far engaged with Swedish models and terms surrounding disability. This exploration has demonstrated that while Swedish models allow for a more flexible understanding as to the importance of impairments in particular scenarios, it is ill-equipped to incorporate broader societal elements in its supposedly 'relational' model and retain a bias towards individualised and medical views on disability/impairments. While the Swedish academic model remains limited in its capacity to address structural discrimination and oppression of disabled people, the social model of disability has been praised for its ability to address these questions (Thomas, 2004b). This section will explore the basic foundations of the social model and some of its critiques. By acknowledging these critiques, I will demonstrate that while being conscious of the ambiguous relationship between disability and impairment in Swedish understandings of disability, by incorporating concepts such as impairment effects and psycho-emotional disablism, I am able to incorporate concepts and knowledge from the social model in ways that are suitable for a Swedish context, where a clear separation between impairment and disability is not possible.

The social model of disability was developed by a group of disabled people in the UK, where they argued that disability is socially produced. Consequently, this model is distinct to the Scandinavian 'relational' model, which did not derive from disabled people's activism. In a seminal document, The Union of The Physically Impaired Against Segregation (UPIAS) produced a statement which argued that "it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society" (UPIAS 1976). This acknowledgement was not something that they saw reflected in broader societal attitudes or academic research.

As such, moving away from medicalised understanding of disability was important for a social model perspective. This was deemed important because "if disability is defined as social oppression, then disabled people will be seen as the collective victims of an uncaring or unknowing society rather than as individual victims of circumstance" (Oliver and Mercer, 2012:14). As such, the social model incorporated the structural oppression facing disabled people into their understanding and challenged the way in which understandings of impairments usually sought to naturalise the societal disadvantage of disabled people. Impairment is therefore separate from disability within the social model. It is, however, unclear whether the social model constitutes a theory or a guidebook for practical action (Söder, 2009: 68).

2.2.1 Critiques of the social model

Despite the prominence of the social model, there has been considerable critique levied against it. This caused Thomas (2007) to argue that it would be more fruitful to talk of several social models of disability. This section will address two key criticisms of the social model: its neglect of impairment and the critique mounted by critical disability studies. Exploring these concerns and how I relate to them will allow the framework that I engage with to become more articulated.

One of the most significant critiques to the social model is against its neat separation of impairment and disability. Exploring this issue, I argue it is important because it has relevance for Swedish disability models. By exploring this, it serves as an important example of how impairments can be incorporated within a social science disability model without conceding it completely to medicine. Shakespeare (2006: 34) writes that at “first glance, many impairment/disability distinctions appear straightforward. If architects include steps in a building, it clearly disadvantages wheelchair users [...] Yet looking closer, the distinction between biological/individual impairment, and social/structural disability is conceptually and empirically very difficult to sustain”. Instead, it is argued that impairment and disability are not dichotomous but placed on a spectrum (Watson and Shakespeare, 2001: 22).

By ignoring impairments, de Wolfe (2012: 618) argued that the social model risks reinforcing the hierarchy of disability that they wish to eradicate. Disregarding the body reinforces the idea of impairments as private, non-political aspects, which means that the social model is unable to fully recognise impairments as a challenge to the non-disabled norm (Best, 2007: 165). As a result, there has been a call for a more embodied notion of disability (Hughes and Paterson, 1997) that incorporates impairments into its framework. In this vein, there have been attempts to recapture the more relational aspects embedded within the social model (Thomas, 2004b) and accounts that develop a more sociological understanding of impairments do not necessarily need to embrace the medical model (Hughes, 2000). This is possible because the body is not exempt from socio-cultural forces. Even physiological phenomenon such as pain cannot be divorced from social and cultural understandings (Best, 2007). As a result, authors such as Hughes and Paterson (1997: 326) maintain that “the impaired body is part of the domain of history, culture and meaning, and not – as medicine would have it – an ahistorical, pre-social, purely natural object”.

By incorporating impairments, the social model can show how impairments impact disabled people’s ability to participate in society and in everyday life (Thomas, 1999, 2004b: 29). Thomas (1999: 43) argues that this is important because

> … this restriction of activity may become a marker for *other* restrictions of activity which do constitute disability if, for example, people in positions of power decide that because I cannot perform such an action then I am unfit to be a paid care worker, or parent, and should therefore be denied employment, or the privilege of becoming a mother.

Not being able to perform particular tasks becomes increasingly key to accessing welfare resources and support and, thus, a more sociological understanding of impairments as suggested by Hughes (2000) and Thomas (1999, 2004b) becomes vital. While both the relational model and the social model sidestep the issue of impairments, the social model is able to incorporate more critical, sociological perspectives on impairments within its model through the utilisation of concepts such as impairment effects. Consequently, the concept of impairment effects is central to understand the relationship between impairment and disability, particularly because of the functional emphasis in Sweden.

Another critique against the social model derives from critical disability studies. Critical disability studies build upon the insights of the social model but

> acknowledge that we are living in a time of complex identity politics, of huge debates around the ethics of care, political and theoretical appeals to the significance of the body, in a climate of economic downturn that is leading yet again to reformulations of what counts as disabled (Goodley, 2013: 632).

While the social model found a home within sociology and social policy departments in the UK, critical disability studies emerged from other disciplines such as psychology, social work, education and the humanities (Goodley, 2013:

633). It shares the criticisms about the social model's neglect of the body and actively advocates for intersectional perspectives to allow the exploration of "convergence and divergence of multiple markers" (Goodley, 2013: 637). It is an approach that challenges the materialist focus embedded in the social model and is defined by post-structural anti-dualists, who seek to challenge categorisations and normativity in relation to disabled people (Vehmas and Watson, 2014). Vehmas and Watson (2014) contend that while critical disability studies offer useful analyses on the cultural reproduction of disability, they struggle with evaluative issues relating to disability and thereby risks obscuring that disability is not just a construction in that there are disabled people. In particular, the cultural disability studies perspective "fails to account for the economic basis of disability and offers only the tools of deconstruction and the abolishment of cultural hierarchies to eradicate economic injustice" (Vehmas and Watson, 2014: 647). Since issues around economy and material resources are some of the key issues that I seek to explore, this limitation of the critical disability studies perspective needs to be taken on board. This is not to say that critical disability studies cannot offer valuable insight. Indeed, the anti-dualist critique from both critical disability studies and some social modelists is something that I have drawn on in my own understanding of disability. However, because I am interested in the material relationship between the welfare state and disabled people, the social model is more useful as I am not looking at cultural aspects. Adjusting the social model in this way to incorporate these insights and be attentive to Swedish particularities becomes possible through the adoption of the concept of impairment effects and, as the upcoming section will demonstrate, psycho-emotional disablism.

2.2.2 Psycho-emotional disablism

A final criticism against the social model is its neglect of emotions and its interplay with disablism. With the social model predominantly focused on structural and physical barriers, there has been a neglect of emotional and social aspects of discrimination (Reeve, 2012; Thomas, 1999). While this chapter will primarily focus on this issue in relation to disability models and theory, it should be noted that the psycho-emotional effects of having an impairment has not escaped the attention of 'mainstream' sociology. Goffman (1990: 14) theorised about stigma and viewed stigma as a relationship and identifies three types of stigma: “abominations of the body”, “blemishes of individual character”, and “tribal stigma”. In his seminal work, he notes several psycho-emotional effects of having an impairment, such as the “stigmatized individual can also attempt to correct his condition indirectly by devoting much private effort to the mastery of areas of activity ordinarily felt to be closed on incidental and physical grounds to one with his shortcomings” (Goffman, 1990: 20). The example he uses for this is the “lame person who learns or re-learns to swim, ride, play tennis, or fly an airplane” (Goffman, 1990: 20). As we will see in the rest of this section, these reflections share a lot of similarities with psycho-emotional disablism, as conceptualised by Reeve (2012, 2002) and Thomas (1999). The concept of stigma will also be explored further in chapter 5.

Incorporating the experience of psycho-emotional effects have a significant impact on disability theory. Reeve (2012: 79) wrote that “whilst the original UPIAS-informed social model definition of disability did not exclude these ‘inner’ barriers, their specific omission meant that they were often overlooked in analyses of lived experience of disability in favour of the more visible ‘outer’ barriers”. For this reason, Thomas (1999) and Reeve (2004: 2012) proposed incorporating psycho-emotional disablism into the social model, which would address the role of emotions in producing and reproducing oppression. It is just about barriers to ‘doing’ but also about barriers to ‘being’ – how disabled people feel about themselves and the emotional experiences of being in the world (Thomas, 1999: 60). Sources of psycho-emotional disablism can range from family members and strangers to welfare professionals or the welfare system more broadly (Reeve, 2004: 84).

Because of the neglect of structural concerns and issues around discrimination, the Swedish models and terminologies remain ineffective in incorporating psycho-emotional disablism into an analytical framework to unpack data. While emotions play a central part in Reeve (2004, 2012) and Thomas’ (1999) work, these are marked by the structural factors that impact the experience of disability. Reeve (2002: 500) argued that in

> the modern welfare state, self-certification has replaced the traditional interview/assessment procedure. Rather than being

> under the gaze of the interviewer, the claimant is required to critically gaze upon their own body and report in detail how it fails to meet the ‘norm’; in so doing, the claimant is creating themselves as disabled.

It is in this way that the welfare state and its infrastructure can be an important source of disablism and emotions play a central role. The normative framework of medical categorisations and the construction of impairment as inherently ‘deviant’ and ‘in need of cure’ can significantly contribute to psycho-emotional disablism. The description offered by Reeve (2002) fits into how assessments or applications for various welfare services are constructed in Sweden and, thus, psycho-emotional disablism is a useful concept to include when considering how to understand disability, disablism, and the impact of welfare reform in Sweden. Crucially, it also allows an analytical framework in which shows the interconnectedness of individual experiences and structural concerns.

2.3 Conclusion: Recognising disability

This chapter has engaged with three prominent models of disability and a group of terminologies that are important to understand disability in Sweden today. The models are the Swedish state perspective on disability, the Scandinavian ‘relational’ model and the social model of disability. By engaging in these models and emerging functional terminologies that are becoming increasingly more popular in Sweden, I have demonstrated how disability is defined in these different sectors and their short-comings and benefits.

The state perspective conflates disability with illness and has increasingly moved to medicalise eligibility criteria for disability-related welfare services and support, which chapter 3 will explore further. The Scandinavian ‘relational’ model has some benefits in that impairments can be relevant in particular contexts but it has an in-built privileging of human-ecology models (Tøssebro, 2004: 5). This leaves the model ineffective in addressing structural concerns, in particular discrimination and oppression. The social model, however, is stronger on issues around discrimination and oppression but it is not a perfect model. Like the ‘relational’ model, it concedes impairment to the realm of medicine and does not recognise the importance of impairment and how it can intersect with disablism. By acknowledging these shortcomings and adapting a social model approach by including concepts such as impairment effects and psycho-emotional disablism, it allows me to develop a theoretical framework in which I can connect the individual stories that my participants share with larger questions surrounding societal structures and discrimination. There needs to be, however, a sensitivity to the fact that in a Swedish context a separation of impairment and disability is difficult to maintain. However, the distinction between impairment and disability has been heavily criticised both inside and outside the social model, so applying a more fluid understanding of this relationship is compatible with a social model-inspired perspective. Consequently, I argue that it is still possible to adapt the social model to a Swedish context.

Throughout my thesis, I will use both disability and impairments as concepts, partly because this thesis is written in English and secondly because it allows me a framework in which I can critique the conflation of illness and disability, which I do in chapter 8. This, however, means that I do not use disability and impairment as done by social model proponents. Instead, I see them as existing on a spectrum; impairment tends to be used to denote bodily or mental variations and disability more broadly tends to refer to barriers that may sometimes be affected by impairments but also by social structures. Because of the ambiguity on this issue within the Swedish language, it is difficult to utilise these concepts in their traditionally binary way. At points where it is clear that impairments cause the predominant barrier, the term impairment effects (Thomas, 1999) will be used but otherwise disability and impairment will be used quite interchangeably. I do not propose it is the neatest utilisation, but it is the most useful one as I believe it will help me capture and reflect the ambiguity that is present in my data on these issues. Further information on translation choices in this thesis will be explored in chapter 4.

3. The neoliberal state and austerity

Thus far, I have demonstrated how I understand disability and how this relates to pre-existing ways of defining the phenomenon. In order to comprehend how disabled people in Sweden have been impacted by austerity measures, there are broader questions that need to be addressed in relation to changes within the welfare state and wider societal developments that have occurred to facilitate and coincide with the emergence of austerity. This chapter will explore this question by exploring the concept of neoliberalism, as well as demonstrating the enactment of austerity and neoliberalism in Sweden. This allows me to articulate what changes have occurred in Sweden and what implications these have for writing about Sweden, especially as it has traditionally been regarded as the epitome of a social democratic welfare state (Esping-Andersen, 1996).

This chapter in some ways also builds on the preceding chapter in that it contributes another piece to explore the relationship between disabled people and the welfare state. The previous chapter allowed me to demonstrate various understandings of disability and, crucially, (alongside chapter 1) to identify the group that has been impacted by welfare changes and austerity. This chapter explores the nature of the welfare state and articulates how I understand the relationship between larger societal developments, here understood as neoliberal in nature, and the implementation of austerity in Sweden. Each of these areas contain extensive debates and key areas of contention are explored to gauge how this thesis relates to these debates. How these debates are understood undoubtedly impact the way that the data has been analysed. Exploring these aspects are essential to connect the qualitative interviews in this thesis to broader socio-economic structures and it enables us to ultimately answer the research questions posed by this thesis.

This chapter will be divided into three parts. The first section will engage with the question of neoliberalism. This is an area with a colossal body of work but, for the purpose of this thesis, this section will look at how neoliberalism is defined and whether or not it is a continuation of capitalist logic or something distinct. This will allow key conceptual clarity for the reader whenever neoliberalism is discussed in this thesis and will ultimately offer a key contribution to knowledge regarding how this is expressed in Sweden. Secondly, the chapter will look at the relationship between the state and the welfare state under neoliberalism. Clarifying this relationship is key to understand how austerity practices have been developed and the importance of the disability category for the welfare state (Stone, 1984). The third section will explore the development of Swedish neoliberalism and austerity and their impact on the provision of disability-related welfare resources and support. This will be done by firstly outlining how neoliberalism emerged within the SAP and, secondly, exploring the economic policies that emerged alongside the expansion of neoliberalism. This means that this section is largely concerned with how austerity was enacted within the Swedish welfare state with regards to disability. This is key to understand the broader events and policy changes that participants related to in their interviews. Ultimately, this chapter will allow us to understand not only this broader trajectory but also some of the nuances and variations throughout the process.

3.1 Neoliberalism

The concept of neoliberalism is hotly contested within sociology and beyond. One of the key critiques of neoliberalism is that it difficult to define with any academic ‘certainty’. Firstly, it is a controversial rubric where those who are usually described as neoliberal reject the term (Klein, 2008: 25; Peck, 2011: 14). Secondly, the prolific use of neoliberalism presents a problem, as McLeavy (2014: 138) notes,

> neoliberalism has emerged as an important referent of political economic change over the past two decades, [but] there remains significant fluidity in the understanding of what neoliberalism actually is, and even if it exists at all given the diversity and contradictions inherent in its principle dimensions

This impenetrable quality of neoliberalism is exacerbated by the fact that there is, within neoliberalism, a divergence between theory and practice (Harvey, 2005: 64). Consequently, it is not unusual for neoliberal practice to operate differently to neoliberal theory. As such, it has been argued that it cannot be regarded as a coherent ideology because “neo-liberalism is […] not one thing. It combines with other models, modifying them. It borrows, evolves and diversifies” (Hall, 2011: 708). This has led Flew (2014: 51) to argue that the term is “best abandoned as having had its intellectual currency devalued through excessive use”.

There have, however, been some efforts to clarify the concept of neoliberalism. Harvey (2005: 2) offers the most broadly utilised definition, which sees neoliberalism as “a theory of political economic practices that proposes that human well-being can best be advanced by liberating individual entrepreneurial freedoms and skills within an institutional framework characterized by strong private property rights, free markets and free trade”. Despite this considerable debate remains as to the usefulness and the nature of neoliberalism within academia. To provide an extensive account of the controversies surrounding the term, I argue that the divisions regarding neoliberalism can be seen as existing on a spectrum regarding the nature of neoliberalism vis-à-vis capitalism.

One of the sharpest divisions in the debate is between those who view neoliberalism as a distinct ideology (Harvey, 2005; Klein, 2008) and those who see it as a continuation of capitalist practices (Doogan, 2009). The former argues that neoliberalism is distinct from other previous forms of capitalism due its reliance on and advocacy for ‘free’ markets. The latter perspective instead focuses on the consequences of neoliberalism, where neoliberalisation causes “a reorganisation of the mechanisms of social power around existing centres of power” (Connell, 2010: 35). This perspective argues that neoliberalism is merely the continuation of traditional capitalist dynamics and the only thing that is ‘new’ is that it is “an ideological offensive, a mode of domination, as Bourdieu suggests, that seeks to create uncertainty and anxiety and fear on the side of labour in order to guarantee its compliance” (Doogan, 2009: 214). There are of course important positions between these two perspectives. Bourdieu (2004a: 53) for example sees it as a continuation of past conservativism but that there are some new elements at work. Consequently, while this spectrum is somewhat of a heuristic device and thereby a representation of ideal types, it is fruitful in distinguishing key differences in this immense body of work.

The discrepancy between these two positions also carries significant importance. In accounts that depict neoliberalism as a distinct new ideology, neoliberalism is described as a new social order "in which the power and income of the upper fractions of the ruling classes – the wealthiest persons – was re-established in the wake of [the stagflation of the 1970s]" (Duménil and Levy, 2005: 9). The practice of 'Keynesian' economics is therefore implicitly regarded as a direct challenge to capitalist powers. This, however, does not follow evidence as there is little evidence to support the claim that the wealthy and powerful ever lost any significant power in the Keynesian era (Davidson, 2010: 12). This claim emerges as even more dubious due to neoliberalism's tendency to exacerbate inequality. For power and economic resources to be increasingly centralised among a small elite, there needs to be a pre-existing power elite. Consequently, the relationship between Keynesianism and neoliberalism is more complex than simply lost power being 'reclaimed'. Further along the spectrum, Bourdieu (2004a: 53) argues that the "conservative revolution calls itself neoliberal, thereby giving itself a scientific air, and the capacity to act as a theory". For Bourdieu, and others in this position, new tools such as financialisaton have been operationalised to achieve 'old' goals. Particularly noteworthy is that for Bourdieu (2004a: 42), this new phase of capitalism is imbued with social neo-Darwinism.

This divergence and fluid nature of neoliberalism has, as noted, been regarded as a charge against the concept's utility. I argue nonetheless that the strength of neoliberalism lies precisely in its broad and divergent perspectives. After all, the differences I have identified are not due to fundamentally different assumptions but rather degrees of difference. This is particularly evident following the 2008 financial crash. In its aftermath, it was claimed that "neoliberalism has self-destructed" (Birch and Mykhnenko, 2010b: 225) and financialisaton, one of the hallmarks of neoliberal economics (Harvey, 2005: 33), was broadly critiqued. Neoliberalism seemed, for a time, to be past its prime and was regarded as a broadly obsolete economic theory. As time has passed, it became clear that what was supposed to kill its utility actually cemented its application and triumph (Mirowski, 2013: 8; Crouch, 2011). If neoliberalism was merely an economic practice, there would be little evidence available to explain this turn of events. By incorporating both of these seemingly disparate perspectives on the nature of neoliberalism, we are able to discern the factors that contribute to neoliberalism's tenacity. This is primarily possible by recognising that it is problematic to view its economic components as divorced from political considerations. It disregards that economic theory is

> never as neutral as it wishes to believe or make out, and the power implemented in its name or legitimated through it, agents and institutions are interposed that are steeped in all the assumptions inherited from immersion in a particular economic world, which is the product of a singular social history (Bourdieu, 2005: 10)

As such, neoliberalism becomes linked to "social and cognitive structures of a particular social order" (Bourdieu, 2005: 10). By maintaining and insisting on a separation between neoliberal practice and theory, it "construct[s], in reality, an economic system corresponding to the theoretical description, in order words a kind of logical machine, which presents itself as a chain of constraints impelling the economic agents" (Bourdieu, 2004a: 96). Economic practice and political agendas are inextricably tied together. Recognising this can also allow us to incorporate important reflections on the nature of neoliberalism as provided by post-structuralist thinkers such as Foucault (1991: 92), since the introduction of economic rationality to political practice was a key defining characteristic of governmentality. While this section has broadly engaged with the broad theoretical standpoints related to neoliberalism, neoliberalism is not merely an intellectual exercise but a set of policies and practices, which gives it an embedded character (Brenner and Theodore, 2002). I broadly seek to bring together the views of neoliberalism is both a political and economic project with the insights articulated above. By doing this, I recognise that there are new elements to neoliberalism – such as the expansion of financialisaton – but fundamentally, these differences are merely new expressions of a new phase of capitalism. In short, I see neoliberalism as the continuation of capitalism and this means that neoliberalism is both an *economic* and a *political* project. These issues will be elucidated in relation to the development of neoliberalism in Sweden, which this thesis will explore in section three.

3.2 The (Welfare) State

The second concern that is necessary for this literature review to engage with is the nature of the state and the welfare state in particular. Neoliberalism is often characterised by a withdrawal of the state as neoliberal theory often advocates for a ‘small’ state (Levitas, 2012: 331). Despite this philosophical claim, neoliberal practice negates this philosophical standpoint. Indeed, as DuRand (2014: 37) notes, the state has not been weakened. This is corroborated by other authors (Baccaro and Howell, 2011: 551), who note that the idea of markets necessitates a state to ensure the creation and maintenance of those markets. On its own, neoliberal interventions “do not produce pure or even near competitive markets but instead provide corporations with lucrative contracts, entry and exit barriers (most famously ‘too big to fail’ status) and unpreceded power and wealth” (Hardin, 2014: 216). The state under neoliberalism actually performs a key function because “the state is able to function as a kind of central committee for the capitalist class, attending to the systemic needs of the capitalist system as a whole” (DuRand, 2014: 41).

There is, however, a debate about how coherent the state is as an institution. Authors broadly agree that the state is constituted by institutions but the degree of cooperation between them varies for several social theorists. Foucault (2004: 77) for example remarked that “the state is nothing else but the mobile effect of a regime of multiple governmentalities” while Althusser (1970) argued that the state is almost completely coherent due to its representation of bourgeois interests. Bourdieu (2004a) contended that the state is divided, with the financial aspects of the state being separate from social care and welfare provision. Bourdieu (2004a: 25) did agree that there is some continuity within the state stemming from the role occupied by the state nobility, who are trained and afforded credentials from academia and science. In this view, the state is not inherently coherent but can become so through political action (Jessop, 1984: 222). This is a view broadly shared by Poulantzas (1978: 14), who wrote:

> Political domination is itself inscribed in the institutional materiality of the State. Although the State is not created *ex nihilo* by the ruling classes, nor is it simply taken over by them: state power (that of the bourgeoisie, in the case of the capitalist state) is written into this materiality. Thus while all the state's actions are not reducible to political domination, their composition is nevertheless marked by it.

Consequently, while the state is deemed necessary for the continuation of neoliberal practices, this does not mean its role is the same. Rather, the state under neoliberalism has its role reconfigured as the state is used as much as it was using its Keynesian era (Harmann, 2007). This is particularly prominent following the financial crash where neoliberalism was deemed to have perished and neoliberal regimes were maintained in this now 'undead' form "due to a political inventiveness which promises little more than to make us and our systems fit for an unknowable, unpredictable and unmanageable future" (Dean, 2014: 159–160). The neoliberal state agenda is about preparing for unknown risky futures, which means that neoliberalism is more broadly associated with "permanent vigilance, activity and intervention" (Foucault, 2004: 132) rather than laissez-faire. Individuals in this context are seen as responsive 'manipulatable people' rather than individuals that are separate from the state (Davidson, 2010: 69).

It is here that the integrated dual approach to understanding neoliberalism, both as a way of looking at the economy and as an ideology becomes beneficial. By regarding neoliberalism in this way, it allows us to recognise the continued importance of the state without regarding it as a deviation from neoliberal practice. Under neoliberalism, the state increases its focus on security, workfare, 'prisonfare' and the penalisation of poverty (Wacquant, 2012). This means that that it

> extolls 'laissez faire et laissez passer' for the dominant, but it turns out to be paternalist and intrusive for the subaltern, and especially for the urban precariat whose life parameters it restricts through the combined mesh of supervisory workfare and judicial oversight (Wacquant, 2012: 74).

It is much less about the provision of care and services, as these are deemed better provided by the market. While the power of a government to survey business is severely curtailed as this is deemed ‘anti-business’, corporate influence is of much greater significance (Crouch, 2004: 94,98), and state intervention is only regarded as acceptable when promoting corporate interests and marketisation. Consequently, this section has established that it is not the case that neoliberalism wants to remove state influence, but rather to alter its form and, as much as possible, transfer the concern over care and healthcare over to market forces. This still means that the state must oversee and create the conditions for the ‘free’ market.

Due to the focus and concern over welfare spending as being increasingly ‘illegitimate’ as a form of neoliberal governance, the welfare state becomes a site for zealous neoliberal reform. For Bourdieu (2004a), it means that the ‘right’ hand of the state – which constitutes financial forces – begins to take away resources from the ‘left’ hand – which is focused on social and welfare services. As taxes are frequently used to fund welfare services, they are in neoliberal theory seen as a threat to the neoliberal creed that profit and market-rule are essential to ensure a ‘fair’ and ‘free’ society (Hall, 2011: 706). The social democratic state in particular is regarded as a threat to this neoliberal utopia due to its high levels of taxation and aspirations for services to be given as a matter of right rather than based on market principles (Esping-Andersen, 1996). Regardless of how much neoliberal thinkers wish to abolish the welfare state, there are practical limitations (Ferguson, 2014). The aspiration to shrink the welfare state and its services on a matter of principle and the extent to which neoliberals have pursued this agenda has caused, according to Fraser (2016), a ‘crisis of care’.

Importantly, it needs to be noted that the limit to which this ‘withering away’ of the welfare state is possible is not merely the result of practical concerns about the continuation of the capitalist state, but also one of electability. In Sweden, the welfare state is incredibly popular in popular consciousness (SOU 2010:04b) and, as we will see in this chapter, a key part of the Moderate electoral success in the early 2000s was due to the abandonment of the goal of the decreasing/removing the welfare state and adopting an ostensibly friendlier attitude towards welfare (Eztler, 2013). This is another reason why neoliberal practice seeks to recalibrate the welfare state rather than to remove it (Pierson

2006: 179). Understanding this is key in being able to discern austerity practices and its relationship to neoliberalism. For example, in Sweden significant changes to disability-related welfare ‘benefits’ have not derived from the outcome of political decisions but from court rulings (STIL, 2014), giving the impression that it is not the ruling parties that are enacting austerity. This gives Swedish neoliberal parties a ‘softer edge’.

The influence of these factors on the welfare state is significant in a variety of ways. The expansion of neoliberal policies has meant a move away from universalism towards means-testing and services are restructured according to ‘activation’ principles, supporting welfare-to-work programmes (MacLeavy, 2010: 135). The influence of this shift has been particularly significant in Sweden and cuts have been justified on the basis that “the incentives to return to work need to be reinforced” (Prop. 2003/04:1). This will be explored more extensively in chapter 8. Writing on neoliberalism, Mladenov (2015: 450) notes that “workfare is also a vehicle of neoliberalisation in the sense that it subordinates social policy (social rights) to the demands of capital accumulation (business interests)”.

Thus far, the chapter has explored the welfare state in a broad sense, but it is important to acknowledge that specifically looking at disabled people complicates this situation further. This is because the welfare state has both conservative and progressive impulses (Bourdieu, 2004a: 33) and nowhere is this as apparent as in the case of disabled people. On the one hand, the state has been essential for disabled people gaining access to substantive rights and services. On the other hand, the state has been key in the reproduction of oppression for disabled people both historically and presently. Two historical examples of this are the forced sterilisation of disabled people in the interwar period (Björkman and Widmalm, 2010; Boréus, 2006; Spektorowski and Ireni-Saban, 2010; Spektorowski and Mizrachi, 2004, 2004; Weindling, 1999) and through practices such as institutionalisation, which were mentioned in chapter 2. Consequently, as much as disabled people rightly critique the state, it is difficult to imagine measures towards equality for disabled people that do not involve the welfare state and its services. Today, the convergence of neoliberalism and austerity has, according to Goodley et al (2014: 981), provided

> an ecosystem for the nourishment of ableism, which we can define as neoliberal-ableism. We are all expected to overcome economic downturn and respond to austerity through adhering to ableism's ideals, its narrow conceptions of personhood, its arrogance and its propensity to buddy-up with other fascistic ideologies.

Neoliberalism, as we have noted, individualises social risks such as unemployment and illness and as a result, the solution becomes self-care and self-regulation (Lemke, 2002: 59). The disciplinary focus is thus placed on the disabled person to deal with these structural aspects by themselves (Soldatic and Meekosha, 2012: 203).

While there are not any statistical figures on the impact on disabled people in Sweden regarding austerity, similar measures in the UK have prompted Dodd (2016: 153) to argue that austerity measures in the UK can be characterised as 'disablist austerity'. This is for several reasons. Under neoliberalism, the individual is predominantly a market agent and participate in the labour market. The state's primary role is to coerce 'the unwilling' and prompt 'the willing' (Soldatic and Meekoska, 2012: 198), increasing the importance of the administrative category of disability (Stone, 1984) in the process. In the neoliberal state, the question of who is able and who is unwilling becomes the key task of the welfare state (Soldatic and Meekoska, 2012: 197). This combined with the Social Darwinist type of characteristic that neoliberals ascribe to the market (Harvey, 2005; Bourdieu, 2004a:42), I argue that there are grounds for concern with regards to how the neoliberal state treats disabled people. These factors open up serious questions regarding how disabled people are treated in a neoliberal society and by the neoliberal welfare state, which I will address throughout this thesis. The importance of disability in neoliberal times can be noted in several ways and there are signs that the heightened moralisation around disability has been not gone unnoticed by politicians subscribing to these beliefs. For example, Fredrik Reinfeldt, a Moderate who would become the Swedish prime minister in the early 2000s, argued in 1993 that the Swedish welfare state made people 'mentally handicapped' (Reinfeldt, 1993).

The final aspect which needs to be covered relates to how the relationship between the individual and the state is conceptualised. Berggren and Trädgårdh (2015) and Trädgårdh (2010) have claimed that the state occupies a particularly active role in individualisation. To a great extent, individuality and individual freedom is characterised as being realised through the state (Berggren and Trädgårdh, 2015), making it a form of statist individualism. This was established in Sweden even before the advent of neoliberalism, and as a result, Swedish society has an incredible emphasis on self-sufficiency and autonomy (Berggren and Trädgårdh, 2015), which are implicitly defined by non-disabled norms. However, Berggren and Trädgårdh (2015) do not discuss that all forms of individualisation requires the state (Poulantzas, 1978:65-66). The utility of Berggren and Trädgårdh (2015) and Trädgårdh's (2010) concept is in its ability to demonstrate that traditional characterisations of individual freedom in Sweden share important common ground with how freedom is characterised in neoliberal theory. The neoliberal view on freedom was succinctly summarized by Foucault (2004: 63), who said that "The formula for [neo]liberalism is not 'be free'. Liberalism formulates simply the following: I am going to produce what you need to be free. I am going to see to it that you are free to be free". This means that under neoliberalism, people are free yet malleable, and participating in markets and employment. This impacts disabled people because collective social provisions are decreasingly justified and there is a renewed focus on making disabled people malleable neoliberal subjects. This means that the institutional and governmental intervention in the lives of disabled people become sanctioned in order to secure this 'freedom'.

3.3 Swedish neoliberal austerity

There is a predominant view of Sweden as having a 'generous' and 'equal' welfare state. This view is predominant in a wide-range of academic and other publications but particularly rose to prominence with Esping-Andersen's (1996) work on welfare typologies, where Sweden became synonymous with the social democratic welfare state, whose key distinguishing characteristic was its generosity. This view is also propagated in other writings as, for example, in Crouch (2014: 116) where he notes that "the [Swedish] welfare states remain the world's most generous and the level of inequality among the world's very lowest". While it is true that Sweden tends to perform fairly well in international league tables, little investigation has been made into the welfare changes that have taken place in Sweden. This remains the fact despite that social policy changes have been more substantial in Sweden than in other comparable countries (SOU 2010:04a), that income inequalities have increased since the 1990s (Copeland et al, 2015: 8), and that many reforms post-1990s are characterised by increasing reliance on the market (Svalfors, 2007: 6). Thus, to understand contemporary austerity in Sweden in relation to disability-related welfare resources, attention needs to be paid to the history of austerity and neoliberalism in Sweden.

Before this can be done, however, it needs to be noted that Swedish austerity practices are rarely defined as austerity measures and, as this section will show, have been chiefly enacted by what I call indirect forms of austerity. I argue that the expansion of austerity – which started in the 1980s but intensified in the early 2000s – can only be understood as *neoliberal* austerity. The emergence of neoliberalism, I argue, is not inherently tied to austerity but, due to historical convergences, they are historically and necessarily linked. As such, I reject the characterisation made by Hassan (2007: 207) and Bauman (2007b) who argued that Sweden has been exempt from the wave of neoliberalism that has swept over the rest of ‘Western’ Europe. Actually, neoliberalism is alive and well in contemporary Sweden and it especially affects disabled people.

Due to the diversity of perspectives on neoliberalism – as previously highlighted – this section will aim to provide “empirically grounded reflections” (McLeavy, 2014: 140) on the nature of Swedish neoliberalism. It will also rely on the dual understanding of neoliberalism, where it is *both* an economic approach and a political agenda. For this reason, the rest of this chapter shall be concerned with providing an account of the emergence of neoliberalism and highlight how its ideology enabled the enactment of austerity measures. The emergence of neoliberalism and the supposed ‘fall’ of social democracy in Sweden is a huge topic and cannot be fully accounted for here but other good accounts of this transformation is available in Östberg (2012), Harvey (2005) and Therborn (2017). I draw on each of these in various ways, but I differ from their accounts by using disability-related welfare policies as a lens through which to understand this development. Therborn (2017) especially calls for a critical re-examination of the Swedish socio-political environment, which this thesis partly seeks to do in this section. In so doing, I will not engage in the reductionist fallacy of reducing neoliberalism to political party affiliations, which is done in other literature on this topic (Eztler, 2013). Instead, I argue that the origins of neoliberalism are much more complex in Sweden and cannot be reduced to a particular party. That said, it is important to recognise that political parties and forces have been instrumental in its implementation. By investigating neoliberalism in this way, it will attempt not to ignore the political form of neoliberalism, which Flew (2014: 52) argued is frequently the case. While the political form of neoliberalism is important, the economic approach to neoliberalism must also be addressed. This will be explored in a subsequent section.

Before delving into the issue of the emergence of neoliberalism in Sweden, however, some context needs to be established regarding the history and character of the Swedish (welfare) state. As such, the first section of this chapter will provide an introduction to the Swedish welfare state in an international comparative context and outline the argument for Sweden being a social democratic welfare state, as offered by Esping-Andersen (1996). This will provide the reader with an estimation of the history and significance of the Swedish welfare state and an idea of what I am arguing against with regards to Esping-Andersen’s work. Following this section, there will be two other sections that will help re-examine the socio-political context of Sweden and argue that it has moved to a societal structure deeply shaped by neoliberalism. The first section deals with the political alterations of the Swedish political landscape and the embrace of neoliberal ideals within the SAP. While the advent of neoliberalism in the UK was quite heavily associated with the Conservative Party (though initiated by Labour), the ascension of Margaret Thatcher, and the drastic alternations in policy that followed, this was not in the case in Sweden, where the emergence of neoliberalism has been exceptionally gradual. In fact, describing Sweden as ‘neoliberal’ is still quite a controversial statement and when looking into its trajectory, there is rarely the kind of ‘singular’ event that was the case in the UK. This is, however, starting to change (Therborn, 2017). The second section of this chapter will account for the policy changes that occurred alongside these political developments relating to disabled people, as these are of essential to answer the research questions. This will also allow us to understand how austerity emerged in Sweden and to elucidate the links between these alterations and neoliberalism. It is in subtle, indirect alterations where the shift towards neoliberalism has been most transparent (Carlén et al, 2014).

3.3.1 The Swedish welfare state

There has been significant scholarship on the Swedish (welfare) state. This is for a multitude of reasons. Partly it has to do with the reputation of Sweden, which is prominent both within academic circles and in popular understandings of Sweden as a country as outlined in chapter 1. The second reason is that, as Ginsburg (1992:30) argues, the most “enthusiastic advocates of the welfare state under capitalism see Sweden as having achieved the closest to the ideal”, pointing to its healthy economic growth, ‘full’ employment, high standards of living alongside “the largest, most expensive and possibly most egalitarian state welfare system in the West”. Because of the prevalence of the Swedish welfare state’s reputation, it is important to spend a bit of time outlining the characteristics and nature of the Swedish welfare state, as this is a point that will be continuously explored throughout this thesis.

The story of the Swedish welfare state is one of gradual development. In many ways, its emergence also started before many other prominent welfare systems. While the British welfare state was established following the Second World War, the Swedish welfare state began to emerge already in the 1930s (Gough, 1979: 147). The foundational philosophy of the welfare state became known as *Folkhemmet* (it translates to The People’s Home). *Folkhemmet* was a broad political agenda that was launched by Per Albin Hansson and it signalled the first shift from the SAP from being representative of a class to being representative of the people (Eztler, 2013: 111, Castles, 1975: 173). In a speech, Hansson outlined the philosophical underpinnings of the concept and said that

> The basis of the home is community and togetherness. The good home does not recognise any privileged or neglected members, nor any favourite or stepchildren. In the good home there is equality, consideration, co-operation, and helpfulness. Applied to the great people’s and citizens’ home this would mean the breaking down of all the social and economic barriers that now

> separate citizens into the rich and the poor, the propertied and the impoverished, the plunderers and the plundered. Swedish society is not yet the people's home. There is a formal equality, equality of political rights, but from a social perspective, the class society remains and from an economic perspective the dictatorship of the few prevails. (Hansson cited in Kielos, 2013)

This philosophy also included a commitment to Keynesian counter-cyclical economic policies that later developed into the aspirations of full employment in the 1940s and 1950s (Ginsburg, 1999: 32). As such, it was very similar to the Beveridge's Liberal Collectivist conception of the welfare state, although it started slightly earlier (Ginsburg, 1999:32). While *Folkhemmet* was and still is broadly associated with social democracy, the concept also maintained other influences as well. It was very much a product of its time as the concept *Folk* maintains similar connotations as the German notion of *Volk*, but with the former having a more democratic undertone and the latter becoming a key concept in Nazi ideology (Andersson, 2009: 54-55). Thus, it is not correct to reduce the foundational ideology of the Swedish welfare state entirely to social democracy, as it was also influenced by the nationalist currents of the time (Kielos, 2013).

Because of the prominence of the SAP – which will be explored later in this chapter in relation to the emergence of neoliberalism – and the strength of the labour movement, this has fundamentally shaped the foundation of the Swedish state. Sweden's noteworthy status in relation to the welfare state has already been discussed, but Sweden has also been of international and scholarly interest with regards to collective bargaining and labour relations (Wilks, 1996). This is because of the central labour relationship model established by the 1938 Saltsjöbaden Agreement, which was a wage negotiating model where "governments could withdraw from the management of wage bargaining, which was increasingly carried out in the form of bipartite bargaining between strong unions and a highly centralized employer organization" (Koch, 2016: 251). In comparisons with other countries at the time, the agreement reached between the labour movement and employers was "early, stable, and institutionalized" (Hedin, 2019: 3). This idea that organisations should negotiate and compromise is also a norm that has effected other areas of civic organisations. This is something that has clearly influenced disability organisations and their relationship with the state, as chapter 2 noted. The power of collective organising and advocacy can have real impact. Östberg (2010: 230), for example, argued that the women's movement prominence is a significant reason for why Sweden always ranks highly in international tables regarding equal opportunity for women.

One of the most influential ways of defining the Swedish welfare state in academic literature derives from the wok of Esping-Andersen (1996), as chapter 1 noted. In his work, Esping-Andersen (1996) identifies three different welfare typologies (liberal, corporatist, and social democratic) and argues that Sweden is the closest realisation of the social democratic welfare state. The social democratic welfare state is subsequently identified by five criteria (Esping-Andersen, 1996):

1. Universalist principles are an underlying characteristic of the welfare state
2. Social rights are independent of pure market forces/labour market participation
3. It seeks an equality of the highest standards, not an equality of minimal needs
4. It has a commitment to achieving/maintaining full employment and keeping as few people as possible on benefits
5. It inspires middle-class fealty.

Universalist principles means that citizens are given "similar rights, irrespective of class or market position" (Esping-Andersen, 1996: 46). This is something that other welfare typologies theoretically also seeks to achieve with means-tested benefits but what makes a social democratic welfare cluster unique is its acceptance of benefit inequalities while blocking off the market (Esping-Andersen, 1996: 48). The extent to which the Swedish welfare state can be regarded as universal has been questioned. Lindbom (2011: 52) recognises that Sweden has never been strictly universal since there has always been a disconnect between the political discourse of the welfare state and programmes; many insurance programmes such as unemployment benefit, sickness insurance, and pensions require participation in the labour market. This discrepancy has increased following rising levels of (long-term) unemployment and many have lost insurance eligibility post-1990s (Lindbom, 2011: 61). In light of this, Sweden should be regarded as relatively universal (Lindbom, 2011: 53).

Social rights as independent of market forces, on the other hand, mean that rights are awarded individuals regardless of their “place within the production process” (Kaufmann, 2013, 141). What makes the social democratic welfare type unique with regards to social rights, according to Esping-Andersen (1996: 43), is that it has a decommodifying elements where “citizens can freely, without potential loss of job, income, or general welfare, opt out of work when they themselves consider it necessary”. The decommodifying aspect of Esping-Andersen’s typology, however, has been criticised for failing to recognise that this potential is offset by the pressure towards full employment and activation policies (Kvist et al, 2012: 7) as well as failing to recognise the role of gender and relying on patriarchal divisions of labour (Cousins, 2005: 112). In the tension between decommodification and measures towards full employment, which will be explored later, Lundberg and Åmark (2001: 161) argue that even at the inception of SAP governance “recommodification was more important than decommodification”.

Esping-Andersen’s criterion regarding an ‘equality of highest standards’ means that the welfare state is a well-funded, high standard solution and this has historically definitely applied to Sweden (Johnson, 2010: 30; Elmbrant, 2005: 17). Often, however, this criterion is conflated with welfare expenditure. As we saw earlier in this section, this sometimes results in the Swedish welfare state being viewed as expensive. The reality of Swedish welfare expenditure is slightly different. When including private insurances in welfare expenditure, Sweden’s expenditure is not extraordinary but rather situated at a comfortable average (Lindbom, 2011: 10). This is also the case with other social insurances and when compared to other OECD countries, Sweden is far from the most ‘generous’ and this is particularly in relation to sick insurance, which is now below the OECD average (SOU 2010:04a). Crucially, this criterion is indicative of the intention that the welfare state is not a refuge for the most desperate, placing it theoretically in sharp contrast to other welfare types such as the liberal welfare type, where welfare assistance is often viewed with stigma (Esping-Andersen, 1996: 26). Finally, it is commonplace in comparative welfare studies to use formal compensation levels rather than actual compensation levels to measure the coverage of the Swedish welfare state, as in for example Bambra and Eikemo (2009). This is problematic as noted in chapter 1, there is a significant discrepancy between formal and actual compensation levels and as a result reinforces the idea that the Swedish welfare state has a particularly ‘generous’ welfare coverage.

The fourth criterion is regarding full employment and its relationship to ‘benefits’. Full employment has for a long time been associated with Swedish welfare policies (Kosonen, 2001: 156). While the issue of employment will be more thoroughly explored in chapter 8, it is worth noting that Sweden’s relationship with employment and benefits is often something that often gets misunderstood. This is partly reproduced through accounts such as Esping-Andersen (1996: 43), who argued that sick insurance in the social democratic welfare type is awarded “with minimal proof of medical impairment and for the duration that the individual deems necessary”. In actuality, Swedish welfare policy has always encouraged and been keen on the readiness to work in order to pay for its social policies (Hort, 2014a: 258) and the workfare element has become increasingly harsher, resulting in “an increased requirement to take up wage labour at whatever pay is offered” (Hort, 2014b: 41). This is because of a central and often overlooked principle within the Swedish welfare state: *arbetslinjen*. Translated as ‘the work line’, it is a principle that views welfare as reciprocal with government policy aimed towards full employment while individuals are responsible to sustain themselves; it is simultaneously a social right and a disciplinary principle, created to decrease the risk of benefit fraud (Johnson, 2010: 39). Beyond this, there is also ambiguity around the notion of societal good (*samhällsnytta*), which also informs the foundations of the welfare state. It implies rights, but it has also been invoked to justify human rights violations such as forced sterilisations (Andersson, 2009: 114; Berman, 2006: 207) and therefore could also imply less ‘generous’ aspects such as efficiency and utility.

The final criterion is around middle-class fealty towards the welfare state. This is about making sure that the welfare state is also attractive to people from the upper and middle-class. Consequently, it is in some ways connected to the third criterion of a social democratic welfare state. To measure the attractiveness of the welfare state as a communal resource, a good indicator is the prevalence of private insurances in the Swedish welfare market, which have traditionally been exceptionally low. Between 2006-2013, however, private insurance increased by 160% (Carlén et al, 2014: 127). Despite the increasing prevalence of private insurance, the idea of a generous, well-funded welfare state is incredibly popular among the population (SOU 2010:04b) although to suggest, as Lindbom (2011) does, that this means that radical reform of the welfare state is unlikely is a bit of a stretch as there has already been significant alterations in policy.

In order to understand the Swedish welfare state, it is important to recognise these elements of the values and constructions around employment, as the Swedish welfare state can be characterised by a form of workfare (Hort, 2014b). It has resulted in Sweden having a “deep-seated obsession with work” (Trägårdh, 1990: 580) and work being seen as goal in itself (Kvist et al, 2012: 6). Berggren and Trädgårdh (2015) highlight that autonomy and independence are a huge part of the Swedish national identity. This is something that the success of the SAP increased rather than mitigated. This is because while having its roots in socialist movements, it was and still is also a *labour* movement. In this way, because it conceptualised the majority of the population as workers and prided itself as being a labour movement, it meant that it was (and still is) through being a ‘productive member of society’ that you prove your commitment to these values. This way of valuing work is a common feature of modern capitalism but because of historical convergences it is particularly prominent in Sweden. I argue that this has significant implications for disabled people and will be a point that will be explored further in several places, especially in chapter 8. Because of the prominence of the SAP, I will go on to discuss the emergence of neoliberalism within the party in the next section because I believe this is central to understand the moment at which my fieldwork was conducted.

3.3.2 The emergence of neoliberalism with the SAP

Due to the unrivalled success of social democracy in Sweden, much of Sweden’s political history can feel like the story about the development, ascension, and collapse of social democracy. The SAP remained in office, winning consecutive victories and selecting the country's prime minister, between 1932 to 1976 (Östberg, 2012) and then again 1982-1991, 1994-2006 and finally 2014 until at the time of writing in summer 2018. Because of the prominence of the SAP and its (arguable) status as "Europe's most successful political party" (Aylott, 1999: 189), the role of the SAP in the neoliberalisation of Sweden needs to be discussed. In fact, I argue that the role of the SAP is essential to understand why the emergence of neoliberalism has been so subtle. Looking at the embrace of neoliberalism within the SAP ranks is therefore essential to understand any shift towards neoliberalism, as many neoliberal policies emerged from the SAP (Linderborg, 2010). While this section shall problematise the party's current social democratic character and charter its broader shift towards neoliberalism, it is important to note that "[a]t almost every stage of its development, [the SAP] has been among the forerunners of the moderate socialist movement in Western Europe" (Castles, 1975: 172) and it was for a long time one of the best organised proletarian movements in the world (Östberg, 2012: 209). To understand how neoliberalism could develop *within* the SAP, it is important to note its history. In this section, I will argue that establishing neoliberalism within the SAP became possible because of the split within the party between different factions and the systematic exclusions of left-wing factions from influential positions helped promote neoliberal policies within the party. This initial section will explore the development of neoliberalism in Sweden as a political agenda and the subsequent section will focus on its economic development as an attempt to adhere to my dual understanding of neoliberalism.

I will focus on the SAP to counteract the inaccurate accounts of neoliberalism as only attributable to certain political parties (Eztler, 2013). Backed by a strong people's movement, upon getting elected into parliament, the SAP leadership wished to transform the movement into a "responsible, reformist, parliamentary party" and, as a consequence, strong leftist factions were driven out in 1917 (Östberg, 2012: 224). Some leftist factions remained within the party and socialist aims lingered in the programme until these were extensively revised in 1944 and then later completely removed in the 2014 party programme. The move away from focusing on class struggle became particularly prominent with the establishment of the *Folkhemmet* philosophy in the 1930s (Ginsburg, 1992:

32). Overall, the shift that occurred over this time was that it refashioned itself as a party of government instead of retaining its original socialist and Marxist ambitions (Steinmo, 1988: 405). This is in line with other left-leaning movements at the time and since (Sassoon, 2013).

While left-wing factions remained within the party, they had declining influence over time regarding the policies the party pursued and weaker positions within the party. This was made possible by the party structure of the SAP. The party structure is a product of the SAP's widely successful past and, as such, consists of several different parts. Some of these enjoy more independence than others and learning how 'the movement', as the structure is often nicknamed, operates can take years (Eztler, 2013: 195-6). There is the main party, the youth party (SSU, Sweden's Social Democratic Youth), the student faction (Social Democratic Students of Sweden), the women's faction (S-Women), and Faith and Solidarity (The Religious Social Democrats of Sweden). As well as these, there is the Swedish Trade Union LO, which is formally independent but remains incredibly closely tied to the party, a Residence Association, the Swedish Cooperative Union, Fondus, and Folksam (an insurance company). Additionally, the party structure also includes AMF (The Workers' Educational Association) and People's Houses and Parks (Östberg, 2012: 208). The SAP is therefore very unique in that all of these various parts are represented within the party. Out of all of these, however, its most significant partner is LO. Adding to the complexity, there are two different hierarchies within the party. One that quite clearly denotes the executive branch at the top, the caucus in the middle, and the districts and associations at the bottom. The second hierarchy consists of a 'small group' and then below that the 26 district ombudsmen. This complicated structure makes the SAP a significantly different entity than other political parties. It cannot operate as, for example, the Moderates, who managed to rebrand themselves and centralise much of its messaging to a degree that the SAP, simply because of its party structure, would not be able to do (Pihlblad, 2012; Åberg and Eriksson, 2010).

It is indeed quite paradoxical for a party that has made 'consensus-making' one of its key political agendas to be so marked with conflict and competing interests. By shutting out left-wing factions and reframing itself as a people's party, it opened up the doors to others beyond the left-wing reformists and as such, conservative and more right-wing elements have equally been a force in the history of the SAP. This tension within the SAP came to a head in the 1990s, which became known as the *decennium horribile* as an internal SAP conflict intensified and, as we shall see later, extensive welfare cuts occurred (Hort, 2014b: 25; Östberg, 2012: 215). During this time, there was also a greater push towards the professionalisation of party politicians after the subsidy that parties get based on electoral performance changed in the 1980s. Professionalisation especially influenced what kind of politician was involved within the higher ranks of the party. For example, in Olof Palme's first government in the early 1970s, half of the cabinet members were affiliated with LO but in the government that left office in 2006, there were only two (Östberg, 2012: 211).

While the party has historically been defined by the tension between the right and left-wing elements of the party, it is oversimplistic to argue that professionalisation automatically favoured the right. There are a significant number of the membership that align themselves with more centrist bureaucratic ideals and see themselves as 'politically neutral' (Eztler, 2013: 204). Thus, a significant part of this centrist element within the party did profit as a result of professionalisation. Because neoliberalism has a way of presenting itself as a 'common sense' perspective (Bourdieu, 2004a), the influence of these 'politically neutral' factions within the party cannot be underestimated. The broader global shift towards free-market, neoliberal policies that occurred during this time can also not be ignored as a factor that informed people's sensibilities of what constituted 'political neutrality'. The political plurality and tension within the SAP are key factors in the shift towards neoliberalism within the SAP but it is rare that these are mentioned (although there are a few exceptions, mostly notably Eztler 2013, Hamilton 2012, and Östberg 2012). Overall, the trajectory towards neoliberalism within the SAP share many communalities to their European counterparts in that the embrace of neoliberalism was the result a long-term development that positioned the centre-right as the new norm.

While the global political shift towards neoliberal sensibilities in the 1980s were significant, there was still a degree of scepticism of these policies within the party. A key figure in normalising and introducing neoliberal ideas within the party was the minister of finance under Olof Palme, Kjell-Olof Feldt. He embraced Milton Friedman's economic theories and argued that the seemingly antiquated Swedish economy needed to be modernised (Östberg, 2012: 220). While this perspective gained traction within the higher levels of the party, it is not fair to say that it was broadly embraced within the party structure as a whole. In fact, a significant part of the polarising and prolonged conflicts that emerged within the SAP during the 1980s and 1990s can be conceptualised as a power struggle between the right and left-wing factions within the party (Eztler, 2013: 204). The most famous example of these conflicts is the very public disagreement with LO that occurred in the 1980s to early 1990s. The government wanted to implement neoliberal austerity programmes and this was something that LO strongly opposed. The conflict was dubbed 'the war of the roses' in the media and relations became so strained that LO formally broke with the SAP and relations remained frosty for a significant period afterwards (Östberg, 2012). In 2010, it emerged that a Swedish public relations firm that were close to the Moderate party had paid significant high-profile SAP politicians to push the party's policies towards the neoliberal right (Nordström, 2010; Suhonen, 2010). It is therefore oversimplistic to argue, in the Swedish SAP case, that social democracy merely resigned itself to neoliberalism (Crouch, 2014: 114).

By exploring the political element of the expansion of neoliberalism in Sweden, I have demonstrated that it was not a lack of imagination or political bravery that caused the embrace of neoliberalism. Rather, it was a result of the systematic exclusion of left-wing factions from the high-profile positions within the party that decreased their influence over time. This left the door open to neoliberal policies to be adopted and normalised within the party. It was further facilitated by the broader push towards neoliberalisation that occurred in other countries and cemented neoliberalism as the new modern 'norm'. This explains why a lot of neoliberal reforms emerged within the SAP (Linderborg, 2010) and also why, when the SAP regained control of the government after the 1991 Moderate government (who had resided over the greatest deregulation in Europe at the time), they did not reverse many of the changes implemented by the Bildt government (Hamilton, 2012: 23-6).

3.3.3 Neoliberalism and austerity in Swedish budgets

While the previous section focused on the political form of the development of neoliberalism in Sweden, this section will focus on its economic character. It will examine the development of disability-related welfare resources and demonstrate how the concern over welfare expenditure emerged concurrently with the expansion of neoliberalism. Austerity measures were a part of the emergence of neoliberal policies within the welfare state, as the previous section demonstrated. Austerity in Sweden was implemented quietly, as the welfare state has broad popular support (SOU 2010:08b), and governments wanted to avoid protests. This has meant that austerity was enacted by slowly gutting existing systems with focus on cuts that affects already ‘weak groups’ (Lindbom, 2011: 33). Combined with the focus on ‘activation’ policies, it has meant that austerity measures have been very prominent in Swedish disability policy. It is partly because, as mentioned in the previous chapter, disability is conflated with illness and thus associated with not-working. Further exploration of this relationship regarding work ability, disability and employment is present in chapter 8.

In this section, I will demonstrate the key changes that have occurred in Swedish disability policy from the mid-1990s to the late 2010s and their connectedness to neoliberal sensibilities. What services and support constitute disability-related welfare resources and support was defined in chapter 1. Because austerity has been implemented quietly, there are few new explicit policies that denote the emergence of austerity measures. Instead, the most notable changes have occurred in enactment of policies or indirect implementations such as increased bureaucratisation. For this reason, exploring budgets from this period is the most revealing as to the character and development of austerity in Sweden.

Further, it is worth noting that disabled people exemplify what Lindbom (2011:33) characterise as a ‘weak group’. This is because they have limited representation in Swedish public life. This can be exemplified in that disabled people are not explicitly acknowledged in budgets, as for example in the 1996/1997 budget (Prop. 1996/97:1). In that document, there are instead estimations of the number of recorded days of ‘unhealth’. The number of ‘unhealth’ days are calculated by the number of subsidy days from sick pay, rehabilitation subsidies, and early retirement/illness benefits, in relation to the number of people covered by social insurances. While all of these implicitly include disabled people (Lindqvist 2012: 74), they are not acknowledged. The lack of acknowledgement of a collective group individualises the phenomenon of disability/impairment and contributes to a political environment where disabled people are silenced and side-lined. This tendency will be explored more thoroughly throughout the thesis.

This thesis understands austerity as a “form of voluntary deflation in which the economy adjusts through the reduction of wages, prices, and public spending to restore competitiveness, which is (supposedly) best achieved by cutting the state’s budget, debts, and deficits” (Blyth, 2013: 2). Austerity has a long history and started off as a primarily economic device but re-emerged throughout Europe in response to the 2008 financial crash (Bramall, 2013). In this respect, however, Sweden is different. As this section will make clear, austerity measures and a concern for the ‘ever growing state’ has been present in disability-related welfare services since the 1980s, but it became particularly prominent after 2005. In many ways, the story of Swedish austerity is related to a financial crash but not the 2008 crash. It was the IT crash of the early 1990s that prompted the push towards austerity alongside a growing ideological push to ‘modernise’ (and thus decrease) the welfare state (this push was explored in the preceding section). LSS, one of the key legislative frameworks which denote services and support to some disabled people, was established because there were concerns that institutionalising disabled people was too expensive and that it would be cheaper to allow them to live in the community (Barron et al, 2000:38). Its implementation was also the result of important lobbying from the disabled people’s movement but its cost-saving quality was attractive to politicians.

In 1995, a year after the implementation of LSS, the government assigned an investigation into how to curb the expenditure of LSS (Altermark, 2017: 108), demonstrating that this concern over ‘cost’ had not been satisfied. The concern over cost remained even with a change in government. In 1996, the incoming Social Democratic government argued in their 1996-1997 budget that the overarching aim of the budget was to decrease spending within the public sector and that the budget should be balanced by 1997 (Prop. 1996/97:1). In the budget, they also acknowledge that they managed to save more money last year by changing sick leave in particular, by requiring more paperwork, employing insurance doctors at the National Insurance Office and these changes overall resulted in a more ‘active’ judgement with regards to sick leave (Prop. 1996/97:1). As such, the expansion of bureaucracy following this time period must be understood as part of the broader austerity agenda. The implications of the increased bureaucratisation is explored in chapter 7. It is a subtle form of austerity – no budget is evidently cut but rather processes are put in place to dissuade applications and indirectly alter eligibility criteria. It is also a useful tool for the broader neoliberal agenda of convincing individuals that social goods cannot be effectively achieved through collective state provisions (Baccaro and Howell, 2011: 122).

In the 2004 budget proposal, which was implemented by a Social Democratic government, there was a renewed zeal regarding disability ‘benefits’. This was prompted by an OECD report, which argued that disabled people should be subject to “mutual obligations” and ‘encouraged’ to enter into employment (OECD, 2003). The aspiration for the budget area claimed that “persons who do not have the capacity to work shall be given a standard of living which is adjusted to the economic development” (Prop. 2003/04:1). The caveat regarding the economic development is new compared to the 1996/1997 budget and the push towards putting disabled people in employment is routinely emphasised. It is a prime example of what Mladenov (2015: 450) noted where social rights are regarded as secondary to market rights under neoliberalism. The budget also contained ideological statements such as “far too many are put on sick leave for far too long, which often leads to pacification and granting of sick and activity compensation. Therefore, an increased investment in employment-focused rehabilitation efforts is necessary as soon as possible” (Prop. 2003/04:1). This is the kind of rhetoric that regards ‘inclusion’ and ‘equality’ as synonymous with labour market participation (Fraser, 2009).

In order to justify this position, the budget references the work of Talcott Parsons (1991) and the notion of the sick role. It is a concept that has been heavily critiqued for ignoring illness, neglecting factors such as class, gender, race, age and ethnicity in medical encounters, and the notion of illness as a form of ‘deviancy’ has been heavily critiqued (Williams, 2005: 125). These reflections are not taken into consideration in the budget. Parsons’ construction of illness as deviancy fits rather neatly into the conceptualisation of disability present in these budgets, which were explored in the previous chapter, and help sustain the view of non-disabled people as the norm and those not fulfilling that norm needs to be subject to medical expertise and be ‘manipulatable’ in a way that Davidson (2010) suggested was characteristic of neoliberalism. Further, they heavily critiqued the idea that the people who are on sick leave (read: disabled people) are justified in being on this ‘benefit’. The budget argued that “that there are studies that indicate that a significant part of those on sick leave are not that because of medical reasons and that many feel that sick leaves can be justified even if one is not ill” (Prop. 2003/04:1). Here, we can see that the budget is clearly shaped by a rhetoric wherein disabled people are constructed as ‘passive’ and ‘non-contributing’ members of society who are not legitimately exempt from the labour market.

The second important budget where one can see the development and intensification of austerity in Swedish disability-related welfare services is the 2006/2007 budget[2] (Prop. 2006/07:1). It is a budget given by a Moderate government, led by Fredrik Reinfeldt. In this budget, an array of changes were proposed – the full extent which cannot be addressed here – but those broadly affecting disabled people are changes to sick insurance, work injury insurance, sick pay, income-based pensions and that the goal for the political area 19 (compensation upon working inability) is revoked. It is here where the austerity measures become more explicit while retaining their subtle characteristic. The most apparent is that the cap on the price base amount, which calculates benefit amounts, is reduced to 7.5 instead of 10. This has the effect of lowering the amount of compensation given to individuals. The decrease is justified because “the incentives to return to work need to be reinforced. This is more necessary than that the sick insurance should give high compensation to persons with high incomes” (Prop. 2006/07:1). It is the kind of argument which is more

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[2] The only type of ‘benefit’ that is not subjected to the change in price base amount caps in this budget is parental leave, an issue which is beyond the scope of this thesis.

akin to a liberal welfare state type (Esping-Andersen, 1996). The budgets for almost all sections of the disability-related expenditure area has significantly reduced following the previous budget.

Another significant shift is in the area of sick pay, which becomes now based on historically generated incomes rather than expected income. This was seen as decreasing ‘welfare fraud’ and, while waiting for the bureaucratic structure to implement these changes, the sick pay was lowered by 1.1% per day. They also reduced the sick pay for unemployed people with a daily limit of 486 SEK, instead of 521 SEK, which is a reduction of 35 SEK per day or 12 600 SEK over the course of a year. The need for ‘quality assurance’ and a ‘legally secure’ sick leave process is continuously emphasised. Another new element is how “the government want to emphasize the significance of running the operation as cost-effective as possible” (Prop. 2006/07:1). The cost discourse is thus evidently beginning to emerge, and its current form will be the focus of chapter 6.

The issue of benefit fraud was raised within the budget and the necessity for “the individual’s commitment and participation” in rehabilitation efforts (Prop. 2006/07:1) was also remarked upon. Within this process, the onus on the return to work gets increasingly shifted towards the individual as employers are relinquished of responsibility for rehabilitation investigations. Thus, austerity starts off as something economic in the budget but is quickly reworked to be a political problem where one allocates blame and responsibility (Bramall, 2013: 2). While the government claims that “several studies have shown that the extent of cheating within the area of social insurance is significantly more extensive than what has previously emerged” (Prop. 2006/07:1), no studies are cited. Indeed, the methodological basis for this claim has been heavily criticised (Altermark and Nilsson, 2017). While the idea of ‘welfare fraud’ has been critiqued for seeking to undermine universal elements of the welfare state (Lundström, 2013), and this charge is worth taking seriously, the important aspect for this thesis is that there is a morality embedded in the austerity narrative, which seeks to put the blame onto individuals and this is of particular importance for disabled people. Disability becomes increasingly politicized and the physical body becomes indicative of a multitude of morals and practices (Soldatic and Meekosha, 2012:195).

At the same time as the budget was passed, there were other relevant changes to disability-related services, the most significant being the changes to personal assistance. Since its implementation, personal assistance costs have increased and between 1995 and 2004, it increased 15% annually (Clevnert and Johansson, 2007: 72), making it a source of political concern. When personal assistance was implemented, it strongly aligned itself with the demands made by STIL, such as “needs expressed in numbers of hours, no medical criteria but the person's total life situation, no means test, […] freedom to purchase services from any service provider including the possibility of employing assistants oneself” to name a few examples (Ratzka, 2003). As such, the responsibility of providing personal assistance is dependent upon the degree of ‘need’. If a person's need for personal assistance exceeds 20 hours, the national authorities cover the cost whereas if it is below 20 hours a week, it is a municipal responsibility (Askheim et al, 2014:7). While the formal eligibility criteria for groups have not been altered – outlined in chapter 1 – it does not mean that changes have not occurred that affect eligibility. Christensen et al (2014:29) note that the articulation of these groups means that while “target groups are defined, the definitions raise questions of interpretation, and thereby also contain possibilities of implicit exclusions which are hard to botton down”.

It is precisely in these ‘judgements’ where austerity measures have taken place and restrictions have been imposed. These implementations and changes have led STIL (2015) to argue that personal assistance is no longer meeting its original intentions. This critique may seem strange as even in government reports, there is an explicit avowal to the idea that disabled people should “live like everyone else” and “is afforded good living standards and a strengthened ability to live an independent life” (ISF, 2014: 27). Notions like ‘equality’, however, are ambiguous (Stone, 2002) and as we have already noted within the 2003/4 budget, this ambition was dependent on the condition of the market.

As noted above, access to personal assistance is determined by the number of qualifying hours of need. The expansion of austerity has meant that the nature of need has been redefined. The qualifying definition of need used to be ‘basic needs’ but now qualifying needs are defined as needs of a “personal and integrity-sensitive nature” (ISF 2014:31). This was determined by a court ruling in 2009 but it was implemented as early as 2007 as standard practice for Social Insurance Agency (STIL, 2014: 5–6). Consequently, assistance such as the "locking wheelchairs and reminders in conjunction with personal hygiene could not be considered to be of personal and sensitive character and therefore cannot be considered as basic needs" (ISF, 2014: 31-2). Any tasks outwith this definition of integrity-sensitive needs are not grounds for eligibility. Other rulings have meant that assisted breathing no longer constitutes a 'basic need' (Bråstedt and Hansson, 2018) and eternal nutrition was initially argued by the Social Insurance Agency not to constitute a 'basic need' beyond adjustments and the turning on and off of the machine, but this was overturned in court (Assistanskoll, 2018; Grill, 2018). What makes STIL (2014: 6) argue that personal assistance is not meeting its original intentions is due to the fact that it is, in this scheme, more about the character of a particular need rather than the existence of need itself.

Beyond the indirect restriction of eligibility, STIL (2014: 17-18) have argued that the austerity measures result in a lack of autonomy and violate people's integrity. There have been instances where welfare professionals have come to people's homes for assessments and asked to watch the applicant shower to determine whether their stated time for showering is 'reasonable' (Pettersson, 2015). Reassessments are also more frequent as a result of austerity measures as is the reliance on insurance doctors when determining LSS eligibility for the third group in particular (see chapter 1). Due to its broader criteria, group three is the largest eligibility group but its size has decreased, from 59% in 2002 to 51% in 2013, making group three the most affected (ISF, 2014: 40,45). There have been calls in parliament to further specify the eligibility criteria for this group in order to manage costs (Betänkande 2014/15:SoU8). That these changes were implemented to manage 'costs' became apparent when a government report (ISF, 2014: 11) stated that "the legislator should examine how the ambition regarding participation should be balanced against the increasing cost".

As is visible in these examples, bureaucracy plays a significant part in the development and enactment of Swedish austerity. It is through increased bureaucratisation and small adjustments in the interpretations of eligibility, for example, that austerity measures have been implemented. It is these kinds of efforts that I refer to as indirect forms of austerity throughout the thesis. Bureaucracy has been at the centre of much sociological concern, as for example with the classic works of Weber (Morrison, 2012) but while this classic scholarship outlines the distinguishing features of bureaucracy, Weber's work does not fully address why bureaucracy occurred (Gorski, 2005). Many writers concerned with bureaucracy end up with a pessimistic view of its potential and emphasise its dehumanising tendency, even if this is up to debate (Jacques, 1977; Bauman, 2000). The impact of bureaucratisation, its dehumanising potential, and connection to austerity is therefore of central importance to this thesis and will be explored further in chapter 7.

There have been some positive developments since the 2006/7 budget, but this does not mean that austerity has been any kinder to disabled people. There has been a slight increase on the price base amount cap but it is not returned to its pre-austerity level of 10 (Regeringen, 2017). Despite this positive development, disability-related welfare services and support are under threat. The Social Insurance Agency sent a letter to the government where they argued that the future of personal assistance was under threat following a series of court cases and budget guidelines (Försäkringskassan, 2017). Also, while the rhetoric of fraud largely coexist with a concern over 'cost', the myth of the disabled person as a fraudster remains and has an impact on practices. There was an attempt initiated by a local Social Insurance Agency to 'catch' disabled people fraudulently claiming benefits in the south of Sweden, by inviting them to stay overnight in a hospital for tests while they were unwittingly put under surveillance from the moment of entry and the notes from the surveillance were admitted as part of the assessment material (Mikkelsen, 2015). There were also explicit cost-saving directives in a government investigation into the future of LSS (which is far more explicit than by previous governments) and the government ultimately had to back away from that directive, following diligent campaigning from the disability movement (Crona, 2018). Thus, while there have been minor increases in compensation levels, the concern over cost has enabled even more radical austerity measures. In this way, we can see that Sweden is following a neoliberal trajectory, as suggested by Baccaro and Howell (2011), and the same kind of shrinking of the disability category (or, in the case of Sweden, illness category) as the UK (Roulstone, 2015).

3.4 Conclusion: Neoliberal Sweden

This chapter has demonstrated how austerity was enacted by looking at governmental budgets, selected at key points to demonstrate how it responded to changing political sensibilities and governmental changes. It has demonstrated that while austerity measures were initiated in subtle ways through techniques, such as not adjusting for inflation and increased bureaucratisation, its discourse and subsequent policy changes became more explicit over time. In Sweden, austerity was made possible by first increasing the bureaucratisation of disability benefits and by increasing the conflation of illness and disability through an increasing reliance on medical assessments. This allows the government to pursue agendas to decrease compensation levels to ‘encourage’ a return to work for disabled people and neglect the role of impairments. This particular tendency will be further explored in chapter 8. As workfare as always been an element of the Swedish welfare state (Hort, 2014a), it could be pursued much more severely. The myth of welfare fraud helped to justify decreasing compensation levels and it allowed for increasingly invasive forms of ‘quality assurances’ in the assessment of disability ‘benefits’ to be implemented. This has had significant influence on disabled people’s willingness to apply for services in the first place, as chapter 7 will show.

Following this trajectory of austerity measures and seeing the development of disability policies, it follows a similar pattern to other countries, most notably the UK (Garthwaite, 2011). As the concern over ‘costs’ regarding welfare expenditure has become more significant, I explore this discourse and its implications in chapter 6. Equally, the role of employment and its implications for disabled people’s rights in Sweden is explored in chapter 8. Most of the austerity measures, while indirect, were instigated by governmental intent but they have rarely been subject to political debate or campaign. Instead, personal assistance reforms, for example, have been pushed through the courts. This targeting of marginalised, individualised groups with little political currency enables the state, I argue, to maintain the myth that they are not seeking to reduce or reform the Swedish welfare state and thus avoid controversy.

Due to the historical convergence of austerity and neoliberalism in Sweden, I argue that they cannot be seen as functioning separately in the present moment. Austerity is inherently tied to neoliberal ideals of shrinking the Swedish welfare state. This does not mean that neoliberalism necessitates austerity. There was some indication from the failed government budget and recent government actions that some standards of living should be raised, but the broader assault on personal assistance, in particular, throw the sincerity of this aspiration into question. Disability and disabled people are still equally contested and subjected to austerity but with varying intensity. Sweden is not identical to British neoliberalism, for example, but it is following the same trajectory (Baccaro and Howell, 2011) and this chapter demonstrated through the prism of disability benefits one of the ways in which welfare institutions have become transformed according to neoliberal aspirations. Thus, this thesis agrees with Hort's (2009: 441) assessment that the Swedish welfare state is moving towards "neoliberalism with a statist and communitarian Swedish-Nordic accent" and this becomes, I argue, particularly evident when looking at the provision to disabled people within the welfare state. The implications for disabled people within neoliberal Sweden shall be explored further in the conclusion of this thesis.

4. Research methods

This research aims to understand how the expansion of austerity has affected disabled people and whether the welfare state has had any impact on disabled people's lives. Placing disabled people at the centre of understanding Swedish austerity is paramount due to the fact that Swedish austerity measures have particularly targeted disability-related welfare resources and support, as chapter 3 demonstrated. It is also important due to how the welfare state conflates disability and illness, as explored in chapter 2, as the targeted nature of austerity can therefore be concealed. In light of this context, I felt like it was important to also convey the broader context within which the experience of disabled people is situated. For this reason, I also conducted elite interviews with disability organisations and welfare professionals alongside those I conducted with disabled people. To capture the multifaceted approach in trying to explore the impact of austerity, the research was centred around three main research aims:

1. To understand how disabled people, disability organisations, and welfare professionals understand the changes in the Swedish welfare state.

2. To see how disabled people in Sweden have been affected by austerity measures.

3. To see what, if any, impact the welfare state has on the experience of being a disabled person in Sweden today.

To explore these research aims, I employed a qualitative methodology. This would allow for the generation of rich, nuanced, data that would not only speak to how austerity is understood in Sweden but also situate the impact of austerity within the context of disabled people's lives. Generating knowledge that allows disabled people who are marginalised in Swedish society to articulate how societal changes impact their lives goes to the heart of what I consider to be a valuable, important, and robust way of conducting sociological research. Especially in light of how disabled people have been historically marginalised in research and had the features of their social oppression reduced to a ‘personal tragedy’ (Barnes and Mercer, 2004: 6).

This chapter will document the research process. It will do this in four sections. The first section will account for the methodological underpinnings of the chosen research method. It will engage with the field of emancipatory research methods and particularly emancipatory disability research methods and its connection to other paradigms such as feminist emancipatory methods as well as materialist influences. By doing this, I need to explore how I position myself in relation to Marxist methodologies. It will result in a discussion around objectivity and the notion of value-free research. This will lead onto demonstrating the broad contours of my chosen method: semi-structured interviewing and how I approached the issue of how to produce high-quality, robust, semi-structured interviewing in light of my ontological and epistemological principles of reflexivity and reciprocity. Here, it is important to acknowledge the question of insider identities. Equally, this section will discuss what it means to conduct sensitive research with participants who experience marginalisation and participants who do not experience that marginalisation. The second section will explore the practice of my doctoral research. It will explore the participant groups, the recruitment criteria, what events informed how the research was conducted and how the ethics process was negotiated. It will explore how I conducted the interviews and negotiated tricky situations and how I managed the data that was generated by the semi-structured interviews. The third section will explore the analysis of my fieldwork data and how aspects such as translation and language was negotiated in this process. By exploring these aspects of the research process, I demonstrate how the data was collected in a scientifically robust manner and offer transparency in that process, as well as addressing difficulties encountered in the research.

4.1 Emancipatory research methodologies

Emancipatory research methods aim to challenge the social relations of research production (Oliver, 1992). It is an ambitious way to approach research that seeks to promote “the empowerment of disabled people through the transformation of the material and social relations of research production” (Barnes, 2003: 6). It is a paradigm that draws on feminist and anti-racist reflections on research methods, and qualitative research has been particularly noted as suitable for emancipatory research (Barnes, 1992). This epistemological position also involves reorienting the focus of research away from individuals ‘coping’ with impairments to “the disablism ingrained in the individualistic consciousness and institutionalised practices of what is, ultimately, a disablist society” (Oliver, 1992: 112). It is not just about challenging power inequalities but actively promoting change. This has been positioned as in direct opposition to positivist research conducted on disability (Oliver, 1992). Barnes (2003: 11), however, highlighted that disability scholars share common ground with positivists and ‘post-positivists’ in that they both assert that there is a ‘reality’ out there. The difference, Barnes (2003:11) argued, is in their position to political neutrality and objectivity.

A key criticism of objectivity is that it “is not that it is too rigorous or too ‘objectifying’, as some have argued, but that *it is not rigorous or objectifying enough*; it is too weak to accomplish even the goals for which it has been designed” (Harding 1993: 50–51). In addition to this, viewing something as ‘objective’ is often the result of perception training that is reproduced through tautological processes (Bauman, 1976:44). Research claiming to be ‘objective’, or in the vein of Weber ‘value-free’, has been critiqued for taking the status quo and structural aspects for granted (Lewis, 1975: 43). Indeed, judgements surrounding human value is central to sociology and, often, when not making value-judgements, it ends up accepting the value judgements of others (Gray, 1968: 176,184). Paolucci (2012: 25) notes that “lack of attention to political relations is a political bias, not a neutral or objective posture”. This means that research can reinforce relationships of inequality (Becker, 1967) and pretending that scientists do not make value-judgements neglects that academics have also always been a part of social movements, as stated by Said (1994: 8). Adhering to ‘objectivity’ also impacts the type of information that is able to be generated. Gouldner (1968: 116) noted that “objectivity expresses a lingering attachment to something more than the purely technical goals of science alone and for more than the valid-reliable bits of information it may produce”; it very rarely ends up conveying anything new about society. This is because, in reality, facts and values co-exist and tend to separate only when unfulfilled potential is addressed. This was observed by Bauman (1976: 73) who argued that, “With Reason forced to abdicate rights to criticize and relativize human reality, men are bound, willy-nilly, to seek levers of their emancipation elsewhere”. Indeed, as Ramazanoglu and Holland (2002: 49) demonstrate, “Rationality does not ensure validity or escape its social constitution”. By drawing on and recognising the contribution of disability, feminist, and critical scholars, the critique of objectivity occupies a central position in my ontology and epistemology as a researcher.

4.1.1 Limitations of emancipatory research methods

In many ways, the emancipatory research paradigm has had a significant influence on how I understand good, valuable, robust sociological research and I will explore these throughout this research chapter. It is, however, important to acknowledge that there are some limitations to the promise of emancipatory research. Exploring these and the practical elements of emancipatory research methods will be explored in this section. This will allow for a more critical perspective on the extent to which emancipatory research methods can be achieved within the context of a PhD and how I diverge from the practical outlines suggested by emancipatory research advocates. The key divergences are both practical and theoretical. While I am drawing on feminist emancipatory writings, it is important to include reflections on disability emancipatory research writings as feminist theory and methodology have done little to include the voices and experiences of disabled women in their practice (Morris, 1992).

While many may agree that objectivity is practically a myth, its implications for research is less clear. While emancipatory research advocates are more forgiving of interpretivism than of positivist research, they highlight issues with this perspective. They argue that the “interpretive paradigm has changed the rules, [but] in reality it has not changed the game” (Oliver, 1992: 106). Importantly, however, this is not just a critique that could be made of interpretivist research paradigms but also around emancipatory disability research. Goodley and Moore (2000: 875) highlight that there are “in-built paradoxes” in advancing an understanding of disability politics while fulfilling the institutional obligations that come with being a researcher. They give the example that writing reports to funders and academic presentations are frequently inaccessible to the disabled people, and in particular people with learning disabilities, whom Goodley and Moore (2000) worked with. Producing academic work can therefore be contradictory to producing information that is accessible to disabled people.

Despite this, there have been attempts to outline practical criteria for how to conduct emancipatory research methods. Mercer (2004: 120) suggested three key criteria for undertaking emancipatory research: 1) it should be “accountable to disabled people/their organisations in their political struggles and empowerment”, 2) it should be “reversing the traditional researcher-researched hierarchy/social relations of research production and challenging the material relations of research production”, 3) and it should be “accepting a plurality of research methodologies/methods”.

Recognising the institutional limitations placed upon researchers, as Goodley and Moore (2000) have done, is becoming increasingly important. Indeed, Barnes (2003: 13) noted that the traditional charge that researchers have benefited on the backs of disabled people can be challenged in that now “a career in social research is more often than not characterised by financial and social uncertainty”. The ability to challenge the institutional pressures and practices embedded in academia therefore becomes significantly more difficult, especially for early career researchers such as myself. It also limits the extent to which I as a researcher can transform the material and social relations of research production. Thus, I remain doubtful of research – in particular doctoral research – in being able to challenge the social relations of knowledge production, as suggested by Oliver (1992). Thus, I have significant reservations regarding the second criterion of emancipatory research as outlined by Mercer (2004).

The context of the research also matters. While I care about my research topic and want to highlight the situation of disabled people in Sweden, I am also conducting this research to gain a doctoral qualification. Even if I was to involve other disabled people within the research process, they would not share the qualification I would gain as a result of this research. Thus, there is not an equality in rewards. I am also asking quite potentially sensitive questions and it would potentially require a significant amount of time from participants. Especially if one follows the advice of people advocating for emancipatory research methods, which such as scheduling several meetings to interview participants and discuss findings (Oliver, 1992: 122). Consequently, adopting this approach felt unethical. Especially since this topic meant that I would be speaking to disabled people who were probably living in highly precarious and potentially impoverished conditions. I also did not have the financial means to offer incentives or rewards for participating. While I attempted to establish some emotional reciprocity during the research, I could not establish a material one and these things matter, especially as I am looking into the consequences of austerity for disabled people.

Additionally, Barnes (2003) notes that allowing disability organisations to set the research agenda and allowing research to be accountable to research organisations is a key feature of emancipatory disability research methods. This is also part of the practical criteria suggested by Mercer (2004). This is not something that I think is appropriate considering the context of this research. As noted in chapter 2, Swedish disability organisations have historically close ties with the state and are seen as broadly engaging in a cooperative role with the state. Having my research be accountable and shaped by invested and arguably elite participants felt ethically problematic. In some ways, this points to an issue highlighted by Gouldner (1968) in his criticism of Becker (1967) – socio-historical contexts and power relationships can vary. While letting disability organisations shape research could be a progressive and unproblematic research choice in the UK, they do not necessarily have the same activist, grassroots history in Sweden and their involvement can be more questionable. Therefore, I agree with Gouldner (1968) that it is to values that sociologists should pledge their allegiance. Consequently, I am committed to uncovering and challenging disablism and argue that this is compatible with an emancipatory research paradigm, despite the fact that I am not letting the research be accountable to disability organisations. Ultimately, I view bringing disabled people's voices and accounting how austerity has affected them to be a fundamentally useful task in that it sheds light on a previously underexplored research topic, namely that of Swedish disablism.

4.2 Materialist influences

The second element that has a significant bearing on my ontological and epistemological position is the influence of materialism. In some ways, this connection goes directly to the heart of the emancipatory research paradigm as its materialist and Marxist influences via the social model is well documented (Barnes and Mercer, 2004: 10). Additionally, Marx's view on the purpose of scientific effort is compatible with the ethos underlying the emancipatory research method, as he famously stated: "The philosophers have only *interpreted* the world, in various ways; the point, however, is to *change* it" (Marx [1845] 1978: 145). Thus, while on the surface the materialist influences of the social model and my own are remarkably similar, there are differences in the materialist interpretations between that of the original social model and my own.

The type of materialism that influenced the social model maintains its focus on structural and material barriers for disabled people and, as Thomas (2004a: 572) noted, sceptical of sharing personal experiences unless "it is in the service of galvanising the broader struggle for social change". This meant that there was a particular focus on economics and market participation (Finkelstein, 2001) and the psycho-emotional aspects highlighted by Thomas (2004a; 1999). This particular focus on the political economy can also be mirrored in Marxist scholarship. There is a significant debate surrounding Marx's work whether or not his earlier philosophical writings ought to be considered as a continuation or as separate from his later more economic work, most notably *Das Kapital* (Musto, 2015). Those who argue for a connection between Marx's earlier work and his later economic work tend to emphasise the humanist aspects of Marx's writings, while those who argued that his earlier writing was superficial tended to develop a more positivist anti-humanist reading of Marx's work (Musto, 2015: 240). I belong to the school of thought who see Marx's early writings as importantly connected to his later work and consequently, the rigid separation between the public and private that exist within the traditional social model is something that I would dispute. The most foundational epistemological and ontological consequence is that I regard social relations as determining the mode of production rather than the mode of production determining social relations (Poulantzas, 1968). This does not mean that my adoption of a social model perspective needs to be entirely abandoned as there are those that utilise the social model that criticise the overemphasis of political economy and the private/public divide that has resulted from these debates (Thomas, 2004a).

4.3 Qualitative research and semi-structured interviews

Having accounted for my ontological and epistemological position, it is important to explore more closely why I chose to approach the research aims by employing a qualitative research methodology. As previously mentioned, qualitative research methods felt like the best way in which to generate nuanced data and understandings of how welfare changes have impacted disabled people. While I am interviewing elite participants, I felt like it was important to centre my research project around the stories shared by disabled research participants. This section will explore the qualitative research methods used, why they were utilised and why semi-structured interviews were seen as best suited to generate the answers to the research aims.

Interviews are arguably the most commonly utilised research method within qualitative research (Packer, 2018: 55) and qualitative interviews are viewed as exceptional at “exploring the points of view of our research subjects, while granting these points of view the culturally honoured status of reality” (Miller and Glassner, 2016: 53). There has been a critique that interviews are context specific but Miller and Glassner (2016: 53) argue that interviews argue that this criticism is exaggerated and that “knowledge of the social world beyond the interaction can still be obtained”. Rubin and Rubin (2005: 3) argue that qualitative interviews are particularly suitable for projects that explore social and political processes. Roulston (2010: 220–221) has noted that interviews have been used in facilitate emancipatory research and in these situations, particular attention is paid to power relationships between the researcher and participant, as well as wanting to open up transformative possibilities.

While concepts such as validity and reliability have traditionally been tests of scientific validity, they have been increasingly criticised by qualitative researchers (Seale, 1999: 465). Instead, it has been argued that it is better to focus on other criteria that are more applicable to qualitative methodologies. It is nonetheless important to note that within discussions of quality regarding qualitative research, the pressure to present a single gold standard must be resisted due to the diversity and reflexivity of discussions within the field (Denzin, 2009: 152). These conversations are important as Ramazanoglu and Holland (2002: 41) argue that “Accuracy, evidence and valid knowledge are needed in order to provide a foundation for practical political responses to the injustices and abuses of power”. Being able to convince a broader public about the quality of the research findings are also essential in attempting to shed light or challenge problematic practices that research within feminist and emancipatory paradigms speak to.

One of these alternative criteria for the robustness of the research is credibility (Rubin and Rubin 2004: 64). This is something that I felt was very important to achieve within the research process. I incorporated concerns over credibility in the sense that I interviewed disabled people who had access to disability-related welfare resources and did not exclude participants who felt as if they were not negatively impacted. By not limiting the recruitment criteria in this way, it allowed me to avoid accusations of a particular agenda and instead try to capture some of the complexity embedded in welfare changes and potential divergences in experiences. While it is true that many participants who contacted me were unsure about whether they fit the recruitment criteria because they assumed that participants had to have been negatively impacted, it enabled me the space to make clear to participants that this was not the case and that I was equally interested in stories from people who saw themselves as ‘spared’ from austerity. Other important criteria such as transparency is achieved through the writing of this methodology chapter, wherein I account for the underlying philosophies, research practices, and dilemmas that affected the production of this doctoral research.

4.3.1 Semi-structured interviews

The type of interview I decided to conduct was, as much as possible, semi-structured in nature. This type of interview is “the workhorse of qualitative research today” (Packer, 2018: 56). In describing semi-structured interviewing, Packer (2018: 56) defines semi-structured interviews as an interview where the researcher has a general plan for the discussed topic but allows significant latitude in how the topic is discussed and interviewees are encouraged to answer ‘in their own words’.

Consequently, as I centred my research on the experience of disabled people and, in keeping with my ontological and epistemological principles, saw them as the experts of their own lives, this was an important methodology to employ to ensure that participants could share their experiences the way that they wanted to. It also meant that they could focus on aspects they found relevant rather than me guiding the conversation too tightly and merely focusing on what I wanted to speak about. Secondly, being sensitive to stories of disabled people’s privacy being invaded by bureaucratic institutions and professionals (noted in chapter 3), I thought that semi-structured interviewing emerged as the least invasive and least time-consuming method to discover the impact of austerity on disabled people. This will be elaborated on further in the subsequent section. Thus, semi-structured interviewing seemed to be the most appropriate method to employ compared to more time-consuming methods, such as ethnography or participant observation.

A topic guide was also constructed to cover the general areas related to the topic. These were mainly focused on generating information about the participant (in the case of disabled people), what their experiences had been like, and what they thought of the political climate for disabled people. This was important to ask, I felt, because the issue of disability has become the focus of significant political debate (see chapter 2 and 3), but rarely include the voices of disabled people. The questions were broadly similar in the topic guides for the professionals and disability organisation representatives. The questions and prompts were kept general and vague in order to allow the participant to guide the general tone and conversation within the interview.

In many ways, semi-structured interviews are a joint production between the interviewer and the participant (Packer, 2018: 70) and where I as the researcher engage in conversation and cues to elicit responses from participants. The implications and consequences of this will be elaborated further in discussions about insider identities and the analysis. But it is also because of this role that the semi-structured interviewer has, which is different from for example a survey, which means that a topic guide is important. Changes to the topic guide mainly consisted of additional prompts about particular aspects (for example bureaucracy) as the fieldwork carried on.

4.3.2 Reflexivity and reciprocity

Building on the critique of 'objective' research, it is important to examine what parameters by which quality of research is determined. Rubin and Rubin (2004: 64) argue that credibility should be the guide for determining quality in qualitative research. This is achieved, according to Rubin and Rubin (2004: 64), by interviewing people who have first-hand experience of the impact of austerity and, as noted previously, I made a conscious attempt to not limit the recruitment criteria to fit a particular agenda. The second perspective is that has been frequently reflected upon in relation to questions of quality is reflexivity. Reflexivity can be used as "as a resource rather than a threat, and to abandon false claims to value-freedom" (Ramazanoglu and Holland, 2002: 51). Guillemin and Gulliam (2004: 275) argued that reflexivity is usually concerned with producing more 'rigorous' research, but it can also importantly invite an inherent ethical consideration into the research process. Reflexivity has been deemed an important tool in breaking down the "the illusion of the absolute point of view" (Bourdieu, 2004b: 95) and in recognising the importance of diverse voices and critiques in research (Ramazanoglu and Holland, 2002: 119). It allows a partial framework in which to acknowledge the 'hidden' socio-political forces that shape research narratives and the political/ideological agendas that are hidden in our writing (Finlay, 2011: 211).

Despite these significant values of reflexivity, Bourdieu (2004b: 89,114) cautioned against reducing reflexivity down to academic narcissism and the only possible way to avoid this is by making sure it is embodied in collectives. Thus, reflexivity necessitates extending beyond the self and including critical examination of the production of knowledge. While this is important, Bourdieu has been criticised for leaving "little indication of how reflexivity should be conceptualized at the level of individual research practices" (Riach, 2009: 359). Similarly to claims made by emancipatory research methodologists to change the social relations of knowledge production, it is difficult to see how this can be achieved in reality considering the current research landscape. It is not clear how to ensure that reflexivity is embodied in collectives nor certain how to achieve this in individual research projects. While I may maintain a critical disposition towards how research is carried out in academic institutions and may have those within my discipline who share those beliefs, whether or not that has any larger structural impact is uncertain as funding bodies and others still largely maintain standards and views of 'objective' research (Denzin, 2009). Consequently, it could be argued that I am limited in this research to a kind of reflexivity that Bourdieu (2004b) may have been critical of. Nevertheless, reflexivity has been identified as an important part of feminist research and other research paradigms that seeks to challenge power inequalities (Hesse-Biber, 2014: 3). It is a way in which researchers can "account for their personal biases and examine the effects that these biases may have on the data produced" (Hesse-Biber, 2014: 3). Thus, even if it may be regarded as 'problematic', it is still an important aspect of producing robust qualitative research.

4.3.3 Insider identities

In the spirit of employing reflexive practices, it is important to acknowledge my own impact on the research in question. In some ways, this influence is evident in the sense that I decided on the topic in question, as well as designed, constructed, and carried out the fieldwork and subsequent analysis. As I will discuss in greater detail later, it was something that affected the recruitment process and inevitably the interviews themselves and how I later analysed the data. Recognising my own position and influence is also important in relation to acknowledging power inequalities within the research process. Packer (2018: 64) explained that the "asymmetry of power in the qualitative research interview is employed to create also an asymmetry of *visibility*. The interviewer becomes invisible and the interviewee is the center of attention”. This process of invisibility is embedded throughout the entire research process. In some ways, this chapter endeavours to demystify my own position with regards to the research process and account for my choices and interpretations to a degree. Packer’s observations do, however, raise important questions with regards to academic practice and as with questions of reciprocity and emancipation, principles I do espouse, I am doubtful to the extent in which this process can be altered to enable a more equal process.

In many ways, the choice of research topic has been fundamentally shaped by my own background - although I am not certain how consciously this has been, as I am aware that in retrospectively looking at my own situation, the link appears more straightforward than I have experienced it to be. As a disabled working-class Swedish woman, who grew up with a single mother who was on sick leave throughout my life, I was conscious of the impact of welfare benefits and its changes. Further, having two non-disabled sisters also made me aware of differences in our experiences that primarily arose from the fact that I had an impairment. I spent most of my childhood becoming intimately acquainted with healthcare professionals, examinations, surgeries and people commenting on my body as being in need of ‘fixing’, as well as the inevitable ‘praise’ I would receive from non-disabled people in instances where my impairment was not visible to them.

I grew up in a context where there was an overwhelming societal and political rhetoric in Sweden that claimed that Sweden had fundamentally solved the issue of class (in particular in the late 1990s and early 2000s) after decades of Social Democratic governance. As policies became more restrictive to people on sick leave in the mid-2000s (see chapter 3), I saw first-hand the impact this had on my mother and our family. It made me sceptical of claims that Sweden was a particularly generous welfare country in the literature I encountered when I began to study at university (for example, Esping-Andersen 1996). Having experienced Sweden in this way undoubtedly made me interested in wanting to study this issue further, but it was also something that I experienced made people more at ease in wanting to speak to me.

During the recruitment process, which will be outlined in more detail later, I was interviewed for two local newspapers that (for a variety of reasons) emphasised my impairment and my area of research and this prompted several people to contact me and wish to participate. One participant, Inga, expressed delight at the fact that I as a disabled person myself was researching this important topic. It was also something that would occasionally come up in interviews. When Emilia spoke of how deeply distressing and inhumane she thought assessment meetings with the National Insurance Office were, she suddenly asked me of my own experiences with them:

> if you were not in a wheelchair or had another problem, you would not be exposed to it, which I think is inhum- it is so violating. I do not know if you have been through it yourself or so. Have you been in one of those?

When I spoke to another participant, after the formal part of the interview was conducted and I was sharing some of my own experiences, they expressed surprise as they had assumed I had the same impairment as them (namely autism). Gender has also been a factor that has been frequently noted as impacting the research process (Vähäsantanen and Saarinen, 2013: 494-5) and this was also the case here but this (and other factors such as class) were less evident throughout the research process. For example, it was at times evident in how male professionals I spoke to spoke to me, but this is more difficult to convey in a written format.

Despite the fact that there has been a tremendous debate within disability studies about who can and should research disabled people (Kitchin, 2000), where some have argued that disabled people are better positioned to research disability due to their own personal experience, I did not experience this to be the case. While my approach might have been informed of my background, I did not immediately share an ‘innate’ understanding of my participants’ experiences. Not only because my participant groups were heterogenous and in particular within the disabled people participant group there were such significant differences in their backgrounds that I did not inherently have any greater insight into their experiences. I have, for example, never been a disabled adult living in Sweden as I was quite young when I moved to the UK. It could be possible that participants who knew I was a disabled woman chose to share aspects of their experiences with me that they would not have with a non-disabled researcher, but it is difficult to ascertain whether this was the case.

4.3.4 Sensitive research and 'vulnerability'

In some ways, the research touched upon sensitive questions (as for example Emilia's quote makes clear) that needed to be approached with care. That sensitive issues might arise from speaking to disabled people about their experiences of the welfare state is a result of the nature of the oppression and discrimination that disabled people have faced in Sweden (outlined briefly in chapter 2). This is not in itself controversial. There is an element, however, where the disablist construction of disability as a personal tragedy (Barnes and Mercer, 2003) as manifested itself within research discourse to suggest that disabled people are inherently more 'vulnerable' research participants. This is a characterisation that I openly reject as part of my research practices.

In fact, I would argue that vulnerability is inherently shared among all people (Fineman, 2015: 613). Disabled people are not inherently less able to consent. Instead, it might be the case that the process of acquiring that consent need to be ensured in unorthodox ways. But that reflexivity and sensitivity and care towards informed consent need to be practiced when acquiring consent is something that applies to all research participants.

When conducting interviews, I was conscious that I might be asking participants to divulge aspects of their experiences that they might find emotionally distressing. For this reason, I made it clear at the beginning of every interview that if I asked a question that they did not want to answer, they could decline to answer it and if they wanted to retract aspects of their interview after the interview was conducted, they could. This was taken up by participants at various times. Some interviews were only sporadically recorded where the participants said when they wanted the recorder turned on and when they wanted to turn it off. Also, when participants demonstrated signs of distress either in their body language (or through their voice, as in the case in phone interviews), I asked if they wanted to continue or wanted me to pause the recording. Another participant contacted me after the interview took place to ask for a particular topic they had discussed to be omitted from the transcript because it made them anxious for fear that it could later disadvantage them in some way, which I happily obliged. In cases where participants divulged histories of abuse and mental distress, I made sure to alert them to useful resources if they needed it or if they wanted me to alert the authorities of it. In these cases, the participants in question declined. Reflection on aspects like these will be done in more detail in the ethics section.

4.3.5 Interviewing ‘elite’ participants

As part of my research, I also interviewed elite participants. Conti and O’Neal (2007: 64) call for researchers to use “qualitative and feminist approaches to studying elites”. They argue that this is important because it helps shed light on how “systems [of power] are interlocking, non-additive and often contradictory” (Conti and O’Neil, 2007: 67). While I decided not to have the issue of elites and power be the focus of my thesis, and thus I interviewed fewer elite participants, the issue of power was something that was at the forefront in my mind. Further, the issue of the complex nature of power was something that emerged clearly in the interviews, as subsequent chapters will demonstrate.

The exact definition of elite has been the subject of significant debate, with Harvey (2011) noting that job title may not correspond to influence or, for example, that influence (or elite status) may change over time. The definition Harvey (2011: 433) utilised defines elites as “those who occupy senior management and Board level positions within organizations”. I would not share this definition of elites, as this would for example exclude the welfare professionals I interviewed as elites but maintain disability organisations as ‘elites’. Instead, how I define ‘elite’ is in relation to influence with regards to the topic area and whether they were interviewed in their professional capacity. Welfare professionals, for example, have at least a marginally better influence over the practice of austerity than disability organisations. Further, compared to the people I interviewed in their capacity as a disabled person, they occupy much more significant status and influence, even if the differential degree of influence might be marginal. In short, I viewed define ‘elite’ as those who occupied relative positions of authority in relation to the research topic. This is because that I view power as being expressed as a relationship, which was highlighted in my epistemological and ontological discussion earlier in the chapter.

While any participant might have their own motivations or agendas for portraying a situation in a particular way (Jacobsson and Åkerström, 2013), the way that these elite participants related to the research questions were slightly different in that they were interviewed in a professional capacity. This made the interviews quite different from the interviews I conducted with disabled people. References to legal and societal structures such as the UNCRDP or bureaucratic particularities were more frequent in those interviews. The welfare professionals I interviewed chose to remain anonymous whereas the majority of disability organisation representatives insisted on using their names and organisations for this thesis, as they saw the interview as being part of their job. While there might have been motivations for these participants to participate, it did not mean that they were not reflexive. Several of the welfare professionals were critical of the welfare system overall and how austerity had impacted disabled people. Many disability organisation representatives were critical not only of society overall or the welfare system but also their own work and the limitations of these, as will become clear in subsequent chapters.

4.4 The fieldwork

In some ways, the carrying out of the fieldwork was a difficult process. Consequently, this section will primarily focus on two main aspects: how the research was carried out and issues and dilemmas that I came to face throughout the process. I will begin by divulging information about the participant sample, recruitment process, the interview process as well as data management. In this process, I will also highlight moments of difficulty that I had to navigate as a researcher. These aspects are important to demonstrate transparency as well as to show how I implemented my epistemological and ontological perspectives in practice.

4.4.1 The participants

As previously mentioned, I interviewed three different participant groups: disabled people, welfare professionals and disability organisation representatives. These groups were chosen in order to shed as much light as possible on the impact of austerity on disabled people. Disabled people were consciously chosen to be the centre of the research with the other participant groups used as a contrasting and contributing voice to the stories that disabled people shared. This is because of my epistemological and ontological position. Further, because of the historical marginalisation that disabled people have experienced and continue to experience, I felt like it was important to have their experiences be the most defining force of what aspects this thesis would focus on. Below is a table that details the participant groups and basic information about the participants. In total, I interviewed 24 disabled people, eight welfare professionals, and eight disability organisation representatives. For the sake of preserving anonymity, some information has been purposefully omitted.

Table 2: Disabled Participants

Pseudonym	**Age**	**Location**	**Impairment type**	**Interview type**	**Current main form of welfare support**
Emilia	20s	Mid Sweden	Visual, mobility, concetration	Face-to-face	Personal assistance
Eva	20s	North Sweden	Hearing	Face-to-face	Assistive aids
Johanna	n/a	n/a	OCD	Phone	Sick pension, care subsidy
Mr Kint	40s	Mid Sweden	Mobility	Face-to-face	Assistive aids
Spiderman	30s	Mid Sweden	Mobility	Face-to-face	Handicap compensation [*sic*], wage subsidy
Tobias	30s	North Sweden	Mobility	Skype	Disability compensation
Jan	40s	Mid Sweden	Mobility	Skype	Mobility service
Louise	40s	South Sweden	Mobility	Phone	Sick compensation

Hans (parent), Catrina (parent), Helena (disabled person)	20s	Mid Sweden	Autism, learning disability, mental health	Phone	Care subsidy, activity compensation, housing support
Julia (disabled person), Therese (personal assistant)	20s	South Sweden	Mobility, visual, concentration difficulties, hearing	Face-to-face	Personal assistance
Jungfru Gunnela	30s	South of Sweden	Aspergers syndrome and anxiety syndrome	Skype	Daily activity, housing support
Markus	30s	South Sweden	Autism, OCD	Phone	Housing support, activity support
Patricia	20s	n/a	Autism	Phone	Work training [*sic*]
Katja	20s	n/a	Autism, marginal retardation [*sic*]	Email	Psychologist, LSS support, guidance, mobility service
Sunetra	50s	Mid Sweden	Asperger’s	Phone	Sick compensation, housing support, custodian
David	20s	Mid Sweden	Asperger’s, depression	Phone	Activity compensation, sick leave, housing support
Hanna	20s	North Sweden	Physical	Face-to-face	Temporary sick leave
Karin	40s	South Sweden	Asperger’s		Housing, daily activity
Anna	20s	North Sweden	Autism	Skype	Sick compensation
Magdalena	50s	South Sweden	Autism	Phone	Daily activity, sick compensation
Margareta	50s	North Sweden	Rheumatism, hearing	Face-to-face	Sick compensation
Västgöten	30s	South Sweden	Autism, ADHD	Phone	Home services, contact person,
BJ	50s	North Sweden	Rheumatism	Face-to-face	Part time permanent sick leave

Inga (parent), Folke (parent), Li (disabled person)	n/a	North Sweden	Mobility	Face-to-face	n/a

Table 3: Welfare Professionals

Pseudonym	Occupation	Interview type	Location
Maria	Psychologist	Skype	South Sweden
Iman	Personal assistant arranger	Skype	Mid Sweden
Lina	Welfare officer	Phone	Mid Sweden
Marina	LSS caseworker	Face to face	North Sweden
Goodrich	LSS caseworker	Phone	Mid Sweden
Erika	Welfare officer	Phone	Mid Sweden
Rebecka	LSS caseworker	Phone	South Sweden
Elsa	LSS caseworker	Phone	

Table 4: Disability Organisation Representatives

Name	Organisation	Location
Mikael	HSO	Mid Sweden
Martin	HSO	North Sweden
Peter	Lika Unika	Mid Sweden
Christine	STIL	Mid Sweden
“Thorsten”	A disability organisation	Mid Sweden
Rasmus	DHR	Mid Sweden
Ken	DHR	Mid Sweden
Nicklas	Autism och Asperger Förbundet	Mid Sweden

The type of disability organisation I interviewed varied. As mentioned previously, disability organisations have a significantly closer relationship to the state in contrast to British disability organisations and are seen as operating on an advisory capacity to the state. HSO is the oldest organisation, which is an umbrella organisation of a collective of disability organisations. After the interviews were conducted, they changed their name to *Funktionsrätt Sverige* (directly translated as Function-right Sweden), to indicate a shift from an impairment focus to a focus on human rights and the UNCRPD. In Sweden, the distinction between whether a disability organisation is *for* disabled people or *of* disabled people is a bit ambiguous as there were both kinds of organisation and the leadership of the organisations could change over time (Persson Bergvall and Sjöberg, 2012). In the present moment, however, Persson Bergvall and Sjöberg (2012: 8) argue that “largely all organisations are led by people with impairments [*funktionsnedsättning*] or close relatives”. While Sellerberg (2009) noted that most organisations are impairment-focused, this is currently beginning to change towards a more general human rights discourse as indicated by the change in name for HSO. This thesis will retain the name of the organisations as they were at the time of the research and not alter them to accommodate subsequent changes. DHR is an organisation with the task of promoting questions that affect people with “decreased movement ability” (DHR, 2017). STIL is a Swedish branch of the Independent Living movement and they offer collective personal assistance support. *Autism och Asperger Förbundet* is an organisation focused on people with autism and Asperger. *Lika Unika* is also an umbrella organisation with an explicit human rights focus.

4.4.2 Recruitment

These participants were recruited using a variety of recruitment strategies. These are important to acknowledge because recruitment influences research in complicated ways (Kristensen and Ravn, 2015). I utilised snowballing techniques among friends and encouraged participants to share information about the research project to anyone they might know. I also posted flyers in public places and notices on social media. As briefly mentioned previously, I was also interviewed for local newspapers in the county where I was staying for the majority of my fieldwork in order to spread awareness of my research project in an attempt to gain participants. I also established a blog where I collected all of the plain language statements and information about the project. When it came to disability organisations, I contacted them directly via email, asking if there was someone in their organisation willing to speak to me and information about the research project.

The flyers were mainly targeting disabled people where I wrote (in Swedish): “Do you have decreases in function/variations in function? Have you had or do you have access to social insurances? Would you like to talk about your experiences?”. A description of myself (with a picture) and that I was from the University of Glasgow looking at the impact of welfare changes followed as well as my email address and a phone number to a research mobile. I put these on free public noticeboards and electronic version on Facebook and Facebook groups for disabled people. Through this process, I also got access to non-public Facebook groups where I also shared information about the research. Friends and family also shared my post on Facebook to their contacts and this way of recruiting was arguably the most successful way to gain participants.

It was just disabled people that I recruited through social media. This was also the case for welfare professionals. I had a social connection to a couple of people who worked as caseworkers and those people were very helpful in sharing information about my research project. One of them vouched for me to gain access to a closed Facebook group for social workers, where I posted and announced myself and my research, where I gained a few participants. Another sent around information among colleagues and the snowballing technique in particular seemed very effective among this group. I made a conscious choice not to recruit through the National Insurance Office as I found it ethically problematic to allow them the role of gatekeeper, given their role in the enactment of austerity for disabled people (see chapter 3). This may have affected my sample among professionals in the sense that it would have to be people who were personally interested in disability issues and were open to discussing them in their personal lives, but I felt like this was a useful trade-off.

As previously mentioned, I was also interviewed by local newspapers in order to gain participants for my research. One local newspaper included an article about me and my research in their human interest section. Another newspaper also wrote an article about me and gave me a mid-spread in the paper as well as put my picture on the cover. In both of these articles, my contact information (mainly my email address) was given. This was a useful way of getting participants as the article was also available and shared online and many following those articles contacted me to be interviewed. One person also phoned the editorial board to get my phone number (because they were not good with email) and from that contacted me to enquire further about participating in the project.

It was also clear that the subject matter did provide a hurdle in terms of recruitment. I had a number of people who contacted me with interest to participate in the research but would disappear from communication for a while. When I checked back to see if they were still interested in participating, it transpired that, since contacting me, they begun to have issues with the National Insurance Office and, consequently, were no longer interested in participating. This was because it would be too emotionally distressing, and they had to focus on the exhausting task of fixing the issue. In this way, the topic itself made the recruitment process slightly more difficult.

4.4.3 The interviews

While my overall method was semi-structured interviewing, the way this was enacted varied a bit between various participants. This was to take into account various impairment effects and the preference of the interview participants. A number were conducted face-to-face while some were done through Skype or via phone. Two participants wrote their responses to my questions – one via instant messaging and the other via email. The interviews varied in length. The shortest interview was around 45 minutes whereas the longest lasted for over five hours. One interview took an entire day, but the interview bit was done intermittently during the course of that day.

The phone interviews were not only an important interview avenue for participants who found the idea of face-to-face interviews too anxiety-provoking or too expensive. They were also useful for practical reasons. Participants were recruited from across the country and for my participants and myself, travelling to every interview location became financially impossible. Phone interviews (or video conferencing) is a fairly inexpensive method and this is particularly important when interviewing financially disadvantaged groups (Block and Erskine, 2012: 430–431; Sedgwick and Spiers, 2009: 5) and with the nature of the welfare cuts in Sweden, some might struggle to physically show up to a specified location. It is also good for covering a large geographical area (Sedgwick and Spiers, 2009: 8). Conducting phone interviews also meant more extensive contemporaneous notes were also able to be generated and these added benefits weighed up the loss of visual information. There have also been concerns over the ability to generate trust when utilising phone interviews but Irvine (2011) noted that if time is spent establishing rapport with participants, the difference between a phone interview and a face-to-face interview are minimised. Also, physical presence does not necessitate better establishment of trust (Irvine, 2011) – rather it is in the clear and frank communication, which would still be a factor in phone interviews.

When the interviews were conducted face-to-face, they usually entailed me meeting participants at their home or a public location of their choosing. This could also produce unexpected moments in relation to adjusting to participants' needs. This was the case when Julia and Emilia, both of whom were interviewed in public places, brought their personal assistants to the interview. This was partly because of their reliance on them to get to the interview but also in the case of one of them, the personal assistant was much more engaged in also answering with the participant. This made me face an unanticipated ethical dilemma (Guillemin and Gillam, 2004) as I was worried that the personal assistants might be asserting themselves too much during the interview. As the interview progressed, however, it became clear that this was part of the role that the personal assistant had in their lives and they seemed perfectly comfortable with their presence and support throughout the interview process.

At times, there were instances where the interviews made me uncomfortable. As I was finishing up a phone interview with a male participant, the participant disclosed that they were as we were speaking had found my Facebook profile and were currently scrolling through my Facebook profile. This made me very uncomfortable and they made comments about my family members' profiles. At the time, I did not address it as I reasoned that they had opened up to me about their lives, that they saw a few pictures of me was a small price to pay. There were also instances where – in particular – male participants would suggest socialising outside the interview (for example, offering to go for coffee) but I declined these offers as I was not sure what their intentions were. Whether or not it was the gender dynamic in these situations that made me uncomfortable, I do not know but I imagine it played a role.

Sometimes accommodating and recognising impairment effects meant that I interviewed the parents of disabled people. This was particularly the case, as the table shows, in the case with Helena's and Li's parents. For Helena, this was because her impairment effects and current episode of emotional distress made it difficult for her to be able to speak to me. In the case of Li, this was because the parents contacted me to share the experiences they had with the welfare system. It transpired that participating in the research project felt like an important facet of their grief process after Li had passed away two years prior to my fieldwork. In this case, I decided to include them in the research and met them a couple of times before conducting the interview to explain the process and the project to them.

4.4.4 Data management

The interviews were recorded on a recorder and on my phone as a back-up in case the main recorder broke down. Files were transported to a password-protected computer. The transcription was done by me, which will be elaborated upon later, and the files that were generated as a result were also stored electronically. Interview fieldnotes were stored in notebooks or on my computer. In the case of notebooks, information about the participants were automatically anonymised as I wrote the interview notes down. Email addresses to participants were kept on a spreadsheet, which was aside from the email address, also anonymised. Coding was done electronically and will be elaborated upon later.

As a form of dissemination of the research findings, I am aiming to provide a summary of my main research findings and explore the possibility of working with the disability organisations I engaged with to disseminate my research findings. This is something that I view as central to my academic work, especially in light of the emancipatory principles of my ontological and epistemological position. Indeed, in literature, Roulston (2010: 221) argued that this kind of dissemination of research findings is central “for demonstrating quality – that researchers have worked to communicate with participants and audiences, and have been successful in fostering productive dialogue and action contributing to social justice goals”.

4.4.5 Ethics

The majority of the participants were given pseudonyms. They were initially asked if they wanted to choose their own pseudonym. This was chosen by a number of participants but in the case where they did not care, I chose their pseudonym. The offer of pseudonyms was offered to all participants but the majority of disability organisation representatives resisting using a pseudonym. As previously mentioned, they felt that it was part of their professional role to speak to me and therefore preferred their name to be in the thesis. Some even requested that the organisation be named in the final product if I used any of their quotes in the thesis. Some of the representatives were not certain whether or not they wanted to be anonymised and following extensive discussions, they finally came to a decision.

An ethics form was submitted that reflected the potential risks and dilemmas that might occur as a result of fieldwork. This form was submitted and approved by the University of Glasgow Social and Political Science ethics board. An interview guide was composed, both in Swedish and in English, as well as plain language statements in various formats to facilitate accessibility. These are available in appendices 1-12. The ethics form passed without corrections.

While the formal ethical process in the UK did not pose any significant challenges, there was an incident at the beginning of my fieldwork that had a significant impact on me and how I carried out the research in relation to (formal) ethics. After having been persuaded by a non-academic acquaintance to contact the Swedish equivalent of the ethics board, which is nationalised, to ensure that I did not need to apply for ethical approval with them. In Sweden, the ethics board is nationalised and its purview is all higher education and university institutions in the country. Each office has a catchment area where applicants submit their application. Due to me not maintaining an institutional affiliation with a Swedish institution, I did not fit the criteria for submitting any additional ethics form. An email exchange occurred where I received numerous harassing emails where I was threatened with being reported to the police if I did not submit an ethics form to their board. This persisted despite the fact that I explained that I had ethics approval from my own institution and that the form did not seem to fit the parameters of my research. It is also noteworthy that the ethics form that the Swedish Ethics Board sees as mandatory is far less detailed in its format and is more tailored towards medical research than social science research.

The experience was marked by considerable harassment by random academic members sending me emails, in addition to one administrator. What I think this is indicative of is the intense amount of gatekeeping that exists in Sweden surrounding research and what kind of research is ‘acceptable’, in addition to how formal ethics can be used as a gatekeeping device as to what research is conducted when centralised to the degree it is in Sweden.

Embedded in this harassment were explicitly disablist arguments like that disabled people could not be a justifiable focus if wanting to know something general, such as whether or not Swedish people had a preference for Pepsi or Cola (as was an unprompted suggestion by a senior academic). What this academic revealed was an attitude where disabled people were not – in his mind – part of the general population. This kind of perspective where disabled people are labelled ‘other’ and separated as different from the general (implicitly understood as non-disabled) population is therefore not just present in welfare institutions, as I will show in subsequent chapters of my thesis, but also evidently present in other institutions such as academia. It also highlights that perspectives of disability studies and disability research, highlighted in chapter 2, are marginal in Swedish academia and have not gained significant traction. The incident also showed that disability research is so associated with health research that it was quite confusing for the Swedish academics that I corresponded with that I was doing disability research from a social science perspective. One of the contributing factors for the harassment I experienced was that they could not imagine that my research was not health-related. This event was something that caused significant emotional distress and made me quite precious about sharing information about my thesis with fellow academics for fear of continued harassment as well as making writing this methods chapter considerably difficult.

4.4.6 Emotional distress for researchers

In retrospect and throughout the entire process, the issue of emotional distress was recurring. This is often something that has been reflected upon in relation to participants (and I covered this in a previous section), but the impact on the researcher is gaining increasing attention. Sampson et al (2008: 929) argue that "It seems that adherence to feminist research principles has sometimes encouraged women researchers to focus so much on the impact and effect of their work on participants that they have overlooked their own emotional vulnerabilities". Indeed, emotion work by the researcher is embedded throughout the entire process of research (Dickson-Swift et al., 2009).

Not only was the emotional distress augmented by the harassment incident but was further exacerbated by the isolation that occurred with moving to do the fieldwork. This was in many ways unexpected and, for future research, I would potentially ensure that I had access to informal support networks as these have been particularly identified as important (Dickson-Swift et al, 2009: 73). Some of the symptoms of vicarious traumatisation, according to Dickson-Swift et al (2009: 73), are "feelings of exhaustion, guilt, anxiety, disconnection from family and friends and social withdrawal" and these were all aspects that I experienced throughout the fieldwork process. A final contributing factor is also that my personal connection to the research topic made emotionally coping with the distressing stories that my participants shared difficult to deal with. It is particular with this aspect of emotional distress for the researcher where I would classify the research process as less 'successful'.

4.5 Analysis

Having so far engaged with the epistemological and ontological underpinnings of my methodology as well as the practical elements of the research process, some attention now needs to be paid to the analysis process. In this section, I will discuss the analysis method and practical process as well as the issue of translation. The issue of translation is central as the interviews were conducted in Swedish but the presentation of research findings is done in English.

4.5.1 Thematic data analysis

In order to analyse the research data, I employed thematic data analysis. Utilising thematic analysis to analyse qualitative research date is one of the most standard analysis methods in social science. Green et al (2007) identify four key steps in relation to how to conduct a thematic analysis: data immersion, coding, creating categories, and identifying themes. This process is not necessarily linear but nevertheless essential to the conduction of thematic data analysis.

The transcripts were all in Swedish and the coding was done in English. Each transcript was read over two times before commencing the coding process. This was done in order to achieve the necessary immersion. I also relied significantly on my fieldnotes throughout the analysis and writing-up phase to ensure that each quote was properly contextualised when making the analysis and how these related to the overall argument each participant made throughout their interviews.

Practically, coding was done in large sections. Entire paragraphs were coded under multiple nodes that corresponded to the subject area that section covered. For example, ‘bureaucracy’ or ‘ignorance’. Because the majority of the transcripts were initially covered in several large codes, each transcript was read through countless times. This process solidified the immersion and the coding process. Then I would go through these big nodes and subcode them to reflect their content even more closely. Bureaucracy, for example, resulted in three large subthemes – ‘Bureaucratic Institutions and Benefits’, ‘Bureaucratic perspectives', and 'Influence of bureaucracy'. The first was merely nodes where welfare institutions or particular 'benefits' were mentioned. The second contained the interviews by welfare professionals and in particular caseworkers. The influence of bureaucracy detailed the way bureaucracy impacted disabled people. Nodes within this cluster were 'avoid applying', 'don't want to be negative' 'forced', 'lots of work' and 'struggle' to mention a few. Mainly I used NVivo as a file organisation system and conducted the analysis by constantly reading through my transcripts, which enabled me to gain a detailed familiarity with the data.

In this way, I wanted my analytical framework to be sensitive to the data rather than my individual preferences. It is clear, however, that in some ways analysis is embedded in the entire research process and "we probably couldn't, even if we wanted to, handle the problem any differently from the way we will end up handling it. We are committed, not by the choice of word, but by the analysis we have already done" (Becker, 1986: 55). This does not mean that particular narratives were discarded but that participants' voices were constantly reflected upon, placed into larger contexts and narratives, as well as unpacked throughout the analysis process highlighted above and throughout the transcription and translation process.

When I had the collection of general codes and more detailed codes to allow me an overview of the participants' different perspectives, I then started reflecting on the overwhelming trends embedded in the interviews in relation to my overall research questions. In doing this, I also had to be conscious of what aspects would have to be explained in further detail to an English audience about the Swedish welfare context. For example, the nature of work and the concept of work ability became increasingly necessary to address. This was in part because the issue of employment was constantly reflected upon in interviews but the concept of work ability, for example, was something that became increasingly important to investigate in order to connect the different elements of what the participants shared. It was with these considerations in mind that I structured my thesis' chapters.

4.5.2 Translation

The data I generated for my thesis was given and transcribed in Swedish and due to institutional requirements, this needed at some point to be translated into English. The process of translation is a complicated endeavour and has had a continuous impact on this thesis. For this reason, it is worth spending some time reflecting upon this as it not only impacts the terminology regarding disability - as chapter 2 made clear - but also have larger, ontological and epistemological consequences. Consequently, this section will first investigate the nature of translation and when and how much of the data was translated.

At first glance, translation appears to be a fairly conventional, technical exercise. However, this obscures the various choices facing the translator and conceals issues around power. Firstly, translation can be done in a variety of ways. Primarily they can be split into four types (Brislin, 1976: 3–4). Firstly, there is pragmatic translation that is focused on the conveying of information as in, for example, translating instruction manuals. Secondly, there is aesthetic-poetic translation, which takes in account the affect, emotion, and feelings of the original language when translating it. The third form of translation is ethnographic translation and it intends to explicate “the cultural context of the source and second-language versions. [It is v]ery sensitive to the way words are used and must know how the words fit into the cultures that use the source and the target languages” (Brislin, 1976: 3). The final form of translation that Brislin (1976: 4) highlights is linguistic translation and it looks at equivalent meanings of the constituent morphemes of the second language. The appropriateness of translation form is often dependent upon the task at hand and the intention of the translator. As such, contrary to popular belief, the role of the translator is central to the process of translation and norms are incorporated into every stage of translation (Wolf, 2007: 10). Indeed, some have gone as so far to argue that translation even encompasses nation state politics and the economic, cultural, and political relationship between languages (Heilbron and Sapiro, 2007: 95). Finally, there is a high degree of interpretation because translation can be seen as “the general term referring to the transfer of thoughts and ideas from one language (source) to another (target)” and this becomes an interpretation as it is being translated and produces an output (Brislin, 1976: 1).

Viewing translation in this multifaceted way reveals the highly political nature of how translation is conventionally viewed. Often, the translations that are deemed the most ‘successful’ are those that are smooth enough to pass for indigenous; failing to adhere to this standard often results in a loss of status for the translator (Sturrock, 2010: 51). In this way, translation is an inherently cultural political practice (Venuti, 2010: 68) and “[t]he link between the manifestation of power and domination in the creation of a translation and the phenomenon of the translator's 'invisibility' seems obvious” (Wolf, 2007: 12). Sturrock (2010: 62) has even argued that the idea of ‘invisible’ translation, which is devoid of the conflicts and choices facing the translator, is in some ways contrary to the nature of languages and the process of translation itself:

> Languages may converge but not merge: it is in the act of translation that their apartness manifests itself. Or it is there that it should do so. And yet we hold that act of translation the most successful which contains no evidence at all of the apartness of languages, but only of a source text flawlessly naturalized, which is to say finally occluded. There is no hint of interlinearity [different choices and interpretations made by the translator which are apparent] in the translations that are the most prized and applauded, because interlinearity would be 'translationese' and who is ever heard speaking up for that?

In this way, translation is not just about the transference of words but, more importantly for this thesis, the transference of ideas and concepts expressed through words. Here, Venuti (2010: 68) remarked that this often means that the ‘foreign’ text gets translated in accordance with values, beliefs, and representations that pre-exist in the target-language; “[t]his difference can never be entirely removed, of course, but it necessarily suffers a reduction and exclusion of possibilities – and an exorbitant gain of other possibilities now imprinted by the target-language culture, assimilated to its positions of intelligibility, its canons and taboos, its codes and ideologies.”

Beyond this, translation forces us to acknowledge the inherent impact translation has on methodological concerns. Temple and Young (2004: 164) highlight that methodological and epistemological challenges arise in research containing translations as “people using different languages may construct different ways of seeing social life”. Drawing on Spivak, they acknowledge that language is more than just syntax as translation inherently carries a set of assumptions and contains “rhetoric, logic, and silence and the relationships between these” (Temple and Young, 2004: 165). This leads them to argue that while the value-laden nature of words is frequently recognised, languages themselves are also value-laden; in translation, the perspective that the translator has on the (social) world of those they are translating influences the translator’s interpretation of what is being conveyed (Temple and Young, 2004: 167).

Translation is in some ways embedded in the research process, especially when dealing with interviews. This is because interviews require the translation of sound into a transcript, which will then form the basis of any written work. Hammersley (2010: 558) impressively highlights this point:

> At the most basic level, the sound stream must be ‘broken up’ into identifiable heard words belonging to a particular language. And because of variation in the pitch of voices, in pronunciation, etc., there will not be any simple correspondence between the sound in etic terms and the words recognized. […] Nor is it a simple matter of turning heard words into written words on a page: generally speaking the aim is to do *this so as to convey what was being said, how, with what emphasis and import, and so on*. And this requires more than just knowledge of the language, narrowly understood in terms of a sound system, lexicon, and grammar. So, the identification and representation of the words being spoken depends to some extent upon our ability to understand what the person might be meaning by what he or she says.

For this reason, the kind of considerations that this chapter has thus far displayed in relation to the issue of translating Swedish into English to some degree also apply to the process of transcription. For this reason, the original (Swedish) transcripts were kept as close to the sound file from which they derived, with all of the awkward pauses and false starts that comes with engaging in speech. The messy Swedish transcripts were then analysed in Swedish, but with English codes to gradually, but not completely, begin to translate the relevant data into English. However, translation of quotes was not done until the presentation of data. This is because Temple and Young (2004: 174) warn that “early ‘domestication’ of research into written English may mean that the ties between language and identity/culture are cut to the disadvantage of non-English speakers” and that this would limit the possibility of participants to express themselves in their native language.

While translation is inescapable, delaying this for as long as possible would allow me to retain a familiarity with the original quotes for as long as possible. My individual influence is, however, is in many ways inescapable. My habitus will inevitably impact the interpretations I make in the translation of what my research participants conveyed (Wolf, 2007: 19-21). This is not different from academic analysis more broadly but by the fact that it is translated material, it does contain an additional level of interpretation that needs to be recognised.

Ultimately, in terms of translation, I thought that it was important to retain as much as possible the sentimental and emotional elements of their stories while also conveying the information in an accessible way for an English-reading audience. As such, my translation choices ended up being a mixture of the pragmatic translation type and aesthetic-poetic translation (Brislin, 1976). This enabled me to try to convey the impact of the information as well as the information itself, both of which are important to answer the research questions. Thus, I am less interested in presenting ‘perfect’ translations that renders my position as the translator invisible. Instead I will keep the ‘tricky’ original Swedish words expressed by my participants in brackets to indicate instances were particularly difficult choices in terms of translation occurred. How I reconciled the translation of disability terminology was accounted for in chapter 2.

4.6 Conclusion: Methodological choices

This chapter has provided details and information about the research process. In particular it focused on the epistemological and ontological reflections that shaped the research, and the practical elements, which had an equally constitutive effect. Issues around power, inequality and fairness have been central to my research practice. As a result, my own influence and experiences in relation to not only the research question but also the fieldwork more broadly became important. In some ways, it was a difficult research process and in particular in relation to managing my own emotional distress, which I had prepared far less for than that of my participants. This despite the fact that I regard vulnerability as universal (rather than a particular aspect of a particular group). I also share difficult or upsetting moments in my research in order to provide transparency and highlight that research around these issues and the dynamics involved can be ‘messy’. I will now go on to present data from my fieldwork in the subsequent chapters before concluding.

5. Being Disabled in Sweden: Stigma, Precarity and Managing

Assessing the impact of something as complex as welfare systems have on individual peoples' lives is a difficult process. At the outset of the research, there was perhaps a sense of naivety that the welfare state only becomes a concern when support is withdrawn. It became apparent once the data collection began and my participants began to tell their stories that it is infinitely more nuanced. The notion that there was a radical political and policy break with the election of the Moderate-led Alliance in 2005, which was discussed in the third chapter and frequently argued in the literature (for example Carlén et al., 2014; Eztler, 2013; Persson et al, 2010), was rarely present in the stories that my participants told me. Often the impact that the welfare reorganisation had had on their lives had a more subtle, albeit central, presence in their lives. Because of this complexity, it is therefore essential to first understand how my participants discussed the social consequences of having an impairment and how this affected their daily lives. Often their experiences were highly influenced by stigma and feelings of exclusion. Further, how they constructed and defined their impairments were permeated by terminologies and perspectives promoted by welfare and healthcare professionals. Finally, this chapter will explore how people 'managed' austerity in their everyday life. This is the first chapter that presents data from my fieldwork.

This chapter will provide a partial answer to research aim two and three, about how austerity has affected disabled people and what, if any, impact the welfare state has on the experience of being a disabled person in Sweden. To explore these questions, the chapter will primarily focus on two aspects: interpersonal and social implications of being a disabled person, especially experiences of stigma and isolation, and the influence of bureaucracy on everyday life. While these are useful to explore as these questions are particularly underexplored in relation to Swedish disability research, as accounted for in chapter 2, the reason for starting with these two aspects in particular is due to their prevalence in the interviews I conducted with disabled people. By exploring these aspects, it helps to discern what is amplified and what is new for disabled people following the intensification of austerity.

5.1 The social consequences of having an impairment

There is plenty of research on Swedish disabled people. A lot of this research, however, focus on specific aspects relating to disabled people. Often this research is quantitative (Grassman et al, 2009; Rydberg et al, 2011; Törnbom et al, 2011; Värja et al, 2017) and/or focuses on specific aspects of the experience of disability, such as for example the access to playgrounds (Prellwitz et al, 2001), personal assistance (Dunér and Olin, 2018), and employment attitudes towards disabled people (Kuznetsova and Yalcin, 2017). To understand how austerity has impacted disabled people, it is important to acknowledge the societal 'eco system' that the participants live within and adopt a holistic perspective to contextualise how they see themselves and their experiences. Particularly the absence of socio-political elements in Swedish disability models, such as discrimination and oppression, prompt me to explore the social consequences of having an impairment in this chapter. This is also useful in relation to the overall topic matter – the relationship between disabled people and the welfare state. Because austerity has been so subtle and indirect in Sweden, it is difficult to gauge any definitive pre- or post-austerity cut-off points. This is not a significant problem as I am not looking to provide a clear pre-austerity landscape but rather to understand the general framework of participants' perspectives before delving more deeply into the impact of austerity.

It should be noted that when participants were asked how they saw disabled people's position in Sweden, there was a note of optimism, especially when including historical context. Karin argued that "at least there is a greater awareness about different needs and it is discussed, and that is at least good but… then it feels like it is still a long way to go until it can be really good but… generally I suppose I can say that it goes forward but slowly". Västgöten made a similar point when he reflected that things had improved since people were burned at the stake or since eugenics was popular. Another area of improvement was identified by Jan, noting that the media landscape for disabled people had improved:

> And then I am thinking more visible maybe in media circumstances and sports and so on and sports, that one promotes a bit more people with different disabilities [*funktionsnedsättningar*] than what one did before – that it happens that one sees people with disabilities [*funktionsnedsättningar*] as TV hosts and even if it is incredibly rare, I still believe in that.

It should be noted that instances of this kind of representation are not extensive. When it came up in interviews, the majority of my participants identified and mentioned the same TV host who had a disability and hosted a popular children's programme on Swedish television. Julia thought that accessibility had improved but people's understanding of disability was very poor and had experienced little improvement. This was the overwhelming sentiment in the findings of my research, despite the initial note of optimism. In this section, I will show that disabled people in Sweden experience significant psycho-emotional disablism and this is evident in how people accounted for (non-)disabled people's attitudes towards disabled people and how people lived, particularly experiencing isolation and loneliness.

5.1.1 Attitudes towards disabled people

When asked about the general view of impairments, Spiderman felt like impairments and disability more broadly were often framed as something that is "pretty tragic and it would be the worst thing that has ever happened to you". Västgöten characterised attitudes towards impairments as the following:

> Well... derogatory, patronising, er… that you are worth less, that… exposed to hatred despite that- well… that one is viewed as less competent often. And no one does not want anything to do with you when one has a disability [*funktionsnedsättning*] so well… yeah. Why they look down on people I do not know but…

This view of impairments as a form of tragedy is frequently identified in British research (Barnes and Mercer, 2003; Oliver, 1990). The tragedy perspective meant for Spiderman that he was often forced to navigate between being seen as an 'inspiration' or an 'embodied tragedy' in interactions with strangers, something which he found offensive and marked by pity. These are often discriminatory tropes constructed around disabled people (Briant et al, 2013). This attitude concealed, according to Spiderman, that he was just a “regular human who is trying their best, like everyone else”. The focus instead became on the many “preconceived notions of how you are supposed to be or… […] in a wheelchair, you get a lot of ‘oh but I know exactly what it is like, I had a cast on my leg for three weeks once’ and well… it is not quite the same thing then but well…” (Spiderman).

Hanna, who used a wheelchair in public, also felt a lot of pity was directed towards her and her wheelchair, causing a fundamental misunderstanding of what her wheelchair meant for her. “Many older people have expressed how dreadfully awful it is with a wheelchair as if it was the end of life, sort of, and I feel like this – no, a wheelchair is a tool. For independence and freedom”, Hanna argued, and that there was even a lot of fear for non-disabled people around wheelchairs, as if the wheelchair was “some fucking weapon of mass destruction or something”. Like Spiderman, Hanna felt like it prevented non-disabled people from seeing her as being fully human:

> People just don’t know how to be around you and a few… are – treat you as if you are an alien. Which is very strange. Em… [silence] It is a little bit as if… because one has a… a *disability* [*funktionsnedsättning*] so… so is it like one is strange and people don’t really think you are a human, that it really isn’t possible to speak to you and so on. While – it isn’t *always* like that of course but… but people get a bit strange while no one would get strange if someone came in on a pair of crutches. That is like not such a big deal, but a wheelchair, then fuck it is like a UFO has landed.

Wheelchairs are visible markers of impairment in public and thus the stigma associated with disabled people would become more pronounced in public interactions (Goffman, 1990). In my interviews, however, it became clear that this was not just something experienced by those with ‘visible’ impairments. David, whose impairment was not physically visible the way it was for Spiderman and Hanna, felt that non-disabled people were very uncomfortable around impairments and he experienced this discomfort too if he disclosed that he had an impairment. “Impairments [*funktionsnedsättningar*] feels still very shameful”, David argued, “and that probably people avoid looking at you, with a group of new people it feels like people […] 'he there, he has a diagnosis or something', no one wants to touch you, sort of". The wish for non-disabled people to keep a distance from disabled people was also something that Anna had noted in her job as a swim coach, where other (non-disabled) coaches were reluctant to take the classes that included disabled people:

> But many were like 'yes but how do you dare be with them? It is really strange' but yeah, I thought it was a little bit exciting to see, to meet someone who works a little bit differently and see, well, no I thought it was interesting but I got a lot of people who thought it was strange that I decided to do it. And I know that there were many within the swimming school who did not want to have that group so… […] It was a little bit 'yes but then you have to socialise with them' and you have to touch each other and so on.

These stories of non-disabled people wanting to keep their distance, wanting to reduce the physical proximity to disabled people have to be taken seriously due to its frequency in the participants' narratives. Feelings of distain and disgust, Hughes (2000) argues, are essential components of disablism and we cannot separate that emotional reaction in the non-disabled imaginary as separate to some mere 'material' discrimination. Non-disabled people deliberately distancing themselves from disabled people created awkward everyday encounters for David, who noted in his interview that often when he would disclose his disability, non-disabled people reacted as if he was the first disabled person they had ever come across. Sunetra thought that attitudes towards disabled people were really poor in Sweden and saw it as linked to how racism operates in Sweden, due to her experience of both of these forms of oppression:

> I think one wants to be open – or a bit like how it is with racism, one does not want to say 'I am not a racist but I think we have too many immigrants' and a little bit like that I think they think – or many think – but yeah, 'of course he should get to do as he wants' and so 'of course they should get to work' but when it actually comes- let us say that someone with Down's Syndrome comes to your workplace – wouldn't you start to think 'but God how slowly this one walks' and not look at the positive 'but how good that we have- he is surely really good at that' so many when push comes to shove, so one starts blaming a bunch of things so I think – no one wants to be openly… discriminatory but when push comes to shove so are they very discriminatory. So there is a big problem and because if one deals with this sneaky discrimination, deals with sneaky racism, because it is flourishing- since I'm adopted I

> feel it too. So I experience both of these worlds and there are *dangerous* levels of this.

For many participants in this research, their experience was that impairments invoked feelings of tragedy, pity, and inspiration among non-disabled people. Being a disabled person was treated as such an exceptional condition, as demonstrated by Hanna and David's comments, that it was not surprising that they felt singled out and unique in social interactions. Thus, their status and their visible declaration of being a disabled person (either through visible markers such as a wheelchair or verbal disclosure) made them standout in social situations, being made into something foreign and strange in the non-disabled imaginary. This is something that this chapter will explore further regarding feelings of isolation that participants expressed in their interviews. In fact, BJ noted that a lot of work was needed to attempt to make people see beyond impairments and regard disabled people as human beings with their own personality:

> It is a pity for *the people over there*. Many people live near people with disabilities [*funktionsnedsättningar*] but do not know about it. As soon as one finds out, they change their perspective because then they realise that 'yes well you're both pretty, cute and intelligent and funny and you know, 'normal' even if I see that you have difficulty in walking up stairs like I do' or simple things like that.

The perspective of disabled people by non-disabled people is open to alteration but that requires significant work by disabled people, or "90% of all rheumatics" as BJ put it, to "work like an animal to prove that they are satisfactory human beings". The work that disabled people have to perform to demonstrate their 'normality' to non-disabled people must be understood as a form of psycho-emotional disablism (Reeve, 2004, 2012; Thomas, 1999). This combined with the constant exotification that people like David experienced in everyday interactions contributed to feeling isolated in society. The way that disabled people were conceived as 'different' in society was so extensive that Jan argued that "being disabled and being divergent is never going to be the norm, it is- it is just like that [laugh] so one probably has to reconcile oneself with having to be a little bit… otherwise. Different. In some circumstances".

5.1.2 Isolation

The experience of stigma and the resulting psycho-emotional disablism were often the central tenants of participant’s experiences. Another, related, aspect that they often shared was feelings of loneliness. The attitudes that non-disabled people have about disabled people can be exclusionary and often made participants feel isolated and alone, as this chapter has already demonstrated. Isolation was something that was recurrent in many interviews. Addressing feelings of isolation is of central importance (Kulick & Rydström, 2015; Thomas, 1999), as this can offer us a lens through which to understand the status of disability in a society, and feeling isolated plays a central component in disablism. The feeling of isolation must be understood as socially produced and in many ways related to the stigmatisation of disabled people in Sweden.

Hanna shared that her impairment made her tired and that meant that she had to carefully choose her activities. While there might be physiological elements as to why she could not be as active as she had been prior to her impairment effects worsening, it did not mean that she was isolated completely. Hanna remarked that “it is fortunate that one can entertain oneself with the Internet and so on”. Having access to the internet was something that she found helpful in alleviating boredom and was a source of social interaction for her, even if she remained in her home. This tether to social interactions, however, could be tenuous and on days when her internet crashed, Hanna was very frustrated with her internet provider. In this way, it is not necessary that impairment effects cause isolation, even if isolation is experienced. Having access to resources, such as the Internet, meant that Hanna was not isolated even on days when she had low energy.

In this way, resource allocation can often counteract the social isolation that impairment effects might cause. The absence of adequate resource provision, rather than impairment effects, were identified by my participants as a creator of isolation. The effect of Julia’s impairments caused her to have little energy and thus she struggled at school. During her school years, Julia had access to assistance offered by the school and a bit of guidance after school, but this was not enough for her needs and “the energy disappeared once I was going to do everything besides school. By myself". This meant that she was rarely able to socialise with her peers outside of the classroom. This absence of sufficient support prevented her from forming what she saw as meaningful relationships with her classmates. In her interview, Julia reflected:

> even as a disabled person [*funktionshindrad*], one *wants* to have a life outside of the school day but it was that that I never got. That it was probably then one most often get friends for life but… then it took too much energy so I couldn't – so I have almost no contact with the people from upper secondary school because I had to quit school after half the time because it wasn't possible without that support.

While it was common that participants felt like they were the 'only' disabled person in social interactions they had in their day-to-day life and that contributed to a degree of loneliness, there were also stories of participants who had disabled friends in their immediate social circle. Participants who lived in big cities, like Jan and Spiderman, had a great number of disabled friends who they saw frequently through their engagement in disability sports. Participants who lived in rural areas noted that they had other disabled friends but here issues like transportation obstructed their ability to socialise. Karin had a friend with an impairment who lived in another city, but because they lived so far away from each other, Karin rarely saw them. The way that spacialities operate to exclude and marginalise disabled people has been noted in disability research (Kitchin, 1998) and was also present in Sweden.

Västgöten spent a significant time in his interview lamenting the lack of social relationships he had in his life, saying:

> … I have had situations many times where it is *me* who contacts people, *I* phone them, *I* write to people on Facebook, it is always *me* who is the driving force in the conversation, but I never get it reciprocated because it is no one who like meets me halfway so it becomes evenly distributed. When I point this out, they get angry at me and call me dumb [*dumförklarar*]. And it is that I feel people have to improve upon, people have to understand how badly I feel about stuff like this and- I think there are quite a lot of people who experience the same thing actually.

All the work, frustration, and disappointment that Västgöten experienced when trying to create meaningful social relationships cannot be regarded as separate from larger societal issues. For him, it went to the heart of feeling like he belonged in his community and its absence was in many ways the main thing he kept coming back to in his interview. The absence of meaningful relationships was not only making him feel alone but made him feel different from the people that were unwilling to become his friends.

Underlying feelings of isolation were also reflected on by other participants. Sunetra had a wide and thriving social life in many respects but “in terms of real friends, I principally have none” and she rarely socialised with people who knew that she had an impairment. This was because she had told a few “and then they have principally completely disappeared”, so it was easier to let them assume that she was a non-disabled person. This was an approach that she even applied to family members, where only a limited number of her close family knew of her diagnosis. Discriminatory attitudes, therefore, severely impacted their relationships to others. The anticipation of discriminatory and hurtful situations also affected how they navigated social spaces and interactions. BJ had developed a sophisticated routine to conceal any visible signs of her impairment:

> … For my part, it is like this that I *never* say that I am a rheumatic unless I have to and I always wear sweaters like these so that when I meet new people, I can remove my hands because it is not possible to conceal that my hands are rheumatic. So I sit like this [sleeves hiding her hands] until I have to start writing. Then I have to take up a pen. Sometimes I even sit and write in my lap. It is *absolutely* no advantage. It is ‘no you will probably become expensive in sick pay’ and so on.

The implication of cost and her being ‘expensive’ is further explored in chapter 6 in terms of government rhetoric and provision of services. It is worthwhile noting, however, that even in everyday interactions, the cost construction significantly impact disabled people, as in the case of BJ. Sunetra and BJ spend a considerable time attempting to pass for a non-disabled person because they felt that it facilitated their interactions with strangers and helped to promote their non-disability-related qualities and characteristics. The fear of discrimination did not always result in concealment but could also produce a feeling of needing to disclose their impairment. Johanna felt compelled to give their partner a copy of their medical record, so that they would “know what they were getting into” at the start of their relationship. The way that their disability status came to override many of the other social markers they possessed or the way that disclosure was deemed necessary indicates that disability is still a highly stigmatised identity in Sweden (Goffman, 1990).

Goffman (1990: 32) argued that those with inborn stigma “become socialized into their disadvantageous situation even while they are learning and incorporating the standards against which they fall short. For example, an orphan learns that children naturally and normally have parents, even while he is learning what it means not to have any”. In case of the participants of this research, being ‘normal’ was understood as being non-disabled and being disabled meant being ‘different’. Some have criticised Goffman’s concept of stigma for neglecting for excluding “questions of how social relations are structured through power” and for divorcing the relationships that create stigma from power relationships (Tyler, 2018: 750-751). Despite this absence in Goffman’s work, it has not stopped other writers from placing stigma in a context that acknowledges socio-political factors and power. In her critique, Tyler drew on Hunt’s (1966) exploration of stigma and disability, where he argued that

> Obviously we who are disabled are deeply affected by the assumptions of our uselessness that surround us. But it is vital that we should not accept this devaluation of ourselves, yearning only to be able to earn our livings and thus prove our worth.

Thus, the stigma that disabled people face are key parts of psycho-emotional disablism, which was defined in chapter 2. Psycho-emotional disablism highlights that it is not just barriers to doing that affect disabled people but also barriers to being (Thomas, 1999). For this reason, the frequent reflections from my participants that lamented the lack of social fulfilment and a need to conceal their impairment reveals a climate of disablism in Sweden that impacts on my participants’ everyday lives. Even though there were some noted improvements in including disabled people in public life at the beginning of this chapter, these developments are clearly not sufficient to argue that disabled people are ‘included’ in everyday Swedish society. This was also clear through the intimate association of disability with difference. What the exploration of isolation has revealed is that even in situations where participants felt like they had a wide social circle, the extent to which they felt like they belonged was limited. Thus, I argue in agreement with Paterson (2012: 170) that formally including disabled people in discourse is not significant without a sense of belonging.

In light of these findings, it is increasingly surprising that Swedish disability models rarely acknowledge discrimination and social factors, as noted in chapter 2. In this chapter, participants frequently indicated discriminatory scenarios in both implicit and explicit ways. Implicitly it is present in stories like Sunetra's and BJ's, who attempted to conceal their impairment as much as possible. There have also been explicit accounts, as in Anna's account of her co-workers not wanting to teach disabled people to swim. Anna described her co-worker's attitudes as 'strange' and in Spiderman's case, he coded discriminatory attitudes as 'patronising' and 'old fashioned' when he encountered them in his everyday life.

5.2 Bureaucratic influence on everyday life

While the first section of this chapter has explored the social consequences of having an impairment, it was clear that the other notable factor that my participants spoke about was the impact that bureaucracy had on their everyday lives. This was clear in implicit and explicit ways. The implicit way in which this was made clear was through the terminology and phrases participants used to talk about their impairments. Explicitly, the impact of bureaucracy was evident in the feeling of precarity that has emerged as a result of the intensification of austerity. Bureaucratisation was key in indirectly implementing austerity, as noted in chapter 3, and the role of bureaucracy was so prevalent in my data that it will also be explored more closely in chapter 7, which will explore how people navigated welfare bureaucracy while this section will explore its impact.

5.2.1 Impairment talk

This section will explore how my participants spoke about their impairments. This is important because, as chapter 2 demonstrated, there is a conflation of illness and disability within the welfare state and impairments are mainly defined by medical terminologies. I argue that by exploring how people spoke about their impairments, it offers a glimpse into how pervasive welfare bureaucracy is in Swedish disabled people's lives.

It was common in interviews for participants to reproduce dominant discourses around impairments in interviews. BJ detailed a familiar relationship to the healthcare system and talked about her impairment as an illness: "I have rheumatism for 26 years, so I was only 24 years old when I got ill […] I have a pretty serious – or aggressive rheumatic illness". She viewed medication as highly important to manage her impairment. It is important to note, however, that she was not the only participant who conflated illness and impairment in their interview. Johanna spoke about how when her son began to demonstrate signs of Asperger's syndrome, she was worried that she had "contaminated" him due to her own impairment. "It was a relief, that it wasn't me who was contagious," she said in her interview, "so when they [welfare professionals] told me that I couldn't have predicted [my son's Asperger diagnosis], that I couldn't have known it, it was… important, very very important".

These discourses reflect how disability is constructed within the Swedish welfare state. Another indicator that demonstrates the pervasiveness of bureaucracy are explicit references to the welfare system made in Magdalena's interview. When asked to talk about herself, Magdalena made explicit reference to LSS eligibility criteria (for these, see chapter 1):

> I belong to [LSS person] group 1, because I have an autism diagnosis but… but I do not have autism in the way that the system have considered it. [laugh] Or however one should express it. Yes, it therefore becomes a little, it is a little bit stiff simply and they… it is difficult. I think one of the difficulties is that I can do things they haven't anticipated but I have difficulties in areas they think are obvious that I should be able to do. And that has made a mess of things.

It is not say that participants are wrong for using medical categories or eligibility criteria to describe impairments, especially since medical categorisations impart impressions that they are 'rigorous' and accurate. Due to its prevalent use in Sweden and the welfare state, it may indeed be deemed to be the most 'obvious' vocabulary to describe impairments. This, however, misses the point that medical criteria can only really serve as a proxy for describing disability and its emergence is situated in a very particular history context (Stone, 1984: 107). It is never as ‘objective’ or ‘politically neutral’ as it appears. Social theorists such as Poulantzas (2014: 29), have noted:

> … to be sure, the body is not simply a biological entity, but a political institution: the relations of the State to the body are thus considerably more complex and extensive than those of repression. Nevertheless, the State is always rooted in its physical constraint, manipulation and consumption of bodies. In every State, this takes place in two ways: through institutions which actualize bodily constraint and the permanent threat of mutilation (prison, army, police, and so on); and through a *bodily order* which both institutes and manages bodies by bending them and moulding them into shape and inserting them in the various institutions and apparatuses. As a material reality, the State is synonymous with a kind of stunting regimentation and consumption of persons’ bodies – in other words, with its incarnation in the very flesh of the subjects-objects of state violence. Since all bodies are political, we cannot speak here of bodily mortification by the State: for that would point to the image of an original body, which, while naturally free, is later politically distorted.

I argue that the observation made by Poulantzas extends even beyond the physical bodily order that the state constructs – it is embedded in *how* we speak about bodies. Even in cases such as Magdalena’s where she openly noted the limitations of the medical perspective on her impairment, she still relied its language to describe it. The ‘deficit’ approach that is evident in Swedish state perspectives on impairment was also present in alternative ways in which participants spoke about their impairments. It was very common for euphemisms to be used to allude to impairments, such as ‘my worries’ or ‘problems’.

What I argue is that this demonstrates the pervasive influence of medical services and welfare bureaucracy on disabled people’s everyday lives. In some ways, it is not a new reflection in sociology. Wright Mills (1940: 906) observed that “Men [*sic*] discern situations with particular vocabularies, and it is in terms of some delimited vocabulary that they anticipate consequences of conduct”. Not to mention that Brubaker and Cooper (2000) noted that the welfare state has an incredible power to define and shape identities. Consequently, any terminology that we use have constraints and external influences. My argument is that how participants spoke about their impairments offers us a lens through which to gauge the indirect influence that these institutions have on disabled people’s everyday lives. That they have influence over the access to welfare resources is in some ways evident, but the prevalence of welfare bureaucratic terminologies in participants’ accounts show that it extends beyond that as well. One of the few accounts that sidestepped these terminologies all together was in an interview with a disability organisation representative who used the term ‘norm-breaking functionality’ to denote impairment. Yet this was exceptional, in that no other interviewee used the term and it has not (so far) been picked up in national discourse.

5.2.2 Precarity

The intensification of austerity has on the one hand meant a reduction of welfare resources, as indicated in chapter 3, but this is not the only consequence of austerity that participants felt. Changes in welfare bureaucracy and the tightening of eligibility criteria not only meant that participants were more at risk of losing useful resources, but had a profound psychological impact on participants. This was true across the board. The fear of having reduced welfare resources impacted even those who had at the time of the interview escaped negative impact or who had even gained increased welfare support as a result of some of the changes. This section will also show that the increased bureaucratisation that followed the implementation and intensification of austerity had a significant impact on disabled people’s everyday lives.

One of the consequences of the intensification of austerity was that the participants I spoke to felt significant dread in speaking to welfare institutions and articulated a reluctance to engage with agencies. Anna admitted that she was afraid of the Social Insurance Agency and worried that they would remove the support she currently had access to:

> I’m so afraid that I will sort of say something that they misunderstand or something so they’ll remove my compensation and it would be nice to be able to influence oneself too, to work and get a salary instead of having to be dependent on them but it is very fortunate that we have them and so.

This sense of precarity was not only fuelled by the intensification of austerity but also amplified by the context in which the research was carried out. As mentioned in chapter 4, a Swedish government minister had argued that severe cuts in disability provision would be necessary to accept Syrian refugees (Grundberg Wolodarski and Nordenskiöld, 2015). This made participants like Katja, who saw themselves as not affected by austerity measures, really worried about the future of the provisions she had access to:

> No, not [affected by any of the changes in the welfare state] yet but I am starting to get worried that I will be affected because of the refugee situation in Sweden. Have heard that they will take money from disabled [*funktionsnedsatta*] in order to contribute to the newly arrived in Sweden. It frightens me because I get subsidies to live. Already living on such a small amount of money as it is. And would never be able to have a job as it seems right now

This fear and concern was something that permeated the majority of the interviews I undertook with disabled people. Consequently, I argue that this is increasingly difficult to argue that there is any disabled person who is ‘spared’ from the broader shift towards harsher austerity in Sweden. While Katja viewed herself as ‘spared’, her comment also indicates that she is living on small means and her income is highly dependent on political decisions. Many participants shared that their standard of living and life choices were subject to a level of scrutiny that non-disabled people do not experience. When Louise got pregnant with her second child, she was worried that she would as a result be deemed ‘fit to work’ and would have her sick leave taken away:

> Yes. At the same time it was like this now that I was pregnant, I was like *completely* terrified for what would happen to my sick compensation. What would happen. Then I phoned the Social Insurance Agency and I almost cried, so I got to sort of- and so I said that there has been an accident, it wasn’t intentional, it wasn’t intentional and it was like before the abortion limit so I thought I’ll do an abortion because… if I lose my sick compensation and do not have anything, then I don’t know – it is not possible. I cannot put a child on this earth if I cannot support it. So I was almost prepared to do an abortion because… well, I had such a panic

Fortunately, the people at the Social Insurance Agency highlighted that it was not their or anyone else’s place to say if disabled people should or should not have children. It is revealing, however, that Louise was worried that taking care of a child would be used against her as an argument that she could have a job. This is illustrative of how pervasive the fear and precarity have become for the disabled people I spoke to. It is also indicative of how pervasive the push for paid employment do not benefit all disabled people, which is something I will explore further in chapter 8. While the aspiration that more disabled people should have access to employment is needed and important, it is also vital to critically challenge this discourse in light of the environment created by increasing austerity. Neoliberalism has a tendency to co-opt progressive movements (Fraser, 2009) and coupled with its entrepreneurial spirit (Harvey, 2005), the concept of work ability is increasing taken to mean the ability to perform activities more broadly. More of this will be explored in chapter 8.

Increased bureaucratisation did not just mean a heightened sense of precarity but also indicated a need for further and more extensive reassessments. Thus, there was a significant impact on disabled people even if their resources and services were not removed. In an interview with Julia (who had her assistant Therese with her to help her throughout the interview), she shared that even though she had been 'successful' this time and got her personal assistance, it did not remove the fear that it would be removed at the next reassessment:

> Julia: I have had a little bit of luck with my assistance reassessments that I have this last time actually been granted *more* – pretty significant increase – of my basic need […] I've been lucky[…]
>
> Therese: At the same time so there's always a risk that they either withdraw or decrease it, so at every assessment it is not like one is certain that – do I get to keep this but it is rather do I get to keep- rather the risk that it is withdrawn.
>
> Julia: Yes it was like the first time I had – then I had 21 hours. 20 hours is marginally on the Social Insurance Agency that it goes to them. So it was really – […] would they count an hour wrong yes well then I would miss my entire evening and night. In assistance. And that is not fun. Or what will they say now about my new hearing aid now that I hear better at the next assessment now that I have had it operated on? Will they decrease hours because I have a hearing aid?

The tightening of eligibility criteria and the opaqueness over how things were assessed caused a real worry about the participants in my research. The feeling of precarity was ever-present for Julia and she worried about her future. Just as Louise was worried that having a baby could cause her to have welfare resources and services reduced, Julia was worried that she would be penalised for having an improved hearing aid. Sometimes it did not even mean that there was an improvement in order for access to welfare resources and services to change. Mr Kint reflected on the strange consequences of austerity in his interview: “why do I not have the right to mobility service [*färdtjänst*] any more when my ability to walk is worse than it was last year?”.

The influence of bureaucracy on disabled people’s lives also increased through the sheer fact that it was not just one service that required more continuous reassessment. This is the case for most disability-related welfare services and support after the intensification of austerity. It particularly affected participants like Julia, who had all of her income and support from the welfare state. Because of her impairment effects, Julia had never had a paid job and saw herself as unlikely to ever be able to have one. She was therefore reliant on the state for most things in her life and only got compensation at the lowest levels. As these support services were not assessed at the same time, just managing on a day-to-day basis required extraordinary administration efforts from Julia and her personal assistants. Overall, Julia estimated that in order to have the bare essentials of her life functioning adequately she would have to deal with over 100 different people on an annual basis. The reassessments caused her a great deal of anxiety and like Mr Kint, Julia found them bizarre:

> … and it is a lot of pressure to know that you are disabled from birth [*barndomsfunktionshindrad*], […] – and *still* having reassessment every other or every third year on something that can *only* go in one direction. One has to be *happy* if it is fixed. And having that pressure, one does not feel *better* to only think in two or three-year intervals throughout one’s entire life.

Her future felt like it was constantly in limbo as her ability to plan was centred around the reassessments. The impact of bureaucratic pressures in accessing resources will be elaborated in chapter 7 but what is outlined by Julia, and other participants in this thesis, must be understood as part of the violence of austerity, which is a “bureaucratised form of violence that is implemented in routine and mundane ways” (Cooper and Whyte, 2017). How the increased institutional violence has impacted disabled people has been explored in the UK (Pring, 2017) but not in Sweden, which is what this thesis seeks to do. What happens for disabled people like Julia, who is completely dependent upon welfare resources to live her life and get an income, is that the welfare state prevents her from envisioning her future and her standard of living becomes entirely dependent on policy changes and assessment outcomes. While this degree of ‘vulnerability’ within the context of my interview participants might be extreme, the general tendency was shared among almost all the participants.

These findings also have broader implications. The fear, precarity and anxiousness as well as the harshness of the reassessments that my participants had to go through fundamentally challenge the characterisation of Sweden as a ‘generous’ welfare state. It is clear through these interviews that the Swedish welfare state is not generous or unconditional, as argued by Esping-Andersen (1996). Not a single participant felt that the Swedish welfare system was exceptionally generous or sufficient for disabled people. It is also noteworthy that Anna, despite having significant reservations towards the Social Insurance Agency, felt the need to highlight how ‘fortunate’ it was to have the Social Insurance Agency. Her comment cannot be divorced from its austerity context and that she is arguing it in a time of significant austerity targeting disability-related welfare resources and support. This indicates that the precarity they felt around their everyday lives also extended to the welfare services they accessed.

5.3 ‘Managing’ austerity

Due to the recruitment criteria not specifying whether or not participants had been negatively impacted by austerity (even though that was frequently assumed by participants during the recruitment), there was a significant divergence in how my disabled participants navigated the consequences of increasing austerity in their lives. Particularly how and whether they avoided the most severe negative impacts of austerity. In some ways, it is difficult to divorce from engaging and dealing with welfare bureaucracy more broadly as it is through welfare bureaucracy that most austerity has been implemented in Sweden. This was explored in chapter 3. Exploring this question of how people 'manage' is important not only because of the heterogeneous group of participants but also to gain as nuanced and complete a picture as possible of the situation of disabled people whom utilise welfare state services. However, this exploration can be full of pitfalls in relation to disability. Magdalena reflected on how disabled people were depicted in newspapers and TV news:

> But I think – we are acknowledged almost exclusively because of our impairments [*funktionsnedsättningar*] and largely only when things are going badly, because we are not getting a service or being denied or something like that, or it is these sunshine stories about how amazing we are *despite* [our impairments]. Or how much we have managed *despite* - as if despite- as if it assumed that it would go badly for us but she has *still* managed. One does not ask some politician if it has been going well because 'he managed it *anyway*'. […] One is so amazing anyway or she does not let the handicap [*handikappet*] stand in her way. Right [sigh] has she any choice? If she has some disability [*funktionsnedsättning*] she has hardly got to choose if it is in the way or not.

Traditionally, the way that 'managing' has been positioned in relation to disabled people have been centred around how they 'overcome' their impairments or 'disregard' them, which is a paternalistic disablist framing. It is not a section about how disabled people 'cope' with their impairments as this general reflection makes little sense divorced from questions about societal barriers and questions of inequality and power. Engaging with how people mitigated the impact of austerity is different, as there are factors specific to austerity which mean that some people cannot 'cope', 'manage' and 'ameliorate' its impact. At its most extreme, this is revealed through instances where disabled people have died in Sweden as a result of austerity. A disabled woman in Sweden died in a shopping mall bathroom the day after she had got her personal assistance reduced in connection to bathroom visits and showering (Westerberg, 2016). Thus, understanding what factors produce divergent impacts with regards to austerity is important. There were a number of factors that were relevant to how the participants that I spoke to 'managed' and 'mitigated' the impact of austerity in their lives. The key factors that were identified were increasing reliance on family members, employment status, and financial resources. This section will explore these aspects in turn before reflecting what this means in a broader sociological sense.

5.3.1 The importance of family

In the interviews, it was clear that for many the role of the family was vital to mitigate the consequences of austerity. Family members would help with filling out forms, finding information, borrowing money, help getting in and out of the shower, medical assistance and a multitude of other tasks. It was often through their help that participants managed to find ways of lessening what could otherwise be extremely dire circumstances. They also played an important part when it came to challenging welfare rejections and managing appeals for many disabled people. This was because the welfare bureaucratic system was not designed to be accessible for disabled people. Helena's father talked about this in the interview I conducted with him and his wife:

> Then one must do that part [signing forms and getting certificates] and then one can go through – with that part it is impossible for Helena [their daughter] to do herself. That's that. And would we not be there, someone else would have to come forward and do that, just as an example. There is no problem of course to do this, but how it works – a thing that they just take for granted so we have ourselves had to sort out power of attorney papers because it is so bureaucratic to have a child with special needs and aptitude handicap [*begåvningshandikapp*] who turns 18 for example, there you have a really good thing to bring up because you are met with so much bureaucracy.

The role of bureaucracy will be elaborated upon in chapter 7 and the importance of family and broader social networks will become more prominent there. Hanna noted that when her application for welfare resources was rejected, she had to ask her family for money: "And now when one has moved away from home and should be grown up, to have to crawl to your parents and ask for money, and that is – they give me money if I want but just that fucking feeling that I have to do it. It is horrible. Actually". Equally, because her partner lived with her, his income was viewed as part of her income and on that basis, some of her applications had been rejected because he had somehow earned 'too much'.

Hanna critiqued the way that the welfare system based on household income rather than individual income:

> … if one lives together with someone that one is together with one way or another, they are expected to take care of them – even if they aren't married. And I think that is fucking sucks actually […] I don't think it is OK that he [my partner] should pay for my life just because he happens to be together with me.

Li's parents shared how when welfare services either were refused or the care that Li received was insufficient, they often had to come in and help Li to make sure that she had the support that she needed. Indeed, the prominence of families in mitigating the effects of austerity is notable. Particularly because it has often been remarked that "availability of affordable and publicly provided services of high quality has relieved families, especially their female members (given the traditional gendered division of labour), of unpaid work as carers for children, people with disabilities and older people" (Kvist et al, 2012: 16). My data suggests this claim is difficult to sustain. When public services decline as a result of austerity and families cannot access equivalent services on the private 'market', families become an important factor in mitigating its effects. The practical implications of this is that support becomes highly precarious when services fail. Family relationships are complicated and while they were positive and important for many of the participants in my research, it would be amiss to not recognise that family relationships could just as easily be sources of abuse and exploitation. This is vital to remember because, as chapter 7 will show, this adds a dimension of precarity as the system might assume that family will be there to pick up what the state drops, but that safety net is not there for everyone.

5.3.2 Financial resources and employment status

The second important factor for participants in this research when it came to avoiding adverse consequences of austerity was financial resources. In some ways, this could overlap with the family factor as well. For example, BJ was able to limit the extent to which welfare bureaucracy impacted her life because she got an inheritance once her parents passed away, which meant that she could limit the scrutiny of the Social Insurance Agency from her life. For Magdalena, even though her sick compensation had not been adjusted for inflation, the fact that she had previously had a job enabled her to receive a high enough compensation level that would enable her to live on her sick compensation:

> It was some – maybe there wasn’t any big difference, now I had an income *before* I had sick compensation, which means that I have a higher sick compensation than what they who never have had a job. Er, so I can live on my sick compensation but no, I do not think it has changed in these 10 years. Over 10 years maybe, some 100 SEK [around £10] or so but no bigger difference.

For Johanna, something that enabled her to forgo applying for number of welfare services was because her husband “earn quite well […] and managed to do a bit of a career so thanks to that we manage on one salary and the Social Insurance Agency”. For people who did not have these family and financial resources, the situation was much more complicated. Julia, who lived below the poverty line due to the low level of financial assistance she received, had to look for money elsewhere to make ends meet: “In order to afford to do certain things I have to apply for foundation [or charity] money so I send *masses* of letters every winter to get money to a lot of aids that are not given by the county council”. This increased the amount of work she had to perform in order to ‘manage’ her everyday life. Due to the increasing frequency of reassessments, this kind of ‘management work’ has increased because of austerity, as previously demonstrated.

5.3.3 Impairment type and time

The final factor that emerged as important in my interviews with disabled people was impairment type and time. Broadly, impairment type did seem to have an impact on the experience people had dealing with welfare bureaucracies. Time was relevant and in some ways intersected with the previous section in that participants who received their welfare support unconditionally around the 1980s or early 1990s were less impacted by the intensification of austerity. It also meant that they tended to receive higher compensation levels from the state.

The impairment type is particularly as important as many LSS services, outlined in chapter 1, are dependent on impairment type. Participants who fit into the first two categories of eligibility - people with a learning disability, autism or autism-like conditions and people with “significant and lasting developmental disability or brain injury at adult age because of external violence or bodily illness” (Riksdagsförvaltningen, 2018) – had an easier time of accessing welfare resources. This is in comparison to the participants who accessed welfare resources through the third criteria – people with “other lasting physical or psychological impairments that evidently is not due to normal aging, if they are great and cause significant difficulties in daily life and therefore constitute a significant need of support or service” (Riksdagsförvaltningen, 2018). This third criteria has been particularly affected by the increasing medicalisation of eligibility criteria, as explored in chapter 3. There were even some participants where it was not clear why they had had a particularly easy application process. This was the case for David, who did not fit the first two group criteria:

> Me: So you did not meet anyone [for your application]?
> David: No, I did not. I did not meet any doctor either but it went straight through without anyone questioning it.
> Me: That must have been nice.
> David: [laugh] Yes. A little strange, I realized after talking to other people but then I didn’t question it.

This experience of not meeting a doctor and have it be accepted was very much an outlier in relation to the other interviews I conducted. It should be noted, however, that despite David experiencing an easy application process, he was struggling to actually have his allocated resources implemented. David had moved municipality and he told me that when he met the caseworker in the new municipality, she “was not in the least bit content over the fact that I had got this decision at my old place”.

5.4 Conclusion

This chapter has explored how the disabled participants in my research made sense of what it meant to be a disabled person in Sweden. They in particular told stories of the stigma, precarity, and isolation that they faced in their everyday lives. The result of the stigma that they experienced in interactions with other people made participants hesitant to ‘disclose’ that they had an impairment unless it was unavoidable. The other consequence was that a number of my participants noted that how they were viewed was almost as if they were not quite human by non-disabled people. This stigma also seemed to indicate that non-disabled people preferred to exist in spaces that did not include disabled people, as the example of Anna’s swimming class makes clear.

Beyond this aspect, this chapter explored how participants attempted to mitigate the impact of austerity and welfare bureaucracy in their lives. Here, financial resources and support from family members were noted as particularly important. Other factors such as impairment type and when they had been awarded the welfare support also played a significant part in whether they were negatively impacted by austerity. Overall, however, even those who saw themselves as ‘spared’ from the most negative aspects of austerity felt like their situation was increasingly precarious and worried about the future. The extent to which feelings of precarity permeated the interviews in my interviews seriously called into question the characterisation of Sweden as a ‘generous’ welfare state, as argued by Esping-Andersen (1996). Because of the extent to which disabled participants had to continuously have their support reassessed, I argued that one of the consequences of austerity for disabled people is that it has increased the levels of bureaucratic violence that they experience. This will be explored more thoroughly in subsequent chapters.

The impact of bureaucracy was further evident in indirect ways, in how disabled participants spoke about their impairments. It often reflected the way in which the welfare state defined disability and often the conflation of illness and disability present within the welfare state was reproduced by participants. There was a distinct absence of alternative conceptualisations in terminologies; even when disabled people highlighted limitations with the medicalised view on disability, they still utilised the dominant vocabulary of the welfare state. That there were few alternative conceptualisations that participants used which were not compatible with the welfare bureaucratic perspective indicates that the welfare state maintains a significant definitional power in relation to impairments.

6. The construction of ‘cost’

As noted in chapter 2, the concern over ‘cost’ in relation to disabled people has had a long history. Forced sterilisation was seen as “as a ‘vaccine’ that would help bring down social and medical costs” (Björkman and Widmalm, 2010: 383). This concern over cost has remerged in Sweden in relation to the expansion of austerity. From having utopian aspirations about equality and highlighting the necessity of well-funded welfare services (Elmbrant, 2005: 30; Johnson, 2010: 17), Swedish welfare discourses are increasingly focused on what can be afforded (Ankarloo, 2008). While it might appear that utopian aspirations have dissipated with the increasing focus on affordability, this is not the case. The neoliberal creed that has dominated contemporary economic theory presents itself as an ‘objective fact’ (Ankarloo, 2008: 13,18) but notions of a self-regulating market are highly utopian (Polanyi, 2001: 3) and neoliberals, by questioning the practice of state intervention in the economy, have been incredibly successful at repackaging moral considerations by embedding them in the construction of their economic philosophy and policy (Harvey, 2005: 83). In fact, “social relations [under capitalism] are embedded in the economic system” (Polanyi, 2001:60), which makes norms and moral assumptions inherent in all economic theory.

This chapter will explore the issue of ‘cost’ in relation to disability-related welfare expenditure and highlight the impact of this discourse on disabled people, disability organisations, and welfare professionals. It will demonstrate that the main way in which disability organisations and disabled people challenged the characterisation of disability-related welfare expenditure as a ‘cost’ was through reframing related welfare expenditure as an ‘investment’. It will also show that while welfare professionals were critical of the construction of ‘cost’, they were nevertheless influenced by its discourse. By exploring these issues, I will ultimately argue that both questions of ‘cost’ and ‘investment’ are framed by the same discourse. It conceals the political choice embedded in austerity practices (Blyth, 2015) and removes the human consequences of austerity. By exploring these issues and the psycho-emotional disablism that it produces, I will argue that the construction of disability-related welfare expenditure as a cost is inherently disablist.

6.1 The morality of expenditure

To say that concerns over disability-related welfare expenditure has been deeply influential in Sweden’s socio-political landscape is not an understatement. Concerns over expenditure was highlighted in a recent report by the Social Insurance Agency, where it was noted that:

> The increase of cost has contributed to a growing concern among the state powers [*statsmakterna*] over time. Several investigations have over the years been launched with the intention of understanding the development of the increasing costs to thereby be able to insert effective measures to break the trend, without for that matter jeopardizing the intention with assistance allowance. (Socialförsäkringsrapport 2017:4)

It is here that the reflection that normative assumptions are embedded in economic theory is important. There is nothing inevitable in characterising expenditure as a ‘cost’. Indeed, in other areas of the welfare state like parental leave, education, and infrastructure, expenditure is frequently characterised as an ‘investment’ and characterising expenditure as investment has historically been the norm in Swedish welfare history. Cost and investment both denote the expenditure of money. The difference, however, between cost and investment is not in the nature of the expenditure but rather the attitude towards the expenditure. Investment denotes something that is likely to generate a ‘return’ while cost indicates an estimation that the expenditure is unlikely to yield a ‘return’. There is no definitive measurement of what is likely to generate a ‘return’ or even what constitutes a ‘return’ in economy. As such, by characterising expenditure in these different ways, it unveils attitudes towards the expenditure in question.

Attitudes and values surrounding particular expenditures can be noted in other ways too, in particular through the language of debt. This aspect is present in a Social Insurance Agency report entitled *Ohälsoskulden 2010* (Socialförsäkringsrapport, 2012:5). The title of the document translates as ‘the debt of unhealth 2010' and it examines welfare expenditure on disabled people. In its summary, the report Socialförsäkringsrapport (2012:5) writes:

> Since 2006 the Swedish Social Insurance Agency has computed the total expenditures for the stock of persons receiving one of the above forms of sickness insurance until the age of 65, when the benefits of all beneficiaries of sickness insurance are converted into old-age benefits, at a given time. [...] This **debt** does not constitute a forecast in proper sense but rather presents the present value of the liabilities at the time the calculations are made. [my emphasis]

While not outright characterising the expenditure as 'cost', the connotation nevertheless remained clear as the document makes an immediate shift – without explanation or justification – from talking about expenditure to characterising said expenditure as 'debt'. The document utilised 'debt' as a framing device for characterising the expenditure throughout the document, so it cannot be chalked up to an accidental mistake in spelling. It does not even take into consideration the moral connotations that are imbued in terms like 'healthy' or 'unhealthy' (Reeve, 2002: 500). Debt is a highly moral characterisation of expenditure as its everyday usage invokes the idea that debt 'has to be paid' - despite the fact that it is counterintuitive to economic practice (Graeber, 2011: 4,6-7). Debt as a concept therefore becomes a highly influential mechanism to justify inequality:

> The very fact that we don't know what debt is, the very flexibility of the concept, is the basis of its power. If history shows anything, it is that there is no better way to justify relations founded on violence, to make such relations seem moral, than framing them in the language of debt – above all, because it immediately makes it seem that it's the victim who's done something wrong (Graeber, 2011: 5)

By characterising expenditure as debt, it is clear that the expenditure is not bestowed willingly and is regarded as something the receiver ought to repay (or at least they are obligated to generate a 'return'). In framing the expenditure as debt, it implies that it is disabled people whom are responsible for the 'debt', even though the expenditure is made by the Social Insurance Agency to disabled people. Consequently, the negative morality surrounding debt becomes intimately connected to the discourse surrounding austerity (Blyth, 2013: 12).

Not to mention that the moral elements of debt is particularly heightened in Swedish, as the Swedish word for debt – *skuld* – is also used to denote culpability, blame and guilt.

6.2 Polite silence: the impact of cost on disability organisations

As noted in chapter 2, disability organisations have historically had a close connection to the state in Sweden. They have historically been regarded as important partners in a “societal conversation” but increasingly, their relationship has become more akin to a lobbying system (Sellerberg, 2009: 92, 88). Because of the prominence of the cost discourse in political debate and the comments uttered by a government minister at the time of the research (noted in chapter 4), the political preoccupation with cost was frequently discussed in interviews. Peter, a representative for the disability organisation Lika Unika, argued that the characterisation of disability-related expenditure as costs served as a barrier to achieving important progress on issues:

> Work on accessibility, we have been working on in the entire disability movement and it has taken such a long *time* […] to get an investigation even and then one sees what is prioritised when it comes. […] big sections of society have been afraid of it because it costs so much *money*, and then one have demanded […] then there are other powers that are of greater importance and if it is like that – when other powers play a greater role behind the scenes.

Mikael from HSO felt that “there is a rhetoric that says – we are welcomed and everyone is listening *politely* [said with affected emphasis] [laugh] but there is sort of… the outcome, the political outcome is pretty weak I would say, unfortunately”. In the interviews I conducted with disability organisations, there was an overwhelming sense of frustration and disappointment with the government over their choice of rhetoric and political priorities. This indicated that while disability organisations are formally recognised as important partners to the government, the extent to which they were listened to and influenced political decisions were fairly limited. Peter felt like questions of affordability was often at the forefront of politicians' minds and the way that his organisation challenged it was by emphasising the investment potential of disabled people:

> that one puts forward guarantees that it won't cost so much and no one actually brings up, which we are trying to do in the disability movement, that it is actually an investment to put money towards accessibility and so…

The concern over cost and 'affordability' can also be found in legislation. The UNCRPD, for example, advocate 'reasonable adjustments', which in a Swedish governmental document was indicated as meaning:

> necessary and suitable changes and adjustments, which do not mean a disproportionate or unjustifiable burden when so is needed in a single case to guarantee that people with disabilities on the same conditions as everyone else can enjoy or exercise all human rights and fundamental freedoms (Ds 2008:23).

There were no guidelines provided as to what would provide a 'disproportionate' or 'unjustifiable burden' but there is an implicit understanding embedded in the writing is that 'unreasonable' would be the 'excessive' financial burden for the employer or the state. There is considerable literature on reasonable adjustment in a UK context and criticisms of what constitutes a 'reasonable adjustment' has been made elsewhere (for example, Wilson-Kovacs et al, 2008). Its relevance is that even questions around unreasonable adjustment reinforce the narrative of disability-related welfare expenditure as a cost. Further, it has a significant impact on the provision and access to resources, support, and rights. Rights/access is to be provided, unless it presents a 'disproportionate' or 'unjustifiable burden', a burden which is understood as financial by both Peter and Mikael when it was discussed. As a consequence, social rights are subordinated to capital accumulation, which Mladenov (2015: 450) argued in relation to austerity.

The political indifference that disability organisations met when discussing concerns with politicians did not just make their work of influencing policy more difficult. It also meant that issues facing disabled people had little, if any, political currency. Martin from a local HSO office argued that the political status of disability-related issues was “essentially nothing” and had barely been discussed at the most recent election. It was something that Mikael thought was a symptom of a long-standing issue in Swedish politics:

> I don’t know, I think that it is… partly I think it has to do with that there is a – a bit of an erasure [*osynlighetsgörande*] that disability [*funktionsnedsättning*] and the issue of disability [*funktionshindersproblematik*] have not for a long time anyway been part of the public conversation

The erasure – or rendering disability invisible, which the original Swedish word *osynlighetsgörande* indicates – of disability in public political debate is interesting on multiple levels and will be elaborated on more thoroughly in the conclusion. What this section has most clearly demonstrated is how the discourse around cost has made their work of influencing politicians more difficult. While it has been exacerbated by the expansion of the cost discourse in Swedish politics, it is also clear that the invisibility of disability has been a long-standing issue in the Swedish political environment.

6.3 Making sense of ‘cost’: the welfare professional’s perspective

Just as disability organisations were concerned over the expansion of the ‘cost’ discourse in welfare debates, it was also referred to in interviews with welfare professionals. Most of the reports that this chapter has so far engaged with were published by the Social Insurance Agency, an organisation that employed a number of my professional participants. Other participants in the professional participant group, as evident in chapter 4, were employed in disability-related welfare services and support. Because the previous section explored the consequences of the ‘cost’ discourse on political advocacy work, this section will explore its implications on bureaucratic practices and work that is exemplified by the welfare professionals interviewed for this thesis.

The main way in which the cost discourse affected participants within this group was through a reduction in resources available to them in their job. While the bureaucratic system itself represents barriers for disabled people and have been impacted by austerity measures, which will be explored in chapter 7, this section explores how welfare professionals navigated the tension between providing disabled people with services and the increasing pressure to consider ‘cost’ and ‘affordability’. It is particularly noteworthy as welfare bureaucrats have been noted for their ‘discretionary’ powers (Lipsky, 2010). Ultimately, this section will highlight that welfare professionals were sceptical of the cost discourse and they challenged it by focusing instead on eligibility criteria. Despite this, however, it did not mean that they were not influenced by the cost rhetoric and broader austerity perspectives. This is was not merely evident in the focus on eligibility but also in that LSS caseworkers often highlighted the importance of gauging the credibility of claims in relation to personal assistance. In these ways, welfare professionals are still affected by the cost discourse.

6.3.1 The critique of cost

Iman, who had worked as a caseworker and had now started her own personal assistance company, noted that there had been political talk about abolishing the personal assistance law and saw “these escalating costs” as the primary motivator. The consequence of mitigating costs, in her view, meant to “strengthen the burden of proof [for applicants] and the possibility to carry out assistance and […]one also has this application process when it comes to carrying out assistance” (Iman). This stopped, in Iman’s view, the “worst leaks” of cost but was concerned that it could develop into that “further persons are not included by the criteria, but I really hope that we don’t have to go that far”. Iman was in many ways echoing the cost discourse rhetoric and reproducing the neoliberal view of (welfare) financial budgets as finite, akin to the shift towards expenditure that emerged with the expansion of neoliberalism as outlined in chapter 3. Consequently, while she criticised the government for contemplating abolishing the PA legislation, she does grant legitimacy to the ‘cost’ concerns expressed by the government and sees limiting individuals’ access as the only available option to curb ‘costs’.

Thus, even though the participants were critical of the cost discourse, it nevertheless had a significant influence, even if it was indirect. One of the instances where this was especially clear was when welfare professionals related to the past. Maria conceded, while being very critical of the austerity measures that had been implemented, that “for that what might also have been a problem before is that there were too many services approved before”. While professionals argued that more oversight was good, they felt like if it may have gone too far in the other direction. Goodrich was critical of the idea that costs were even being mitigated because “even if the Social Insurance Agency talks about their increasing costs, there are more who get rejections at the Social Insurance Agency”. He also noted that, under the new system, it was not as if the overall ‘cost’ of personal assistance had decreased but instead it had merely moved budget posts, onto the municipality:

> there are many who instead get personal assistance from the municipality instead when the total cost of the assistance does not minimise but instead many of these people who get granted personal assistance, who get rejections [from the Social Insurance Agency], can get 40-50 hours from us but the Social Insurance Agency still rejects their application. (Goodrich)

In this quote, he points to the tendency that occurs when the municipality and the Social Insurance Agency arrive at highly disparate eligible hours. What Goodrich demonstrates is that there has been a shift from state provision to local municipalities being responsible for services. The shift has created a heavy burden on smaller, less populous municipalities, which others also observed. Marina expressed incredible frustration over the burden that had been placed on municipalities and the consequences this had for ‘service users’. This shift has enabled the ‘cost’ discourse to move from being a rhetorical device at the national level to a practical concern at the local level.

The second consequence that Goodrich highlighted was that the ‘need’ for personal assistance did not disappear. While the state can reject and delegate services to municipality services as a potential second course of action, this was not possible for municipalities; they had to find some way of compensating for the Social Insurance Agency’s rejection in a difficult economic climate. The additional pressure on municipality budgets created practical issues for welfare professionals in these areas, and while they often resisted pressure to consider ‘costs’, it was something that frequently shaped what they heard in meetings and from their bosses:

> I don’t really notice it, but it is the only thing that we hear [laugh]. That in meetings and conferences and our bosses and politicians so the only thing we hear about is money and money and there aren’t any money and budget budget budget (Marina)

For Marina, it was most important to take into consideration the individual need but she also noted that

> at the same time we are controlled by municipal guidelines and economy […] we have delegation and so but if I see that this application requires massive personnel resources or it will be around the clock, then I have to take it with my boss, we do that or some special case.

In other words, as much as she resisted, she did acknowledge that there was an institutional pressure to adhere to political concerns and financial constraints despite her own reservations. She concluded, however, that “I refuse to be influenced in my decision [so] [my boss] better fire me [if he is not happy] [laugh]”. In this way, it is important to acknowledge that while street level bureaucrats (Lipsky, 2010) might have some influence over policy, it is perhaps not so clear-cut to say that they ‘create’ that policy as institutional guidelines may remove the ability of caseworkers to individually carry out policies according to their wishes.

6.3.2 Eligibility, not cost

It became clear through interviewing caseworkers that when the issue of cost came up, it was not the case that every caseworker felt as pressured to take financial pressures into consideration. Elsa regarded herself quite exempt from this pressure and other caseworkers similarly expressed that this allowed them to focus on eligibility to particular resources rather than the cost. This section will explore the focus on eligibility criteria and while it was framed as form of a resistance for welfare professionals, it will demonstrate that it is not exempt from the broader austerity framework of the Swedish welfare state.

Elsa felt very grateful that her workplace was not overtly concerned over how much services ‘cost’. Instead, the conversation at her workplace was much more focused on whether applicants had a ‘right’ to services by meeting the eligibility criteria:

> But… I can imagine that there are in other municipalities where they talk more about economy and one should think how one works a case but at the same time, I have no other experiences [of working in another municipality] that confirm that but I experience that one does not talk about economy in the casework but one talks about whether one has a right to the particular service or not. (Elsa)

The key for Elsa was eligibility, not the financial ‘cost’ of awarding services. This was also echoed by Goodrich who said that “I never think of the municipality’s economy when I work and make a decision but I award based on what one has a right to and what others in the municipality usually get in that municipality”. Both Elsa and Goodrich shared this perspective, although Elsa viewed herself as more ‘free’ to make decisions based on ‘need’ rather than ‘cost’ and Goodrich, while resistant, was aware of the financial limitations of his municipality. He had previously worked in a municipality that had been wealthier and felt that when he had worked there it had been easier to get decisions approved. Now working in a much more ‘diverse’ and poor area, he found things were significantly more difficult. Elsa also did not feel the same kind of implicit bureaucratic pressure that Marina referred to in the previous section. Elsa noted feeling trusted and supported rather than surveyed in her occupational role.

While the caseworkers were very critical of the cost discourse, eligibility criteria are not exempt from its influence. As demonstrated in chapter 3, changes to eligibility criteria to things like PA provision and higher degrees of medicalisation restrict access. Consequently, eligibility criteria are deeply imbedded in indirect forms of austerity that Sweden has been implementing since the 1980s and even more intensely since 2005. Further, it has been observed that eligibility criteria leave significant room for interpretations and assumptions on the part of the caseworker, which makes eligibility criteria “contain possibilities of implicit exclusions which are hard to button down” (Christensen et al, 2014: 29). The opacity of eligibility criteria could allow for a narrowing of eligibility without having to directly alter the articulated guidelines because it depends on subjective assessments and legal interpretations. This is similar to the issue regarding ‘reasonable adjustments’ as noted in the previous section.

Thus, the reverence for eligibility criteria as something distinct from the ‘cost’ discourse conceals the trajectory of how austerity measures have been operationalised in Sweden. The link between the narrowing of eligibility and austerity was not clear to participants and this must be understood as an expression of structural production of un-knowing, which chapter 7 will explore in further detail. The reshaping of eligibility criteria is in line with how Askheim et al (2014: 8) noted the trajectory of austerity in the Swedish provision of PA:

> The tendency in Sweden now is towards efforts to reregulate the arrangement, in order to put an end to disadvantages resulting from the extensive amount of freedom built into the model. The main reason for this is that PA has become too costly. The national authorities are undertaking efforts to control the arrangement in a more active way, in order to secure good quality services and ensure that the resources are spent in legitimate ways. Special measures are being taken to prevent cheating and errors in the process.

The changes to eligibility criteria, indirect through the redefinition of ‘basic needs’ and explicit in harsher medical criteria, represent a key way in which the welfare state is trying to ‘reregulate the arrangement’. Not only does the characterisation of PA as containing ‘excessive freedoms’ clearly frame the issue as a too liberal assessment system, the (assumed ‘too’ high) level of expenditure is also regarded as illegitimate. The role of these subjective and normative assessments within the bureaucratic system cannot be underestimated. It is these that has allowed for a tighter reinforcement of eligibility criteria and a higher degree of medicalisation of eligibility criteria without resulting in overt policy changes. The vagueness of eligibility criteria, therefore, is what made indirect implementation of austerity possible.

6.3.3 Credibility

Thus far I have demonstrated that while welfare professionals were critical of the cost discourse present in public debates, they were nevertheless impacted by its existence in explicit or in implicit ways. Although focusing on the eligibility criteria was regarded as challenging this austerity rhetoric, eligibility criteria have been significantly altered in response to increasing austerity. The final issue that emerged when discussing with welfare professionals the cost issue is that of credibility. This was especially prominent with LSS caseworkers and how they assessed claims by disabled people for personal assistance. Elsa explained what it was like to assess a claim:

> …we look at what [the claimant] has highlighted how long different things take and then one has to make an assessment in that it is a – that it is a credible magnitude, er, if you say that a shower takes two hours so maybe one really has to be able to justify what it is that makes it so that it takes two hours.

The idea of credibility clearly played a central part in the assessment procedure. Elsa was not the only caseworker to address this issue in their interview. Goodrich argued that he felt that claimants often exaggerated their needs in their application:

> Yes, there are a few who report that it can take up to two hours to shower although… although it is completely unreasonable the time they account for certain things to take, one or two hours, to shower and even if one meets the children [for example], one can understand that it takes its time but a bit of it is very exaggerated. Then we do our own calculation what we think is credible and so on like how long it takes and things like that. But certain things like getting dressed and toilet visits and wiping oneself and so on, sometimes it feels like a few exaggerate [these] a lot.

What is noteworthy here is that he utilises the exact same example as Elsa as to what constituted ‘unreasonable’ or ‘incredible’ claims. This is despite the fact that they are from vastly different parts of Sweden and have, to my knowledge, never worked together. Showering, in particular, has been and continues to be a contentious example in relation to estimations of time needed to cover one’s basic needs. Not only because of the reoccurrence of this in interviews with caseworkers, but also because there have been newspaper articles about caseworkers coming to disabled people’s homes asking to watch them shower to confirm that their claim is accurate (Pettersson, 2015).

While caseworkers generally considered personal assistance claims very difficult to estimate (see chapter 7), Goodrich viewed them as easier to determine because they were more ‘straightforward’. This simplicity stemmed from the fact that it was just about measuring how much time it took for each instance. Other assessments, Goodrich thought, were more complicated because “how many hours relief, how many hours accompaniment – what is reasonable[3] [is difficult] because there is a lot of opinions, there is no right or wrong so to speak”. While he openly reflected on the interpretive role he occupied with these other assessments, he did not extend this analysis to personal assistance. Despite that personal assistance assessments also required judgements and interpretations as to what is deemed ‘credible’, he did not view personal assistance-related assessment as arbitrary or equally ambiguous as in other assessments. It is possible that it is through the quantification and the breaking down of a process to small fragments which gives personal assistance this air of certainty for Goodrich, as this is a fundamental aspect of bureaucratisation (Bauman, 2000).

By invoking the standard of credibility (or unreasonability), Goodrich could maintain his role as an ‘objective’ professional. Embedded in the call for ‘credibility’ is the kind of assumptions and interpretations that create implicit exclusions that are difficult to highlight, as argued by Christensen et al (2014). These kinds of discretionary and professional assessments are embedded in the role of the street-level bureaucrat (Lipsky, 2010) and will be elaborated upon further in the subsequent chapter on bureaucracy. Just as claims about ‘reasonable adjustments’, there is no clear-cut understanding of what would constitute an unreasonable or reasonable claim with regards to integrity-sensitive needs. Normative values and assumptions are central to how these ideas are interpreted and understood by caseworkers. It was not clear what parameters they used to judge that two hours was an excessive claim. It was not clear whether they made these assessments in relation to other disabled people or if they used non-disabled people as the norm. For this reason, questions need to be asked about what is regarded as a ‘reasonable’ claim in this environment. Due to the welfare state’s tendency to conflate illness and disability, noted in

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[3] This could also be translated as ‘credible’ as they are interchangeable in Swedish

chapter 2, and its subsequent tendency to use non-disabled people as the norm, it is likely that this is the case here, but it is difficult to ascertain for certain. These tensions and ambiguities are central to bureaucracy and welfare professionals' practice. This will be explored more extensively in chapter 7. In light of the tightening of eligibility criteria through the redefinition of basic needs as integrity-sensitive needs, I argue that we need to understand the emphasis placed on the 'credibility' of claims as in line with the tightening of eligibility criteria and thus indirectly connected to the cost discourse. Especially as the cost discourse implicitly calls for greater vigilance in protecting disability-related services and support.

Overall, I have demonstrated that while the welfare professionals I interviewed were broadly critical of the cost discourse present in public and political debates, they were nevertheless impacted by its rhetoric. It was common for professionals to concede that there had been a problem with Sweden's welfare state being too generous in the past and in this way we can see that the cost discourse is utilised as an austerity-justifying rhetoric to legitimise cuts to welfare provision. In this way, their resistance to the cost discourse remained marked by austerity in different ways. They challenged the idea that costs should be taken into consideration when making assessments and instead wished to focus on eligibility criteria and the credibility of claimants' estimations. This resistance, while admirable, is limited by the fact that eligibility criteria, the importance of credibility, and preventing 'unreasonable' claims are all tied to austerity measures. Eligibility criteria has become medicalised, as noted in chapter 3, and preventing 'unreasonable' claims is tied to the need to prevent welfare fraud, which is a discourse that emerged alongside the intensification of austerity (Lundström, 2013; Altermark and Nilsson, 2017). Their ability to resist the cost discourse and its accompanying austerity is also limited by the fact that they work and operate within a structure that has implemented an increasing number of checks and balances on claims. This was demonstrated by Marina, who noted that while costs did not come into consideration for her, if her assessments were deemed to require significant resources, they had to be double-checked by her superiors and this was also noted by other caseworkers.

6.4 The impact of ‘cost’ on disabled people’s lives

This chapter has so far explored the impact of the ‘cost’ discourse on political and bureaucratic practices. What became clear during the fieldwork, however, is that its effects were not limited to these two spheres. Due to the pervasiveness of the cost discourse in welfare debates and disability service provision in particular, it was often something that disabled people reflected upon in their interviews. Importantly, participants noted that by saying that the welfare provision they relied upon was too costly, it was not far away from arguing that disabled people themselves were too ‘expensive’ to have in society. “It is fun that we [disabled people] cost too much money”, Jungfru Gunnela remarked, “when it is common that we have difficulties managing financially”. Thus, in order to resist the characterisation of being a ‘cost’ for society, participants in my research frequently constructed themselves and their needs as ‘investments’ for the state. This section will explore how the cost discourse contributes to significant psycho-emotional disablism for disabled people. Finally, it will demonstrate how the cost discourse conceals the human cost of austerity and how ‘cutting costs’ have worsened the quality of available services if restriction to services cannot be achieved.

6.4.1 Investments, not costs

As with my other participants, disabled people were highly critical of the idea that disability-related welfare expenditure was too ‘costly’. The central form of resistance that my participants utilised to challenge the cost discourse was by arguing that these expenditures were actually ‘investments’. Julia challenged the cost discourse by arguing that its financial viability was tenuous because it did not take into consideration long-term consequences and could consequently increase costs for the welfare state:

> Or as in my case when it comes to aids, I get to take some expensive medications, that the county council [*landstinget*] pays a large part of and make a decent electric wheelchair but I tested on the aids fair, both an electric and a manual wheelchair that I didn’t have pain because I sat in such a good way, imagine to give two wheelchairs, that maybe last 10-15 years, if you’re lucky at least 10 in any case, and not have to deal with the cost of

> medicine on some really expensive medications for ten years instead. But they only think about costs for a year or a length of office.

What is notable about this quote is that Julia is ostensibly talking about something that would increase her quality of life. This, however, was not something that she identified as the primary benefit. Instead, the investment that Julia identified was that it would decrease costs for the county.

BJ criticised cost by arguing that the concern over expenditure was not uniformly applied to all sectors of the welfare state:

> There was some medicine against some really rare illness that cost 4 million per year because there were so few patients and then the county council had said no you don't get that medicine anymore because it is too expensive and then I think like – er... four million? Let's see, if we instead did so that we made sure that drunk idiots [*sic*] that cost the emergency room ten thousands of SEK on the weekend because they have injured themselves when drunk, if we made sure that that didn't happen, we'd have four million to that poor person's medication.

In her example, BJ positioned the need of the medicine against its expense and highlighted how the 'cost' of it was utilised to reject its provision. What her example also clearly demonstrates is that the moral vocabulary of expenditure – articulated at the beginning of this chapter – is not lost on disabled people. Through discourses of cost and investment, distinctions are made between worthy and unworthy recipients of welfare expenditure. Through her example, BJ is not only highlighting this aspect but directly challenging the problematisation of expenditure by the state in one area but not in another.

Hanna argued that the short-sightedness of 'cost' exacerbated people's illnesses and consequently, she argued that it was a poor investment for the welfare state:

> To be able to feel better, one must also be well psychologically and can one never like do something fun and the only thing that you can do is put money on rent, food and like a bit of fuel [...] one is only going to get worse and I don't get how they've squared those things.

That austerity exacerbates poor health is an observation also supported by research (Stuckler and Basu, 2013). The reformulation of ‘costs’ to ‘investments’ broadly follow the same trajectory. As in Julia’s quote, the basis for Hanna’s critique of the cost discourse stemmed from the fact that it did not constitute a return. By acknowledging that the state wants to reduce the number of people who are ‘sick’, she challenged that this would be possible when the state is not providing people with an adequate standard of living. Again, Hanna is talking about measures that would improve her quality of life, but this is not what constitutes the ‘return’ she identified by reframing the necessary expenditure as an investment. The return that she noted is that the number of sick cases would be reduced.

This criticism of the cost discourse was also articulated by Mr Kint, who criticised the way in which government agencies accepted or refused particular aids. He wanted an accessible bike and the municipality argued that they could not afford it. Mr Kint argued that ultimately it would be better for the economy as it would keep him healthier for longer and not put as much pressure on healthcare services:

> If this aid enables me to for example go cycling every day, is it not better for the societal economy compared to if I get a really expensive whatever-they’re-called three-wheel mopeds or vespa or whatever it is where I’m sitting still and don’t move?

Magdalena could not understand the rationale that defined the cost discourse in relation to disability-related welfare provision, because people who had comprehensive assistance “if they didn’t get help, they’d be at the hospital […] and being in the hospital costs very very much. One day at the hospital costs more than the assistance does”. The identified return here is that expenditure is reduced, not that disabled people are able to live and engage in their communities.

These examples highlight something crucial regarding the cost discourse. As highlighted earlier in the chapter, the difference between investments and costs is regarding the likelihood of a ‘return’. Otherwise, the logic underlying both of these normative frameworks around cost remain the same. The consequence for disabled people when utilising investments to challenge the characterisation of disability-related welfare expenditure as a cost is that ‘the return’ they identified in their criticisms were not of an immediate personal nature, but of a more abstract, societal benefit. What this is lost (or, more accurately, what remains unaccounted for) is the human, real-life impacts of austerity. While they could tangentially feature, it was never the benefits to disabled people themselves which were identified as the ultimate ‘return’. The identified ‘returns’ were instead aspects like becoming a more ‘productive’ (read: labour market participating) citizen or lower costs for the state. The human elements of these conversions are thus more incidental rather than a central component. This is a continuation of the kind of rationale that underlies the capitalist system which externalises social/human costs. It also exacerbates the structural invisibility facing disabled people that disability organisations identified in this chapter and the dehumanisation that disabled people spoke about in the previous chapter. These factors will be expanded upon in the conclusion of this thesis.

6.4.2 Psycho-emotional disablism

Having to disregard one’s own needs and instead focus on benefits for the state come at a significant emotional cost for disabled people. But it is not merely in this regard that the cost discourse exacerbates feelings of exclusion and result in significant emotional distress and stigma for participants. As noted earlier, after having characterised disability-related welfare expenditure as a cost, it is merely a step away from viewing disabled people themselves as a ‘cost’ or a societal burden. The participants I spoke to were aware of this. When Louise acquired her impairment and was granted sick leave, she felt that:

> it was immediately so that I didn’t want to be a burden on society […] I can feel ashamed for [being on benefits] – no I don’t want to burden anyone else and… I don’t want that anyone should pay taxes on my behalf and so on… No, I think it is very very difficult to think that… I don’t want to be a burden.

The view of disabled people as ‘burdens’ become amplified when their needs are constructed as expenses that do not generate a ‘return’ and the idea that there is a limit to what Sweden can ‘afford’ (Ankarloo, 2008) is promoted. The implicit construction of disabled people as ‘burdens’ become particularly evident when recognising, that the humanity of disabled people and the human consequences of austerity remain incidental and do not constitute relevant ‘returns’ in a cost-benefit analysis. In this way, the ‘cost’ discourse quite easily produces forms of psycho-emotional disablism (Thomas, 1999). This concept was explored in chapter 2. Psycho-emotional disablism is enhanced by the ‘cost’ discourse in that when participants resisted the ‘cost’ discourse by viewing themselves as investments, this required having to put one’s own needs and wishes to the side and frame how particular measures would improve things for the broader non-disabled society. Psycho-emotional disablism is also a reaction to the daily structural inequality that face disabled people (Reeve, 2002: 495). As Reeve (2002, 501) writes:

> The cost to the claimant of accepting these disability benefits is that they are forced to adopt the negative identity of a disabled person, someone who is abnormal and incapable; for many, the emotional cost is too high and, instead, they prefer to manage without the financial benefits provided by the state.

What Reeve describes here was highly potent in the interviews I conducted for this thesis. Stories of how participants would avoid applying for welfare benefits because the emotional toll it took on them will be expanded upon in chapter 7.

Another consequence of the cost discourse is that it can open the door to challenge disabled people’s eligibility or ‘right’ to services. By constructing ‘costs’ as immense and resources as limited, it promotes the idea that welfare services ought to be reserved for the most ‘needy’, which is completely contrary to the construction of the Swedish welfare state as suggested by Esping-Andersen (1996), who sees this rhetoric as more associated with a liberal welfare type. The implication of the cost discourse is therefore that there are disabled people who are ‘illegitimately’ claiming ‘too much’. In this way, the cost discourse can be connected to the construction of disabled people as likely sources of welfare fraud. These ideas have impact on disabled people’s everyday lives. Hanna shared a story where she shifted her legs while sitting in her wheelchair and “then there was someone who was like ‘You shouldn’t have a wheelchair if you can move that well!’ and I like… ‘no, but maybe you shouldn’t have a mouth if that’s how you express yourself’”. Rasmus, who was interviewed in his capacity as a member of DHR, spoke about how it was a daily occurrence that people would glare at him in public. He also spoke of having had quite extensive adjustments made on his car and to try to minimise the perception that he was living a life of luxury on the back of the state, Rasmus would try to talk to people about what these adjustments enabled him to do if people approached him in public. In this way, the cost discourse help to reproduce forms of discrimination, or at least make disabled participants more aware of this in their interactions with others.

6.4.3 Consequences of ‘cutting costs’

Another obvious consequence of the ‘cost’ discourse is that it results in the expansion of austerity measures that seeks to reduce ‘costs’ by removing access to welfare services for disabled people. While the emotional consequences of this has already been elaborated upon and how it amalgamates with discrimination, it is important to acknowledge that the loss is not just emotional for disabled people. It also has significant material consequences and can result in the physical removal from public space. In some ways this coincides with the precarity noted in chapter 5, but due to its significance it is worth expanding upon this in this chapter. The cost discourse transforms normative assessments regarding expenditure into a depersonalised, bureaucratic questions of reducing expenditure that makes it difficult to address the impact of austerity in public debates.

With services and support increasing being reserved for the most ‘needy’ through stricter eligibility criteria, Julia was concerned that if she was reassessed during the summer – when the warm climate would help alleviate some of her pain – there was a danger that “they would then remove everything”. This would result in her being relegated to an involuntary isolation in her home. She was not the only participant with this concern. Ken, interviewed in his capacity as a representative of DHR, noted that “we may have got rid of the institutions as big complexes but instead […] we [are] about to reinstitutionalise ourselves but the institution instead becomes your own home”.

The cost discourse conceals the normative values that underpin the views on disability-related welfare expenditure, and it turns the political choice that is austerity (Blyth, 2013) into a technocratic exercise of reducing numbers. This means that the human impact of these measures is externalised and deemed to be beyond the scope of the conversation. As a result, Rasmus felt like it was easier to organise politically as an organisation and make claims about rights to resources collectively in a way that was not possible in his personal life. Hanna echoed this sentiment, feeling as if her life was “borrowed from the Social Insurance Agency”. These aspects, however, are not included in any cost-benefit analysis related to austerity. Being a disabled person that is reliant upon welfare resources and support means being subjected to significant bureaucracy – its impact has been explored in chapter 5 and will be elaborated further in chapter 7 – and having one’s standard of living controlled by welfare professionals. The cost discourse exacerbates this further as it removes the human cost of austerity out of the conversation.

When removal of access cannot be achieved, there are other ways of lowering the ‘cost’ of a service. This was something that became clear in my interviews when disabled people shared their experiences. When not able to reduce access to a service, the cost of a service could be minimised by making it low-status, with little compensation and with no qualification criterion for those carrying out those services and more akin to a voluntary service rather than performed by professionals. This is significantly less expensive as it would not require any significant training or oversight. This has consequences not only for the quality of that service but also on how the services were carried out. The key services that were plagued by this problem in my interviews were contact people, attendants, fiduciaries, and personal assistants. This section will explore these in turn.

A contact person is a non-professional whose main purpose is to break a person’s isolation and give ‘advice’ in less complicated situations. Contact people receive compensation, but it is not a great sum of money and often regarded as a form of compensated voluntary work and something that contact people do on their ‘spare time’. For Jungfru Gunnela, it didn’t work out with her contact person because she had numerous commitments and activities that she prioritized over helping Gunnela, which caused them to only rarely see each other. When Gunnela cancelled the service because contact person amplified her stress levels and caused significant distress, Gunnela's re-application was rejected because it was then deemed that the people working at her assisted living facility would take on that role. There were also instances in my interviews where contact people had been abusive. Katja shared that her previous contact person would frequently bully her and rarely took her perspective into account regarding what activities they would do together. This was just one of many examples, Katja argued, of "very cruel people who are supposed to help me with my day". It was quite common that these people would frequently quit and, at one point, Katja had three different contact people during a six-month period, which she found incredibly distressing.

Guidance services are offered as part of LSS and are meant to offer an attendant, who is also supposed to 'break isolations' and get disabled people 'into society'. This service was riddled with similar problems. A big problem, Sunetra found, was that "it is difficult to get an attendant, since it is not seen as equal to a job but as a spare time activity that people do on their spare time". She had received a decision that gave her the right to an attendant during entire days when she needed it and because of Sunetra's active lifestyle, that meant that it could be "at different times every week". This made the post difficult to fill and the municipality had a responsibility to fill the need within three months, otherwise they would receive a fine. This pressure to fill the post caused the municipality to often just take "the first best" and not someone who fitted with Sunetra's needs. "They haven't wanted to work," Sunetra told me, "they have said that their pay is too poor and that is not something I can influence because they are employed by the municipality". This often resulted in the 'personal chemistry' not being right or the attendants simply not showing up where they were supposed to, despite her being heavily reliant on them in certain situations.

Sunetra had also had problems with fiduciaries[4]. One had prioritised her own needs over Sunetra's:

> She had just started her own company that was… how should I say it? In the healthcare sector. She followed along to a few hospital

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[4] There are various kinds of fiduciaries but the one that Sunetra needs is one that helps her when she is in contact with government and healthcare authorities.

> appointments and other things, and, in those meetings, she would talk about her company and market herself and her company instead of helping me.

Another fiduciary she had “had five companies, his own companies, in addition to having ten other tasks [read: people who needed a fiduciary] in Sweden”. For this reason, she never got the appropriate assistance and help that she needed from her fiduciary. Formally, she had the service she was entitled to, but the way that it played out in practice meant it was more or less useless to her.

It further transpired that personal assistants could sometimes be the source of similar issues. This had been the case for Li, according to her mother Inga and her father Folke. They would steal things from Li and Inga told a story about how one assistant had stolen theatre tickets but snuck them back a few days later once she had realised it said ‘wheelchair user’ on one of them and the other was designated for an assistant, and thus not something that she could use. This, according to Inga, had been a recurring problem. “It was very scary,” Inga admitted, “Several instances like that. She lost a few things that never returned”. The thefts were not something that they ever reported to the police. Partly because it had at first been such a surprise but also because Li needed assistants. Therefore, in order for Li to get what she needed, Inga needed to work with the assistants to train them in how to help Li. This training was essential because the assistants almost never had any prior care experience or experience in dealing with disabled people. During our interview, Inga made an off-hand remark that one of the few things that she found personal assistants really had any knowledge about was how to drive and most had used their time as a personal assistant to save up money to go travelling rather than viewing it as a career. In light of this situation, it made instances such as theft and other situations difficult to address. Inga described it in the following way:

> I had to work professionally and there are some things that you just have to let pass because it is not possible to handle. It is not possible to handle. You can’t just fire people then and there – it is not possible. You have to swallow quite a bit. You have to.

She shared a story of another disabled person she had read about who had been cheated of “almost lost everything she owned but it was never possible to prove”. It was clear in the interview that this was something that still distressed

Inga, despite several years having passed. Inga worried that had Li been alone, she might have been placed in a similar position and because Li was so reliant on her assistants, it had not been possible for Inga to address every injustice that had been carried out against her daughter because there were so few options available to them.

6.5 Conclusion

What this chapter has demonstrated is that the cost discourse has impacted each participant group of this thesis. Fundamentally, the cost discourse justifies the intensification of austerity and undermines the provision of welfare resources and the fulfilment of substantive rights for disabled people. The hesitancy towards substantive rights that resides within the ‘cost’ discourse is more explicit than it is in the traditional ‘welfare fraud’ myth, which is much more about ‘protecting’ various resources from misuse (Lundström, 2013). As such, there is a tension between lowering costs and providing services. This was evident in a report on the development of personal assistance where the Social Insurance Agency remarked:

> At the same time as this development [personal assistance] has enabled for many people with different types of impairments to live as others – and therefore contributed to fulfil the intention of the reform - have made it so that the total costs for assistance allowance have increased significantly over time, from about three billion SEK in 1994 to almost 26 billion SEK in 2016 (Socialförsäkringsrapport 2017:4)

While they acknowledge that personal assistance is a significant step towards equality and autonomy for disabled people in everyday life, there is an implicit concern that the costs are too great. That these two elements are juxtaposed to each other suggest that the governmental body is aware of the tension between fulfilling substantive rights and increased expenditure and that these aspirations may not be compatible. The ISF (2014:11) report argued that “the legislator should examine how the ambition regarding participation should be balanced against the increasing cost”. Consequently, instead of challenging the idea that these services are ‘costly’, it is the future viability of these services that are questioned. The underlying moral and political choices are concealed by the cost discourse’s technocratic veneer.

The normative assumptions it conceals are related to how disabled people are viewed in society and what standard of living they ought to be given if they are reliant on welfare services. Christine, as a representative of STIL, argued that the cost discourse was not just about whether or not too many people get personal assistance but:

> it is also about what level one expects that people who use personal assistance should live and there might be other forms of living – like for example group homes or home care – that one perceives as more cost-effective even though it won’t be, because it is also about – I believe – this perception about equal living conditions as unreasonable, one thinks that they should settle with less and so on.

That personal assistance is now regarded as ‘too costly’ is interesting because one of the chief reasons for its implementation was that it was ‘cheaper’ than home care services and institutionalisation (Anderberg, 2009: 6; Barron et al, 2000: 38). The expectation that people who are seen as ‘unproductive’ ought to settle for less is in many ways inscribed in the welfare structure. Stone (1984) noted that any redistributive efforts towards disabled people needed at the same time to reinforce the supremacy of the primary distributive system, meaning paid labour, and, to achieve this, any disability provision should not be comparable or preferable in quality to what would be generated in the labour market. Thus, the idea that disabled people who cannot work because of their impairment effects ought to have a good standard of living is a direct challenge to this fundamental principle of the welfare state. There is a level of disablism embedded in the cost discourse, however, that need to be acknowledged. This is because the cost discourse in Sweden is never applied to (non-disabled) children, who are not by rule engaged in paid employment and are also given welfare support. If there was not a discriminatory element underlying this discourse, non-disabled children would also be subject to this rhetoric and subsequent austerity measures.

7. On Bureaucracy

Bureaucracy has emerged as a key element from the undertaken fieldwork. Being a disabled person in Sweden who is reliant on welfare services and support require extensive engagement with bureaucracy. In addition to this, bureaucratisation has been one of the key methods of implementation of indirect austerity in Sweden, as chapter 3 highlighted. Consequently, it is worth expanding further on the experience of engaging with bureaucracy for disabled people and on the perspective of welfare bureaucracy from welfare professionals. Building on the definition of bureaucracy as offered by Selznick (1943: 51), bureaucracy contains four key elements:

- the delegation of functions
- the bifurcation of interest between the initiator and the employed
- a need for control over conditions
- officials' actions have increasingly internal relevance for the organisation, where their issues are increasingly defined as issues for the organisation

While Selznick (1943) offers a good general understanding of bureaucracy as a system, I am going to focus more on its impact on people's lives. For this reason, I will use bureaucracy as a term to denote the procedure and tasks involved in systems of administration based on the principles of rationalisation and impersonal exercise of power through the bifurcation of interest as noted by Selznick. Bureaucracy also includes "means-ends calculus, budget balancing, universal rule application" (Bauman, 2000: 17). As such, bureaucracy will be used to describe the activities of and with organisations that have a systematic and hierarchical character. This chapter will primarily focus on the impact of welfare bureaucracy on people's lives unless otherwise stated. It is, however, important to note that bureaucracy is not isolated to welfare services but is also connected to other sectors such as healthcare, employment, housing and law.

That bureaucracy was frequently discussed and reflected upon by participants is in retrospect not surprising. The welfare state entails increasing levels of bureaucratic processing (Lipsky, 2010: 7). Indeed, as Stone (1984: 12–13) highlighted, disability-related welfare ‘benefits’ are fundamental to the structure of the welfare state. It is because the conditions for disability ‘benefits’ ultimately defines what is expected of non-disabled people and under what conditions people can opt out of the expectation of paid labour market participation. Consequently, access to disability-related services and support must be heavily regulated using bureaucracy to maintain the primacy of the main wage-earning system. This is to ensure that eligibility is determined ‘impartially’ (Clarke and Newman, 1997: 5). Bureaucratisation is also an important form of indirect austerity, as evident in chapter 3.

This chapter will present the perspectives of primarily two participant groups: disabled people and welfare professionals. The reason for focusing on these two participant groups is because there is a tension inherent in the concept of disability, as highlighted by Stone (1984) in that disability is on the one hand part of a lived experience but it is also for welfare professionals an administrative category. By engaging with these two participant groups, this chapter can allow some further clarity on the tension between these two perspectives. Firstly, this chapter will account for how disabled people were impacted by bureaucracy before highlighting how they navigated the welfare bureaucratic process. The main stages in this process are understanding the system, dealing with rejections and appeals, accepted applications and forced allocation of services and support and, finally, avoiding applying for welfare services and support. Secondly, the perspective of welfare professionals will be accounted for by exploring the impact austerity has had on their working practices and how they navigated the diffuse and vague directions articulated in guidelines for disability-related welfare support and services. These two explorations open up important questions as to how the opposite of knowledge, in this thesis referred to as ‘un-knowing’, is structurally produced in the welfare bureaucratic system.

In this chapter I will argue that there are numerous barriers for disabled people to access welfare support. They are not just related to strict austerity measures, such as more limited interpretations made by courts, but also how knowledge is distributed in the welfare system, which proved to be a significant barrier. Both barriers are highly bureaucratic in nature. For many disabled participants, the problems they faced when applying for welfare support discouraged them from applying for additional resources and it also has severe impact on their sense of self. This extensive impact is indicative of the power that bureaucracy has over shaping the experience of having an impairment for disabled people in Sweden. As such, this chapter provides important answers to research aim one, two, and three.

7.1 Impact of welfare bureaucracy on disabled people

Before delving into how disabled people navigated welfare bureaucracy, it is worth exploring the general impact that engaging with welfare bureaucracy had on the participants of this research. This will help elucidate the extent to which the experience of having an impairment was associated with welfare bureaucracy by the people I interviewed. Particularly as bureaucracy entails separating various aspects of its practice to various fields, trying to get a sense of the overall impact is important.

When conducting the interviews during my fieldwork, it was striking the extent to which participants related their experience of having an impairment to the welfare system. Even questions like “tell me about yourself, who are you?” became questions that some immediately connected to bureaucratic structures. One participant even began her interview by replying: “Do you mean what benefits I have access to and so on?”. While bureaucracies and law have a profound impact on welfare recipients in general (Sarat, 1990), this influence is particularly prominent for disabled people as many of them are reliant on welfare services to manage their daily lives in a way that is not comparable to non-disabled people. Hanna defined her experience with welfare bureaucracy as the following:

> Generally a lot of hassle I would say because it is so incredibly bureaucratic all of it and it is almost like you apply for the right to apply for something. There is an absurd amount that one has to apply for and […] it is almost as one must on like seven lines summarize one’s entire life and they want to know all details but you have seven lines to tell them and if you happen to write any

> little thing incorrectly, it can be the difference between like having enough to manage or not get anything at all.

While there were some participants who navigated welfare bureaucracy with ease, as noted in chapter 5, this was not the case for the majority of the participants. Many participants noted that managing and understanding the paperwork was difficult and with the increasing pressure of reassessments, this became increasingly cumbersome. It is important to note, however, that this was in some ways not new. Many participants noted that welfare bureaucracy had always been difficult, but the issues and difficulties embedded in the bureaucratic system had magnified as a result of increasing austerity.

Although the bureaucratic process in general felt abstract, it is vital to note that its influence was not abstract for the participants in my research - it was immediate and significant. BJ estimated that every time she needed to engage with welfare bureaucratic institutions like the Social Insurance Agency, she had to put in at least 20 hours of work. It was something that gave her incredible anxiety:

> It does not matter – excuse me – but it does not make a *fucking* difference when one has contact with them - the hell starts with paper management and forms and filling them in and motivations and that was not good enough and it will- you know […] I am terrified of them. Every time I get a letter from there [Social Insurance Agency], I get a lump in my stomach. Bugger. Now they have found some hell again. And I am not like I think that they will take my compensation away, because I know how I live and roughly what the regulations look like, but they often find like 'now we are lowering it with 30 SEK'. (BJ)

Having to engage with bureaucratic institutions and the work that it required fuelled the sense of precarity that BJ and other participants experienced as a result of expanding austerity, as noted in chapter 5. This was not just because of the fear of sanctions, as BJ did not feel like that would be applicable in her situation, but because of the sheer effort it required in the first place. Thus, anxiety is not just produced by the fear of having one's support cut (as chapter 5 noted) but also by engaging with the welfare system. It is important to note that the fear of cuts could also amplify this other general anxiety. This was already partly explored in chapter 5, where the importance of family members was noted in managing the effects of austerity. With informal carers already stretched to help out - a patchwork of familiar support provided to cover patchy welfare coverage - many were worried about the possibility of being able to manage their daily lives in light of the looming insecurity surrounding welfare benefits.

In light of the fact that bureaucracy itself could be anxiety producing and that chapter 5 already noted that the welfare state was a significant source of psycho-emotional disablism, there are questions regarding how long-term exposure to this extensive bureaucratised form of violence (Cooper and Whyte, 2017) affects a person. Julia, who among the participants of my research were among those most dependent on welfare services and support, shared how engaging with welfare bureaucracy and healthcare bureaucracy had significantly impacted her sense of self. Julia felt “like a ball, that some unit or specialisation […] throw away, a ball in a direction but there is not really anyone who knows who will receive it”. The high degree of specialisation within the healthcare system meant that when Julia came in to ask for some sort of support, the engagement she received from healthcare professionals was isolated to particular aspects – psychiatry is only interested in emotions, neurology only in pain and so forth. This had a profound impact on Julia’s sense of self and well-being:

> At the same time like – yeah, ‘but see yourself as a person’! Yes, but there is *no one* who asks me questions about all of me. Why should I see myself as a person? When I feel like a ball that is thrown around and never received. […] Even when I’ve drawn myself at the psychiatrist’s, I’ve drawn myself in various parts. ‘No but where are you?’ Yes but this is how I am because you ask me like this. Why should I see *myself* as one when *no one else* – other than my nearest and dearest – see me as one.

The degree of specialisation in the systems that she had to engage with meant that there were not many who treated her as a complete human being instead of a set of disparate symptoms. To cope, Julia had adjusted her self-perception so that it more closely aligned to how the healthcare system was organised. She spoke of separating herself into various ‘selves’ that she brought out when speaking to healthcare professionals. While Julia had a medical doctor who attempted to counteract this treatment and deal with her concerns and needs on a holistic level, it was something that Julia noted as exceptional in relation to her general experience of healthcare professionals. The dehumanisation that Julia experienced in the healthcare sector is part and parcel of bureaucracy more generally. Dehumanisation, Bauman (2000: 103) noted, “is inextricably related to the most essential, rationalizing tendency of modern bureaucracy”. This is made possible through distantiation and reducing the ‘object’ of bureaucratic practice to quantitative measurements (Bauman 2000:102-103). By exploring Julia’s case, it is possible to see how dehumanisation is connected to psycho-emotional disablism within the welfare state.

7.2 Navigating welfare bureaucracy

While the preceding section documented the impact on bureaucracy for my participants, this section will explore how my disabled participants engaged with welfare bureaucracy. Although the extent to which participants engaged with welfare bureaucracy varied, the general trend could be summarised in four stages. These were 1) understanding the system and submitting the first application, 2) rejections and appeals, 3) successful applications, and even 4) avoiding applying in the first place as a result of prior experience. These four stages will be focused on to illustrate *how* bureaucracy influenced the participants of this research beyond the general impact highlighted above. This section will elucidate that there are barriers for disabled people in accessing welfare services and support at each of stage.

7.2.1 Understanding the welfare system

The Swedish welfare system is notoriously opaque. Sweden has a long tradition of strong professionalised state bureaucracies (Blomqvist, 2004: 143) and with the expansion of the welfare state in the post-war period, bureaucracy naturally flourished alongside it. The result is that the Swedish welfare state has a sophisticated bureaucratic structure – the impact of which is seemingly everywhere and nowhere all at once. On an everyday level, this meant that the welfare system and navigating its bureaucracy was difficult, challenging, and frustrating. No one I interviewed for this thesis described the system as accessible and sensible. Understanding the system and what ‘benefits’ to apply for was for every participant a massive undertaking and far from easy. Information about services and support was not easily accessible to disabled people and often awareness or knowledge of potential resources depended upon social networks and informal advice.

Anna shared how she found applying for services and support in her interview. Her mother was a significant source of support and help for her during the application process. When Anna had read that there was a service that she might find useful, she asked her mother to check if their municipality offered it. Anna’s mother was initially told that it was not available in their municipality, but she later found out that this was not true:

> Then, it was my psychologist at the hospital, she had another patient that had been granted accommodation assistance and had applied for it, and then she told me that ‘well it seems to exist, should we look it up?’ and then it turns out that it did exist.

While these personal networks and informal advice was essential for many to navigate the Swedish welfare system, it did not necessarily mean that the information that was generated was accurate. This is not a comment on those networks, it is an indictment on the enigmatic nature of the welfare state. Anna’s impairment effects did not significantly impact her ability to navigate the welfare state, but for those whose impairment effects did impact their ability to navigate the welfare system, it in practice meant that their parents had to manage the entire process. Helena and her parents were noted in chapter 5, but this was also the case for Patricia, who was not sure what ‘benefits’ precisely she had access to as these were entirely managed by her parents. Overall, however, it is clear that the first barrier for disabled people accessing welfare services and support is information about the application procedure and the knowledge of what to apply for in the first place.

7.2.2 Rejections and appeals

Once an application has been made, there is a waiting period in which the decision is made. Sometimes, the initial response to filling out an application for a disability-related 'benefit' was rejection. Anna applied for sick leave, but her application was initially denied because of a technicality; she had quit her university course before she had applied for sick leave and she had not known that while at university she had a right to apply for sick leave. Anna recounted the consequences of that decision:

> I went two years without compensation. So money that I had saved with the idea that 'yeah maybe build a house sometime in the future' – that I got to live up [laugh]. It was very very – but I have my mum and […] and she works with well.. she keeps an eye on stuff like that and she and helped me a lot with all of that and finally it was solved. But it was very difficult to get in the beginning and it is a small struggle every year when one has to reapply.

To manage in the wake of a rejection, many participants lost their financial security and future plans in order to make ends meet. Even here, family members were again highlighted as a crucial touchstone in what was a tumultuous time. The consequences of receiving a rejection, as Anna's comments makes clear, often resulted in the financial status of that person to disintegrate and it was psychologically distressing for many participants. For Karin, her rejection for sick leave and subsequent 'outinsurance' (she was kicked out of the welfare system entirely due to the 'too long' duration of her sick leave) fuelled her emotional distress so significantly that she struggled to recall the details:

> There was a very short period where I was outinsured, when I had to go to The Swedish Public Employment Service and register and… and then I would get… I don't remember exactly because it was such a messy period but I know that I was there for some meeting and there was going to be some form of assessment but then I think it took longer than expected and then it wasn't really done because they then came to the conclusion that I had sent in the correct papers and medical certificates so it hadn't been necessary to start with. It was really messy and really weird and I did not feel good at all because I remember pretty poorly actually

Interviews I carried out with welfare professionals indicated that while Karin struggled to remember details of her experience, her situation was far from unusual. Marina, a welfare professional, remarked that it was common for disabled people to have their applications rejected and that it was an incredible undertaking to even begin the appeal:

> it is an incredible process. There is writing, it is being sent to administrative law, then it is going to be communicated – yeah, you know, it is a long process and if one is old or ill or have a learning disability [*begåvningsfunktionsnedsättning*], it is not so easy in this administration jungle, it isn't.

The work required to manage an appeal provides a significant barrier for disabled people without sufficient support. Because of the arduous process and the situation that the applicant might find themselves in at the time, it might not be possible or desirable to start a lengthy process of appeal. Rejections are obvious barriers to access, and while there are of course grounds on which rejections can be legitimate, some examples provided by participants indicated that it was common for applications to get rejected on shaky grounds – an incorrect date, an insufficiently specific medical certificate, or a medical academic journal hypothesising that maybe a medical condition could potentially improve (which there was no way of knowing).

A more accessible alternative than outright rejection for many of the participants I spoke to would be requests for amendments. Instead, coupled with the incredible process of appealing a decision, rejections constitute an especially difficult barrier to access for disabled people. This is not just because of the emotional investment and time required but, as Marina highlighted, the appeal process itself can be particularly inaccessible due to some impairment effects. In this way, the appeals process is filled with barriers and, thus, it is not a stage of the process that is freely accessible to disabled people. Even if impairment effects are not an issue, other factors such as financial resources or a useful social network were usually needed to successfully navigate an appeal.

7.2.3 Successful applications and forced allocation

While rejections were common to welfare ‘benefit’ applications, there were also stories of successful applications. This is to be expected as the recruitment criteria, highlighted in chapter 4, required having had or having access to some form of disability-related welfare support. In fact, some participants did not experience any significant issue with applying for disability-related welfare services and support. As highlighted in chapter 5, a degree of this had to do with the timing of the application. Magdalena had a permanent decision since before the 1980s. Margareta, like Magdalena, applied for her benefit before the 1990s and she applied for a relatively low amount and felt like there was no major issue with her application. These stories of incredible bureaucratic ease, however, were very much the exception to the rule. In addition, it was not just that some people had a successful award of welfare services and support, some was forcibly allocated.

Sunetra was forcibly allocated welfare services following the birth of her son. As far as she could gather, this was because there was an assumption that she was a threat to her son on account of her Asperger’s and would thus ‘struggle to emotionally connect to him’:

> Had I said no, they would have taken my son away from me. […] So I didn’t have much of a choice. […] I didn’t get to go home from the maternity ward until everything was arranged because they threatened with ‘if you don’t do this, you won’t get to have your son’.

Sunetra was called to coordination meetings with a range of representatives from several welfare services where they mapped out services that she would be allocated. To this day, she is not exactly sure who was at that meeting or what they agreed to because the minutes are classified and she cannot access them. When she challenged the grounds for secrecy, an official apparently told her that the documents were classified so she could not challenge the decision.

This is addressed because it is important to acknowledge the complicated relationship between disabled people and the welfare state, as noted in chapter 3. The welfare state is simultaneously the result of progressive campaigns/protests and a tool of repression (Bourdieu, 2004a: 33). It is particularly evident in the case of disabled people where the welfare state, for example, were key enactors of forced sterilisation. This historical tendency has left a legacy and elements of this form of oppression linger. On the other hand, what becomes clear from the consequences of austerity in Europe and elsewhere is that welfare services and resources are key for many disabled people to live full and equal lives. These two aspects are not mutually exclusive. This duality of the welfare state is embedded within it. In fact, there also seemed to be a duality playing out in relation to disabled people and welfare services and support. Maria, a psychologist at a rehabilitation centre, argued that she felt as if there were “two tracks” for disabled people within the welfare state:

> On the one hand, there are these people that [the welfare state] wants to get pushed out from the labour market because they have too great difficulties or too great – we think that that they sometimes still would manage only if one could create this ‘something’ so. So partly [the welfare state] wants to push out, because one does not really get them into anything but then there are also those that we see that – that [the welfare state] wants still to get them in somehow in the system of society – then we have those others, where we see, but where it is very difficult for them to get what we feel they reasonably should have, so it is almost like there are two tracks.

What she is saying that there seems to be two ways in which disabled people are treated: either forced out to the labour market or kept on welfare services and support. This echoes the dual tendency of the welfare state as noted by Bourdieu. What Maria also noted is that there is probably potential to enable disabled people into employment if the state was willing to help make things more accessible. This is a view that is compatible with a pre-neoliberal conceptualisation of the role of the state and the relationship between disabled people and employment will be further explored in chapter 8.

While the majority of the participants were to varying degrees belonging to the former category, Sunetra belonged to the other category, who were prevented from exploring other options such as paid employment and had no choice in whether or not she was to have welfare services and support. This was also something that she reflected upon in her interview. She found it strange that in a situation where most people struggle to get adequate support, she had had support thrust upon her without her consent. Thus, while stories of struggling to navigate the welfare bureaucratic system were the norm of this research, it is important to acknowledge that not all allocated services and support are ‘success’ stories. Sunetra’s story demonstrates the extent to which welfare bureaucracy can insert itself into a disabled person’s life.

7.2.4 Avoid applying

This section has so far explored three different stages of welfare bureaucracy that disabled people face when attempting to access disability-related welfare services and support. Beyond these, there is a crucial final stage that is important to consider: namely, the reluctance to apply for services. This section will explore this phenomenon. This was a frequent technique of how people ‘managed’ the extensive bureaucratic undertakings inherent in applying for welfare support, partially outlined in chapter 5.

The reasons why participants did not apply for services that they were eligible for varied considerably. Eva avoided applying for new aids because she found that the process by which the aids were assessed was invasive and embarrassing. Hanna could apply for some extra money to help her with the additional costs associated with her impairment but because of the amount of effort and the relatively low compensation level, she decided not to apply as there were other services that were more pressing for her. As demonstrated in the previous chapter, the people helping Katja out were abusive, so she cancelled her service and did not reapply. BJ received an inheritance, which meant that she could stop relying on services she found intrusive and the inheritance enabled her to reduce her contact with the Social Insurance Agency. These are just some of the very many examples where participants withdrew or avoided services because of the hassle and work associated with it. That the bureaucratic process of applying and receiving benefits was riddled with problems was noted by Tobias, who said that “one always has problems with the Social Insurance Agency, there is nothing that goes smoothly there”.

It should be noted that this did not mean that the participants did not have a need for these services or that they would not make things easier for them – it was rather that the cost of applying was deemed too great for the relative low reward. Thus, even when they were aware that they were eligible for some support, they could decide not to apply for something. For Hanna, who recently became reliant upon disability-related welfare services, had a negative experience of the process of trying to navigate bureaucracies and felt that non-disabled Swedish people had little awareness of what it meant to be a disabled person who is reliant on welfare support:

> … people should actually know what it means to get one's money paid out by The Social Insurance Agency, how big of a change that is and… […] how it is living from month to month, how it is that… yeah well this whole thing about feeling like you don't have power over your own life but that you all the time have to hope that people – others – decide the correct things for you

This goes back to what was pointed out in chapter 5. Being a disabled person who is reliant on welfare services in Sweden meant that significant aspects of your life and its quality becomes determined by the state and the individual has little influence. Ultimately, Hanna felt that for welfare professionals, "I can imagine that it is easy to become a bit – what's it called? Jaded? – when one works with it – yeah yeah this is just casefile number blah blah – but this is what it is like, this is a life". The dehumanization that Julia felt going through bureaucratic processes was something that Hanna also noted. By reducing a person's needs or standard of living to abstract quantifiable measurements, the humanity of welfare applicants gets ignored and side-lined.

Further, because of the degree and the nature of the need that disabled people have on welfare services, it is more difficult for them to challenge the bureaucratic system. There are multiple barriers erected to dissuade disabled people from applying or accessing services within the bureaucratic system. This section has dealt with each of these in turn. What it has found is that the most significant barriers within the bureaucratic process is knowledge of the system, understanding and managing appeals and these barriers are so significant that many participants chose to avoid applying for support. While the majority of the participants struggled to access sufficient support, it is also important to note that there were also participants who were forcibly allocated welfare services and support. This duality in the treatment of disabled people was something that

Maria saw as part of the welfare system, effectively making it a ‘two track’ system, where you were treated differently depending on where you found yourself within the system.

7.3 Professionals’ perspectives on disability ‘benefits’

Karin’s story from earlier in the chapter is an important reminder that when rejections from the welfare state occur, they can exacerbate mental distress and it may affect a person’s recall of events. For this reason, I thought interviewing welfare professionals would allow me a good window into how common rejected applications were and how they impacted disabled people, who might not be in a position to speak to me directly. It also allowed me the opportunity to understand, from their perspective, how they viewed the expansion of austerity in Sweden. This is particularly important because of the important role that bureaucratisation has played with regards to the implementation of austerity. Consequently, this section will explore how welfare professionals understand the changes that have occurred within the welfare state, how they view disability-related services and support like LSS, and what are the current ‘problems’ facing the welfare state. Exploring this will allow me to elucidate more clearly the tension that Stone (1984) noted of disability as an administrative category and disability as a lived experience. This will give insight into how welfare professionals reconcile this tension inherent in their jobs.

7.3.1 The impact of changes for welfare professionals

Much of what the welfare professionals divulged in the interviews for this thesis corroborates the stories offered by disabled participants – that the welfare system had become much stricter and difficult to navigate for disabled people and that people were given access to fewer resources, which put many disabled people in financially precarious positions. The interviews also underscored the effects of changes on professionals’ role in the system. Goodrich felt like the overall changes to the welfare state, which were outlined in chapter 3, had been noticeable in his job:

> There have been many cuts and stuff like that and on the one hand it is more difficult to get help at all and when I started to work within the social services 25 years ago, then it was considerably easier to get help from the municipalities with different services and it was much less controls and stuff like that.

He attributed the change to municipalities having fewer economic resources and that this worsened financial situation “forced [the municipality] to decrease [services] and have much harsher checks”.

Overwhelmingly, the caseworkers and professionals indicated that with the pressure of ‘harsher checks’ there were increasing levels of paperwork and more frequent follow-ups on approved applications. According to the interviews, this coincided with decreases in staffing at many locations. Lina noted that in her workplace “we are fewer staff than we were before” and this had implications for what they were able to offer people who came to the rehabilitation centre. She was unaware of how much other organisations had cut but they would get notifications from the Swedish Public Employment Service or the Social Insurance Agency that “it was a resource that we had before, but that does not exist any more and now we are going to do this in this way instead, and then it does not exist” (Lina).

Many of the professionals I interviewed expressed a displeasure at the decrease in staffing and the increased pressure on checking decisions. This was predominantly because these changes meant that they saw far fewer clients in person and instead spent a majority of their time filling out forms. This occurred while there was a structural pressure to see more people, Erika noted. Erika had purposefully taken the new guidelines to mean that she was meant to have more in-depth conversations with ‘clients’ and resource providers, but this was not a common perception. Other colleagues took the new guidelines to mean that the follow-up requirement for approved applications could be fulfilled by a monthly call to the service provider (and thus not speaking to the ‘client’). What these changes meant in practice was that welfare professionals spend considerably less time supporting and guiding disabled people through the application process. As noted previously in this chapter, knowledge and awareness of the welfare system is difficult to gain and the lack of that knowledge is a significant barrier for disabled people to access welfare resources. Thus, we can see how the increase in administrative tasks and fewer employees worsens disabled people's access to welfare services.

Erika associated this with the expansion of NPM measures in the welfare sector, "that one should count hours, how many contacts one has and so on, these latest years anyway". The expansion of new public management has occurred in Sweden and has been noted in Werne (2014), Svanborg-Sjövall (2014) and Werne and Fumarola Unsgaard (2014). This corresponds to observations made by Hoggett (2005: 186) that the consequence of NPM is that "the ethical and moral foundation of public service has been suppressed more completely than in any equivalent state. Efficiency rules, and the de-moralization of public office have brought about a deep-seated demoralization of the public service workforce". Though the demoralisation is not complete, as the data for this thesis suggests. The welfare workers that were interviewed for this thesis often expressed anger and dissatisfaction with the current situation in their chosen fields. Nevertheless, while they had noticed a shift with the intensification of austerity and its effects on disabled people, they mostly noted changes to their work practices.

7.3.2 LSS uncertainty

LSS is a key form of provision for many disabled people. As highlighted in chapter 1 and 3, it was implemented during a recession in the 1990s and it has higher aspiration levels than SoL. This is because while SoL aims to provide a 'reasonable' standard of living, LSS aims to provide a 'good' living standard (Lindqvist, 2000: 410). Throughout the interviews, the importance of LSS cannot be understated. For disabled people who were around before its implementation, it had changed living conditions significantly. Welfare professionals and disability organisations highlighted its importance when it came to promoting disabled people's inclusion in society. For some people, like Goodrich, LSS embodied the kind of 'generous' welfare provision that, in his view, made Sweden better at providing for disabled people than other countries. While it has been viewed positively, the welfare professionals I interviewed found the legislation incredibly difficult to navigate and it is this aspect that this section will explore.

The most surprising and equally most prominent theme that emerged from discussions with welfare professionals was the degree to which LSS legislation was seen as difficult and opaque. That it presented as such for disabled people is not surprising, but it was unexpected that this wold be a sentiment that welfare professionals shared with disabled people. The greatest source of confusion was for many caseworkers the third eligibility criteria – impairments which are “great and prolonged” (Elsa). Even though Marina had worked for over ten years with LSS legislation, she still found it difficult to navigate:

> It is probably because I think LSS is difficult myself. Now I’ve worked with it for 10 years.[…] but almost all LSS caseworkers say that – it is not easy… to understand all the time. […] It is almost like reading the Bible, you understand, it depends on what interpretations you bring to it.

Echoing that sentiment, Maria also noted that there was a profound misunderstanding of LSS between various welfare professionals. She had in her professional capacity met a number of people who had been assigned an autism diagnosis because other welfare professionals thought it would make it easier for them to “get a bunch of stuff” (Maria). This perception, however, was and is not in line with what LSS offers disabled people and the notion that it was more ‘generous’ than other services was something she challenged in her interview.

In hearing from professionals, it soon became clear that they are asked to reconcile almost Kafka-esque eligibility criteria and it is thus not surprising that the legislation felt elusive and difficult. The third eligibility criteria, defined in chapter 1, may appear straightforward at first glance, but it prompts a number of questions. Elsa outlined some of these in her interview:

> Is it prolonged? And already there, it turns into, ‘OK what is prolonged?’. The prepatory work says it cannot be of a transitory type, ehm, not temporary or transitory but it does not need to be life-long either, sort of. No, ok, where does one end up then? What does that mean? OK, then one has to go and check, OK, what does the court judgements say? What does the courts say and then one is supposed to do kind of judgement that what does the doctor say? Often the doctors say […] ‘we don’t know, it is not possible to say what the prognosis is and one is like ‘yeah but come on give me a little bit more here’ [laugh] […] Then maybe one has decided that it is prolonged, then one has to decide, is it great? And then

> one is supposed to make the judgement if those significant difficulties lead to a great need of support and services.

Determining what is prolonged but not temporary or transitory but not necessarily permanent is not an easy task. The subsequent issue is then how to balance interpretations made by courts and those made by physicians and physicians are notoriously cautious in giving predictions. That bureaucratic processes overestimate the ‘certainty’ of medical prognoses in the case of disability was something that Stone (1984) reflected on and the tension here becomes plain. Doctors are often reluctant to make predictions, but the welfare system requires future estimations in order to assess eligibility.

Once these aspects are determined, the question remains whether the identified impairment results in a great need. Reliance on court decisions, for example, can be problematic as they have been the main enforcers of austerity but also the guidance that resulted from those court rulings originated from welfare bureaucratic praxis rather than the legislation itself (as explored in chapter 3). In light of these aspects, it is not surprising that bureaucratic assessments are influenced by subjective assessments and judgements in interpreting guidelines.

While Goodrich in the previous chapter noted that he found personal assistance an easy service to evaluate, this was not shared by other caseworkers. Elsa found making decisions on personal assistance particularly difficult because she was located in a small municipality and only dealt with a handful of cases each year. For those who worked in larger municipalities, they would have a team dedicated to just personal assistance applications, for example, and they would have greater peer support when it came to determining eligibility or sharing experiences. This also meant that caseworkers that worked in larger municipalities had a much more fragmented way of working than those in smaller municipalities, who dealt with a multitude of claims, often both covering LSS and SoL claims.

Highlighting this confusion and opaqueness surrounding the legislation is important because it shows that it is not just disabled people who are confused by the system; this confusion also extends to welfare professionals, who struggle to interpret vague guidelines. Guidelines became even more vague with the intensification of austerity in the early 2000s, as there were continuous shifting directions given to welfare professionals. Maria said that she had tried to figure out on what basis directions had changed but had not been able to find any concrete evidence and instead had to rely heavily on word of mouth regarding the nature of the new guidelines. Since this was such a prominent issue among various participant groups, this will be analysed and expanded upon further on in this chapter. The evidently structural nature of this confusion cannot be divorced from the bureaucratic process and its role within in the process needs to be understood. I argue that the bureaucratic process structurally produces ‘un-knowing’, which is the opposite of knowledge.

7.4 Knowledge of the system

By exploring the experience and perspective on welfare bureaucracy from two participant groups – disabled people and welfare professionals – a significant theme has emerged as common between the two groups. This is confusion and uncertainty. As a consequence, it is important to explore this uncertainty or ‘unawareness’ and what this might mean sociologically. That the welfare state is opaque is not a new phenomenon – indeed, it is built into the nature of the welfare system and its bureaucracy. Lipsky (2010: 64) observed the following:

> Most clients would like to know more about how to negotiate the system, but this information is rarely provided to all clients. Rather, street-level bureaucrats exercise discretion by providing this information on a selective basis. This becomes one of the few ways they are able to favor [*sic*] clients without directly abridging bureaucratic norms of fairness. They make no decisions in favor [*sic*] of one client over another. They simply inform clients selectively how to utilise the system to best advantage. Thus they respect fairness in decision making; it is only information that is selectively distributed.

I have also already noted in chapter 5 and in this chapter that knowledge of the welfare system was an important factor in navigating or ‘managing’ bureaucracy. Equally, the distribution and importance of knowledge is something that has been frequently explored in sociological literature. Hart (1971) noted with his inverse care laws that knowledge of bureaucratic norms disproportionately favour middle-class people.

Stories of welfare professionals failing to disclose other services that disabled people were eligible to apply for were, as this chapter has shown, common. This is also something that has been observed in literature (Lipsky, 2010: 65). In chapter 5, the vital role that family members and social networks played in being able to ‘manage’ the effects of austerity were highlighted. They are also central in ‘managing’ the welfare state. In that chapter, I mentioned Helena and her parents, who had little experience of the welfare system prior to having their daughter. This had a significant impact on their ability to navigate the welfare system and while the process is continuous and on-going, they characterised it as a situation with a ‘steep learning curve’. However, Helena and her parents were not alone with this experience of the welfare system. People with no prior knowledge of the welfare system told stories of how once their application had been rejected, they had not been signposted to other services that they could be eligible for. This had the result of placing those disabled people in positions of quite significant financial hardship.

People with an extensive knowledge of the welfare system and how it operated, however, had a different experience. They were not only more comfortable challenging problematic questions by welfare professionals, but they were also much more able to, for example, challenge medical certificates and tell the doctor to redo them if they did not meet the standard for the service that they were applying for. This was the case for Louise. Louise had extensive knowledge of how various welfare benefits operated prior to acquiring an impairment so she was able to often successfully challenge professionals when she was given insufficient advice or assistance. Practical experience and expertise were also resources that could help offset poor execution of welfare services. For example, when Li had poor and insufficient care from a long-term hospital stay, her mother – who is a trained nurse – could alleviate the consequences of the hospital’s poor treatment of her daughter. This kind of practical knowledge could often serve to alleviate the consequences of poor services and minimise the impact to the individual, but it can only do so much. Li, who had multiple impairments that had a significant impact on her health, ultimately died as a result of poorly coordinated healthcare services. Because of the degree of specialisation within the healthcare services and the lack of coordination between different areas, a life-threatening condition was not caught in time and Li passed away.

7.4.1 The structural production of ‘un-knowledge’ in bureaucracies

Consequently, having established that knowledge is important in order to navigate the bureaucracies, questions remain with regards to the confusion and opaqueness that even the welfare professionals experienced regarding the welfare system. This is even more surprising as they are ostensibly the ‘experts’ with regards to welfare bureaucracy. As noted, the role of knowledge within the welfare state has been written about but what is not known or how things become ‘unknowable’ is not equally explored. This is also reflected in language. The opposite to knowledge could be argued to be ‘ignorance’ but this word has pejorative connotations and does not fully capture any potential structural element of the term. The closest term that I can consider as reflecting the opposite of knowledge would be ‘un-knowledge’ and thus this will be the term used to denote this throughout the rest of this chapter.

It could be argued that the opaqueness of the welfare state could be easily explained by its size and that the puzzlement of welfare professionals could be chalked up to simple confusion. Stopping the explanation here, however, I think is an insufficient sociological answer to this phenomenon. It is far too common and widespread to adequately suffice as an answer. Capital demonstrates how privileges such as ‘acceptable’ tastes and knowledge is structurally produced (Bourdieu, 2008). If knowledge is structurally distributed, it follows that its adverse – ‘un-knowledge’ – can also be structurally produced. Also, to suggest that its production can be explained by the absence of (for example) relevant legitimised capitals is also not sufficient. This would explain why disabled people might struggle to understand the welfare system but not why welfare professionals, who ostensibly appear to have every tool at their disposal, also struggle to comprehend welfare bureaucracy.

Why is this important to acknowledge? Quite simply because 'un-knowledge' is fundamental in maintaining and reproducing structural inequality, as Cohen (2001: 5) observed:

> The political echoes of these states of mind [un-knowledge] may be found in the mass denial so characteristic of repressive, racist and colonial states. Dominant groups seem uncannily able to shut out or ignore the injustice and suffering around them. In more democratic societies, people shut out the results not because of coercion but out of cultural habit – turning a blind eye to the visible reminders of homelessness, deprivation, poverty and urban decay

Bauman (2000: 95) also pointed out that the invisibility of Holocaust victims was essential to protect individuals' sense of morality; it decreases the risk of them having a crisis of virtue. Knowledge about oppressed populations thus become hidden, remote, and 'unknown' to the general population in bureaucratic societies. Distantiation and dehumanisation is something that I noted earlier as being part of bureaucratic rationality, but this is not fully achieved without un-knowledge accompanying this as a method of achieving distantiation and dehumanisation on a macro level. While this is applying the question of un-knowledge to a structural level, this is revealing because it highlights the structural element of un-knowledge and it also provides an understanding of how un-knowledge operates on subsequent levels.

Un-knowledge is also produced at a meso level. This is inherent in bureaucratic practice and can be seen as part of the rationalisation process within bureaucracies. Cohen (2001: 6) argues that codes of secrecy and silence on issues is done to "prevent outsiders knowing about discreditable information; there are unspoken arrangements for concerted or strategic ignorance. It may be convenient not to know exactly what your superiors or subordinates are doing". Importantly, this is not to say that welfare professionals always *choose* to be silent or not know about potential issues but rather that their way of working is structured in such a way to produce a kind of bureaucratic un-knowledge. Another example of this is also visible in the difficulty in discerning the impact of austerity on disabled people through statistics in Sweden. The way that compensations levels are calculated, as noted in chapter 3, are so opaque and individualised, it is difficult to discern more widely. Additionally, because of how austerity has been implemented, it is difficult to assign a direct cause or change in order to make that information statistically valuable. The role and importance of un-knowledge is therefore particularly important in times of austerity.

Bureaucratic un-knowledge is essential to the welfare state through the rationalisation process. Rationalisation is a dominant feature of bureaucratic philosophy and, in relation to the topic at hand, it can be keenly visible through the application decisions made by caseworkers. Rationalisation, according to Cohen (2001: 8), is “not a refusal to acknowledge reality, but a denial of its significance or implications”. Rationalisation process within the bureaucratic system helps render bureaucratic actions adiaphoric, ‘neutral’ against technical values (Bauman, 1991: 144). This can be seen in the previous chapter on cost, where what is ‘credible’ in an application was a source of concern for some caseworkers and eligibility was not seen as connected to the ‘cost’ discourse they critiqued. This distances the welfare professional from the decision and the roles that they play, where the pressures to consider ‘costs’ linger yet far enough away to resist.

Because of the distantiation and dehumanisation of the ‘objects’ of bureaucratic rationality, where (for example) railway managers “do not deal with humans, sheep, or barbed wire; they only deal with the cargo, and this means an entity consisting entirely of measurements and devoid of quality” (Bauman, 2000: 102–103), the cost of austerity is rendered a distant ‘unknown’, something which is structurally removed from sight and consideration. The human cost of austerity measures becomes external to the process itself and, thus, separate from the tasks of the bureaucrat. Disabled people, who are the objects of bureaucratic management, become in this equation ‘unknown’. For this reason, it is important to take the structural production of un-knowledge seriously. The separation that occurs is key in stripping benefit applicant of their humanity and maintain the ‘rational’ integrity of the bureaucratic process. It is worth noting, however, that this separation is muddled and complex in the case of the welfare professionals I interviewed. Many of them were critiquing the extensive bureaucratic procedures that were enacted to ensure ‘quality’ and ‘reliability’ as counterintuitive and invasive. It is worth noting, however, that most of those who critiqued this were people who were not caseworkers but worked in other aspects of disability-related welfare services, such as psychologists or physiotherapists. Thus, there are indications that the structural production of un-knowing is produced equally across the welfare state but dependent upon context and location in the welfare system.

By recognising how un-knowledge is produced and its relationship to rationalisation in particular, it allows us to understand the confusion of the welfare professionals regarding the welfare system more clearly. The vagueness of the LSS legislation that confused them is in some ways due to how eligibility criteria is defined within the Swedish welfare state, as previously argued, but it is also (I argue) due to the way in which rationalisation produces things, events, or people which are ‘unknowable’. It helps conceal the impact of austerity and the impartiality and technocratic view of the welfare state can be maintained. This is important because it is the ‘impartiality’ of bureaucracy and the idea of due process that “legitimizes the effects the judicial and legal system has on people’s lives. Similarly, the norm of fair treatment in public agencies combines with the theoretical right to appeal to legitimize the actions of administrative agencies” (Lipsky, 2010: 43). Recognising that un-knowledge is not merely a natural state resulting from the absence of knowledge, but also structurally produced has wide-ranging consequences, which will be discussed in the conclusion of this thesis.

7.5 Conclusion

This chapter has explored the issue of welfare bureaucracy through the perspective of two participant groups: disabled people and welfare professionals. It has demonstrated how disabled people have navigated welfare bureaucracy and how it has impacted them. As in chapter 5, the expansion of welfare bureaucracy following austerity has impacted the disabled participants in the sense that it increased the precarity they experienced and exacerbated feelings of fear and anxiousness, due to the opaqueness and uncertainty of the welfare bureaucratic process. In this chapter, I explored in more detail in what ways disabled participants engaged with welfare bureaucracy and found that at each stage there were barriers for disabled people. These were not just in terms of understanding the system but also present in for example being able to appeal decisions. A significant way in which participants responded to the uncertainty, and the psycho-emotional disablism that the process caused, was by avoiding to apply for services if they could. This practically meant that needs were unfulfilled, fulfilled informally by family members, or other financial resources were utilised to avoid the hassle associated with welfare bureaucracy. The implications of this will be explored further in the conclusion of this thesis.

For welfare professionals, the most notable change that had occurred with the expansion of austerity was the changes in work patterns and the type of work they primarily engaged in. As a result, the outcome of the tension between disability as a lived experience and disability as an administrative category was chiefly resolved for the caseworkers by focusing on the practical tasks. The most surprising aspect is that even these participants, who are ‘elite’ participants and arguably ‘experts’ of the welfare system, were uncertain and hesitant towards disability-related welfare services and found them difficult and confusing. Due to the consistent theme of uncertainty and confusion present among both participant groups, I argue it is important to take the structural production of un-knowing seriously. This is not just because of its prevalence but also because of how it fits in with issues around rationalisation, which is a key characteristic in bureaucracies. This will be explored further in the conclusion of this thesis.

8. Disability and employment

Encouraging employment has been a key theme in justifying austerity measures, as chapter 3 demonstrated, and in chapter 6, I argued that the Social Insurance Agency viewed employment-enhancing expenditure as an 'investment'. This characterisation of expenditure reveals a positive attitude towards that expense. This was in sharp contrast to the view that the agency took towards expenditure related to non-employment-based forms of support, for example sick leave. Thus, employment plays an important part for the agency that is qualitatively different from, for example, the role of personal assistance or sick leave. Because of the centrality of employment in rhetoric and due to its frequent discussion in my interviews, it needs to be explored for this thesis. This will help answer all three of my research aims.

As noted in chapter three, the role of employment is also important to understand in relation to the Swedish welfare state, especially as the role of employment within the Swedish welfare state can be misunderstood. Esping-Andersen (1996: 43) argued that the goal of the social democratic welfare model was de-commodification, which "occurs when a service is rendered as a matter of right, and when a person can maintain a livelihood without reliance on the market". This would suggest that services are distributed independently of labour market participation. This, however, misrepresents the view and role of employment within the Swedish welfare system. Hort (2014a: 258) pointed to the fact that the relationship between employment and welfare provision has been more complicated than Esping-Andersen's work implies:

> Have social welfare benefits been characterised by less generosity and harsher tests since the 1980s? Has more emphasis been placed on the recipient's willingness to work? […] in one sense, these questions are wrongly phrased for Sweden. The fact is that Swedish welfare policy has always been keen on readiness to work. Social policy must pay at all times.

What Hort argues is that enabling employment has always been a central component to the Swedish welfare state. The (supposed) generosity of the Swedish welfare state was not just created out of a will to promote social justice but it was also because it was seen as “a valuable contribution to the competitiveness of the Scandinavian economies” (Brandal et al, 2013: 11–12). The ‘investments’ made in the welfare state after the Second World War and until the 1980s were done to generate a more ‘competitive’ workforce. In light of this, the relationship between employment and welfare ‘benefits’ can be understood in Sweden as a form of ‘workfare’, which is not just a result of recent welfare changes but from a long-standing philosophy that reforms need to be financed (Hort, 2014a). Indeed, Trägårdh (1990: 580) suggested that “the egalitarian thrust of Swedish society is in fact partly offset by a desire to reward hard work”.

Beyond the welfare state, employment is also an important issue of equality. In our current capitalist system, employment is one of the most effective ways to generate an income and a research report by the Swedish Public Employment Service (Arbetsmarknadsrapport, 2018: 13) demonstrates that disabled people (or as the report defined it, “people with a decrease in function which means a decrease in work ability”) are among the groups that run the highest risk of long-term unemployment. A noteworthy observation about this report is that when it accounts for who contacts the Swedish Public Employment Service, they lack information on disabled people but have information on other significantly disadvantaged groups – those with pre-high school education, people born outwith Europe, and elderly people (Arbetsmarknadsrapport, 2018: 26). Employment was also a frequent reference point for all of the participant groups in their interviews. Equally, as chapter 6 and this chapter so far has made clear, increasing participation of disabled people in employment is a key concern of governmental bodies. Despite the broad enthusiasm and concern over disabled people’s employment status, employment for disabled people is not equal to non-disabled people.

This chapter will explore the complicated relationship between disabled people, impairments, and employment in a capitalist economy. I will do this by first by accounting for the perspectives offered by two participant groups on the issue of employment. These are disability organisation representatives and disabled people. I will first account for the perspective of disability organisations and how they viewed employment. This will show how they were frustrated by political inaction and how they were reluctant to address issues related to welfare due to a desire to focus on ‘rights’, a shift in which employment plays a central part. They also criticised existing employment support available to disabled people. Despite this, their criticisms and concerns mirror much of the government rhetoric regarding employment. Secondly, this chapter will explore how disabled people viewed employment. This section will show how employment has both empowering and oppressive aspects. All disabled participants viewed employment as a good thing and saw it as key to contributing in society, but for disabled people who saw themselves as unable to enter into paid employment, the mechanisms within the welfare system to encourage employment felt punitive. This will help shed light on some of the inherent complexities embedded in the question of employment for disabled people and its moral connotations and will result in a discussion about the nature of employment.

8.1 Disability organisations and employment

Just as employment was a central issue for governments, employment was a key focus for the disability organisation representatives that I interviewed for this thesis. This section will explore the issue of employment as understood from their perspective. What will emerge from this exploration is that disability organisation representatives regarded employment as a ‘right’ and the consequences of austerity was seen as a ‘welfare issue’. Thus, employment and austerity measures were conceptualised as distinct from each other, even if there was some recognition that there was a tangential connection. This section will help to illuminate contributing factors to the response to austerity from representative bodies and to illustrate the tensions inherent within the issue of employment for disabled people.

The representatives I interviewed from various disability organisations placed significant importance on the issue of employment. Rasmus, the president of DHR, viewed the issue of work as a central component to the inclusion of disabled people:

> It is about the clarity that we as an organisation – the ideology that we advocate for- we have to be clear by saying that – […] people with disabilities want a job just like everyone, want to be active like everyone else, there is no difference generally speaking in how human beings are in that way. And.. on the other hand, there is a bigger difficulty in getting into the labour market if one has more worries [impairments] and there are more obstacles in the way and so on.

The desire for employment is something that is upheld as an indicator of the shared interests between disabled people and non-disabled people. Peter from Lika Unika even noted that the “big cause that we use as an illustration to talk about human rights is […] is the question of jobs”. As such, in both of these examples the question of employment was framed as one of ‘rights’.

8.1.1 Government inaction in relation to employment

On the face of it, it was not surprising that government rhetoric surrounding employment is overwhelmingly positive. This is also evident in areas outside the issue of ‘costs’. This discourse is also reproduced in other areas. For example, in describing a TV advert (Arbetsförmedlingen, 2018), the Swedish Public Employment Service wrote that “many with disability [*funktionsnedsättning*] today are without work. We want to get employers to deliberate differently when they recruit, and show that everyone can have a self-evident place in working life. The goal is to get more employers to utilise that competency” (Arbetsförmedlingen, 2018). Employment is regarded as an inherent good by the government – as demonstrated in a budget document where it is stated that (Prop. 2003/04:1) “being able to participate in the working life and thereby manage your own breadwinning is crucial to live a good life”.

Despite this positive attitude, disability organisational representatives were highly critical of the government in relation to employment. Peter argued that “I think one should be crazy- crazy angry over the fact that [disability] does not get mentioned when one discusses unemployment or exclusion [*utanförskapet*] in the labour market because there are so many”. This would suggest that despite the positive feelings expressed with regards to employment by both the government and disability organisations, there is a significant tension between their ostensibly identical discourses. Ramus, the president of DHR, noted of the current climate that

> we are a bit frustrated that we don’t get any traction for our most important questions, for example, the labour market question is rarely discussed- the last couple of years so have they not really discussed any new questions really – it is the same questions all the time - nothing happens in that area

What is also noticeable is that while disability organisations acknowledged to a degree that barriers to employment exist for disabled people, this had limited traction in government representations of the issue. In the television advert that was previously discussed, the Swedish Public Employment Service seeks to ‘encourage’ employers to rethink their attitudes towards hiring disabled people, focusing on the employability-potential of disabled people, while not acknowledging barriers to employment or discrimination. For example, even though the advert focused on the encouragement of employment for disabled people, any representation of employers is remarkably absent. Also absent is any representation of support aids or resources like personal assistance.

One way in which this can be understood is that while the government places their onus on the employability of disabled people, the representatives I spoke to about this issue discussed the need for government intervention or changes to policies to fulfil the goal of employment for disabled people. Here the general socio-political context in Sweden becomes highly relevant. As mentioned in chapter 3, government interventions within the labour market have drastically altered with the expansion of neoliberalism where their chief objective is now strengthening the role of private business. This may be one of the reasons why representatives felt like there had been such indifference from the government on this issue. There are, however, other contributing factors. As we shall see in the next section, the way that disabled people are constructed in relation to employment might also explain why issues around discrimination are only addressed in a limited way.

8.1.2 Work ability and the administrative concept of illness

When discussing employment, the question of work ability was also addressed. As explained in chapter 2, this is a central concept within the welfare state in relation to disability. This is because disabled people are often identified through the welfare state by their having a ‘decreased work ability’. This was something that disability organization representatives met with criticism. Peter thought characterising disabled people in this way was something that prevented politicians and others from seeing it as a social justice issue. “[By talking] about a decreased work ability as a result of [impairment] it makes the question a question of individual responsibility and medicine,” Peter sighed. Mikael argued that because of the concept of work ability “then the entrance to work becomes – what can you not do? And that is the wrong starting point if one should talk work and getting into employment”. Instead, Mikael thought that “labour market politics and supportive efforts must aim towards, er, having the opposite starting point – that is today, what does this person have in terms of resources and assets?”. But it the criticism around overemphasising the negative aspects of impairments is not something that disability organisations are alone in sharing. Chapter 2 did show that the government similarly argued that it was important to focus on the ‘ability’ of a person rather than the loss in relation to work ability (SOU 2008:66).

This question of work ability becomes particularly confusing when compared to the opposite of a decreased work ability, as Mikael noted that “it becomes tricky - what is a 100% work ability?” It is clearly premised on the idealised construction of a worker that not even non-disabled people fulfil (Paulsen, 2014). This is something that has had some reflection in disability literature – most notably in Abberley (1996), who argued that the ‘inclusion’ of disabled people is dependent upon and subordinate to the logic of production, and I will explore this in more detail later in this chapter. Crucially, however, as chapter 2 made clear, those who are identified as having a decreased work ability are characterised as ‘ill’. Thus, to completely understand the role of employment in Sweden and the criticism of work ability vis-à-vis disabled people, it becomes necessary to revisit the conflation of illness and disability in Sweden, outlined in chapter 2.

One of the by-products of the conflation of illness and disability is erasure. The extent of this erasure fairly extensive. This can be exemplified in my interview with Christine, a representative of the disability organisation STIL, who described her feelings when the Social Democratic-Green coalition was elected after eight years of bourgeois[5] rule:

> one was pretty positive… or cautiously positive anyway to this new social democratic government and that they said in the declaration of government that we are going to strengthen the right for people with disabilities and that they sort of knew that this group has been pretty harshly affected these last eight years [by] a pretty aggressive alliance [the right-wing bourgeois political parties, led by the Moderates] politics and I suppose that one thought like 'now things are changing!' sort of. 'He said disability!'

The fact that disability (more specifically, *funktionsnedsättning*) was even mentioned in a speech was considered to be a massive shift. This was something quite a few participants initially reflected upon in their interview. Despite that this was a landmark moment, it has not significantly altered the government's view of disability and disabled people. This is because of the extent to which the conflation of disability and illness is built into the welfare system.

Stone (1984) argued that the disability category was developed in order to reconcile the fact that social membership was dependent upon work but that there were those who were seen as legitimately exempt from working. Thus, disability became an administrative concept within the welfare state. This is an important concept, Stone (1984: 22) argues because "Since the categories serve to define the boundaries, they must themselves be defined in ways that contribute to a stable resolution of the tension between the work-based and the need-based systems". We can see, however, that in the absence of a conceptualisation of 'disability' in Sweden, this role is taken up by illness.

In a government document examining the concept of work ability, it stated that "since the administrative authority has a need of strictly guarding the entrance to the insurance and shut out those who do not have a right to long-term

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[5] This is a common word that is used in Sweden to describe the right-wing 'blue' political parties, thus it has no (direct) relation to the Marxist/sociological concept in this context

compensation, the picture of the illness' effects and limitations in ability becomes of central importance" (SOU 2008:66). Thus, it is more reasonable in the Swedish context to talk about *the administrative concept of illness*. In light of the fact that the body becomes the site of moral judgements (Soldatic and Meekosha, 2012: 195), it is not surprising that the way in which illness is increasingly structured is deeply shaped by neoliberal mantras of individual responsibility and choice, which is evident as the document (SOU 2008:66) continued:

> If it on the other hand in the first instance is about finding ways back to employment, *everything* that might have significance in the individual case becomes important. Things aside from what can be tied to the illness can be the most important. In that case, it is not the administrative authority but the individual who is the principal owner of the result. There can be support to gain from administrative authorities, employers, and others, but in the last and final instance, it is the individual who must take responsibility for what she/he wants and can [do]. Individualisation, difference, imagination and not to say the least, the individual's own active participation is then the most important.

If one is to make the argument that there is something 'relational' about the Swedish understanding of disability, it is clear it is highly selective. Non-medicalised factors can be invoked to encourage or justify a return to employment but not in the case of determining an exemption from the labour market. As a result, the question of a return to employment is framed as one of will rather than ability. Further, it also privileges medical interventions ahead of social solutions to get disabled people in employment. The increasing political focus on the concept of 'illness' in Sweden since the end of the 1980s also unsurprisingly coincided with increasing medicalisation (see chapter 3, but also Lindqvist, 2012: 25).

Because of the absence of disability as a concept and the reliance on 'illness', there is not the same space to carve out an understanding of disability that is not necessarily beholden to the health-illness paradigm. By framing disabled people as 'ill', it leaves the door open for questions about 'cures', 'restoring one's work ability', or, at its worst, viewing disabled people as objects of medical interventions (Oliver, 2005: 36–37). Here, the concept of work ability conforms to this framework, as Mikael remarked in his interview, "it is about a fictive picture that a human being is fully healthy and fully able to work [*arbetsför]* and become temporarily ill and temporarily decreased in work ability and then back to full work ability and fully able to work again”. In this way, non-disability becomes the unchallenged, unmentioned norm and thus indicative of the “ideology of normality” where the aim is to restore the “disabled person to normality, whatever that may mean” as highlighted by Oliver (2005: 36). The inferred ‘normality’ in these policy documents is one of an employed, work-able, non-disabled person. The association with cures in relation to illness – coupled with the entrepreneurial spirit of neoliberalism that you can ‘create your own job’ - enables the state to move away from categorical exemptions from the labour market towards rare, individualised, and highly stringent exemptions. Thus, it is not a surprise that illness became increasingly important with the implementations of austerity measures in Sweden (Lindqvist, 2012: 25) – rather they are intimately connected.

8.1.3 Rights, not welfare

As previously mentioned, disability organisations emphasised employment as a ‘rights’ issue. This, however, did not come without its tensions. Many of the representatives I spoke to were critical of the government support that was available for disabled people to increase the likelihood for them to be employed. Rasmus shared that this sometimes meant that they as an organisation took a completely different stance on issues compared to their members:

> … we sometimes get to hear from members ‘why are you so critical of the wage subsidy? It is why I can work’ for example but… […] we are pushing the issue that… if one is to value people’s labour power – ability to work and quality – that is to say the employment seeker’s qualities should be the guiding principle, not the subsidy. So the wage subsidy is a tool and not a goal.

The scepticism of the existing support was so extensive that sometimes it was characterised as part of the problem. Rasmus highlighted that with activity compensation there was “for example, automatically, you end up as a youth with a false security that you have difficulty getting out of, that you get branded with for the rest of your [working] life” so that as an organisation “we have mostly driven the question from that we should have a fair labour market, we shall work to represent people with disabilities in the labour market”. Peter argued that Lika Unika had put the focus on work because “work is the basis for much other things in life and the ability to pay or life overall what one can afford to do and so on”. He did, however, also acknowledge some shortcomings of that perspective as

> of course – does one have a real job and get good money so it doesn’t matter in some ways if one’s sitting trapped inside because one cannot access the public transport system because it is not accessible or buildings aren’t accessible or cannot be able to get information, so there are a lot of areas to acknowledge. (Peter)

In fact, when asking about the changes that have occurred in relation to sick leave and whether that was something they had worked with, there was a remarkable hesitancy to engage with sick leave and welfare-related changes. This is partly a by-product of Sweden’s treatment of disability-related issues as a question of care. This has a caused a situation where most of the representatives I spoke to felt like it was important to reframe the focus on rights rather than care or welfare. This was most clearly articulated by Peter who argued that to change things for disabled people, “it requires this change that it is not about welfare, care or patient perspectives. It is about rights”. The binary construction of these issues can thus be understood as a result of the historical dominance of treating disability as a healthcare and care issue.

Ken, the association secretary for DHR, described the feeling as the following:

> I would not- I would at least wish but then I might be wrong but to not put a parallel between that one talks about that… that even the bourgeois government was very [active] with just this about sick leave and they made it more difficult to get sick leave compensation and… and that question I hope does not have a- it is at least my wish that it would not have a connection to… what should I say? […] To contributions to people with disabilities [*funktionsnedsättning*]

This was also felt by Rasmus, who said that “we [DHR] have a tradition of not really being massively… good – or we do not want to be so superfocused on carrying issues about benefits”. He did note that they tried to work for both employment-focused efforts and welfare rights since “it is also the case that those who cannot work but must have a reasonable living standard and be able to live and have a good leisure, it is important” (Rasmus).

8.1.4 Samhall and desired employees

Even when the importance of welfare support in enabling employment was recognised, it was not without its complications. This section will explore one of those issues by focusing on the protected employment form, available to eligible disabled people, provided by Samhall. Samhall was explained in chapter 1 but it is essentially a service for disabled people who are deemed not to be able to manage the requirements of employment outside protected employment forms. Exploring this support service will illuminate another issue related to the tensions between the labour market and disabled people that occur when disabled people are in employment, not just seeking employment. The issue is that even in protected employment forms, disabled people experience discrimination and are seen as ‘less valuable’ labourers. Mikael argued that

> the supports that are aimed at people with disabilities, they were introduced in the 1980s, because then wage subsides and Samhall were created. Much of those politics and those efforts look the same today, they have not changed considerably. On the other hand, the labour market has changed extremely since then so, er, they are very blunt instruments and they are, er, generally ineffective.

In other words, certain support systems that have been erected within the welfare state to facilitate employment for disabled people have not changed to keep pace with ‘modern’ labour market requirements with more flexible work conditions and service-focus. Samhall, in Mikael’s view, did not result in disabled people entering into unsubsidised employment, but, as noted by Rasmus previously, rather tended to trap them in that support service, where employment is protected. Here, it is also important to acknowledge that discussions around Samhall also featured in other interviews and, while these participants did not get their own section in this chapter, it is worth unpacking what welfare professionals said about Samhall. This will enable us to understand the issues around disability (un)employment in relation to welfare services and the concerns that have been highlighted by disability organisations in a contrasting light.

While disability organisational representatives were highly sceptical of supported employment forms because they were seen as ‘antiquated’, Maria – a psychologist for a rehabilitation centre – noted that there had been considerable developments regarding the function and tasks available at Samhall:

> it has become very tough – much more difficult work tasks at Samhall. Before, they had more stuff like assembly or stuff like that. But now it is much more like that they are supposed to go out and work in like companies and it demands quite a lot that one should be able to take responsibility and can organise and plan and so on. So, we have several people that they, well, wanted to get rid of quite simply because it is not possible to match them with the jobs that they have.

This was not something that this research intended to find or even found much discussion on prior to undertaking the fieldwork. What seemed like an isolated remark gained increasing relevance as it appeared again in an interview with Lina, a welfare officer, who said that disabled people who struggle with these new conditions are being encouraged by Samhall to quit:

> [Samhall] is having a real difficulty in finding tasks for these people and Samhall can’t fire, which has made it so that they have said OK you can come in and sit on a stool and wait and sit out your time at Samhall. And it has been very difficult for many of our users and many have been put on sick leave because it has been so psychologically difficult to go to work. […] Which means that many have gone there, and sat down, and waited out the time and felt incredibly bad but… now I think that Samhall has managed to move most of them that they don’t want. And besides, I am in conversations with Samhall then which is… […] there are so many different bosses that I have probably spoken to five-six different ones, but they all say like ‘yes but I don’t understand why there is such a resistance towards resigning?’

It is clear from the data that they are pushing towards working conditions that are more akin to the general labour market. As such, this places the aspiration of including everyone in employment in a difficult light. The services that are supposed to aid those who do not conform to the productivity expectations of the general capitalist labour market are wanting to adopt to the production models that are precisely the working conditions that are not suitable for many within the service. The tendency for 'inclusion' efforts to be dependent upon the productivity pressures was described by Abberley (1996: 74):

> The work-based model of social membership and identity is integrally linked to the prevention/cure-oriented perspective of allopathic medicine and to the specific instrumental logic of genetic engineering, abortion and euthanasia. Ultimately it involves a value judgement upon the undesirability of impaired modes of being. However, this logic allows for the integration of perhaps a substantial proportion of any existing impaired population into the social work process, but only insofar as the interface between an individual's impairment, technology and socially valued activity produced a positive outcome. Thus the abolition of an individual's disablement is ultimately dependent upon and subordinate to the logic of productivity

The tensions around productivity and changing production models was not something that disability organisation representatives reflected upon in my interviews, but it is an important tension to acknowledge in relation to employment. Particularly as, as this section has explored, the rhetoric around employment within disability organisations and the government share many similarities. Despite these similarities, however, the government discourse is less likely to focus on issues around discrimination and instead focus on the employability of disabled people. Further, in order to fully understand the role of employment within Swedish society and within the welfare state, it became necessary to further explore the issue of work ability and what the consequences are when disability is conflated with illness. Broadly speaking, it makes it difficult to argue that there is any legitimate categorical exemption from labour market participation and by having the reason for decreased work ability be characterised as an illness, it very easily has connotations that there is a 'cure' available. As previously discussed in chapter 2, this has been heavily criticised in social model literature.

8.2 Disabled people and employment

This section will explore how disabled participants for this research viewed employment. This can be broadly summarized by two opposing perspectives. For those who saw themselves as able to participate in the labour market, employment was viewed as a positive potential that could be available to them barring the removal of certain barriers. For those who viewed participation in the labour market as unlikely due to their impairment effects, employment pressures were seen as a measure of control and discipline – a consequence of a Draconian welfare system. What also became clear was that work was not just about the ability to have an income or to be included – work contained a moral element that impacted the way that disabled people related to the idea of employment. Investigating these aspects will clarify what the consequences of austerity have been for disabled people and the role that employment played in the everyday life of disabled people. While I argue that there are complex, contrary elements simultaneously interacting with each other in relation to disabled people and employment, the way that austerity measures have been implemented contradicts the governmental aspiration to enable employment for more disabled people, which was noted earlier in the chapter.

8.2.1 The potential and morality of employment

Employment was a frequent theme within my interviews. Out of my participants, Anna, Spiderman, Mr Kint, Jan, Eva, BJ, Louise, Västgöten, Patricia and Sunetra, all had varying degrees of employment. Others had recently been made unemployed. Many reflected on how difficult it was to even get a job interview. When I interviewed Markus, he was in the middle of looking for employment and he emphasised how important employment was to him:

> [It is] very important. Partly to develop intellectually, professionally and get a social context, stimulus, get an opportunity to get a salary. […] Then you get to be something more than just a person with Asperger’s and you get to show that you also manage to have a work identity. That. No, but there are many benefits with having a work- or having an adequate pursuit […] It is important, jobs. I think that definitely.

For Markus, unemployment was linked to social isolation and he saw the potential of a job as a way of breaking this pattern. In this narrative, it is clear that he sees work as an important component in changing how people perceived him and that it could give him a context in which he would not just be seen as a person with an impairment. This indirectly also meant that he framed his diagnosis as something that needed to be overcome by the collection of other identities to offset the negatives he associated with his disability-related identity.

While employment was seen as important, the participants were aware that they faced several obstacles in accessing employment. Tobias commented that “one has it considerably more difficult – if it is a difficult labour market for people normally [*sic*] to get a job, it is even more difficult for us. Yeah”. One of these obstacles that emerged throughout the interviews was the role that welfare resources could play in facilitating employment opportunities. David really wanted to work but often felt that welfare professionals “see me as *ill* all the time and it is not quite where I want to be in life – I want to do something instead, I want to work with something that I am good at instead of sitting sighing over the things I’m not so good at”. This is a clear example of psycho-emotional disablism. Thus, the reflection that the welfare state could be a source of psycho-emotional disablism was also evident in my data.

That welfare services could feel more like a hindrance than an enabling force was also shared by Magdalena, who after having had sick compensation and rehabilitation compensation, who was told by the National Insurance Office that

> after two or one repeats, [they] decided that I got sick compensation full-time until further notice and they thought that there was no point to examine if there was any work ability in me. I thought that was wrong. I could probably see that there was reason to think that I had it difficult in many ways but some form of work ability I thought they could have looked at and my doctor and I agreed about this too but… yeah, they ran us over and yeah, it is a bit unusual to get forced compensation [laugh]

Västgöten was also hesitant to contact welfare services because of a similar situation that happened to his mother and he largely associated welfare services with being trapped on ‘benefits’. Sunetra, like Magdalena, was also merely informed that she had been granted early retirement in a letter “where it said that I was not available for the labour market within a foreseeable future and I could not appeal”.

Even among participants who were unable to work, employment and work was a frequent discussion point. Johanna has been put on sick leave twice and she described feeling like a ‘failure’ the first time it happened:

> The first time it happened, it felt like a *colossal* failure. One wants to. One seeks… I belong to the generation where it is self-evident that you work. […] I got shit from elderly relatives that I did not go on to college but […] [when I went to school] we who were pretty pleased, we went out and worked.

Her identity was so wrapped up in employment and signalled to her an inclusion into what you were supposed to be. As for so many others in this research, employment had long been regarded as the thing ‘that you were supposed to do’ and not being able to participate in it, resulted in a flurry of negative feelings of having ‘failed’ in life. Equally, for Louise, when she was put on sick leave, she described the situation as completely altering her perspective:

> … suddenly, I become a *sick pensioner* [direct translation of the Swedish word, which is the same as early retired]. It was completely... devastating. For me it was incredibly difficult. [...] For my own part, it has pained me incredibly that I have all my life been high preforming, diligent… it’s gone well and I have been regarded as a competent person and interesting to that I suddenly just become… what am I really? And of course, because of that I have questioned my own worth a lot.

In order to understand the particular emphasis that Louise placed on sick pensioner, it is necessary to understand the cultural connotations around being a ‘sick pensioner’. In Sweden, the connotations around being on permanent sick leave is that you are most likely to be a working-class woman with (sometimes) low educational status. Thus, there is also an element in Louise’s story that is connected to class and, in some ways, this transition and loss of status were more difficult for her than the acquirement of an impairment. Despite principally feeling that it should not be stigmatised, now belonging to this heavily stigmatised group was traumatic for Louise.

A similar shift in perspective happened to Hanna, as she became ill. This was to some degree already covered in chapter 5. Being employed, working and being an effective worker was very important to Hanna and she would pursue tasks to the detriment of her own health if she was asked:

> … many people who are put on sick leave really want to work – there are very few people who think it is really nice to be put on sick leave. Em, and [people] do their best and I know that I would do that too and it would… I mean, come and back and bite me the day after, sort of. And… well, I more or less said so to my caseworker, because she understands how I am, that I sort of rather sacrifice myself than let work or something suffer.

The wish to work again was also felt by Karin, who described herself as someone who had had sick leave in all of its various forms. “I really do hope that I will sometime going to be able to work again,” Karin reflected in her interview, “but it is a comfort anyway to have this for now so that it doesn’t… because it creates an incredible amount of stress just on its own to not quite have a working economy and it has been filled with hassle before”. Johanna even viewed being given early retirement as being “thrown out of the system”. The system, in this case, was synonymous with paid employment.

Despite the broad optimistic aspirations towards work being present among participants, the next chapter section will show that the relationship between disability and employment is not solely positive in a Swedish austerity context. As much as people may wish to work, there are those for whom this is not a feasible option and, here, employment and the focus towards getting people into employment become a significant barrier for disabled people; they struggled to be exempt from the labour market participation despite being too ‘ill’ to work.

8.2.2 Unable to work, work as discipline

In chapter 7, Maria made a comment that there seemed to be two separate ‘tracks’ of how the state treated disabled people: one that kept disabled people on ‘benefits’ and was reluctant to allow them to get out and one where there were those who feasibly could not work but were forced into the labour market. Based on the tendencies so far displayed in this section, there seemed to be something to this remark. Many disabled people expressed a desire to work – but for some their impairment effects made this difficult. Sunetra reflected on her experience of getting a diagnosis, which she regretted to some degree:

> … it was fucking stupid, pardon the expression, to get a diagnosis. I thought it would help, but it didn't. It hindered. And I can see in the different forums online *now* that those who are younger, they are fighting with roughly the same thing that I have done. But now the systems are shaped in such a way that you don't get sick compensation in the same way – or lasting sick compensation. Instead, they are forced to try to find a job, while *I* who want to work, me they trap [in the benefit].

She had a completely different experience to those who are now trying to access services. Indeed, experience of welfare services and systems differ over time as changes in policy are implemented. The participants I interviewed who were put on sick leave in the 1990s and earlier had a significantly easier time than those who were attempting to access sick leave now. As displayed in this and other chapters, people felt like being placed on sick leave had been too easy before and had prompted disabled people not to be included in working life. The 'younger' group that Sunetra referred to, however, are those who are currently trying to access disability-related welfare resources through the newer legislation that followed the intensification of austerity. For this group, as this section will demonstrate, work is often not possible and the pressure to find employment is not the encouraging potential that participants like Markus highlighted in the previous section. Instead, it acts very much as a disciplinary tool and the pressure to participate in the labour market leans closer to oppressive than empowering.

One of the measures that were implemented with the intensification of austerity in Sweden was a stronger emphasis on reassessments, as chapter 3 demonstrated, and these changes were openly regarded as 'reinforcing incentives to return to work', as highlighted in this chapter. During the Moderate-led Alliance era of austerity measures, there was a time limit on sick leave and, because of how this was implemented, it had the effect of pushing many people out of the welfare system entirely. This happened to Karin, as previously mentioned in this thesis, who got 'kicked off' the welfare system for being on sick leave for 'too long'. The time limit on sick leave that caused

Karin’s situation has since been abolished at the time of writing, but this does not mean that the issue has entirely disappeared.

The extent to which recipients of sick leave are deemed ‘fit for work’ has escalated to the point where the Swedish Public Employment Service has criticised the Social Insurance Agency for not giving ‘sick people’ sick leave (Sivberg, 2018). The fundamental issue, according to reports, is that the two agencies interpret ‘work ability’ differently and the agency argues that many who come to them are too ill to participate in work-preparatory activities and those who despite their condition manages to stay need additional resources, which the agency is now demanding from the government. In some ways, this kind of split is reminiscent of the two hands of the state, as theorised by Bourdieu (2004a). There seems to be, however, a key difference. While Bourdieu argued that there seems to be a wall between the social security side of the state and the financial, the case in Sweden seems to suggest that there is a split even *within* the social security section of the state.

It is also important to acknowledge the psychological cost to being excluded from the welfare system as a disabled person. When Jungfru Gunnela had to go through a work ability assessment, she found it incredibly difficult:

> The work ability assessment was even more stressful. I became suicidal because of it. My back problems and my problems with my pelvis became worse as a result of the stress. [Several muscles] locked themselves. I got a blockage in my breathing. I could not lie in bed and focus on the breathing and one body part at a time because I was crying so heavily. I was entirely finished.

Nowhere in this process was there a focus on Jungfru Gunnela’s wellbeing, the welfare resources that she was relying on were disappearing, and it is difficult to make the case that this was ‘encouraging her into employment’. The effect of falling through the ‘safety net’ of the welfare state actually exacerbated her impairment effects and, in this way, it is arguable that the way that austerity measures were implemented to take that in consideration. Rather, the implementation of austerity enforced a more punitive approach to preserve work as the main distribution system. Indeed, the way that employment operates in situations like these is akin to the tendency highlighted by Wacquant and Adams

(2009: 79) where “the dependent poor as a troublesome population to be subdued and ‘corrected’ through stern behavioral controls and paternalistic sanctions, thus fostering a programmatic convergence with penal policy”. For someone in a situation like Jungfru Gunnela’s, the expectation of work becomes a disciplinary pressure and when one cannot fulfil the expectations that have been placed upon them, there is a price to be paid, which was in Jungfru Gunnela’s case the cost of her mental and physical health and wellbeing.

Despite the positive views of employment and the government encouragement, there were indications in my interviews that employment was not a guaranteed protection against austerity measures. Christine, a representative from STIL, argued that austerity measures and how these were carried out were indifferent to the employment status of disabled people. Seeing how the cuts had impacted disabled people with personal assistance, Christine noted that being in employment had in some instances been used against disabled people in PA re-assessments:

> I’m thinking that in the last eight years in Swedish politics, it has really been about the work line[6], that one should to any price work and one should not – quote – ‘be a burden on society through the sick leave insurance’ or so, but this was not been applied to people with assistance, because there – or sometimes or sometimes not, but since […] one needs the assistance to carry out work or maybe not even the fundamental needs to be in a condition to carry out a job to begin with, it has not been fulfilled. So at the same time as the politics have signalled the importance of work and profitability, it has not been applicable to people with norm-breaking functionality and I’m thinking that that is about preconceptions that one should not have a job or it does not matter that one doesn’t have a job or that it is not as important work as other members of society. […] In some ways, one is perceived as inconceivable in society if one has a job as a person with norm-breaking functionality because it is not expected to sort of be included in this picture of a person that one should take care of a little, who should get some basic needs and then that’s good.

Despite personal assistance’s potential to enable employment, this was disregarded with the implementation of austerity measures. In Christine’s view,

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[6] The work line [*arbetslinjen*] is a welfare political concept that is about the reinforcement of work to ensure that welfare resources and services ‘pay’

this speaks to a larger question about whose work is valued and whose work is seen as unimportant. For her, disabled people occupy this latter category. When disabled people are employed, this is in some regards viewed as a surprise as Swedish society has a paternalistic attitude towards disabled people. The way that austerity has reshaped the definition of basic needs, and how personal assistance eligibility has moved away from needs in a broader sense towards functional fulfilments of things such as being able to go to the bathroom (STIL 2015), does not suggest an ambitious attitude towards disabled people's standard of living. In that way, employment is seen as a 'surplus gift' given to disabled people. Christine relayed stories of how disabled people have had to effectively resign from their jobs because their personal assistance was being reduced or withdrawn. Consequently, as much as the government espouses ideals that disabled people should be included in employment, the effects of austerity have for many effectively shut them out of this possibility.

In this section, how disabled people discussed work has been explored and it has found that the aspiration and desire to work was broadly shared among the participants, even those who recognised that their impairment effects prevent them from participating in paid employment. This is because work was not just about enabling the gathering of resources or even 'inclusion', but work operated as a moral signifier as it was often regarded as synonymous with 'societal contribution'. The moral signifier of work becomes key in understanding how participants viewed welfare state resources as stigmatising; being put on services like sick leave was often seen as being disregarded from societal contribution all together. It also became clear that while welfare services like personal assistance can greatly enable employment, welfare services can also be experienced as a hindrance. This was particularly notable among participants who had been forced onto particular benefits or deemed 'unfit to work' following inadequate assessment procedures. While the government rhetoric is positive towards disabled people being in employment, it is also clear from the data of this research that the way austerity measures have been implemented creates a fickle relationship to employment – whether you were in employment or not during reassessments could just as well work against you as in your favour. For those who are unable to work, the pressure towards employment becomes oppressive and punitive. Consequently, it is clear that employment is far from an inherent good, especially within the context of austerity.

8.3 Employment, labour, and work: a discussion

Throughout this chapter, employment has been shown to be a key factor for political and representative interests in the public sphere as well as for disabled people themselves. The importance of employment was not just reflected on by participants in employment or who were seeking employment. Even for those who could not participate in employment because of their impairment effects, the desire and goal of employment to some degree remained the same. What this indicates is that work was not just an instrumental task that was necessary to maintain a particular quality of life. Work had, for them, a highly moral component that even went beyond a desire towards inclusion. Work conveyed something about them as people and was something that would prevent them from being seen as burdens or ‘costs’ to society, which was explored in chapter 6. Employment is therefore seen by many as the ultimate sign of inclusion and acceptance.

As previously noted in chapter 3, Sweden has a particular fascination with work and the moralisation of employment is in many ways central to Swedish national identity. Based on the data, I argue that the moral component to work has intensified because of neoliberalism and the expansion of austerity. In particular, because neoliberal ideology idolises individual agency and self-reliance (Hughes, 2015: 992), it augments the importance of autonomy and independence. The intensification of these values has also found an easy ally in the moral vocabulary of austerity measures (Clarke and Newman, 2012). In this way, it follows that claims of ‘wanting to work’ was present among all participants – even those who knew that they were unable to work because of their impairment effects. Work is not just about the collection of material resources on which to live or about ‘inclusion’, for my participants, but it operates as a signifier of moral worth, participation, and the kind of autonomous ideals that is embedded in the Swedish socio-political sphere, and which have been intensified as a result of expanding neoliberal austerity.

As noted in chapter 3, Swedish neoliberal attentions have been particularly focused on the welfare state and provisions for disabled people especially. While Sweden has for a long time been keen on work, with for example the policy of full employment during the post-war years, and this aspiration remains, the provider of this full employment aspiration has changed. During the post-war period, its provider was predominantly the state but with the expansion of neoliberalism, the main guarantor of employment is now the market. This has had key impacts on the welfare state, as noted by MacLeavy (2010: 135):

> The welfare state is no longer viewed as a 'safety net' for people with low or no incomes, but has been restructured to support training and the use of compulsions in relation to welfare-to-work programmes. In this sense, it functions somewhat like a 'trampoline', not only catching people but bouncing them back into the paid labour market

The welfare state has become even more tailored towards 'enabling' employment and this has impacted how welfare services are delivered, which is supported by this thesis. An important note is, however, that while the 'welfare trampoline' catches people – this is not as certain for disabled people as it is for non-disabled people as, for some disabled people, impairment effects lessen their ability to conform to the expectations placed upon them in this 'new' system.

While the time limitation on sick leave has since been abolished, other factors such as the cost discourse, highlighted in chapter 6, and access to bureaucratic knowledge, as demonstrated in chapter 7, make exemptions from labour market participation less justified and more difficult for disabled people. To further understand this paradoxical relationship between the Swedish labour market and disabled people, it is worth noting a reflection made by Paulsen (2010: 70) about Sweden's relationship to employment:

> To be sure, integration could be made into a question about physical accessibility to public spaces and so on, but the function of society that makes the disability [*funktionshindret*] truly

> handicapping [*sic*] is of course that which it constitutes of wage work. For an impairment, which leads to decreased work ability, to cease to be a disability, it is not enough that the work is adjusted according to disability or facilitated with help of personal assistance and other aids – as long as the coercion to work remains such a central part of our lives, the disability will remain a disability. […] Maybe it is just because the full integration of people with disabilities so clearly assumes the work society's end that the adjustment to wage labour take such grotesque forms.

As such, he argued that the complete inclusion of disabled people would necessitate a deconstruction of how our society currently conceptualises labour. What is further attractive with Paulsen's (2010) hypothesis is that it incorporates the oppression of disabled people in Sweden – through institutionalisations and its subsequent removal of rights and forced sterilisations – into explanation rather than characterising it as an aberration. Indeed, one of the key underlying principles of institutionalisation was about helping, controlling, preventing and/or restoring work ability among the population (Lindqvist, 2012: 11). The coercion to labour and the labour market's pressure to have an increasingly 'productive' and 'competitive' workforce makes disabled people's inclusion in the labour market at best dependent upon their ability to adapt to these expectations, as Abberley (1996) noted. In this way, the way that disabled people get treated in the labour market is reminiscent of Marxist conceptualisations of "the immense reservoir of subemployed labor" who "holds on its lowest levels the pauperized layers of the population, that bottom sediment which is drawn into employment only infrequently, sporadically, and at peaks of 'prosperity'" (Braverman, 1976: 400).

It should be noted here that I am not interested in reproducing the "a vision of an 'underclass' of parasitic undesirables who live off the hard-working moral majority" (Hughes, 2015: 1001) in making reference to the distinction between productive and unproductive labour. Instead, I argue that the concept of the reserve army of labour reveals something interesting about capitalist logic. It is not that disabled people are 'unproductive' but, rather, the concept highlights how social relations are embedded in capitalism and thus creates these distinctions:

> Thus the distinction between productive and unproductive labor, which disregards its concrete form in order to analyse it as a social

> form, far from being a useless abstraction, represents a decisive point in the analysis of capitalism, and shows us once more how social forms dominate and transform the significance of material things and processes (Braverman, 1976: 412)

In this way, distinguishing between various forms of labour as ‘productive’ and ‘unproductive’ are underpinned by the similar kind of moral estimations central to the construction of ‘cost’ versus ‘investment’. To make a distinction between these is essentially to disregard that they perform similar functions (Braverman, 1976: 423) but are regarded differently. In the area of work, similar remarks have been made, for example, with regards to ‘productive’ and ‘reproductive’ work (Fraser, 2016); the capitalist system requires both to function but tends to only reward one of these to any significant extent. To talk about ‘unproductive’ labour is merely to point to labour which the capitalist system does not reward because it cannot maintain its profit-generating pressures. Continuously throughout this thesis, I have pointed to various forms of work required of disabled people to have their everyday life be manageable, for them to flourish the best of their ability under a welfare context defined by austerity and uncertainty. There is work involved in understanding the welfare system, navigating it, appealing rejections, and handing in applications on time a year or two later when you have to go through the same process again. There is work involved in finding other solutions when your support gets withdrawn, it is work to force yourself to view positives where others can only find negatives, work to manage people’s views and expectations. If you have a personal assistant, there is work involved in making sure that the schedules line up so that you have someone to help you. There is constantly ‘work’ involved in being a disabled person. Some of these ‘works’ are necessary to ensure survival and some are similar to tasks in the labour market – like that of managing schedules and holidays.

These activities need to be acknowledged but that is not to suggest it is directly equivalent to an ability to take on a job in the labour market. The production pressures that exist in the capitalist system require a systematic, continuous flow of productivity – ideally as unencumbered by human reality as possible. It has been shown that this productivity ideal is not even realised by non-disabled people (Paulsen, 2014) but this thesis argues that it is part of the non-disabled privilege to be able to pause, have that extra cup of coffee, or decide to reorganise your filing system on your computer, without fundamentally having your ability to 'work' questioned. Those breaks and adjustments to allow 'breathing spaces' in workplaces are for non-disabled people not indictments on their ability. For disabled people, whose needs might not conform or might extend beyond these small acts of workplace productivity rebellion, this is not the case. Then it becomes a question of what constitutes a 'reasonable' adaptation for their employer.

It is the ability of work or tasks undertaken outside the labour market to be more responsive to human needs that makes paid work in the capitalist labour market fundamentally different from 'work' carried out outside this sphere. Some, but importantly not all, disabled people can participate in the labour market and, indeed, some participants were at the time of data collection. It is for those, however, who cannot participate in the labour market under its productivity requirements, where the tension becomes most evident. This is particularly clear in the Samhall example. Even in services that are supposed to be exempt from the traditional productivity model offers no reprieve. Even here, the inclusion of disabled people is subsumed under the logic of capitalism. For this reason, positive rhetoric around employment for disabled people in Sweden under the context of austerity needs to be approached cautiously.

8.4 Conclusion: Disability, impairment effects, and employment

In this chapter, I have explored the issue of employment as this was a frequently recurring theme throughout my interviews. All of my participants viewed employment positively. Disability organisation representatives viewed it as an important rights issue and because of the history of how disability-related issues have been talked about in Sweden, they were reluctant to address welfare issues. They were also critical of the concept of decreased work ability and there were many services, but in particular, Samhall was not working according to its intentions. Disabled people were also deeply positive towards employment and this was particularly the case for disabled people who viewed themselves as likely to participate in paid employment. My interviews also demonstrated that there have been cases where disabled people who were employed under protected employment forms were ‘encouraged to leave’ because they did not fit the production model that was being implemented at Samhall. This opens up important questions whether disabled people’s employment is truly guarded and respected, despite the positive rhetoric.

Recognising the complex and nuanced relationship that many disabled people have to employment is essential to critically engage with the Swedish austerity discourse and to fully account for the impact of austerity on disabled people. As Iman, a former caseworker, remarked in her interview, “working life in Sweden has been so effectivised in the tiniest detail so that one should have as minimal a workforce as possible that everyone should really work as two did for maybe 20-30 years ago”. The productivity expectations in the labour market has massively increased in Sweden. This is true for both disabled and non-disabled people, but it particularly has profound implications for disabled people’s participation in the labour market because of impairment effects. For disabled people who viewed themselves as not able to participate in paid employment, employment pressures felt restrictive and punitive. What this demonstrates is that although disabled people are systematically discriminated against with regards to employment, employment can also be used as a punishment for disabled people who do not live up to the constructed non-disabled work norm offered by the welfare state. It is for this reason that Abberley (1996: 71) warned, “just because a main mechanism of our oppression is our exclusion from social production, we should be wary of drawing the conclusion that fighting this oppression should involve our widescale inclusion in social production”.

In this chapter, I also proposed that because of the absence of disability as a concept in Swedish and the conflation of disability and illness that exist in government discourse, it is suitable to amend the ‘administrative concept of disability’ as highlighted by Stone (1984) to a Swedish context and instead talk about the administrative concept of illness. The key distinction between these two concepts is that illness reinforces more much strongly the idea that labour market participation is possible for everyone and reduces the ability to make exemptions to labour market participation. This is because illness has a historically significant relationship to medical professionals and the idea of ‘cures’ and ‘fixes’ that aim towards ‘restoring’ a non-disabled ideal. By conflating disability and illness, Swedish government policy can entirely sidestep the issue that some might not be able to participate in the labour market and systematically make invisible disabled people who do not fit into the health-illness paradigm.

9. Thesis Conclusion

This thesis has engaged with the question of how disabled people in Sweden have been affected by austerity measures. I sought to investigate this phenomenon by interviewing three participant groups: disabled people, disability organisations, and welfare professionals. The research was guided by three key research aims:

1. To understand how disabled people, disability organisations, and welfare professionals understand the changes in the Swedish welfare state
2. To see how disabled people in Sweden have been affected by austerity measures
3. To see what, if any, impact the welfare state has on the experience of being a disabled person in Sweden today.

To examine these aims, I conducted 40 semi-structured interviews. 24 of these were with disabled people who self-identified as disabled and had or had previously had access to disability-related welfare support and services. Eight of these were interviews with representatives from Swedish disability organisations. Finally, eight interviews were conducted with welfare professionals who worked either as caseworkers at the Social Insurance Agency or disability-related welfare support services. Further detail on the methodology is in chapter 4. These research aims have informed various aspects of my thesis chapters. Throughout the interviews, each participant group acknowledged that the most significant change that has occurred in relation to the Swedish welfare state is austerity and that the societal climate had as a result become ‘tougher’ for disabled people. These views served as a backdrop to articulate the experiences of disabled people in this environment. The most prominent effect of austerity is that it increased bureaucratic power in influencing disabled people’s lives and caused disabled people to feel powerless to influence or mitigate the invasion of privacy that resulted from applying for welfare benefits and support.

This chapter will begin by drawing out the main findings as a result of the research aims. After the findings have been presented, I will draw out limitations of the research. Subsequently, I will articulate the four key themes that underline my research findings. These themes are class, bureaucratic power, invisibility, and economics and its role in marginalisation. Finally, I will highlight what I think these themes indicate about areas for future research.

9.1 Overview of thesis

This section will explore the findings that have been outlined in the preceding four chapters. The first data chapter explored what it means to be a disabled person in Sweden and began to tease out some of the key ways in which they had been impacted by austerity and disablism. Consequently, this chapter was mostly concerned with research aim two. This chapter found that my disabled participants found public attitudes and understandings of what it meant to be a disabled person to be poor. There was also significant stigma attached to being a person with an impairment that made several participants feel isolated. Being a disabled person also entailed having a close engagement with welfare bureaucracy and, with the expansion of austerity measures, many participants felt highly precarious. This became clear throughout the interviews as even those who did not see themselves as affected by austerity at the time of the interview worried that they soon would have vital resources removed from them. To manage with the bureaucratic demands placed on disabled people when seeking welfare support, family members and financial resources were identified as key sources of support.

The second data chapter looked at the justifying discourse, that welfare resources and support for disabled people is simply ‘too costly’, which emerged following the expansion of austerity. This chapter included perspectives from disability organisations, welfare professionals, and disabled people. In this way, this chapter helped to answer aspects of research aim one and research aim two. They all viewed changes in the welfare state as restricting welfare resources and producing a tougher societal climate for disabled people. In this chapter, it became clear that even when challenging the cost discourse by arguing that expenditure on welfare resources are ‘investments’, it still placed the impact on disabled people as secondary or invisible consequences because the same values inform both costs and investments in economic theory. This results in significant psycho-emotional disablism (Thomas, 1999). Even when overtly challenging the idea of ‘costs’, participant groups ended up indirectly reaffirming aspects of this discourse.

The third data chapter explored more closely the impact of bureaucracy on disabled people. This was to provide further answers to research aim three and one. It included both perspectives from welfare professionals and disabled people to get a closer sense of the impact of welfare bureaucracy. To attain access to welfare resources and support disabled people needed to navigate several stages of welfare bureaucracy. The first stage was gaining an understanding of how the welfare system operated, and the second stage was dealing with rejections and appeals. For those who managed to gain access to support, the third stage meant achieving a successful application but there were also participants who had got welfare resources forced upon them. The final stage of bureaucratic impact were stories of disabled participants avoiding applying for welfare resources, even when they thought they fit the eligibility criteria. This was one of the most common accounts among my disabled participants.

Professionals, on the other hand, found the rapidly changing guidelines in this area difficult to manage. They noted that disability-related welfare assessment eligibility was difficult to determine and that the LSS legalisation in particular was notoriously vague. Due to the prevalence of uncertainty expressed by both participants groups, I explored the structural production of un-knowing to understand how knowledge and its opposite were distributed within the welfare system and how it advantaged some applicants over others. The way that bureaucracy operated to make things and people ‘unknowable’ were key elements in how bureaucracy dehumanises disabled people, an aspect which will be explored further in this chapter.

The final data chapter looked at employment. This was because employment-focused efforts were one of the few supports that the state defined as an ‘investment’. This chapter was chiefly concerned with research aim two and three. This chapter found that while politicians were rhetorically optimistic about disabled people’s employment, disability organisations felt like they rarely took action or listened to what would improve the lives of disabled people. Because of the focus on employment was seen as a ‘right’ and welfare services and support being seen as a ‘care’ issue, disability organisations were hesitant to address some austerity measures. They also noted that they thought several supported employment forms were outdated for the current labour market. There seemed to be indications in my data that this is resulting in disabled people who previously gained access to supported employment forms being ‘encouraged to resign’. This was because they were seen as not fitting the changing production demands of protected employment forms, which are increasingly focused on service-related employment.

All of my disabled participants identified employment as important. For many, it was seen as a crucial step towards ‘inclusion’ in society and to not be ‘dependent’ on welfare services. It became clear, however, that employment was not just about accessing needed resources, but it also operated as a moral marker as someone who ‘contributes’ or has a ‘successful’ life. For my participants who could not adhere to the employment demands of the capitalist labour market, the push towards employment was seen as a disciplinary measure exerted over them by welfare bureaucracies. It was also clear in interviews with disability organisation representatives that in the current age of austerity, even being in employment was not a safeguard against austerity. In this way, while employment is seen as important, disabled people’s employment is not seen as something that should be necessarily preserved. This exploration highlighted a need for a much more nuanced and critical approach to employment to not advantage some disabled people at the expense of other disabled people.

9.2 Limitations of research

The previous section explored the key findings of my research. Having pointed to key findings of this research, it is also important to acknowledge the limitations of this thesis' scope before drawing out the themes of this thesis. I will address two main limitations. These are related to the demarcation of the disability experience focused on in this thesis and whether there is a reproduction of pessimism embedded in the focus of this thesis.

There are of course elements of the disability experience that are not covered here. Family, housing, or intimate relationships, for example, are not extensively covered in this thesis. These aspects undoubtedly form key part of people's everyday lives just as, for example, bureaucracy or any of the other aspects this thesis has addressed. The elements I have chosen to focus on in this thesis resulted from understanding what experiences were shared by my heterogenous participants. Not only are the disabled people I interviewed from diverse backgrounds, but this was further exacerbated by also interviewing disability organisations and welfare professionals. Partly the focus of this thesis derived from triangulating the points of view from the participants and partly from an effort to answer the initial research aim. This is not meant to be an opus on being a disabled person in Sweden. Aspects such as gender and 'race' are also not extensively explored despite the that for many participants both or either of these elements did feature in their experience of being a disabled person. The reason why these elements were not developed further was because while elements of participants' experiences were gendered, there were no clear-cut patterns in how gender impacted their experience of austerity. These elements were also not as explicitly emergent as, for example, class, which I will explore further in the subsequent section of this conclusion.

Finally, there is the question whether the focus of this thesis is deliberately focusing on the 'difficulties' people encounter in their everyday in relation to the welfare state. As chapter 4 indicated, I went out of my way in the fieldwork process to not assume that my participants had been adversely affected by changes in the welfare state. When presenting my research topic, I framed my remit as looking at changes in the welfare state rather than austerity, but my participants connected those changes to austerity. This points to the fact that participants were very aware that things were being made more difficult – there was not a single participant articulated the view that the welfare state has become more ‘generous’. The focus on ‘barriers’ or ‘difficulties’ in accessing welfare services in this thesis is because, while the participants might be grateful that services existed, few would characterise agencies like the Social Insurance Agency as a ‘functioning’ welfare institution. Those who had to engage with welfare services were very frustrated with its current administration and development and this was reflected in the data. As the interview guides in appendices 7-12 make clear, if anything, questions were posed in a way to allow for more positive answers, but this tended not to be the dynamic that would develop in the interviews I conducted. Thus, the focus on ‘difficulties’ in the welfare system was the result of participants’ frustration with the welfare system.

9.3 Emergent theme: Class

Having addressed the key findings of this thesis and its limitations, I will now address one of the key emerging themes of this thesis. The participants in my research had quite varied experiences of austerity and to understand what made a difference for my participants, it was clear that financial resources played a significant part. Participants like BJ, who had extensive cultural and financial capital to draw upon could limit the extent to which she had to engage with the welfare state. This also limited the impact of austerity measures on her life. For other participants, such as Julia, whose main source of income was provided through the welfare state, any alteration was a source of incredible uncertainty and risked depleting the few resources she had at her disposal. It became clear that the class position of my participants was a key factor of in whether they ‘managed’ in times of austerity.

Despite the strong Marxist and materialist influences on the social model (Oliver, 1990; Oliver and Barnes, 2012; Thomas, 1999) and the recognition that the emergence of capitalism resulted in the devaluation of disabled people

(Abberley, 1996; Oliver, 1990), class is remarkably underexplored in disability studies. This is not to say that the connection is unexplored. Vernon and Swain (2002: 89) notes that the foundation of disability theory associates disability with social class but does not expand on this further. Oliver and Barnes (2012: 117) note that “as class privilege increases, the impact of disablism, racism, sexism, heterosexism and ageism may decrease” with the note that this will “almost certainly be reversed for those at the foot of the class structure”. Borsay (1986) notes that “handicapped members [*sic*] of the upper and middle classes, with wealth and investment incomes, higher salaries or better superannuation schemes, have a very different experience of impairment to people who must rely exclusively on state social services”. Morris (1991: 116) notes that disabled people might because of their class position ally themselves with organisations for disabled people rather than organisations of disabled people. When addressing intersecting forms of oppression, Morris (1991: 118) acknowledges the importance of not treating intersecting forms of oppression as mere ‘add-ons’ and while listing these, places each intersection in text with the exception of the intersection of class and disability, which gets relegated to brackets. When analysing parenting books dealing with raising disabled children in the US, Calton (2010) notes that the perspectives offered in this genre focus on middle and upper-class parents while working class perspectives are completely absent. This is relevant, Calton (2010: 849) notes, because the parents in the memoirs were able to draw on “significant resources of time, money, and social connections to cope with the extra needs of their children”. Björnsdóttir and Traustadóttir (2010) explored class to some degree in their intersectional analysis of Islandic young adults with learning difficulties. Heeney (2015) noted classed notions of parenting norms and how that affects parents of disabled children.

The influence of class, however, does not expand beyond these points in disability studies. The major contribution of this thesis is the influence of class on the experience of disability. The reflections of Borsay (1986) and Calton (2010) are correct but my research expands on these points and point to significant implications, particularly in relation to the welfare state. These will be explored further in the subsequent theme. Before embarking on these, however, it is worth expanding on what the theoretical implications of the neglect of disability in relation to class and how I understood and related to the issue of class in my research.

9.3.1 Implications for theory

While the absence of class analysis on social model perspectives and disability research more broadly is notable, it is not the only neglect. Disability has also been ignored in many significant class textbooks, such as for example Crompton (1998) and Hamilton and Hirszowicz (1993). The fact that disabled people are more likely to be in poverty is frequently reflected in reports (for example Tinson et al 2016) but the extension of this fact to theorisations of class has been limited. The neglect of recognising class in relation to disability does not merely have practical implications. I argue that the absence of recognising disabled people and class has a major impact on (in particular) Marxist class analysis, as it limits the extent to which Marxists can fully critique capitalism. Marx and Engels (1969) noted that one of the most prominent features of capitalism was its propensity to use worker's bodies as tools, making workers "an appendage of the machine" and "the cost of production of a workman is restricted, almost entirely, to the means of subsistence that he requires for maintenance, and for the propagation of his race", making capitalism dependent upon the consumption and reproduction of bodies. They did not, however, note the existence of disabled people or the ability of capitalism to produce impairments (though that has later been explored later in literature such as Abberley 1996). According to Marxist analysis, the utility of workers is directly related to their ability to maintain 'productivity' for the bourgeoisie and any interference in the pursuit of profit should be removed (Marx and Engels 1969). In this way, disabled people occupy an undesirable position in capitalist societies and, thus, the capitalist order is inscribed with non-disabled ideals that need to be maintained.

I argue that the neglect of disability in relation to class causes an overemphasis on the productivity elements of capitalism and a valorisation of labour. The valorisation of labour is even visible in Marx and Engels (1969) with reference to the lumpenproletariat, which they described as a 'dangerous class' and "the social scum, that passively rotting mass thrown off by the lowest layers of the old society". Chapter 3 of this thesis showed how this was also the case in Sweden and that the association between class and labour market position remains strong today, now reemphasised with neoliberal redefinitions of class as being in employment or unemployed. While there is a debate about whether the lumpenproletariat constitute a class in a Marxist sense (Welshman, 2007: xiii), it is clear that there is a clear lineage from the concept of lumpenproletariat to the more contemporary idea of underclass, which has a specific connection to Sweden. In the 1960s there was a concern expressed by SAP economist Gunnar Myrdal that there was an underclass of "unemployed and, gradually, unemployable persons and families at the bottom of a society" (Welshman, 2007: xiii). Just as Marx and Engels were concerned with the 'unproductive' elements of the lumpenproletariat, the underclass concept evokes the same imagery.

My argument is not that all disabled people should be or is classed as part of the lumpenproletariat or the underclass but rather that disabled people would (probably) be classified as such in classic social theory (if mentioned). But even if one maintains these classifications, this is not straightforward. Where disabled people would be included would depend upon the nature of people's impairment effects and whether it would impede the generation of profit. Overall, however, I am critical of maintaining the distinction between the lumpenproletariat/underclass and proletariat/working class. As I stated in chapter 8, making that distinction invokes the idea of the lumpenproletariat/underclass as an unproductive 'parasitic' class and neglects that the lumpenproletariat/underclass actually fill many of the same functions as the rest of the proletariat (Braverman, 1976). Ignoring disabled people and the way that capitalist system treats them and (under)values them undermines the extent to which capitalism as a socio-economic system can be criticised. The fact that many socialist movements ended up having to protect capitalism to pay for social reforms has been extensively explored in Sassoon (2013). I argue that by also ignoring disability in relation to class, movements also had an insufficient critique of capitalism, as it conceded key normative assertions to capitalism by unproblematically valorising labour and not problematising the capitalist norm that everyone can and should work. Theoretical exploration regarding the implications of the full inclusion of disabled people in Marxist class theory is therefore desperately needed but beyond the scope of this thesis.

9.3.2 Deciphering class in my data

Class is a concept with a number of meanings (Crompton, 1998: 10) and it is a concept that changes alongside society changes (Dorling, 2014). For a long time, class was defined in relation to income and quantifiable due to the inheritance of Marx and Weber (Bottero, 2004b) but increasingly, cultural elements are included in class analysis (Bottero, 2004a: 986; Bourdieu, 2008). Correspondingly, there has been a shift towards regarding class as something individualised (Bottero, 2004a). Bottero (2004a) is concerned that the concept of class has become too opaque as there is a tendency for individualised notions of class to collapse into the 'old' collective notions of class. While this concern is notable, I do not see this as an impediment for the use of class as an analytical concept in which to understand the experiences of my participants. Drawing on a Bourdieusian conceptualisation of class (Bourdieu, 2008) means recognising that class is also a relationship (Bottero, 2004b: 139). In recognising class as a relationship, I do not see an inherent antagonism between individualised, culture-focused notions of class and the 'traditional' collective notions of class. Indeed, connecting individualised notions to collective experiences is at the heart of sociological thinking (Bauman and May, 2006). Arguably, you can also see that connection being made in *The Communist Manifesto* (Marx and Engels 1969) with the recognition that class relationship influenced the mode of production. Cultural notions and values are driving how society is structured and how institutions function, as I claimed in chapter 4.

Particularly because class became an emergent theme in my research, it meant that it was not something that I had expected to be as prominent. This meant that I had not explicitly asked participants, for example, about how they perceived their class position or what level of income they had. Further, by seeing class as a relationship that incorporates economic, cultural and social capital, it also means that merely focusing on economic capital for example would be inappropriate. Through my interviews, it became clear that there were significant differences between participants. This was not merely because it was raised by participants themselves, as explained above. A disabled person who had never had a job due to their impairment effects, and were entirely dependent on state support for their income and would consequently only be entitled to the most basic level of support, were clearly identifiable as working class. Participants, on the other hand, who had high levels of university education, partners who earned enough to cover most of the living expenses for the family, and access to alternative sources of financial support outside the welfare state were as such identifiable as middle-class. They may have not been comfortable middle-class but the difference in trajectories and experiences were clear. This relational identification of class may not be the most clear-cut but due to the way that I understood class I do not see this as an impediment from the utilisation of class. Further, due to the lack of any substantial exploration of the influence of class on disability to draw on, this was the neatest understanding of class I could devise to unpack my data at the time.

The recognition of class influence on the experience of disability ended up being essential to unpack the diverse experiences of the welfare state that existed in my fieldwork data. It became particularly prominent in relation to how experienced and engaged with the welfare state. This aspect will be further explored in my second theme which looks at bureaucratic power.

9.4 Emergent theme: bureaucratic power

The second theme of my research is the centrality and influence that bureaucracies – and in particular the welfare state – has on the experience of being a disabled person in Sweden. Bureaucratic and institutional power over disabled people is not new. Institutionalisation and forced sterilisations of disabled people are both two clear examples of this fact. While no longer as extreme, the influence of bureaucracy on disabled people’s lives is still present. It has been recognised that in order for an ‘independent’ life to be realised for disabled people, it involves engagement with professionals and welfare bureaucracy (Helgøy et al, 2003). There have been studies (Hultman, 2018) looking at disabled children and adolescents’ experiences of engaging with bureaucracy to access personal assistance and the perspective of welfare professionals with regards to personal assistance assessments (Hultman et al, 2018). Historically, the perspective on disability in Sweden was heavily draped in paternalism with the view that the “state knows best” (Roulstone, 2013: 4). The connection between disability and bureaucracy was extensively explored in theoretical terms by Stone’s (1984) classic work and its historical impact noted by Hughes (2002). My research, however, makes clear that the influence of welfare bureaucracy is increasing in light of austerity and has a significant impact in my participants’ everyday lives.

The disabled people that I interviewed were quite clear that the relationship that they had to the welfare state had for a long time not been positive. Feeling scrutinized and fearful was not new, but the overwhelming answer in my data was that austerity had amplified the negative elements of this relationship. Disabled participants were fearful and worried over the future of many welfare resources they needed in their everyday lives (personal assistance in particular), which they now for the first time saw at risk of disappearing. While engaging with bureaucratic entities such as the Social Insurance Agency had always been a source of frustration or regarded as a nuisance, it was clear that participants felt the tone and behaviour of welfare bureaucracies were much more aggressive and hostile towards their applications at the time of the interviews.

As chapter 2 made clear, one of the most prominent changes following expanding austerity is that the definition of basic needs in relation to personal assistance assessments has been redefined to indicate ‘integrity-sensitive’ needs. The redefinition to ‘integrity-sensitive’ needs has not only resulted in sharper eligibility criteria, as I made clear in chapter 2, but I argue that it has also reinvigorated the insight and power of welfare bureaucracy to scrutinize disabled people when they apply for welfare services and support. The need to interrogate, confirm, and estimate intimate details of disabled people’s lives are now inscribed in the assessment process. For example, it is no longer whether you need help with toilet visits. Instead, the new definition causes an artificial break in this process and an increased focus is placed on isolated elements such as help while on the toilet or wiping. To apply for welfare support and services, disabled people are consequently forced to reveal more intimate details about their everyday. The redefinition to ‘integrity-sensitive’ needs necessitates higher scrutiny and the integrity of the welfare applicant is waved during the assessment of ‘needs’. The need for increased scrutiny of welfare applicants is justified by invoking the risk of ‘welfare fraud’, even though the methodology used to calculate welfare fraud is highly inappropriate and flawed (Altermark and Nilsson, 2017). The redefinition of basic needs to ‘integrity-sensitive needs’ in combination with other austerity measures have resulted in “emphasizing a medical discourse that promotes functionality and care needs at the expense of social needs” (Hultman et al, 2018: 910).

The exposure to this shift, however, cannot be understood without incorporating class. The power that welfare bureaucracies had over disabled people’s lives varied depending on class position. Participants who could rely upon resources and support outside of the welfare state – for example on the ‘free market’ – could opt out of the application process if it was too stressful and invasive, as chapter 5 made clear. It was also clear in the data that other biproducts of class positions such as cultural and social capitals also played a part in how they navigated the bureaucratic system, as chapter 7 indicated. For those with high levels of legitimised cultural and social capital, they could rely upon friends divulging helpful information about the application process or assist on appeals. For participants who had no alternative sources of support and resources, ostensibly the more working-class participants, they had no choice but to go through the assessments.

Bureaucratic influence is not merely limited to welfare bureaucratic assessments or awards. The way that impairments and disability is characterised within bureaucratic systems impacted how my participants saw themselves and related to their impairments during my interviews. As indicated in chapter 2, Swedish understandings of disability and impairments are heavily medicalised and this was also found in interviews. The classification schemes, the position of disability-related welfare resources and the general framework in which disability gets identified all impact upon identification (Brubaker and Cooper, 2000). In short, Brubaker and Cooper (2000:15) note that (state) institutions “includes the power to name, to identify, to categorize, to state what is what and who is who”. The illness or medical connotations of disability that is present in Swedish political debate and policy was in some ways reproduced in most of the interviews I conducted. Participants utilised a number of terms to denote their impairment. Participants alluded to their ‘problems’ or ‘worries’, which acted as euphemisms for impairments. The most common descriptor, however, was medical categories or the identification of impairment through describing the impact of their impairment. This is not to say that identifying disability in these ways is inherently wrong, though I noted problems with conflating disability with illness is chapter 8. Instead, they are primarily indicative of the pervasiveness of bureaucratic power in Swedish society in relation to disability. This needs to be examined further especially as the power of bureaucracies seems to be resurging following austerity. Therefore, the worry that participants expressed about the risk of reinstitutionalisation in chapter 6 needs to be taken seriously, especially as institutionalisation would probably not emerge under the exact same institutional form as in the past but now under much more individualised and neoliberal lines. What this also suggests is that there is a need to revisit classic sociology issues, such as bureaucracy, to explore how they are changing in these neoliberal times.

9.5 Emergent theme: invisibility

The third major theme that emerged through my work is that of invisibility. Even though this research utilised a wide range of participants with various perspectives on what constitutes the ‘disability problem’ (Stone 1984), there was a wide agreement among my participants that disabled people remained largely ‘invisible’ in Swedish society. This manifested itself in the recruitment of participants as friends of mine saying things like “I don’t know any disabled people… I mean, I know one person but they have dyslexia, so that might not be what you are looking for”. In other words, they would acknowledge an impairment or related medical category but not acknowledge that as being indicative of a person with a disability.

Another way in which this invisibility was expressed is present in the enactment of disability-targeted austerity. Because of the indirect, subtle way in which austerity has been implemented in Sweden it is difficult to gain a coherent overview of what has occurred on a structural level. At the time of conducting and writing up this research, there has been no coherent statistical overview of how disabled people have been impacted by austerity. Austerity's opaqueness is key to understand what has happened in Sweden and how participants orientated themselves in Sweden's austere landscape. Since Swedish disability-related welfare services and support as well as the compensation level are individually calculated based upon a number of factors that make the actual compensation level lower than the formal compensation level (SOU 2010:04a), it is difficult to quantitatively draw out exactly how many disabled people have lost access to resources. By simply not knowing this information, raising structural critique of austere practices becomes difficult.

It was partly because of this and all the other ways in which disabled people were rendered invisible in everyday life that the structural production of un-knowing becomes significant. I introduced this concept in chapter 7 in relation to understanding the ambivalence and uncertainty expressed by welfare professionals and disabled people in relation to how the welfare bureaucracy operated. Consequently, it was operationalised to grapple specifically with the uncertainty and 'unawareness' that my participant groups expressed in relation to the welfare state and austerity. It may have broader applicability but it is beyond the scope of this thesis. That un-knowledge of a phenomenon is structurally created can be seen through the fact that there is an absence of statistical information on how disabled people have been impacted. Additionally, the way that illness and disability is conflated within the welfare state prevents an articulation of what measures might need to be put in place for people who cannot participate in a capitalist labour market. Its absence reinforces the obligation to work.

The structural 'unknowns' matter because they inevitably impact how people understand themselves, as argued above, but also how they related to their surroundings. The conflation of disability with illness also makes any kind of articulation of disabled people as a socially oppressed group more difficult. This also meant that although participants could point to factors that would suggest that they had been impacted by austerity, they were uncertain if this was the case or to what extent their situation was common. By making the impact of austerity on disabled people ‘unknowable’ in this way, it also limits potential for wider societal discourses to acknowledge these changes. This made the disabled participants I spoke to feel like there was little public understanding or outcry for developments that threatened their rights or ability to live ‘equal’ lives on par with non-disabled people.

That un-knowledge performs a key function within the welfare system is not new. It can be seen in theoretical explorations into the welfare state and how neoliberalism has affected it. Bourdieu (2004a), for example, highlighted this issue by conceptualising the state as having a left and a right hand. The left is filled with primary teachers, family councillors and others who carry out ‘front line’ social protection services while the right hand constitutes the technocrats of the finance department, banking services, and ministerial cabinets (Bourdieu, 2004a: 1–2). The relationship between these two hands are increasingly characterised by dysfunction and tension because, as Bourdieu (2004a:2) notes, “the left hand of the state has the sense that the right hand no longer knows, or, worse, no longer really wants to know what the left hand does”. This tendency becomes amplified during austerity measures where essentially the right hand begins to want to minimize the left as much as possible. This kind of structural ‘un-knowing’ is characteristic of most organisations, not just the welfare state, as “organizations depend on forms of concerted ignorance, different levels of the system keeping themselves uninformed about what is happening elsewhere” (Cohen, 2001: 11). The concealment of causation that occurs as a result helps to distance professionals from decisions but also, what is relevant for this thesis, is that un-knowledge also plays a significant role in minimising the increasingly antagonistic relationship between these two sectors. If information how cuts are impacting the welfare sector is difficult to come by, as interviews with my participant groups suggested, professionals and others only have a vague sense and dissent could be easier to manage.

The process that disabled people have to engage with in order to access welfare resources contributes to that invisibility. When applying and engaging with services, participants spoke of having to fragment or present their lives in particular ways to successfully obtain access. The continuous necessity of fragmenting oneself and one's life has significant on people's self-esteem. This was particularly evident in the case of Julia who struggled to see herself as a unified complete person due to the extent to which she engaged with welfare bureaucracies. While other participants may not have expressed the same level of disassociation and feelings of invisibility, it nevertheless featured as elements in for example applying for welfare resources for the first time. Instead of being seen as a person with multiple facets to one's personality, participants like Louise felt that once they acquired an impairment, that became the overwhelming aspect in how others saw them and elements of this is reinforced through the application process. The fragmentation of disabled people's lives during the application causes distancing and this is part of a dehumanising process (Bauman, 2000: 102-103). This kind of practice can cause significant suffering as my data clearly indicates and for this reason, how people and phenomenon are rendered socially 'invisible' needs to be taken seriously.

9.6 Emergent theme: economics and marginalisation

The fourth theme that emerged following my research is economics and its role in marginalisation. In some ways this theme is an extension of the two proceeding themes. Bauman (2000: 13) noted bureaucracy had a "tendency to subordinate thought and action to the pragmatics of economy and effectiveness". As chapter 7 noted, we also cannot conceptualise 'economy' as exempt from normative influence – rather norms are essential to the articulation of financial systems and economic practices. These norms and values are inherently embedded in economic systems and this insight is embedded in Marxist theory. Polanyi (2001: 60) notes that "social relations [under capitalism] are embedded in the economic system". Thus, it is not the case that morality has been abandoned in the pursuit of profit but that norms and the economy remain closely interlinked.

The key consequence of the reversal of this relationship that occurred with the shift to industrial capitalism, however, is that many moral and societal considerations are expressed through the language of economy, rather than through the language of social relations. Indeed, as Marx and Engels (1969) famously stated, our economic system is the outcome of the development of social relations. This means that economic theory is not exempt from moral assessments and judgements that are frequently observed in social life but is as defined by these conditions as any other product of social life. In this way, this chapter agrees with Sayer (2000: 80) in that “in order to explain economic actions in general, it is necessary to acknowledge the extent to which these are influenced by moral sentiments and norms”.

Economic theory is one of the forces that facilitates the bureaucratisation of norms and values into societal institutions, ‘rational’ practices and making them appear ethically unproblematic. In chapter 6, it was clear that there was significant distancing and dehumanisation embedded in the justifying narrative of austerity. The austerity discourse and its investment alternative both tenders the impact on disabled people as secondary and invisible. This invisibility is both embedded in the norms and values of the underlying and even when disabled people utilise ‘investment talk’ to challenge austerity. In this way, in the case of disabled people, it is not just that economic actions and practices exacerbates marginalisation but that it can also assist in the creation of marginalisation. That marginalisation is evident when disabled people’s standard of living being on par with non-disabled people is not being viewed as a sufficient ‘return’ on expenditure, which is the implication of the ‘cost narrative’. It is partly a reflection of values already present in some parts of society, but it also helps promote, and effectively ‘neutralise’ these sentiments in others as they become regarded as extensions of bureaucratic rationality.

In fact, by focusing on disabled people and how they have been impacted by austerity highlights the need to resist the naturalisation of these norms. The difference between being characterised as a societal ‘cost’ and being a ‘burden’ on society is arguably non-existent. This is where disputing economic theory in this way and recognising its role in marginalisation becomes vital. Particularly because there is a Social Darwinist tendency embedded in neoliberal ideology, present in its free market ideology and neoliberal economics, where the market chooses “winners and losers and to determine value” (Tienken, 2013: 305;

Leyva, 2009; Bourdieu, 2004a). This perspective quickly translates to human beings. As Hughes (2015: 992) notes:

> Neoliberalism proposes a doctrine of the survival of the fittest in a market unrestrained by collectivist forms of interference. The waste products of such a system are, from this perspective, a burden on those who can (are able to) cope and prosper.

My research clearly shows that disabled people are increasingly left to ‘fend for themselves’ as collective provisions decrease following austerity. Even more concerning is that there is no inherent check and balances on the emergence of that discourse. Bureaucracy “makes cruelty and barbarism possible because it has no sense of suffering” (Hughes, 2002: 576). Norms become rationalised by their inclusion in economic theory and subsequently bureaucratised through the enactment of measures and policies to adhere to their stated aims. Consequently, it is necessary to take the Social Darwinist element embedded in neoliberal theory seriously and how it, in particular, targets disabled people.

9.7 Areas for future research

The themes and issues explored in thesis highlight the need for further research in a multitude of areas. This section will explore some of the most pressing aspects that I have identified as needing further investigation. I will explore these areas in turn before concluding. Broadly speaking, I have identified three main areas that require further academic attention. These are Swedish disablism, the impact of class on disability, and the resurgence of social Darwinism in neoliberal times.

There have been plenty of studies that have looked at disablism in a particularly UK context (Morris, 1991; Oliver and Barnes, 2012; Thomas, 1999) but there has been a surprising lack of this kind of scholarship in a Swedish context. While there have been observations that Swedish disability research seems to move closer to its British counterpart (Söder, 2009: 71) but this is still in development and due to for example the absence of a direct equivalent of a ‘disability’ concept, a direct conversion is improbable. Because of socio-economic circumstances and Swedish history, disablism would probably take on slightly different expressions. This thesis can be seen as part of an endeavour to expand this scholarship, but more is needed.

The second area in need of further exploration is the impact of class on disability. This thesis has sought to open this area to closer scrutiny, but more research is needed. In relation to the welfare state and austerity, class seems to be a significant alleviating factor but, also, the limitations of class privilege in relation to disability also needs to be explored further. Studies looking specifically at this relationship would be welcomed.

Finally, what the findings of this thesis also makes clear is that another area in need of academic attention is the resurgence of Social Darwinism under neoliberal conditions. Not only is this pressing due to the prominence of neoliberal thought in contemporary society and neoliberalism's inherent Social Darwinist elements, but also because of the accompanying discourses around welfare benefits, people in poverty, and disabled people. As part of that area of further study, the role of economics in rationalising these ideas needs to be explored.

9.8 Conclusion

This thesis sought out to explore how disabled people in Sweden had been impacted by austerity measures. Through that exploration, it became clear that disabled people have been severely impacted by austerity – not only through the reduction of resources that austerity inevitably entails but also affected by emerging discourse that characterise disabled people as 'too costly' for society. All of my participant groups understood the changes that have occurred in Sweden as being indicative of a harsher societal climate that disadvantaged disabled people. Underlying this shift, it also became clear that there were pre-existing elements that have been exacerbated as a result of austerity.

Disabled participants spoke of the power that bureaucracies have in determining their standard of living and their daily activities. This indicates that the welfare state has a significant impact on the experience of being a disabled person in Sweden today, especially if one is in need of welfare resources and support. Austerity has endowed bureaucratic institutions with further invasive powers in order to prevent ‘welfare fraud’ and a push towards seeing that those most ‘in need’ gain access to services has resulted in more invasive assessment practices. Beyond that, the way that the public discourse around ‘costs’ in the welfare state have been conducted has resulted in significant psycho-emotional disablism (Thomas, 1999) for my participants. It is, however, also clear that class was a significant factor regarding the extent to which they experienced adverse impacts. Disabled people with other financial resources could opt out of welfare services if they deemed the process to be too invasive, whereas participants who did not have access to other financial resources were in a sense left without a ‘choice’ but to endure the assessment procedures, appeals, and re-applications. It is also clear that middle-class participants were more able to smoothly navigate these processes if they wanted due to their possession of more legitimised cultural and social capital compared to their working-class peers.

Appendix 1: Participant Information Sheet (disabled people) (Swedish)

University of Glasgow

College of Social Sciences

Informationsblad

Titel och forskarens kontaktinformation

Funktionsnedsättningar och den svenska välfärdsstaten

Forskare: Ida Norberg

Kontaktinformation: i.norberg.1@research.gla.ac.uk

Telefonnummer: XXXXXX

Hej,

Jag heter Ida Norberg och jag doktorerar vid The University of Glasgow och jag forskar om hur folk med funktionsnedsättningar har blivit påverkade av förändringarna inom välfärdsstaten. Jag skulle vilja prata med dig som identifierar dig själv som en person med funktionsnedsättning(ar) om dina vardag. Detta informationsblad är bara så du får en aning om vad det innebär så ta därför din tid och läs igenom detta. Du får gärna fråga mig något om du har några frågor eller så kan du diskutera det med andra om du vill.

Tack för att du läser detta.

Vad är syftet med denna studie?

Det jag vill veta är hur nedskärningarna och utformningen av välfärdstjänster har påverkat personer med funktionsnedsättningar i Sverige.

Varför har jag blivit frågad att delta?

Jag skulle vilja prata med dig för att du är en person som identifierar dig själv som en person med funktionsnedsättning(ar), är 18 år eller äldre, och du har eller har haft tillgång till funktionsnedsättningsrelaterade socialförsäkringar eller andra välfärdsinsatser.

Måste jag delta?

Nej. Du måste inte delta, det är helt frivilligt. Du behöver inte delta om du inte vill. Du får återkalla ditt deltagande när du vill utan att ge en anledning.

Vad händer om jag bestämmer mig för att delta?

Du kommer bli intervjuad/frågad om dina upplevelser och du kommer bli frågad om det är okej att intervjun används både före och efter intervjun.

Kommer mitt deltagande vara konfidentiellt?

Om du väljer att delta så kommer all information behandlas konfidentiellt. Dock finns det undantag i extrema fall om du berättar att du tänker skada dig själv eller andra. Då har jag en etisk plikt att vidarebefordra den informationen till relevanta organisationer så att rätt stöd kan ges. Dessutom är det viktigt att du förstår att informationen du ger mig i denna situation är inte 'legally privileged' – detta betyder att (i väldigt extrema fall) polisen/domstolar kan begära forskningsdata.

Vad kommer hända med resultaten av studien?

Reslutaten kommer vara en del av min doktorsavhandling i sociologi på The University of Glasgow och kan också vara med i framtida publikationer, artiklar eller presentationer. Detta är så klart anonymt.

Vem organiserar och finansierar forskningen?

Forskningen är självständigt organiserad men finansierat av stipendium från the ESRC (Economic and Social Research Council) i Storbritannien.

Vem har granskat studien?

The University of Glasgow’s etiska kommitté har granskat studien.

Kontakt för mer information

Du kan kontakta forskaren genom informationen på första sidan eller alternativt:

Om du har några farhågor om hur detta forskningsprojekt är utfört kan du kontakta The University of Glasgow’s College of Social Sciences Ethics Officer Dr Muir Houston, email: Muir.Houston@glasgow.ac.uk eller så kan du kontakta min handläggare Professor Nicholas Watson, email: Nicholas.Watson@glasgow.ac.uk

Appendix 2: Participant Information Sheet (English)

Plain Language Statement (or Participant Information Sheet)

Study title and Researcher Details

Disabled people and the Politics of the Welfare State

Researcher: Ida Norberg

Contact: i.norberg.1@research.gla.ac.uk
Telephone Number: xxxxxxx

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

The purpose of the study is to understand how the post-recession climate has impacted disabled people in Sweden.

Why have I been chosen?

You have been chosen because you are either (a) a person who identifies as disabled and have or have had access to disability-related benefits, (b) a civil servant working with either LSS, LASS or sick leave, or (c) a parliamentary politician working with disability-related issues.

Do I have to take part?

Participation in this research project is strictly voluntary so you do not need to participate if you do not want to. You are free to withdraw your participation at any time without giving a reason.

What will happen to me if I take part?

You will be interviewed by the researcher or have your letter included in the research material. You will be asked if you consent to the subsequent material being used both prior and after the collection of data.

Will my taking part in this study be kept confidential?

Please note that assurances on confidentiality will be strictly adhered to unless evidence of wrongdoing or potential harm is uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies.

What will happen to the results of the research study?

The research will inform the completion of a PhD in Sociology at the University of Glasgow. The data may also be used for publications such as books or articles or public presentations.

Who is organising and funding the research?

The research is independently organised by the researcher but funded by the ESRC (Economic and Social Research Council).

Who has reviewed the study?

The study has been reviewed by The University of Glasgow's ethics committee.

Contact for Further Information

You can contact the researcher with the information at the top of the form or, alternatively:

If you have any concerns regarding the conduct of this research project, you can contact the College of Social Sciences Ethics Officer Dr Muir Houston, email: Muir.Houston@glasgow.ac.uk

Appendix 3: Participant Information Sheet (welfare professionals) (Swedish)

University of Glasgow

College of Social Sciences

Informationsblad

Titel och forskarens kontaktinformation

Funktionsnedsättningar och den svenska välfärdsstaten

Forskare: Ida Norberg

Kontaktinformation: i.norberg.1@research.gla.ac.uk

Telefonnummer: XXXXX

Hej,

Jag heter Ida Norberg och jag doktorerar vid The University of Glasgow och jag forskar om hur folk med funktionsnedsättningar har blivit påverkade av utförsäkringarna, omstruktureringarna och nedskärningarna inom välfärdsstaten. Jag skulle vilja prata med folk som jobbar på Försäkringskassan deras arbete. Detta informationsblad är bara så du får en aning om vad det innebär så ta därför din tid och läs igenom detta. Du får gärna fråga mig något om du har några frågor eller så kan du diskutera det med andra om du vill.

Tack för att du läser detta.

Vad är syftet med denna studie?

Det jag vill veta är hur nedskärningarna och utformningen av välfärdstjänster har påverkat personer med funktionsnedsättningar i Sverige.

Varför har jag blivit frågad att delta?

Jag skulle vilja prata med dig för att du jobbar på Försäkringskassan med funktionsnedsättningsrelaterade bidrag eller för att du jobbar med liknande insatser för människor med funktionsnedsättningar.

Måste jag delta?

Nej. Du måste inte delta, det är helt frivilligt. Du behöver inte delta om du inte vill. Du får återkalla ditt deltagande när du vill utan att ge en anledning.

Vad händer om jag bestämmer mig för att delta?

Du kommer bli intervjuad/frågad om ditt arbete och ditt perspektiv på ändringarna i samhället de senaste åren för folk med funktionsnedsättningar. Du kommer bli frågad om det är okej att intervjun används både före och efter intervjun.

Kommer mitt deltagande vara konfidentiellt?

Om du väljer att delta så kommer all information behandlas konfidentiellt. Dock finns det undantag i extrema fall om du berättar att du tänker skada dig själv eller andra. Då har jag en etisk plikt att vidarebefordra den informationen till relevanta organisationer så att rätt stöd kan ges. Dessutom är det viktigt att du förstår att informationen du ger mig i denna situation är inte 'legally privileged' – detta betyder att (i väldigt extrema fall) polisen/domstolar kan begära forskningsdata.

Vad kommer hända med resultaten av studien?

Reslutaten kommer vara en del av min doktorsavhandling i sociologi på The University of Glasgow och kan också vara med i framtida publikationer, artiklar eller presentationer. Detta är så klart anonymt.

Vem organiserar och finansierar forskningen?

Forskningen är självständigt organiserad men finansierat av stipendium från the ESRC (Economic and Social Research Council) i Storbritannien.

Vem har granskat studien?

The University of Glasgow’s etiska kommitté har granskat studien.

Kontakt för mer information

Du kan kontakta forskaren genom informationen på första sidan eller alternativt:

Om du har några farhågor om hur detta forskningsprojekt är utfört kan du kontakta The University of Glasgow’s College of Social Sciences Ethics Officer Dr

Muir Houston, email: Muir.Houston@glasgow.ac.uk eller så kan du kontakta min handläggare Professor Nicholas Watson, email: Nicholas.Watson@glasgow.ac.uk

Appendix 4: Participant Information Sheet (disability organisations) (Swedish)

University
of Glasgow

College of Social
Sciences

Informationsblad

Titel och forskarens kontaktinformation

Funktionsnedsättningar och den svenska välfärdsstaten

Forskare: Ida Norberg

Kontaktinformation: i.norberg.1@research.gla.ac.uk

Telefonnummer: XXXXX

Hej,

Jag heter Ida Norberg och jag doktorerar vid The University of Glasgow och jag forskar om hur folk med funktionsnedsättningar har blivit påverkade av förändringarna inom välfärdsstaten. Jag skulle vilja prata med funktionsnedsättningsorganisationer om deras perspektiv på detta och deras arbete. Detta informationsblad är bara så du får en aning om vad det innebär så ta därför din tid och läs igenom detta. Du får gärna fråga mig något om du har några frågor eller så kan du diskutera det med andra om du vill.

Tack för att du läser detta.

Vad är syftet med denna studie?

Det jag vill veta är hur nedskärningarna och utformningen av välfärdstjänster har påverkat personer med funktionsnedsättningar i Sverige.

Varför har jag blivit frågad att delta?

Jag skulle vilja prata med dig för att du är en representant från en funktionsnedsättningsorganisation om ert perspektiv på detta och om hur funktionsnedsatta personer behandlas i samhället rent allmänt.

Måste jag delta?

Nej. Du måste inte delta, det är helt frivilligt. Du behöver inte delta om du inte vill. Du får återkalla ditt deltagande när du vill utan att ge en anledning.

Vad händer om jag bestämmer mig för att delta?

Du kommer bli intervjuad/frågad om din organisation, ert arbete och ert perspektiv på ändringarna i samhället de senaste åren för folk med funktionsnedsättningar. Du kommer bli frågad om det är okej att intervjun används både före och efter intervjun.

Kommer mitt deltagande vara konfidentiellt?

Om du väljer att delta så kommer all information behandlas konfidentiellt. Dock finns det undantag i extrema fall om du berättar att du tänker skada dig själv eller andra. Då har jag en etisk plikt att vidarebefordra den informationen till relevanta organisationer så att rätt stöd kan ges. Dessutom är det viktigt att du förstår att informationen du ger mig i denna situation är inte 'legally privileged' – detta betyder att (i väldigt extrema fall) polisen/domstolar kan begära forskningsdata.

Vad kommer hända med resultaten av studien?

Reslutaten kommer vara en del av min doktorsavhandling i sociologi på The University of Glasgow och kan också vara med i framtida publikationer, artiklar eller presentationer. Detta är så klart anonymt.

Vem organiserar och finansierar forskningen?

Forskningen är självständigt organiserad men finansierat av stipendium från the ESRC (Economic and Social Research Council) i Storbritannien.

Vem har granskat studien?

The University of Glasgow's etiska kommitté har granskat studien.

Kontakt för mer information

Du kan kontakta forskaren genom informationen på första sidan eller alternativt:

Om du har några farhågor om hur detta forskningsprojekt är utfört kan du kontakta The University of Glasgow's College of Social Sciences Ethics Officer Dr Muir Houston, email: Muir.Houston@glasgow.ac.uk eller så kan du kontakta min handläggare Professor Nicholas Watson, email: Nicholas.Watson@glasgow.ac.uk

Appendix 5: Consent form (Swedish)

College of Social Sciences Research Ethics Committee

University of Glasgow

College of Social Sciences

Consent Form

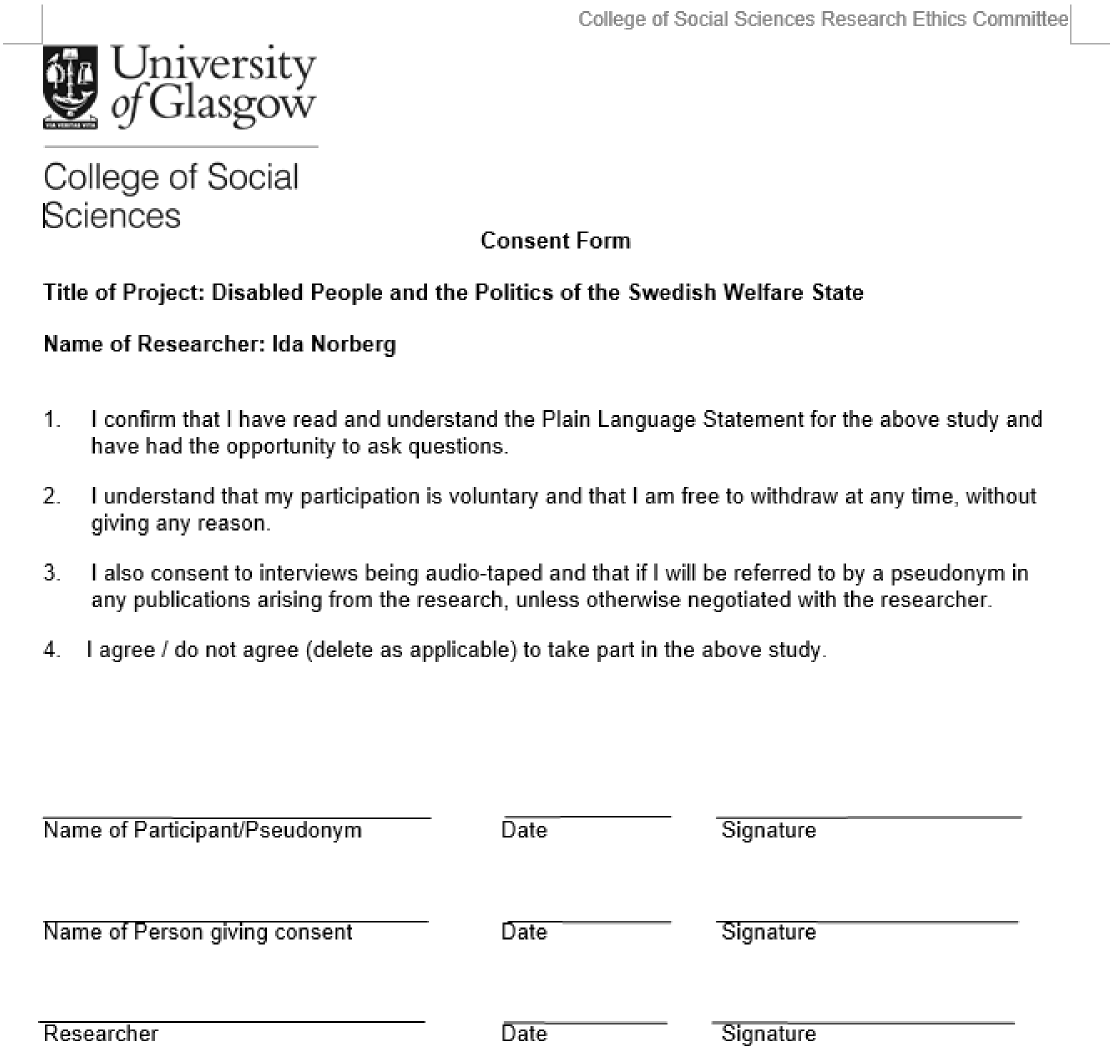
Projekttitel: Funktionsnedsättningar och den svenska välfärdsstaten

Forskare: Ida Norberg

1. Jag kan bekräfta att jag har läst och förstått informationsbladet för den ovannämnda studien och har haft tillfälle att ställa frågor. ☐
2. Jag förstår att mitt deltagande är frivilligt och att jag kan säga upp mitt deltagande när som helst, utan att ge en anledning. ☐
3. Jag godkänner också att intervjun blir inspelad och att jag kommer att få ett pseudonym i alla publikationer som byggs på detta forskande, så vidare något annat inte blivit beslutat i samtal med forskaren. ☐
4. Jag godkänner / godkänner inte (ta bort det som inte är relevant) att delta i denna studie. ☐

Deltagare/Pseudonym	Datum	Signatur
Namn på den som ger godkännande	Datum	Signatur
Forskare	Datum	Signatur

Appendix 6: Consent form (English)



College of Social Sciences Research Ethics Committee

University of Glasgow

College of Social Sciences

Consent Form

Title of Project: Disabled People and the Politics of the Swedish Welfare State

Name of Researcher: Ida Norberg

1. I confirm that I have read and understand the Plain Language Statement for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I also consent to interviews being audio-taped and that if I will be referred to by a pseudonym in any publications arising from the research, unless otherwise negotiated with the researcher.
4. I agree / do not agree (delete as applicable) to take part in the above study.

Name of Participant/Pseudonym	Date	Signature
Name of Person giving consent	Date	Signature
Researcher	Date	Signature

Appendix 7: Topic Guide (disabled people) (Swedish)

Exempel på frågor: Människor med funktionsnedsättningar

- Berätta lite om dig själv, vem är du?
- Hur ser en vanlig dag för dig ut?
- Vilka socialbidrag har du haft/har du?
    - Hur länge har du haft dem/hade du dem?
    - Förändrade ditt liv på något vis?
        - Om reducerat eller borttaget, ändrade det ditt liv på något vis?
            - (Har de fortfarande tillgång till vård?)
            - (Har du hört om någon annan som fått sina bidrag neddragna?)
        - Om kvar, tror du din upplevelse är typisk?
    - Möter det dina behov?
        - Ja? Nej? På vilket sätt?
        - Om nej, vad skulle du behöva?
- Hur skulle du beskriva den politiska miljön för folk med funktionsnedsättningar i Sverige idag?
    - Tycker du det har varit de senaste 20 åren: har det varit det samma eller ändrats på något vis?
- Hur skulle du beskriva den sociala miljön för folk med funktionsnedsättningar i Sverige idag?
    - Tycker du det har varit de senaste 20 åren: har det varit det samma eller ändrats på något vis?
    - Tror du att saker och ting kan förbättras för folk med funktionsnedsättningar? Och i så fall, på vilket sätt?
- Någonting annat du skulle vilja diskutera/prata om som vi inte har pratat om än?

Appendix 8: Topic Guide (disabled people) (English)

Disabled people

- Tell me a little bit about yourself. Who are you?
- What does an average day look like?
- For how long have you had/did you have [type of benefit(s)]?
- Did that change your life in any way?
- If got reduced or revoked benefit, did that change anything in your life?
- Does it meet your needs? Yes? No? If so, in what way?
    - If no, what would meet your needs to do you think?
- How would you characterise the policy environment for people with disabilities?
    - Do you think it has fared in the last twenty years: stayed the same? Changed?
- How would you characterise the societal environment for people with disabilities in Sweden generally?
    - Do you think it has fared in the last twenty years: stayed the same? Changed?
    - Do you think things can improve for disabled people? If so, in what way?

Appendix 9: Topic guide (disability organisations) (Swedish)

Exempel på frågor: Funktionsnedsättningsorganisationer

- Hur skulle du beskriva den politiska miljön för folk med funktionsnedsättningar i Sverige idag?
    - Tycker du det har varit de senaste 20 åren: har det varit det samma eller ändrats på något vis?
    - Är det olika vid olika delar av landet? (exempelvis: Umeå, Göteborg, Stockholm)
- Hur skulle du beskriva den sociala miljön för folk med funktionsnedsättningar i Sverige idag?
    - Tycker du det har varit de senaste 20 åren: har det varit det samma eller ändrats på något vis?
- Tror du att saker och ting kan förbättras för folk med funktionsnedsättningar? Och i så fall, på vilket sätt?
- Berätta lite om er organisation?
- Hur ser en vanlig dag för dig ut?
- Någonting annat du skulle vilja diskutera/prata om som vi inte har pratat om än?

Appendix 10: Topic guide (disability organisations) (English)

- How would you describe the political environment for people with disabilities in Sweden today?
    - How do you think it has been for the last 20 years: has it been the same or changed in some way?
    - Is it different in different areas of the country? (for example Umea, Goteborg, Stockholm)
- How would you describe the social environment for people with disabilities in Sweden today?
    - How do you think it has been for the last 20 years: has it been the same or changed in some way?
- Do you think that things can improve for people with disabilities? If so, in what way?
- Tell me a little bit about your organisation?
- How does a normal day look like to you?
- Something you want to talk about that we haven’t yet?

Appendix 11: Topic guide (welfare professionals) (Swedish)

Exempel på frågor: Caseworkers och dylikt

- Försäkringskassans service till funktionsnedsatta människor har ändrats mycket de senaste åren, är detta någonting du har märkt i ditt jobb?
    - Om ja, hur har det påverkat ditt jobb?
- Hur skulle du beskriva den politiska miljön för funktionsnedsatta människor?
    - Tycker du det är den samma eller har det ändrats?
    - Tycker du det är annorlunda där du är gentemot landet som stort eller är det lika? Om detta, på vilket sätt?
- Är det något om ditt jobb du skulle vilja ändra?
- Är det något du tycker speciellt mycket jobb i ditt jobb?
- (Vad tycker du allmänheten har för uppfattning om Försäkringskassan/ditt jobb?)
- Något vi inte hunnit prata om än som du skulle vilja prata om?

Appendix 12: Topic guide (welfare professionals) (English)

- The Social Insurance Agency's service to disabled people have changed a lot these past years, is that something you have noticed in your job?
    - If yes, how has it affected your job?
- How would you describe the political environment for disabled people?
    - Do you think it is the same or has it changed?
    - Do you think that it is different where you are compared to the country as a whole? If yes, in what way?
- Is there anything about your job you'd like to change?
- Is there something you especially like with your job?
- (What do you think the public perception is about the Social Insurance Agency/your job?)
- Något vi inte hunnit prata om än som du skulle vilja prata om?

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