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Isabella Bertmann

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An Empirical Study on Social Protection and Disability in South Africa

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An Empirical Study on Social Protection and Disability in South Africa

With a foreword by Prof. Dr. Elisabeth Wacker

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Foreword by the Editor

As far as quality of life is concerned, everybody wants to hit the jackpot. Both the poor and the rich long for it. In the case of life risks, social service systems may guarantee appropriate support and contribute to maintaining or enhancing a person's quality of life; at least that is what we expect in the so-called Global North. We tend to assume that some kind of help can always be found, when it is needed. But can one thrive without sufficient social protection?

Indeed, who supports a person in need when there is little or no social protection? And what is the impact of a small monetary benefit for underprivileged people confronted with challenging circumstances? The study conducted by Isabella Bertmann investigated these questions in the South African context with a particular emphasis on the circumstances of persons with disabilities. The Sociology of Diversity Chair at the Technical University of Munich, Prof. Elisabeth Wacker, and the Executive Dean of the Faculty of Law at the University of Johannesburg, Prof. Letlhokwa George Mpedi, reviewed and assessed this PhD-Thesis, entitled "Taking Well-Being and Quality of Life for Granted? An Empirical Study on Social Protection and Disability in South Africa" before awarding it the highest honour (summa cum laude). The investigation was focused on the aims and effects of the so-called "Disability Grant" – both theoretically and empirically, based on an exemplary field study. In this context, funds are allocated under social security conditions that diverge widely from the systems perceived as self-evident in many Western societies. With its focus on a group with specific diversity attributes, i.e. persons living with considerable impairments, the study examines the development, social significance, subjective assessment and effectiveness of this form of social protection in South Africa. It concludes that a potential effect of these grants is that "material capital" can be transformed into "social capital" under certain circumstances.

The qualitative study first discusses theoretical issues: from the clarification of basic questions to an intersectional reference to disability and poverty, which play a central role in the dissertation. Based on state-of-the-art academic and international standards, the study presents definitions of poverty and disability and delineates the central ethical issues deriving from a human rights perspective. It reviews social policy and social inclusion from an international perspective and offers a contextualisation of the South African social protection system within a global perspective on the opportunities and limits of social policy and its intentions as to inclusion and distributive justice. With a reference to Rawls, a bridge is built towards the group of people with impairments who, from his perspective, are characterised as "people who are not capable of self-supply". The chapter "Approaching Quality of Life and Well-Being from a Multi-Disciplinary Perspective" then explores questions linked to the "quality of life" and "well-being" constructs with their strongly subjective dimensions – in terms of both underlying ethical intentions and conceptual operationalisation. The thread, here, is provided by Amartya Sen's widely acclaimed Capability Approach that also highlights the link to the economic or materialistic aspects of benefit systems without losing itself too deeply in the maze of justice issues. This theory also opens up multidisciplinary perspectives on "well-being" and "quality of life" through the recourse to the agency approach as it ties in with the internationally accredited classification system of the World Health Organisation, i.e. the International Classification of Functioning, Disability and Health (ICF). This link thus enables a practical reference to various social security systems as well as a comparative approach.

Issues of social and disability policy in South Africa, as well as aspects of rehabilitation, compensation for disadvantages and participation frame the empirical study. Unsurprisingly, facts are (and must be) mentioned that highlight glaring inequalities and the challenges entailed for the existing social protection system when it comes to mitigating them.

In the ensuing field study, these theoretical considerations then meet practical research. The type of qualitative data collected is described and justified – from the generation of (interview-based) data to its interpretation. Here, living conditions are spotlighted and framed by the Capability Approach. Thanks to the sensitive touch of the study, it successfully manages to carve out how (much) "social capital" can be unlocked with the help of a monetary benefit. One of the merits of the attentive text analysis is that the transition between "disability" and normality" is acknowledged as a fluid process rather than the result of a "simple attribution". It also emphasises that "normality" always lies in the eye of the beholder or, as an interview partner worded it, "We are normal as other people". Nevertheless, through the analysis of everyday life, the study also reminds us that the life course is influenced by a number of obstacles. This insight is then related to Sen's agency concept and exemplified in the form of typologies.

So what is the study's unique contribution to the field? Just as South Africa is full of contrasts, the discussion of results is fittingly multi-perspective. It shows that – as already hinted at in the underlying hypothesis – financial benefits do display a considerably enabling potential. Indeed, the effect of these benefits goes well beyond the purchase of aids (support provided by objects or surroundings). In fact, the monetary contribution leads to considerable social esteem, hence a form of participation. South Africa thus positions itself as a state less focused on becoming a caring provider than an empowering enabler in a participative citizen society. And it does so despite the admittedly long road and the fact that this path is riddled with multiple exclusion risks that still have to be addressed. In the spirit of Nobel laureate Sen's Capability Approach, the study also stresses that individual room to manoeuvre (self-determination) is a necessary indicator. Hence the author directs her readers' attention to the necessity of paying increased attention to risks inherent in disability and poverty and respective participation restrictions as well as of setting standards for countries that aim towards social justice (beyond quality of life and equal opportunities for everyone).

In sum, this opus very convincingly conveys that studies on and from the Global South can provide globally relevant findings. Indeed, the insights uncovered by this fascinating and unusual investigation can be easily related to the current scientific discourse on poverty and disability. The study could thus inspire German social policy, which is still caught in a non-cash benefit system, as well as contribute to a rapprochement between a fairly self-centred rehabilitation science and much more broadly defined international inclusion discourses. It could also provide a path towards removing the artificial divides between social economy and social welfare. Therefore, a broad dissemination of this work as well as sequels would be highly desirable.

Elisabeth Wacker

Prologue: The Importance of Inclusive Social Protection – Experiences of a Social Worker

“For instance I had a client but he just died. This man was brought to our group. He was, he was in a wheelchair which was so old, was brought when we were initiating the group. But I never saw him after that, I was so concerned so I asked the guy who brought him then, I asked: ‘Is, is the guy?’ He said: ‘No, he is at home.’ I said: ‘No, I want to go and see him.’

When I saw him, […] the, the situation was so bad. The, the shack it was one room-shack full, like this guy before he was disabled, he could fix electricity things […]. So the, the shack was full of those electrical devices […], those electric appliances. It was full dirty, the bed he was sleeping in, the blanket that he was using. And can’t move. The wheelchair is broken. I managed to get a wheelchair for him at *name of organization*.

Actually they borrowed him they said the, the wheelchair that would be perfect for him is an electrical one. So I had to apply for it. So they borrowed him another good condition wheelchair […]. So this guy has an ID. But he, he cannot get a grant. Because the ID is saying he is female, but he is a male. Then I contacted Home Affairs. And this guy can’t travel from *name of area* to Home Affairs. So it was that long process asking Home Affairs to do a home visit.

And then I also requested in the organization for money for food. Because this guy would go on for days without food. The, the situation was so terrible really. So on that day that I got the wheelchair, I got 200 rand from here from the office. So we bought food. This guy, that’s his friend, was cooking the food for him. So after that I referred the guy to this organization, *name of organization*. They have a soup kitchen, they have food parcels. And when I went there, I, I delivered the referral letter myself. I spoke to the social worker. […] ‘Did you realize that?’

They know him. There were home-based carers who were going there. But I don’t know why they stopped going. So the social worker promised that now they have ordered the food parcels so they will give the food parcel. But unfortunately after that I got sick, I was in hospital for a month. While I was in hospital, I received an SMS that this guy passed away because of hunger, you see.

Those are the situations that other people are facing, you see […]” (SWO_V, EX10, Western Cape).

Words of Thanks

This thesis presents the results of my work as a member of the Max Planck Fellow Group "Inclusion & Disability" at the Max Planck Institute for Social Law and Social Policy and as a PhD student and member of the Graduate School at the Technische Universität München.

The country focus of this thesis is on South Africa. First, I would therefore like to express my gratitude to a number of people for supporting my research activities in the Eastern and Western Cape. During my stays in Cape Town and Port Elizabeth, I was overwhelmed by my interview partners' willingness to share their knowledge, opinions, and life experiences with me. Thank you all.

I would also like to thank everybody else who provided support in one way or another during the last years, for example by challenging my ideas and giving advice regarding the content of this thesis, by contributing towards maintaining and widening my own capability set, and by creating invaluable opportunities that helped me in pursuing this project.

In this regard, I am especially grateful to Professor Elisabeth Wacker, Professor Letlhokwa George Mpedi, Dr. Hannemor Keidel, Professor Theresa Lorenzo and the Disability Studies Program at UCT, the Centre for Disability Law and Policy at UWC, Dr. Laura Dobusch and the other members of our Max Planck Fellow Group, the staff members at the Max Planck Institute for Social Law and Social Policy, all my colleagues at TU Dortmund and TU München, and my former colleagues and superiors in Bonn and Eschborn.

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Finally, yet importantly, I want to thank Andreas, my parents, and my sister Julia, as well as my friends all over the world for their continuous support, wisdom, and especially patience.

Isabella Bertmann

Contents

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List of Abbreviations

BIG	Basic Income Grant
BMZ	Bundesministerium für wirtschaftliche Zusammenarbeit und Entwicklung
CA	Capability Approach
CBR	Community-based Rehabilitation
CDG	Care Dependency Grant
CRPD	Convention on the Rights of Persons with Disabilities
DG	Disability Grant
DICAG	Disabled Children’s Action Group
DPO	Disabled People’s Organization
DPSA	Disabled People South Africa
DWCPD	Department of Women, Children & People with Disabilities
GDI	Gender-related Development Index
GEM	Gender Empowerment Measure
GIZ	Deutsche Gesellschaft für Internationale Zusammenarbeit (GIZ) GmbH
GNI	Gross National Income
GNP	Gross National Product
HDI	Human Development Index
HDR	Human Development Report
HPI	Human Poverty Index
ICESDF	Intergovernmental Committee of Experts on Sustainable Development Financing
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairments, Disabilities, and Handicaps
INDS	Integrated National Disability Strategy
MDG(s)	Millennium Development Goal(s)
MDS	Ministério do Desenvolvimento Social e Combate à Fome (Brazil)
NP	National Party
ODI	Overseas Development Institute
OECD	Organisation for Economic Co-operation and Development

OSDP	Office of the Status of Disabled Persons (South Africa)
OWG	Open Working Group
PMG	Parliamentary Monitoring Group
RSCAS	Robert Schuman Centre for Advanced Studies
SAFOD	Southern Africa Federation of the Disabled
SAHRC	South African Human Rights Commission
SDG(s)	Sustainable Development Goal(s)
TB	Tuberculosis
UIF	Unemployment Insurance Fund
UN	United Nations
UNAIDS	Joint United Nations Programme on HIV/AIDS
UN DESA	United Nations Department of Economic and Social Affairs
UN GA	United Nations General Assembly
UNDP	United Nations Development Programme
UPIAS	Union of the Physically Impaired Against Segregation
WB	World Bank
WHO	World Health Organization

1 Introduction

In research and practice alike, it is often stated that, together with further groups (e.g., children or elderly people), persons with disabilities[1] are more likely to be affected by poverty than other members of society. Commonly referred to as one of the "most vulnerable groups,"[2] persons with disabilities are said to be more exposed to environmental barriers and societal injustices, and to experience poverty and social exclusion more intensively than the social majority or mainstream society. Indeed, persons with disabilities are one of the population groups with the lowest access to resources, social goods, and services, and at the same time have the highest vulnerability to risks. Reasons for this include environmental aspects, such as the inaccessibility of information or buildings, but also include social barriers in numerous areas. Due to a variety of marginalizing and stigmatizing practices, which might for example lead to their exclusion from the education system or labor market, persons with disabilities often belong to the poorest sections of

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[1] The term "disability" requires further explanation and contextualization, e.g., in relation to "impairment." This will be taken up in detail in chapter two. For the moment, and for the purposes of this introduction, the presented understanding is in line with the conceptualization of "disability" as outlined in article 1 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN 2006). According to this explanation, the term "persons with disabilities" refers to experiences of social and environmental barriers that negatively influence the social participation of the persons concerned. The term "impairment" is (only) used when the focus is on the individual and his/her body or medical condition. Different disability models, the terminology (e.g., "persons with disabilities" in contrast to "disabled people"), and further issues regarding the conceptualization of "disability" and its use in this thesis will be dealt with in the second chapter.

[2] According to Barrientos (2010: 581), "vulnerability" can be understood "as the strong likelihood that individuals, households, and communities will be in poverty in the future." The concept is however not clearly definable, as it might refer to a variety of different aspects (e.g., risk, danger, in need of support) and includes different types of vulnerability (i.a., structural, contextual, personal). The same holds true for the term "vulnerable group(s)," which might refer to different groups in society and can vary according to the context in which it is used. In addition, the members of a specific "vulnerable group" might not be very homogeneous (Larkin 2009: 1 ff.). Thus, McClain-Nhlapo (2010: 123) comments that "[a] category like 'vulnerable groups', while useful at certain levels of analysis, becomes an obstacle when it hides essential differences in poverty determinants of various vulnerable sub-groups, such as people with disabilities."
Regarding a discussion of vulnerability and the different consequences that risks can entail, see also Loewe (2008a: 35 f.).

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society. The effects of social inequality are most likely to occur if participation in the education system and labor market is limited and are manifested when, in addition, the perceptibility and obviousness of certain characteristics and distinguishing features are high:

> "Je selbstverständlicher eine Evidenz der Offensichtlichkeit unterstellt werden kann, um so direkter bietet sich ein Merkmal als Bezugspunkt von Unterscheidungen an und um so stabiler bleibt es als Unterscheidungsgrundlage wirksam" (Bendel 1999: 306).[3]

Against the thematic background outlined above, the main concern of this thesis is to find out about the connection between social policy, more precisely mechanisms of social protection, and the quality of life of persons with disabilities, as well as conceptualizations and perceptions of disability and poverty. Specific questions include the following: How do concepts of disability and poverty affect their quality of life and well-being?[4] What role does the concept of social protection[5] play in enhancing their living standards? And which aspects contribute to the implementation and achievement of (disability-)inclusive social development? The thesis focuses on the Disability Grant (DG) and the Care Dependency Grant (CDG) in South Africa and their effects on the living conditions of poor persons with disabilities. In order to be able to analyze the specific situation in South Africa and the way the social protection benefits can influence a person's living situation, general theoretical considerations have to be introduced first. In this thesis, I am going to argue that Amartya Sen's Capability Approach[6] (e.g., Sen 1992; Sen 1999; Sen 2009) is an adequate framework with which to analyze the effects of the grants on people's quality of life, given the thematic complexity outlined above. Briefly, the approach conceptualizes development as "expanding the real freedoms that people enjoy" (Sen 1999: 3). Thus, it is necessary to remove external constraints and the "various types of unfreedoms that leave people with little choice and little opportunity of exercising their reasoned agency" (ibid.: xii).

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[3] Own translation: "The more self-evident obviousness can be assumed, the more directly does a characteristic serve as a distinguishing feature, and the more stable it remains as a valid basis for differentiation."

[4] A detailed discussion of the terms "quality of life" and "well-being" is included in chapter four.

[5] Social protection can be understood as "the last line of defence against poverty" (Mont 2010: 317) and can comprise several forms of benefits: cash or in-kind, contributory vs. non-contributory, etc. For a long time, "social protection programmes – particularly safety nets – were seen solely as a way of catching people who fall into poverty and providing them with basic necessities" (ibid.: 318). Now, the consideration of a variety of risks is more in focus. This perspective can be broadened by focusing on the potential of social protection for social development and inclusion more generally. The terms "social protection" and "social security," as well as "social assistance" and "social insurance," will be discussed further in chapter three.

[6] For an initial introduction to the Capability Approach, see, e.g., Robeyns (2005) or the edited volume by Comim et al. (2008).

Following the approach, it is important to investigate the chances and options people have—rather than focusing solely on the amount of money or other resources available to them. The spectrum between commodities and resources on the one hand and a person's achievement on the other are the focal point here. This is important for both those who are classified as "poor" and for those to whom the attribute of "disability" is assigned.

On this basis, chapter two defines and conceptualizes disability, and refers to authors and arguments that challenge the still common—medically oriented—perspective on disability. The chapter aims to explain the conceptualization of disability and its relation to the concept of impairment. Furthermore, the focus will be on attribution processes ("Zuschreibungsprozesse"), different disability models, and cultural issues regarding the understanding of disability in different social contexts and countries. In addition, the complex relation of disability and poverty will be explored. The role of disability law and policy, as well as their contribution towards the elimination of social exclusion and processes of stigmatization, will also be elaborated on. The following chapter, chapter three, looks into social policy and social justice from a theoretical and policy background. Concepts and definitions of social security and social protection, their origins, and current developments are highlighted in further detail. The chapter ends by building a bridge to the second chapter through a discussion of the link between the thematic fields of disability and social protection. Aspects such as access to measures and services, targeting,[7] and disability assessment are of importance in this regard. This is followed by an in-depth discussion on quality of life and well-being in chapter four, with a particular emphasis on the Capability Approach.

In order to adequately investigate the inclusion of persons with disabilities in social policy and within a specific social system,[8] it is important to provide an overview of existing studies, the sociopolitical situation, and the country's legal framework. This is the topic of the subsequent part of the thesis (chapter five), which presents details regarding the focus country of this project: South Africa.

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[7] Measures that are targeted at specific groups of people could cause high administrative efforts and costs. In addition, errors can occur in cases where a person does not receive a benefit even though he/she deserves it. Or, alternatively, if somebody does not deserve a benefit but nonetheless receives it (e.g., Mkandawire 2005: 9; also Burgess/Stern 1991: 62 ff.). Mkandawire (2005: 14) refers to Sen (1995: 13), who has added another argument in favor of universalism instead of targeting: "any system of subsidy that requires people to be identified as poor or that is seen as a special benefaction for those who cannot fend for themselves would tend to have some effects on their self-respect as well as on the respect accorded them by others."

[8] As will be shown below, there is a difference between social security and social protection. "Social system" is applied here as an umbrella term including measures of social protection and social security but also other approaches or means used by governments and other actors to promote social development.

The chapter aims to highlight the focus and orientation of South Africa's social and disability policy. Thus, it will create a link to the theoretical arguments presented up to that point. Concrete aspects include the question of which definition and understanding of disability is prevalent, what kind of conclusions can be drawn on this basis, and what practical effects result from this. For example, is disability regarded as a mainstream or cross-cutting topic in social law and social policy? This information serves as the background for the second major part of the thesis: the empirical results of a qualitative data collection and analysis.

For that purpose, two closely related qualitative data collection approaches[9] were chosen: firstly, expert interviews with professionals in the fields of disability law and policy, which reveal information about the policy level. These interviews were also informative and substantial as far as the interview partners' own background was concerned, as most professionals had personal disability experiences. Secondly, personal interviews were conducted that were semi-structured and contained narrative elements, so that valuable firsthand experience on disability and social protection could be collected during the field phase in South Africa.[10]

The analysis of the interview transcripts is presented in detail in chapter seven, followed by a presentation of the results and respective conclusions in chapter eight. Last but not least, at the end of the thesis, I will relate these findings back to the international discourse on social protection, poverty alleviation, and inclusive development outlined in the first chapters. The main line of argument of my thesis is to reconceptualize disability and poverty as far as access to social protection and the enhancement of quality of life are concerned. By approaching both categories from a capability perspective, it is possible to take into consideration aspects of diversity and move away from a deficit-oriented and vulnerability-focused perspective on human differences. Questions of needs and rights as well as personal agency play an important role for equality in social participation and development.

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[9] I abstain from an extensive discussion of the advantages and disadvantages of qualitative and quantitative data collection (see, e.g., Wolf (1995); von Saldern (1995)). In order to generate satisfying research results, ideally both sources of data are needed. For the context of this project, one asset that qualitative approaches offer is to generate context-sensitive data in order to reflect the complex reality as far as the living situations of persons with disabilities in South Africa are concerned. In addition, the thesis endeavors to make a contribution to the application of the Capability Approach in the context of qualitative research.

[10] For details, see chapter six.

2 Definitions of Poverty and Disability

The sociological and political discourses around categories like gender, race, and class have yielded a variety of critical approaches, points of view, and academic literature. Disability, however, has for a long time been dealt with mainly in fields like pedagogy, medicine, and psychology.[11] The emergence of the disability rights movement, both on a national and international level, has led to new research disciplines such as disability studies. In combination with the opening up of sociological or intersectional research on this "new", i.e., neglected, category, more critical approaches and more heterogeneous perspectives on "disability" were developed. Waldschmidt and Schneider (2007: 10) argue that disability is needed as a category to guarantee a certain degree of social stability and differentiation, and to maintain ideas of subjectivity and corporeality in order to be able to construct "normality."

As far as colloquial language and the everyday use of words are concerned, dictionaries refer to "disability" from an individual-centered and medical perspective, focusing on a person's body. This can, for example, be seen in the Oxford Advanced Learner's Dictionary (n.d., dictionary entry on "disability"): "a physical or mental condition that means you cannot use a part of your body completely or easily, or that you cannot learn easily." Impairment and handicap have quite similar definitions in this and other encyclopedias. Even though the dictionary acknowledges that "many people now think it [i.e., handicap; IB] is offensive" (ibid.), it can be noted that in spoken language the three terms are still often used interchangeably or without further reflection. A negative view on and medical understanding of disability characterize their use. Exactly this combination of words and their underlying meaning also formed part of an influential conceptualization of health by the World Health Organization (WHO 1980), namely the International Classification of Impairments, Disabilities, and Handicaps (ICIDH). The use of the term "handicap" received much criticism for being deficit-oriented, and the following—and still valid—WHO classification was renamed as the International Classification of Functioning, Disability and Health (ICF). While "handicap" is no longer in use, it refers to the two aspects "impairment" and "disability" (WHO 2001); a person's impairment can be assessed by means of body functions and

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[11] For a discussion of the sociological discourse on "disability" in the last 50 years (in Germany), see, e.g., Wacker (2011).

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structures. In addition, limitations regarding a person's activity and participation are examined. Even though contextual factors are taken into consideration in the ICF, the classification still appears to be very health-focused.

The differentiation between impairment and disability was also taken up by the Convention on the Rights of Persons with Disabilities (CRPD) (UN 2006), which was adopted by the United Nations (UN) in December 2006[12] and contains the following explanation in its first article:

> "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (UN 2006).

As will be shown below, both international frameworks (CRPD and ICF) follow the logic of the so-called social model of disability. In addition, the CRPD can also be said to reflect a "rights-based approach to disability." Although those frameworks and models constitute international consensus, they can nonetheless be criticized as insufficient to adequately capture the "phenomenon" of disability (Waldschmidt 2005: 19 ff.; Shakespeare 2013: 217 ff. (critique on the social model); Degener 2009: 201[13]). A deeper engagement with the historical development, as well as the attempt to theorize the concepts and meanings of disability from a sociological perspective, is therefore necessary. This chapter thus

- concentrates on the thematic areas of diversity, discrimination, and injustice;
- traces the development as well as the theoretical underpinnings of different disability models and their use;
- gives an insight into the discussion on inclusive development; and
- provides a justification on and explanation for the use of the term "disability" and related words throughout the thesis.

In addition, some general points for discussion concerning disability law and policy will be presented. Concrete aspects of the field of South African disability law and policy are included in the relevant chapter (five).

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[12] The Convention entered into force on May 3, 2008, after having been ratified by 20 countries (and the Optional Protocol by 10 states).

[13] Degener (2009: 201) argues that even though the social model was primarily the counter-concept of the medical model, in international legal sciences the rights-based approach to disability was preferably used.

2.1 Defining Disability

Many arguments from the international scientific discourse on disability can be exemplified by referring to the above-mentioned quote taken from the CRPD, which aims to describe who persons with disabilities are. Among them, the following aspects will be discussed here: (1) capturing “disability” through a dynamic concept, (2) finding the correct denomination for the group of persons concerned, and (3) recognizing the significance of the social model of disability. As can be concluded from the fact that the text passage quoted from the CRPD regarding persons with disabilities does not appear in the convention’s second article on “definitions,” the passage is not to be understood as a final and universal determination of what “(a) disability” is. Rather, it presents a dynamic concept where the boundaries between disability and non-disability are fluid and depend on social, cultural, political, and personal circumstances (Waldschmidt 2005: 25; Meekosha/Soldatic 2011: 1391). The meaning and impacts of the ascription of a disability status can vary for each individual, especially in different cultural and sociopolitical contexts.

Historically, the emergence of modern medicine has led to a process of medicalization and, in the long run, to the application of the singular attribute “the disabled” (or, e.g., “der/die Behinderte” in German), which was—and still is—used to characterize people, while overlapping all other criteria or characteristics.[14] The choice of words, the social reactions, and practices like the institutionalization of persons with disabilities have been denounced by the international disability rights movement.[15] In Germany, for example, the “Krüppelbewegung” (cripple movement) fought against separation and exclusion, and advocated for self-determined living.[16] Despite the fact that the movement started several decades ago, the negative view on disability had for a long time been manifested in the use of language. As Degener (2009: 204) notes, the definition of disability was also a highly contested subject among those responsible for the drafting of the CRPD. The explanation or quasi-definition included in article 1 can be seen as a compromise, and it does have a political significance as it appears in an international human rights treaty already signed and also ratified by more than 150 countries worldwide (UN Enable 2015).

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[14] Bendel (1999: 304, footnote 6) gives the example of toilets for men, women, and “the disabled.” In addition, he refers to Beck (1986), who introduced the concept of a quasi-natural (“quasinaturvermittelter”) status as far as people’s ethnic origin is concerned. This concept is transferable from “ethnicity” to “disability.”

[15] The history of the South African disability rights movement will be briefly outlined in chapter five.

[16] For a historical overview of the German disability rights movement, see, e.g., Köbsell (2006).

The aim was to ensure that all people with impairments[17] are covered by the CRPD, irrespective of the cause of their impairment and/or levels of social acceptance. In addition, the social dynamics, barriers, and processes of in- and exclusion should be reflected on in order to avoid perpetuating and maintaining the individual model (Degener 2009: 204). However, as the contested nature of the concept is not reflected in this smallest common denominator, it cannot necessarily be regarded as a success from a critical scientist's (or self-advocate's) point of view (ibid.). And, interestingly, the wording does not reflect international discussions in disability studies and research; many scholars and opponents of the individual and medical model of disability favor the term "disabled people" over "persons with disabilities." This is also underlined by the fact that organizations representing groups of persons with disabilities are called "Disabled People's Organizations" (DPOs) and not "Organizations of Persons with Disabilities." The aim is to express that people become disabled by external factors and barriers, whereas the term "persons with disabilities" might suggest that the disabilities somehow belong to the persons concerned. A counterargument highlights that "persons with disabilities" can be favored as it places the individual/the person—and not the disability—at the center of attention (Oliver 1990: xiii).[18] Disabilities, understood as the interactions between impairments and disabling external factors, are of minor importance. Even though this understanding can be questioned (see also footnote 18 below), the term can be seen as adequate to highlight that mainstream society ascribes attributes to certain people, with which they are then specified or categorized. Thus, it is not only the social, environmental, and architectural barriers—which are referred to by the use of "disabled people"—that are decisive; the processes of ascription and categorization that result from normative notions and ideas of normality are perhaps even more so. In addition, the term "disabled person" or "disabled people" is very closely related to the previous use of the term "the disabled" already referred to above. Acknowledging the criticism of the term, this thesis remains in line with the CRPD understanding by using "persons with disabilities."

The social model of disability was influenced by the British disability rights movement[19] (more specifically the Union of Physically Impaired Against Segre-

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[17] The difference between impairments and disabilities, which is also included in the first article of the CRPD, will be discussed below.

[18] An interesting blog article by disability rights activist Lisa Egan (2012) discusses these issues from a critical insider's perspective. She rejects the use of "to have a disability" and—like other disability activists—strongly criticizes the "people first" argument presented here by using the example of gay people, who are not referred to as "people with gayness."

[19] In this context, Waldschmidt notes that a theoretical deficit exists regarding the development of a disability model or concept in German-speaking disability studies (Waldschmidt 2005: 27).

gation (UPIAS)) and coined by disability activists such as Oliver (e.g., 1990). According to this model, a distinction needs to be made between impairments—referring to a person's biomedical condition—and the concept of disability, which is the result of the interaction between impairments and social, cultural, and architectural barriers (Shakespeare 2013: 216). These external factors or barriers play an important role, as they hamper or completely prevent equal rights and participation for persons with impairments. Thus, the "limitations" and medical conditions of a person are no longer the center of attention. This understanding does not neglect the existence of a physical, sensory, psychosocial, or cognitive aspect, namely a person's so-called impairment. But it does move away from the deficit-oriented perspective—manifested in the individual/medical model of disability—towards a focus on social aspects.

According to Waldschmidt (2005: 23), both the individual/medical and the social model of disability in essence focus on disability and persons with disabilities as "problems," even though the potential solutions to the "problems" are different. In both approaches, strategies are used to either make the individual pursue his or her social duties (individual/medical model) or achieve social participation and self-representation (social model) on an equal basis with others. The focus is not, however, on mainstream society and processes of in- and exclusion, which go along with the ascription of a disability status and a strong or static conception of "normality." As a consequence, the attribution leads to the fact that persons with disabilities are included in specific social subsystems and institutions, e.g., in the fields of work (sheltered workshops), education (so-called special schools), and housing (residential facilities) (Bendel 1999: 304 f.). Waldschmidt (2005: 17 ff.) highlights the shortcomings of the social model and on this basis argues for the introduction of another concept: the cultural model of disability as a summary of different approaches from the cultural sciences, in which the focus is no longer on persons with disabilities but on society with its processes of categorization, exclusion, and stigmatization. The understanding and construction of "normality"—as opposed to anything or any person that is regarded as "different" or "abnormal"—is the center of attention here. Thus, persons with and without disabilities are no longer to be seen as two separate groups of people who are not connected. Rather, dynamic processes take place, making it impossible to clearly distinguish between the two perceivably mutually exclusive categories: "disabled" and "non-disabled." In this sense, the term "disability" does not refer to a personal characteristic but to a social relation. It reveals less about the person to whom this attribute is assigned than it does about those who use this differentiation:

> "Die soziale Verortung und der Sonderstatus, der sich mit dieser Zuschreibung in aller Regel verbindet, verlieren unter diesen Voraussetzungen ihre mehr oder weniger

> selbstverständliche Rechtfertigung in mangelnden geistigen oder körperlichen Kompetenzen und Fähigkeiten. Relevant wird vielmehr der soziale Prozeß [sic] der Entwicklung und Handhabung der Unterscheidung behindert/nichtbehindert als Moment der Konstitution sozialer Differenzierung" (Bendel 1999: 304).[20]

The contextuality and dynamic nature of the concept "disability," and the fact that the boundaries between disability and non-disability are far from clear-cut, could be illustrated by a variant spelling of the term: dis/ability. In order to avoid confusion (e.g., with regard to terms like the disability rights movement) and to improve readability, the idea is not implemented in this thesis, even though it does seem appealling. The separation of the prefix "dis" and "ability" can also serve to highlight what has been referred to in the literature as "ableism," namely the negative view on disability and negative practices towards persons with impairments:

> "a network of beliefs, processes and practices that produce a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability, then, is cast as a diminished state of being human" (Campbell 2001: 44, footnote 5).

2.2 Disability at the Intersection of External Barriers, Body Features, and Identities

Notwithstanding the foregoing, the awareness and personal experiences of an individual are decisive, as the "impairment is not something that can be set aside from the social reality of the disabled people's lived experience" (Meekosha/Soldatic 2011: 1390). Oliver (1996: 5) therefore states that three elements are relevant for the definition of disability:

1. that the person has an impairment;[21]
2. that the person experiences external limitations or restrictions; and
3. that the individual identifies[22] him- or herself "as a disabled person" (ibid.).[23]

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[20] Own translation: "Under these circumstances, the social location and the special status that is usually connected to this ascription lose their more or less self-evident justification in missing cognitive or bodily competencies and capacities. As a moment of constituting social differentiation, the social process of developing and handling the differentiation disabled/not disabled becomes much more relevant."

[21] Whereas Oliver mainly refers to physical impairments, persons with mental or psycho-social impairments need to be taken into consideration as well.

[22] For a discussion of the concept of "identity" with regard to students with disabilities in South Africa (and with reference to the Capability Approach), see Mutanga (2013).

[23] This last aspect, however, is only partially relevant for small children, who might not yet be

This definition is remarkable as it does not explicitly involve processes of ascription by other people, or mainstream society, but includes the—unquestioned—presence of an impairment as one of three relevant aspects. In line with current discourses in gender studies, one could question the dichotomy between (bodily) impairment and (external) disabilities or restrictions. Analogically to arguments in gender research (e.g., expressed by the well-known scholar Judith Butler), the biological, unquestionable, and naturally defined body and its impairments can be seen as a cultural or social interpretation rather than something unalterable and automatically existent qua nature (Waldschmidt 2005: 22).[24] However, in the field of disability research, for example, Shakespeare (2013: 220) nowadays[25] also argues that impairments do play a role—in addition to the removal of barriers and the fight against social exclusion. In this regard, disability needs to be distinguished from other diversity categories such as gender or sexual orientation[26] because

> "[t]here is nothing intrinsically problematic about being female or having a different sexual orientation, or a different skin pigmentation or body shape. […] Remove the social discrimination, and women and people of color and gay and lesbian people will be able to flourish and participate. But disabled people face both discrimination and intrinsic limitations. […] [E]ven if social barriers are removed as far as practically possible, it will remain disadvantageous to have many forms of impairment" (ibid.).

Like gender, age, or sexual orientation, disability counts as a form of horizontal inequality. In addition, disability is one of the aspects of diversity that have negative connotations and effects for the individual to whom this status is ascribed. In contrast to vertical inequalities (such as levels of income or education), horizontal inequalities do not necessarily lead to limited access to social goods or positions. However, a decline in social status and the effects of social inequalities are often the case for persons with disabilities; research has shown that, due to social mechanisms (e.g., exclusive practices, processes of stigmatization, or negative perceptions), disability can be regarded as a central form of social inequality (Maschke 2007: 299).

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capable of self-identification.

[24] See, e.g., Meekosha and Soldatic (2011: 139), who claim that a person's impairment is or can be "the outcome of deeply politicized processes of social dynamics *in* bodies, that then become medicalised and then normalised through a raft of moral discursive and real practices" (italics in the original).

[25] Different from some of his previous publications.

[26] Here, Shakespeare contradicts Egan's (2012) view on gayness and disability, presented above (see footnote 18 of this thesis).

Shakespeare (1994: 296) therefore argues that the social model needs reconceptualization[27] and that “people with impairment are disabled, not just by material discrimination, but also by prejudice. This prejudice is not just interpersonal, it is also implicit in cultural representation, in language and in socialization.” He expands on this by referring to people’s impairment as something that frightens others: “disabled people remind non-disabled people of their own vulnerability” (ibid.: 297)—an argument that is in line with Waldschmidt and Schneider’s point (see the beginning of chapter two) that the category “disability” is needed as a basis for the construction of “normality” by others.

Worldwide, stigmatization and exclusion have a long tradition; persons with disabilities were often discriminated against and have, for example, been presented in freak shows in former times, including, more recently, on television (Radtke 2003: 10 f.). For Shakespeare (1994: 287), this is a “clear example of the way that human beings were seen as non-human, as potential exhibits in what was perhaps a cross between a zoo and a museum.” Even though these extreme ways of objectification no longer take place, a different form can be found nowadays: charitable behavior towards persons with disabilities. Sympathy motivates other people to donate money or show paternalistic behavior patterns (even in instances when persons with disabilities do not require or want any assistance or help), but it also leads to them feeling better off and more powerful (ibid.: 287 f.).[28]

In the social contexts of the most prominent disability studies researchers (e.g., Oliver and Barnes 1998 or Shakespeare 1994; 2013), the biomedical and charitable view on disability was challenged along with a new thinking about bodies and society. And “[t]he capacity of social structures and cultural discourses to sort and define bodies, and to shape bodily experience, was recognized” (Connell 2011: 1370). In terms of these social structures, the specific background of this research project (social protection and inclusion in South Africa) needs to be taken into consideration. The fact that the social model and other views on disability are transferred to the so-called developing countries[29] without conside-

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[27] Bérubé (2009: 357) criticizes the social model due to the fact that “it fails to account adequately for people with cognitive disabilities,” because “disability studies theorists have tended subtly to emphasize physical over cognitive disabilities, particularly severe cognitive disabilities, in part because you don’t find a lot of people with severe cognitive disability holding academic positions.”

[28] As will be shown below, this can also be true for the interview partners, especially an interview partner who raises funds for black orphans despite having little money himself.

[29] The term “developing countries” replaces the colloquial term “third world,” which was widely used during the time of the Cold War and comprised the former colonies in Africa and Asia. It

ring the local realities can be criticized due to the “heavy emphasis on determination by social systems” (ibid.). Concepts and theories that are developed in the industrialized countries, or, as Connell puts it, the “metropole” (ibid.: 1371), depend on historical circumstances and have been designed against the background of the researchers’ social heritage. Often, no reference is made to the global scale, as concepts are discussed “through the lens of social policy interventions and disability politics in the global North” (Evans/Atim 2011: 1438).

In line with this, Connell (2011: 1369 ff.) suggests the concept of “social embodiment” in order to reflect the reflexive relationships between bodies as participants in social dynamics on the one hand and the influence of social dynamics on bodies on the other. This concept implies an understanding of disability as evolving over time, and it aims to conceptualize and describe the experience of those living in developing countries more adequately. In addition, aspects of colonialism and gender are included in the model.[30] Colonialism and globalization have affected gender dynamics orders in various societies, and the value of Connell’s concept can be highlighted with an example from the field of reproductive health: the so-called fetal alcohol syndrome (ibid.: 1373). South Africa faces a particular challenge here due to historical reasons, as the problem of alcohol misuse is a result of the white settlers’ attempt to socially control the native population. These aspects should also receive more attention from the disability rights movement (Meekosha/Soldatic 2011: 1393). However, “it is not alcohol alone that produces the pattern of impairment but alcohol plus social and economic deprivation” (Connell 2011: 1377).

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is criticized in political science literature and other fields today. Acknowledging the shortcomings of this term and the diversity of the range of countries addressed, and in the absence of a more suitable collective name, this thesis uses the term “developing countries.” As described by Lemke (2008: 61), the so-called developing countries can be further divided into different subtypes. When referring to development policy and practice, an additional/alternative differentiation exists: countries in the Global North and those in the Global South—alluding to postcolonial dependencies. However, as “Global South” would also include countries like Australia and New Zealand, this term is not fully adequate either.

[30] Shakespeare (1994: 298) also refers to gender and feminist work and highlights that the “ethic of invincibility or perfectibility […] should not strictly be viewed as a human trait, but should perhaps be specifically identified with masculinity, which is the real focus of concerns with potency, with supremacy, and with domination.”

2.3 The “Vicious Circle” of Poverty and Disability

Social and economic deprivation, poverty, and disability are global issues. They play a role in all countries[31] and societies, regardless of their geographical location, political system, or other categorizing criteria. Nonetheless, the proportion of poor people and the severity of the related consequences are specifically greater in developing countries. In addition, the percentage of persons with disabilities living in these countries is higher than in others (WHO 2011: 262). They might face a higher risk of living in poverty, e.g., due to the limited financial resources of the state, high levels of unemployment, and infrastructural challenges. Their living realities can be characterized by stigmatization, and cultural and religious beliefs might lead to practices of exclusion and ill-treatment of adults and children with disabilities.[32] Thus, the participation of persons with disabilities in social, cultural, and political activities and their access to resources is often limited (UN 2011: vii).

In addition, living in extreme poverty or in a country that is affected by disaster or conflict situations might also cause long-term sicknesses or impairments. This does hold particularly true for preventable conditions resulting from “communicable, maternal, and peri-natal disease and injury” (Emmett 2006: 210). This two-way relationship (between poverty and impairment or disability) has become known as the “vicious circle of disability and poverty” (Yeo/Moore 2003: 572; for more detailed explanations on the interrelations, see also Ingstad/Eide 2011: 5 ff. or Emmett 2006: 210 ff.). A strategy or guiding principle that has emerged in response to the challenges described above is “disability-inclusive development”

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[31] In a number of publications, Beck (e.g., 2007) argues that it is necessary to shift the focus away from the concept of nation states. Against the background of globalization, he questions the institutional order in which states play the major role. However, especially in developing countries, the provision of social policy and social protection has until now been mainly exercised through national efforts. The relevant budgets need to be allocated and focus areas defined. A slightly different situation exists in the European Union, where nation states have given up a certain degree of sovereignty to the supranational level. However, Lingnau and Waldschmidt (2009: 4) argue that social policy is still largely the responsibility of the individual EU member states. From a global perspective, issues of “global social policy” are discussed among political scientists and other scholars—see also chapter three for details.

[32] In their comparative analysis of ethnological studies on the living situations of persons with disabilities, Neubert and Cloerkes (1994) showed, more than 20 years ago, that the meaning and definitions of disability as well as the social reaction towards persons with disabilities can vary widely across cultures. Twenty years later, Rimmerman (2014) traced the historical roots of the conceptualizations and definitions of disability by referring to religious sources. His book “Social Inclusion of People with Disabilities. National and International Perspectives” does, however, focus on countries in Europe as well as on Israel and the United States of America, i.e., not on developing countries.

(see, e.g., McClain-Nhlapo 2010 on disability mainstreaming and inclusive development). On the basis of the (few) available data and anecdotal evidence, it appears that many organizations in international cooperation follow the so-called "twin-track approach" to make development efforts (more) inclusive; this includes specific programs or measures addressed at persons with disabilities as a target group, which are combined with or complemented by the inclusion of disability and the needs of persons with disabilities in mainstream programs and strategies.[33]

However, neither concept—poverty nor disability—can be universally defined and both vary according to context (see, e.g., Ingstad/Eide 2011: 3 ff.). They are ascribed to groups of people, e.g., by researchers, policymakers, or others, according to allegedly objective criteria. Especially for people living in developing countries, this can have an influence not only on the individual and his/her living conditions but also on the situation of the whole family or household. Even though these facts and interrelations are widely known today, there is still a lack of evidence regarding the situations of persons with disabilities—and not only as far as prevalence rates are concerned. Details regarding their living standards and experiences of inclusion and exclusion, especially in developing countries, need further consideration (ibid.: 21 f.; also Emmett 2006: 208 ff.). None of the existing definitions and models adequately capture the "phenomenon" of disability in a universally valid way. Both the World Report on Disability and the CRPD therefore highlight the importance of further data collection and continuous research (WHO 2011: 45 ff.; UN 2006: article 31). An increase in data on disability ("data revolution") is also proclaimed in the context of the post-2015 agenda: the follow-up initiative of the Millennium Development Goals (MDGs) (see below).

For a long time, poverty was measured on the basis of income, its definition being a lack thereof. A common distinction regarding income levels is, for example, made between "relative poverty" and "absolute poverty"[34] (Ingstad/Eide

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[33] In the context of poverty and disability, other approaches are part of the discourse and development practice, among them the multi-sectoral strategy of "Community-based Rehabilitation" (CBR) (see, e.g., the CBR Guidelines published by WHO (2010)).

[34] Sen (1984: 326) discusses poverty in absolute and relative terms and explains the shift from an absolutist understanding of poverty to a relativist one. He argues in favor of an absolute measurement:

"I shall argue that ultimately poverty must be seen to be primarily an absolute notion, even though the specification of the absolute levels has to be done quite differently from the way it used to be done in the older tradition. More importantly, the contrast between the absolute and the relative features has often been confused, and I shall argue that a more general question about ascertaining the absolute standard of living lies at the root of the difficulty."

He also rejects the idea of seeing poverty as inequality—whereby "the issue of inequality of capabilities is an important one" (ibid.: 343)—and explains different ways of conceptualizing and measuring poverty that were used since the middle of the twentieth century. In Sen's view, 2011: 3 f.), with thresholds set by the World Bank for the first time in 1990 in order to measure absolute poverty (World Bank 1990, see also Ravallion et al. 2009: 163). Many people worldwide live below the poverty lines of $1.25 per day (more than 20% in developing countries) and $2.50 per day (more than 50% in developing countries) and might therefore be exposed to social exclusion and stigmatization (World Bank 2013: 5; the poverty lines are regulary updated). The money-based definition, or "income approach," (Loewe 2008a: 37) allows for comparisons and an easy collection of data. It can, however, be criticized as inadequate to describe the complexity and multidimensionality of poverty experiences, structural inequalities, and disparities on different levels.[35] Using a figure like Gross National Product (GNP) per capita as an index to measure development is nowadays widely seen as inadequate or insufficient. Moving away from the amount of money available on an individual or household level, the concept of "overall poverty" (Ingstad/Eide 2011: 4) includes aspects such as a lack of, or insufficient, protection against risks that can occur throughout the life cycle, such as sickness or loss of income. In addition, access to services like medical treatment or clean water and sanitation should be named as further aspects. The "basic needs approach" (introduced in the context of the International Labour Organization's World Employment Conference (ILO 1976)) correspondingly focuses on minimum consumption levels in a variety of areas. In 1990, the United Nations Development Programme (UNDP) published a new index with the release of the Human Development Report (HDR) (UNDP 1990): the Human Development Index (HDI), which was developed by the Pakistani economist Mahbub ul Haq. On the basis of Amartya Sen's considerations regarding development, which formed the basis of his well-known "Capability Approach" (see below for details), economic aspects were no longer used as the sole criterion for the definition and measurement of poverty.[36] As economic growth does not (only/necessarily) lead to a better standard of living, conceptualizing poverty from a multidimensional perspective is much more appropriate. The concrete index developed by UNDP, which includes information about the life expectancy of a states' population and educational aspects, was nonetheless criticized for not providing much more information about, and insight into, poverty levels than "traditional" GNP measures[37] (McGillivray 1991: 1467).

"*absolute* deprivation in terms of a person's *capabilities* relates to *relative* deprivation in terms of commodities, incomes, and resources" (ibid.: 326, italics in the original).

[35] For a discussion on the use and definition of poverty lines, see Burgess and Stern (1991: 44 f.).

[36] For a contextualization of the CA and other income definitions, see Loewe (2008a: 38).

[37] The Human Poverty Index (HPI), the Gender-related Development Index (GDI), and the Gender Empowerment Measure (GEM) are further indices developed by UNDP (Fischer et al. 2004: 31 f.) with the aim of describing poverty levels and people's living situations.

2.4 Excurse: A Short Insight into the Field of International Cooperation

The road towards the new post-2015 development agenda mentioned above, which follows the MDG process, has been a very long one. In more than fifty years of international cooperation and development policy since World War II, different targets and strategies have been defined by the UN every decade in order to reduce global inequalities and enhance wealth and well-being in poorer countries all over the globe. The various decades have brought with them diverse concepts of development and so have led to new initiatives and programs that were supposed to address the shortcomings of the previous years. After the period of decolonization, development was firstly regarded as an aspect of economic growth. Whereas the positive effects of this strategy were visible in industrialized countries, many problems related to poverty (hunger, inaccessibility of healthcare, lack of education) could not be solved in developing countries. It soon became apparent that "trickle-down" effects[38] of economic growth to poor and marginalized population groups were not taking place as planned. Different approaches were tried in the following decades. They were characterized by varying ideas and emphases, of which some core elements are summarized in the following, rather simplified, overview:[39]

Decade	Main explanation for poverty in developing countries	Focus of international development efforts
until 1970s	Underdevelopment of economic and political systems in countries in Africa, Asia, and Latin America	"Modernization strategies": economic growth and industrialization
1970s	Exploitation of the developing countries by industrialized countries	"Dependence theory": decoupling of the "periphery" necessary In addition: "basic needs approach"[40]

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[38] The idea of "trickle-down" effects refers to the theory that an increase in the wealth of richer population groups, as well as economic growth on the macro level, automatically entails (positive) effects for other levels/poorer population groups as well.

[39] The complexity of the history of international development cooperation efforts and explanatory approaches to poverty and development cannot be discussed in detail here. A further examination of international development policies and strategies (Poverty Reduction Strategies, the donor harmonization enshrined in the Paris Declaration on Aid Effectiveness, etc.) and non-governmental approaches to combat poverty would go beyond the scope of this thesis. For an overview and more detailed explanation of the seven major development theories and further concepts, see, e.g., Thiel (2001: 11 ff.).

[40] For some helpful comments regarding "basic needs," see Sen (1993: 40, footnote 30).

Decade	Main explanation for poverty in developing countries	Focus of international development efforts
1980s[41]	A lack of internal reforms, inefficiency of state structures, etc.	“Neoliberalism”: structural adjustment programs
1990s	Complexity of (internal and external) factors and problems	“Sustainability”: ecological and social aspects (normative and strategic concept, teleological, less explanatory than previous theories)

Figure 1: Development decades 1960s-2000s

(own overview based on Fischer et al. (2004: 13 ff.); Eberlei (2008: 593 ff.); Thiel (2001: 11 ff.); Lemke (2008: 64 ff.))

None of these approaches brought with them a significant modification or improvement of the lives of many people worldwide. In 2000, a change was initiated as the UN member states adopted the Millennium Declaration and in this context, in 2001, also decided on eight goals[42] that were supposed to be achieved by 2015. The first goal explicitly demands that extreme poverty be cut by 50% within a period of fifteen years.

MDG 1: “Eradicate extreme poverty & hunger”

Target 1a)
“Halve, between 1990 and 2015, the proportion of people whose income is less than $1.25 a day”
Target 1b)
“Achieve full and productive employment and decent work for all, including women and young people”
Target 1c)
“Halve, between 1990 and 2015, the proportion of people who suffer from hunger”

Figure 2: MDG 1

(quoted from UN n.d.-a)

The goals are included in this chapter for two reasons. Firstly, to highlight the conceptualization of poverty that has been the international consensus since 2000.

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[41] Due to inadequate approaches and measures, during this decade the living situation of many people worldwide is said to have worsened, including an exacerbation of poverty and inequality.

[42] The other goals are: 2) “Achieve universal primary education,” 3) “Promote gender equality and empower women,” 4) “Reduce child mortality,” 5) “Improve maternal health,” 6) “Combat HIV/ Aids, malaria, and other diseases,” 7) “Ensure environmental sustainability,” and 8) “Global partnership for development.” For further information, see, e.g., UN (n.d.-a).

As can be seen in figure two, the understanding of poverty in the first goal is based on income shortage and economic activity. The poverty line for extreme poverty set by the World Bank (WB) was used, and the official indicators referred to aspects such as the proportion of employed people living on less than $1.25 per day and the prevalence of underweight children under five years of age (UN n.d.-a).

Secondly, the MDGs reflect the complexity of development and poverty, as they underline the multidimensionality of poverty mentioned above (keyword: “overall poverty”). They refer to aspects such as health, education, and environmental issues. Even though the MDGs present a pioneering way of tackling global poverty, they have been subject to various criticisms. The goals have, for example, been scrutinized regarding certain limitations, e.g., gender issues and—despite the existence of goal number seven on sustainability—the small amount of attention given to sustainability (e.g., Nuscheler 2006; Wittmann 2006; also Loewe 2014: 7 ff.). As far as a human rights point of view is concerned, the MDGs did not focus on the poorest population groups in an appropriate way. In addition, social security and social protection did not receive any attention at all in the goals (van Ginneken 2011: 115).[43] Furthermore, it would have been decisive to pursue achievement at nation-state level and not only on a global scale; it would then be harder for states or regions with high achievement rates to conceal less positive results or even deteriorations from other countries or parts of the world (United Nations Millennium Project 2005: 3).

Even before the end of the MDGs in 2015, it became obvious that, on a global level, the goals would not be met. One conclusion that can be made from this is that big regional differences exist in terms of achievements and resources, e.g., between countries like China and states in sub-Saharan Africa (Sangmeister 2014: 55; also UN 2013: 7). Although it was possible to significantly reduce global poverty, new goals are needed for the coming years in order to improve the living situation of all persons worldwide. Despite the previous achievements in terms of global poverty alleviation, a focus on poverty reduction is still an important element (Sangmeister 2014: 56).[44] The UN Secretary-General Ban Ki-moon[45] was asked to initiate a new development plan following the MDGs. As a consequence, a specific task team worked on recommendations for a post-MDG framework. In

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[43] In this context, van Ginneken argues for the adoption of national social protection floors with basic social security guarantees (in line with the ILO’s requirements), which will be discussed further in chapter three.

[44] With reference to the ongoing debate regarding a stronger focus on poverty reduction and basic needs—instead of following a more comprehensive understanding of development (“Basic needs first!”)—Sangmeister (2014: 55 ff.) draws comparisons to the development paradigms of the 1970s and 1980s. He criticizes these strategies as an “aberration” (ibid.: 57).

[45] UN Secretary-General since 2007 (status: 2016).

addition, the UN Conference on Sustainable Development (Rio+20) had already laid the groundwork for the development of global goals for sustainable development (Sustainable Development Goals (SDGs)) in 2012.[46] In 2013, the UN decided to combine both processes into one and the post-2015 development agenda was introduced (Loewe 2014: 6), which "should have the strengths of the MDG concept while [at the same time] avoiding its weaknesses" (ibid.: 9).[47] The agenda does not focus on developing countries only but will be valid worldwide. New goals were identified that will, however, not be discussed in detail here due to their high actuality and the draft nature of the relevant documents.[48]

2.5 Disability Rights and Policy—Towards Inclusive Development

Although a further critical examination of the MDGs, and international cooperation and development policy,[49] would go beyond the scope of this chapter, one additional aspect is worth noting here: The MDGs themselves, the 21 targets, and the 60 related indicators did not explicitly mention persons with disabilities or further marginalized groups (Gooding/Mulligan 2010: 1). Therefore, it can be questioned whether persons with disabilities were considered as a target group for development projects and initiatives. The difficulty in meeting the MDGs without addressing disability issues was also acknowledged by former World Bank President Wolfensohn (McClain-Nhlapo 2010: 111 and 121). The explicit consideration of persons with disabilities in the MDG Progress Report 2010 (UN 2010: 18) can thus be seen as a (late) achievement, even though the focus was on education (goal 2) and so represents a thematic limitation. As a subsequent adjustment to the

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[46] In a recent article, Tardi and Njelesani (2015) provide an insight into the latest developments by analyzing the degree to which persons with disabilities are recognized in the Outcome Document of the Open Working Group (OWG) on Sustainable Development Goals (SDGs) of July 2014 and the Report of the Intergovernmental Committee of Experts on Sustainable Development Financing (ICESDF), which was published in August 2014.

[47] According to the Report of the High-Level Panel of Eminent Persons on the Post-2015 Development Agenda (UN 2013: Executive summary and pp. 7 ff.), the main demand made in this context is that a global partnership be developed that comprises the following five elements: 1) "Leave no one behind," 2) "Put sustainable development at the core," 3) "Transform economies for jobs and inclusive growth," 4) "Build peace and effective, open, and accountable institutions," and 5) "Forge a new global partnership."

[48] Websites such as the UN's informational platform on the Sustainable Development Goals (UN n.d.-b) or an internet platform facilitated by the Overseas Development Institute (ODI n.d.) give a general insight into the post-2015 development agenda.

[49] The English language distinguishes between *policy* (content), *polity* (structures), and *politics* (processes). In languages such as German, for example, all three dimensions are covered by one term: "Politik." Here, the term *disability policy* is used as a translation of the German term "Behindertenpolitik" used by Maschke (e.g., 2004) and other authors.

MDGs, the United Nations General Assembly (UN GA) adopted several resolutions in the years after the Millennium Declaration: among them, Resolution No. 64/131 entitled "Realizing the Millennium Development Goals for persons with disabilities" (UN GA 2009) and Resolution No. 65/186: "Realizing the Millennium Development Goals for persons with disabilities towards 2015 and beyond" (UN GA 2011). Furthermore, the General Assembly published a report in 2011 that reviewed the MDG process and recommended strategies for the inclusion of disability-related aspects in MDG initiatives (UN 2011). The executive summary responds to the criticism in that it highlights the importance of including persons with disabilities for a successful realization of the MDGs (ibid.: viii).

Making valid judgments (on the basis of scientific data) on the relation between the realization of the goals and the challenging living situations of persons with disabilities in developing and other countries was difficult. On the basis of available evidence, the necessity of additional efforts to enhance quality of life for persons with disabilities globally and reduce inequalities and social exclusion worldwide could be assumed. In parallel to the MDG process, another global initiative was therefore inaugurated in recent years that impacted on disability policy and implementation in a variety of countries: the elaboration and entry into force of the CRPD, as mentioned above. Its 50 articles cover different areas of life and interpret the existing human rights standards against the background of the specific experiences and living situations of persons with disabilities (Bielefeldt 2009: 13). More precisely, focusing on social inclusion and individual autonomy gives momentum to the further development of the human rights discourse. Thus, the convention contributes to the humanization of society as a whole:

> "Indem sie Menschen mit Behinderungen davon befreit, sich selbst als „defizitär" sehen zu müssen, befreit sie zugleich die Gesellschaft von einer falsch verstandenen Gesundheitsfixierung, durch die all diejenigen an den Rand gedrängt werden, die den durch Werbewirtschaft und Biopolitik vorangetriebenen Imperativen von Fitness, Jugendlichkeit und permanenter Leistungsfähigkeit nicht Genüge tun. In diesem Sinne kommt der „*diversity*-Ansatz", für den die Behindertenrechtskonvention steht, zuletzt uns allen zugute" (ibid.: 16, italics in the original).[50]

The convention can be regarded as an innovation as it brings with it several novelties in international law (Degener 2009: 200). Of significance are, for example, the monitoring mechanism and the Optional Protocol, the latter of which can be

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[50] Own translation: "Liberating persons with disabilities from seeing themselves as 'deficient' also liberates society from a mistaken fixation on health, by which all those who do not fulfill the imperatives of fitness, youthfulness, and permanent performance pushed forward by the advertising industry and bio politics are marginalized. In this sense, the '*diversity* approach' of the CRPD is beneficial for all of us."

separately signed or ratified by States Parties.[51] The Convention also entered into force very quickly on May 3, 2008, after 20 countries had ratified it. In addition, it only took five years to draft and negotiate the document.[52] Regarding the concrete rights enshrined in the treaty, the common distinction between political and civil rights on the one hand and economic, social, and cultural rights on the other is not strictly followed.[53] One of the major assets of the convention is its global and universal character and its bindingness under international law for those countries that have signed and ratified it. Broadly, the CRPD contains the following elements:

Articles	**Main content**
Art. 1-9	General aspects (e.g., definitions, general principles)
Art. 10-30	Catalog of concrete rights (e.g., inclusive education, political participation)
Art. 31-40	Implementation and monitoring of the treaty
Art. 41-50	Information regarding the ratification and further technical regulations

Figure 3: Summary of CRPD articles

(own overview on the basis of Degener 2006: 106 f.; for a more detailed explanation, see Aichele 2008)

In the context of this thesis, article 28 on an "Adequate standard of living and social protection" is of particular relevance as it contains provisions regarding "the right of persons with disabilities to an adequate standard of living for themselves and their families, including adequate food, clothing, and housing." Furthermore, persons with disabilities are entitled "to the continuous improvement of living conditions, and [states] shall take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability" (UN 2006: article 28).

Looking at disability policy[54] from a welfare-state perspective, it can be regarded as a component of social policy for persons with disabilities and as part of the

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[51] Thus, the overview regarding signatures and ratifications of the CRPD contains four different numbers: Convention: 159 Ratifications/Accessions, 160 Signatories, Optional Protocol: 88 Ratification/Accessions, 92 signatories (UN Enable 2015).

[52] In 2001, Resolution 56/168 (UN GA 2001) was passed; this set up a committee to work on a convention focusing on the rights of persons with disabilities. The process was characterized by strong participation from civil society, in accordance with the international disability rights movement's slogan "Nothing about us without us" (Degener 2009: 202). Degener (2006: 104 f.) provides a broader overview regarding the history of the CRPD process, including earlier attempts by Italy and Sweden to develop a convention.

[53] This differentiation is reflected in two human rights documents that were adopted in 1966: the International Covenant on Civil and Political Rights (UN 1966a) and the International Covenant on Economic, Social and Cultural Rights (UN 1966b).

[54] For an overview regarding current trends and approaches in disability policy, in particular from a German perspective, see, e.g., Wacker (2011).

social policy approaches for dealing with social risks or risks in the life cycle (Wansing 2006: 102 ff.). For Maschke (2004: 403), disability policy—similar to protection against risks such as old age or sickness—aims to minimize the effects of disability for persons with disabilities themselves and also for the environment. Loss of income due to disability should be prevented or compensated. Both Wansing's and Maschke's descriptions of the status quo of social policy present disability from an individual-centered and medical point of view. In addition, neither concept is easily transferable to the realities of developing countries, where social policy approaches might have to respond to very different social realities than those in European/industrialized countries.

For European welfare states, Maschke (ibid.: 408 ff.) identified three elements or approaches of disability policy: a focus on rehabilitation, a focus on compensation, and a focus on participation. Drawing on Esping-Andersen's (1990) typology of welfare-state regimes,[55] Maschke's three examples are Great Britain (liberal welfare state), Denmark (social-democratic welfare state), and Germany (corporatist-statist welfare state). In Germany, for example, a policy mix with elements from all three types can be found. Reform processes have led to positive effects on the living situations of persons with disabilities. Among them is the shift from rehabilitation and compensation towards social participation (Maschke 2008: 241 f.), e.g., through the "personal budget" for persons with disabilities that was implemented in 2001. Instead of receiving services, persons with disabilities can apply for a personal budget and thus be employers themselves. Bureaucratic hurdles and the complexity of the whole application process can, however, be identified as obstacles for this initiative, even though it aims to increase social participation/inclusion[56] and improve the quality of life of applicants (Wacker et al. 2009: 41).

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[55] For an explanation of the use of the term "welfare-state regime," see Esping-Andersen (1990: 2), also Gough (2004: 22 ff.). I will refer to the typology again in the third chapter, on social policy.

[56] Social inclusion can be seen as a "neutral" counterpart or opposite term of social exclusion, e.g., in accordance with Luhmann's (e.g., 2002) theoretical approaches (systems theory). It can also be regarded from a moral or normative perspective, e.g., in line with the CRPD. Understood as such, it is more of a social ideal, dealing with basic social aspects, respect for diversity, and equality of opportunities for every member of society (Wansing 2013: 11). For a further discussion of the terms, see, e.g., Rimmerman (2014: 33 ff.). He explains that if being seen as mutually exclusive concepts, "*[i]nclusion* is viewed as a desirable outcome or as a strategy to combat social exclusion, whereas *exclusion* is viewed as an expression of poor social cohesion" (ibid.: 35, italics in the original). It is, however, possible to have exclusion and inclusion at the same time, similar to Luhmann's understanding. With concrete reference to persons with disabilities, people "can have respected and dignified lives within their extended families but at the same time experience rejection and denial of their rights within their communities" (ibid.).

As outlined above, persons with disabilities have for a long time been regarded as objects of social policy, for whom welfare and care were regarded as adequate approaches. With the emergence of the disability rights movements, a shift towards the recognition of persons with disabilities as civil rights subjects became apparent. Anti-discrimination laws play an important role in this context, and institutions like the European Union have committed themselves to following a rights-based approach (Degener 2009: 201). On a European scale, the developments culminated in the European Year of Persons with Disabilities in 2003 and the ratification of the CRPD by the EU. On a global level, the United Nations System has set standards regarding the inclusion of persons with disabilities, culminating in the entry into force of the CRPD in 2008.

Year(s)	Instrument/initiative	Implication/explanation
1981	"International Year of Disabled Persons"	- Theme: "full participation and equality"
1982	"World Programme of Action concerning Disability"	- Global strategy with recommendations regarding the prevention of disabilities, rehabilitative measures, and equalizing opportunities
1983-1992	"United Nations Decade of Disabled Persons"	- Time frame for the implementation of activities recommended in the World Programme of Action
1993	"Standard Rules on the Equalization of Opportunities for Persons with Disabilities"	- Summary of the World Programme of Action - 22 rules in four chapters - Apointment of a Special Rapporteur[57] to monitor the implementation of the Standard Rules
2006	"Convention on the Rights of Persons with Disabilities"	- Entry into force on May 3, 2008 - Aim: "full and effective participation and inclusion in society" (article 3) for persons with disabilities

Figure 4: Relevant UN initiatives[58]

(own overview based on information from UN Enable n.d.)

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[57] From 2009 until 2014, Shuaib Chalken, a (former) Disability Rights Activist from South Africa, held the position of "Special Rapporteur on Disability" for the Commission for Social Development. Since December 2014, Catalina Devandas from Costa Rica has been the first "UN Special Rapporteur on the rights of persons with disabilities."

[58] The recognition of disability in the SDGs is a further step towards achieving/striving for disability inclusion worldwide.

In order to adequately meet the needs of persons with disabilities, the consideration of their expertise is decisive. DPOs have therefore been consulted in various processes, and the CRPD requests that "States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations" (UN 2006: article 4). In addition to governmental efforts and the official ratification process, the mobilization and active commitment of DPOs is important, and a strong civil society (with its watchdog function) is necessary (Meekosha/Soldatic 2011: 1384). In this context, Connell (2011: 1378) highlights that

> "[i]n the developing world—given the willingness of local elites to reject human rights regimes as neocolonial impositions, and of metropolitan powers to ride over human rights in pursuit of profit and security—it is often NGOs rather than states that pursue rights agendas. […] Politics among disabled groups is also likely to take different forms in the global South from those familiar in the global North. This is not only a matter of different cultures."

3 Debating Social Policy and Social Inclusion from an International Perspective

As discussed in the introduction, in order to effectively fight poverty, it is not sufficient to rely on economic growth and its trickle-down effects—there is a requirement to meet people's needs, engage in comprehensive strategies for poverty alleviation, and adhere to human rights standards. According to UNDP's Human Development Reports, economic, political, social, environmental, and cultural aspects are important for the enhancement of people's living situations worldwide. This is reflected by the variety of topics covered in the annual reports since 1990. To name but a few:

Focus on	Title	Year
Social aspects	"People's Participation"	1993
Economic aspects	"Economic Growth and Human Development"	1996
Political aspects	"Deepening Democracy in a Fragmented World"	2002
Cultural aspects	"Cultural Liberty in Today's Diverse World"	2004
Environmental aspects	"Beyond Scarcity: Power, Poverty and the Global Water Crisis"	2006

Figure 5: Focus areas of the HDRs

(own overview based on the table of contents in the latest HDR (UNDP 2014))

The HDR of 2014 (UNDP 2014: 101 f.) answers the question of how societies might be able to redress divisions and exclusions with the following answer: "[b]y improving the availability of basic social services, strengthening employment policies and extending social protection." The different approaches have to be applied jointly and comprehensively. On the level of nation states,[59] they mainly fall into the field of social policy.

However, a universally valid way of implementing this suggestion is impossible, given the variety and complexity of social structures and cultures, political systems, state budgets, and further aspects. The primary aim of and "reason for

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[59] The concept of nation states will not be discussed here. For further details, see, e.g., several publications by the German sociologist Ulrich Beck, who questions the focus on nation states in today's globalized world. See also footnote 31 of this thesis.

I. Bertmann, *Taking Well-Being and Quality of Life for Granted?*, Gesundheitsförderung - Rehabilitation - Teilhabe,
https://doi.org/10.1007/978-3-658-19812-1_3

introducing a social policy is to enhance conditions of social well-being in society" (Midgley 2009: 5); that is, for all population groups. On an international level, aspects of (global) social policy[60] are debated in several forums and can be found on the agenda of a variety of organizations, among them the International Labour Organization (ILO), the Organization for Economic Cooperation and Development (OECD), and the United Nations Department of Economic and Social Affairs (UN DESA). As an extensive debate on previous developments and current trends would go beyond the scope of this thesis, initiatives like the ILO's Social Protection Floor and the respective recommendation (ILO 2012) and the Social Security (Minimum Standards) Convention (No. 102) (ILO 1952) will only be mentioned. In this context, the ILO's comprehensive World Social Protection Report 2014-15 (ILO 2014) is also worth noting.[61]

Primarily, this chapter engages in defining social policy and referring to its (moral)[62] foundations, before turning to a clarification of the terms "social security" and "social protection" and focusing on the implementation of social policy and the design of social security systems in developing countries. The final part of this chapter focuses on persons with disabilities as one of the target groups of social policy endeavors.

3.1 Social Justice and Social Inclusion—the Basis for and Goal of Social Policy

The origins of the term "social policy" can be found in Germany,[63] where solutions for the so-called social question had to be sought, primarily with a focus on pauperism,[64] in the context of the *Vormaerz*[65] era, and then with a focus on the situa-

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[60] For a discussion of the term "global social policy," and its implications, see, e.g., two working papers by Lutz Leisering (2008b; 2008c). The latter asks whether "social assistance is a case of global social policy" (Leisering 2008c: 24) and comes to the conclusion that, among other aspects, "the rise of social assistance as a global issue is remarkable because the social assistance sector lacks a pivotal international organisation (like the ILO with regard to labour law or, partly, social insurance or the WHO with regard to health) as well as an established policy community" (ibid.: 28).

[61] For a discussion on the future of social assistance, see, e.g., Leisering (2008a: 95 ff.).

[62] For a discussion on "morality" in the context of social justice, see, e.g., Koller (2012: 50 ff.).

[63] As I explain in this section, the origins of social policy, social justice, and related terms go back to developments that occurred in the context of European industrialization. Their transferability to realities in other countries can be debated and will be touched upon below.

[64] The term refers to mass poverty, which did, for example, occur in Germany in the period of industrialization due to a variety of factors.

[65] In its narrower (and political) sense, "Vormaerz" refers to the period between 1830 and 1848.

tion of workers in the industrial revolution. Over time, the term took on new dimensions—covering, for example, state endeavors but also communal or company social policy (Kaufmann 2009: 27). Nowadays, it is addressed at the whole population with the aim of achieving social cohesion and social inclusion. According to Kaufmann (ibid.: 28), social policy has only been in use internationally since the Second World War and is in many instances used synonymously with "welfare policy." As Midgley (2009: 5) explains, social policy[66] includes government programs and policies directed at the welfare of a country's population, as social welfare or social well-being[67] is the main aim of social policy. According to his definition, social welfare is "a condition or state of human well-being that exists when peoples' [sic] needs are met, problems are managed, and opportunities are maximized" (ibid.: 6), thus referring to the linguistic origin of the term[68] and moving beyond the rather narrow understanding of the concept "social welfare" as it is often applied: in the sense of charity and government services aimed at the poor. In addition, social policy is often used synonymously with social security:

> "Auf internationaler Ebene wird Sozialpolitik oft mit Sozialer Sicherheit gleichgesetzt. Dieses Mißverständnis [sic] entsteht einerseits durch das dominierende Gewicht dieses Teils der Sozialpolitik im Rahmen der öffentlichen Ausgaben, andererseits durch den Umstand, daß [sic] die Träger der sozialen Sicherung als einzige über wirkungsvolle internationale Vereinigungen verfügen" (Kaufmann 2009: 28).[69]

Especially in modern welfare states, social policy can include various policies and instruments in the fields of education, labor, health, and also housing (Huf 1998: 23; Hudson et al. 2008: 1 ff.). In a country like Germany, the success of social policies and governmental efforts is often measured by the benchmark of "social justice" (Nullmeier 2009: 9). The principle of social justice proposes the normative foundation for a social order in which certain obligations of social coexistence, on the one hand, as well as the same rights and responsibilities for all members of a society, on

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[66] The term social policy also refers to an academic field that is concerned with critically examining the relevant policies and endeavors (Midgley 2009: 13 ff.).

[67] Midgley (2009: 6) uses social well-being and social welfare as synonyms: "When social policies have a widespread, positive effect, social conditions in society as a whole improve, producing a condition of social welfare or social well-being."

[68] The term "welfare" can be traced back to the word "farewell."

[69] Own translation: "On an international level, social policy is often equated with social security. One reason for this misunderstanding is a result of the predominance/dominant weight of this part of social policy in the context of public expenditure. Another is the fact that the social security institutions are the only ones possessing effective international unions/associations."

the other, are to be sought. Although the concept of “social justice”[70] is a contested one without a clear definition (Koller 2012: 48), its achievement is the primary aim of the modern welfare state. It serves as an umbrella term for a variety of understandings of justice:

> “die Verteilungsgerechtigkeit, insoweit eine Gesellschaft als ein *gemeinschaftliches Unternehmen* begriffen wird; die Tauschgerechtigkeit, insoweit eine Gesellschaft wirtschaftliche Aktivitäten mittels *vertraglicher Transaktionen* koordiniert; die politische Gerechtigkeit, insoweit die gesellschaftliche Ordnung *institutionelle Herrschaft* erfordert; und die korrektive Gerechtigkeit, insoweit auftretendes *Unrecht* der Berichtigung bedarf” (ibid.: 55, italics in the original).[71]

It is thus not surprising that social (in-)justices and the respective policy responses are described and categorized differently by various authors. For example, Maschke (2007) identifies three cases of social injustice that are seen as illegitimate in modern societies and therefore need social policy responses:

Form of inequality	Explanation	Concept	Sociopolitical strategy
Vertical inequalities	Differences are so high that they lead to a limitation of life chances	- Poverty - Deprivation	- Compensation - Rehabilitation and integration
Vertical and horizontal inequalities	Partial or complete exclusion from one or more social institution(s)	- Social exclusion	- Participation and inclusion
Horizontal inequalities	Limitation of life chances across class and other boundaries The disadvantage results from the horizontal inequality, but cannot causally be derived from it[72]	- Discrimination (as illegitimate form of disadvantage)	- Equality and anti-discrimination

Figure 6: Cases of social injustices and the respective social policy responses

(own overview based on Maschke 2007: 299 ff.)

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[70] Justice has been a highly debated concept since Ancient Greece; the term “social justice,” however, is connected to European industrialization and the social questions associated with it. It is nowadays mostly used in political discourse (Koller 2012: 48).

[71] Own translation: “distributive justice, insofar as a society is understood as a joint venture; transactional justice, insofar as a society coordinates economic activities via contractual transactions; political justice, insofar as the social order requires institutional sovereignty; and corrective justice, insofar as occurring injustice needs correction.”

[72] E.g., two people have the same qualifications for a job but do not receive the same salary due to a horizontal inequality.

Koller (2012: 48), in turn, identifies five aspects of social justice: legal equality, civil liberty, democratic participation, equality of opportunities, and economic balance. The fair distribution of goods, the just access to resources, and the opportunity to realize personal life plans can be named as important components of social justice (Liebig/May 2009: 4). As will be argued again later on (see chapter four), the strong focus on the access to basic goods can be debated and needs to be broadened. In any case, social policy provides responses to social injustices of different kinds, as it

> "bezeichnet politische und verbandliche Aktivitäten sowie gesetzgeberische Maßnahmen, die sich auf die Absicherung existenzieller Risiken, die Verbesserung der Lebenssituation sozial Schwacher, Gefährdeter oder Schutzbedürftiger und die Regelung der spannungsreichen Interessenunterschiede zwischen Arbeitgebern und Arbeitnehmern beziehen" (Schubert/Klein 2011: 270).[73]

Governmental social policy responses to the above-mentioned challenges include various elements and have been classified by Esping-Andersen (1990: 26 ff.) in his famous typology, also mentioned above. The liberal, the corporatist,[74] and the social-democratic welfare state are all "preoccupied with the production and distribution of social well-being" (ibid.: 1). Varying grades of decommodification, which means the degree to which social benefits are detached from employment,[75] play a role in this regard. In addition, many countries worldwide have different ideologies underlying their social policies. Whereas the liberal welfare state primarily offers a basic safety net, the social-democratic system redistributes income between different social groups. In that case, the quest for social equality is central. Although redistributory aspects are not decisive here, the focus on income protection is highest in the corporatist (or conservative) regime (Hudson et al. 2008: 19). It is important to note at this point that Esping-Andersen's analysis focuses on social rights, private vs. public service provision, and stratification as the three core elements according to which social policies should be reviewed regarding what and how provisions are made and who can benefit from and have access to them (ibid.: 8 ff.). The central question of the welfare-state debate can thus be phrased as "whether, and under what conditions, the class divisions and social inequalities produced by capitalism can be undone by parliamentary democracy" (Esping-Andersen 1990: 11).

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[73] Own translation: Social policy "refers to political activities and those of associations as well as legislative measures that relate to protection against existential risks, the improvement of the living conditions of people who are socially deprived, vulnerable, or in need of protection, and the regulation of the tension-filled differences in interest between employers and employees."

[74] Several other terms are in use in the literature: e.g., corporatist-statist or conservative.

[75] I.e., the relation between social security and the labor market.

The role of governments and state contributions in this area only started to grow in the twentieth century, while families, churches, and non-profit organizations have traditionally played a major role. Reasons for these changes include cultural factors, among them processes like industrialization and urbanization, as well as the commitment of individuals such as far-sighted politicians.[76] As a government activity, social policy is highly influenced by lobbying through interest groups. Concrete mechanisms used by governments in the field of social policy provision include budgetary allocations/social services, statutory regulation, and the tax system (Midgley 2009: 5 ff.). The affordability of social policy measures is a challenge for many states with restricted financial resources. As will be discussed at a later point, limited financial resources can thus serve as an argument against the provision of concrete measures or social programs. In this regard, alternative responses to social challenges, which go beyond the state level, play a major role. In the subtitle of their article on "Social security in developing countries," Burgess and Stern accordingly pose the very broad questions of what should be provided, why, by whom, and how (Burgess/Stern 1991: 71 ff.).[77]

For the provision of social security in developing contexts, public action is required and social, political, and humanitarian organizations are involved as far as the protection and improvement of people's living circumstances is concerned (Drèze/Sen 1991: 28 f.). Esping-Andersen's typology cannot easily be transferred to developing countries,[78] and while "much of the social development literature remains unfamiliar to Western scholars" (Midgley/Sherraden 2009: 279), social policy in developing countries has in turn not received a great deal of attention in comparative welfare-state research yet (Wehr 2009: 170). It can be argued that "transitional countries are expanding welfare institutions following Western models rather than responding to economic globalization by >social dumping< or >race to the bottom<" (Leisering 2008a: 76). Midgley and Sherraden (2009) describe the origins of the "social development perspective," which is particularly relevant in developing countries and combines economic aspects and social welfare with reference to the "time of World War II when the era of European imperialism and colonialism was coming to an end" (ibid.: 280).

The concept of social development was initially mainly in the focus of community-based projects (ibid.: 280 f.). In a nutshell, its idea and aim is to ensure

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[76] From a German/European perspective, the first German Reich Chancellor Otto von Bismarck played a major role in defining and implementing social policy.

[77] As early as 1988, von Benda-Beckmann et al. (Eds.) published their well-known volume "Between kinship and the state," which highlights the various levels and possibilities for the provision of social security in developing countries.

[78] Atkinson and Hills (1991) critically examine whether it is possible to learn from developed countries (focusing on Britain, France, and the US) and use their experiences for social security systems in developing countries.

participation in the productive economy for everybody by providing people with the necessary “skills, knowledge, resources, opportunities, incentives, and subsidies” (ibid.: 283). A central component of the concept is a bottom-up approach to development that focuses on poor population groups and “the need to ‘put people first’ in development processes” (World Bank n.d.-a). In most of the developing countries, however, comprehensive approaches do not (yet) exist and only a small minority of the population is reached. Reasons include lacking resources as well as administrative challenges (Burgess/Stern 1991: 41 f.). Worldwide, contemporary developments also involve a high level of fragmentation, alongside greater individualism. As some critics argue, “[t]he prescriptions for large-scale planning contained in social development thinking are […] unworkable in the postmodern era” (Midgley/Sherraden 2009: 292). Social development is thus a rather optimistic (and partly utopian) approach, involving various agents such as the state, the community, and the market (ibid.: 283 ff.).[79] The two authors identify three preconditions or principles that need to be fulfilled for social development. It is necessary to

- harmonize policies in the fields of the economy and social issues;
- orientate economic development towards the promotion of well-being for all members of the population; and
- create social welfare programs that are oriented towards investment (ibid.).

By complying with these aspects, social inclusion and cohesion can be promoted, and social change and progress may be reached.

3.2 Concepts of Social Security and Social Protection

As early as 1948, standards regarding social security were set by the Universal Declaration of Human Rights (UN GA 1948).[80] In accordance with article 22, for example,

> “Everyone, as a member of society, has the right to social security and is entitled to realization, through national effort and international co-operation and in accordance with the organization and resources of each State, of the economic, social and cultural

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[79] For a critique on the social development approach or perspective, see Midgley/Sherraden (2009: 291 f.).

[80] The Universal Declaration of Human Rights is not a legally binding agreement. It is, however, possible to speak about customary international law. In contrast, the Covenant on Economic, Social and Cultural Rights and the Covenant on Civil and Political Rights, both of which contain several elements of the Declaration, have a legally binding character.

> rights indispensable for his dignity and the free development of his personality" (ibid.).

In addition, the subsequent article highlights "the right to just and favorable remuneration ensuring for [her-/]himself and [her/]his family an existence worthy of human dignity, and supplemented, if necessary, by other means of social protection" (ibid., article 23 (3)). A third article adds to these provisions and is also related to the topic of social security: Article 25 (1) calls for everybody's

> "right to a standard of living adequate for the health and well-being of [her-/]himself and of [her/]his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control" (ibid.).

Several aspects are worth noting and of relevance for the following sections. Primarily, the articles do not give detailed definitions or explanations of what "social security" and "social protection" are. Only the concept of "standard of living" is further specified in article 25 as comprising aspects such as food, medical care, and social services and as being the basis for a person's "health and well-being." This is closely related to the basic needs approach, which is focused on minimum consumption levels. Secondly, the very same article explains the right to security against certain events in the course of one's life—such as disability or unemployment. However, the more specific term "*social* security" is not mentioned in this regard, nor is the concept of "disability" defined.[81] Thirdly, both articles contain links to a person's "dignity." Article 22 mentions "the free development of [an individual's] personality," whereas, in article 23, the precondition for an "existence worthy of human dignity" is a "just and favourable remuneration." This remuneration can be counted as one potential social protection measure, as the article goes on to call for additional means of social protection if necessary.

These observations reflect the complexity of the relation between and the definition of social security, social insurance, social assistance, and social protection, as well as the need for a precise definition of these terms. Furthermore, one needs to take into account that the Universal Declaration of Human Rights was adopted in 1948; several initiatives and approaches have followed since. According to the Social Security (Minimum Standards) Convention (ILO 1952), for example, nine areas for social insurance and social assistance exist: "sickness," "unemployment," "old-age," "employment injury," "family," "maternity," "invalidity," and "survivors" (widowhood). Referring to the ILO's understanding and differing

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[81] The relation between disability and social security/protection will be discussed in the following subchapter.

from the previous paragraph, van Ginneken (2003: 5) emphasizes "that social security aims at protection, and that its role should not be confused with policies for the promotion of employment and the economy." In addition, van Ginneken (1999: 5) previously stated that social security can be broadly defined as "[t]he provision of benefits to households and individuals […] through public or collective arrangements […] to protect [people] against low or declining living standards […] arising from a number of basic risks and needs." Burgess and Stern (1991: 43) provide a narrower definition by stating: "the objective of social security as being the prevention, by social means, of very low standards of living irrespective of whether these are the result of chronic deprivation or temporary adversity."[82] Thus, depending on the view one takes, aspects of prevention, protection, and promotion can be considered for a definition of social security.

Social security and social protection are part of social policy. However, the precise meaning of social security varies according to countries and contexts. Moreover, social protection is sometimes used synonymously because income provision or financial support is an important component of social security (Hudson et al. 2008: 15).[83] The need for relevant measures emerges because of "widespread, persistent deprivation, and […] the issue of fragility of individual security" (Drèze/Sen 1991: 10). In addition, it cannot be expected that economic growth will automatically help to overcome deprivation and reach the poorest members of society. A comprehensive and carefully planned legal and political framework of social protection could therefore contribute to alleviating deprivation and enhancing living standards (ibid.: 31). Hudson et al. (2008: 18) argue that the very same goal of income protection can be handled differently in various country contexts. Thus, both moral and political aspects need to be taken into consideration and the respective decisions have to be taken—a balance needs to be found between the citizen's rights or entitlements and their responsibility and autonomy.[84] According to van Ginneken (2011: 114), the right to social security comprises four elements: "income security for workers," "affordable access to health services," "support for families, children and dependant [sic] adults," and "social assistance schemes."

On a more abstract level, Drèze and Sen (1991: 5) state that "[t]he basic idea of social security is to use social means to prevent deprivation, and vulnerability to deprivation." They divide social security into the following two elements: "the *protection* of living standards from serious declines […] and the *promotion* of

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[82] For an explanation of the exclusion of certain aspects, see ibid.

[83] For a discussion of the term "social protection" and the World Bank's as well as the ILO's understanding of social protection and social security, see Kabeer (2008: 3 ff).

[84] With respect to the field of health, this has, for example, been described with the patient typology developed by Koyuncu (2007), which explains the relationship between the health system and different grades of patients' self-responsibility, sovereignty, and participation.

these standards to permanently higher levels" (ibid.: 30, italics in the original)—as well as the same protection and promotion of incomes and entitlements (ibid.: 4). Similarly, three possible approaches or strategies provide compensation and reduce the negative impacts of external shocks that might occur over a person's life cycle: protecting people from risks, satisfying needs through social assistance, and extending rights through social inclusion in order to combat vulnerability (Munro 2008: 27 ff.; Barrientos 2010: 580).

Hand in hand with conceptualizing and defining social security, social protection, and an adequate standard of living in the context of social policy, responsibilities and ways of implementation need to be addressed.[85] For von Benda-Beckmann and von Benda-Beckmann (2007: 28), all "[p]eople usually compose a social security mix consisting of various arrangements for social security." Human diversity plays a role in that these "mixes are specific to gender, age, class and status" (ibid.). In this context, everyday life experiences and permanent exchange and support relationships contribute to the protection of livelihood (Steinwachs 2006: 22). Alongside the concept of interaction and social relationships, the aspect of the construction of identity is of importance. As Steinwachs (ibid.: 19) puts it:

> "Für die Herstellung sozialer Sicherheit kann dies heißen, dass Evokation von Unterstützung und die Zugehörigkeit zu sozialen Gruppen, Netzwerken und Beziehungen im Rückgriff auf die Konstruktion von Identität erfolgt."[86]

Moreover, she explains that, instead of focusing on a complete formalization, it might be useful to focus on various forms and arrangements and consider the necessity of redistribution: "Förderung vielfältiger Formen und Arrangements bei gleichzeitiger Reflexion der Folgen sozialer Differenzierung und der Notwendigkeit von Umverteilung und gegenseitiger Abstimmung" (ibid.: 24).[87] Steinwachs (ibid.: 14 ff.) therefore proposes a conception of social security in which social relations and social structures play a major role. Her analysis focuses on interfaces and interrelations in everyday life that exist or develop due to the actions and activities of social actors. In addition, she highlights the formation or development of social protection as an ideal or desire—rather than conceptualizing it as a real

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[85] For an overview of the positions of important actors in international (development) cooperation regarding the topic of basic social protection, see Loewe's (2008b) study "Positionen wichtiger entwicklungspolitischer Akteure zum Thema soziale Grundsicherung," i.e., "Positions of important development actors regarding the topic of basic social protection" (own translation).

[86] Own translation: "For the creation of social security, this can mean that the evocation of support and the belonging to social groups, networks, and relations happens by referring to the construction of identities."

[87] Own translation: "promotion of diverse forms and arrangements while at the same time reflecting the results of social differentiation and the necessity to redistribute and mutually coordinate."

condition. Through actions, social security is constantly produced and re-produced. Achieving social security should thus not be seen in absolute terms but as a field of (social) interaction.

Taking up the various facets of the elements discussed so far, and especially the focus on protection against different risks, Devereux and Sabates-Wheeler (2004) provide a comprehensive working definition of social protection that forms the basis of the following parts of this thesis. Social protection is used as an umbrella term for

> *"the set of all initiatives, both formal and informal, that provide:* ***social assistance*** *to extremely poor individuals and households;* ***social services*** *to groups who need special care or would otherwise be denied access to basic services;* ***social insurance*** *to protect people against the risks and consequences of livelihood shocks; and* ***social equity*** *to protect people against social risks such as discrimination or abuse"* (ibid.: 9, emphasis and italics in the original).

The focus of the presented definitions, as well as of existing analyses in this field, is either on formal systems or on institutions and mechanisms that specifically aim to provide social security (see, e.g., Steinwachs 2006: 12). Against this background, the term "social security" will from now on be used in direct quotes and in cases where reference is made to the formal and governmental efforts within a social security system (e.g., in South Africa); otherwise, this thesis will stick to the term "social protection."

It is problematic that many people worldwide are not covered by contributory schemes as they are not in the position to pay contributions. This holds especially true for people who are not in formal employment (van Ginneken 1999: 3 f.). Various alternatives exist for the achievement of poverty alleviation and protection from vulnerability: micro-insurances and mutual societies, universal benefits, or social assistance (Overbye 2005: 255 ff.). Needs that cannot be covered by a form of insurance can or should be met by non-contributory, tax-financed forms of social assistance. These can be either cash or in-kind, with means tests and/or income tests as a precondition. An additional form of social assistance is basic income grants or universal benefits that do not need a means test (van Ginneken 1999: 5). It is the provision of social cash transfers in particular that Leisering (2008a: 94) considers to "mark a new stage in the >socialization< of development policy, that is, they add to the increasing emphasis on social protection in development policy." Aiming to capture this "increasing emphasis on social protection," Brunori and O'Reilly (2010) discuss several explanations of social protection in their review of definitions collected for the 2010 European Report on Development (RSCAS 2010). Furthermore, they present the definition used by the report, which also highlights the importance of vulnerability. It differentiates between social insurance and social assistance as part of social protection, supplemented by “inclusion efforts”[88] to ensure accessibility to both forms of social protection: Social protection is defined as

> “[a] specific set of actions to address the vulnerability of people’s life *through social insurance*, offering protection against risk and adversity throughout life; *through social assistance*, offering payments and in kind transfers to support and enable the poor; and *through inclusion* efforts that enhance the capability of the marginalised to access social insurance and assistance” (ibid.: 20, italics in the original).

Even though the right to social protection has already been enshrined in the Universal Declaration of Human Rights (UN GA 1948), social protection has received more and more attention in the field of development policy and practice in recent years (Hilser 2014: 139 f.). It can be said that “[s]ocial protection has emerged as a policy framework addressing poverty and vulnerability in developing countries” (Barrientos 2010: 579) over recent decades. It can be distinguished from “the wider set of anti-poverty policies” due to “its focus on vulnerability” (ibid.: 581). It is thus not surprising that, alongside other aspects of social policy, social protection has been the center of attention at international events like the World Summit for Social Development in Copenhagen (1995). According to Midgley and Sherraden (2009: 281), the UN convened the summit as a response to the increase in poverty and deprivation that occurred due to

> “the advocacy of neoliberal, free-market economic policies by the International Monetary Fund, the World Bank, and several Western governments in the 1980s [which] undermined the social welfare gains that had been recorded in many parts of the world.”

The so-called Copenhagen Declaration and the adoption of the MDGs five years later underlined the importance of social development policies,[89] including the commitment to poverty alleviation, healthcare, and gender equality (ibid.).[90] A short discussion document published by the United Nations System Task Team on the Post-2015 UN Development Agenda (2012: 11), entitled “Social protection: A development priority in the post-2015 UN development agenda,” accordingly expresses the demand that

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[88] For a broader discussion of social inclusion in the context of disability, see, e.g., Rimmerman (2014).

[89] Following the discussion on international cooperation and poverty reduction efforts (see chapter two), Barrientos and Hulme (2010: 9) provide an overview of the implications of the different Millennium Development Goals for social protection. Whereas the second target of the first MDG (“Halve the proportion of people suffering from hunger”), for example, promotes the provision of nutritional interventions or basic income grants, targets seven and eight (can) lead to an improved access to health services.

[90] For a brief overview of the approaches and perspectives of various international actors, see, e.g., Barrientos/Hulme (2008: 4 f.).

> "[i]n view of the multiple roles that social protection can play in social and economic development, the post-2015 framework should contain an objective that ensures the inclusion of all groups in development and society through extending adequate social protection. The post-2015 debate needs a renewed and comprehensive focus on poverty, income distribution and social inclusion. Social protection is the ideal conduit."

3.3 Social Protection for Persons with Disabilities

In the previous subchapter, the provisions set in the Universal Declaration of Human Rights with respect to the thematic field of social protection have already been discussed. According to article 25, every person "has the right to a standard of living adequate for the health and well-being of [her- or] himself." This includes elements like food, healthcare, and shelter, as well as "security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his [or her] control." The definition lists disability as one of the risks that can occur in the course of the life cycle. In addition, it connects disability with a "lack of livelihood." Following this definition, disability is a risk for which protection has to be guaranteed as a human right. Several aspects or questions need to be raised here: What view on or definition of disability underlies that article? Is it adequate to see disability as a situation or a state that occurs as an "event"? Furthermore, the enumeration of risk factors allows the conclusion that they are to be seen as separate, largely unconnected, or even collectively exhaustive. But what does this mean for the relationship between disability and sickness, or disability and unemployment?

The CRPD (UN 2006) specifies the above-mentioned provisions as follows in article 28 ("Adequate standard of living and social protection"):

> “2. States Parties recognize the right of persons with disabilities to social protection and to the enjoyment of that right without discrimination on the basis of disability, and shall take appropriate steps to safeguard and promote the realization of this right, including measures:
>
> a. To ensure equal access by persons with disabilities to clean water services, and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs;
> b. To ensure access by persons with disabilities, in particular women and girls with disabilities and older persons with disabilities, to social protection programmes and poverty reduction programmes;
> c. To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care;
> d. To ensure access by persons with disabilities to public housing programmes;
> e. To ensure equal access by persons with disabilities to retirement benefits and programmes.”

Figure 7: Article 28 of the CRPD

(quoted from UN 2006)

With the enumeration mentioned above, the CRPD contains a variety of measures that can be used and implemented to guarantee the right to social protection. Access to clean water, services, and assistive devices, as well as access to poverty reduction programs, are only some of the specific claims mentioned. The CRPD contains further aspects such as the guarantee of access to specific disability-related assistance, for example training and financial support. In addition, arrangements regarding aspects of living and pensions are mentioned (UN 2006). It is remarkable that the concept of social protection is so broadly defined here. As the World Report on Disability (WHO 2011: 11) confirms, in order “[f]or safety nets to be effective in protecting disabled people, many other public programs need to be in place, such as health, rehabilitation, education and training and environmental access.” The interrelations between these different measures (intersections, overlaps) and the relation between poverty reduction and social protection do, however, not receive attention in the article. In addition, concrete steps or measures to implement the programs are not specified.

Some aspects of social policy with a focus on political considerations and the improvement of the living realities of persons with disabilities have already been tackled in the previous chapter (e.g., with regard to Maschke). He argues that social policy is also responsible for avoiding that the exclusion of persons with disabilities or other groups from one social functional system (e.g., education) automatically lessens accessibility to another (e.g., the labor market) (Maschke 2007:

309). Together with the labor market and the education system, the social security system is one of the central institutions of processes of exclusion (ibid.: 307). Regarding the provision of social protection, persons with disabilities are often seen as incapable of providing for their own income. This is also expressed in the following quote, in which Esping-Andersen (1990: 42) argues that the "model of the liberal 'good society' contains a number of […] weaknesses", as "[i]t assumes that all individuals are indeed capable of market participation, something which of course they are not. The old, the infirm, the blind, and the crippled [sic] are forced into family dependency."

The clarity with which he expresses his argument ("of course they are not") is clearly based on the medical model of disability and the deficit-oriented perspective described in the first chapter. Similarly, Kersting (2000: 32) explains that several groups of people do not have anything to offer that could be of interest to other members of a reciprocal society and are thus the addressees of social protection measures:

> "Die Adressaten der sozialstaatlichen Versorgung sind Arbeitslose, Arbeitsunfähige, Rentner, Kranke und geistig, psychisch und körperlich Behinderte, all die also, die sich in einer Gesellschaft der Gegenseitigkeit, des wechselseitigen Vorteils nicht behaupten können, da sie nichts anzubieten haben, das zu erwerben andere interessiert sein könnten."[91]

By referring to Rawls, Kersting (ibid.: 33) calls this group of people "Selbstversorgungsunfähige," i.e., people who are not capable of self-supply. With reference to the social model of disability, this line of argumentation can be weakened as the problem does not lie with the individual who is not able to contribute to society or provide for his/her own income but in the social structures that prevent equal participation in the education system and labor market. Thus, according to Mont (2010: 324), a "comprehensive approach would make the environment as inclusive as possible – physically, culturally, legally and so on – in order to eliminate the barriers preventing people with disabilities from escaping poverty." However, as long as this has not been achieved, social protection programs are needed to secure a minimum living standard. According to Swartz/Schneider (2006: 236):

> "[s]ocial grants and what are disparagingly termed 'hand-outs' for disabled people, are seen as being associated with attitudes towards disabled people which are patronizing and 'welfarist'. Rather provide skills and jobs than disability grants, the social model would argue […]. Where jobs are scarce in the country as a whole, however,

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[91] Own translation: "The recipients of welfare services are people who are unemployed, unable to work, retired, sick, or who have a cognitive, mental, or physical impairment—thus all those who cannot assert themselves in a society of reciprocity, of mutual advantage, as they do not have anything to offer which others might want to purchase."

> where access is a general problem, where there is inadequate provision of basic assistive devices needed by some disabled people, it is inevitable that, invidious though this situation may be, the emphasis time and again comes down to the appropriate provision of social security in the form of grants."

The aspect of specific schemes or grants for persons with disabilities will be discussed first: They might have lower incomes due to (systematic) exclusion from the labor market or previous exclusion from the education system (resulting in lower qualifications and lower salaries, and thus fewer possibilities to contribute to the household in income). In addition, due to insufficient services or inaccessibility of structures, family members of persons with disabilities might stay at home and provide care free of charge. Without a job in the formal labor market, the payment of contributions to insurances becomes a challenging task. As is the case for every person, persons with disabilities who are in formal employment are confronted with different entitlements and conditions than those who are unemployed, and "there is a tendency to divide disabled people into [these] two categories" as far as social policy is concerned (Marriott/Gooding 2007: 5). In addition, persons with disabilities might have to deal with higher costs, e.g., resulting from special medical care, rehabilitative equipment, payment of care providers, or inadequate transport (Emmett 2006: 214 and 217). As will be shown in the empirical part of the thesis, this also holds true as far as the living realities of persons with disabilities in South Africa are concerned. Thus, specific measures for persons with disabilities might be considered appropriate.

However, "programmes targeted at people with disabilities can create work disincentives that act against their capacity to achieve an independent means of generating a livelihood" (Mont 2010: 321), and dependence could be the result (Marriott/Gooding 2007: 61 f.). [92] In addition, specific social protection programs entail administrative efforts and challenges (Mont 2010: 330), and they might be seen as a backward step to the medical understanding of disability (Marriott/Gooding 2007: 4)—due to both the fact that the target group needs to be defined and that assessment criteria are to be determined. In sum, aspects that need to be taken into account by social and disability policy are the practices and consequences of social exclusion, the need for care, and the compensation of extra costs, as well as the assessment and definition of disability (Schneider et al. 2011: 38). Despite these aspects, cash transfers can also have positive implications for the

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[92] The authors do, however, argue that it is rather the absence of alternatives that makes people rely on the DG, and the grant is thus "a response to the need for support rather than creating dependency" (Marriott/Gooding 2007: 61).

recipients as they might lead to higher self-esteem for the person who receives the money and can thus contribute to the household income.[93]

The implementation of mainstream social protection programs and measures in some countries (e.g., Brazil, Indonesia) has led to a significant rise in coverage rates—with an impact on those groups in society that are often described as vulnerable.[94] Nonetheless, social protection coverage is still low and requires further upscaling (Barrientos/Hulme 2008: 3 f.). In addition, van Ginneken (1999: 3) highlights that "[t]he exclusion of informal sector workers and other vulnerable groups from social […] protection is part of a larger process of social exclusion that can be seen both as an attribute of individuals and as a property of societies." Despite the (estimated) high prevalence rates of persons with disabilities worldwide and knowledge of the potential and positive effects of social protection programs, there is still a lack of evidence as to how persons with disabilities can benefit from mainstream and specific social protection programs (Marriott/Gooding 2007: 25 f.).[95] In addition, it is not widely known what kinds of barriers affect their access to various forms of (mainstream) social protection (and social security) coverage (Mont 2010: 320; also Marriott/Gooding 2007: 4 and 31 f.).[96] This thesis can offer a contribution to the discussion, as its focus is on a specific social protection scheme targeted at children and adults with disabilities. Mainstream programs are not part of the analysis and could be a point of reference for future research projects.

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[93] Being the "breadwinner" of the family can have both positive and negative implications, as will be confirmed in the empirical part of the thesis.

[94] For details regarding the term "vulnerability," see footnote 2 of this thesis.

[95] Mainstream programs are, e.g., a general unemployment benefit or access to basic healthcare. More specific measures include cash transfers such as the Disability Grant in South Africa, which will be described in detail in the following chapter.

[96] For a discussion on the removal of physical and social barriers that prevent access to mainstream social safety nets, see Mitra (2005: 23 ff.). For the important observation that persons with disabilities and their organizations are often not involved in the design of social protection schemes and systems, see Marriott/Gooding (2007: 20 f.).

4 Approaching Quality of Life and Well-Being from a Multi-Disciplinary Perspective

In several disciplines (e.g., economics, philosophy, social sciences), drawing on a number of approaches, questions of quality of life, standard of living, and well-being are investigated. The terms are often used synonymously, but they can refer to different concepts and approaches: Whereas well-being generally refers to individuals and experiences, quality of life can refer more to the level of society and contextual aspects (Gasper 2010: 351). This distinction is very useful for the purpose of this research project, as the perspectives and experiences of persons with disabilities are as important as the careful examination of the social circumstances they live in. As already described, both perspectives are captured through the data collected by interviewing individuals and experts. Amartya Sen's CA will be used as the theoretical framework of this thesis, as it allows for "interpersonal comparisons of well-being" (Robeyns 2011: n. pag.) and appears to be one of the most comprehensive approaches for the thematic scope of this project, especially as far as capturing the multidimensionality of poverty is concerned.[97] With its intended openness, it needs to be complemented and specified with further approaches and theoretical considerations (Sen 1993: 48 f.; Robeyns 2005: 94). This chapter therefore begins with a general overview of possible conceptualizations of quality of life and well-being, before introducing the CA and justifying its use in this thesis. Finally, yet importantly, its potential for the concrete investigation of the quality of life and well-being of persons with disabilities in South Africa will be presented, before turning to the empirical data collection in chapter six and the results of the qualitative data analysis in chapter seven.

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[97] For a discussion of the challenge of conceptualizing poverty and choosing relevant dimensions in the context of research projects, see, e.g., Alkire (2007).

I. Bertmann, *Taking Well-Being and Quality of Life for Granted?*, Gesundheitsförderung - Rehabilitation - Teilhabe,
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4.1 Introduction: Conceptualizing and Measuring Quality of Life and Well-Being

Many scholars, from a variety of disciplines, work on approaches, tools, and frameworks to assess quality of life[98] and well-being. The boundaries between the two concepts often overlap, which is why a clear distinction is difficult to make. Gasper (2010: 351), for example, differentiates between six aspects in evaluation and states that "[n]either well-being nor quality of life is a determinate or definite single thing" (ibid.: 352). According to his explanation, it is difficult to actually achieve well-being and/or quality of life, as "there is [not] only one true version" (ibid.: 353) of either one. What is meant here is that the terms are not to be used as very concrete concepts but rather as stimuli or collective terms to ask "who is doing what to/for/with whom, when, where and why?" (ibid.). Coming to conclusions about the "good life," potentially even in a universally valid way, is not possible. Similarly, Warren and Manderson (2013: 14) argue that "quality of life is a subjective evaluation […]. But it is also constructed at policy and program levels, and at both individual and societal levels, it is shaped by various contextual factors – social, cultural, political, economic, and psychological" ones.

Following Phillips (2006) and Gasper (2010), seven research areas or "families of approaches" (Gasper 2010: 354) can be identified, under which most approaches can be subsumed:[99] (1) "subjective well-being," (2) "health-related quality of life," (3a) "utility," (3b) "needs and capabilities," (4) "poverty studies," (5)

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[98] Knecht (2010: 16 ff.) describes the first use and the spread of the concept of quality of life. He links it to the field of social policy (especially in Germany) and provides a historical overview. On his website, he also offers a compilation of quotes—tracing the history of the concept of "quality of life" from Aristotle to current debates, e.g., regarding objective vs. subjective approaches or the use of quality of life in fields such as architecture (Knecht 2013).
In his thesis on the quality of life of persons with intellectual impairments living in two residential facilities in Germany, Schäfers (2008: 81 ff.) extensively discusses methodological aspects, concrete studies in German-language research, and instruments that have been used for QoL-assessment of this target group. Among those are the "Comprehensive Quality of Life Scale," the "Quality of Life Questionnaire," and others.

[99] Several frameworks exist to capture aspects of quality of life and well-being, and research communities have been developed that deal with specific aspects: The focus of the Human Development and Capability Association is an engagement with well-being research from a development perspective, using Amartya Sen's CA as a basis. Similarly, the International Society for Quality of Life Studies brings together quality of life research(ers) from various disciplines, while the focus of the International Society for Quality of Life Research is mainly on health-related quality of life.
Approaches to measuring quality of life include the Quality of Life Scale, the Medical Outcomes Study Short Form-36, the Quality of Well-Being Scale, and others. Warren and Manderson (2013: 3) make the criticism that "the instrumentation to assess quality of life is used internationally, and [that] little attention is given to the relevance of context to people's performance

“community studies,” and (6) “societal quality of life constructs.” Except for in the two research streams (1) and (3a), which focus on aspects of subjective well-being, objective well-being is generally the center of attention. In his overview of approaches, Gasper (ibid.) highlights focus areas and disciplines in which the different approaches are mainly used. However, the strict separation between objective and subjective approaches, or between the different areas or types identified, is not necessarily appropriate. For example, a person might pursue goals that do not make him or her happy, but nonetheless be of the opinion that this is the right thing to do or “lack(s) the courage to demand any radical change” (Sen 1999: 63). People may adapt to (bad) conditions to make their situation bearable and therefore become satisfied with what they have (regarding this aspect of “hedonic adaptation,” see, e.g., Binder 2013: 2). Drèze and Sen (1991: 5) explain that people’s “deprivation, then, may not at all show up in the metrics of pleasure, desire-fulfillment, and so on, even though he or she may not have the ability to be adequately nourished, comfortably clothed, minimally educated, and so on.” Here there is a similarity with the aspect of the “disability paradox” that occurs when “people with disabilities report high quality of life, despite living a life that others perceive as characterized by hardships and, thus, as undesirable” (Warren/Manderson 2013: 5, see also Albrecht/Devlieger 1999: 978 f.). According to Graf (2011: 18), two aspects are worth noting in this regard: (Individual) well-being is not the single most important value, and well-being does not equal happiness or pleasure.

The concept of quality of life is often applied in health science, and being in good health is then associated with a good quality of life. In addition, it is “an indicator for […] high-quality health services” (Warren/Manderson 2013: 11). On this basis, “poor health, disease, and disability are correlated with poor quality of life” (ibid.: 1). Regarding the topic of disability, the volume edited by Warren and Manderson (2013) engages in a critical discussion of potential approaches towards the assessment of the quality of life of persons with disabilities; the authors explain that “research emphasizes the social production of disability and highlights the artificiality of categorizing quality of life outcomes by ‘types’ of disability” (ibid.: 4). Bearing this in mind, health-related research on the quality of life of persons with disabilities is challenged, and clinical approaches face opposition when encountering sociological or disability studies research. This can be explained by returning to the debate on definitions of disability and dealing with diversity. Thus,

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on such measures or on how this is influenced by the social, political, cultural or economic environment in which they live.” The World Health Organization’s instruments WHOQOL-100 and WHOQOL-BREF, as well as the Personal Well-Being Index, provide the potential to capture contextual factors as well (ibid.: 4).

Diener and Suh (1997: 213) highlight “that social indicators, subjective well-being measures, and economic indices are needed in unison to understand human quality of life, and to make informed policy decisions.”

in order to assess the quality of life of persons with disabilities, a broader framework will be used that does not focus on individual features alone.

4.2 Amartya Sen's Capability Approach

As opposed to welfarist approaches and theories based on income, which Sen (1992; 1999; 2009) criticizes and rejects for several reasons[100] (Robeyns 2005: 96; Teschl/Derobert 2008: 129 f.), the CA focuses on a multidimensional concept of poverty and development. Income is seen as a means to well-being—but the underlying assumption is that other aspects do capture well-being more adequately. Sen's ideas and ways of conceptualizing poverty, which he has been developing based on the idea of "capabilities"[101] since the 1980s (Deneulin/McGregor 2010: 502), are reflected in the Human Development Index (see chapter one of this thesis) and based on a critique of other theories of well-being, especially Rawls' *A Theory of Justice* (1971).[102] The main advantage of Sen's approach is its openness and adaptability, which has led to the fact that it is used and applied in a variety of disciplines and for a multitude of topics.[103] The approach needs to be deliberately substantiated according to the research question(s) and epistemic interest of a concrete investigation. This offers a great spectrum of potential applications in a variety of (e.g., cultural) contexts (Graf 2011: 24).[104] This aspect is confirmed by Robeyns' (2005: 94) statement that

> "[t]he capability approach is a broad normative framework for the evaluation and assessment of individual well-being and social arrangements, the design of policies, and proposals about social change in society. […] Note that the capability approach is not a theory that can *explain* poverty, inequality or well-being; instead, it rather provides a tool and a framework within which to *conceptualize* and *evaluate* these phenomena" (italics in the original).

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[100] For details, see below.

[101] For a discussion of whether, for Sen, capabilities are really the most central aspect, see Baujard/Gilardone (2015). They argue "that the most important aspect for Sen is not capability but rather the process through which public decisions are made, highlighting in particular the role of individuals in public reasoning. […] A consequence of this argument is that Sen's contribution to justice should not be remembered for a capability theory but for something very different: a theory of human agency and public reasoning, both being intimately related" (ibid.: 12).

[102] For a critical examination of Rawls' theory in the light of justice and development, see, e.g., Kesselring (2003: 66 ff.).

[103] For a discussion of the innovative character of the approach and the way in which it can be applied in a variety of disciplines, see Robeyns (2006: 370 ff.).

[104] Graf (2011: 23) highlights the cultural dependence of questions such as the worth and weighing of capabilities and functionings.

Gasper (1997: 286 f.) identifies the contributions of the Capability Approach by naming five aspects, among them the fact that the CA helps to conceptualize "development" and influences other discourses in that it contributes to the specification of terms like "needs" and "basic needs." There are, as with any other approach or theory, also limitations or points of criticism, which will be addressed below.

Amartya Sen first reacts in his early writings (e.g., 1982a) to Rawls' ideas regarding social justice. For Rawls (1971: 11 ff.), a just social structure is only possible if all members of a society are interested in cooperation and adhere to certain rules. "Fairness" is an important component of human coexistence—and not the maximization of individual self-interests (Kesselring 2003: 66 ff.). In his theory, Rawls basically argues that each person needs to pursue his/her concept of a "good life." However, individual ways of life have to be restricted—in the sense that agreements have to be found that are seen as just or fair for people with varying and contradictory understandings of a good life. In Rawls' (1971: 93) view, there are some basic goods that build the foundation for all possible ways of life in a society:

> "though men's [and women's] rational plans do have different final ends, they nevertheless all require for their execution certain primary goods, natural and social. Plans differ since individual abilities, circumstances, and wants differ; rational plans are adjusted to these contingencies. But whatever one's system of ends, primary goods are necessary means."

In contrast to utilitarianism, the focus of his theory is thus not on the idea of achieving the greatest degree of happiness for the largest group of people (Kesselring 2003: 68). Rather, a basic structure is just if all persons concerned are satisfied with it—irrespective of their own social position—and possess the capacity to positively evaluate the arrangement (ibid.: 79).

Sen criticizes Rawls' and similar approaches as inadequate for making statements about social justice and individual well-being.[105] Sen (1984: 343) explains that

> "[c]apabilities differ both from commodities and characteristics, on the one hand, and utilities, on the other. The capability approach shares with John Rawls the rejection of the utilitarian obsession with one type of mental reaction, but differs from Rawls' concentration on primary goods by focusing on capabilities of human beings rather than characteristics of goods they possess."

Graf (2011: 15 f.) summarizes Sen's arguments by explaining that if all members of a society were sufficiently equal, it would be possible to make interpersonal

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[105] For an overview of central points of criticism, see also Knecht (2010: 41 ff.).

comparisons on the basis of basic goods and so express the advantage of the individual in accordance with Rawls' theory. Rawls' focus on the fair distribution of goods lacks a focus on positive freedoms. For Sen (1984: 338 f.), Rawls does not pay (enough) attention to the fact that age, gender, and other factors (such as disability) determine the options people have in life, regardless of their (equal) amount of basic goods. In addition, Sen criticizes Rawls' focus on political rights, which Rawls favors over economic resources (Kesselring 2003: 94). Following Sen, food and income are of higher importance than fundamental political rights, and capabilities and opportunities that are *de facto*—and not only *de jure*—available should be the center of attention (ibid.: 100).

In sum, investigations of material goods, primary goods, or basic services do not serve to adequately conceptualize "development" or "poverty," or to come to conclusions about people's well-being and social institutions. Even though two individuals might have the same amount of goods at their disposal, different personal, cultural, social, and environmental circumstances might lead to differences in their use of them and the consequential effects regarding their living situations. Thus, a focus on the intrinsic value of goods does not take the real (and diverse) living situations of the people concerned into account (Graf 2011: 13). In addition, the goals that people have might not be equal to achieving well-being. Rather than focusing on achievements themselves, the evaluation of well-being should thus be centered on the "freedom of achievement" (Zimmermann 2006: 472).

4.2.1 Martha Nussbaum and the Capability Approach

In addition to Amartya Sen, a second person has had a great deal of influence on the development and spread of this approach: the American philosopher Martha Nussbaum.[106] Even though there are certain similarities between the two approaches (both Sen's and Nussbaum's versions of the approach are based on a critique of utilitarian perspectives), several elements differ considerably. Robeyns (2005: 103 ff.) summarizes the following major differences: Nussbaum's version pays more attention to people's skills and personality traits as far as capabilities are concerned. Furthermore, her approach identifies three categories of capabilities (basic, internal, and combined capabilities), including a concrete list of capabilities that need to be fulfilled. Sen (1993: 47), however, considers Nussbaum's conceptualization of a good life as "tremendously over-specified." Nonetheless, both worked on the approach together and jointly edited a conference volume on "The Quality of Life" (Nussbaum/Sen 1993) that brings together various contributions

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[106] For an explanation of the foundation of Nussbaum's works, see, for example, the foreword written by Pauer-Studer in Nussbaum (1999).

from the fields of health and gender studies. Nussbaum specifically focused on gender issues in a variety of publications, and her arguments are based on Aristotelian conceptions and positions (Pauer-Studer's foreword in Nussbaum 1999: 7 ff.).

In his overview of "Sen's Capability Approach and Nussbaum's Capabilities Ethics," Gasper (1997: 282) highlights that Sen does not adequately link concepts like agency and capability to their respective understanding in social science, whereas "Nussbaum gives a richer, more realistic picture of people and of agency, choice and action." In addition, by referring to the image of a building, Gasper (ibid.: 293) explains that "Sen offers tools, a frame; Nussbaum goes ahead to offer a whole mansion, and chooses to err if anything on the side of detailed specification, to stimulate reactions and drive a debate that can then improve the conception." Thus, her version of the CA and her critical contributions to the question of social justice and quality of life should not be disregarded, though the focus is on Sen's framework.

This thesis refrains from focusing too much on Nussbaum's ideas and publications for two reasons: Firstly, due to the general conceptualization of a "good life" that she has developed against the background of capabilities and functionings. It is very philosophical and moralistic, and, even though she uses the same terms as Sen, the informational basis of her theory is different (Graf 2011: 23, footnote): "Eine Fähigkeit ist in ihrem Sprachgebrauch zu verstehen als ein allgemeines Vermögen oder eine Disposition, die im Wesentlichen in der Person selbst verankert ist, und nicht eine echte Wahlmöglichkeit, wie das bei Sen der Fall ist."[107] The second reason for not focusing on Nussbaum's version is more specifically related to the topic of this thesis and has to do with her view on and consideration of disability, as will be outlined below.

4.2.2 Basic Concepts and Coherences

The CA identifies two important concepts for the assessment of a person's quality of life: On the one hand, the individual's actual living situation is important (represented by the "achieved functionings"), on the other, it is strongly connected to the available options (Sen calls this the "capability set"), of which a person chooses a certain collection according to his/her preferences or values (Robeyns 2005: 95). Therewith, the approach focuses on the realization of individual ways of life and the possibilities (and potential) people have to develop their own conception

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[107] Own translation: "In her use of language, a capability is to be seen as a general capacity or disposition that is mainly intrinsic in the person him-/herself, and not a real option, as is the case with Sen."

of a “good life” (Otto/Ziegler 2010: 11). The central concepts of the CA are thus capabilities and functionings. Sen (1993: 31) explains their meaning in the following way:

> “*Functionings* represent parts of the state of a person – in particular the various things that he or she manages to do or be in leading a life. The *capability* of a person reflects the alternative combinations of functionings the person can achieve, and from which he or she can choose one collection” (italics in the original).

Examples of functionings include being healthy or being well-nourished, whereas capabilities stand for people’s options to choose the way of life they prefer (Robeyns 2005: 95). A prominent example that is used in various publications refers to the functioning of being well-nourished. For a person who has access to food, the following variety of aspects is of importance in accordance with the CA: (1) the choice/decision of wanting to eat, (2) the intentional activity of eating, (3) the mental states when eating, (4) the process of digesting, (5) the state of being well-nourished, (6) all activities (e.g., working, playing sports) that are only feasible when someone is well-nourished (Graf 2011: 19 f.).

The level of functionings is, however, not the most important concept of the approach. The individual’s freedom to lead the kind of life he/she wants is more important and is captured through the concept of “capability,” which “represents the various combinations of functionings (beings and doings) that the person can achieve” (Sen 1992: 40). Useful clarifications on the choice of the terms and their meaning are expressed by Sen (1993) in response to criticism his approach received from Cohen (e.g., 1989) and Nussbaum (e.g., “Nature, Function, and Capability: Aristotle on Political Distribution” from 1988).[108]

Whereas Sen originally chose to call a vector or combination of several functionings a/one capability, in recent publications the terms are applied differently, in the sense that a capability set consists of various capabilities:

> “In this [i.e., the original; IB] terminology a capability is synonymous with a capability set, which consists of a combination of potential functionings. Functionings could therefore be either potential or achieved. […] In that terminology [i.e., the one applied by other CA scholars; IB] the capability set consists of a number of capabilities, in the same way as a person’s overall freedom is made up by a number of more specific freedoms” (Robeyns 2005: 100).

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[108] Sen refers to the publication from 1988 that appeared in *Oxford Studies in Ancient Philosophy: Supplementary Volume*. The list of sources of this thesis includes the 1987 version (working paper) with the same title.

In addition, Sen uses the specification of basic capabilities, which "refer to the real opportunity to avoid poverty or to meet or exceed a threshold of well-being" (Crocker/Robeyns 2010: 69). As far as the choice of the term itself is concerned, Gasper (1997: 290) alludes to the fact that the term capability[109] is closely related to "ability" and "capacity." Used in plural, the word "capabilities" suggests that a number of abilities and/or skills exist.[110] The following subchapters refer to the capability set as the collection or variety of a person's capabilities.

Coming back to the example of food, the difference between the terms and ideas of functionings and capabilities, as well as the importance that Sen attaches to the concept of capabilities in his writings, can be illustrated as follows: Not only the actual situation of a person is decisive but also, or even more so, the different options the person could select from and the concrete functionings that a person could achieve if he/she chooses to do so (Graf 2011: 22). For example, did a person have the option of deciding whether or not to stop eating and be hungry (e.g., in the context of a fasting cure or due to political or religious reasons), or does he/she not have any food available (due to lack of money, crop failure, or other reasons)? Income, goods, and services (i.e., resources) are the basis of or the means to well-being. The characteristics of goods and services can enable a functioning: a bicycle, for example, can "[enable] the functioning of mobility, to be able to move oneself freely and more rapidly than walking" (Robeyns 2005: 99). For persons with mobility impairments, this functioning could be enabled through the provision of a wheelchair[111] or other assistive devices, which would then lead to a similar effect as the bicycle.

It is important to note that the degree to which a person can convert goods into functionings is influenced by so-called conversion factors. The social and personal circumstances in which a person lives are decisive, and they present an important aspect in the data analysis. As far as the living situations of persons with disabilities are concerned, social, environmental, and architectural barriers can therewith be focused on in detail. It is not only in this specific respect that the approach gives credit to human diversity and individuality—a person's history and psychology, which might influence his/her choices of available options, are also relevant here.

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[109] In addition, Gasper (1997: 290 f.) differentiates between "S-capabilities" and "O-capabilities," and also introduces the term "P-capability." S-capabilities stand for skills, while O-capabilities refer to a person's opportunity set. A P-capability implies a potentiality that would—in his view—be equivalent to a basic capability ("B-Capability") in Nussbaum's writings (Nussbaum 1987: 27).

[110] E.g., in "Capability and Well-Being," Sen (1993: 30) comments on the use of the term capability by admitting that it "is not an awfully attractive word."

[111] Admittedly, this example is somewhat simplified, as social and environmental factors are not taken into consideration.

Even though this offers a high potential for the adequate capture of a person's living situation and environment when investigating his/her quality of life, the approach has been criticized for being too individualistic and for not paying sufficient attention to groups and social structures (Robeyns 2005: 107). It "acknowledges the importance of social structures […] only so far as they influence *individual* well-being and freedom" (Ibrahim 2013: 5, italics in the original).[112]

Coming back to the example of a wheelchair user, the assistive device does not directly enable the functioning of mobility if external barriers exist. In this case, it would be necessary to improve the accessibility of infrastructure and buildings. Conversion factors can be personal (e.g., a person's physical or health condition, literacy, etc.), social (comprising social norms and public policies), or environmental (e.g., the climate or the geographical location) (Robeyns 2005: 99). All aspects mentioned so far, including conversion factors, capabilities, and functionings, depend on the sociopolitical and economic circumstances a person is living in. As far as the living situation of persons with disabilities is concerned, important aspects that need to be taken into consideration are, for example, the health system and access to (inclusive) education.

The general ideas of the presented approach are captured well in the following quote:

> "The CA does not just draw the researcher's attention to what individuals actually do, their functionings, as is mostly the case in current education and social research. With the concept of capabilities, it also offers a frame for analyzing the options for action that persons recognized for the formation of what they themselves perceive as a 'good life'. Following the French sociologist Pierre Bourdieu, we can call the concept of capabilities a thinking tool designed not to sort the social world into prefixed categories but to satisfy the relational character of the social world in which the impact of practices depends on the social context in which they occur" (Schäfer/Otto 2014: 8 f.).

As well as empirical applications of the approach, which will be discussed in further detail in subchapter 6.1, it has provoked a number of theoretical discussions—either about underlying concepts (e.g., agency, Crocker/Robeyns 2010) or

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[112] The June 2013 Edition of the E-Bulletin of the Human Development & Capability Association focuses on "Collectivity in the Capability Approach" and thus poses a response to the criticism that the CA is too individualistic by suggesting and discussing the concept of "collective capabilities" (which also received some criticism, including from Sen himself). With reference to Ibrahim (2006), Ibrahim (2013: 4) defines collective capabilities as "those capabilities that result from the exercise of collective agency and whose benefits accrue to the individual and the collectivity. They are capabilities that the individual alone would neither have nor be able to achieve" and adds that "collective capabilities therefore [demonstrate] how individuals can act together as agents of change, rather than each one of them pursuing his/her choices alone" (ibid.: 5).

related theories (e.g., the so-called Lebenslagen-Ansatz ("conditions-of-life-approach"), Leßmann 2007; also Knecht 2010: 70 ff.) or about specific elements of the approach itself. In his PhD thesis, Knecht (ibid.) combines the CA with sociological approaches and discusses the question of how the welfare state produces quality of life. He criticizes Sen for not making use of sociological theories but instead distancing himself from sociology (ibid.: 11). On this basis, Knecht uses a variety of sociological theories to complement the approach (e.g., Bourdieu's social capital and Foucault's discourse theory) and develops it further into a theory of resource transformation (ibid.: 14).[113] Among other topics that have received extensive attention in the literature are, e.g., the highly debated question of compiling a list of capabilities that are valid for different contexts and cultures. As opposed to Sen, Nussbaum elaborated just such a list of central capabilities and argues for the following ten elements:

1. "Life"
2. "Bodily Health"
3. "Bodily Integrity"
4. "Senses, Imagination, and Thought"
5. "Emotions"
6. "Practical Reason"
7. "Affiliation"
8. "Other Species"
9. "Play"
10. "Control over One's Environment"

Figure 8: Nussbaum's list of capabilities

(quoted and summarized from Nussbaum 2006: 76 ff.)

In summary, "the CA serves as the fertile base for producing new approaches towards the analysis and facilitation of the 'good life' of persons, in case it is complemented by other concepts" (Schäfer/Otto 2014: 7). Apart from being "*underspecified*" (Robeyns 2006: 353, italics in the original), the CA has received criticism for being too individualistic (Robeyns 2005: 107) and further "strengths are re-construed as potential weaknesses by critics" (Clark 2005: 5), e.g., the fact that the approach is very open and can be completed with other approaches and theories.[114]

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[113] Knecht (2010: 286) also calls it a theory of social inequality. Among many other aspects, he discusses to what extent quality of life (with life expectancy being the outcome indicator) is a goal of the German welfare state.

[114] For further criticism, see also Knecht (2010: 66 ff.).

4.3 Quality of Life According to the Capability Approach

The question arises of how all concepts and details relate together in the assessment of people's well-being and quality of life, and, in addition, how quality of life and well-being are conceptualized and distinguished from one another in accordance with the approach. About 20 years ago, Gasper (1997: 284) gave an overview of the main concepts and interrelations, tracking the way "[f]rom resources through to quality of life." His and Robeyns' (2005: 98) schematic illustrations of the main features of the CA have a lot in common in the way they present the key concepts and their linkages. Gasper's overview (1997: 284) differentiates between three possible ways of interpreting well-being:

1. by taking into account the fulfillment of preferences;
2. by investigating happiness and/or satisfaction; and
3. by assessing well-being on the basis of further aspects, like capabilities and functionings.

These three aspects can either occur jointly or be regarded as different issues (reflected through the supplement "&/or" in the overview) (ibid.). A person's quality of life is then distinct from the well-being of an individual and goes far beyond one's own well-being, as it also involves aspects such as sympathy and a person's commitment for other people (for details, see below). This subchapter focuses on quality of life as understood by Sen.

4.3.1 Standard of Living, Well-Being, and Agency

In order to evaluate and describe a person's living situation, Sen (1993: 35) himself distinguishes between four concepts: "well-being freedom," "well-being achievement," "agency achievement," and "agency freedom," all of which refer to different facets of a self-determined lifestyle. According to Robeyns (2005: 102), the relation between these concepts can be brought together by linking up standard of living, well-being, and agency in the following way:

> "The standard of living is 'personal well-being related to one's own life'. If we add the outcomes resulting from sympathies […], we measure well-being. If well-being is supplemented with commitments […], then we are focusing on overall agency (Sen, 1987). Moreover, all of these concepts can be further specified as being either achieved outcomes, or the freedom people have to achieve these outcomes, independent of whether they opt to achieve them or not" (see also Gasper 1997: 285 and Ruta el al. 2006: 6 f.).

For the moment, the relevant concepts can be systematically summarized in the following overview:

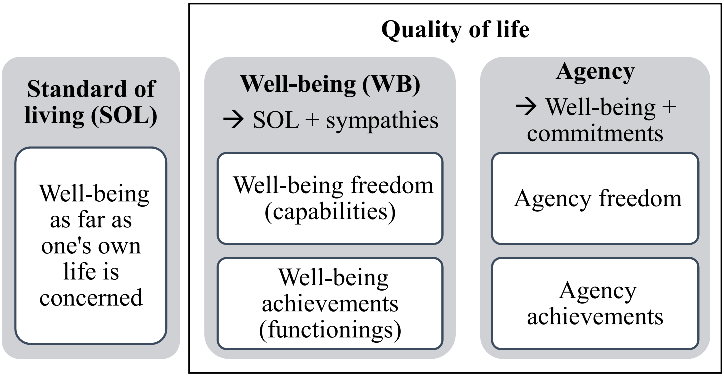

Figure 9: Systematic overview: standard of living, well-being, agency, quality of life

(own overview based on Robeyns 2005: 102, see quote above)

Gasper (1997: 285) concludes that, in the approach, well-being and standard of living are more relevant than quality of life, as functionings and capabilities are concepts that have (mainly) been defined as far as a person's own situation is concerned. In *The Idea of Justice*, Sen (2009) provides a clarification when he explains that, in situations of deprivation, the well-being of an individual might be more relevant than his or her agency achievements (the latter of which might perhaps not be possible for the person), as

> "the state may have better grounds for offering support to a person for overcoming hunger or illness than for helping him to build a monument to the person's hero, even if the loyal guy were to attach more importance to the monument than to avoiding hunger or illness" (ibid.: 288).

Agency is therefore to be understood as activities or situations that are not necessarily favorable to the person who acts (Robeyns 2005: 102). A potential consequence might even be a reduction in one's personal well-being (Crocker/Robeyns 2010: 75). Ruta et al. (2006) refer to Sen (1993) and present the relation between these concepts in a somewhat different manner. They argue that "a person's well-being can be assessed in terms of their capability to achieve personally and socially valued functionings. At one point he [i.e., Sen; IB] even goes so far as to equate this with a definition of quality of life" (Ruta et al. 2006: 6 f.). Following Sen

(1993: 31), "[t]he approach is based on a view of living as a combination of various 'doings and beings', with quality of life to be assessed in terms of the capability to achieve valuable functionings," i.e., the options that a person can choose from. In this context, emphasis is put on the question of what is to be valued and against which background individuals judge their living situations and the options they can choose from (ibid.: 31 ff.).

As far as individual wishes and personal identity are concerned, Teschl and Derobert (2008) discuss Sen's idea that people have several identities, each with certain interests and specific needs—even though most people would see themselves as having one unique identity.[115] The authors criticize Sen's approach towards (a person's multiple) social identities and highlight that, for the assessment of people's well-being and agency, the following aspects are of importance: "the gap between what somebody wants to be and the social or relational constraints preventing her from becoming it." In addition, "to know *who* the person is helps us learn about the social context in which she lives," and "people's identity will be formed and influenced by their interaction with others" (ibid.: 153 and 154, italics in the original).

4.3.2 Agency (and) Freedom

As could be seen with respect to the concrete investigation of quality of life, agency receives a lot of attention in the CA. In line with Crocker's and Robeyns' (2010: 75) argumentation, the research should therefore not only focus on

> "what it means for an individual's life to go well or for a group to be doing well, and which capabilities and functionings are most important, but also who should decide these questions, how they should do so, and who should act to effect change".

Thus, the concept of agency freedom, and its two constituent parts (agency and freedom), will be looked at in further detail. The concept of agency has already received much attention in Sen's earlier publications (e.g., Sen 1982b; 1985b) and has been taken up by various scholars working with the CA (e.g., Deneulin 2008). Crocker and Robeyns (2010) also engage more deeply with the idea of "agency," as understood and used by Sen. As a more descriptive concept, for which Sen primarily argued, agency helps to conceptualize actions or goals that are not beneficial or conducive to one's own well-being:

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[115] This thesis will come back to the concept of identity when presenting the research results.

> "A person's agency achievement is his or her deciding and acting on the basis of what he or she values and has reason to value, whether or not that action is personally advantageous. A person's agency freedom is the freedom to so decide and the power to act and be effective" (ibid.: 75, see also Sen 1985b: 203 f.).

This offers the possibility of not only evaluating people's well-being but also of capturing aspects that go beyond self-interest and personal well-being. The descriptive view of agency is complemented by a normative one, introduced by Sen (1992: 58) through the distinction of "*realized* agency success" and "*instrumental* agency success" (italics in the original).[116] The latter refers to action(s) undertaken by an individual him- or herself, whereas realized agency success points towards the fact that the achievement of functionings can increase through public action or public policy (Crocker/Robeyns 2010: 77, with reference to Sen 1999). It has to be noted, in this regard, that "[m]any good (and bad) things happen to people because of what other agents do for (or to) them" (ibid.). However, it is more decisive for people to live their lives individually and collectively, "sometimes realizing their own self-regarding goals, sometimes realizing (or helping realize) others' goals, and sometimes by forming joint intentions and exercising collective agency" (ibid.: 79). On the basis of Sen's writings, the authors identify four dimensions of agency:[117]

Dimension of agency	**Explanation**
"self-determination"	"the person decides for himself or herself"
"reason orientation and deliberation"	"the person bases his or her decisions on reasons"
"action"	"the person has a role in performing"
"impact on the world"	"the person […] brings about […] change in the world"

Figure 10: Dimensions of agency

(based on and quoted from Crocker/Robeyns 2010: 80, italics in the original)

According to Zimmermann (2006: 471), the environment plays a major role as far as agency is concerned, as "Sen insists on the embeddedness of individual agency" and the CA "seeks to address individual agency within complexity and social

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[116] Crocker and Robeyns (2010: 78) distance themselves from this view and instead suggest a tripartite understanding of agency, namely the "agency of others," "*indirect* agency," and "*direct* agency" (italics in the original). This suggestion will not be discussed in further detail here, although their choice to neglect Sen's concept of "realized agency" is worth noting.

[117] For the—intrinsic, instrumental, and "constructive"—value of agency, see also Crocker/Robeyns (2010: 83).

diversity." However, Zimmermann identifies limitations regarding Sen's use of agency. Personal decisions and values are focused on here, but the approach does not provide for the analysis of how essential skills can be acquired and how social support may be guaranteed. Neither do interactions, which are a central component in sociological analyses, receive attention in the framework. According to Zimmermann, this leads to two implications for the empirical application of the approach: Firstly, changes in the environment and dynamic processes can hardly be captured adequately. Additionally, it leads to an underestimation of power relations (ibid.: 474 f.). In this regard, a dynamic and active understanding can, or rather needs, to be differentiated from the more static or descriptive view (see also Ritter 2014: 146). In accordance with her line of argumentation, Zimmermann (ibid.: 471 ff.) thus distinguishes "positional agency" from "situated action" in order to understand freedom as a process and to "allow one to complete – at an empirical level – the shift from generic individuals to singular persons claimed by Sen at a theoretical level" (ibid.: 475). Zimmermann furthermore argues for a process-oriented analysis that considers temporal aspects and elements of interaction (ibid.: 480). Taking into consideration the past, present, and future of a person, and avoiding focusing on just one point in time, can help to reveal a great deal of information about a person's capability set:

> "In shifting moments or situations of crisis, opportunities and individual skills become more salient; capabilities, or the lack of capabilities, become more visible; conversion operators are revealed as operational or missing. Depending on persons, situations and configurations, the same element (such as training for instance) can constitute a resource or a conversion operator reflecting the open and basically plural character of the conversion concept" (ibid.).

It becomes obvious that a qualitative research approach might be an appropriate way of dealing with these challenges as far as the empirical application of the CA is concerned, and chapter six will present a way and method of operationalizing these theoretical considerations. Generally, the preceding subchapters have highlighted that the CA provides a platform to examine the way in which people are able to shape and influence their own lives according to their preferences and decisions. The next subchapter investigates the concretization of the CA in the fields of disability (policy) and social protection, before combining the previous explanations and handing over to the empirical part of this thesis and the country in focus.

4.4 Disability and Social Protection—Thematic Contextualizations of the CA

Apart from discussions on specific aspects and concepts that belong to the approach itself, the CA literature has also generated a large number of studies on various topics, such as education (e.g., Unterhalter 2005; Walker 2006) and health (Prah Ruger 2010). The CA takes human diversity into consideration in that it addresses "interpersonal variations of the relation between resources and freedom" (Zimmermann 2006: 472). Furthermore, Goerne (2010: 17) argues that the elements of the CA "put much emphasis on human diversity, i.e., the diversity of needs and plurality of choices. This emphasis can serve as the starting point for an analysis of policy *outputs*, focussing especially on the concepts of individualisation and diversity" (italics in the original). The topic of disability is a suitable example to demonstrate this and further to show the openness of the CA and the need to refer to other theories and approaches when applying the CA, as Robeyns (2005: 94) points out in one of her articles.

4.4.1 The Capability Approach and Disability

With reference to Rawls' *A Theory of Justice* (1970), Pogge (2007: 74) argues that the well-being of persons with disabilities is "below that of an able-bodied person with the same social primary goods […] because the disabled person is likely to be less successful in his or her pursuit of the three fundamental interests." Rawls public criterion, which focuses on social goods alone, is therefore inadequate according to Pogge as it does not take aspects like impairments or chronic illnesses into account. It becomes, however, obvious in Pogge's further elaborations that he does not engage in a critical discussion on disability and the respective dynamics of ascription and stigmatization. Rather, he writes about "genuine disabilities" (locating the "problem" within the individual) and argues that "[i]t *is* worse if those already struck with blindness must also occupy the lowest position in terms of social primary goods" (ibid.: 75, italics in the original).

The CA, as originally developed by Sen, criticizes Rawls' focus and—among other aspects—contains elements that capture some of Pogge's arguments on Rawls, e.g., when he states that "an appropriate list of social *and natural* primary goods for assessing individual well-being" is preferable over "a public criterion that disregards information about individuals' natural endowments and is sensitive only to their social positions" (ibid., italics in the original). However, in terms of dealing with the living situations and well-being of persons with disabilities, both Sen's (and Nussbaum's) writings and publications on the CA can also be criticized and need further examination as to their conceptualization of disability. Capability literature that does not specifically focus on the topic of disability sometimes contains examples that neither reflect the social model nor follow a rights-based approach to disability. This can, e.g., be seen with reference to Sen (1993: 44), who wrote that

> "an active exercise of freedom […] would be of no direct relevance in the case of babies (or the mentally disabled [sic]), who are not in a position to exercise reasoned freedom of choice (though babies *can* sometimes be amazingly cogent, choosy, and insistent)" (italics in the original).

In one of her articles, Robeyns (2005: 97) mentions "a person's additional physical needs due to being physically disabled." As explained in chapter two, people's disabilities are a result of various social and attitudinal barriers, even though someone might live with an impairment, have learning difficulties, and/or need assistive devices.[118] Thus, the view that Robeyns and Sen take here is aligned with the medical and individual understanding of disability, a fact that needs to be critically examined when evaluating the suitability of the CA for the investigation of the well-being and quality of life of persons with disabilities. In the context of disability, Sen's arguments are not completely adequate (see also Kesselring 2003: 102). No distinction between a person's impairment and the concept of disability is made, and even though conversion factors exist as a unit of analysis in the CA, social and environmental barriers do not receive enough attention. Further examples of publications on capabilities that do not focus on the topic of disability or were not written by disability researchers, but nonetheless refer to persons with disabilities, include, e.g., Graf (2011: 16). He provides an example from the field of positive and negative freedoms and explains that a person who "suffers" from a disability cannot go into the park and therefore does not have the positive freedom to do what he/she likes—the negative freedom is however not affected. On the contrary, if a person does not go there due to the fact that criminals might follow and attack him/her, the person has neither the positive nor the negative freedom. Here again, the medical and individual-centered perspective on disability is prevalent. Notwithstanding the fact that someone might have an impairment that influences his/her daily living (as also discussed in chapter two with reference to Shakespeare), the "inability" to go into a park depends much more on external factors, such as the provision of a wheelchair or other assistive devices and the elimination of barriers, such as stairs, uneven pathways, etc.

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[118] For a discussion on capability aspects with regard to persons with cognitive impairments, e.g., against the background that they might need a guardian to represent them, see Bérubé (2009: 357 ff.).

Against the background of the presented approaches towards the quality of life of persons with disabilities, it is therefore necessary to take into account current discourses and concepts from the field of disability studies and research in order to enrich Sen's theoretical framework. As specified by Robeyns (2006: 360 ff.) in her overview of applications of the CA, several authors have already focused specifically on the living situations and the deprivation of persons with disabilities in relation to the CA. This was, for example, done by explaining how to understand the conceptualization of disability through the CA (Mitra 2006), presenting potential connections between the CA and the social model of disability (Burchardt 2004), highlighting the similarities and differences between the International Classification of Functioning, Disability and Health, published by the WHO in 2001, and the CA (Welch Saleeby 2007), or focusing on special (needs) education[119] (Terzi 2005; Reindal 2009). Mitra (2006: 245 f.) comes to the conclusion that the "approach allows researchers to analyze how disability results from the interaction among the individual's personal characteristics, available resources, and environment."

These publications specifically written on the CA and disability show that the important aspects are not the vulnerability or even "deficits" of an individual but rather the chances and opportunities offered or denied by society. If complemented by approaches and theories from the field of disability research, such as the social model or the ICF, the CA can be seen as a suitable framework to discuss the impact of disability policy on the living standards, inclusion, and social situation of persons with disabilities. However, the CA has not received broad attention among disability studies researchers yet, and not many CA researchers focus on the topic of disability (especially when it comes to seeing disability as a social construct and not as a medical condition).[120] The living conditions of persons with disabilities have, in addition, not received much attention in Amartya Sen's own writings ei-ther (ibid.: 240).

In her book on "Amartya Sen's Capability Approach: Theoretical Insights and Empirical Applications," Kuklys (2005) investigates the living situations of persons with disabilities in the UK. Although quantitative in nature, the results of her study are interesting as she, for example, approaches the question of the impact of disability on poverty. Kuklys (ibid.: 83) states that "disabled individuals suffer from lower income generating capacity and, in addition, from a lower capacity to convert resources into functioning" (though not highlighting/discussing the

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[119] Terzi (2005: 443, abstract) refers to the "dilemma of difference," which describes the challenge of treating every pupil equally while at the same time adequately addressing diversity and individual needs.

[120] Interesting studies that focus on the topics of disability and use the Capability Approach as an analytical framework are, e.g., "Comparing incomes when needs differ: Equalization for the extra costs of disability in the U.K." by Zaidi and Burchardt (2005) and "Disability Policy Shortcomings in Afghanistan" by Trani et al. (2009).

reasons). In her study, disability is furthermore seen "as an additional needs factor" (ibid.). According to her, the most striking effect is that "nearly half of the population living in households with disabled members lives below the poverty line" (ibid.: 99). Two policy conclusions arise: the levels of benefits for persons with disabilities are not "high enough to compensate for the entire additional consumption cost" (ibid.). Furthermore, poverty measures should be complemented by "measures adjusted for disability" (ibid.). Similar to other publications, the view on disability expressed here can be associated with the medical rather than the social model of disability, as an individual-focused perspective is taken.[121]

4.4.2 Focus: Nussbaum and Persons with Disabilities

Of further importance are writings on disability published by Martha Nussbaum, as she specifically engages in a discussion on the quality of life of persons with disabilities. Regarding Nussbaum's writings on persons with intellectual impairments, Bérubé (2009: 352) comments that "Nussbaum's willingness to take cognitive disability as a challenge for moral philosophy has been exemplary."[122] Despite this acknowledgment, some of Nussbaum's publications (e.g., Nussbaum 1995) can be criticized due to her view on disability. One quote can serve as an example here:

> "It follows from this that certain severely damaged infants are not human ever, even if born from two human parents: again, those with global and total sensory incapacity and/or no consciousness or thought; also, I think, those with no ability at all to recognize or relate to others. (This of course tells us nothing about what we owe them morally, it just separates that question from moral questions about human beings.)" (Nussbaum 1995: 82)

As Gröschke (2000: 138) argues, the bio-ethical judgments on persons with disabilities that she presented in this publication are completely erroneous and might be based on the fact that she is not an expert on the living situations of these children and how they interact with their environment: "Dieses krasse Fehlurteil der Philosophin dürfte einer völligen persönlichen Unkenntnis der Lebensäußerungen und kommunikativen Möglichkeiten schwerstbehinderter Kinder geschuldet sein"

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[121] Robeyns calls the two studies by Zaidi & Burchardt and by Kuklys "*partial* capability applications," as they "only focus on functionings deprivation in terms of material well-being; a full assessment of the functioning well-being of the disabled might also reveal other considerable deprivations" (Robeyns 2006: 366, italics in the original). In addition, only one dimension of human diversity is focused on (see ibid.).

[122] With reference to Nussbaum's book "Frontiers of Justice," Schäfer and Otto (2014: 9) highlight the question of "how to apply the CA to individuals who do not dispose of the necessary critical reflection such as children or the mentally disabled [sic] remains an open question."

(Gröschke 2000: 138).[123] According to Müller (2004), Nussbaum's view on humankind is characterized by perfectionism, as she creates an ideal picture of a human being. However, she does not succeed in answering the important question of what rights people who are not "human" according to her understanding have and what kind of protective mechanisms are in place to ensure that they are appropriately treated. In sum, Nussbaum seems to neglect (or not to know) the dangers of her argumentation (Müller ibid.: 40).

On the basis of her list of basic capabilities (Nussbaum 2003: 41 f., see also figure eight), Nussbaum makes a differentiation between human and non-human life. The aspects compiled in her list are "viewed as necessary or essential (and together sufficient) for something being counted as human being" (Crocker 1995: 172). If capabilities are lacking, or not achieved, an individual might not fulfill the criteria of humanity nor achieve a good quality of life. Following this line of argumentation, Crocker (ibid.) provokingly states that "a creature would be 'lacking in humanity' if it were blind. However, this strong interpretation would entail that Stevie Wonder was not human." This view can (and needs to) be criticized, and not only from a disability rights perspective.

In her major publication on "Frontiers of Justice," Nussbaum (2006) argues in a somewhat different direction and tries to prove her personal involvement with and knowledge of persons with disabilities by portraying some individuals whom she personally knows. For example, she states that "[c]hildren and adults with mental impairments are citizens. […] Any decent society must address their needs for care, education, self-respect, activity, and friendship" (Nussbaum 2006: 98). Although Nussbaum's version of the approach will not be given a central position in this analysis, it might be important to keep her version of the approach and her publications on disability (e.g., 2006, 2009) in mind. I agree with Gröschke's (2000: 138) argument that her work should not be disregarded: "Es wäre jedoch bedauerlich, wegen dieses substanziellen Fehlurteils diesen konstruktiven Ansatz einer Ethik des guten Lebens zu diskreditieren."[124] For example, Nussbaum's work on gender issues and capabilities is definitely worth acknowledging.

4.4.3 The Capability Approach and Social Protection

Maschke (2007: 303) summarizes three ways of measuring social welfare and poverty on different levels: Objective measurement can either be conducted

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[123] Own translation: "The philosopher's extreme misjudgment is probably the result of an absolute personal ignorance of the life expressions and communicative potentials of severely impaired children."

[124] Own translation: "It would be regrettable to discredit this constructive approach of an ethic of good life on the basis of this substantial wrong judgment."

through focusing on income and resources or take into consideration personal preferences and social structures by focusing on a person's living situations ("Lebenslagen") and assets/standards in central areas of life. By taking into consideration a person's own interpretation and social environment, poverty experiences can be investigated by directly measuring welfare on the basis of satisfaction. Sen's ideas, especially if complemented by other concepts or research approaches, combine elements of all three categories and thus go beyond any of them.

As explained by Robeyns (2005: 94), the CA can be applied for a variety of purposes and within many fields: e.g., development studies, social policy, or philosophy. Sen also included the topic of social protection in his publications (e.g., Drèze/Sen 1991). More than 30 years ago, for example, Sen (1984: 343) noted that "since poverty removal is not the only object of social policy and inequality removal has a status of its own, […] the issue of inequality of capabilities is an important one […] for public policy." However, Knecht (2010: 69) argues that the topic of social protection does not receive adequate attention in Sen's work:

> "Ein weiteres Problem, das Sen im Unklaren lässt, sind die Themen Risiko und Unsicherheit. Das Leben, die Nutzung von und die Verfügung über Ressourcen, die Art und Weise wie Transformationen vor sich gehen, all das ist zu einem großen Teil nicht planbar. Daraus ergibt sich die Notwendigkeit Risiken zu bearbeiten. Bei Sen bleibt dieser Aspekt unterbelichtet und wird nur als Ad-hoc-Argument [d.h. anhand konkreter Beispiele; IB] eingeführt."[125]

Rather than focusing on the reduction of monetary poverty, the analysis conducted in this thesis thus focuses on the capabilities and opportunities that are provided through measures of social protection and other social policy interventions. In this respect, in accordance with Robeyns (2005: 96), the CA serves as a "framework of thought," namely regarding South African social policies:

> "The capability approach is primarily and mainly a framework of thought […] for a wide range of evaluative purposes. The approach focuses on the information that we need in order to make judgements about individual well-being, social policies, and so forth, and consequently rejects alternative approaches that it considers normatively inadequate; for example, when an evaluation is done exclusively in monetary terms" (ibid.).

Goerne (2010) investigates the potential of the CA, in particular for social policy analysis. He concludes that "the CA [is] a concept *especially* useful for the analysis of mature welfare states, although it was developed with economically developing

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[125] Own translation: "The topics of risk and insecurity are a further problem that Sen leaves unspecified. Life, the use of and the disposal of resources, the way in which transformations occur, all this is not calculable to a large extent. Thus, it is necessary to work on risks. This aspect is underexposed in Sen's work and is only introduced as an ad hoc argument [i.e., on the basis of concrete examples; IB]."

countries in mind" (ibid.: 17, italics in the original). And even though South Africa cannot be counted as such a "mature welfare state," the framework that the CA offers will be used for the analysis of South African social policy in this thesis. More precisely, it is applied when approaching the interview partners' quality of life, taking into consideration their access to social protection coverage and further elements of disability and social policy—and not only concentrating on the receipt or non-receipt of the DG. In this respect, the analysis draws on the argument that "social security refers to the conversion of resources into actually (un)fulfilled social security needs, or 'living standards' in Sen's […] terminology, at whatever level of poverty or wealth" (von Benda-Beckmann/von Benda-Beckmann 2007: 31). Accordingly, Drèze/Sen (1991: 31) argue that

> "a foundational issue concerning the whole idea of social security is the choice of 'evaluative space', that is, the variables in terms of which the success or failure of social security is to be judged. […] [And] ultimately the success and failures of social security would have to be judged in terms of what it does to the lives that people are able to lead."

According to Bliemetsrieder and Dungs (2013: 280), situations of social hardship are a negation of freedom in Sen's view. Thus, questions regarding social and human development need to take into account the expansion and multiplication of real freedoms. This broad approach towards social protection is in line with Barrientos' (2010: 585) argument, when he states that

> "the capability approach could provide a better grounding for social protection, by focusing on functionings and capability as the informational basis of social protection, and in the process unfolding the production of well-being and associated vulnerability as the context in which social protection operates."

As such, it is also important to highlight whether a grant for persons with disabilities that is linked to a certain level of monetary poverty is an adequate instrument a) for the provision of social protection and b) for the promotion of social inclusion and social justice.[126] In order to cover the aspect of freedom in practice, this thesis puts a strong focus on the topic of "agency." As discussed above with reference to Steinwachs (2006) and—in another context—Zimmermann (2006), the dimension of time (i.e., changes over the life course) and the dynamics of social interaction (e.g., the family or personal relationships) also play a role in this regard.

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[126] For a discussion on the use of the capability framework in the context of social justice and inclusion, see, e.g., Bertmann/Demant (2014).

5 Contextual Framework: Social and Disability Policy in South Africa

One of the first things that comes to mind when thinking about South Africa is the country's recent history, which has profoundly influenced the social structures and living realities of a total population of around 54 million inhabitants[127] (Statistics South Africa 2014: 3). Between 1948[128] and 1994, racial segregation was prevalent in South Africa and enforced by the National Party (NP). Inequality and socioeconomic disparities are still widespread today: Even twenty years after apartheid,[129] differences between ethnic groups in terms of living standards, access to services, the chances of finding work on the regular labor market, and other aspects are clearly identifiable.

5.1 Contemporary South Africa: Two Sides of the Same Coin

South Africa's history, with its long period of racial segregation, has shaped its (current) social structures, and has been influential as far as political and legal developments are concerned. Concretely, apartheid led to negative effects such as family breakdowns due to internal labor migration. In addition, the high number of people affected by HIV/AIDS in South Africa[130] has had an impact on family structures (e.g., regarding household heads), health situations, and, consequently,

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[127] Details according to the 2014 mid-year estimates by population group: African: 43,333,700 (80.2%), Coloured: 4,771,500 (8.8%), Indian/Asian: 1,341,900 (2.5%), White: 4,554,800 (8.4%) (Statistics South Africa 2014: 7).

[128] Interestingly, the first apartheid government came into power in 1948—the year in which the UN adopted the Universal Declaration of Human Rights. Along with a few other countries, South Africa did not ratify this declaration (Dubow 2012: 1).

[129] In their "Dictionary of South African History," Saunders and Southey (2001: 12) define apartheid as a "[t]erm often used loosely to include all forms of racial segregation," which "was coined to refer to the policy adopted by the National Party (NP) in the early 1940s to extend existing segregation, to make it more comprehensive, apply it more rigorously, and broaden its application." Thus, a couple of years later "apartheid had become – in the guise of 'separate development' – a policy to enable white supremacy to survive in the face of an emerging African nationalism, by dividing and repressing that nationalism, and obscuring a naked white supremacist position" (ibid.: 13).

[130] According to estimates by UNAIDS (2013: A8), approximately 18 million adults (between 15 and 49 years of age) are infected with HIV in South Africa.

I. Bertmann, *Taking Well-Being and Quality of Life for Granted?*, Gesundheitsförderung - Rehabilitation - Teilhabe,
https://doi.org/10.1007/978-3-658-19812-1_5

working capacities and productivity, as well as potential economic consequences due to the high number of deaths (Horton 2005: 113 f.). With lower wages, higher poverty rates, and fewer opportunities to find employment, the economic situation of women is worse than that of most South African men (Goldblatt 2014: 23). Also, vast differences exist between the nine South African provinces in terms of resources, poverty levels, and other socioeconomic indicators.

There is, however, another "side to the coin"—e.g., as far as the provision of rights and the country's constitutional framework is concerned: As a result of the social injustices that occurred during the apartheid era, the Constitution, which was adopted in 1996 and developed with the contribution of civil society representatives (Howell et al. 2006: 46), is widely said to be one of the most progressive constitutional and legal frameworks worldwide. Furthermore, in recent years South Africa has undergone strong economic development. The World Bank (n.d.-b) classifies most of the world's economies according to their gross national income (GNI) by using the so-called Atlas method. For several years now, South Africa has been counted as an upper-middle-income economy[131] according to this classification. Together with Brazil, Russia, India, and China, it is one of the "BRICS" countries.[132] However, characterizations like this one mainly refer to economic aspects; they do not provide details regarding the political system, the legal framework, and the sociopolitical situation, or include aspects like inequality in income distribution or unemployment. In addition, no information is given by these criteria on the actual living situation of the people, their life satisfaction and life chances, or on (negative) facets like social discrimination, exclusion, and power relations. However, these sociopolitical factors are of relevance when focusing on the development of a certain state or society—while being aware that they are more difficult to measure and monitor than quantifiable economic indicators. A prominent example of

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131 Currently, the World Bank (n.d.-b) uses the following classifications:

- "low-income economies": GNI per capita of $1,045 or less in 2014;
- "middle-income economies": GNI per capita of more than $1,045 but less than $12,736, with a separation of "lower-middle-income" and "upper-middle income" countries at a GNI per capita of $4,125;
- "high-income economies": GNI per capita of $12,736 or more.

The UN Development Programme and the World Bank use different wording and measurements to classify countries worldwide. This leads to the fact that countries might be classified very differently in the two systems of measurement, e.g., due to the fact that the UNDP uses life expectancy, education, and living standards, whereas the World Bank uses GNI per capita (Fischer et al. 2004: 29).

132 The term "BRIC" was coined by Jim O'Neill (Goldman Sachs). It stands for Brazil, Russia, India, and China, later on complemented by South Africa (BRICS). The tension between economic potential on the one hand and social cleavages and problems on the other is a joint characteristic of the BRICS states.

such an assessment tool is the already mentioned Human Development Index (HDI), which shows that social development in South Africa can be described as "medium human development." Of the 187 states included in the ranking, South Africa occupies position number 118, together with the Syrian Arab Republic[133] (UNDP 2014: 165). The reason lies in the above-mentioned fact that South Africa is a country with a difficult historical background, especially as far as social justice is concerned, and has been, up to now, characterized by unequal distributions of resources, wealth, and power—more than two decades after the end of apartheid.[134] According to the Human Development Index, 17.1% of the population lives close to multidimensional poverty (ibid.: 181, the percentage figure refers to 2012).

What does this mean for the living situations of the citizens, especially those who still experience the impacts of apartheid very profoundly, e.g., in their daily lives in South African townships?[135] In an ethnographic research study, Legg and Penn (2013: 20) describe the following characteristics of a specific South African township, which are also applicable to a variety of other areas, including rural ones or other townships:

> "[…] only 35% of Khayelitsha's population is permanently employed. Others rely on survival activities and casual labor. Average household income levels are low: 72% of households survive below subsistence levels, and 19% of people are in receipt of social income support such as old age pensions, […] disability grants, child support grants, and grants-in-aid."

This quote covers a broad thematic spectrum and alludes to the living realities of people living in poverty contexts. In this regard, it also already highlights the relevance of the different grants in South Africa, among them the DG. The following chapters will focus on the different aspects of disability (policy) in South Africa, the living situations of persons with disabilities, including their families, as well as the topic of social protection. This will give evidence of the difference between

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[133] The findings of the HDR 2014 on Syria need to be put into the context of the country's crisis. It is, for example, mentioned when the report discusses forced migration (UNDP 2014: 76 f.).

[134] While a Gini coefficient of 0 means equality, an index of 100 stands for absolute inequality. South Africa has an income Gini coefficient of 63.1, i.e., high income inequality (UNDP 2014: 170). With 54.7, Brazil's Gini index, for example, is lower (ibid.: 169).

[135] "Township" or "location" is a term used for the living areas close to South African towns in which the non-white population had to live during apartheid. The townships are very distinct from each other. Whereas in some areas, many people live in shacks and do not have access to clean water, electricity, or proper roads, some townships nowadays have areas in which people with middle incomes live (e.g., in Soweto in the province of Gauteng).
Khayelitsha is one of the largest South African townships with a population of mainly Black African people (City of Cape Town 2013).

the policy level and legal framework on the one hand and their realization on the level of practical implementation on the other.

5.2 Disability (Policy) and Inclusion

As Swartz and Watermeyer (2006: 1) summarize in the introduction of a comprehensive collected edition on “Disability and Social Change”[136] in South Africa,

> “[t]he painful legacy of institutional racial discrimination shared by all South Africans, and the remarkable emergence of our nation from decades of conflict, have left an awareness of the oppressive appropriation of the race paradigm indelibly etched on the national psyche […] [and] an awareness of gender as a potentially oppressive marker of differentness has grown amongst the South African populace […]. The idea of ‘oppression’ is firmly attached within South African colloquial culture to the idea of race; however, the marker of disability has yet to achieve this status.”

As in many other countries, the exact number of persons with disabilities is difficult to determine. Globally, the World Report on Disability speaks of approximately “15% of the world’s population” (WHO 2011: 29). Various statistical attempts come to different conclusions—which is also due to data collection methods and the way disability is defined across contexts and cultures, and even on a national level (Emmett 2006: 209). Irrespective of the precise number of persons concerned (i.e., living with impairments and facing barriers that may hinder their participation in a variety of areas), many developments in terms of disability rights and policy in South Africa are worth noting and indicate that the concerns of persons with disabilities are taken into consideration on the political level: Shortly after its adoption, South Africa both signed and ratified the CRPD in 2007. Even earlier, important policy documents like the Education White Paper 6[137] on Special Needs Education (Department of Education 2001) and the White Paper on an Integrated National Disability Strategy (INDS) (Office of the Deputy President 1997) were published. In theory, these documents and developments provide a strong basis for the social inclusion of persons with disabilities in contemporary South Africa. Furthermore, in 2009, President Zuma launched the Department of Women, Children and People with Disabilities (DWCPD). However, since its dissolving, this area of responsibility has been moved to the Ministry of Social Development. This does not necessarily have to be evaluated negatively; if it entails a broad understanding of social development that aims to achieve social inclusion

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[136] Eds. Watermeyer, Brian et al. (2006).

[137] For an explanation regarding the nature and binding force of white papers and other legal documents (bills, laws, acts) in South Africa, see, e.g., the explanations provided on the website of the so-called Parliamentary Monitoring Group (PMG n.d.).

and cohesion—and is not aligned with the provision of social assistance to allegedly poor and vulnerable population groups. Seeing disability mainly as a welfare issue can, however, be criticized.

The following subchapters will look into South African disability rights and policy in more detail. By focusing on the South African disability rights movement first, the way towards the above-mentioned policy and legal framework can be traced historically (see subchapter 5.2.1). In addition, the documents and initiatives already mentioned will be further examined in subchapter 5.2.2 in order to underline the argument that, on the political as well as the legal level, the rights of persons with disabilities are guaranteed. This subchapter then leads to the examination of social protection, especially regarding persons with disabilities and their families, in South Africa. Against the background outlined above, these parts of the thesis will address the theoretical discussion of disability and social protection, including questions such as mainstream vs. specific schemes, targeting, and disability assessment, in the South African context.

5.2.1 The South African Disability Rights Movement

In South African history, the struggle for human rights has a long tradition—culminating in post-apartheid events such as the process of developing the country's Constitution and the work of its Truth and Reconciliation Commission[138] (Dubow 2012: 9). Following the "key moment in the process of linking anti-apartheid struggles to the international human rights movement" (ibid.: 16) in the 1970s, the South African disability rights movement was also strongly influenced by worldwide efforts against discrimination and in favor of equal rights for persons with disabilities.[139] Discrimination and social exclusion affected both black and white persons with disabilities, as well as those with other ethnic origins, and the view

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[138] The Truth and Reconciliation Commission was set up after the end of apartheid in order to investigate the human rights violations that took place up until 1994. Three committees existed: The Human Rights Violations Committee, the Reparation and Rehabilitation Committee, and the Amnesty Committee.

[139] As shown in chapter two, in 1981, the United Nations declared the "International Year for Disabled Persons," followed by the "World Programme of Action concerning Disabled Persons" and the "United Nations Decade for Disabled Persons" (1983-1992). A significant outcome of this decade was the adoption of the "Standard Rules on the Equalization of Opportunities for Persons with Disabilities" in 1993.
Although the United Nations' International Year was not recognized by the South African government, it did proclaim a National Year of Persons with Disabilities for South Africa in 1986 (Office of the Deputy President 1997: Chapter Two).

on and treatment of disability was based on the medical and deficit-oriented understanding introduced in the second chapter of this thesis. However, their experiences “under apartheid were very different and reflected the general inequalities between white and black people in South Africa” (Howell et al. 2006: 48). Persons with disabilities were thus involved in “both a struggle against apartheid and against how people understood and responded to disability” (ibid.: 49). This quote is important, as it addresses the intersectionality[140] of two categories: race/ethnicity and disability. Gender-related differences and experiences can, for example, be mentioned as further intersectional aspects.

The disability rights movement in South Africa was shaped by several well-known individuals and activists (e.g., Friday Mavuso), as well as by many organizations that represent persons with disabilities and/or provide services and support to individuals and their families. Not many books or articles exist that cover this. This part of the chapter therefore mainly refers to two publications by Rowland (2004), who describes the movement from a very personal perspective, and Howell et al. (2006). In this overview on the history of the South African disability rights movement, the latter publication in particular focuses on the years from 1980 onwards, starting with the foundation of Disabled People’s South Africa (DPSA) (as a “cross-disability” organization) in 1984.[141] Some key actors, and also some of the interview partners in this research project, have a very good insight into the development of the movement and its events, campaigns, and achievements. Their knowledge therefore flows into the empirical part of the thesis. As the biggest and most influential association, DPSA played (and still plays) an important role on a provincial and national level.[142] As with other DPOs and NGOs, strategies that were used included self-advocacy and empowerment efforts. Apart from this umbrella organization, further groups and programs were created, such as a specific program for women and the Disabled Children Action Group (DICAG), which is now an independent organization. DPSA also worked towards the

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[140] The concept and study of intersectionality (e.g., Crenshaw 1991) focuses on the overlap of different categories in one person (e.g., being female, black, and homosexual) and the respective consequences.

[141] In their chapter, they also refer to uprisings against apartheid in the 1970s that were massively repressed by the state and resulted in many impairments, e.g., because people “were shot by the police” (Howell et al. 2006: 52). The same occurred at the beginning of the 1990s, when there was “ongoing violence in the country, with strong evidence pointing to the apartheid government as either deliberately fuelling the violence or at best failing to address it in any meaningful way” (ibid.: 56).

[142] For a characterization of non-governmental organizations in general, see Frantz and Martens (2006: 57 f.), who explain that NGOs have to fulfill tasks and take over certain functions in the political decision-making process within a national political system and also on an international/ transnational level. This can, e.g., be done by drawing attention to problems and needs for action (“agenda-setting”/“advocacy”).

recognition of disability issues in the political sphere and fostered exchange with movements outside the country, e.g., through the Southern Africa Federation of the Disabled (SAFOD) (Howell et al. 2006: 56 ff.).

For example, Howell et al. (ibid.: 61) report that, during the apartheid years, "black disabled women were one of the most marginalised sectors, experiencing the most severe effects of poverty and social exclusion." Even today, the lives of many persons with disabilities in South Africa—be they women or men, black, white, or with another ethnic background—is characterized by multidimensional experiences of poverty, deprivation, and also stigmatization. Gender does not only play a role as far as the living situations of women (or men) with disabilities themselves are concerned; their roles as mothers/fathers and caregivers are also important: More female-headed than male-headed households are poor. And "within the context of women-headed households and early pregnancies, women face enormous challenges in raising disabled children, leading some commentators to talk about the 'feminisation of poverty'" (Emmett 2006: 207). According to Emmett (ibid.: 218), concrete challenges that female-headed households with early pregnancies might face include, among others:

- the fact that giving birth and taking care of a child affects the mother's educational career;
- fewer chances to marry or high rates of separation due to "the limited experience of the couple and the additional demands of parenthood" (ibid.); or
- worse nutritional provision for the child, thus low birth weight and other complications that might lead to impairments.

In addition, the complex relationship between race/ethnicity, poverty, and disability is significant for the South African context, for example as far as the living situation of children and adults with disabilities in townships is concerned. Accessibility of transport, infrastructure, healthcare, etc. are relevant issues here. Of further importance is the impact of HIV/AIDS on the lives of persons with disabilities. Both disability and HIV/AIDS are connected with a high probability of stigmatization. But, as Swartz et al. (2006: 110) show by referring to a keynote speech that was given by Nkosi Johnson, an HIV-positive child, during the 13th International AIDS Conference in 2000 in Durban, the "attempt to portray HIV-infected people as 'normal' may have had some unfortunate unintended consequences for people with disabilities"—especially when "normality" is equated with physical or bodily integrity. On the whole, it can be concluded that the efforts of the disability rights movement—both as far as individual as well as collective struggles are concerned—bore fruits on the level of disability rights and policies.[143] However, Howell et al. (2006: 79) admit two challenges: "the movement itself and its ability to effect internal changes necessary to meet the challenges of the new democracy" and the "need to ensure that progressive advances achieved through new policies are translated into actions," i.e., the transformation of legal and political provisions to the level of implementation and into the living realities of people all over the country. The social structures of the apartheid time (partly) continue to exist, but effects are partially cushioned through social policy.

5.2.2 Disability Rights and Policy in South Africa

On the basis of the efforts and work of civil society, and DPOs in particular (Matsebula et al. 2006: 85), the Constitution of the Republic of South Africa (N.N. 1996) contains important provisions regarding the protection of the rights of persons with disabilities. Among them is the promotion of equality and the prohibition of discrimination, as enshrined in section 9 on "Equality":

> "(1) Everyone is equal before the law and has the right to equal protection and benefit of the law.
>
> (2) Equality includes the full and equal enjoyment of all rights and freedoms. To promote the achievement of equality, legislative and other measures designed to protect or advance persons, or categories of persons, disadvantaged by unfair discrimination may be taken.
>
> (3) The state may not unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, ethnic or social origin, colour, sexual orientation, age, disability, religion, conscience, belief, culture, language and birth.
>
> (4) No person may unfairly discriminate directly or indirectly against anyone on one or more grounds in terms of subsection (3). National legislation must be enacted to prevent or prohibit unfair discrimination.
>
> (5) Discrimination on one or more of the grounds listed in subsection (3) is unfair unless it is established that the discrimination is fair."

Figure 11: Section 9 of the Constitution of the Republic of South Africa (N.N. 1996)

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[143] See, e.g., the different interviews included in Rowland (2004), e.g., with the Member of Parliament and former Deputy Minister for Women, Children and Persons with Disabilities of the Republic of South Africa, Hendrietta Ipeleng Bogopane-Zulu.

Several other relevant political documents exist in the area of disability law and policy in South Africa, with “disability” being included in general laws such as the Labour Relations Act (Department of Labour 1995), the Employment Equity Act (Office of the President 1998), and the Promotion of Equality and Prevention of Unfair Discrimination Act (N.N. 2000).[144] The South African Department of Labour (2007) even published an information document, entitled “Technical Assistance Guidelines on the Employment of People with Disabilities,” on how to employ persons with disabilities and how to implement the Employment Equity Act. The fact that it was published seven years after the Employment Equity Act itself is perhaps an indicator of the lack of progress up to that date. Concretely, the aim of the document is to make employers “understand the Employment Equity Act of 1998 and its Code of Good Practice on the Employment of People with Disabilities. This includes non-discrimination and affirmative action measures and provides guidelines on how to implement it” (ibid.: 1). Several parts show a very considerate approach towards the living situation of persons with disabilities—however, the understanding of disability is more of a medical than a rights-based or social model one:

> “A disability is a condition caused by an accident, trauma, genetics or a disease which may limit a person’s mobility, hearing, vision, speech, intellectual or emotional functioning. Some people with disabilities have one or more disabilities” (ibid.).

In contrast to the more general pieces of policy and legislation, specific documents referring to persons with disabilities and their living situations include the Department of Social Development’s Policy on Disability (n.d.) and the White Paper on an Integrated National Disability Strategy (Office of the Deputy President 1997) (for details, see Howell et al. 2006: 67). On a provincial level,[145] examples include the Integrated Provincial Disability Strategy of the Western Cape (Office of the Premier 2002) and the Policy Document for People with Disabilities in the Nelson Mandela Metropolitan Municipality (Nelson Mandela Bay Municipality 2007). The efforts of the disability rights movement not only led to the inclusion of important provisions on disability in the Constitution, as explained above, but also to the establishment, in 1997, of a specific coordination point in the office of the then Deputy President Mbeki[146]—the same year the INDS was published. It was called the “Office of the Status of Disabled Persons” (OSDP) and had the task of working on disability mainstreaming (Matsebula et al. 2006: 85 f.).

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[144] For a discussion on disability legislation in South Africa, see Dube (2005).

[145] These two provinces were chosen as the interviews conducted for this project also focus on the Eastern and Western Cape.

[146] Vice President from 1994-1999, South African President from 1999-2008.

As a white paper, the content of the INDS is not legally binding,[147] but this document is comprehensive in the different areas that are covered in the “policy guidelines”: among them healthcare, accessibility, education,[148] labor, and housing. The topic of social protection, which will be focused on in the next subchapter, also plays a decisive role. The various facets of disability rights and policy included in the white paper are also enshrined in the CRPD. Having ratified this convention, South Africa is obliged to implement it. Like any other state party to the treaty, the South African government is requested to regularly provide information about the progress of the treaty’s implementation. The first state party’s report was due in 2010—two years after the entry into force of the convention.[149] The final version of the first report was finally approved by the South African Cabinet in April 2013 and then submitted to the United Nations High Commissioner for Human Rights, from whose website it can be downloaded (Republic of South Africa 2013).

As far as South African disability policy is concerned, it is difficult to come to conclusions in accordance with Maschke’s (2004, 2008) framework and its three ideal types of “rehabilitation,” “compensation,” and “participation”. As Maschke’s framework is based on European welfare states, the elements of his classification cannot easily be transferred to the South African context. Further difficulties lie in the classification itself, as disability policy is a cross-sectional issue that comprises many different tasks and also contains elements from and has effects on several other policy fields (Maschke 2004: 404 ff.). Furthermore, ideal types—as analytical (and not empirical) categories—do usually not appear in pure form and are rather abstract. They do not necessarily reflect reality, in which a mixture of elements from various ideal types can occur.[150] This also holds true for the South African context.

Certain elements of the three ideal types of disability policy (rehabilitation, compensation, and participation) can be found in South Africa.[151] Aspects pertai-

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[147] See also footnote 137 of this thesis.

[148] For a discussion of educational opportunities for persons with disabilities in South Africa, with a basis in Education White Paper 6, see, e.g., Soudien/Baxen (2006) or Naicker (2006).

[149] It was only in 2012 that a draft version of the report was made available and could be downloaded from the website of the former Department of Women, Children and People with Disabilities (DWCPD) for comments. The introduction justified the delay in preparing the report by explaining that the first draft had to be revised in a second round due to poor quality (for details, see DWCPD 2012: Foreword).

[150] The concept of “ideal types” goes back to the German sociologist Max Weber (1864-1920).

[151] Due to the fact that Maschke developed his typology on the basis of European welfare states, it is only partially adequate to use it in the South African context. In addition, without professional experience in and a deeper knowledge of current trends in South African politics in this particular

ning to the ideal type of participation-oriented disability policy include the Promotion of Equality and Prevention of Unfair Discrimination Act (N.N. 2000) mentioned above, as well as the Constitution, which contains the claim for non-discrimination in section 9 (N.N. 1996). Elements of rehabilitation do exist through the Employment Equity Act (Office of the President 1998), which has the following purpose:

> “to achieve equity in the workplace by […] promoting equal opportunity and fair treatment in employment through the elimination of unfair discrimination; and […] implementing affirmative action measures to redress the disadvantages in employment experienced by designated groups” (Chapter I.2).

As far as guidelines for accessible buildings, transport, and communication are concerned, the Integrated National Disability Strategy contains several recommendations (Office of the Deputy President 1997: 70 ff.). The South African system of social protection addresses the provision of compensation in particular, the third ideal type of Maschke’s classification. In this context, persons with disabilities are seen as worthy and poor—leading to the payment of cash transfers financed through the tax system. This is the case in South Africa through the provision of the DG.

In addition, it can be stated in more general terms that there is a gap between the (progressive) legal and policy level, and the state of implementation as far as the living realities of most South Africans are concerned (Howell et al. 2006: 79). In many instances (not only regarding South African disability policy), budgetary restraints can be identified as the reasons for the fact that practical implementation is lacking. With totals of ZAR 7.9 million (2015/16) and 8.3 million (2016/17) (National Treasury 2014: 131), the highest budget line in the expenditure estimates for the “Rights of People with Disabilities” of the South African Treasury for the upcoming years concerns “Monitoring and Evaluation for the Equalisation of Opportunities for Persons with Disabilities.”

5.3 Social Policy/Protection and Social Development

According to the Committee of Inquiry into a Comprehensive Social Security for South Africa, the definition of social protection should be a rather wide one with

> “developmental strategies and programmes which are more appropriate for a developing country [sic] such as South Africa; it provides a coherent framework for integra-

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field, and against the background of a dynamic policy field with certain recent developments, I refrain from conducting a conclusive determination concerning the most suitable type.

> ting economic and social policy interventions, and could also facilitate integrated private-, public- and community-sector interventions and benefit systems" (Olivier/ Mhone 2004: 161).

Concretely, the report states that

> *"[c]omprehensive social protection for South Africa seeks to provide the basic means for all people living in the country to effectively participate and advance in social and economic life, and in turn to contribute to social and economic development.*
> *Comprehensive social protection is broader than the traditional concept of social security, and incorporates developmental strategies and programmes designed to ensure, collectively, at least a minimum acceptable living standard for all citizens. It embraces the traditional measures of social insurance, social assistance and social services, but goes beyond that to focus on causality through an integrated policy-approach including many of the developmental initiatives undertaken by the State"* (Committee of Inquiry into a Comprehensive System of Social Security for South Africa 2002: 41, italics in the original).

In accordance with the definitions and overviews presented in chapter three, the report highlights the relation between measures of social insurance, social assistance, and services on the one hand and further policy endeavors aimed at achieving social inclusion and social protection for all inhabitants on the other. When describing and discussing the features of the South African social security system as it is today, many of the aspects mentioned in chapter three can be taken up and discussed with a specific focus on the South African context. For example, similar to the developments in European states, the negative impacts of industrialization (e.g., poverty) led to the creation of social protection measures on the basis of the former colonies' welfare policy, especially the British one. A national pension was offered, even though it was first given to the white population only, before being extended to others. Further grants were introduced, but, in the context of apartheid, the social security system was racialized—a challenge that had to be dealt with after achieving democracy in 1994 (Goldblatt 2014: 23 ff.; also Patel 2005: 70 ff.). During apartheid, differences existed in terms of the availability and number of social protection mechanisms available to different population groups: Patel thus argues that "[b]lack welfare needs were neglected during the apartheid era" (ibid.: 71), reflecting the general political and social practices of racial discrimination. The colonial period had led to a "favouring [of] whites as the welfare elite" that "permeated social welfare thinking for more than two centuries" (ibid.: 67).

According to Olivier and Mpedi (2009: 19), the system is comparatively comprehensive in relation to other middle-income countries. Even though the South African Constitution (N.N. 1996) does not provide a definition of social security, its goal is to "[i]mprove the quality of life of all citizens and free the potential of each person" (ibid.: Preamble). Concretely, "[s]ocial security is an umbrella concept which, from a South African perspective, includes social assistance and social insurance" (Olivier/Mpedi 2009: 1).[152] Disability is a relevant issue as far as both aspects of social insurance[153] and social assistance are concerned, but this thesis focuses on the provision of social assistance and related means, mainly for three reasons:

a) In order to capture what is being done to tackle social insecurity apart from (or rather in combination with) the provision of "compensation" (e.g., as far as adequate housing is concerned, for details see, e.g., Coulson et al. 2006);
b) As the inclusion of persons with disabilities in the regular labor market is still low, most persons with disabilities are poor (Emmett 2006: 222) and thus do not have access to social insurance and the benefits it provides;
c) The focus on the DG allows for the investigation and discussion of a variety of other aspects such as problems associated with HIV/AIDS (Nattrass 2004; also Swartz et al. 2006):

    - the general high rate of unemployment alongside the fact that there is no Basic Income Grant (BIG) or any other unemployment benefit for the working-age population;
    - the question of access to (free) healthcare; and
    - the high income gap and level of inequality among the population, with households headed by white Africans having more than 5.5 times the wages of households headed by black Africans (Statistics South Africa 2012: 5).[154]

To illustrate this last argument, the figure below shows the average annual household income[155] by population group:[156]

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[152] Among others, there is an "Unemployment Insurance Fund," the "Road Accident Fund," and the "Compensation for Occupational Injuries and Diseases" (for details, see, e.g., Olivier/Mpedi 2009: 20 ff. and below).

[153] For an overview of social insurance coverage in cases of temporary or permanent injuries and how to calculate the compensation, as well as on the aspects of prevention and (re-)integration, see Olivier/Mhone (2004: 144 f. and 154 f.).

[154] Regarding racial inequalities and the question of whether or not there are more people with disabilities among black South Africans, see Emmett (2006: 224).

[155] A South African rand is equivalent to approximately 6.5 euro cents, or approximately 7 cents in US dollars (March 2015).

[156] Focus on household heads.

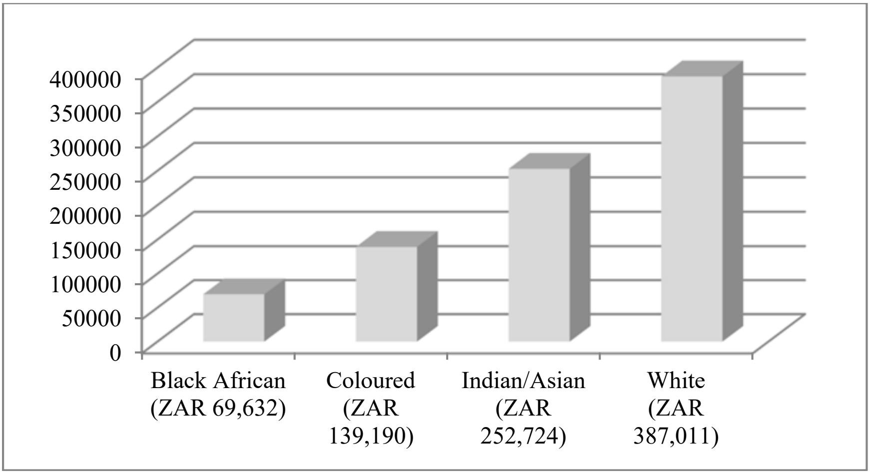

Figure 12: Household income by population group (2010/11)

(own figure based on Statistics South Africa 2012: 5)

In accordance with the broader definition presented above, Olivier and Mpedi (2009: 6) also argue that it would be important to concentrate on "the causes of social insecurity (in the form of, amongst others, social exclusion or marginalisation), rather than on (merely dealing with) the effects" through the provision of compensation.

5.3.1 The Right to Social Security

According to the South African Constitution (N.N. 1996), a comprehensive social security system has to be built that includes the "right of access for everyone and financial viability" (Olivier/Mhone 2004: 118). However, some concessions exist: The right can be realized progressively, the state can take reasonable measures, and the existence of resources is a precondition (see ibid.). In addition, no agreement exists "on how comprehensive social security should be" (Patel 2005: 125). In its section 27, the Constitution, for example, highlights the access to healthcare services and social protection, as well as food and water:

"(1) Everyone has the right to have access to-
(a) health care services, including reproductive health care;
(b) sufficient food and water; and
(c) social security, including, if they are unable to support themselves and their dependents, appropriate social assistance.
(2) The state must take reasonable legislative and other measures, within its available resources, to achieve the progressive realisation of each of these rights.
(3) No one may be refused emergency medical treatment."

Figure 13: Section 27 of the Constitution of the Republic of South Africa (N.N. 1996)

The South African system of social security is so far focused on compensation and not so much on prevention or (re)integration into the labor market. The system's focus is on the regular labor market and formal employment, and private saving mechanisms (especially in the fields of retirement and health) play an important role (Olivier/Mhone 2004: 145). The right to social security enshrined in section 27 of the Constitution is regularly enforced in court cases[157] that challenge the government to extend access to and the reach of social security. Questions raised concern the extension of social security to South African residents, gender equalization,[158] the age of children who are to receive the Child Support Grant, and others. According to section 184(3) of the Constitution (N.N. 1996), the South African Human Rights Commission (SAHRC)[159] is asked to

> "require relevant organs of state to provide the Commission with information on the measures that they have taken towards the realisation of the rights in the Bill of Rights concerning housing, health care, food, water, social security, education and the environment."

The Report of the Committee of Inquiry into a Comprehensive System of Social Security for South Africa (2002: 124) called for a "uniform adjudication system"

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[157] Well-known examples are the *Grootboom* case, which dealt with the right to access to adequate housing, and the *Soobramoney* case, which dealt with the right to access to healthcare. For details and background information regarding the court cases, see, e.g., Olivier and Mhone (2004: 126 ff.).

[158] For a discussion on gender issues in social security, see below and Goldblatt (2014: 28 ff.).

[159] The Human Rights Commission is an institution established by the Constitution to monitor the strengthening of human rights in South Africa. Disability (together with older age) is one of the strategic working areas of the commission. According to its website, its "mandate requires that it protects, promotes and monitors the advancement of human rights in South Africa without fear or favour. With regard to disability, research is regularly conducted to consider the manner in which the rights of persons with disabilities are being realised or being violated through actions of the State or other actors" (SAHRC n.d., see also McClain Nhlapo et al. (2006)).

in order to deal with social security claims.[160] Apart from national legislation, international treaties and conventions and agreements with other countries (e.g., Mozambique, the Netherlands) are of relevance for South Africa.[161] The country is a member of the Southern African Development Community (SADC), which has a Charter of Fundamental Social Rights in SADC as well as a specific Code on Social Security for its member states.

5.3.2 Social Assistance vs. Social Insurance

The country's historically developed system of social security contains several elements and is "characterised by a strict distinction between social assistance and social insurance" (Olivier and Mhone 2004: 145, see also Patel 2005: 124). The right to social security comprises both, whereby social assistance serves to support persons "if they are unable to support themselves and their dependents" as specified in section 27(1) of the South African Constitution (N.N. 1996). There is no definition of the meaning of social security in the Constitution, thus a link to the conceptual discussion on social security and social protection in subchapter 3.2 is hard to draw on the basis of the constitutional framework alone. In the same section, 27, the Constitution refers to access to healthcare and an adequate food and water supply. The concrete meaning and elements of the right to social security in a South African context have thus to be seen in the context of concrete measures and programs that are in place and offered by the South African state. As far as social insurance is concerned, the goal is to secure income by paying benefits that form a percentage of the insured person's wage (Olivier/Mhone 2004: 142). Whereas the Unemployment Insurance Fund (UIF) consists of contributions paid equally by employers and employees, the Compensation Fund is based on employer payments against the background of risk assessments. In addition, the Road Accident Fund covers traffic-related impairments, and further work-related injuries are covered by yet another piece of legislation. All of these are regulated by specific acts[162] and focus on the protection of employees (ibid.: 145 ff.).

Moreover, as explained by Goldblatt (2014: 25), tax support allows employees to fund health and retirement insurance on a private basis, whereby contributory social insurance schemes offer certain benefits in the case of unemployment, maternity, sickness, or adoption, as well as a survivor's benefit. Regarding

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[160] See also Olivier/Mhone (2004: 126).

[161] For an enumeration of further relevant treaties, see Goldblatt (2014: 26).

[162] Relevant statutes are: Unemployment Insurance Act No. 63 (Republic of South Africa 2001), Compensation for Occupational Injuries and Diseases Act No. 130 (Republic of South Africa 1993), Road Accident Fund Amendment Act No. 19 (Republic of South Africa 2005). For an overview of the social assistance and social insurances statutes, see Olivier/Mhone (2004: 123 f.).

access to healthcare, a distinction has to be made between a “public health system [that] is poorly funded and inadequate” and a “private health system [that] is beyond the reach of the vast majority of South Africans” (ibid.). As the focus of this thesis is on access to social protection in the context of poverty (though the meaning of social protection goes beyond this), further aspects of social insurance will not be discussed in detail here—although an investigation of the inclusiveness of the social insurance system is generally deemed important. In addition, it will be highlighted again that disability is not seen as an issue that is to be connected with poverty and deprivation only. Rather, the focus is on the effects that the DG and CDG, which are provided on the basis of certain criteria, can have—notwithstanding the fact that a twin-track approach towards social protection (i.e., mainstream as well as specific mechanisms) and complementary measures towards social inclusion have to be considered.

The labor force in South Africa amounts to approximately 20 million people. Of this group, around 15 million are employed, but only about 10 million in the non-agricultural formal sector (Statistics South Africa 2015: iv). Many people are therefore excluded from the group of “employees,” as defined by South African social security laws, and therewith from most of the South African system of social insurance. This holds true, e.g., for self-employed people and those who are informally employed, for those who do not receive any compensation for workplace injuries or in the case of unemployment (Olivier/Mhone 2004: 119 f. and, for further labor market indicators, see Statistics South Africa 2015: iv). Coming back to ethnic differences, many black South African workers are not covered because they have jobs in the informal sector (Olivier/Mhone 2004: 146). Against the background of no unemployment benefit, despite very high unemployment rates,[163] this is of specific significance. With respect to general social security principles such as social solidarity, sharing of risks, and pooling of resources, the system is not comprehensive (enough) so far either (ibid.: 157). Burial societies to cover funeral expenses (for details, see, e.g., Thomson/Posel 2002) or micro-insurances (for details, see, e.g., Mpedi/Millard 2010) are ways to overcome this shortage and extend social protection coverage in South Africa.

It can be stated in general that “[t]he nature of structural unemployment in the face of a changing global economy that marginalises unskilled workers expands the necessary scope of a social safety net,” as “millions of potential workers are vulnerable to unemployment and the resulting impoverishment” (Samson et al. 2002: 13). However, the nature of the South African social assistance grants leads to the fact that many South Africans living in poverty do not qualify for any of the

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[163] According to the Quarterly Labour Force Survey (Statistics South Africa 2015: iv), approximately 4.9 million people were unemployed in the last quarter of 2014, which is equivalent to an unemployment rate of 24.3%.

schemes. On the basis of the Social Assistance Act (2004), several cash transfers are offered with the aim of providing at least a minimum income to the recipients. Among these are the Grant for Older Persons, the War Veterans Grant, and the Foster Child and Child Support Grant, as well as the CDG and DG.[164]

5.3.3 The Disability Grant and the Care Dependency Grant

As previously explained, a non-contributory, tax-financed cash transfer can be received by persons with disabilities: the so-called Disability Grant. In addition, the CDG exists for children and young people under 18. Grants for persons with disabilities have been in existence for a number of years. Nowadays, the DG is the only grant available for people (from all population groups) who are of working age and unemployed. It is not directed at the household or family—distinguishing it from, e.g., the conditional "Bolsa Família" program in Brazil,[165] but at the individual. As can be seen below, the applicant's personal context is only taken into consideration insofar as the means test includes the income of the spouse in the assessment if an applicant is married. Other criteria, such as, e.g., household size (in terms of the number of people living in the household) or the number of children an applicant has to care for, are, however, not taken into consideration.

The issue of targeting, i.e., the provision of a social protection scheme to a specific group of people, is a debatable one. Sen (1995: 11), for example, calls the topic of targeting a "serious problem." He criticizes the fact that people who receive a benefit on the basis of targeting are seen more as passive receivers than active agents of their own life. But "[n]ot to focus on the fact that they think, choose, act, and respond is to miss something terribly crucial to the entire exercise" (ibid.).[166] As defined in the South African Social Assistance Amendment Bill (Republic of South Africa 2010), a person can apply for the DG if he or she is a South African citizen or a permanent resident or refugee (residing in South Africa), is between 18 and 59 years of age, and submits a medical report that is less

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[164] For further information on the grants and their requirements, see, e.g., the website of the South African Social Security Agency (SASSA). The maximum amount for both the Disability Grant and the Care Dependency Grant is ZAR 1,410 (as of April 2015).

[165] Families receive a cash benefit and—if they have children—have to ensure that they go to school. For further information, see, e.g., the website of the Brazilian Ministry for Social Development (MDS n.d.).

[166] It is for this reason, for example, that the personal budget in Germany was created in order to turn persons with disabilities from recipients of services into people who can employ care staff according to their needs and wishes—or use the money for accompanied/supported free-time activities or other forms of assistance. People receive a cash payment ("Geldleistung") instead of a benefit in kind ("Sachleistung") (Wacker et al. 2009: 31 ff.).

than three months old. The bill constitutes a change of the definition of disability as included in the South African Social Assistance Act of 2004, in that it contains a substitution of section 9[167] of this act. Concretely, if people want to apply for a DG, they have to comply with a number of requirements:

- "You must be a South African citizen, permanent resident or refugee;
- You must live in South Africa;
- You must be between 18 and 59 years of age;
- You must submit a medical / assessment report confirming your disability;
- The medical assessment must not be older than 3 months of date of application[;]
- You and your spouse must meet the requirements of the means test;
- You must not be maintained in a State institution;
- You must not receive another social grant for yourself."

Figure 14: Requirements for a DG application

(quoted from an information brochure on the DG, SASSA n.d.: 1)

Even though, in terms of eligibility, the definition of disability has changed with the 2010 Amendment Bill, this set of criteria for the assessment procedure "requires an emphasis on the individual with an impairment" (Swartz/Schneider 2006: 240). The choice of requirements proves that the understanding of disability is medically oriented and not in line with the social model approach and the definition of disability as contextualized by disability studies scholars (see chapter two).

However, this is a rather recent development and so far not widely in use. In addition, the personal budget is only one small part of the services and schemes available for persons with disabilities in Germany.

[167] From 2004 to 2010, a change of the—very medical view on disability—is visible.
Section 9 of the Social Assistance Act (Republic of South Africa 2004) explains that:
"A person is, subject to section 5, eligible for a disability grant, if he or she
(a) has attained the prescribed age; and
(b) is owing to a physical or mental disability, unfit to obtain by virtue of any service, employment or profession the means needed to enable him or her to provide for his or her maintenance."
By contrast, the Social Assistance Amendment Bill (Republic of South Africa 2010) contains the following provision in section 9:
"A person is, subject to section 5, eligible for a disability grant, if he or she has
(a) **[has attained the prescribed age; and]** a disability;
(b) **[is, owing to a physical or mental disability, unfit to obtain by virtue of any service, employment or profession the means needed to enable him or her to provide for his or her maintenance]** met the prescribed requirements of the means test and the income threshold;
and
(c) attained the prescribed age" (emphasis in the original; for details regarding the precise meaning of bold and underlined passages, see the general explanatory note in the bill).

Eligibility is a general challenge when it comes to the provision of benefits targeted at persons with disabilities. Questions to consider include the definition of disability and the methods to be used for the assessment (these can be either quantitative or qualitative techniques, or both) (Andrews et al. 2006: 246). Individual characteristics form the basis for the decision of who will receive a certain benefit. Specific challenges include the fact that some forms of impairment might not be clearly visible or assessable, and some people might underperform as they are in need of the benefit and want to fulfill the eligibility criteria rather than being declared to be “healthy” or “not disabled,” and ultimately “not eligible.” As far as the assessment procedure is concerned, a community assessment scheme was thus introduced and piloted to shift the focus from the individual towards social issues (Mont 2010: 324 f.).

The distinction between disability and chronic illnesses, including the differentiation between more social and more medical aspects, is not always clear. Due to very high prevalence rates, the question of whether or not an infection with HIV or having AIDS can be counted as a disability is of specific importance in South Africa. These issues have, for example, been discussed in the literature by Leclerc-Madlala (2006) and Nattrass (2004), who argues that people who have AIDS are “faced with a stark choice between income and health,” as “[a]ntiretroviral treatment restores the health of people previously sick with AIDS, thus rendering them ineligible for the disability grant” (ibid.: 5). On the basis of her research, Nattrass also argues in favor of a BIG: “given the context of the [sic] AIDS and the perverse incentives associated with the removal of the disability grant, this amounts to one more argument in favour of the introduction of a BIG” (ibid.: 17). This would prevent people from not taking their medicine in order to be sick enough to pass a medical examination that qualifies them for the DG. According to Swartz et al. (2006: 112), it might even be “that people will cause themselves to become infected with HIV, so that they can access a disability grant to support themselves and their families.” Further questions to be considered as far as the DG is concerned are whether or not AIDS causes impairments and/or whether being HIV-positive or having AIDS can count as an impairment in itself:

> “Given the spread of the epidemic in South Africa, there seems little doubt that there will be an increase of people who develop disabilities secondary to being HIV positive, quite apart from the more general debate about whether HIV-positivity itself constitutes a form of disablement in itself” (ibid.).

HIV/AIDS does not just play a role in the social assistance debate; its impact on persons with disabilities in general has not yet been investigated in great detail (ibid.: 108). Risk factors include the fact that persons with disabilities might not know much about HIV/AIDS and modes of infection, e.g., because accessible information or appropriate education material is not available and/or accessible to them. In addition, it is often believed that persons with disabilities are not sexually active, which leads to underestimating their risk of infection (for further reasons regarding a lack of HIV prevention for person with disabilities, see ibid.: 109). The problematic fact that persons with disabilities have not explicitly been mentioned in the MDGs is also of high relevance in this regard: Goal six called for combating HIV/AIDS, malaria, and other diseases (see chapter two). In order to have a global and far-reaching impact, global projects and programs would have to adequately consider all vulnerable groups, including persons with disabilities. In a country like South Africa, general rates for sexual crimes are high (for more detailed information, see, e.g., Statistics South Africa 2000). Persons with disabilities are even more likely to be affected. Especially among women and children with disabilities, but of course also among boys and men, the risk of sexual abuse is particularly significant (Swartz et al. 2006: 109).

As will be described in relation to the empirical results, further important issues regarding the grant system require researchers' as well as policy makers' attention. Among them are practices of fraud and the fact that high administrative costs occur when implementing this kind of social assistance scheme—aspects that van Ginneken (1999: 9) has previously identified in relation to other social assistance schemes:

> "The principle advantage of such social assistance pension benefits is that they can be targeted to those who are most in need, but they require sophisticated administration to determine who is really deserving and to ensure that the benefits reach the target population effectively. Thus, the costs of delivering the benefits are often high and, without an efficient and accountable control and monitoring system, leakages and corruption are likely."

Against this background, it is very interesting to investigate what the grant is actually used for, why people seek to obtain it, and how the money is spent by its recipients—an area which the South African system of social grants does not focus on on a structural level. Once obtained, the grant can be used according to the needs and decisions of the recipients, as long as family structures or other forces in the individual's personal context do not prevent this.[168] Previous research exists, e.g., with a focus on a psychiatry clinic in the township Khayelitsha[169] and the question of how people try to secure a grant (MacGregor 2005) and the social and economic effects of the DG in the KwaZulu Natal province (Johannsmeier 2007). In her study, Johannsmeier (ibid.: iii), for example, comes to the conclusion that "while the DG may be one means to inclusion, disability cannot be relegated solely

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[168] As will be demonstrated with the empirical data analysis, many recipients do not use the (complete) grant for their own needs.

[169] See footnote 135 of this thesis.

to a social assistance domain. Rather, an intersectoral and ‘twin-track’ approach is needed.” In addition, a thesis submitted at the University of Cape Town (Ong’olo 2009) focuses on the role of the DG in the lives of persons with visual impairments in a certain area of Cape Town. The present research project takes up Johannsmeier’s arguments and conclusions by moving beyond the amount of the grant and the question of how it is spent.

Against this background, where should the focus of this thesis be directed? In accordance with Sen (1995: 17) and the arguments presented in the preceding chapter, “it is important to see human beings not merely as recipients of income but as people attempting to live satisfactory lives.” In addition, “poverty [should] not simply [be seen] as low income but as the lack of real opportunities to have minimally adequate lives” (ibid.). To what extent the DG can make a contribution will be analyzed in the second part of the thesis: the empirical analysis.

6 From Theoretical Considerations to Practical Research: The Qualitative Data Collection

Several authors (e.g., Graf 2011: 26) characterize the CA as a normative framework that provides (no more than) the informational basis useful to focus on the lives of people and to investigate their living situations—beyond a narrow focus on monetary poverty. For successful application in research practice, it is necessary to complement the approach with further normative assumptions and explain the exact purpose for which the CA has been chosen and will be used. With respect to qualitative applications and investigations in social sciences, or, more specifically, sociology, Zimmermann (2006) identifies a particular problem. She explains that "even though such an approach develops a challenging attempt to conceptualize freedom with regard to public action, it provides neither a theory of society nor a methodology of inquiry, dimensions that are both required for sociological investigation" (ibid.: 469). Thus, one has to ask "under what conditions can the capability approach be more than a normative horizon for the sociologist?" (ibid.).[170] It becomes obvious that, especially regarding its focus on capabilities, several compromises are required. On the one hand, this relates to the more approach-immanent factors, i.e., aspects that concern the approach in itself. For example, the achieved beings and doings are easier to investigate than the options a person can choose from. If the focus is indeed on capabilities then their absence seems to be easier to investigate than concretely existing capabilities (ibid.: 478). On the other hand, factors that can perhaps be referred to as approach-external or approach-related (i.e., concerning the application of the approach in a specific research project) also play a role. The way the CA is operationalized does, for instance, highly depend on the concrete research questions and the methods that will or can be applied in a certain setting. Ritter (2014), for example, uses the approach for a biographical study on the living situations of young mothers. In her research, the approach offers the possibility to

> "explore how people deal with possible discrepancies between their biography and the societally supported normal life course. It can investigate how people make sense of societal guidelines, how they perceive institutions of the welfare state in terms of

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[170] From my point of view, the same holds true for further disciplines in social sciences.

I. Bertmann, *Taking Well-Being and Quality of Life for Granted?*, Gesundheitsförderung - Rehabilitation - Teilhabe,
https://doi.org/10.1007/978-3-658-19812-1_6

> enablement or restriction, and how they master their lives, even though not fitting into the age-structured frame of social policy with all its consequences" (ibid.: 154).

Furthermore, Ritter's arguments in favor of the CA for biographic research are "a holistic assessment of the capabilities of an individual by taking the whole person and her [sic] life with both past and future aspects into account" and the fact that the CA "takes the idea of ethical individualism seriously by giving voice to the single person" (ibid.: 147). With this explanation, Ritter also addresses, or rather contradicts, the limitation already mentioned above, namely that the approach is of a static nature (see, e.g., Leßmann/Rauschmayer 2013: 103) and does not allow for the assessment of changes that occur in a person's life course. Following this brief insight into empirical challenges and potential applications, the next subchapter will present further ways to empirically apply the approach, before coming to conclusions about the methods chosen in this particular research project.

6.1 Empirical Application(s) of the Capability Approach

In her discussion paper on "Challenges in Applying the Capability Approach Empirically: An Overview of Existing Studies," Leßmann (2012) discusses different possibilities for the application and operationalization of the CA in empirical research. She presents the methods that have been used up until that point and requests "a more rigorous documentation and justification of the methods employed" (ibid.: 1). Similar to Zimmermann's arguments regarding capabilities and freedom (see subchapter 4.3.2), several challenges can be identified, of which Leßmann addresses two major ones: the plurality of dimensions or capabilities and their respective selections, and the idea of freedom of choice. When aiming to draw conclusions about quality of life and well-being in the context of empirical studies, one important question that arises is how to select certain capabilities (Crocker/Robeyns 2010: 72 ff.). Researchers have to make a decision regarding "the choice between functionings and capabilities, the selection of relevant capabilities, and the issue of weighting the different capabilities for an overall assessment" (Robeyns 2006: 353).[171] Alkire (2007: 7 and 20) describes five methods for the selection process, which are complemented by Leßmann with a sixth.

As can be concluded from the overview, in a broader sense, the third and fifth methods are of relevance in this research project. Regarding method three, called

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[171] Even though the decision as to whether to focus on achievements or opportunities is also relevant when it comes to the analysis of qualitative data, the methodological challenges described for the application of the CA mainly refer to statistical data and quantitative measurements (Robeyns 2006: 354).

“public ‘consensus’,” the CRPD can be named as a framework of reference. Alongside the MDGs (and SDGs), which were introduced in chapter two, and the universal human rights mentioned by Alkire as having “achieved a degree of legitimacy as a result of public consensus” (Alkire 2007: 7), the CRPD can be seen more specifically as an international standard in the field of disability policy and social inclusion. Even though there are countries that have not yet ratified this human rights document, the provisions set out by the CRPD are not debatable as such. As outlined above, the convention reflects a global consensus stemming from intensive consultations and discussions. The rights enshrined in the CRPD are no more or less than the universal human rights valid for every human being, but they present a specification of the specific situation and experiences of persons with disabilities (Bielefeldt 2009: 16).

	Methods	**The selection of capabilities is based on**	**Of interest for this project**
1	**“Existing data or convention”**	- “convenience or a convention that is taken to be authoritative” (Alkire 2007: 7)	
2	**“Assumptions”**	- assumptions of the researcher about people’s beings and doings and their values	(X)
3	**“Public ‘consensus’”**	- a collection of aspects that is based on public consensus and is thus seen as being legitimate to a certain extent, e.g., the MDGS and universal human rights—or, as in this case, the CRPD	X
4	**“Ongoing deliberative participatory process”**	- including the perspectives of people/ stakeholders and conducting participatory research	
5	**“Empirical evidence regarding people’s values”**	- empirical data, as has been done, for example, in studies on mental health and social benefits	X
6	**“[Measuring] dimensions using multivariate analysis”**	- multivariate analysis and the construction of “dimensions that are presumed to be latent “behind” the manifestations of the variables” (Leßmann 2012: 5)	

Figure 15: Overview on how to select capabilities

(based on and quoted from Alkire 2007: 7 and Leßmann 2012: 4 f.)

Regarding method five, “empirical evidence regarding people’s values,” one cannot completely rule out the fact that personal assumptions might be included in qualitative research. This method will thus (more implicitly) also influence the analysis. For this research project, empirical data was gathered through personal interviews, as outlined in the next section, in order to find out about the preferences and behavior patterns of the interview partners. The analytical method outlined in subchapter 6.3 tries to present a potential solution to the problem of personal assumptions by using a text-based method of analysis and interpretation, with a strong focus on linguistic elements. In order to take into consideration the claim of the international disability rights movement (“Nothing about us without us.”), it might generally also be appropriate or possible to use method four, but this project did not include elements of participatory research. Robeyns (2003: 70 f.) complements this overview of capability selection methods by identifying five criteria and thus trying to bridge the gap between Nussbaum’s list and Sen’s open approach, in which he “argues for always deriving a new list from each context (research questions, data availability, cultural context, etc.), without expressing a more specific opinion about how this might be done” (Leßmann 2012: 5). Robeyns’ (2003: 70 f.) suggestion to implement this includes the following relevant criteria:

- the aspect of “explicit formulation” (it is important to discuss and defend the list);
- the principle of “methodological justification” (the method that has been used to generate the list should be presented and justified);
- the challenge of “sensitivity to context” (the appropriate “level of abstraction” has to be found according to the research background—e.g., philosophy, economics, etc.);
- the idea of “different levels of generality” (coming from an “ideal” list to a “pragmatic” one that gives credit to the availability of data);
- and the “criterion of exhaustion and non[-]reduction” (all relevant aspects need to be included).

If the decision is made to investigate a person’s capabilities—one of the relevant dimensions as far as a person’s quality of life is concerned—the question arises as to how this can actually be done. The central focus of the CA concentrates on rather intangible aspects when it comes to trying to assess a person’s capability set. But how can the options that are potentially available to a person be assessed? By drawing on existing qualitative projects and publications (e.g., Comim 2008, with a combination of qualitative and quantitative data), the data collection and analysis carried out for this project aims to provide some answers and, in doing so, make a contribution to this debate.

6.2 Research Approach and Data Collection

Zimmermann (2006: 479) argues that "[i]f one is interested in grasping the different dimensions of capabilities, including conversion processes and what people value, a comprehensive and qualitative moment is required, at least as a complement to other methods."[172] In order to answer the research questions elaborated above, which comprise both the question of conversion factors and personal values, and judgments as far as quality of life is concerned, qualitative data was considered specifically useful. Two interview forms were therefore selected:

- expert interviews with interview guidelines; and
- personal interviews as guideline interviews with narrative elements.

In total, 25 semi-structured interviews were included in the data analysis; they were conducted in the Eastern and Western Cape provinces of South Africa between November 2011 and March 2012, and 12 personal interviews and 13 expert interviews were carried out. Various individuals and staff members of DPOs contributed to this research project by assisting in the finding of interview partners. Interviews were conducted with professionals working in the thematic fields of social protection and disability policy, persons with disabilities and their families, and DPO staff and DPO members. By using qualitative interviews, the research allows for flexibility and openness towards the conceptualization of a "good (quality of) life." However, direct questions regarding the quality of life of the interview partners (such as "How do you evaluate your well-being?"/"How good is your quality of life?"/"What do you understand by quality of life?") were avoided, as ideological statements or subjective understandings might have been the consequence.[173]

Therefore, specific areas had to be identified and pre-defined for both the interview guideline and the analytical framework that were deemed suitable to reveal information about the aspects in focus (Przyborski/Wohlrab-Sahr 2008: 20 f.) and to come to conclusions regarding the thematic areas of well-being and quality of life. Without engaging in subjective well-being research too deeply, this project

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[172] For a comment on qualitative vs. quantitative data collection, see footnote 9 of this thesis.

[173] Przyborski/Wohlrab-Sahr (2008: 20) explain this aspect in relation to research on power in heterosexual relationships. They suggest, rather than asking the interview partners explicitly about the topic of power, searching for fields in which this aspect is important and that therefore might reveal how power is distributed in situations of decision-making.

intended to perform a balancing act by drawing on suggestions expressed by Binder (2013: 2). According to him, all approaches (both subjective and objective) have certain weaknesses, thus a combination of some sort seems to be a promising alternative. The supposed objectivity of the CA and its paternalistic tendency, which "could lead to individuals being declared as well-off in functionings space [i.e., as far as functionings are concerned; IB] without them sharing this assessment" (ibid.), will be dealt with in a constructive way by including elements of subjective well-being in the data analysis. Following Binder (ibid.: 15 ff.), this can be done in several ways:

- by including happiness ("being happy") as a valuable functioning (as is done by some capability researchers);
- by taking a look at the effects of capabilities, i.e., "substantive freedoms," on subjective well-being; or
- by focusing on "happiness-relevant functionings" (ibid.: 16).

Each individual has a set of resources that are/can be transformed into happiness-relevant functioning achievements, which means the beings and doings that (serve to) make a person happy. In this regard, personal agency is also of importance, as "it is the individual that is responsible to critically reflect on what sort of pursuit of happiness it wants to follow or whether or not the individual wants to use the conditions provided to further one's own well-being" (ibid.: 23). On a more abstract level, focusing on the increase of a person's capability set provides the potential to respect human differences as well as personal choices and values, including the opportunity to achieve happiness. Rather than directly focusing on the increase of individual well-being from an "objective" point of view, the individual preferences are taken into consideration. However, it remains to be seen whether this approach will be fruitful when it comes to evaluating the living situations of persons with disabilities (in South Africa).

Apart from the current living situations of the interview partners, the information they provide regarding alternative options or potential and future ways of living that they would like to pursue plays a role as well. By including these elements, an attempt is made to identify capabilities—or rather the respective limitations and constraints regarding the achievement of the respondents' goals and ambitions. Information that is provided by the interview partners about their social grants and the other services they have access to not only offers details on the social security system on a more general level but also contributes to the concrete analysis of their well-being and quality of life.

The description of the process of data collection can be summarized by the following overview:

Overview of the research process	
Research interest/ research problems[174]	• How does the South African social security system promote social protection and inclusion for persons with disabilities in social policy/disability policy and practice? • What is the impact in terms of people's well-being and quality of life? • How can the results be related to the international discourse on social protection, poverty reduction, and inclusive development?
Thematic framework	• Social protection & social development • Social policy & poverty reduction • Definitions of disability & disability models • Disability rights & policy • Standard of living, well-being, & quality of life
Research approach	• Capability Approach
Input	• Documents • Existing research (secondary sources)
Data collection methods	• Qualitative data collection (primary data) - Personal interviews (semi-structured) - One group interview - Expert interviews with professionals In addition: semi-formal conversations that serve as background information
Instruments	• Interview guidelines - Expert interviews - Personal interviews
Sampling	• Combined methods - Use of "gatekeepers" - Snowball method (by contacting organizations)
Analytical method	• "Integratives Basisverfahren" - Analytical heuristics/interpretation guidelines - Elements of content analysis

Figure 16: Overview of the research process

(own overview)

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[174] In her diploma thesis, Birkholz (2014: 49) refers to Rosenthal's (2014) introductory book on interpretative social research and explains that, in order to achieve a very open research approach, the subject or area that the researcher is interested in should be outlined and a "research problem" be identified, instead of formulating research questions in a very detailed manner (see also Rosenthal 2014: 15 ff.).

6.2.1 Access to the Field, Sample, and Data Collection

As will be shown below, the analysis of the data followed an approach that is as open as possible, as was the sampling method.[175] Interview partners could be members of any of the following categories: persons with disabilities themselves, family members, parents of children with disabilities, or professionals working with this topic in different ways. Their "common denominator" was the fact that they shared specific experiences and conditions with respect to the topic of disability, especially in the South African context. For this research project, interview partners did not have to know each other, belong to certain organizations/institutions, or be in contact with each other. The field of research could not (and did not have to) be demarcated as such. For example, it was not the aim to choose people with a specific impairment only. Rather, the idea was to interview persons with disabilities receiving the DG, and people who had (professional) experience of aspects of social protection. However, some people who were contacted and invited to an interview were assumed to receive the DG, but, during the interviews, it was discovered that they did not receive it[176] (either because they had never applied for it or because they were not granted the money due to a variety of reasons, including the level of household income and assets[177]).

This was not deemed problematic: Interviews with people who did not receive the grant at the time of the interview made contrasts possible and were therefore also included in the analysis. A decisive restriction was posed by the fact that the interviews had to be conducted during two research stays in the Eastern and Western Cape with a total duration of about three months and with limited prior access to organizations or contact to gatekeepers. The local distribution of the 25 interviews that form part of the data analysis reflects the fact that more time (about two thirds of the total) was spent in the Western Cape. In addition to the focus on the DG (and CDG), people who had experience working on the regular labor market, but also in DPOs or sheltered workshops, as well as people who were unemployed at the time of the interview were interviewed. The idea was to find a range of different cases, taking into account criteria such as socioeconomic background, family structure, race, age, and gender—without, however, predefining the proportion of female to male respondents, the number of people in a certain age range, etc.

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[175] The Grounded Theory knows this method as "open sampling" (Strauss/Corbin 1996: 152 ff., particularly 154).

[176] The main reason was that the gatekeepers were misinformed or did not know the current grant status of the interviewees but nonetheless kindly established contact with the interview partners.

[177] More precisely, it is not the household income that counts, but the means test focuses on the income of the applicant and—if applicable—his or her spouse.

Gatekeepers assisted in finding interview partners, and the search for respondents was supplemented by snowball sampling.[178] In general, using gatekeepers proves particularly useful in areas that require a certain degree of trust because the living conditions and personal experiences of persons with disabilities living in poverty can be understood as a sensitive context—especially if the questions are posed by a researcher from a different cultural and socioeconomic background who does not have a personal impairment or disability experience (though with disability experiences in the close family).[179] This is particularly relevant as the researcher is a white, European female with a very different background than most of the interview partners, especially with regard to living in (extreme) poverty, living in a township, and being confronted with different forms of stigmatization and exclusion on the basis of disability and poverty.

Most of the experts had personal experiences with disability (be it through their own impairment or due to family members/children with disabilities), therefore these interviews also contain personal elements. Several institutions and individuals assisted in finding interview partners, and the interview partners themselves, researchers, and fellow students recommended further possible candidates. Different methods were used to establish contact: via e-mail, letter, or through a personal appeal. In addition, different locations were chosen for the interviews to take place: within a private environment, at work (sheltered workshops/DPOs), or in the institutions that facilitated the contact with interview partners, as well as in public places such as cafés. The duration of the interviews varied (between around 20 minutes up to 2 ½ hours) and depended on a number of factors (regarding the common duration of qualitative interviews, see also Kruse 2014: 261). On one occasion where interviewees were interviewed at work, interview time was limited as the interview partners/workers were paid according to the quantities produced in their workshop. The management therefore decided that (for their own benefit) they should not be absent from their workplace for too long.

For all interviews, information sheets were used to brief the interviewees about the contents and goals of the research project and to highlight that their individual participation in the project/interviews was voluntary.[180] Participants did

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[178] For critical aspects regarding snowball sampling, see Kruse (2014: 255).

[179] In this context, Kruse (2014: 306) describes several positive and negative aspects that can occur if the interview partners and the researcher share similarities and knowledge, or, on the contrary, if their relationship is characterized by a clear distance. The latter can facilitate explication, meaning that proximity and confidence might lead to interview partners not speaking about certain topics—due to the assumption that the researcher is knowledgeable as far as a topic or a specific aspect is concerned.

[180] In addition, the interview partners were provided with contact details for any further inquiries on the project, but no interview partner made use of this.

not expect to receive any compensation (apart from the reimbursement of taxi costs to the place of interview if applicable). In addition, interview partners were informed that all conversations would be recorded[181] and saved according to the protection of data privacy guidelines and that the information would be kept confidential by presenting study findings in summary and in an anonymized form. Participants were furthermore informed that some quotes might be extracted in order to highlight or explicate findings, but without mentioning real names or further personal details that could lead to the identification of the individual(s). For all recorded interviews, consent forms were filled out and signed by the researcher and the respective interviewed person.[182] In addition, a protocol was filled out for every interview, containing descriptions of the interview situation and particularities or difficulties that occurred during the interview.

The guideline for both the expert interviews and the personal interviews contained several parts, all of which began with a rather open question and were followed by so-called maintaining or immanent questions (in order to ask the interview partner to continue or elaborate on certain points), and concrete sub-questions (exmanent questions) (see figure 17). Depending on the progress of the interview(s), the order of the questions was dealt with in a flexible manner.

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[181] Interviews that were not recorded at the request of the interviewee (e.g., with a teacher in a daycare center), conducted in a province other than the Eastern or Western Cape (via phone), or hardly transcribable due to poor audio quality were not included in the data analysis. Audio quality was an issue for many interviews, especially if they took place in the public sphere, in homes where other family members were interrupting, in workshops in which the general level of background noise and interaction was high, and in cases when interviewees spoke very quietly.

[182] Ethical consent was granted by the Ethics Council of the Max Planck Society, as well as the Human Research Ethics Committee at the University of Cape Town's Faculty of Health Sciences (yearly renewal from 2012 to 2015). In addition, ethical clearance for an expert interview was granted by the Research Ethics Committee of the Department of Social Development (Western Cape), subject to several conditions (e.g., the department "should have the opportunity to respond to the findings of the research"). Despite various attempts to arrange a meeting, an interview did not take place and I therefore refrained from complying with any of the requirements outlined in the letter.

Part 1 (2, 3, …): Primary question/stimulus		
Aspects to be investigated	Maintaining questions	Concrete sub-questions
- Own understanding/ definition of the interview partner - Positive/negative judgements	- "Anything else?" - "How do you mean that?" - "Could you provide an example?"	- Sub-questions, which structure the interview more than the primary questions but do nonetheless have to be open

Figure 17: Structure of an expert interview guideline

(figure based on Kruse 2014: 217)

In summary, the following distribution of interviews arose:

		Western Cape	**Eastern Cape**	**No. of interviews**	**No. of interview partners**
Personal interviews (12)	Interviews with parents of children/young adults with disabilities	🧍 + 🧍 + 🧍 + 🧍 [183]	🧍 🧍 🧍 + 🧍 [184]	4	8
	Interviews with adults who worked in a sheltered workshop	🧍 🧍	🧍 🧍	4	4
	Interviews with adults who did not work (neither in a workshop nor in the open labor market)	🧍 🧍 🧍 🧍	-	4	4

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[183] One group discussion with three mothers and a young adult. Main focus of all interviews: the family situation and young adult life.

[184] Three interviews: two with mothers, one with a mother and a father. Thematic focus of all interviews: the family life and early childhood development.

		Western Cape	**Eastern Cape**	**No. of interviews**	**No. of interview partners**
Expert interviews (13)	DPO/permanent workshop staff or DPO members, most of them active in the fields of disability policy/lobbying and advocacy work	🧍 🧍 🧍 🧍	🧍	5	5
	Social workers in sheltered workshops and a daycare center	🧍 🧍	🧍 🧍 + 🧍	4	5
	Other experts on disability policy/ social protection (incl. university staff)	🧍 🧍 🧍 🧍	-	4	4
Sum		17 (20 persons)	8 (10 persons)	25	30

Figure 18: Overview of interview partners
(own overview)

6.2.2 *Content of the Interviews with Professionals ("Experts Interviews")*

Expert interviews are guideline interviews.[185] The term "expert," however, is contested and can be understood in broad or narrow terms. Two specific aspects have to be discussed here. Firstly, most of those who were contacted for an expert interview were persons with disabilities or had family members with disabilities. Therefore, autobiographical elements were part of the interviews, and the differences between expert and personal interviews were/are not always clear-cut. In

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[185] For further information, see, e.g., the collected edition by Bogner et al. (2009).

addition, persons with disabilities can be seen as “experts in their own cause”[186] or on their own life, as they are specialists when it comes to the topic of disability, the concrete living situations of persons with disabilities, and the challenges faced.[187] This understanding of experts (Kruse (2014: 175) calls it “voluntaristic”) is very broad and not practical when it comes to qualitative research methods, as expert knowledge can then no longer be differentiated from other knowledge—and the specific format of “expert interviews” would lose its legitimation (ibid.: 175 f.). However, experts can be seen as representatives of behavior patterns, views, or knowledge of a particular group or topic (ibid.: 168 f.) Therefore, a distinction was made for the purpose of this thesis between interviews that covered the interviewees’ private lives and interviews with persons with or without disabilities who dealt with the topics disability and social protection on a professional level or in the context of voluntary involvement, e.g., through lobbying and advocacy work within a DPO.[188] In this thesis, the terms experts and professionals are used to refer to these interview partners. Apart from the voluntarist understanding outlined above, two further approaches exist to identify experts: one is the “constructivist” approach. The third understanding is based on the sociology of knowledge—an expert is conceived on the basis of the specific structure of his/her knowledge (ibid.: 176 f.).

But what kind of knowledge can an expert have? According to Przyborski’s and Wohlrab-Sahr’s (2008: 131 f.) explanations, three types of expert knowledge can be identified: corporate knowledge (“Betriebswissen”), interpretive knowledge (“Deutungswissen”), and context knowledge (“Kontextwissen”) (see also Kruse 2014: 178 f.). This research project combined these different types and aspects, as interview partners were asked about the institutional context in which they worked (e.g., a sheltered workshop), and their interpretive knowledge was also part of the interview (e.g., as far as lobbying and advocacy work in a DPO is concerned). In the latter case, for example, the interview partners expressed their opinion regarding the major problems and barriers that persons with disabilities

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[186] Especially for the experiences of persons with disabilities, the German language has the term “Experte/Expertin in eigener Sache.”

[187] As will be highlighted with respect to the analytical method, linguistic aspects play a role. That means it is not only important what is being said but also how the interview partners say it. In many personal interviews, markers can be identified that express the expert knowledge of the interview partners. They underline the expertise, but also the self-positioning of the interview partners, as will be explained in more detail below.

[188] Referring to Meuser/Nagel (2009) and Bogner/Menz (2009), Kruse (2014: 178) highlights the fact that differentiation between experts and private persons is problematic, as this indicates that in expert interviews, it is not the whole person that is important, but only the expert part of the person and his/her respective knowledge.

are confronted with in South Africa. Mostly, however, the experts provided context knowledge about the target group and main subject of the thesis: persons with disabilities and their (quality of) life.

In order to reflect several interview forms and their peculiarities, an interview guideline[189] was used that comprised more general and more concrete questions. Different guidelines were used for the experts on social protection and those who were experts on the topic of disability. To illustrate and justify how questions were developed, the interview guidelines will be described in further detail in the next subchapter. In accordance with standards of qualitative data collection, conducting interviews (and the respective instrument, i.e., the structure and content of the questionnaire/guideline) should follow certain guiding principles. However, these can be disregarded or weakened (which distinguishes this form of data collection from standardized methods), as the most important aspect is that all relevant points and topics that the researcher wants to investigate are covered and that this happens in an atmosphere that is conducive and pleasant for the interview partner. This also (or even more so) holds true for the personal interviews. Przyborski and Wohlrab-Sahr (2008: 143) explain this requirement of qualitative research in the following way:

> “Ein Leitfadeninterview, in dem allen Befragten dieselben Fragen in exakt der gleichen Reihenfolge gestellt werden, suggeriert Vergleichbarkeit und damit eine Nähe zu standardisierten Verfahren. Letztlich riskiert man aber mit einem derartigen Interviewerverhalten, dass Interviews mit relativ geringem Informationsgehalt zustande kommen, die weder den Kriterien standardisierter noch denen qualitativer Sozialforschung entsprechen. Sie sind schwer zu interpretieren, weil die Relevanzstrukturen der Befragten aufgrund von Interviewerintentionen nicht entfaltet werden konnten.”[190]

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[189] As Kruse (2014: 168) explains, expert interviews are a specific form of guideline interview. Thus, they do not really have methodological characteristics that are distinct from other guideline interviews. Rather, they can be seen as specific due to the target group or, more precisely, the group of interview partners.

[190] Own translation: “A guideline interview in which all interview partners are asked the question in exactly the same order suggests comparability and thus a proximity to standardized procedures. Ultimately, this kind of interview behaviour entails the risk of obtaining interviews with little informational content, which neither correspond to criteria of standardized nor those of qualitative social research. They are difficult to interpret, as the structures of relevance of the interviewees cannot be unfolded due to the interviewer’s intentions.”

Interview guideline (professionals)

How would you describe the social security system in South Africa?

- How would you define social security?
- Which aspects, measures, and policies belong to the system?

How would you explain the access to social protection for persons with disabilities in South Africa?

- How is disability defined by/within the social system?
- Could you explain the most important features of the “Disability Grant” and the “Care Dependency Grant” to me?
- Are there any other social services that persons with disabilities can apply for and on which factors does this depend?

Have you ever given assistance to persons with disabilities with respect to the application process for a grant? Could you please share your experiences with me?

- Could you describe a typical assessment procedure?
- Please imagine that a person wants to apply for a grant, what does he/she have to do?

What would you say is the impact of the social grants on the lives of persons with disabilities?

- If you think of a person with disabilities that you personally know:
    - Could you describe what effect the grants have on the living situations of an individual with disabilities?
    - What could the person use the money for?

Let me please ask some further questions regarding living situations of persons with disabilities in South Africa.

- Would you give me some insight on the work opportunities that exist for persons with disabilities?
- How is the situation regarding the supply of care for persons with disabilities in the health sector?

How would you describe the general inclusion of persons with disabilities in social life?

- How important is social security for an active participation and inclusion?
- Which role does the UN Convention on the Rights of Persons with Disabilities play in South Africa?

Is there anything else I should know to better understand the topic/context?

- Do you have any questions that you would like to ask me?

Figure 19: Guiding questions for the expert interviews

(own overview)

At the beginning of the expert interviews, the interview partners were asked to explain their working environment and the organization they work in or that they represent. The overview above shows a summary of primary questions/stimuli (highlighted in gray) that were then used in varying order and quantity throughout the expert interviews—depending on the dynamic of the interview; some interview partners covered topics that were supposed to be discussed at a later stage of the interviews when they responded to earlier questions. Out of the whole collection of sub-questions developed, a few are included in figure 19 as examples. In some interviews, more sub-questions were needed.

6.2.3 Personal Interviews

The personal interviews were conducted using a guideline that contained questions regarding specific processes (e.g., experiences with the DG application), as well as stimuli designed to find out about the respondents' personal opinions and living conditions. In this regard, the interviewees had to reflect on their experiences and draw abstract conclusions about their lives (Przyborski/Wohlrab-Sahr 2008: 95 f.). These two aspects represent the area of tension between openness and structuring of a guideline interview. A further challenge that had to be dealt with was the diverse narrative competences or levels of engagement of the interview partners. In both the expert and personal interviews, the same question or stimulus could lead to extremely different answers—in terms of the scope of the content and focus but also regarding the length of the responses. This could be a challenge for the interviewer as maintaining the interview thus sometimes proved to be difficult.

Both the conversation with one mother **and** father (see the overview table in subchapter 6.2.1) and the group interview[191] were not planned as such in advance and therefore needed to be dealt with in a spontaneous manner.[192] The father of a

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[191] As the group shares joint experiences and meets/exists without the context of the interview situation, it can be called a "real group" ("Realgruppe") (Kruse 2014: 200). Regarding the principles of conducting a group discussion, see, e.g., Przyborski/Wohlrab-Sahr (2008: 109 ff).

[192] This is due to the fact that interviews are a complex combination of interaction and communication (Kruse 2014: 287 ff.), especially when they cross cultural and national borders. It is, for example, sometimes necessary to spontaneously react to certain developments and requirements: In the research process, the fact that a father stayed at home to participate in an interview that was envisaged as being with the mother only or that several planned individual interviews with mothers were reorganized as a group discussion are examples of this. Despite these unplanned interview situations, I would like to raise the criticism that in some other interviews not all the rules regarding qualitative research were/could be completely followed. For example, one interview partner prepared a short statement on social protection and disability to be read by him at the beginning of the interview. In addition, in some interviews, the interview partners expected

small child decided not to go to work on that day in order to be able to participate in the interview. Thus, the two interview partners (mother and father) communicated as a family or couple rather than as individuals, which also provided information about the relationship and the family dynamics (Przyborski/Wohlrab-Sahr 2008: 122). For example, the father was the main respondent, although the mother was specifically addressed from time to time. Negative outcomes that can occur when interviewing two people at the same time include the fact that the interview partners might try to maintain a certain façade in order to present unity as a couple or family and to develop a joint identity. In this particular case, the relationship between the mother and the father was perceived to be a rather complex one that was not completely revealed in the interview. Further details regarding that interview will be presented in the results section (chapter seven).

As far as the one group interview with three mothers and a young adult is concerned, it must be highlighted that certain dynamics can occur in group discussions[193] that give a different type of insight into the lives of the interview partners, compared to individual interviews. Single conversations with those women might not have led to the same level of openness, intimacy, and emotionality, due to, among other factors, the personal background of the researcher, as explained above. In this case, sharing similar living situations with other interview partners can be regarded as a facilitator for the sharing of personal and discomforting experiences. In the course of the interview, several very personal and emotional moments occurred. At the beginning of the discussion, the participants were asked to speak about their children's disabilities—however, it was left open to the discussants as to whether they should focus more on medical aspects ("impairments") or on aspects related to social life and external barriers (which would be referred to as "disabilities" as argued in the second chapter). The question was meant to be an introductory stimulus to which all mothers could answer in as much detail as they wanted. However, all the interview partners answered in a rather comprehensive manner. Thus, throughout the group discussion, not many maintaining questions or sub-questions from the interview guideline could be posed as the discussion developed its own dynamic. It was characterized by long statements from the participants rather than an intense discussion on particular issues.

In a survey on experiences with research projects in foreign languages, Kruse et al. (2012) present recommendations and reflections regarding challenges that

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to receive information from the interviewer and also asked questions. The development of those interviews towards conversations was, however, not seen as negative, as the interview partners gained confidence and then shared many personal insights.

[193] The development, specific features, and advantages of group discussions are, for example, discussed by Kruse (2014: 189 ff.).

occur when doing research in another cultural context and a language that is different from one's mother tongue. Conducting interviews in a foreign language can have—positive as well as negative—implications for data collection. Some of the experiences described are similar to events that occurred in this project. Among them is the requirement to conduct interviews personally, even though this entails using English as a common language, despite the fact that neither the interviewer nor the interviewee speak it perfectly. It is, however, possible to directly interact. When using interpreters, this immediacy and openness might get lost in the interview situation. Relatedly, the study published by Kruse et al. (ibid.: 27 ff.) also contains reflections on the use of amateur translators, a strategy that was also used as an option in some of the interviews conducted in this research project. A social worker and a staff member from a daycare center were present during a few interviews in order to have the option of making use of translation if necessary. This, however, led to some interview situations in which short parallel non-English conversations took place in order to clarify or discuss certain aspects in the interview partners' mother tongue. Despite having been asked in advance not to actively interfere, the social worker who was present at some interviews repeated some questions, or asked some further questions herself, so that a small number of interviews did not represent the typical one-to-one relation between researcher and interview partner.

On the other hand, these two women knew the parents and also provided support that was necessary for reasons of safety in the township (due to their local and cultural knowledge). Their presence could have had similar effects to the specific situation of the group interview: The interview partners' answers might have been more personal and/or detailed due to the presence of familiar people. The overview below shows a summary of primary questions/stimuli (highlighted in gray) and sub-questions used in the personal interviews to find out details about the thematic areas to be covered. In contrast to the group discussion, the beginning of the personal interviews with single individuals contained the invitation to describe a usual day in the family life. However, this question could pose problems and queries from the interview partners, such as: *"I don't understand the question. You want to know what I do during the day or [...] what happens in this house during the day?"* (Ms. A, PI01, Eastern Cape).[194] In this and similar cases, interview partners were then more concretely asked to describe what happened on a specific day during the previous week. Incidents like this one demonstrate challenges that can occur in qualitative research and highlight the importance of keeping in mind one's own system of reference and personal experiences.

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[194] The overview of pseudonyms can be found in subchapter 6.4.

Interview guideline (personal interviews)

Could you please describe a usual day (in your family) for me?

- Where and how do you live? Could you describe your home for me?
- How many family members live together?
- Who goes to work? And where?
- Who goes to school?
- How do you spend your free time? Do you have hobbies?
- Do you have much contact with your neighbors and community members?
- Do you have any connections with/receive support from an institution?

How would you describe your health situation?

- Do you have any health problems? Are these short-term or long-term problems?
- What can you do when you are sick?/Where do you go to get help?

Is there a family member who receives a Disability Grant or Care Dependency Grant? If yes, how did it come about that you applied for the grant?

- How did you first hear of the grant?
- Why did you want to apply for the grant?
- Who was an important contact person with respect to information about the Disability Grant?

How would you describe your experiences with the grant application procedure?

- What kind of documents have to be handed in?
- Where did you have to go to apply for the grant?
- Did you have any assistance with the paperwork?

How did the decision about being granted the assistance influence your everyday life?

- How did you hear about the decision?
- How long did you have to wait?

What has changed in your life through the grant?

- What kind of differences are these?
- What happens with the grant?
- How can you use it?

Can you remember the situations when you had a problem that you could not solve on your own? How did you deal with it?

- What or who helps you if you face problems in your everyday life?
- What kind of problems can these be (e.g., communicational or physical barriers)?
- Is there, e.g., any (disabled people's) organization that may help you?

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Please imagine that we will meet again in five years. What will your life look like?[195]

- How would you spend your time?
- Is there anything you would like to experience which you cannot do at the moment?

Is there anything important regarding this topic about which we have not spoken yet?

- Do you have any questions that you would like to ask me?

Figure 20: Guiding questions for the personal interviews
(own overview)

6.3 Analysis of the Data

The researcher is required to reflect his/her own context, be sensitive towards the context in which the research is conducted, and consider the influence of their own background both on the research and analytical process (Kruse 2009: 9). As can be seen from the experience of conducting the interviews, the field phase revealed that qualitative research is dependent on many parameters, and there is no such thing as an “ideal” situation. The researcher has to adapt to various circumstances and reflect/react to the specific situations that occur.

As already mentioned, all interviews that are included in the data analysis were recorded digitally. Immediately after the interviews, a summary was written using a short questionnaire/guideline. The summary included the overall impression of the interview as well as specific incidents or elements that were worth noting from the interviewer’s point of view. Regarding the transcription of the interview material,[196] the challenge of dealing with a high expenditure of time while at the same time encountering the positive aspect of a profound concern with the interview material should be acknowledged as two contrasting experiences (Kruse et al. 2012: 60 f.). The program f4 was then used for the interview transcription, while MAXQDA was used for the coding and analysis (see below for details). To a large extent, the rules for the transcripts followed Dresing and

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[195] According to Kruse (2014: 222), hypothetical questions should be avoided in interviews. However, this question was purposefully applied here to implicitly inquire about the persons’ aims and ambitions, and thus to find out what people value and miss in their lives.

[196] Two students (one South African student and one German student who had spent a semester abroad) kindly offered to assist in transcribing a small number of interviews. However, despite their language skills and cultural knowledge, many mistakes were made. Therefore, many passages of the interviews had to be revised, and I decided to carry out the transcriptions myself.

Pehl's (2013: 20 ff.) simplified transcription system[197] and comprised the following elements:

Transcription rule	Example (if applicable)
• original wording was used (no summaries)	
• abruptions of words and sentences were included[198]	"dis, disability"
• syntactical as well as grammatical mistakes were not corrected	"she come there"
• full stops were used more frequently than commas, especially if the voice was lowered	
• significant pauses (of different length), were indicated with three points in brackets	"(…)"
• signals to confirm understanding were not transcribed, unless they formed the sole answer (e.g., affirmation)	"mmh"
• emphasis was highlighted by capital letters	"YES"
• for each contribution (even short ones), a new paragraph was used	
• emotional non-verbal utterances were added in brackets	"(laughs)"
• words that were not understandable were marked with a question mark in brackets, guesses were put in brackets together with a question mark	"(?)" "(quadriplegia?)"
• the researcher was named "IB", the interviewed person(s) "I1," "I2," etc.	
• the transcripts were saved in .rtf format and then transferred into the program MAXQDA for analysis	
• all interviews were anonymized, e.g., regarding names of persons, cities, or organizations (for details, see, e.g., Kruse 2014: 366)	
• words that were added were inserted together with square brackets	"[to]"
• in contrast to the pauses, in the results presentation (direct interview quotes) in the next chapter, words that were left out were marked with square brackets and three points	"[…]"
• direct speech was identified by using single quotation marks	"… '…' …"

Figure 21: Overview of transcription rules

(according to Dresing/Pehl 2013: 20 ff.)

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[197] The original German term is "Vereinfachtes Transkriptionssystem."

[198] This is a variation from the rules, as these suggest leaving out each abruption of words and sentences unless they are used as a stylistic device to emphasize what is said (e.g., "It was very, very hot.").

6.3.1 Analytical Method

In order to be able to come to conclusions about the quality of life of persons with disabilities in South Africa and the role of social protection, an analytical method had to be chosen that could assist in summarizing and structuring the content of the expert interviews, while at the same time leaving an openness regarding the personal interviews and narrative elements. Qualitative content analysis is a method that is often used in the context of expert interviews. In German-speaking research, the "Qualitative Inhaltsanalyse" is mainly associated with Mayring (e.g., 2010). The aim of this method is to interpret text material systematically by using clearly defined rules and respecting—among others—the following aspects (ibid.: 48 ff.):

- embedding of the material in the communication context;
- a systematic, rule-driven approach;
- categories are at the center of the analysis; and
- the analysis is theory-based.

The coding system, whereby codes can be either deductive or inductive, is of central importance. The latter are codes that emerge from the material itself. Deductive codes, on the other hand, are codes that are developed on the basis of the theoretical concepts and approaches (ibid.: 83). However, Mayring's method, as well as other forms of coding, received criticism due to their focus on paraphrasing whole sentences and the interview content in general and their neglect of pragmatics. Even if the linguistic competence of the interviewer or the interviewee is not at a native-speaker level, for the context of data analysis one has to assume that the persons said *what* they wanted to say and *how* they wanted to express it (Kruse/ Schmieder 2012: 266):

> "Eingeschränkte Komplexität auf der Ebene des Sprachsystems (falls die Sprechenden eine fremde Sprache sprechen) oder eingeschränkte Kompetenz zum Erkennen von Komplexität auf Ebene der Sprache im Vollzug (falls Forschende in fremden Sprachen forschen) dürfen nicht zu der Unterstellung […] führen, dass das kommunizierte Sinnsystem weniger komplex ist bzw. dass es durch ein Komplexität ausblendendes Verfahren analysiert werden kann" (ibid.: 267).[199]

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[199] Own translation: "Limited complexity on the level of the language system (if the speakers speak a foreign language) or limited competency regarding the recognition/understanding of complexity on the level of applied language (if researchers do their research in foreign languages) should not lead to the assumption […] that the communicated system of sense is less complex or that it can be analyzed by an approach that hides complexity."

One method that allows for reconstructive procedures in social research, particularly also in the context of foreign-language projects, is the so-called "integratives Basisverfahren" (own translation: "integrative basic approach") developed by Kruse and colleagues, with reconstructive-hermeneutic elements (e.g., Kruse 2014: 472 ff.; Kruse/Schmieder 2012: 251[200]). The method (or "toolbox," as Kruse (2014: 475) also calls it) is based on a detailed description of linguistic phenomena in the text without referring to or following a single analytical method of qualitative data analysis (such as content analysis). Rather, with reference to several theorists/epistemologists (among them Alfred Schütz and Karl Mannheim) and other qualitative data analysis approaches (e.g., Lucius-Hoene/Deppermann 2004), this toolbox presents a way of integrating a variety of elements of and approaches towards qualitative data collection.[201] Thus, it allows for an analysis of agency and the data-centered and systematic reconstruction of

> "kognitive Repräsentationen von Handlungs- und Wirkmächtigkeit […] im Zusammenhang von Fragen zu der Konstitution von Lebensgeschichten, zu Lebenswelten, zu Handlungsmaximen, zu Ich- und Gemeinschafts-Konzepten, zu Gottes- bzw. Transzendenz-Verständnissen, zu subjektiven Krankheitstheorien, zu Bewältigungsprozessen" (Kruse/Schmieder 2012: 289).[202]

Especially in the context of foreign language research, this analytical method thus offers the opportunity to move away from a Eurocentric point of view and background of experiences. The way in which it is applied here allows for the combination of inductive and deductive elements in a very open way—by investigating the content of the interviews, but even more how the interview partners express their answers:

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[200] Kruse/Schmieder (2012: 252 ff.) also discuss three methodological challenges in qualitative research in detail. These are: (1) the problem of foreign understanding according to Schütz (1974); (2) the confrontation with the symbolic meaningfulness of expression/verbalization; and (3) the indexicality of linguistic and symbolic communication.

[201] Kruse (2014: 476 and 567) provides a schematic overview of the different steps and elements that are included in the process.

[202] Own translation: "cognitive representations of agency and effectiveness in the context of questions regarding the constitution of life stories, living environments, guiding principles, concepts of self and community, understandings of God and transcendence, subjective theories of illness, or coping processes."

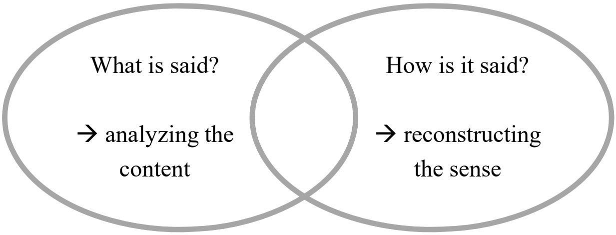

Figure 22: Elements of the interview analysis
(own overview)

In addition, the application of such a multi-perspective procedure does not follow strict rules or steps, as this would oppose the openness of a reconstructive approach. But, as Kruse argues,

> “[d]a […] niemals ohne eine Forschungsfragestellung und damit ein bestimmtes Erkenntnisinteresse geforscht werden kann, werden in jeder noch so offenen Analyse spezifische *forschungsgegenständliche Analyseheuristiken*, d.h. thematische (Sub-) Dimensionen verfolgt” (Kruse 2014: 477, italics in the original).[203]

Following two workshops on qualitative research and the analytical method developed and presented by Kruse and colleagues (e.g., Kruse 2014), in which the application of the method was practiced, it was possible to discuss short interview passages in a group of fellow PhD students in order to a) further practice the coding and interpreting of the material and b) receive feedback from others on certain ideas and ways of interpretation. In any case, it is important to reflect one’s own background and assumptions, because otherwise, researchers “run the risk of getting trapped in the pitfall of unquestioned judgment: implicit valuation of success and failure according to their own measures of normality and the dominant idea of a normal life course” (Ritter 2014: 148). Although the members of the analysis group were neither English native speakers nor did they work in the thematic field covered in this PhD thesis, the exchange was useful in order to gain analytical practice as well as to reflect on challenges that might generally occur in the analytical process.

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[203] Own translation: “as research is never conducted without a research question and a respective research interest, the most open analysis will follow specific analytical heuristics pertaining to the research topic, i.e., thematic (sub-)dimensions.”

6.3.2 Analytical Procedure

As described above with reference to Binder, it might be that people do not share the positive assessment as far as their functionings are concerned (see subchapter 6.2). The analytical method used in this thesis does therefore include objective as well as subjective elements, and is deemed suitable to capture all relevant aspects. By combining both the very open method described by Kruse (2014) and elements of content analysis, the analysis of the data followed three steps.

First of all, codes or categories were developed to identify and systematize major topics in accordance with central elements of the CA: Which information is revealed about resources (capability inputs), conversion factors, a person's "beings and doings" (functionings), as well as the thematic areas in focus (social protection and disability policy)? On the basis of literature studies and existing research, pre-defined codes were used, but these were complemented by aspects that emerged during the interview analysis. In parallel, what might be translated as "analytical heuristics"[204] (*Analyseheuristiken*) and "interpretation guidelines" (*Interpretationsleitpfade*) were used when working with the interview material in order to a) come to conclusions regarding central motives and b) focus on how information was provided by the interview partners. Kruse explains the idea behind these analytical helpers and their application in the following manner:

> "Unter *Analyseheuristiken* sollen dabei *konzeptionelle* ‚*Scanner*' verstanden werden, mit denen im Rahmen von biografietheoretischen, soziologischen, psychologischen, subjekttheoretischen, etc. Fragestellungen Bedeutungsmuster in den textuellen Phänomen verfolgt und benannt werden können. Unter *Interpretationsleitpfaden* sollen *sprachlichkommunikativ-deskriptive* ‚*Scanner*' verstanden werden, die im Rahmen des vorgestellten integrativen, texthermeneutischen Analyseansatzes, der als interpretatorische Grundlegung streng deskriptiv mikrosprachliche Phänomene auf den drei bzw. vier sprachlichen Aufmerksamkeitsebenen (Interaktion, Syntax, Semantik; Erzählfiguren) fokussiert, als Handreichungen dienen sollen für die Aufmerksamkeitssteuerungen des ‚Sehens' von sprachlich-kommunikativen Phänomenen" (Kruse 2011: 199, italics in the original).[205]

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[204] Throughout her diploma thesis, Birkholz (2014: 57) calls them "heuristics for analysis." In line with the translation of "analytical method" for "Analysemethode," I decided to use "analytical heuristics" for the German term "Analyseheuristiken." For a better understanding, Kruse (2014: 390) also introduces them as "language containers" (German: "Sprachcontainer") in order to illustrate the difference between the heuristics and categories/codes used in deductive approaches.

[205] Own translation and summary: "*Analytical heuristics* are *conceptual scanners* to find patterns of meaning in the textual phenomena. *Interpretation guidelines* are *linguistic descriptive scanners* to facilitate the identification of linguistic-communicative phenomena on the following four

On this basis, the analytical scheme was developed and transferred to MAXQDA. After transcribing all the interviews, each interview transcript was then uploaded into the program and all interviews were coded[206] with the help of the software. Both new codes for the content analysis as well as new heuristics for the deeper analysis of text segments were added once they emerged[207] from the interview material.[208] The third step of the interview analysis then focused on the interpretation of the elements found in the interviews by comparing individual cases and identifying patterns.

As the whole coding system was quite differentiated and contained a variety of levels (tree structure), the following table will only provide an insight into some of the codes and sub-codes used:

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levels of attention: interaction, syntax, semantics, and narrative figures."

For details regarding these levels and respective approaches (e.g., objective hermeneutics), see Kruse (2011: 165 and 171): Examples are: (1) interaction: positioning, dynamics in the interview, etc.; (2) syntax: use of pronouns, negations, breaks, etc.; (3) semantics: choice of words, semantic fields, etc.; (4) narrative figures: stylistic devices, plots, etc.

According to Kruse (2014: 480), the fourth level should now rather be seen as a cross-cutting issue, as it becomes important at a later stage of the analysis. It is more abstract than the linguistic aspects of the other three levels.

[206] For a discussion of the term "coding" and differences between codes and analytical heuristics, see Kruse (2014: 387 ff.). Regarding a differentiation between coding and qualitative content analysis, see Schreier (2012: 42 ff.). Here, the word was applied for both elements of the analysis: The use of the categories/codes to systematize the content of the text, and the detailed analysis of text segments.

[207] As Birkholz (2014: 86 f.) correctly mentions, "categories can change their status from inductive to deductive categories. A concept of category that was developed inductively through the analysis of text passages becomes deductive the moment I search for comparable passages in other parts of the text or in other texts."

[208] As suggested by Kruse (2014: 393 f.), the text was broken into small segments and sequencing was made use of. The fact that one and the same text passage could refer to a variety of different analytical elements meant that each interview transcript was filled with a number of notes and marks.

After finishing the coding of all the interviews and with many impressions of the interviews in mind, the chapters on disability, social protection, and South Africa were written before turning to the empirical part and finishing the analysis. The idea was to facilitate referring the findings to the theoretical framework when presenting and interpreting the data, and also to be able to decide about the content and importance of topics and elements for the first (theoretical) chapters on the basis of the deep insight into the data material. The further analysis then consisted of identifying a) text-segments for a re-analysis, b) passages suitable for quoting and c) central themes and motives in accordance with Kruse's method. For these purposes, all interviews were reviewed again and an overview table was prepared for each of them, in which the most striking elements were noted. This might not follow a certain method or rule, but it allowed for the structuring of the material and ultimately developing a structure for the seventh chapter, in which the challenge of presenting the results from 25 qualitative interviews had to be mastered.

	Codes	**Selected sub-codes/areas (examples)**
Thematic areas of the thesis	Disability policy and implementation	• Work and labor market • School/education • Transport, mobility, accessibility
	Social policy	• Social protection • Demographic aspects • Health and healthcare system
Capability Approach	Conversion factors	• Environmental factors, e.g., physical barriers • Personal aspects, including family background/personal history • Social factors, e.g., experiences of stigmatization and discriminatory behavior
	Capability inputs and resources	• Social grants • Income • Assistive devices
	Choice	• Mechanisms of preference formation • Social influences on decisions/ actions
	Achieved functionings	• Daily routines or daily life • “Doings” • “Beings”

Figure 23: Overview of codes

(own overview)

In the analysis, some of the heuristics and interpretation guidelines developed by Kruse were used. Kruse (2014: 477) differentiates between methodological heuristics (e.g., *agency analysis* or *positioning analysis*)[209] and those that depend on the research question.[210] For example, Kruse (2011: 200) identifies experiences of one’s own biography and respective conceptualizations of time (“Erfahrungsmodelle von Lebenszeit und Biographie”), which are called *biography and life cycle* in this thesis. Apart from using some of his suggestions, specific concepts were identified for the context of this research project. Using this set of scanners could help reveal information about the interview partners’ values and attitude towards life, and thus to come to conclusions regarding people’s agency (and ultimately

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[209] In addition, Kruse (2014: 477) enumerates argumentation analysis, metaphor analysis, and discourse analysis as methodological heuristics.

[210] Here, Kruse refers to Blumer’s (1954) “sensitizing concepts.”

their capability set). In order to give an insight into the framework, two of them are briefly referred to in the overview below.

Analytical heuristics	**Interpretation guidelines**
Agency[211]	→ How does the speaker explain that an action took place? → E.g.: "I went to school." vs. "My parents sent me to school." Kruse distinguishes various forms of agency, e.g. • anonymous agency; • collective agency; and • structural agency.
Biography and life cycle	→ How does the speaker experience and recount time and biographical elements? → E.g., "And then […]. And then […]. And then […]" vs. "First […]. Later […]. Ultimately […]." Kruse enumerates several dimensions, e.g. • linear time models; • a cyclic time model; and • the fragmented understanding of time.

Figure 24: Examples for analytical heuristics and interpretation guidelines

(Kruse 2011: 200 ff.; Kruse 2014: 495 ff., regarding agency see also ibid.: 502 ff.)

The first heuristic, agency, is also one of the most important concepts of the approach as outlined above. Experiences of time and biography will be analyzed in order to grasp developments and changes over a person's life course. Thus, procedural elements can be captured in order to understand freedom as a process (as discussed in the CA chapter). Both heuristics as well as the analytical method as a whole allow for the identification and analysis of (subjective perceptions of) scopes of action and decision-making:

> "Das Agency-Konzept erfasst die subjektiven Vorstellungen, die Menschen davon haben, *wer* (oder *was*) *wann wo wie was* zum Zustandekommen von Ereignissen beiträgt. Diese Forschungsperspektive liefert eine Analyseheuristik, die es ermöglicht, die vielfältigen Subjektiven und sozialen Vorstellungen der eigenen (Nicht-)Beteiligung am Zustandekommen von Ereignissen differenziert herauszuarbeiten" (Kruse 2014: 504, italics in the original).[212]

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[211] Agency will be an important aspect in the results chapter. It is used in many different contexts and dimensions within social sciences. For a detailed overview on agency research and examples from various research settings, see, e.g., the compiled volume by Bethmann et al. (2012).

[212] Own translation: "The concept of agency comprises the subjective ideas that people have of *who*

Forms of agency are, however, difficult to capture. By referring to Helferrich (2012), Kruse (2014: 502) introduces agency as one of the methodological (as opposed to research-specific) analytical heuristics. Helfferich (2012: 14) describes the indefinite variety of forms that agency can take, as it is complex and variable. According to her, agency might refer to concrete actions that entail certain impacts. It can furthermore be understood as an action that can be observed, as the power or authorization to act, or as subjective interpretation.[213] Agency can be dualistic (e.g., self-determination vs. heteronomy) or multidimensional on a continuum (e.g., powerlessness, influence) (ibid.: 22). Lucius-Hoene (2012: 40) summarizes that two major analytical approaches can be identified: agency between power relations, heteronomy and autonomy (social theory approaches/action-theoretical approaches); and the reconstructive analysis of subjective perceptions of agency. All this makes agency a complex phenomenon. In qualitative research with concrete texts (e.g., interview transcripts), the concept can be traced linguistically by looking at the way an action is reported (ibid.: 49 ff.): e.g., in the first person perspective, by referring to “one” (in the sense of the German indefinite pronoun “man” or the French word “on”), or by informing the conversation partner who the agent of an action was (for a detailed discussion, see Helfferich 2012: 12 f. and Kruse 2014: 502 ff.).[214]

For example, Mr. J reports how his impairment occurred, namely through an accident. He mentions this event twice in the interview and does not position himself as the agent in the sentences, but rather as someone to whom something happened without him being able to interfere. In the first passage, he says that *“I was in an accident with this arm.”* And in the second passage, he explains that *“from the dockyard, I worked in a garage […] and from the garage I moved to *company* and then to *company*. And there I got the accident”* (Mr. J, PI08, Western Cape). The second quote in particular shows that Mr. J does not see himself as actively involved in the occurrence of the accident.

(or *what*) contributes *when where how what* to the occurrence of incidents. This research perspective offers an analytical heuristic which enables the identification of the various subjective and social ideas of one’s own (non-) contribution to the occurrence of incidents.”

[213] For a further discussion regarding subjective perceptions of one’s own agency and respective theoretical constructs, see Helfferich (2002: 25 ff.).

[214] Two further analytical approaches/levels, namely the interaction between interviewee/speaker and interviewer/listener (Lucius-Hoene 2012: 57 ff.), and the analysis of larger parts of the text against the speaker’s biographical and cultural context (ibid.: 62 ff.), are also based on linguistic analysis. The latter is related to positioning analysis, which again shows the intertwinedness of the concepts and approaches used in this thesis. Kruse (2014: 506) describes agency and positioning analysis as going “hand in hand.”

6.4 Presentation of the Results

The systematization of a large part of the results in accordance with the preceding theoretical considerations was, however, a challenge. This was due to the fact that the analytical heuristics and the elements of the CA cannot be brought together on a 1:1 basis, but rather overlap. In addition, the main concepts of the CA are difficult to identify in qualitative interview transcripts. A large part of this thesis focuses on the options the DG offers to different people on the basis of their varying living situations and personal backgrounds. However, access to the grant and the availability of services and infrastructure are already strongly connected to both the social context and the person's biography. That is to say, analytical heuristics like *experiences of time and biography* and *coping strategies* are not only relevant as far as the background (social context, preference formation mechanisms, personal history, and psychology) and its influence on the individual conversion factors, the capability set, and aspects of choice are concerned (see above) but also regarding the analytical focus on capability inputs. The heuristics of *agency* and *hopes and ideas for the future*, in contrast, are more relevant for the investigation of capabilities and achieved functionings. *Positioning* and *identity* derived from Kruse's (2011: 202) "Selbstaussagen und Eigentheorien" cannot be detached from the overall consideration of a person's life. Again, the focus on these aspects can be regarded as a great asset, in contrast to quantitative studies.

In accordance with the overview in subchapter 6.2.1, the expert interviews were assigned to three groups: Firstly, experts who work in a DPO/permanent workshop staff or DPO members active in the fields of disability policy/lobbying or advocacy work. These differing aspects have been grouped together as they often overlap in different job positions. The second "group" of professionals consists of trained social workers—or people who work as (auxiliary) social workers—in sheltered workshops. Their profile also touches on aspects of disability policy and lobbying/advocacy work, but, more specifically, they engage in a variety of activities as described below. The third group consists of other people working in the field of disability rights/policy and social protection. This category includes university staff and independent experts. The interview partners were given the following pseudonyms for the presentation of the results:

Personal interviews

Interview number	**Province**	**Month/ Year**	**Short explanation**	**Pseudonym**
PI01[215]	Eastern Cape	Nov. 11	Mother of a young child with disabilities, black	Ms. A
PI02	Eastern Cape	Nov. 11	Mother and father (not married) of a young child with disabilities, black	Mr. B, Ms. C
PI03	Eastern Cape	Nov. 11	Mother of a young child with disabilities, black	Ms. D
PI04	Eastern Cape	Nov. 11	Female employee with disabilities in a sheltered workshop, mother of one child, black	Ms. E
PI05	Eastern Cape	Nov. 11	Female employee with disabilities in a sheltered workshop ("worker"), white	Ms. F
PI06	Western Cape	March 12	Young woman with disabilities, not employed, black	Ms. G
PI07	Western Cape	March 12	Man with disabilities, not employed, father of three children, black	Mr. H
PI08	Western Cape	March 12	Male employee with disabilities in a sheltered workshop ("worker"), married to another workshop worker, coloured	Mr. J
PI09	Western Cape	March 12	Female employee with disabilities in a sheltered workshop ("worker"), mother of several children, coloured	Ms. K
PI10	Western Cape	March 12	Group interview: three mothers of young adults with disabilities, one young adult with disabilities, coloured[216]	Ms. L, Ms. M, Mr. N, Ms. O

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[215] PI = personal interview.

[216] As explained above, the group interview took place unexpectedly (for me). I intended to interview one of the mothers as an expert, and the others, whom she had invited, individually. Due to the group interview, in which she was included, her role was not clearly definable, and her position seemed to be somewhere "in between," as she shared both expert knowledge and

Interview number	**Province**	**Month/ Year**	**Short explanation**	**Pseudonym**
PI11	Western Cape	March 12	Man with disabilities, not employed, father of two children, black	Mr. P
PI12	Western Cape	March 12	Man with disabilities living in a residential facility, not employed, white	Mr. Q
Total: 12 interviews, 16 persons				

Figure 25: Overview of personal interviews and pseudonyms

(own overview)

Expert interviews

Interview number	**Province**	**Month/ Year**	**Short explanation/ category**	**Pseudonym**
EX01[217]	Eastern Cape	Nov. 11	(1) DPO/permanent workshop staff or DPO members, most of them active in the fields of disability policy/lobbying and advocacy work	DPO_I (m)[218]
EX02	Eastern Cape	Nov. 11	(2) Social workers in sheltered workshops and a daycare center[219]	SWO_I (f) SWO_II (f)
EX03	Eastern Cape	Nov. 11	(2) (Here: not a full employment)	SWO_III (f)

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individual experiences. When the others referred to her in the interview, they did not refer to her as “just” another mother and a peer but as the expert/group leader. For example, all the other mothers thanked her for her encouragement and support throughout the years, which underlined her “special” position in this situation. In the presentation of the results, she is nonetheless referred to as a “private” person, namely Ms. O, and not as professional.

[217] EX = expert interview.

[218] (m) = male interview partner, (f) = female interview partner.

[219] The words “sheltered workshop(s)” and “protective workshop(s)” are used synonymously, as most interview partners used them in this way. In general, they refer to specific working environments for persons with disabilities in which they can receive a small salary (mainly as a supplement to their DG). The concrete tasks and orientation of different workshops can take various forms, some of which are presented and discussed in the course of the next chapter.

Interview number	Province	Month/ Year	Short explanation/ category	Pseudonym
EX04	Western Cape	Feb. 12	(3) Other experts on disability policy/social protection (incl. university staff)	DEX_I (f)
EX05	Western Cape	Feb. 12/ March 12 (two parts)	(1)	DPO_II (f)
EX06	Western Cape	March 12	(3)	DEX_II (f)
EX07	Western Cape	March 12	(2)	SWO_IV (f)
EX08	Western Cape	March 12	(3)	DEX_III (m)
EX09	Western Cape	March 12	(1)	DPO_III (f)
EX10	Western Cape	March 12	(2)	SWO_V (f)
EX11	Western Cape	March 12	(1)	DPO_IV (f)
EX12	Western Cape	March 12	(3)	DEX_IV (f)
EX13	Western Cape	April 12 (phone)	(1)	DPO_V (f)
Total: 13 interviews, 14 persons				

Figure 26: Overview of expert interviews and pseudonyms

(own overview)

7 Analysis of Voices from South Africa: Living Conditions in the Spotlight

The information that is used to come to conclusions regarding social protection, disability, and quality of life in South Africa draws on the firsthand experiences of both people who shared their individual living experiences and experts.[220] It has been generated through the qualitative research method presented in chapter six, which—in addition to presenting the content—allows for a large degree of openness and focuses very much on how the information was provided by the interview partners. Due to the close connection between the professionals' views and the personal experiences, the content of all interviews is presented in one single chapter. For example, aspects such as the political and legal framework in terms of social assistance are jointly presented with the personal situations of DG recipients. In general, the aspects in focus will be described and interpreted by using many direct quotes in order to give an original and unfiltered insight into people's living realities. To protect their privacy, no names are used and information (e.g., names of schools, streets, hospitals, and cities) that might identify the person who is quoted is not included.

The division of this chapter and the order of the subchapters follow the elements/concepts of the CA, which have been summarized by Robeyns (2005: 98) in a clearly structured overview. For the purpose of this thesis, Robeyns' suggestion was adapted, and the numbers of the subchapters were added to clarify the overall structure of this chapter:

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[220] As stated above, the data collection took place in 2011 and 2012. Thus, the contextualization of the results mainly refers to the framework that was valid at that time. Most arguments made, however, can still be regarded as valid for South Africa, and they also present more general considerations and remarks regarding social assistance for persons with disabilities that go beyond the country focus. Regarding a summary and discussion of more recent developments concerning eligibility and assessment for the Disability Grant, see, e.g., Kelly (2013).

I. Bertmann, *Taking Well-Being and Quality of Life for Granted?*, Gesundheitsförderung - Rehabilitation - Teilhabe,
https://doi.org/10.1007/978-3-658-19812-1_7

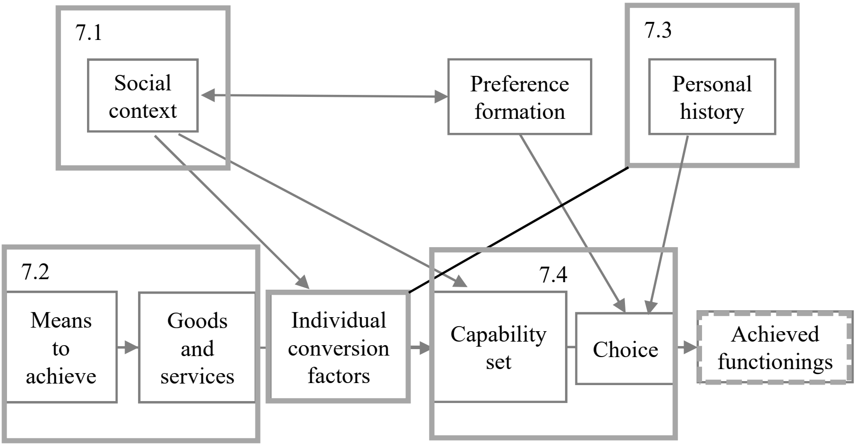

Figure 27: Overview of central elements of the CA

(copied and adapted from Robeyns 2005: 98; chapter structure added)

The chapter will start off by describing the social, political, and legal context in which the interviews have to be embedded and that was described and evaluated by the interview partners (7.1). This will be followed by a specific focus on the question of capability inputs and resources, more specifically the South African DG and CDG (7.2). Subchapter 7.3 investigates the interview partners' living circumstances against the background of their personal history. Here, the topic of positioning and self-identification also plays a role. The last subchapter (7.4) approaches the question of how the individuals (can) make use of the options that are available to them. Various forms of agency and of the realization of opportunities could be identified in the interviews. They are based on the beings and doings that the interview partners describe ("achieved functionings" in accordance with Sen's CA). At the beginning of each subchapter, the key aspects to be tackled will be highlighted.

7.1 The Societal, Political, and Legal Context

The focus of this subchapter is on

- aspects of social policy;
- disability policy and implementation in South Africa; and
- the working context of the respondents, a) regarding the question of access to the labor market for persons with disabilities and b) the role that social workers play.

7.1.1 Social and Disability Policy

As explained in the fifth chapter, in South Africa significant social inequalities can be found together with large differences between income levels. Social inequalities in general, and especially in relation to persons with disabilities, are thus a recurring theme in the interviews. However, disparities not only exist between population groups in terms of race/ethnicity but also between people living in different South African provinces. And there are variances between urban, peri-urban, and rural areas within the provinces. Against this background, the interview with DEX_I is very revealing, as she had interesting and in-depth experiences in a rural area in one of the former "homelands."[221] The neglect of these areas has led to high levels of poverty and fewer opportunities to generate income, and also to particular challenges regarding infrastructure in various fields: availability and accessibility of education, transport, health, and information. Lacking financial resources and a *"lack of political will for disability at provincial level"* (EX04, Western Cape), that DEX_I identified in her previous work in a rural area, make it difficult to introduce disability as a mainstream topic. In contrast, for *"HIV, TB, maternal and child care, there's plenty of training, plenty of attention"* (ibid.), from her point of view. Insufficient resources also lead to the fact that the supply of assistive devices is difficult, especially in rural areas.

In addition, together with several other interview partners, she highlights that disability-related knowledge is lacking, e.g., regarding the appropriateness of specific devices like wheelchairs:

> *"All the crutches and wheelchairs originally came from the central store in the kind of central hospital for the region. Which was fine, you put your order through and just hope that you get what you ask for. Although the guy in charge of that particular store didn't see any reason for anything other than a […] standard chair. Whereas we know*

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[221] During apartheid, the homelands (also called "Bantustans") were areas in which black South Africans were forced to live as part of the policy of racial segregation.

> *that the large, the majority of people need something different to the basic. So he would just order loads of the basic chairs and not understand why we asked for anything else that was more expensive. So there's those kinds of issues"* (ibid.).

In addition, DEX_I explains that the large distances or rough terrain in rural areas can pose problems regarding a variety of aspects, e.g., as far as access to water is concerned, and leads to higher costs and fewer goods being supplied (e.g., medical items or assistive devices) as things need to be carried from the cities to the rural areas. Despite some similarities, e.g., regarding infrastructural aspects, rural areas are distinct from peri-urban settlements (townships) as

> *"[a] big thing in rural is distance and geography. So a rural, I mean I had one, I mean I had so many disabled people living at the bottom of very steep (?) roads at the top of the hill. There is no way. I mean I had one child with *impairment*, who was BIG. I mean he was probably not much shorter than me and he was, I mean they called him *vegetable* because he was large. And he had no mobility at all. [...] And his mother, to get him up to the road, to get him to hospital, you know, no chance. Whereas if you are in an informal settlement, you know, there might be a path. It might be a bit flatter, it might be a little easier to get around. [...] so the one thing is, is geography and terrain. Also things like, if there are river floods, you actually can't get to the hospital in some areas. Transport is a problem. It's much more scarce. So, you know, there might only be two taxis an hour. And because the distances are bigger, I think it is more expensive"* (ibid.).[222]

As another interview partner, DPO_III, explains with respect to people in rural areas, *"they are hungry for information. You know they are very isolated in the rural areas. That might be the only one serving disabilities for kilometers around. And in fact for [...] *disease*, they've got a doctor that comes once a year"* (EX09, Western Cape). In contrast to this rather negative view on rural life, DEX_IV argues that in *"poor and less resourced communit[ies],"* some things might even work better (EX12, Western Cape). The interview partner does not elaborate on this view, but reasons might be a) the fact that innovative solutions have to be found against the background of few resources and little budget, and b) that community and family structures prevent exclusion and separation of, for example, persons with disabilities.

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[222] The analysis will not go into too much detail, but it is already obvious from this quote that, in this interview, reference to specific persons is not always made in a very respectful manner (such as describing a child as being like a vegetable due to his physical appearance). In addition, when speaking about patients who would come to the hospital for rehabilitation, she says that "*we had some really brilliant rehab candidates, who would come religiously for their appointments*" (EX04, Western Cape). Taken out of context, this quote sounds positive. However, the interview partner continues by explaining that people only came in such a regular manner when they wanted to obtain the DG, which shows that the explanation is to be understood in an ironic manner.

In the interviews with the professionals, one major theme or problem was identified that entails and touches upon a variety of aspects and areas: the topic of accessibility. As DPO_II explains,

> *"inaccessibility, I'm not only speaking about access to buildings and stuff like that. […] transport is a core issue, inaccessibility, people […] can't access hospitals. They can't (?) economic empowerment programs. Just sorry about that. (speaks on the phone) […] So public transport will be the thing that will solve most of our problems. (…) Not having access to transport if, if you are to ask any disabled person, it's about not having access to public transport. Ok, there are other issues. The housing, appalling, housing. You see people, the living situation of people, inclusive education, you know, those things are really key"* (EX05, Western Cape).

Thus, concrete fields that are mentioned are transport, hospitals/healthcare, economic empowerment programs, housing, and education. As far as the use of language is concerned, the word "key" can be regarded as a symbol of accessibility. Having the key to a building or means of transport offers the possibility of entering and using them. But this "key" is so far not available to everybody. For wheelchair users, for example, one difficulty arises from the fact that taxi drivers charge a fee for the passenger as well as for his/her wheelchair, thus imposing an additional cost burden on the person. This seems to hold true for different regions and provinces, as several interview partners in both interview forms spoke about this phenomenon with reference to minibus taxis, which are a common means of transport in South Africa. SWO_IV's explanation can serve as an example:

> *"You look at the transport, the transport from here it's quite, it's quite a distance. (?) like a wheelchair member in a wheelchair which goes then to, to the mall. And he takes his wheelchair. Then he pays for himself plus his wheelchair. Yes, (?) the wheelchair must be taken with as an extra person. […] I think in most areas they don't just allow you to get in, cause you're taking up the space of another person (?) business, it's their business, you know, it's their livelihood"* (EX07, Western Cape).

Both sides of the coin are illustrated here: The situation that the wheelchair users face and also the fact that the taxi drivers need to charge double as they are dependent on every single paying client. A potential solution that would change the situation and make taxi travel possible for wheelchair users, while at the same time respecting the taxi drivers' position, could involve transport vouchers; according to DEX_I:

> *"You know, one thing that we tried to start was getting taxi drivers not to charge double for wheelchairs, that would be a start. If there was a system of transport vouchers for disabled people, I think that would make a big difference. Because also things like, you know, somebody who would otherwise maybe be able to walk some of the distance, has to take a taxi, that's one thing. And we have free healthcare for disabled people, I don't think it's always enforced, but also the cost of access in*

> *healthcare is not so much that user fees as the transport to get there"* (EX04, Western Cape).

DEX_I's statement also confirms the interdependence of service provision and policy fields explained above, in this case between healthcare and transport. In the field of housing, accessibility is also an important aspect.[223] SWO_I states that there are not enough *"homes for disabled people."* (The existence of group homes, i.e., specialized living facilities, was however not critically discussed by her.) In addition, she comments on government housing for persons with disabilities: *"As in the government provides the poor with houses and so, the disabled people should also have houses that suit disabled persons, and there is very, very few, and they have to wait very long to get them"* (EX02, Eastern Cape). This is confirmed by DPO_V, who describes the situation of a client who is also confronted with long waiting times to get an RPD house (i.e., a house subsidized through the South African Reconstruction and Development Programme):

> *"And then I have one guy who actually applied for his own home which is a what we call RDP homes. Which is being adapted at the moment for him. He's been waiting forever. I mean (?) forever (he's?) waiting for about fifteen years for his home. […] And he's still not in. So this house is adapted for wheelchairs which is a type of ramp (?) it has grab bars in the bathroom, that type of thing, that's (?) accessible, I just asked him, spoke to him last week about it and he said: 'All the windows were stolen.' He (?) can't move into the home, into his home because the windows are gone"* (EX13, Western Cape).

Even more challenging are situations in which persons with disabilities rent premises and live in little shacks at the back of their relatives' homes, as DPO_V remembers: *"And they, they rent a little shack at the back, like in the backyard of their (?) parents' home or family's home and they contribute to electricity and you know water bills and groceries and things like that"* (ibid.).

An underlying aspect that was identified by my interview partners is the lack of staff who are well-trained enough to implement policies appropriately. According to DEX_III, it often happens that people in relevant parts of the ministries and administrative structures are not trained in aspects of disability policy and are well aware of this fact: *"[T]he especially academically qualified directors and managers they almost feel embarrassed or inferior for not knowing how to design their service delivery program so that it includes persons with disabilities"* (EX08,

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[223] But accessibility can take more forms than constructional measures to enable access into a building. It can also refer to access to information, as well as communication. It goes hand in hand with the topic of universal design (very closely related to universal design is the approach of "design for all"), i.e., the design of products and surroundings in a way that they are usable for the maximum number of people without any adaptation.

Western Cape). Reasons for this include knowledge transfer and consultation processes not taking place. SWO_V thus calls for proper consultation processes from the political side and involving persons with disabilities as knowledge bearers in order to be able to provide what is needed to successfully support independent lifestyles (EX10, Western Cape). According to DEX_III, it is important to provide adequate training on governmental level and to have close cooperation and exchange with the disability sector. SWO_II, who is not from South Africa, compares the country's situation to her own home country and identifies a strong political commitment on the part of persons with disabilities in South Africa:

> *"Whereas here, you see people go marching to the municipality to the, to the mayor. Having their forums, fighting for their rights, which is, I think it's kind of amazing and probably because they are in the beginnings, but it's really awesome how they kind of make themselves public"* (EX02, Eastern Cape).

But DEX_III identifies that the disability rights movement is not united and—in relation to the expression *"unity builds strength"* (EX08, Western Cape), which he mentions with reference to anti-apartheid struggles—would *"need […] a united team"* in order to *"get things done"* (ibid.). Similar to these assessments and views on the (advisory potential of the) disability movement and the lack of knowledge regarding disability mainstreaming on the political side, SWO_II, as well as other experts, calls for an integrative approach in the field of disability and (inclusive) social protection, in the sense that the whole project and program cycle needs to be taken into consideration: The first focus should be on the planning phase, but the level of implementation and the need for monitoring are also important: *"[T]he first point of reference should be your planning. […] Jointly with planning, goes the implementation and, and to monitor is it working, what is the problems, how do you fix those problems"* (EX02, Eastern Cape). From DPO_II's point of view, not enough resources are used to implement the policy framework in place—especially the CRPD. Against this background, she highlights the importance of bills as opposed to (non-binding) policies, as these *"will have attachments to it. It's budget, it's monitoring and evaluations, implementation plans"* (EX05, Western Cape). DPO_II concludes *"that they're not putting their money where their mouth is, because if you commit by signing the treaty, a treaty is a commitment"* (ibid.).

7.1.2 Access to the Labor Market

As has been described in the chapter on social policy, the labor market and paid (formal) employment are important factors as far as social policy and social protection are concerned. DPO_I reports his own previous attempts to find an occupation on the regular labor market: *"I didn't see it at the time, but they employed* *five of us disabled guys, and we ended up all in security control room”* (EX01, Eastern Cape). Despite identifying as a *“disabled guy”,* my interview partner sees himself as an *“exception to the rule”* (ibid.):

> *“I’m qualified, I’m intelligent, I got tertiary education, yet here I’m sitting, watching a camera all day. And every six months they promised us full-time employment, and every time the sixth month came up they said: ‘No, it’s gonna be another six months.’ […] And I just fortunately for myself, I just said to them: ‘Thank you for the opportunity, but that’s it, I’m done here.’ And, but the other guys stayed on. You know what: the only reason I left is ‘cause I had options. ‘Cause I have tertiary education. Now, what you gonna understand is when you see me, I’m the exception to the rule. A disabled guy or a person with a disability is actually the correct terminology in South Africa, who’s got, who finished school first of all and who’s got tertiary education, who drives his own vehicle, transport, I’m in the 1%. There you see the 99%”* (ibid.).

The rather long quote in which DPO_I positions himself, but also speaks about biographic experiences, reveals several issues: First of all, there seem to be different groups of persons with disabilities according to DPO_I’s understanding. The differences result from their having varying degrees of access to resources and education (and ultimately, the labor market). Due to his own background, my interview partner’s focus is on the completion of tertiary education. It is to be seen as an asset as far as access to (better) jobs is concerned. For him, having achieved tertiary education offers “options,” and there is a causal connection or link between having tertiary education, being able to leave a job that is not optimal, and finding work in a different place. Put into the framework of the CA, my interview partner’s capability set is bigger than those of his colleagues. From his perspective, wheelchair users in particular are in a different position, due to the fact that *“all the resources are being pumped into your mainstream schools, not to your special schools”* (ibid.). He adds:

> *“And so, the only reason why I’m successful today is because I didn’t end up in a wheelchair. Now if I had, I shudder to think where I’d been today. Because I wouldn’t have, I might have finished school, I might probably wouldn’t have got a good education, I probably wouldn’t have qualified for tertiary. I would be, more likely would be staying at home with my parents, living off a Disability Grant. Because I didn’t have options. And that’s why I could leave that company after two years. Because I had options whereas the other four guys with me, they didn’t have options, they were the 99%. Not the 1% like me”* (ibid.).

In line with further elements of the transcript, a central theme could be identified from this interview that can also be recognized in other transcripts: “**transitionality**” (in the sense of transformation). This refers to the speaker’s own situation “between the worlds,” but also alludes to the fact that changes are ongoing, which (can) have an influence on the definition of and policy approaches towards disability and inclusion. Concretely, he argues: *"So in South Africa we're still very much, because we're (?) in the rest of the world, we're in the process of moving from the medical to the social, but we're still stuck in the middle"* (ibid.). Manifestations of this theme are prevalent in DPO_I's interview, as far as different areas of his life are concerned. He felt that he fell somewhere in between categories when he was at school; he broke his neck while playing sports but is not a wheelchair user.[224] DPO_I makes contradictory statements regarding his impairment and the meaning of disability for him. At the very beginning of the interview, when he speaks about the origin of his impairment, he says that

> *"I always said, you know, that it would have been better for me if I was in a wheelchair, because that's fine. I could have lived with that. Whereas now, I'm kind of stuck in the middle. So, I'm not in a wheelchair and I'm not fully recovered"* (ibid.).

For him, this, and the fact that there was no improvement after a certain point, was *"incredibly frustrating"* (ibid.) when he was still at school. Whereas at one point, he states that *"I always said, you know, that it would have been better for me if I was in a wheelchair, because that's fine. I could have lived with that,"* later on in the interview he explains that *"[t]he only reason I managed to finish my schooling, get a good education, get tertiary education, and now that I am successful, is because I didn't end up in a wheelchair. I was on crutches"* (ibid.). While these two sentences seem to be contradictory at first sight, they show that transitions can occur (and transformations are necessary) on a variety of levels. Identification and contact with fellow students would have been easier for him—or at least he supposes so—as a wheelchair user. This might have facilitated a clear categorization and assignment. Being able to walk, but only on crutches, made it much more difficult to find his own place and be treated respectfully by other people. At the same time, walking with crutches allowed him to continue going to the same school after his accident. DPO_I would not have been able to attend this (or another) mainstream and inaccessible school as a wheelchair user. Thus, having had an incomplete injury has different (positive and negative) implications for him, even in the very same context of schooling.

On a personal level, my interview partner experiences the need for transformation and adaptation. For example, in the work context, DPO_I's current position requires him to be much more open and outgoing than he used to be. Thus, he compares himself to a shell that needs to be opened. Also, the image of doors is used by him, which can also be seen as an image of transition, namely from one room to another. And even if the threshold is not physically crossed, one can at least see further than before when a door is opened and get an insight into a room

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[224] As it was an incomplete break, he can still use both of his hands and walks using crutches.

(or area) that one was previously not aware of. Thus, new opportunities can be created or might be available. This image is quite useful when it comes to the situation of persons with disabilities in South Africa. Transformation is needed on both the individual level as well as on the societal level. One way to achieve this, according to this interview, can be found in education.

Although she feels that her own impairment/health status is deteriorating (*"I'm feeling like I'm going back, I'm going backward"* (PI04, Eastern Cape)), Ms. E argues that advances have taken place on a social level, and the theme of "transitionality" can thus also be found in this interview transcript. In a certain way diametrically opposed to her own (health) situation, which is changing from good to bad, she states that *"at least the things are better now than the last, then long ago times, you see, things are getting better"* (ibid.). To achieve further advances on both the individual and the societal level, empowerment and capacity building are relevant strategies named by DPO_I. This requirement is explicitly confirmed by SWO_II when she states that

> *"[t]hey weren't exposed, ya. They've got matric, but weren't exposed to situations where they can stand up for their rights. You understand. Because she is quite satisfied to work here and to get that minimum wage. Where her counterparts, somebody else who matriculated with a working out there would earn far more what she earns"* (EX02, Eastern Cape).

The words *"out there"* express a large area outside, an unknown (and potentially dangerous) field which is not in the protective realm of the workshop. DPO_V also speaks of *"the outside world"* (EX13, Western Cape). Against this background, another interview partner confirms the importance of empowerment and emancipation, which can be achieved through the acquisition of skills and further qualifications—either through organized courses, or even through private studies if money is scarce. This is a strategy used by Ms. E:

> *"Oh, I like to read. I li, I like to read. But the problem with that I didn't have money to go further with my studies. I wanted to be a social worker, but I didn't have funds to go to school. I like to read, even now, sometimes I just go and do some short courses and all those things, that is what I like to read"* (PI04, Eastern Cape).

However, these empowerment and education efforts need to be complemented by social transformation and changes. In most interviews, the situation in sheltered workshops played a bigger role than jobs on the regular labor market, as access is very scarce. The workshops have different purposes and orientations. SWO_IV's workshop does not produce items to be sold (apart from cards that are produced in the computer classes), but the workers mainly fulfill routine tasks in the production chain that companies outsource to them. Due to fire regulations, the workshop is only allowed to store a certain amount of products in the building. If they finish their order(s) quickly, they do not have additional work for the rest of the week:

> *"Now they can only deliver thirty. So within two days, then that is worked up, because we've got such a big amount of members. [...] Then we have to wait. So we're waiting, we're working three days, and we're waiting two days. And then we're working four days, and we're waiting one day"* (EX07, Western Cape).

Interestingly, this is not seen very negatively; it rather seems to be of importance that people have a place to go to and where they can interact socially (and parents or family members can go to work or have free time)[225]—whereby social interaction in this case means being among other persons with disabilities. As the quote above suggests, the workshop's focus is on the provision and receipt of services rather than being a productive work environment for persons with disabilities:

> *"And this is also we find that it is a social, where they can, where they, the, [...] say the partner, or the father or the mother can go out and we find most of them here in *area* goes to (?), which is like working in service, and then the member then comes to the center. So would have the interactivity of the rest of the group, [...] and the parent could then (see?) to the other siblings or go out to work and that gives them also that break. And we find that the members then have that interactive (?) with the rest of people with disability"* (ibid.).

According to various experts, the focus of the workshops, their respective mandates,[226] and their compliance with state requirements determine whether or not governmental subsidies can be obtained. There are various forms, ranging from subsidies for each individual who attends the workshop (as explained, e.g., by SWO_IV), to the transport costs to the workshop as explained by DPO_V, or subsidies for the interview partners' salaries (e.g., in the case of SWO_III). In the last of these cases, the fact that her subsidy has not yet been granted leaves SWO_III with little money despite being employed as a staff member in the workshop (EX03, Eastern Cape). At the time of the interview, she (only) received the grant and spoke of a high amount of debt.

Funding constraints even lead to the fact that in another workshop, according to SWO_IV, *"they have people coming in, and they pay to be there, whereas our members don't pay. They pay to be at that workshop, you know"* (EX07, Western

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[225] And the money that they get there is to be understood as a supplement to their Disability Grants (70% of the production earnings are given to the workers).

[226] Depending on the institutional/organizational background, there are workshops that focus on people with different types of impairments. Some professionals therefore explain that they have been asked by the government to include persons with other forms of impairment as well.

Cape). This confirms the view of workshops as "places to stay" rather than productive work environments. And in order to be placed outside of a workshop, DEX_IV mentions a program of supported work in which *"the parents will pay to have their children on those programs"* (EX12, Western Cape). Against the background of article 27[227] of the CRPD (UN 2006), the information presented in these quotes can be criticized. Whereas it might be assumed that the workshops and programs are well-intentioned, their inclusive and rights-based character is highly doubtful if, as in this case, people have to pay money to be allowed to participate. Fittingly, DPO_II critically comments that

> *"the protective workshops exploit people to some extent as well. 'Cause if I can get someone who can push a production line or cut my chips packets in such a way that they can fill boxes. If I have to do it in my factory, it will cost me hundred rand a minute for that process, for that line process to happen. If I take this to the protective workshop it costs me ten cents a minute. You know what I'm saying? So, if it so happens that people, I mean work is trade-off. You work to get money. That providing work and doing work for someone, providing a service, is a trade-off for money. So I see that trade-off as being exploited. Because you're not getting the value of the work that was done"* (EX05, Western Cape).

Due to the constraints that many people face with regard to administrative purposes (such as registering for the transport system Dial-a-Ride or applying for the DG), SWO_V states that *"they rely on the social worker entirely for everything"* (EX10, Western Cape). Thus, some workshops also provide skills training as a preparation for the regular labor market because *"things have to be maintained"* (DPO_V, EX13, Western Cape), as many persons with disabilities did not go to school, need constant stimulation, or have to be empowered to claim their rights. In SWO_IV's workshop, the people are also taught to respect certain regulations and structures so that they could fit in well as employees of a company or shop—provided they were able to find a position on the regular labor market one day. Regarding skills training, she shares that

> *"[w]e are a adult multi-diagnostic protective workshop, adults ya, we, we look at the whole person. So we have the contract work, [...] but when they came in, some of them were at home and they didn't have schooling, so we go and do the, we do the very basic, you know, write their name and numeracy that type of thing. (?) started for the last three years, we have a computer classes, we have secured fundings for*

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[227] Article 27 refers to "the right of persons with disabilities to work, on an equal basis with others," including "the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities" (UN 2006).

> *computers as well as the trainer, so they, that's, and that has flourished quite well"* (EX07, Western Cape).

The computers that are used for the skills training have already been stolen from the building several times. Originally, the idea was to offer this service to the community and let other people come to the workshop to use the computers as well. After these negative experiences, the computers were, at the time of the interview, only used for internal educational purposes. This example also confirms the high level of poverty and criminality among many communities in South Africa. First of all, community members cannot afford their own computers and would thus use the service of the workshop. Secondly, poverty and the need for income/money are so high that robberies like these occur frequently (in this case three times in one building). Luckily, the workshop has *"secured fundings for computers"* (ibid.), which can be regarded as a privileged position to be in, as the workshop does not have a lot of money in general:

> *"I mean I think we are still more fortunate than most workshops. We still have a contract, we still have a combi, people that are able to come down, we can provide a light lunch every day. So we're still providing those services, which (?) a lot of the workshops don't. So although we moan, but we're still more fortunate than somebody else"* (ibid.).

The difficulties of the workshops underline the need to implement article 27 of the CRPD and provide access to the regular labor market. One of DPO_I's tasks is, against this background, to sensitize companies towards disability, as specific perceptions of and views on disability (as well as unawareness) seem to prevent companies from employing persons with disabilities. One example he gives of why this task is important is the different treatment of persons with different impairments:

> *"But I know in terms of physical, I get treated a lot better than a person in a wheelchair. You would not believe it. And it's just something about a guy being in a wheelchair that there's a perception that this person is less of a person or that there's something wrong with their mental capacity. I don't know if it's got something to do with the fact that you're looking down on the person, or, you know, what it is. But people in wheelchairs get put in more of a box than I do. I don't know why. Maybe it's because I'm standing up, I'm on my feet, I'm on the level of the person. […] I've seen it. I get treated differently. I get treated with more respect"* (EX01, Eastern Cape).

SWO_IV thus underlines the importance of sensitization in the regular labor market in order to make it possible for people with disabilities to find work:

> *"Because they go out, you can do, there they will have the job (shadows?) and the job coaches and that. But in our situation, we have to employ more people, 'cause there's*

> *three of us, then where does that funds come from? […] We cannot, I can't cope, we can't cope here, with that kind of. So as much as we want them to go job-shadowing and that, somebody has to go out and go sensitize the factory or the, the place where they're going to work and say look, this is who we are, please sensitize the workers that that company has got, to say this is the person coming, he would need to have his chair put there, or his telephone, you know, changed to suit the need, you know that type of thing. […] And I mean that's the challenge that we, they want us to do it, but there aren't the structures in place to do it. The funds is not there to allow. The funds is not there"* (EX07, Western Cape).

This does not just apply to the field of employment; awareness-raising on the level of society and accessibility regarding institutions (such as mainstream schools, universities, and ultimately companies) is also needed. With his current position, to a certain extent DPO_I serves as a facilitator: *"'Cause I'm now the guy who gets the opportunity to open doors for other people"* (EX01, Eastern Cape). To achieve this, he can draw on personal experiences and positions himself, as it were, at the threshold of non-disability and disability, thus reflecting the blurring of clear boundaries. Interestingly though, similar to other interview partners, DPO_I clearly distinguishes between different types of impairments, and specifically emphasizes people with so-called cognitive impairments as being different from others, especially as far as the labor force is concerned.

Closely related, SWO_IV sees a need for sheltered workshops and is not of the opinion that they can be replaced or abolished completely. For this purpose, it is even necessary that people who could possibly move on to employment (and gain a "real" salary) on the regular labor market stay in the workshop to guarantee the institution's sustainability:

> *"[I]n my experience, there will always be a need for the workshop. No what government says, no matter who says to me. That is my opinion. There will always be a need for those, there is a need for the guys to, to progress out of and that you can see. But if they want to cut, the, the workshop to be self-sustainable, we cannot just sit with those that are the lowest of the lowest functioning. 'Cause how do you sustain the workshop? […] They want us to progress that the people go out of the workshop, that I can understand. But they also have to allow us to keep some of the higher functioning so that the workshop can also continue. [...] But there will always be, no matter what government says in my view, there will always be a need for, for protective environment"* (EX07, Western Cape).

And DPO_I argues in a similar way on the subject of the organization he is currently working for. He states that

> *"[c]ertain guys have got a certain level of disability. The reality is (they'll?) never gonna be able to function in the open labor market. We've gotta accept that a certain*

> *point you've got a, unless, you know, a company can go to the extreme turns of accommodating them. But we, we don't have that here in South Africa, where companies are willing to do that. So all they have at this point is our protective workshop"* (EX01, Eastern Cape).

As can be seen here, the experts also express a rather medically oriented view on disability, as both speak about people with varying functionings, and thus focus mainly on what different people can(not) do.

7.1.3 The Role of Social Workers

The interviews revealed a broad spectrum of tasks that social workers have to fulfill. Due to the fact that their workshop is oriented towards production, SWO_I finds her work *"frustrating sometimes. That you have lots of good ideas and you might, and you can't do them because of the production-orientated style"* (EX02, Eastern Cape). Other workshops, SWO_II adds, rather focus on *"[r]ehabilitation, bringing the person back, giving self-worth to the person,"* thus showing them *"you CAN do something, that type of thing"* (ibid.). Still other workshops combine both elements: fulfilling contract work for companies and having their own products. Regarding her working areas, SWO_II, for example, identifies three (more general) levels of social work: a) case work with individuals, including referrals, b) group work, and c) community work:

> *"I am going to speak on what is supposed to be done in social work. In social work you get the three main methods. The case work and that case work is being done when somebody as an individual has a problem. A social problem no matter what the problem is. […] Then you get your group work, which is not being done here and which I cannot do here because we are concentrating on production. But another organization where production is not the emphasis would have group social work via the group method. […] Community work, that is a little bit more in the field that is also not, hasn't been done here a lot, but I've, we are getting the green light now"* (EX02, Eastern Cape).

So far, it is thus not possible for the social workers to engage in community work in their daily workshop routine, which would allow them to focus on a person's environment and not work with an individual and his/her problems in an isolated manner only. This quote reflects the dilemma between an individual/medical model and a social model approach, and, in practice, change only seems to happen slowly. SWO_IV characterizes her daily working profile much more broadly, and neumerates that she currently, and since the beginning of the workshop, serves in the kitchen and as *"manager," "driver," "supervisor,"* and also *"mother"* (EX07, Western Cape). The fact that she describes one of her roles as "mother" could be seen as a hint as to the protective character of the workshop. People can only start coming to the workshop when they are 18 years old and legally "adults," but the word "mother" suggests that the interview partner regards them as being in need of guidance and care. It might also refer to the fact that some workshop members live(d) in difficult situations with their families, and the social worker sees herself as a substitute for family support.

Against this background, DPO_V highlights the strong commitment of the social workers, which even leads to them using their own (private) resources if necessary:

> *"So have, so we have targets to meet with the, with the constraints that we have. We end up using our own resources. For instance, when I'm sending my, my clients [SMS], I use my own airtime. But because we're thinking about the people. Even the salaries that we get here, are FAR lower than the salaries of the social workers in government. And I, I can say confidently we are doing a FAR better job than them. Because we specialize. But it, it needs someone with passion. Otherwise, if you don't have passion, you won't be able to carry on with this kind of challenge, so"* (EX13, Western Cape).

Apart from her own cell phone, the social worker also uses her private car. In her particular case, the fact that her predecessor was Afrikaans-speaking poses additional challenges, e.g., as details in the work files are not completely understandable to her, and for consultations/conversations between herself and clients, interpretation by her colleague is sometimes needed. In general, she states that, due to the limited (financial and personnel) resources, her work consists of a lot of "crisis management" and ad hoc reactions to the most pressing issues. It becomes obvious that this kind of work requires a high level of motivation and personal commitment. The staff members of a daycare center can also serve as an example that, in this field, a high commitment towards the job, despite low wages, is required. DPO_IV also explains: *"So people actually work here and they have a second and a third job and they make it happen because this is their passion and they want to be here"* (EX11, Western Cape). Many organizations also need or benefit from unpaid volunteers who are interested in working in this area, but DPO_IV highlights that it is difficult for her to find people if she cannot provide any compensation or salary.

7.2 Capability Inputs and Resources

The focus of this subchapter is on

- the purpose and meaning of the grants;
- the access to the DG/CDG, with a focus on the grant application process;
- eligibility criteria;
- the receipt and use of the grant; and
- aspects of evaluation and monitoring, including the question of fraud.

7.2.1 Meaning and Purpose of the Grants

Capability inputs and resources can refer to money or other tangible goods that are available to people, but resources do not necessarily have to be sums of money; they can comprise infrastructural or in-kind support and benefits as well. Many members of a sheltered workshop, as well as other persons with disabilities who do not have any form of formal, informal, or sheltered employment, receive the South African DG. The professionals were therefore concretely asked about their experiences with the grant application and their knowledge of the use of the grant by recipients whom they personally know. The grant recipients (or applicants) responded to similar questions from a personal perspective. As already indicated, especially for those working in a sheltered workshop, the DG is generally only complemented by a small remuneration. Most of the interview partners who receive a grant do not have a lot of money apart from the cash transfer, which is not surprising as an income threshold exists that is strictly adhered to. Ms. F, for example, explains that the DG serves as their income as *"we work by such a place. We're not like in the normal place where people earn a salary or that"* (PI05, Eastern Cape). In addition to the grant, the workers in the sheltered workshop get paid a small amount of money. The interview partners express different opinions regarding the amount of the grant: Whereas Mr. B states that

> *"we cannot say it is small, we cannot say it is big, that lies on the government. It is the government determines how much grant should the disabled people get or should the, should the old people get, you see. So I cannot say it is, it is not enough. Because it is determined by the government, you see"* (PI02, Eastern Cape).[228]

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[228] Mr. B does not specify who "the government" is. For him, it does not seem to be of relevance whether it is SASSA or another department, or whether state level or any other administrative layer is meant. Even though the interview partners are well informed about the research project and the fact that it is a PhD project, Mr. B expresses various concerns and requirements in the

Other respondents say that it is too little, as, e.g., expressed by Ms. E: *"[T]he grant is not enough, it is a small amount, you can't get everything out of that grant. [...] But at least to, to get something, is better than nothing"* (PI04, Eastern Cape).

When asked about the purpose of the grant, DEX_II replied that the DG is *"the primary vehicle for government to try and eradicate poverty through social assistance. [...] And it does in my belief make an impact on community level"* (EX06, Western Cape). SASSA wants to pay *"the right social grant, to the right person, at the right time and place,"*[229] but DEX_II states that *"trying ensuring that in terms of disabilities remains a challenge"* (ibid.). The experts have different views on the purpose and value of the DG (and CDG), which is connected to their understanding and definition of disability. DPO_II critically comments that

> *"having disability in a welfare focus places a lot of burden on a country. It places a lot of burden on the, on the country's fiscal thing. 'Cause if you have to look into national, what our government is paying out for Disability Grants, it's an astronomical amount of money"* (EX05, Western Cape).

DEX_III identifies two objectives that the DG should fulfill: (1) reduction of poverty for people *"who are not expected to participate fully in the labor market"* (EX08, Western Cape), and (2) *"increase [of] investments in health, education, and nutrition"* (ibid.) with the aim of promoting economic growth and, ultimately, development. The high unemployment levels, together with the persistent social problems that South Africa faces (and that are a result of apartheid), are, according to his statements, to a large extent responsible for the high crime rates the country is confronted with, including those for murder, rape, and robbery. According to DPO_V (and others), the function of the DG is to keep persons with disabilities alive, and it thus serves as a last resort for when other resources are scarce or unavailable: *"[t]he money is basically just used to survive"* (EX13, Western Cape). This does not, however, necessarily mean that only one person in a household needs this money to prevent malnutrition and starvation. DEX_II explains that

> *"it provides a family, it wouldn't only provide for one person, most of the time for, for, if you look at, at the norm client or you know, the, the, I'm struggling to get the word now, the, the average client that we get, comes from a low socioeconomic background. And for that client, in receiving the grant, it would not necessarily only mean food for me, because I'm now thinking just basic things, you know. Food and shelter, it would not only provide for me, but it would be assisting also the family of mine. If*

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interview, as though he was under the impression that the interviewer was a representative of the system. This impression might have been influenced by the presence of the social worker and the daycare center staff member in the interview.

[229] This SASSA slogan, which can, for example, be found on their website, is not only valid for the Disability and Care Dependency Grant but also for the other social assistance mechanisms offered.

> *I'm disabled, and I'm staying with the family, I would be valuable for the family in terms of my money"* (EX06, Western Cape).

This quote alludes to the fact that the receipt of the grant entails a questionable form of appreciation and recognition of the usefulness of the DG recipient for the household. In this context, DPO_V remembers that *"a few years ago I had a lady who actually survived on the Disability Grant with thirteen other family members who was not working"* (EX13, Western Cape). From her point of view, most recipients are really good at financial planning; they administer their grant independently and have enough money left for themselves even if they assist the family and pay for things in the household. Despite critical aspects, for many individuals, and also families, the DG and/or CDG are important. Even though the amount is not very high, Ms. A wants to receive the CDG for her daughter, but due to the fact that the father earns an income that is above the relevant threshold, the family does not get a grant. However, the family consists of seven people, all of whom have to manage on Ms. A's husband's income. As a result, the family cannot afford a specific school for their child, as the mother explains: *"It's too expensive, I can't afford it. […] I am not working. There is one person that is working in this house […] and there is no grant, I can't afford it"* (PI01, Eastern Cape). Her case is worth mentioning as the point of reference regarding the eligibility criteria are the applicant's income and, if applicable, his/her spouse's income. The number of family or household members is not taken into consideration for the application procedure: *"They* [i.e., SASSA; IB] *don't care about the, the other, like, because we are seven, ne. And there is one person who is working. All of us we are depending on him"* (ibid.).

Another mother, Ms. D, explains that there are five people living in the household (mother, father, three children), of whom only the father has a job. However, his income must be comparatively low, as the family does receive the CDG despite his salary. In general, the CDG serves to support parents or caregivers who cannot find employment at all, do not have employment that would allow them to work from home or have flexible working hours in order to look after the child, or do not receive a high salary. The grant thus not only serves to cover extra costs but can also be a (partial) substitute for income. DEX_II argues that, especially in cases where the education level of the parents is low, alternatives to the grant are scarce:[230]

> *"those children's parents or mother cannot necessarily substitute an income, because of the fact that the type of, their level of education would also be low most of the time.*

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[230] The interview partner states that the education level "*would be low most of the time*" (EX06, Western Cape), thus associating the fact of having children with disabilities with low education levels of the parents. This argument is not further elaborated on in the interview.

> *So, the type of jobs that they would access is whole day jobs, and not jobs that would allow them for the time that the child is at school to go and do my work and then by, by the time that the child is getting home, then I'm at home to be able to care for the child, which, which, which plays a large responsibility on that actual income coming from the grant. Because you don't have anything else to have a income from or to generate an income as a parent"* (EX06, Western Cape).

The issue of care and staying at home to assist family members with disabilities is, however, not only of importance as far as children are concerned. SWO_V highlights that many adults are also in need of care and assistance, which leads to the fact that family members have to stay at home and cannot go to work if they face difficulties in finding an external caregiver. This results in situations in which *"people with disabilities [...] are locked in their homes by family members who have to go to work. [...] They are not locking them because they don't care, because they, they cannot depend on this grant, you see. They need also to make an income*" (EX10, Western Cape). As an alternative, daycare centers can be a "*support base for working parents, and guardians, and foster parents, and also for the single parent. Because there is this need for a lot of people to be able to earn extra money. Some of the kids is fortunate to receive a grant, depends on what the income of the family is"* (DPO_IV, EX11, Western Cape). The interviewee does not resolve the contradiction in this statement: The children are fortunate if they receive a grant, but they can only receive it if the family income is low enough. Perhaps the children would be much more fortunate if the family income was high and could satisfy the whole household's needs. The choice of words in this context is worth noting, as "fortunate" implies happiness, but the noun "fortune" also alludes to (monetary) wealth—a term that does not seem to fit well as far as people who are eligible for social assistance measures are concerned.

The seriousness of income shortage can also lead to further difficulties: As many people do not have enough money despite receiving the DG, several experts explain that people borrow money from others (referred to as "loan sharks") and are persuaded to buy insurances, thus ending up in a spiral of debt that is almost impossible to pay off when the DG is the main source of income. However, the DG is also sometimes not applied for by people who would be entitled to receive it, and who fulfill all the eligibility criteria, but would not depend on it, as in the following case: When their son was still under 18, a white family would not have received the CDG due to both parents' income. As their son has since become an adult and does not have his own income, his application for a DG has good prospects—provided his impairment is recognized as permanent under the legal framework (which seems to be likely as he is a young adult with Down syndrome). He still lives at home with his parents, does not have his own income, and, in this regard, not much seems to have changed between his childhood and reaching the age of majority. As his parents pay for everything that he needs, the son is currently not reliant on the grant, which is why his parents have not yet assisted him in the application. When asked about the DG application, DEX_IV reflects that *"I wouldn't mind using it (...) for him. You know, if we had that amount"* (EX12, Western Cape).

The mother as the acting subject decides that she would use the grant for her son and presents at least two people as the recipients of the money (*"if we had that amount"*). The part *"I wouldn't mind"* furthermore confirms that the grant is not urgently needed, and that the potential application for the grant is not based on her son's decision or initiative. The interview partner is considering an application in order to save the money and perhaps use it when he wants to move out. However, it is not yet clear what the grant could be used for; one (potential) option could be his own flat. In this case, the grant could be seen as a means of security—although it can be assumed that the family could continue supporting the son if he did not have an income or if the income was not high enough. In any case, it seems that the grant would never be necessary to support the whole family but could be used in its entirety to benefit the son himself.

7.2.2 Eligibility Criteria and Grant Application

Most of the interview partners know about the DG and CDG—and many of them make use of professional support regarding the application, especially by requesting or accepting help from social workers. As far as knowledge about the grant is concerned, DEX_I remembers that *"[i]n terms of information about the grants, everybody knows about the grants. I mean it's, it's the main source of income for a lot of families"* (EX04, Western Cape). An important aspect revealed by Ms. G is that, in her case, information is solely retrieved through the media: *"And the thing we get, we only get information about the grant from the news or the speeches that is made on television"* (PI06, Western Cape).[231] Whereas Ms. G lives in an urban area, DEX_I's working context was rural with very limited infrastructure (see above), where mouth-to-mouth information is assumedly more common. When asked about the concrete application process, the interview partners reacted differently. Information ranged from ignorance (in the sense of unknowingness) to a very detailed description of the whole procedure. Interestingly, knowledge regarding the grant system did not necessarily coincide with a high level of education. Ms. G, who had finished secondary education and wanted to start studying, was not sure about the DG application and referred to her mother

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[231] DPO_IV confirms that changes in the grant system (e.g., a new payment contractor) are "*communicated over the radios and TVs*" (EX11, Western Cape).

for further information. In addition, she said: "*I've always received a Disability Grant as far as I know"* (PI06, Western Cape), even though when she was younger she must have been receiving the CDG. It is interesting to note that she is not well informed about the different grants that can be obtained—which is consistent with her prior explanation that they do not receive much information on the grants.

Mr. Q, for example, *"didn't [even] have to apply for it. We were appointed a social worker, and that social worker did it on our behalf. So, she came along with the forms, filled them all in for us, and then she sent them all off"* (PI12, Western Cape). This is in line with information retrieved from the expert interviews and shows once again the variety of tasks and responsibilities taken over by social workers. In addition, the interview partners highlighted the role of doctors in the application process. For many, it seems, the positive or negative evaluation of the grant application depends only on the doctors' recommendation—and some people even seem to think that the decision about their grant application was taken by a doctor him-/herself, as, e.g., expressed by Ms. A: *"I go there and there is a doctor, ne, who give the grant to the people who are disabled and sick, whatever"* (PI01, Eastern Cape).

The grant cannot be obtained if a person (together with his/her spouse) earns too much money according to the terms of the means test, i.e., the assessment of their income and assets. The officials who are involved in the grant application procedure—be it doctors or social workers—are aware of this. Therefore, they sometimes will not let a person apply for the grant or will at least recommend not doing so because they can already foresee the result, as in the case of Ms. A: "*I go to my doctor and the doctor didn't give me the information. She said to me there is no need because I won't get it anyway because of my, my husband's salary"* (ibid.). But the means test is not the only challenge. Originally, Mr. P's grant had to be renewed every year, even though he is a wheelchair user and no changes are to be expected. But

> *"the Disability Grant I had to every year renew, renew, renew, so I went back to my doctor and so my doctor doesn't need the, I gave him the papers, and he get my file, because the other doctor didn't put in permanent, (?) permanent but he didn't do that. But that doctor that I have now, he filled in the form and he put in permanent. So, because my disability is, is permanently"* (PI11, Western Cape).

In addition, by focusing on the choice of words and the respective assessments and personal statements made by the interview partners, the analytical method revealed further information about the significance and challenges of obtaining the grant. For Ms. E, who works in a sheltered workshop, has her own house, and went to a (mainstream) high school, the grant application was a long procedure: *"So it's, it's a long, long journey to get to, to the grant"* (PI04, Eastern Cape). The metaphor used here is a very interesting one, especially with respect to the question of how social grants might influence the perception of social protection among the interview partners. The interview partner does not use any other metaphors or include any further information that might allude to how, when, or with what means of transport this journey towards the receipt of the social grant is undertaken. However, it must have a beginning and (ideally) an ending, and therefore a sort of travel route exists. But the interview partner is on the journey for a long, long time, and although the final destination is known to her, she does not know whether she will arrive there and be granted the money. A similar experience was had by Ms. D, who explains that *"[f]rom the time you make it there, you go to other desk and desk and desk. So the last one they will tell you that you must wait you'll get your money the next month"* (PI03, Eastern Cape). Her description contains hints regarding the (long) duration of the application process, but she does not question that the decision taken will be in favor of the applicant in the end. Mr. J quantifies the time he had to wait to get his DG at *"about four months"* (PI08, Western Cape). However, due to the eligibility criteria, applying for a grant does not automatically also lead to its receipt.

The system that is in place has undergone several changes and now comprises certain elements that should guarantee its smooth implementation. For example, application forms are not given out to the clients or applicants any more, as was the case in the past. One of the reasons is to prevent fraud. In addition, when the forms are filled in by officials (and not the applicants themselves), fewer queries and incorrect entries arise, as DPO_IV from the Western Cape explains. She also clarifies that the Department of Health is a collaborator on the medical assessments. Standards have to be adhered to in order to minimize fraud and prevent reassessments due to complaints. Thus, doctors also need to be trained as *"they should know the parameters in which they should be making a recommendation"* (EX11, Western Cape). With this quote, the interview partner highlights (and confirms) that doctors play an important role in the process, but the final decision is taken by SASSA staff. The medical assessment is only one—yet an important one—of the components that are needed for the grant application. It could be that, on the basis of a doctor's recommendations and assessment, a grant is not awarded permanently (or even not at all).

The insecurity regarding the outcome of the application and the large amount of time that applicants have to wait for the result show that a) an immediate response to a need is not provided by the system, and that b) longer-term planning, which would require a certain amount of security, is not really possible. For Ms. E, for example, the way towards the grant is characterized by uncertainty, as she cannot say when, or if at all, she will reach her final destination. Will she receive the money and what will that mean to her? And if she does not receive the grant, what does that imply? Until the decision is taken and communicated to the interview partner, a sense of insecurity and passivity can be assumed—an aspect that will be looked at in further detail below ("agency"). In addition, the route towards the grant is paved with obstacles, as Ms. E, who calls herself *"severely disabled"* in this instance, finds the whole application procedure tough: *"[I]t's so hard, because before you, you get into social development, you have to make an appointment […] like I'm severely disabled, but I have to go there and get a date to come back again"* (PI04, Eastern Cape). Barriers seem to exist that not only come into play for a person as "conversion factors" that influence how commodities can be turned into capabilities; the barriers and external factors an individual is confronted with already have a large influence as far as access to resources ("capability inputs") is concerned. Can resources be obtained at all, i.e., to what extent can resources be accessed and are they (re-)distributed in an equal way to everybody? Returning to an experience from her private life, SWO_I confirms the difficulties that grant applicants experience in this regard:

> *"[I]t's a hassle and it's really for a person like I am actually right now applying for a Care Dependency Grant for my brother-in-law. And the process even through her [i.e., the social worker's; IB] help and her connections is so discouraging for the, for the applying person, and then, like when I was going to the hospital for the second time because the hospital didn't tell us that we must leave the forms in the hospital. So we took it and took it to SASSA, and thinking ok now we just hand it in, and then we find we actually had to go back to the hospital and leave it at the hospital and then from there it's being picked up, and then you actually have to call SASSA again to find out nobody informs you, you, it's you, it's your responsibility. […] So it's a lot of discouraging factors really, and the, like my father-in-law he was really frustrated and he was almost giving up. So he basically wanted to sacrifice 1140 rand only because of this up and down. And he has actually the chance of his own transport and his own comfort kind of. […] So I think it is very, very depressing and discouraging to get the grant to be honest"* (EX02, Eastern Cape).[232]

In the case that a person's application for a DG is not evaluated positively, he or she has

> *"the right to ask SASSA to reconsider the decision that they've made. […] That reconsideration would require technical expertise looking at your documents and reconsidering and, and, and then deciding whether the original decision that SASSA made would be upheld, or whether it would be dismissed. Or varied at times in terms of especially the Disability Grants. Because you would get that originally the doctor*

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[232] With "to get the grant," the interview partner does not mean that it is disappointing to receive the grant but that the path towards receipt of the grant is not easy and can lead to frustration. Taken out of its context and/or interpreted differently, one might also understand that the receipt of the grant itself leads to frustration, e.g., against the background of dependency that it entails or due to the amount of money that is received.

> *would recommend a six months temporary grant, and then upon the, the scrutiny of the technical expertise again, which would be a medical doctor of course, would advise on a twelve months. So it would be varied"* (DPO_IV, EX11, Western Cape).

If the person does not make use of this method of complaining but wants to hand in a new application (e.g., if personal or living circumstances have changed), this is only possible after a waiting period of three months. This leads to fewer applications and is also seen as discouraging applicants from re-applying. One important aspect in this regard is the question of who counts as "disabled" in terms of the legislation and is thus entitled to receive the grant. The relevant legal framework has already been presented in the chapter on South Africa. Commonly, disability and welfare issues are seen as strongly connected. Against this background, a statement by DEX_II is interesting from a linguistic perspective, as she expresses exactly this phenomenon and equates a person and a grant by beginning a sentence in the following way: *"But, if you are a temporary Disability Grant, can be, it means that it is a grant between three months Disability Grant awarded between three months, and twelve months"* (EX06, Western Cape). In addition, the interview partner presents varying views on the definition of disability. In one passage, she refers to a person who is currently receiving tuberculosis (TB) treatment and thus *"disabled for less than three months, essentially it means you will be disabled for less than three months, which a Disability Grant, temporary, do not cater for"* (ibid.). The view that someone who is receiving TB treatment is classified as "disabled" within the social security framework confirms the medically oriented definition of disability.

7.2.3 Aspects of Evaluation and Monitoring: System-Related Challenges

Against the background that most people cannot find work and their only means of income is the DG, many people fear the loss of the grant, e.g., in the context of reassessments. But DEX_III draws attention to the fact that the DG is also seen as a disincentive to work and that there is a possibility that people who receive the grant do not want to trade their grant for employment. Thus, government *"is not to increase the social grants, because it will make us lazy. It will be a deterrent for someone to get up and go and look for a job and I still argue that a living wage is not going to be a deterrent, it's a living wage"* (EX08, Western Cape).[233] My interview partner thus opposes the government's view and argues that most persons with disabilities would go to work and earn some more money if they could.

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[233] The level of the grant is regularly slightly increased. It is worth taking into consideration whether the grant should be increased significantly or rather substituted with other measures of social protection.

But he does criticize people for *"not using it basically for the purpose [...] and they spend it unwisely,"* which he evaluates as a *"waste of tax payer money"* (ibid.). Here, DEX_III denies some persons with disabilities the competence to adequately use their grant and handle their own financial affairs.

As men and young people tend to migrate to the cities in search of work, it is mostly old people, women, and children who stay in the villages—thus, the composition of the population is *"quite [...] strange"* (EX04, Western Cape), according to DEX_I's point of view. This had an influence on the clientele that came to her hospital for DG applications and further consultations. In this regard, she expresses her impression of people's personalities and character traits, though these generalizations need to be treated with caution: *"like rural people, there were no really clever malingerers. People aren't, they aren't sort of artful in that way. They're quite straightforward. Which I think is in some ways I guess they're, they're quite naive, but it's a good thing, (?) people are a bit more honest"* (ibid.). In her everyday experience, people frequently applied for the DG without fulfilling the criteria, but they pretended to do so. Concretely, she describes the situation at her previous workplace in the following way: *"I mean every, every therapist has a window that they watch people walk away from where, because then, you see, you know, the limp is gone, or the walking stick is being carried, or whatever it is. So you can often pick up things like that"* (ibid.). Even though he is not professionally involved in DG applications, Mr. P has witnessed something very similar, as he explains in the following quote:

> *"You see because a lot of people is misusing the Disability Grant, you see, because some people don't have a disability but they, they get a Disability Grant. Why? I ask myself that. [...] 'Cause I saw people, they come in with crutches, looking (?) disabled, some people come in with wheelchair you think they're disabled. After they come out, they walk next to wheelchair or they push the wheelchair, they take the crutches, put it under their arms, they walk out, they've got the money"* (PI11, Western Cape).

Trying to bypass the regulations also occurs as far as the possession of identification documents is concerned. IDs are an important requirement for the receipt of the DG, and the application can fail if a person does not have an ID. Sometimes, however, belated registration can be difficult. Instead of paying a certain amount for the ID application (140 rand at the time of the interview), people prefer to spend the money on food. The fulfillment of a basic need is seen as more important than the long-term assets that an ID document brings with it. An example of getting around not having ID documents is described by DEX_I: She knows of parents who do not have IDs and therefore ask their neighbors to pretend that a child is theirs and collect the grant on behalf of the "real" family. (The exact benefit for the neighbors does not become clear in the interview, but it can be assumed that the grant is somehow shared between the two households.) In one particular case, this arrangement became difficult when the mother finally got her own ID and would then have been able to apply for the grant herself—but the neighbors did not want to terminate the agreement:

> *"So, the situation the particular interview was about was a mother who then got her own ID and wanted the children back. And the neighbor didn't want to give them over. So she, the mother had been caring for the children all along, but officially, they, they were the neighbors' children"* (EX04, Western Cape).

Another phenomenon, as far as grants for children are concerned, is the trend of having several foster children with disabilities, as people can then apply for two grants. According to DEX_II, people

> *"then would accumulate disabled children, because of the, the double, two grants that you would be eligible for, which is also, could be a, a cause for concern. Not in all the cases, because you, you really get people who are passionate and really, you know, truly dedicated to, to the (?) and for those who are disabled"* (EX06, Western Cape).

It is not only applicants who try to get around the regulations; some experts also mentioned ways to bypass the rules and procedures, e.g., as far as having the necessary documents is concerned. Or, more concretely, as in the case of a person who receives the DG and earns a little bit of money with manual work. As their income is subject to fluctuations, the interview partner, who is in charge of confirming this income, always certifies a smaller amount so that the person can receive the whole amount of the DG. In addition, DPO_III accuses government employees of bribing other people in order to register to *"get themselves on* [i.e. the grant system; IB] *or their mother or cousin or something, you know"* (EX09, Western Cape). If they have the opportunity and connections, some professionals try to help and influence the application process in favor of their clients. DPO_V, for example, reports that she assists her clients by phoning the SASSA office in advance and thus using her connections and relationship to speed up or facilitate the grant application process, which might take quite a long time, as presented above. From SWO_V's point of view, SASSA does not adequately assist persons with disabilities in accessing the services they offer. A concrete example she gives is the so-called Social Relief of Distress,[234] which the South African Social Security Agency seemed to be "hiding," according to SWO_V: *"SASSA is hiding that"* (EX10, Western Cape). In her opinion, *"if you don't know about that, your client won't get. And even with that, you have to motivate, to write a report, that's not a problem […], but the, the, the services that they offer to clients, they don't disclose all the, all of that, you see"* (ibid.).

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[234] DEX_II: "*a food parcel, I think that's the option […] at the moment*" (EX06, Western Cape).

7.2.4 Use of the Grant

The grant recipients can use the money according to their own needs and requirements. No rules regarding usage exist, and, in most cases, the DG is not used for disability-related extra expenses only but to cover subsistence costs. The concrete spectrum, however, is very broad: For some interview partners, the grant seems to cover their basic costs. For others, it seems to be more of a drop in the ocean.

Mr. J (who lives in a group home with other workshop workers and his wife) seems to be able to pay for everything he needs with the grant: *"there where we're staying, we pay six hundreds and fifty a month, that is our rent for the month. The others is over by clothes, cigarettes and your toiletry. […] Cigarettes, toiletries and say luxuries and that"* (PI08, Western Cape). Cigarettes are not seen as luxuries, but the word substitutes the word "clothes," which is said in the first sentence. Apart from clothes, "chips and chocolates" are concretely named as further luxury products at a later point in the interview. What is missing here in this list are groceries, which are bought *"every Thursday, that's how we go on"* (ibid.). In addition to the DG, all the people living in the group home get a small salary from the workshop under certain circumstances: *"if there's no work, we don't get. […] If there's no work, we don't get our money for (that?)"* (ibid.). In this particular case, the DG seems to be sufficient to guarantee a decent living because there is remaining money which can then be used for so-called luxuries.[235] This might be the case because the living environment is peri-urban and rather poor, with, presumably, comparatively low rents. The fact that it is a supported group home might also mean that it is financially supported or already paid for, with rent paid by the residents only being used to cover current costs in the household. In addition, the residents only have to pay for themselves and do not provide financial support to family members or their fellow residents.

Mr. P owns a house and therefore does not have to use his DG for the payment of rent. As he has a wife who is not employed and three children, the grant seems to be the only income in the family:

> *"And if I need something myself, I use it for myself as well. If I need it, if I don't need it, I don't (care?) about it, 'cause the thing is this. I'd rather give it to my family than take it to myself and go (waste it?) with my friends. No, I'd rather give it to them. I can use it, or what they can do, buy clothes, or buy anything you want to buy. Or if I want to buy myself clothes, I go to the shop myself. (I?) don't like people to buy me clothes. I wanna buy myself what I like"* (PI11, Western Cape).

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[235] The fact that chips and chocolate are items that fall under "luxuries" is another question and provides a good insight into the living situation and poverty level of the interview partners.

There are various possibilities for how the money is spent and the part *"buy anything you want to buy"* suggests that the grant can cover all items that the family wants to purchase. What other resources the family has does not become clear in the transcript, but Mr. P uses many services that do not cost money (sports club, public library). In contrast to these two examples, SWO_III complains that her small salary and the amount of the grant are not enough, especially for herself and her family, as

> *"it's so little. And I'm not even paying much of *organization*. I can't cope. And my husband is not working. I have to pay the rent, I have to pay the school things. [...] It's just not enough, for me. For me. Besides that, I got debts, man. And you know with this retrenchments and all that. And at that times that I didn't work although they said they're going to re, that that debts is going away, it didn't. Every time when I get a new job then that people is on my case"* (EX03, Eastern Cape).

For Mr. H, the DG is the only source of income. He cannot find any employment despite continuously applying for jobs. His explanation is as follows: *"I said no maybe, because I'm disabled maybe I'm not supposed to, to work. Because in my CV, I, my status (tell?) my status, my health. I'm physically disabled. Maybe, maybe because I'm, I'm disabled. I'm not able to work"* (PI07, Western Cape). Currently, his grant is under revision and he does not have money at all. But when he usually receives it, most of it is given away to his children:

> *"Because I told myself that as long my child get, get what they want. I make sure that. I must buy what they want. And I told them that I'm not working, I (?) this amount, my child. I'm gonna make sure that if you want something, I gonna give you. But IF I don't, I don't have it, you must understand that I don't have it, because of this little amount. On my side, yes I, I buy but I left by my (?) it was (...) 2006 to buy myself. Because my last born is (*month* 2006?). That's the year I left, that is the year I stopped to buy myself. Because I'm look after my children"* (ibid.).

He also wants to save for a new house so that his children might be able to live with him: *"If I can get home, the house, the big house, make sure that my child have the place to live. If I can get that house, (my?), everything is ok to me"* (ibid.).

For many households, income shortage is the reality: *"With 1140 [i.e., rand; IB], if you work it out, if they pay a rental, and their food, and some of them have maybe two or three children with it, then it's not sufficient. So they just have to cut the cloth according to the material that is given"* (SWO_IV, EX07, Western Cape). Against this background, DEX_I provides an explanation of how individuals and whole families can actually survive on very small amounts of money and not starve: *"And you see a ten kilo bag of pap, which is maize meal. [...]. And that's the food, there is no, I mean in some houses, there's no salt, there's no sugar, there's no milk, there's no nothing. You eat pap. And that's it"* (EX04, Western Cape). This does not correspond to a healthy and balanced diet. In this context, from a European perspective it might appear somewhat unusual that, despite having a minimal budget for food, so-called burial societies, in which certain amounts are saved to cover funeral expenses, can play a prominent role. DEX_I explains that, for many people, saving money in order to be buried adequately *"is respect for who they are, for them being a person"* (ibid.). Rather than focusing on their everyday survival and nutritional condition, having enough money in order to have a respectable funeral is culturally important and is considered to be *"the absolute minimum for human dignity"* (ibid.).

The question of human dignity becomes relevant in various other contexts as well. DEX_I provides an example of a concrete situation in which human dignity, individual autonomy, and bodily integrity were not given priority over the whole family's needs. A woman was in hospital who was highly likely to have a spinal cord injury. It was not possible to take x-rays, which is why she was supposed to stay in bed. However,

> *"[g]rant day came around. And the family came to say (?): 'We need to take her to the pay point, so that she can collect the grant.' Now the pay point was just round the corner, but it was sort of into the wheelchair, […], down the road, into the queue, all the way round. And the chance, I mean it was, it was a horrendous risk and we explained to the family: 'If you take her, the chances of her incurring a serious sort of permanent disability are huge.' (?) And they looked at us and said: 'Please give us the wheelchair, we are going to take her.' And, I mean, I understood (?), and she said: 'I'm going, I'm going to collect my grant.' She had her family, all her family members, all the adults in her family were standing at her bed, looking at her, saying: 'Come on, you know, we've gotta go, we've gotta get the family money now.' And they were prepared to take the risk that she would be paralyzed for life. Because they needed the money that month. And it's, it's a sort of different concept of, you know, the rights of the individual. (?) individualist of the society, it's very much about the part (you?) play in the whole"* (ibid.).

The professional advice not to take the woman out of the hospital is overruled by the family's decision to collect the grant, thus ignoring the dangers of their action and demonstrating that the family member is primarily the source of income, and only secondarily does her physical integrity play a role. She is thus an indispensable family member—but her rights and health are violated as they weigh against the whole family's survival over next couple of weeks, which is the time period the grant is supposed to cover. In many instances, the grant is an important factor for more than one person.

The interview partners who received a CDG used it for both food in general and also for specific food items for their children, and medicines. For example, Mr. B explains:

> *"Now the way we are using this money at home, is sometimes as I am paying a small wage as well, sometimes we use here for food, for groceries. *Child* doesn't eat like normal person, you see. He have to eat soft food. Sometimes you buy her some (?), sometimes you buy her those noodles (?), beefs, (?) and so forth. You know she eats soft foods, *child*. So we do buy all, all those things. We buy her medications as well"* (PI02, Eastern Cape).

And Ms. D similarly explains, with respect to the use of the CDG for her son, *"[t]he most of thing they help to buy (hygienes?). He don't eat everything here in my house. You give him a food he don't want, you must go and buy something special for him, you see"* (PI03, Eastern Cape).

Whereas Ms. G remembers that all the money was already used for her when she was younger (and she was staying at a boarding school), nowadays she uses the grant for herself to buy *"disposables"* (i.e., disposable nappies). In addition, she says that the money is used *"if maybe I have a job interview and I have to hire a car, or I'm gonna go to hospital, (?) and I keep money aside"* (PI06, Western Cape). This example shows that the grant is used to cover extra costs that are related to her impairment and the specific needs that are partially caused by external factors (e.g., a transport system that is inaccessible for a person using an electric wheelchair, as in this case). However, in another text passage, Ms. G states that *"the grant to me doesn't seem like it's gonna help much"* (ibid.). It can be interpreted that she is not only referring to the fact that not many costs can be covered by the grant but also that, for her, a very different form of help or assistance would be required (above all an accessible transport system).

Ms. K, who lives with her mother (the only other person who works in the household), one of her sons, and two of her brothers, explains that she only uses a small amount of the grant for herself and gives the rest to other household members:

> *"I can't say I, I had enough, because I, like I say I must give my mom and the odds I have, I must spend on me. Because I must give my children also something to spend on them, and after all I look in my hand I have only maybe a twenty or thirty rand. What must I (do?) with a fifty rand? Only spray or roll-on and that's things for me to (cater?)"* (PI09, Western Cape).

Clothes (e.g., a sweater) and shoes are concrete items that she mentions as products that she buys for her sons or herself. In addition to the grant and the small remuneration she receives in a sheltered workshop, Ms. K receives money when she works on the weekends: *"And that money if I get it there and come home, I give it my mom, she buys things in the house"* (ibid.).[236]

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[236] The working activities that she pursues are interesting in that a doctor previously told her that

As opposed to the interview partners quoted at the beginning of the subchapter, in the later cases, the grant is an additional, but not the sole, source of money. It allows the buying of "extras"—either for the children or for the interview partners themselves: For Ms. E, living independently includes *"dress[ing] yourself properly, wash[ing] yourself, [...] at least you can buy something this month for you to wear, and that other month something to eat and all those things"* (PI04, Eastern Cape). What is striking here is that the last part of her sentence suggests that food is not bought every month. This could mean that either the food that is bought lasts for a long time (as explained by one of the experts, who referred to pap, a foodstuff that is cheap and at the same time filling), that specific food items are not bought regularly, or that being hungry is accepted in order to also buy other items apart from food.

In the current system, from Ms. E's point of view, the money that can be obtained through a grant is no more than a partial compensation for not having any income: *"The grant is not enough, it is a small amount, you can't get everything out of that grant. [...] But at least to get something, is better than nothing"* (ibid). She explains that persons with disabilities do not want to depend on grants and do not want to be seen as such: "*if the people can accept people with disabilities and they don't see them like they are depending on, because the people with disabilities [don't] want to depend on the grants. They want to live (the life?) like other people and be recognized*" (ibid.). What is criticized in this quote is the charitable view of persons with disabilities, presenting them as needy recipients who are dependent on a grant instead of being active and equal citizens who are socially accepted.

For this and other interview partners, (in-)dependence is an important concept. Ms. E expresses the wish to be independent several times throughout the conversation. The people from whom Ms. E wants to be independent are her parents: The receipt of the DG *"changes a lot, because sometimes yo, your parents can't, they are not working, so at least when you get something, (?) some changes in your life. Like you can manage yourself now, don't depend on other people to do those things"* (ibid.). This indicates the role that parents (or the whole family)

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she cannot work any longer "*because of my illness, I can getting in the (?) or something and that I getting hurt, so I can't.*" Ms. K describes that she is "*having fits*" (i.e., seizures) and "*the doctor is finding out I'm suffering from my nerves*" (PI09, Western Cape).

Seizures do not necessarily have to do with epilepsy but can also be related to mental health conditions, as seems to be the case here. MacGregor (2005: 3) found out from her interview material that "'having nerves' could be read as representational of a broader experience of social suffering, but equally as encompassing deeply distressing bodily sensations born of the struggles of survival in such a place." This might also apply to this interview, as my interview partner's living situation is a difficult one.

play in her life, and is related to the presented conceptualization of social protection "between kinship and the state" (see chapter three for details).

In contrast to the above-mentioned examples, Ms. F, a white middle-aged woman, still lives with her parents and brother in a one household. Both her payment from the sheltered workshop and the DG *"goes into my bank, and if I need anything, I just go and draw out whatever I need"* (PI05, Western Cape). This can be *"airtime"* (budget for the cell phone), *"something nice,"* or *"some clothes."* In addition, *"[n]ow I've now gotta go and draw money out to buy my boyfriend some for Christmas present."* Otherwise, the money *"just stays in the bank and just stays interest in that till I (if I?) need it"* (ibid.). This is very similar to DEX_IV's case, quoted above, who is considering applying for the DG so that the money can be used or saved by her son (EX12, Western Cape).

7.3 Individual Conversion Factors: The Social, Environmental, and Personal Context

The focus of this subchapter is on

- own and foreign perceptions of disability and normality, as well as potential transformative changes perceived on societal level;
- external influences and barriers in the lives of the interview respondents; and
- the role of the family and the specific situation of women/mothers.

7.3.1 Conceptualizations of "Disability" and "Normality"

When asked about her living situation in her house, Ms. G, for example, first of all refers to her family (before describing the house and the obstacles that she is confronted with in her daily life) and states that *"I live with my family, we live ok"* (PI06, Western Cape). She compares their family life to that of other *"black families"*:[237] *"We are like any other family. [...] Ok, black families don't have much privacy and we share everything"* (ibid.). Here, the ethnic origin is presented as relevant before the disability comes into play. As in other interviews, the interview partner's own classification or understanding of themselves as belonging to the

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[237] Here, the interview partner positions herself as "black." In the group interview, one respondent explains that "*most of our coloureds, we don't like reading, we don't go, like going to libraries and stuff like that*" (Ms. O, PI10, Western Cape). Wanting (and needing) to know more about her child with disabilities led to her overcoming and breaking with what she considers to be a typical behaviour pattern of coloured people.

category of "disabled persons" occurred in an intersectional manner and often regarding concrete areas of life, e.g., nutrition, the labor market, or housing. Mr. Q argues that *"as a disabled person, one actually have to watch what you eat"* and he states that he *"live[s] in a home which provides bedrooms for 16 ably disabled members of society. People like myself"* (PI12, Western Cape). Ms. E also counts herself as belonging to the group "disabled people," which is confirmed by her explanation that *"they are connected with companies that employ disabled people, so if there is a vacancy, they will let me know"* (PI04, Eastern Cape). Other interview partners indirectly self-identified as being persons with disabilities through confirming the receipt of the grant. When asked about her healthcare, SWO_III clarifies that being a person with disabilities is not the same as needing medical treatment (which was not the intention of the question): *"I don't use any medication, I'm not sick. I'm just disabled"* (EX03, Eastern Cape).

When he started participating in a support group, Mr. H was told by the others that *"we need you present in the thing* [i.e., the group; IB]*"* (PI07, Western Cape). This was taken up very positively by him: *"I appreciate, because people who are living dis, disabled, you are not recognized by other people. I'm not recognized. […] You know mos what I'm saying? I'm come here, they say to me, […] 'we need you presently'"* (ibid.).[238] The recognition and dignity that this entails for him are enormous, as the following quote reveals:

> *"They [i.e., not the group members; IB] insult me because of my disability. And […] that I cannot do anything because I'm disabled. […] That's why by the time they started this group, I (had?) appreciate it. Maybe people can understand that people who are disabled are human beings"* (ibid.).

Mr. H was also asked to invite other persons with disabilities. He said that *"I'm coming here to make sure that all the people who are disabled, physically disabled are here and (make these what you have?) seen there"* (ibid.). A similar wording is used when he speaks about his children, namely that he *"want[s] to make sure that they're going to school. Going to school and, and buy (?) and make sure that my child can get all this stuff"* (ibid.). It is important to note that he has a very strong idea of what matters to him, and the responsibility he feels towards his children and also to the group seems to be very high. In addition, he did not go to a medical appointment on the date the interview took place (which was one of the days the group met): *"As I, I, I said to you, I'm supposed there today, at the *date*. (?) I didn't go there because of the, the, this project. I must be here"* (ibid.). He seems to attach a higher priority to participating in the group than attending his medical appointment. One cross-cutting theme could be identified in this and other interviews, which I called "**recognition from others**."

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[238] "Mos" is an Afrikaans word meaning that something is already known or evident.

As also illustrated by Mr. P, for example, being an active member of the community is of a great deal of importance for and interrelated with the active realization of his aims and ambitions. His intrinsic motivation to shape his living situation is high. After his accident, accepting his acquired impairment and coming to terms with it was an important step for him, and he keeps telling himself that

> *"in my mindset, if I, if I can work, and if I get a work, I'll go for that, because nothing is pushing me back. [...] Because if I push myself back, it's my fault. I can't blame any other people, not government, not the able-bodied people, I can't blame anyone. I have to blame myself. That is my blame there, because I'm pushing myself back, and I don't have to do that. That's the only thing"* (PI11, Western Cape).

However, it is also important to learn to accept help if needed: *"If I can't do it, who's gonna do it for me. I have to lower myself down if I ask that person. And that's what the disabled person must realize as well. (?) not to be independent on your own, but be dependent as well"* (ibid.). In relation to social protection measures and other support structures, the duality of outside support and personal motivation is also crucial in his view, because *"government, government can come (?) around about say 60%, but that person has to come 40% as well, because you have to support yourself as well. Because you can't expect government to support you a 100%"* (ibid.).

Another example of the way the interview partners see themselves and want to be seen is the reference to the word "mindset" in the sense of (self-)motivation, e.g., as far as the motivation to pursue physical exercises and a personal fitness program are concerned. This can be illustrated with the following example, in which Mr. Q directly relates his mindset to an improvement in his quality of life:

> *"So the mindset is you have to do these things. If you don't do it, if you're too lazy to do it, well then you gotta degenerate. If you have [the?] mindset, and the strength, to, to go for it all the time every single day, then, well your quality of life is always gonna be a bit better"* (PI12, Western Cape).

It can be argued that the use of this term combines both aspects of agency and elements of positioning. In the quote, the interview partner highlights the importance of regular exercises and says that people need to be active agents[239] and *"go for it"* (ibid.) on a continuous basis in order to achieve positive changes regarding their quality of life. His understanding of mindset in this regard refers to the fact that people need to actively want to improve their situation and have to motivate themselves on a day-to-day basis. Strength and laziness are presented as contrasts here, and if somebody does not have the right mindset, he or she finds him-/herself in the position of being lazy rather than strong. My interview partner

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[239] The topic of agency will be discussed further in subchapter 7.4.

positions himself as knowledgeable, and to a certain extent superior, as he found a way to contribute to the improvement of his quality of life—which some persons with disabilities, who are "*too lazy*" in his view, do not seem to (or want to) pursue. A theme that could be identified in addition to the above-mentioned recognition from others is the "**self-respect**" that a person also needs in order to feel accepted by and welcome in society.

It is mostly the interview partners who have extensive experience regarding stigmatization and exclusion who use comparisons in the interviews and create a dualism of "normality" and "specialty." Ms. E speaks about going to school as *"the normal thing that the other people are doing, 'cause disabled children are supposed to stay at home and all those things"* (PI04, Eastern Cape). For her, the fact of having finished her schooling prevented her receiving the DG for a long time because she was considered capable of working by the people in charge of evaluating her grant application. Having completed mainstream education made her a "normal" person in the officials' eyes: *"by that time when you pass matric, they see as normal persons, because the, the disabled people can't go to school. So that is when they didn't want to give me money. They said I must go and work because I've got matric"* (ibid.).[240] On an underlying level, the interview indirectly alludes to the fact that the provision of social assistance and grants used to be different for people with different ethnic origins: *"But at the end, because of the South Africa change and get another government, that I got it, the, the, the Disability Grant then"* (ibid.).

Normality was a recurring theme in this interview. It could, however, refer to different facts: For Ms. E, it was important to be seen as "normal" in a variety of contexts—e.g., at school. At first, she was not recognized by her fellow classmates, but she explains in the interview that *"at the long run, they see that I was a normal person as they are"* (ibid.). In the interview, the acceptance of being regarded as "different" is divergent according to the effect it has. At school, "normality" brings with it participation, and deviation is therefore seen as negative. The interview partner wanted to be accepted by her fellow classmates and waited until they regarded her as an equal peer. But as far as her application for the DG (and reasonable accommodation) is concerned, she accepted "being different." This is reminiscent of what Terzi (2005: 444) calls "the dilemma of difference" in her article about education for children with disabilities:

> "The dilemma of difference consists in the seemingly unavoidable choice between, on the one hand, identifying children's differences in order to provide for them differentially, with the risk of labelling and dividing, and, on the other hand, accentuating

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[240] Matriculation, abbreviated as matric, refers to the precondition for studying at a South African university. It is commonly used in order to refer to graduation from high school.

> 'sameness' and offering common provision, with the risk of not making available what is relevant to, and needed by, individual children."

Mr. P contrasts being "able-bodied" and "disabled," and, despite being a wheelchair user, describes himself as "able-bodied": *"[T]hat's why I say, I don't see myself as disabled. I see myself as an able-bodied person"* (PI11, Western Cape). For him, the crucial aspect is to be as independent as possible by *"pushing myself to the limit by doing things that I do"* (ibid.). Related to this, it became apparent that most interview partners do not see themselves as "special," and they do not want to be regarded as such by others. Self-identification as persons with disabilities does not automatically imply an approval of special treatment: Ms. E, for instance, wants

> *"to live like other people, to, to, to work outside with people with no disabilities, not to stay in the place like because sometimes you feel like you are, you, you belong with the people with disabilities. And I like to belong with other people, so, with the community, with other people, so that I can live my life like them. And, and that is what I want in the end"* (PI04, Eastern Cape).

And she concludes: *"We are normal as other people"* (ibid.), and, as such, persons with disabilities want to be treated equally. My first interview partner, Ms. A, a mother of a small child, reports on her usual day at home and the tasks that are fulfilled in the household. In this context, she says: *"Nothing else. Nothing special we do"* (PI01, Eastern Cape). This is confirmed in a subsequent part of the interview when she almost literally repeats *"Nothing else, nothing special"* (ibid.). It might be concluded that, in her opinion, her family life is not distinct from the lives of other families. Whether it is real families in her neighborhood and in the township, other (hypothetical) families with or without children with disabilities, or her own extended family that serve as a counterfoil for this argument is, however, impossible to say. In any case, family played a major role in most of the interviews, also as far as questions of normality and self-understanding were concerned.

7.3.2 External Influences and Barriers

The topics of transport and mobility are named repeatedly as influential on the living conditions of the interview partners—both by the professionals and by the other interviewees, especially those using wheelchairs. The personal interviews thus confirm the assessment and perception shared by the professionals. For Ms. G, for example, transport is the most important issue that could change in her life, as *"transport is just, it would make one huge difference"* (PI06, Western Cape).

An accessible transport system would be very helpful in qualifying for employment, finding a job, or getting to work and thus having a higher income than the value of the DG that she currently receives:

> *"[I]t would be important for me to find work, because I think I would, I would be qualified, if I studied, I would be qualified enough to get like ten times more money a month than I get now. So, the grant to me doesn't seem like it's gonna help much. If I, if, if they could sort out, if they could find a way to get us a transport system that works, then we can go anywhere whenever we want"* (ibid.).

SWO_III, for example, uses the bus provided by her employer. Due to her educational background, she considers herself capable of finding employment on the regular labor market. However, the fact that most other employers cannot guarantee transport for a wheelchair user makes her decline job offers. She even states that she feels fear as far as transport is concerned:

> *"And that's why I'm so afraid. I know I can get other work outside, but I'm so afraid of the transport issue. It's not a [...] I made now how many nine applications for work, but my mind is not there. But I just thought about my family, and my living circumstances. That's why I'm approaching that people for work. But then I think: Are you going to transport me like *organization* transport me? If not, so then I'm not gonna take your job. I'm sorry. If you can't make a plan for me, then I'm not gonna take your job"* (EX03, Eastern Cape).

When speaking about his professional life, the main barrier towards a job for Mr. Q is not his own impairment or the related social reactions/circumstances but his age—or rather the social treatment of older people: *"At 50 years of age, it's very difficult to get a job. Any job that you apply for they have age stipulations"* (PI12, Western Cape). In one of the expert interviews, DPO_I reports similar experiences but with a focus on disability rather than age as the relevant category:

> *"I must have gone for between ten and 15 job interviews. And I remember walking into the interviews. After the first six, seventh one, and just seeing the people's faces who were going to interview me and thinking to myself: '*Name*, you are wasting your time.' 'Cause they don't see you as an individual, they don't. All they're seeing is a guy on crutches and you see it in their minds, that they're thinking: 'How can this guy do the job?' But not being able to see past that. Where I'm intelligent, I'm qualified. Just with a bit of support, just through reasonably accommodating the workplace, I could very possibly do whatever job they require of me. And I got desperate"* (EX01, Eastern Cape).

In contrast to this experience, Mr. J started working in a sheltered workshop more than 20 years ago because he could no longer work in his previous position due to an accident he had with one of his hands. He likes working in the workshop, where he found work after a doctor told him about *"a place in *region*, handicap center* *where there is work"* (PI08, Western Cape). One day after handing in a letter from the doctor to the social worker at the workshop, he started working there. Nowadays, he has a supervisory role and is the first person in the workshop in the mornings, preparing the work for all the others. Even if his previous employers would take him back, he could not do the manual labor he used to do. Therefore, the workshop seems to be a suitable option for him: *"There is not heavy work on my hand also. I can't pick up heavy stuff with my hand"* (ibid.). Previously, *"I used to work very heavy, but now this is light work here now"* (ibid.). When he was still at school, Mr. J used to do a lot of sports and broke his ankle playing rugby. After this accident, he stopped going to school. It can be speculated that further education might have opened up further working opportunities for him (as an alternative to manual labor) nowadays. In addition, some sort of reasonable accommodation in the workplace might allow him to pursue a job on the regular labor market.

For one of the professionals, continuing mainstream education and, to a certain extent, being forced by her parents (more concretely, the father) to keep going to school can be named as a reason why she is not unemployed today: SWO_III attended a regular school but had polio as a child and thus had difficulties walking when she was young. When she asked her father to send her to another school because of her inaccessible school building, he decided to take her to a hospital instead and arranged for an operation; my interview partner knew nothing about this until the day of the operation came: *"And so we went, hey, this is not a school for disabled kids, this is a hospital"* (EX03, Eastern Cape). She had to stay in the hospital for a long time and received private education there. The operation and the following treatment resulted in her being able to finish her education at her previous school; she used her wheelchair to get to the building and then used her crutches inside. Only after giving birth to her children did she stop walking altogether; she now uses a wheelchair again (while crawling at home).

In her daily life, the inaccessibility of her home poses a challenge:

> *"But I did apply for a RDP house, that is in 1994 already. My house got 15 stairs up to the rooms. (laughs) Every day when I come home, I first do all my things downstairs, whatever I must do. Cook, dish up, washing the dishes, after that I'll go up [...]. Because I know when I'm up, I'm up. And when I'm down, I'm down. Like in tomorrow morning, [...] because my husband brings my washing water, he brings my tooth brush, water, pee pot, everything to my room. And then he takes everything down"* (ibid.).

Other interview partners also speak about inadequate accommodation. For example, in the context of the description of their house, Mr. B mentions that *"electricity has been cut off on this house"* (PI02, Eastern Cape). Thus, the family has

> *"an illegal connection now of which it's very, very dangerous to us because sometimes the electricity goes out. When it comes back it comes back so strong. You never*

> *know what effect will it have on this TV, effect will it have on the machine, or the effect it will have on the fridge when it comes strong. It's either it will be flames. There as well we've got pipes that are leaking as well that need to be fixed. You see. We are not living in a good, in a good environment as far as condition is concerned"* (ibid.).

In addition to the fact that their *"house is small, it's very, very small"* (ibid.), Mr. B and Ms. C seem to be waiting for their house to be renovated.[241] Mr. B does not explain why he does not actively engage in renovating the house himself, but this fits to his general behavior of not actively taking processes into his own hands but instead waiting for things to happen. The couple is also worried because the person who sold them the house *"has been selling this house to different people"* (ibid.), which also leads to further conflicts between the family and other people.

Barriers and inadequate circumstances can exist both out- or inside the house, as Ms. G explains in the following quote:

> *"[E]ven like houses that they build, that they build here, some of them are not made for people with disabilities, because they would build these weird houses, with the staircase at the door and every time we have to struggle, and ask for help, and maybe it's a bad thing, but I'm a proud person [...] and even like, even inside the house, it's just, the tables are high and the kettles are high, so sometimes I can't even make my own cup of tea [...] not everything is gonna be ok, like gonna be perfect the way it's supposed to be. So I just need to cope"* (PI06, Western Cape).

Apart from the information given about the non-accessibility of (government) houses, the interview partner speaks about her own pride, the "struggling"—an experience she shares with other persons with disabilities—and (necessary) coping mechanisms. For the moment, the perspective towards environmental barriers is worth noting. The personal aspects of struggling and coping will be discussed below. Whereas the medical model of disability would specify that a person cannot use a house due to his/her bodily characteristics, the interview partner calls the houses "weird" and in this way seems to shift the focus from the individual person to the constructional design. In addition, the outdoor area poses problems for a wheelchair user like Ms. G: *"Sometimes it rains, and then here outside it's sandy so my wheelchair sinks in and most of the time I need help"* (ibid.). The space around the house is not constructed in a way that would allow her to move around with her (electric) wheelchair easily. However, the fact that the insulation of the house does not seem to be adequate is something that does not just relate to the wheelchair-using interview partner but affects the whole family: *"I would like to say the house sometimes, when it's winter, it's ice-cold, and when it's hot, it's hot"*

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[241] Concretely, he says that "*we are still waiting for what is going to happen here. Because they were talking about renovating this house even*" (PI02, Eastern Cape).

(ibid.). As can be seen, the rest of the family would also benefit from proper accommodation.

7.3.3 Between Resources and Capabilities: The Role of Families and Relationships

A mother of a young boy, Ms. D, focuses on her son when describing the family life and daily activities in the household. In addition, her choice of words and the incidents that she describes underline the division between the family and the external world, the inside and the outside, symbolized or represented by the house in which the family lives: *"He play everywhere here in my house"* as well as *"everyone here inside my house is happy for helping *name* you see"* (PI03, Eastern Cape). By using the words play and happy, a positive connotation or atmosphere within the family context/household can be assumed. However, the mother also states that *"[s]ometimes he make us a big trouble"* and that *"sometimes I have a big different problems here in my house"* (ibid.). Both of the statements in which she describes a break in the harmony in the household are introduced by the word "sometimes," which is taken up again when she speaks about her teenage child who is *"[s]ometimes listening, sometimes don't listen"* (ibid.) later on. In most instances, the atmosphere in the household seems to be characterized by harmony. And the interview partner adds that *"I don't use other people"* (ibid.) to solve problems, but rather discusses the issues with the other family members, after allowing herself time in which to calm down. In addition, the relationship between her children is described in a positive manner when she explains that the children stand up for their siblings: *"Because sometimes when I speak loud for this one, the big one, the small say: 'Please Mama, don't speak so loud'"* (ibid.).

Even in the case of adult interview partners and interview partners with adult sons or daughters with disabilities, it is the parents in particular who provide support and guidance. But it is also necessary to have support structures in the form of *"good school[s], what could be done. And how they could teach the children (?) how much they could learn things. And be a, you know, sort of a godsend to the parents who really, they couldn't work because they had to stay at home to look after these children"* (DPO_III, EX09, Western Cape). Especially in cases of persons with cognitive impairments, but also in instances where persons with physical impairments have high care needs, the role of the parents and the relationship between parents and their (grown-up) children is described as complex and multidimensional. For instance, DPO_III has a very close relationship with her son and even calls him her *"best friend"* (ibid.). They share several hobbies, and the interview partner states that, after him being a child who *"was a worry"* (ibid.), they have matured together. Finally, *"with patience and long suffering, we eventually became grown-up"* (ibid.). The process of distancing oneself from the parental home (or, the other way round, letting the children go) is not very advanced in this case, even though the mother says that she is *"not gonna hang on to *name*, if he wants to go and stay at the [group] home. But he's very happy in *area*"* (ibid.). This might have to do with the mother's age and loneliness (due to being widowed), the fact that she *"like[s] to be needed"* (ibid.) by others and thus wants to care for her son, or the uncertainty of whether—or fear that—he might be harmed by others (e.g., in public transport vehicles), which *"is why I think one can't help being a little bit protective"* (ibid.).

From several interviews with parents (in both interview forms), it became obvious that there are not only social circumstances that limit a person's potential to convert goods into capabilities but also that concrete decisions taken by the parents are not always supportive of a person's capability set and freedom: In the case of DPO_III, for example, the parents *"never bought him a bicycle to this day, he's never had a bicycle. Because he would have been gone and out, you know, heaven knows where"* (ibid.). This could have an influence on his mobility and capability of using a bike as a means of transport, for sports, and/or as a recreational activity.

Ms. F and her brother (both above the age of 40), who also works in the sheltered workshop, still live at home. Alternating with her boyfriend's parents, their parents provide transport to the workshop in which their daughter and son work once a week. Ms. F explains that her boyfriend's and her own *"parents arranged it"* (PI05, Eastern Cape), thus providing an insight into her perceptions of agency and independence. The fact that, in a different part of the interview, she calls the men and women who are working in the sheltered workshop in which she is employed "boys" and "girls" might also reveal something about her positioning in- and outside the family and her understanding of her and her brother's situation (as persons with disabilities). Even though she is over 40 years old, she does not refer to herself and her colleagues as "women," and being transported to and from work by her parents does not seem to be questioned by her at all. In addition, she states that they are *"not like in a normal [work] place"* (ibid.) as workshop workers.

The meaning and concrete arrangement of family support can take different forms: Among other things, financial help is given, e.g., to an interview partner, Mr. Q, who lives in an institution where the rent is too high to be covered by the DG. Thus, his strategy is *"to supplement my income and in order to do that, I have had friends and family that pay the difference. [...] But it was hard for me to do that, take money from people it's not really, if I had a choice I wouldn't"* (PI12, Western Cape). Apart from the fact that the DG is not sufficient for the interview partner and so he has to rely on his support structures, the way he expresses this is worth noting. It is interesting that he admits to having no alternative but to take money from others—however, the choice of words suggests that he still does not feel powerless or helpless. He is the agent in his situation: He has to (actively) supplement his income (see also subchapter 7.4).

Mr. Q is a middle-aged man who previously worked in the entertainment industry and then decided to take on a job in a different sector as he intended to marry and wanted to have a more secure income for his planned marriage and family life. At the time of the interview, his situation is very different. Deviating from his prior life plan, he is not married today and does not have a job any more:

> *"I was planning on getting married, and so I thought I'd get a job, 'cause the man is supposed to bring the money in, it's a very sort of chauvinistic, not meant to be chauvinistic, but it's just I think it's quite, it (?) the man is supposed to be the (?) the central pillar in, in, in the family, and be the one that is there for his wife and his children"* (ibid.).

Of the three male interview partners I spoke to in the personal interviews (apart from the group interview, in which one interview partner was also a young man), two made a similar argument—irrespective of other characteristics like race/ethnicity or socioeconomic background. The employment that Mr. Q previously had was in the formal sector. It also allowed him to pay for his rehabilitation on a private basis, for which he was criticized by his therapists: *"They all said: '*Name*, don't waste all your money. Please save at least some of it for an electric chair.' And I fought against that the whole time"* (ibid.).

Mr. P, in contrast, is married and gets support from his wife as

> *"my wife, she is looking, I won't say she's looking after me but she IS looking after me part and partial [sic], and I'm looking after myself as well because I'm capable of doing the things that I don't say other disabled people cannot do but I'm doing things that I can do. But I put my mind to, if I wanna make me a coffee, I do"* (PI11, Western Cape).

He has an accessible house, is mobile with his wheelchair, moves around in the community,[242] and can fulfill many tasks on his own: *"I make myself food, I do it myself. I wash myself, get in my wheelchair myself"* (ibid.). He can thus be called independent to a large degree but, if needed, has the backup of his wife.

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[242] The interview took place at a public place (café) in the center of Cape Town, and he traveled by public transport from "his" township.

7.3.4 The Situation of Mothers

When asked about a usual day in the family, Mr. B immediately uses the opportunity to speak about his partner's unemployment and says that *"it's not that she doesn't, she doesn't want to go around to look for a job. She does want, you see. But if she walks long with this, with this leg of hers, she sometimes comes (and is?) complaining about pains and so forth, you see"* (PI02, Eastern Cape). The mother's unemployment and the unpaid care work done by her are recurring themes in the interview. The support that would be necessary for the child and the family as a whole does not seem to be existent, and with the difficulties that the parents face in their relationship, the environment their two children live in is not a very stable one. Even though both parents could have lived with their families (*"I could have stayed with my family and she could have stayed with her family"* (ibid.)), Ms. C bought the house so that their children *"can have a proper environment to grow in,"* as explained by Mr. B. He reports that their aim is to have *"[a] healthy and safety accommodation for the child, for both of us to grow these children in the future. In a, in a good future"* (ibid.). Safe and functioning accommodation, which does not threaten the family's health, can be noted as one of the elements of a "good future" and thus a good life in the eyes of the interview partner.

Even though a qualitative interview analysis does not include the frequency of specific words, it is important to note that the mothers in the other interviews hardly speak about or mention the fathers of their children. Ms. D refers to her husband only once in her answers and states that *"their father try to help. But the man is always the man. It's not the same as I"* (PI03, Eastern Cape). In addition, she speaks later on about *"my child"* (ibid.) and explains how she realized that he had an impairment and the steps she took (e.g., regarding the application for a CDG) as a consequence. The doctor told her to wait until the child was five years old before applying for a grant as he was of the opinion that the child *"is all right"* (ibid.) and his *"brain is going to be all right in that time"* (ibid.). A current medical issue, about which she has not yet contacted a doctor, is a rotten tooth. Due to the child's epilepsy and the fact that "[m]y other cousin was going to take a tooth out and then was dead" (ibid.), she is afraid of having it removed. The help that she expresses a need for, not only regarding this medical aspect but also, for example, when asked about the time when her son cannot go to the daycare center any longer, has to come from outside of the family. However, she has not found anyone yet who could help her teach her child to become more independent and to be able to speak, walk, go to the toilet, etc. She also needs a wheelchair for her child to be more mobile, as the child is *"very heavy,"* her *"back is going to be so sore,"* and her legs also suffer: *"my legs I feel so tired"* (ibid.). Ms. D has to wait for her daughter to come home in order to be able to leave the house without (worrying about) her child. In contrast to her husband, Ms. D's elder daughter can deal with her brother in a way that reassures the mother enough to leave her child with her. Both a lack of professional support and the inaccessibility of services become obvious, as does the capability limitations these entail.[243] This is interesting against the background that the family receives medical aid and is in that respect more privileged than most of the other interview partners. It can be seen very clearly that income and access to higher quality services in the field of healthcare do not automatically mean that the family is confronted with fewer challenges in other areas.

The role of siblings and close family members in supporting the parents (especially mothers) should not be underestimated. The family plays a significant role here, and parents like Ms. A explain that they taught their other children to care and be responsible for their siblings with disabilities. It can be concluded from this that the parents assume that the other children will be in a position that at least allows them to take care of their sister. When asked about their children's future, Ms. A confirms that she has not yet thought about it as her children are still young. However, she states: *"I know one thing which we try to do in this house to make others understand *child*, you know. To make others know their responsibility. If we are not here, *child* is their responsibility"* (PI01, Eastern Cape). This family does not have any confidence in state mechanisms or external support structures and cannot rely on the extended family. Thus, they have to focus on internal family cohesion and ties, and the sense of responsibility of the other children. This leads to the parents being worried *"if something maybe can happen in this age, in this stage, like when they are all [...] still young, all of them, what would happen"* (ibid.).

In the concrete case of Ms. D, the explanation regarding her child's future is characterized by a high emotionality, expressed through the fact that she starts crying when responding *("look me now"* (PI03, Eastern Cape)). The relationship between the mother and her child is a very close one, and she explains that she does not want him to live far away from her, e.g., in an institution. However, she has to fulfill a lot of tasks in order for him *"to be happy"* (ibid.) and summarizes having a child with disabilities as being *"a big challenge"* (ibid.). In her case, this is due to the fact that *"you're supposed to smile all the time. [...] So I'm feeding, I'm smiling, I'm joking, I'm do all the things"* (ibid.). But she has the *"wish that I wish I will get that help"* (ibid.). Concrete suggestions include the option of

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[243] Similar to further interviews, the mother asks the interviewer for help. In this case, it is crucial to be able to refer the interview partners to other people who might be able to help, which was done here by clarifying the interviewer's role and, at the same time, referring to the manager of the daycare center and her role in supporting the family.

teaching the child sign language so that he can communicate with her (and others) more easily.

A short example given by Ms. O, in which she explains the situation when her son was younger, could be categorized as tragic and funny at the same time:

> *"[T]hen the husband will sit with him and then I will sit, and sometimes I would say to my husband, I'm going to the toilet quickly, then I sit in the toilet but I sleep in the toilet, I'm not going to the toilet, I'm just needing to escape and the only place that I could escape to was just to go to the toilet, and just close the door and then I would sleep. Then my [laughs] then my husband would come and say (?) because he's also tired"* (PI10, Western Cape).

But it also happened that a mother did not see any other option apart from smacking her child in the face due to being overwhelmed by the circumstances. Emotional situations seem to be very common, and they come to light (again) in the group interview as in the case of Ms. M:

> *"You don't mind me shedding a tear […], but I actually said for ten years I'm not crying any more, but now it seems to be coming back again. And I'm *name*'s mommy, and I'm, I'm glad to have *name*. Because at birth, doctors also gave up hope for him, doctors always said to me, he will only live for three weeks […]. In actual fact, when I went in and then they asked me if want abortion or anything, and I said: 'No, I'm not, I'm not gonna have that, I want to bring my child.' And then when I gave birth to him and doctors, […] and the doctors said no they gonna cut his life now because there's no hope for him, there's no hope (laughs) and then eventually we started praying for him and then, as I was opened my eyes, I just saw his feet just hanging like that and I (?) and then from there I took it"* (ibid.).

When parents like Mr. B and Ms. C decide that *"the conditions [aren't] as conducive as"* (PI02, Eastern Cape) they consider adequate for their child, the decision to take care of the child at home or send her to a different school is taken. Another mother, Ms. A, explains that there is one school in the area that does not accept children who use disposable nappies, and in another school, *"it's like they just keep the child. Nothing else they are doing there and I don't like *child* to go there"* (PI01, Eastern Cape). The inadequacy of the service (in this case, education) that is provided leads to the mother's decision not to send her child to that school. However, this is only possible if alternatives (such as other schools) exist or if it is possible for the child to stay at home with the parents (which might be a less preferable option from an educational point of view). The fact that there are other schools that her child could attend allows the mother to have some time without her child, thus not only influencing the child's capability set but also broadening her scope of action.

Most mothers seem to be in a conflict between their own needs, the family life in general, and concern for their children with special needs. Ms. D, for example, explains that it took time to accept her role as a mother of a child with disabilities, and her narration shows the differences and changes in her positioning over time: *"And the time I'm struggle with this children, there was no one for me. It's just me, and he, and the God"* (PI03, Eastern Cape; on this statement and the reference to "God," see also below regarding agency). Nowadays, her child is in a daycare center, and is still very young, but Ms. D reacts to her child's needs in a rather pragmatic and knowledgeable way: *"[H]e's hungry now. You see. I just feed. […] Want to play, I must bring all the toys"* (ibid.). In summary, her learning curve and interaction with the child is summarized by Ms. D in the following way: *"But it's nice if you understand the fact. Because now I know my child"* (ibid.). Having children with disabilities seems to require specific knowledge and understanding—due to specific needs that have to be addressed and also (or even more so) due to external reactions and disabling circumstances. The interviews brought to light the need for and lack of support. Ms. A, for example, explains that she *"used to go to that social worker I was talking about. But when *child* started there* [i.e., going to the daycare center; IB], *I stopped going to her. There is nobody else"* (PI01, Eastern Cape). Apart from that, there is no exchange with or support from neighbors or peers (i.e., other parents of children with disabilities). As her daughter and one of her other children are only a year apart, she would have needed help when they were younger as *"[i]t was hard, you know, to take care both of them at the same time"* (ibid.).

The neighbors[244] and other families with disabilities are not used as resource persons. Many parents report negative attitudes from neighbors and other people, expressed, for example, through a mother's impression that her child was like *"a cursed baby"* (Ms. A, PI01, Eastern Cape) for them. Using the word "baby," even though the child is already of school age, can be considered as a hint towards the (over-)protective behavior of the parents. The choice of the word "baby" could, in addition, also allude to the fact that the child is not taken as seriously by other people as the other children in the household. The sentence *"you don't want to take your baby in that situation"* (ibid.) and the fact that the parents always explain to their other children that the child *"is the first priority of everyone in this house"* (ibid.), also meaning that all the others are responsible for her when they are older, can be considered as a confirmation of this protectiveness. A similar point is made by a father, Mr. B, who explains in one passage of the interview that *"our first priority first is the child"* (PI02, Eastern Cape). In addition, Ms. A explains that

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[244] The neighbor's home is seen as unsafe by Ms. D. On the one hand, the interview partner does not want her child to break anything. On the other hand, "*a lot of people come there in that house*" and "*[t]hey were using alcohol and all that*" (PI03, Eastern Cape).

they used to treat their child differently than the others due to the fact that they did not know *“how to take care [of] a disabled child”* (PI01, Eastern Cape). An occupational therapist then told the parents to change their behavior and treat the child *“like she is normal”* (ibid.). There are certain things that the young girl cannot do, for example walking or talking. Although these aspects are presented as facts by the mother without adding any personal comment, the negative reactions and even harmful actions of others are emotionally connected and accompanied by concrete expressions like *“It’s sad. And painful.”* (ibid.), which emphasizes these aspects.

Ms. A uses a strong metaphor when explaining how her daughter was treated in the first daycare center she attended: *“When you see other children make your child like, it’s like a dog, you know. It doesn’t feel right”* (ibid.). By including the metaphor of an animal, especially one that is usually domesticated and obeys the commands of its owners, she explains how the other children exercised control over her daughter—presumably in a rather inhuman way. She also reports negative experiences with close relatives and how nobody offers to take care of the child for certain periods of time to *“relieve”* (ibid.) the parents. The meaning of relief cannot be clearly deconstructed here as it could either refer to the child herself showing challenging behavior, meaning that the parents need some time off (which could then be associated with the medical understanding of disability), or, in accordance with the experiences shared by the mother, it might well refer to the amount of external pressure and negative reactions that the family has to deal with (social model approach). These kinds of experience also took place with other children at the child’s previous daycare center, who are referred to as *“normal children”* (ibid.) by Ms. A and who did not play with her daughter *“in a right way”* (ibid.). The protection and self-exclusion that follows from that, e.g., by taking children out of a daycare center or school, is one way of individually reacting to social stigmatization and practices of exclusion. The close family bond as opposed to the dissociation from external structures is worth highlighting.

7.4 Dimensions of Agency

The focus of this subchapter is on

- the “freedom to act” of the interview partners, which can be identified by focusing on the way they position themselves and present how situations or actions came into being;
- eight dimensions of agency derived from the interviews; and
- case studies which serve as examples thereof.

7.4.1 Divine Protection

When asked about her daily routine, Ms. A states that the family members *"just stay here"* (PI01, Eastern Cape), referring to their house. The house is a refuge for the family, where they are protected from the outside world, e.g., from discrimination by neighbors. On Sundays, the family goes to church, and the mother goes to the prayer meeting on Saturdays. The children's father (her husband) has a job during the week and stays at home on Sundays to cook; on Saturdays he *"[s]ometimes [...] go out to some other guys"* (ibid.). During the course of the week, the mother usually stays at home, takes care of the household, and reads the bible. The activity of sitting at home is expressed several times throughout the interview. The use of the word "sitting" suggests a form of stability, a comfort zone in which the family (and especially the mother and her child) do not have anything to fear. As argued above, it can serve as a symbol showing that protection against discrimination and external influences is only possible in their own home or with the (extended) family—and at church.

However, SWO_I reports incidents in which *"you will find locked-up people in, in shacks that are like disformed and that are basically that spend all their life in that house because they can't get out, and there is no way to end this. I doubt that ever a doctor has seen them kind of, you know"* (EX02, Eastern Cape). This stands in great contrast to the protective environment described by my interview partners and the defending statement by one expert that people do not want to treat their family members badly but have to lock them up at home as they need to go to work and do not see an alternative (see above).

Even though there are many DPOs that could be a point of reference, outside the family and also outside the house, the only other place many families (can) go to is the church. Ms. G, for example, says that she does not know about any organizations that could support her: The family *"never get[s] information on, on organizations for people with disabilities. Never, never, never"* (PI06, Western Cape). But she is involved in a support group, knows about and uses Dial-a-Ride, and receives the DG. The question that is not answered here is whether or not she really needs external support (and in what form) and if she would be able to seek out information should she wish to do so. Apart from the immediate comfort zone of the house and the support provided by the close family, "**divine protection**" emerged as a central theme from several interviews. It becomes obvious that some of my interview partners feel that protection and support is (only) provided by "God" and church structures. This is quasi-confirmed by Ms. A when she concludes her last statement by saying: *"But God knows what he's doing"* (PI01, Eastern

Cape).[245] A similar view is taken by Ms. K, who would like to live on her own to *"make a better life for myself"* (PI09, Western Cape). She needs to wait to get a house and, in order to be able to live independently, her children would have to find an employment. Thus, she says that *"God will help me that my two boys will get the work, I will survive. Because I pray every night, I pray and ask God to help me. And he will. May, it will not be now, but he will help me, he will"* (ibid.). And Mr. B even gave his daughter a name that expresses his belief in God: *"Maybe should we have maybe a good accommodation, a good accommodation, then maybe things will improve. But through *religious name* as my second child was called, I know that these things will happen one day"* (PI02, Eastern Cape). This could be seen as an excuse, but it could also be a proof of absolute frustration and the lack of alternatives, leading to the fact that no active action is undertaken. When explaining his daughter's impairment, for example, Mr. B refers to his patience:

> *"It is God who gave us this child. As a result I named this child before she was born that she is *name*, in other words accept what God gives, you know. Then, the other one I gave was *name*. That we have to think that God (does?) have to have patience. So that are the two names that I put there. You see that. It is God's reason so we have to be patient. Maybe there are some things that are going to come"* (ibid.).

7.4.2 Avoidance Strategies

When I asked Ms. K to describe her living situation to me, she replied: *"My living is not so good"* (PI09, Western Cape). Currently, she lives in one household together with her mother, one of her two sons, and two of her three brothers. The sons and the brothers do not seem to get along well, and she uses various expressions to elaborate on the situation in the household. These range from *"the things in the house is not right. Everything is complicated in the house" to "[t]hey are also arguing [...], they are struggling, [...] then they are shouting at me and [...] I don't know what is happening there"* (ibid.). The men argue about food in the household and seem to drink a lot of alcohol, and Ms. K describes this as *"stress and fight"* (ibid.), indicating the presumable brutality and severity of the conflicts that take place. Her coping strategy is to go to her room and sleep after coming back from the sheltered workshop in the afternoon. It seems that, for her, the workshop is a shelter in the true sense of the word:

> *"I'm coping with it, because I'm taking my tablets, and that's why I'm fine, but here by my work, I'm fine. But at home I'm not. Because they are stressing and all that. So,*

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[245] This corresponds to the argument presented by Rimmerman (2014: 24 f.) that "God" has chosen some people who then have to deal with their impairments/disabilities.

> *here I'm fine, but not at my (house?). […] But it's better to sit here (as with?) by my home, my house. Because there we (can?) stress and fight and that's why I'm gonna sit here by my work and I'm fine"* (ibid.).

Even if there is not much work to do at the workshop, Ms. K prefers to spend her time there. As seen in other parts of the interview, e.g., the fact that she does not know (or does not want to remember) certain circumstances and incidents, she seems to be avoiding conflicts and challenges. A central theme that might be derived from the interview can thus be called "**avoidance strategies**." What can be used to support the identified theme are the following aspects: Ms. K does not know how long she has been receiving the DG, and she also does not know when exactly she started working in the sheltered workshop. With respect to her sons' working interests,[246] her brother's impairment, on the basis of which he also receives the grant, and her application for her own house, she replies with exactly the same sentence: *"I don't know, I didn't ask"* (ibid.). Also regarding other issues, she often answers that she does not know.

The same theme can be found in another interview: As opposed to many interview partners, who expressed a strong desire to be socially included and treated equally by others, e.g., as far as education is concerned, Ms. G explicitly states that *"for most people I think it would help if disabled people studied on their own"* (PI06, Western Cape). For her, *"what would be best for us, is (if?) we got taught at a different, ok, residences, we can live together, but in, in the classroom. Because then it would make things easier, so"* (ibid.). The example she uses to substantiate her argument concretely refers to two deaf students, who were at her school: *"[T]hey said they're battling to keep up. Because ok there's one […] who can lip-read. But the teacher's moving up and down, and he's not always facing her, so she, heaven knows how she gets all her information"* (ibid.). Although the interview partner confirms that the school was accessible for her as a wheelchair user, it did not cater for students with other impairments—so the interview partner's claim in favor of separate schooling has to be contextualized against the background of inadequate provisions ("reasonable accommodation") at that and other schools. As long as accessibility in various forms is not guaranteed, joint and inclusive schooling is challenging.

On a more personal level, this interview partner reports neglect by her fellow classmates, for instance when she was left behind when breaks were over and all the other students quickly went back to the classroom. At school,

> *"I was the only one in my class of a hundred people in a wheelchair. […] A nightmare. […] I prefer studying from home, because it's a nightmare being there. Because*

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[246] The question (or strictly speaking two questions) was (or were): "What kind of work could that be; what would they like to do?"

> *they're not always, they're not always helpful. And they don't always watch what they're saying. And, and some of them just don't care"* (ibid.).

As a consequence, she *"kept [...] distance from everyone else"* (ibid.) and tried to be in the classrooms on time—even if it meant being there an hour too early. This is interesting as her boarding school was *"a multi-disciplinary school"* with *"different kind of disabilities"* (ibid.), so one might expect respectful treatment and mutual support. Nonetheless, her equal participation and consideration from others was not guaranteed. The influence of these experiences becomes obvious as far as her current living situation (her beings and doings) are concerned.

A phenomenon that requires reflection and further analysis is the tendency to prefer being around peers with disabilities—or not having friends at all (as Ms. G explains in another part of the interview):

> *"I don't have friends here. [...] I'm not a friends kind of person, because I like keeping to myself. Because sometimes you would find that, you know, having friends, people they are used to going where they want to go. And sometimes I won't be able to go with. At the end of the day, I don't want them to kind of feel forced to be my friend. So I prefer not having friends as such"* (ibid.).

As transport is *"a nightmare"* (ibid.), this influences her mobility, and she does not meet the few friends she has very often. When Ms. G has needed to use public transport, she has experienced events such as taxi drivers showing inappropriate behavior towards herself and her mother. On one bus journey, they got off the bus before reaching their actual destination, partly because, in the bus, the other *"people were not also understanding"* (ibid.). She immediately weakens this negative experience by assuming that *"maybe it had nothing to do with us"* (ibid.), which fits to further passages in the interview: At home, her siblings *"basically irritate [her]"* and they *"just don't get along"* (ibid.) due to being brothers and sisters. Contradictorily, however, she *"help[s] them out with homework"* (ibid.) together with her mother in the afternoons and then states that *"we're ok with each other, in our own kind of way"* (ibid.). Her reaction is to talk as little as possible with them, which is one way of dealing with conflicts in order to avoid negative reactions and problematic situations. The duality between "her" and "them," and the distance between the brothers and sisters, becomes even more obvious when she refers to her siblings as *"the kids [...] coming back from school"* (ibid.) in one part of the interview. She tries to avoid conflicts, even though this entails the loss of interaction and restricts positive experiences such as having friendships. So apart from infrastructural barriers and the lack of resources, which prevent her from moving around freely, social barriers and other people's behavior, to which she reacts in her specific way, i.e., coping by avoiding, have an influence on her agency and ultimately the options that are available to her.

7.4.3 Reliance on Others and Outsourcing of Responsibility

The hobbies of the parents, especially the father, play a role in the organization of one of my interview partner's leisure time activities. Before speaking about her own hobbies, Ms. F explains that *"my father loves the beach. [...] but not, he's not very fond of braaing"* (PI05, Eastern Cape).[247] The parents and extended family structure are part of the safety net for the interview partner and her brother, together with further structures and networks: The sheltered workshop provides a work environment which is accepted unquestioningly by Ms. F. For the eventuality that something were to happen to the parents, the interview partner has saved some money (stemming from the DG and the payments she receives in the sheltered workshop) in the bank. In addition, the mother is *"trying to find a place"* (ibid.) for her son and daughter to stay because the aunt and uncle are *"also not as young anymore"* (ibid.). Ms. F explains that any medical issues are covered through the mother's medical aid. It can be concluded that Ms. F and her brother do not live independently but instead are highly dependent on their parents in a variety of fields: among them accommodation, health, and transport. A theme that can be identified in this interview is thus "**reliance on others**." If anything should happen to this part of the safety net, further elements are available and are established as alternatives, not just as far as the money-related elements are concerned (such as being on a waiting list for a sheltered home).

My interview partner used to do a lot of sports, she participates in a choir and further activities at church, has a solid friends structure and *"keep[s] herself busy"* (ibid.). It is thus not astonishing that when asked about future life plans and things that she cannot do or experience at the moment, the only (yet important) element is an independent life with her boyfriend: *"We may can get married and we can have our own house and our own life"* (ibid.). But living apart from the parents or family is not necessarily the ultimate goal of other interview partners. When asked about her future life, Ms. G, for example, places independence in the sense of mobility and income on a higher level of priority than being independent from the family: *"Yes, I want to be working by then with my own car, I wouldn't mind still living here at home"* (PI06, Western Cape). The interview partner states this notwithstanding the conflicts that she has with her siblings, the problems that exist with the accessibility of the house, and further issues that could—at least from an outsider's perspective—potentially have an influence on her thoughts about leaving the family home.

A related dimension to "reliance on others" could be identified in the interview with Mr. B and Ms. C. When asked about a usual day in the family, Mr. B says that the child is *"our first priority first"* (PI02, Eastern Cape; see also above).

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[247] South African expression for having a barbeque.

But, throughout the whole interview, the speaker changes his narrative perspective and positioning, which is very interesting to observe. Whereas at one point in the interview, he *"want[s] to be honest"* (ibid.) and reports *"trying to run away"* (ibid.) from a conflict, which results in him running the mother over, he makes both parents *("we were quarreling,"* etc.) responsible for that incident. In addition, Mr. B hardly ever lets his partner speak, describing the family life and her individual situation on her behalf. On the one hand, he presents himself as an active member, and even the head, of the household—but, at the same time, his usual approach is to wait and see what happens instead of taking the initiative and initiating changes, as already shown above. In parallel, he makes a variety of other actors responsible for what occurs and has already occurred to him and the family: his child's school, the hospital, which keeps losing the child's files, the owner of the petrol station who did not care about his partner when she had an accident caused by a customer, the fraudulent person who sold them the house, his own parents and relatives, and others. From his point of view, a variety of people can be blamed for his own and his family's situation. A theme that is related to the topic of conversion factors (external circumstances), but also touches upon agency, can thus be identified in this interview transcript: the "**outsourcing of responsibility**" to other persons in his living environment.

7.4.4 Pragmatism and Adaptation

One of my interview partners, SWO_III, has already experienced many strokes of bad luck in her life. She describes them vividly, and the descriptions are characterized by a certain brutality that might be due to the severity of the incidents that occurred. This holds true for burning herself as a child (a *"walking flame"* or *"raw meat"* (EX03, Eastern Cape)), being operated on without giving consent (her legs hanging in the air are described as *"a meat that you must eat,"* and she says that she *"was on painkillers forever"* (ibid.)), and losing her youngest child when it was just a baby. In addition, she handles having to crawl to move around in her house, being dependent on her husband regarding her personal hygiene, and other aspects with a form of "**pragmatism**" that could not be found in other interviews. For example, when her legs hurt after the operation, she found a strategy to bypass the way in which she was supposed to keep lying in bed—until the doctors and nurses found out one morning. In addition, she is still waiting for an RDP house—but she would also be satisfied with a lift being built into her current house. In order to achieve anything at all, she intends to avoid being strictly precise about her needs in the housing application process:

> *"But I'm not going to tell the counselor, I'm not gonna tell the people I can cope in that house. Because then they're going to give me that house. I must talk like the disabled people talk, like the (?) person in the wheelchair talks: I can't get out of my wheelchair to get on the toilet. I must now especially get someone to go and put me on the toilet. Although I know if I could have entered my toilet, I would have done it myself. But I can't now, because a wheelchair can't come in. Not (?) I need to have somebody with me to help me and then I have to pay that one also because it's my caregiver, mos. [...] Or whatever"* (ibid).

Here, being able to cope somehow does not seem to be sufficient for her, but she identifies a (pragmatic) way that might help her achieve her goals. In addition, it is interesting to observe that she compares herself to and at the same time distances herself from "disabled persons," even though she herself uses a wheelchair outside of the house.

Closely related to the theme of pragmatism is the topic of "**adaptation**," which can be exemplified by quoting the interview with Mr. Q. He explains that *"you just work your way through it"* (PI12, Western Cape) when difficulties arise: Circumstances are seen as challenges that he has to deal with—but he does not give up his independence and personal autonomy in these instances. When asked whether there are any things that he cannot do at the moment, Mr. Q concretely mentions that he *"miss[es] the (?) being experimental and learning to do things new and finding new tastes, and acquiring new tastes, and different countries' foods"* (ibid.). Cooking and enjoying good food and wine are free-time activities that he cannot do any more—but, during a variety of other free-time activities, he and the other residents *"have a lot of fun here"* (ibid.). In addition, Mr. Q's free-time activities are characterized by *"a very solid friend structure. I've got my, my Oktoberfest-buddies [laughs], I have, I have horses for courses, you know, if I need somebody to go with me to sports events, then I have friends for that"* (ibid.). Whereas in his context it is rather a matter of adapting to the given circumstances in one's personal life, the duality of independence vs. adaptation is also expressed in the expert interview with DPO_IV, in which she described the purpose of her daycare center as *"support[ing] the individual to be as independent and socially, as, as, as compatible as possible in the community out there"* (EX11, Western Cape), thus referring to adaptation in the sense of being compatible to social rules.

7.4.5 Cooperation and Mutual Support

Mr. J lives in a group home together with his wife and other people working in a sheltered workshop. He is assistant supervisor at the workshop and also takes responsibility for the household*: "every Saturday, I wash the dogs, clean the garden, sweep around the house and [...] the cooking in the house I do for my, for all* *of us, I do the cooking"* (PI08, Western Cape). His responsibility, however, is linked to a form of "**cooperation and mutual support**" that he also expresses with reference to the workshop: *"But now I'm alone, in the morning, and there is always someone helping me"* (ibid.). After the enumeration of the household activities quoted above, he does not speak of himself only but says that *"when we're finished, we just relax and listen to the radio, I mean the tapes"* (ibid.). He is married, but the word "we" might refer to all the other members of the group home. From the interview, it can be concluded that Mr. J is satisfied with this living situation. Perhaps the housemates can be regarded as a substitute for his family. His work, his living situation in the house, and his free-time activities are three aspects that Mr. J evaluates positively about his life. He confirms this positive view on the workshop a couple of times, saying *"I like working here," "we all like it here,"* and *"I like it here"* (ibid.). And the workshop workers get along *"very good. Ok, here's now and then an argument, but then *name of social worker* sort it out, and everything is fine"* (ibid.). There also seems to be harmony in the household, as the inhabitants *"get on very good in the house"* (ibid.). With respect to his free-time activities, he says that *"I like my music"* and that he *"got a nice garden down there"* (ibid.). All in all, Mr. J seems to be happy with his lifestyle, and the workshop and group home seem to be satisfying alternatives for him. After his accident, he told the doctor that he *"just sit[s] and listen[s] to tapes and music"* (ibid.), and, before moving to the group home, he *"used to board by [his] sister in law"* and *"it wasn't going very nice at that place"* (ibid.). Exercising responsibility jointly with others and living independently to a certain extent (namely in a group home) are factors that seem to contribute to his quality of life.

Only some interviewees reported that external support structures, such as social workers or peer groups, have a great significance. This mainly holds true for the participants of the group interview in the Western Cape. The assistance they received is very distinct from the experiences of being left alone that the first interview partners in the Eastern Cape shared in the interviews. Whether this is due to geographical location (including provincial differences), the ethnic affiliation of the interview respondents, or other reasons cannot be concluded from the interviews. The mothers who participated in the group interview underlined the importance of exchange and the advantage of sharing similar experiences. Their common situation leads to them sharing both good and bad moments: *"the fact that we've got something in common, we as parents have got something in common, and (?) when we cry, and when we cry, we know why we're crying, you know. And when we laugh, we know why we're laughing"* (Ms. O, PI10, Western Cape). The mothers speak about concrete incidents, which could serve to emphasize this statement.

The women report that they are confronted with varying degrees of frustration and disappointment,[248] and all negative experiences are encountered with persistence and involvement, especially when the women are encouraged or supported by others. Interaction with "allies" is a very important strategy towards social change, sensitization, and striving for inclusion. In addition to this peer exchange, formal structures like schools or crèches play a role, as parents require help to teach their children everyday life skills. Their sons and daughters are already adults at the time of the interview and the interview partners have known each other for a long time. They compare their difficulties and challenging situation to warlike conflicts, and Ms. O even states that *"we're fighting the same battle"* (ibid). Many words, throughout the group discussion, stem from the thematic field of conflict, among others power (empowerment/powerful), strength/strong and fighting. The battle they find themselves in manifests itself in the opposition between family structures and cooperation and mutual (peer) support on the one hand, and professionals like doctors, who do not necessarily argue and act in the best interests of the mothers of children with disabilities, on the other:

> *"And the doctors gave up on this child, (but?) after that weekend, when I took him back to his doctor, his doctor was quite surprised, she said: 'Is this *name*? Are you sure?' […] This is the child that everyone gave up on, so […] he's big and strong now. And, and, and he's coping"* (Ms. L, PI10, Western Cape).

Peer support also played a role as far as the living situation in Mr. Q's group home is concerned. He is satisfied with the living circumstances, but argues that *"yes, we, we live well, but we, we have to pay for it. So. And, and there are guys here, that can't afford, so we find, we try and find ways and means to raise funds for them. Anyway, that's, that's about it"* (PI12, Western Cape). Living in sheltered housing has to be paid for, and the better the quality, the more expensive the rent or necessary contribution is. Of Mr. Q's fellow residents, not all can really afford their stay in the house. Their resources would not be sufficient to allow them to stay there, but, with complementary resources, e.g., through fund-raising, enough money can be obtained. With (some) limitations regarding the quality of service provision and comfort, less costly opportunities exist: Some residential facilities work on the basis that everybody has to contribute as much money as he or she can, but *"that doesn't necessarily mean that it helps with the infrastructure of the home"* (ibid.), as Mr. Q says. In other residential homes, all residents have to pay an equal contribution. But, in all cases, if people are not able to afford it, additional

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[248] For example, Ms. O speaks about her "*third child, and my, my other children (two prior?) before him was fine, there's nothing wrong, and then questioning myself why must I have this child? Why why why? You know, I don't want this child. […] And I was very upset, (when/then?) sometimes *name* would cry all night then cry and cry. And it's so frustrating because you're tired, and you want to sleep*" (PI10, Western Cape).

funds need to be sought. As in Mr. Q's case, other residents then *"try and find ways and means to raise funds for them"* (ibid.). It is interesting to note that, despite not having much money himself, Mr. Q takes it for granted that he should help his fellow residents in the facility—one of several examples of altruism and solidarity apparent in the interviews.

7.4.6 Freedom to Act: Self-determination

As referred to in a previous part of this chapter, Mr. Q used to work in the entertainment industry and is a rather outgoing and positive person who attaches importance to shaping (components of) his own life. In one instance, Mr. Q describes himself as *"the, the old flirter I suppose, I used to be, you know"* (PI12, Western Cape). In addition, he makes several jokes throughout the interview, e.g., when speaking about the costs of assistive devices such as wheelchairs: *"I mean you can buy a car, a second-hand car for, for less than that, you know. [...] It's insane. And that holds four people, hahaha. That only holds one and it hasn't even got an engine"* (ibid.). He lives in a residential facility, which is quite expensive. Apart from his DG, he receives money from his friends and family. Mr. Q is not working on the regular labor market, but he does peer counseling and writes short stories. As he explains, this is due to his age and the fact that there are jobs that he does not want to do. Thanks to his support structures, he is not confronted with a threat to his existence. Not working or not doing paid work does not mean that he has to accept a deterioration in the quality of his living circumstances. Thus, the situation can be called comfortable compared to other people in similar situations. What seems to make his life good (in his own view) and leads to him state that he is *"a happy quad"*[249] (ibid.) is the potential to fulfill his dreams and follow his interests.

Immediately, at the very beginning of the interview, Mr. Q explicitly refers to his freedom of choice and the opportunities he has to shape his own life and living environment in the residential facility in which he lives:

> *"It's not the house with the best quality, but it, it, it affords you a lot of freedom that you don't get in a lot of places. The *name* for example, next door, they all have to be in bed at nine o'clock. I only go to bed at eleven thirty. Things like that, you know. So, you can go out to anytime you want. We, it's treated as a, as a home, more than, so it's a home, not an institution. It feels like a home to me and I'm happy (?) I like my room, I mean. I put it up all of this myself. It was an empty bare room, everything you see here, I've done myself, so the little (?) and the basin and then the wooden bed in the corner that was it. It's the way I like it. It's me"* (ibid).

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[249] Abbreviation for "quadriplegic."

As he explains, some items are provided by the house, but he did all the interior design himself. He likes to go to bed late in the evenings and could potentially leave the house at any time. Doing these things is related to or results in the feeling that the residential facility is a home and *"not an institution"* (ibid.). Though other cases might exist, a private home is usually both a place of retreat and the area where a person can make decisions about his or her lifestyle without external interference. In most institutions, as also explained by Mr. Q, certain rules exist and residents have to adhere to specific structures that do not necessarily correspond to their individual way of living. Mr. Q uses going to bed, going out, and decorating/setting up the room as examples of self-determined living. Interestingly, two of these examples involve time, namely going out at *"anytime"* and going to bed at *"at eleven thirty"* (ibid.). Thus, it is not only the possibility of deciding to do certain things that is of importance; the concrete form or arrangement (in this case, the exact time) is also important.

What cannot be discerned from focusing on this isolated quote is the fact that Mr. Q is quadriplegic and—as opposed to his statement above—cannot go out anywhere he wants or at any time without assistance or further arrangements, such as booking the bus or being accompanied by someone else. At a later stage of the interview, Mr. Q reveals that (similar to other residents in the house) he is not able to do many things with his hands, as the staff members

> *"do all the manual tasks that we can't do with our hands on a daily basis. They dress us. I can't undo my own buttons. So they undress me, they put me to bed, they bathe me, they feed me. No, they don't feed me, I feed myself. But certain meals need to be"* (ibid.).

So his description of installing the equipment in the room and doing *"everything you see here"* (ibid.) himself does not mean that he actually physically placed the items in the room but should be understood in the sense that he independently decided on the items and their positioning in the room, as well as on the structure of his day. Even though maximal flexibility for all residents will not be possible at all times, e.g., due to limited personnel capacity, the interview partner can express needs and his wishes are realized to a large degree.[250] The possibility of "**self-determination**" in the given context is a theme that can be identified from the interview analysis. In many instances, Mr. Q presents himself as an active participant who is (at least partially) involved in making decisions that lead to certain

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[250] When the interview was supposed to take place, for example, Mr. Q was doing exercises and practicing standing with some staff members, which he referred to later in the interview: "*I'm sorry I'm dehydrating a bit, I need to drink some water while we're, we're busy, because of that standing and everything, it's quite, it's quite draining. I timed this meeting with you incorrectly but only because I forgot that we were gonna stand and I apologize for that"* (PI12, Western Cape).

situations and occurrences. One does not get the impression of a passive recipient of help and assistance (despite the fact that he has to take money from his family) but of somebody who has the opportunity to choose from a collection of various resources—according to his needs and wishes. In addition to doing things for himself, he invests his time and energy in generating money for other people: *"I do that every year, I raise funds, I try and raise funds every year doing that. Not for myself, but for a home for black orphaned children in, in *township*"* (ibid.). What can be seen here is a commitment that is not necessarily favorable to the agent, Mr. Q.

One aspect that does not seem to fit is Mr. Q's reply to the question about his life in a few years' time. Self-determining and strong-minded as regards his current beings and doings, he does not know how to reply to that specific question and is not very certain about his future:

> *"I may have stopped procrastinating. And I may have (...) see, I'm happy with my life style. What I'm not happy with, it just brings it back to the lifestyle, like finances and stuff like that. So I don't need a lot to change. What you would have found, what you'll find in five years' time is, is that, I actually don't know how to answer the question. 'Cause I may, I have this mindset of perhaps building a house and moving into it, but I don't know if I wanna do that. But if I've done that, I'm gonna need a form of income. And in order for me to have a form of income, I'm gonna have to, to (?) a job for myself. And I'm a terrible entrepreneur. [...] Let's just say then, certain goals and bucket list things that I hope, I would have achieved by then"* (ibid.).

There are a couple of alternative or rather overlapping scenarios. This passage could be read as meaning that Mr. Q's capability set is already very large and he will be able to live his life as he would like in the future. Seen differently, it could be concluded that the coping strategy of getting on with his current situation is so successful (as he says during the interview: *"you just work your way through it"* (ibid.)) that he barely misses anything and does not have very concrete aims and ambitions for the future. The interview partner has become so used to his situation that he evaluates it in a very positive manner, i.e., he adapts to the circumstances as Sen (1985a: 21 f.) has argued. On the other hand, however, he might have very concrete aims and ambitions (such as a house) that he is hesitant to express, as he seems to realize that their successful implementation is hardly possible for him. Here, he draws a direct link between the lack of capability inputs (job/income) and a limited capability set, in the sense that building a house for him is not an option at this point in time.

Mr. P's way of life in general is not very similar to Mr. Q's, but their approaches towards acting and governing their own lives seem to be comparable nonetheless. Mr. P's day is characterized by many activities, all of which are self-organized. For example,

> *"I go to the library, then I go to the day hospital, like I see the social workers, speak to them about other people (with?) disability, how we can help them, and what we can do to make the place a better place for disability people, people with disability, and to interact with able-bodied people as well. […] 'Cause the thing is this, if I can do it, any other disabled person can do it. […] If I don't go to the day hospital or anything, do that, then I just sit at home, watch DVD, go to my friends, play cards, eat, and watch DVD again. 'Cause I love DVD. I love movies"* (PI11, Western Cape).

Mr. P is not in formal employment at the moment, but he has some daily routines, tasks, and hobbies that he really likes. His expression of activities and "beings"/"doings" that he favors is clear, straightforward, and positive. This also holds true for the people who live in the same area *("And, you see, the people around me, (now?) I love them. I love all of them."* (ibid.)), his various sports activities (*"And love my sports."* (ibid.)), his engagement in a DPO (*"Now I got, I won't say my own branch there in *area*, but I'm sitting on the board and I like it. I really love it."* (ibid.)), and social interaction in any form (*"I'm doing it, because I love to do it, and I love to be around people. Not only with disability. But people with ability as well."* (ibid.)). In his case, helping himself and being completely independent is limited by the fact that he currently cannot find employment, even though he has tried several times. Similar to Mr. Q, who is in a very different situation as far as all other living circumstances are concerned (see above), Mr. P compensates for this fact with activities that he finds meaningful and that give him the feeling of being needed and being able to make a contribution by sharing his own experiences with people who are in hospital. In this regard, Mr. P also strongly supports the idea of empowerment and teaching people to do things for themselves, rather than being protective and doing everything for them.

8 Discussion of the Results

This thesis does not suggest that money is not an important factor when it comes to the topic of quality of life. In accordance with the theoretical and analytical approach, however, many more factors are important in the process of achieving inclusion, providing social protection, and ultimately allowing conclusions to be drawn about people's quality of life. It is important to focus on elements beyond monetary, measurable, and quantifiable aspects. The main results and arguments presented in this chapter are as follows:

- 8.1: In accordance with the literature, the framework of thought that was chosen for this thesis, the CA, is basically suitable for application in the fields of social protection and inclusion of persons with disabilities. As presented, it has to be enriched and specified in this thematic regard as well as with reference to the country and social context in which it is used (here: South Africa), but it can then be useful in investigating the impact of the DG.
- 8.2: The interview analysis revealed the importance of agency, which is connected to the personal evaluation of the interview partners' living situations. It was hardly possible to make any statements regarding the interview partners' capability sets, i.e., the opportunities and options that are potentially available to them. What could be identified, however, was a variety of agency dimensions that can be associated with the various barriers and external factors that influence the freedom that the interview partners have to decide on their own lifestyle and act according to these decisions.

8.1 Taking Well-Being and Quality of Life for Granted?

A social assistance measure like the DG (or CDG) on its own does not seem to lead to the multifaceted enhancement of the quality of life of individuals, with quality of life being understood much more broadly than mere survival and the overcoming of absolute poverty. This is in line with Amartya Sen's CA, as introduced and discussed in previous sections of the thesis. The main advantage of the CA as an open "framework of thought" is that it enables the conceptualization of quality of life not in absolute terms but according to the individual preferences of

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a person and by taking into account a variety of aspects beyond resources and income, such as a person's individual and social background. Being aware of the limits of the CA and the criticism that the approach is not dynamic enough (Leßmann/Rauschmayer 2013: 103) and does not focus on the topic of insecurity or risks that can occur in the lifecycle (Knecht 2010: 69), the fields of social protection and social inclusion are suitable for consideration in relation to the CA. A qualitative research design with biographic elements (as applied in this research project) can overcome this alleged shortfall, and it can capture changes and developments over the life course—with the restriction that it involves only those aspects that the interview partners implicitly or explicitly share in their narrations. The interviews revealed that an analysis of the quality of life of persons with disabilities and the topic of inclusive social protection touches upon a variety of policy fields and comprises many different aspects, as a broad thematic spectrum was covered in the interviews: housing, labor, health, transport, etc. In addition, many social realities are reflected in the debate on disability and inclusion (e.g., rural vs. urban settings or unemployment and related consequences).

The method thus proved to be suitable to approach the topic of social inclusion and identify a variety of barriers as well as missing support structures for persons with disabilities in South Africa. For example, these include the inaccessibility of transport and other facilities (such as schools and offices).[251] Many interview partners emphasized the challenges that the topic of transport entails, e.g., as far as access to a job on the regular labor market is concerned. The different living environments (townships vs. more prestigious neighborhoods) and their locations and connections to the transport system should also be taken into consideration in this regard. The topic of accessibility as it relates to transport is also very concretely relevant to access to healthcare and education. People who want to reach the nearest hospital or school might have to use public transport to get there; for a wheelchair user, the use of minibus taxis is very difficult, if not impossible. Where existent, other forms of public transport are not (yet) fully accessible either. An alternative offered in Cape Town is the Dial-a-Ride system. The service allows people who cannot use vehicles such as buses or trains to get from their home to their workplace.[252] One interview partner also explains that it is used for the transport of members to daycare centers.

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[251] This does, for example, also include aspects that have not received extensive attention in this thesis, such as access to clean water and sanitation.

[252] Interestingly (yet not surprisingly), the information page of the City of Cape Town (n.d.) concerning Dial-a-Ride mentions "people with disabilities who—due to the nature of their disability—are unable to board and/or alight from mainstream public transport," thus locating the difficulty in the individual instead of the inaccessibility of the transport system.

For the white interview partners, transport was mainly privately arranged and did not seem to be a decisive factor regarding the question of access to work. However, the lack of employment is due to more factors than simply an inaccessible transport system. Sufficient education and qualifications, as well as reasonable accommodation on the part of workplaces, were not available for many interview partners. Rather, participating in sheltered workshops (or, alternatively, being unemployed) was the reality. Here, funding problems and missing resources were identified as major obstacles, alongside unclear responsibilities. As early as school age, there are specific offers for persons with disabilities. These only enable or empower a person to seek work on the regular labor market in some cases. Thus, a career path is sketched out as soon as a person enters the workshop, or, even earlier, as soon as a person enters special schooling (in the case of those who have had their impairments since birth or childhood) or is in hospital/goes through rehabilitation due to an accident or otherwise acquired impairment.[253] A position on the open labor market might not be the right path for every person, but several strategies would have to be applied in order to provide inclusive and equal access to the regular labor market: These include, for example, diversity management endeavors and sensitization efforts on the employer side, together with capacity building for (potential) employees.

In addition, the interviews revealed that the current structures are very much dependent on highly motivated social workers who fulfill a variety of tasks regardless of being remunerated in an inadequate manner. In many instances, due to financial restrictions, not many personnel are involved in the day-to-day management of the workshop. The role of the social workers depends on the general staff structure (and relevant financial resources) in an organization or workshop. They are often confronted with limited resources and thus need to prioritize their work according to urgency (which is an especially difficult undertaking when it comes to several people living in similarly challenging circumstances). Despite the commitment of the social workers, a lack of expertise, e.g., in the ministries, was an important point raised in the interviews. The interviewed professionals furthermore criticize the lack of adequate services and state involvement, and not only in relation to persons with disabilities. In a quite general statement, SWO_I says that *"South Africa is not a welfare state, and we do not take responsibility for [...] any not only disabled persons, the elderly, the child, the whatever. It's a across the board welfare service"* (EX02, Eastern Cape). Implicitly, this sentence, for example, also confirms the fact that most offers for early childhood development in South Africa are privately organized and funded—thus many families have to take care of their children at home until they reach school age. Also, for most adult

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[253] Several experts explain that people become members of workshops on the basis of referrals from hospitals or schools. In addition, there are also self-referrals.

interview partners, family life and support played a major role in the arrangement of their lives, and families take over a variety of responsibilities to compensate for what is lacking.

As far as capability inputs from the state are concerned, the social protection measures that are provided by the South African system of social security offer room for discussion and criticism. For example, the exact function of the DG is judged differently by the interview partners. The question of the appropriateness of specific cash transfers for persons with disabilities, connected with the critical reflection on the close connection of the topics of social assistance and disability, is an aspect that should be discussed in general but also more concretely with respect to the DG. DEX_III, for example, takes a very critical position regarding the overall grant system and the approach towards social protection in South Africa. From his point of view, changes in the grant system as a whole are required. Reducing poverty levels and promoting social development could also help to reduce crime (statistics) and thus motivate foreign investment to *"promote more economic development and employment opportunities for South Africans"* (EX08, Western Cape).

The spectrum of expenses that need to be covered by the DG, and the number of people who (have to) benefit from one grant, is quite broad. As opposed to social protection measures in other countries, the grant is primarily meant for the individual. In practice, however, what often occurs is that persons with disabilities are the sole breadwinner in a family due to their grant and thus have a specific status among all family members. Contributing to the family income (or even being the only person who provides the income) can influence a person's self-esteem and ensure positive treatment from others. On the contrary, it can also lead to abuse and difficult situations, as explained above by DEX_I with the example of a woman who had to leave a hospital in order to collect her grant despite there being a high medical risk in doing so. In any case, most interview partners only use part of the grant for themselves and share the rest with their (extended) family. For some interview partners, however, the grant is not required to cover the costs of daily living for themselves or their family, such as food costs. It is, in those cases, rather a means of security or a supplement to existing resources in the household. In the absence of an alternative, most recipients are grateful for the grant, even though they criticize the concrete form that it takes.

The grant serves a variety of purposes for the interview partners, and it can be seen positively that this one measure can be applied in such a flexible manner. For some, it helps to cover (all) the expenses of daily living. For others, it allows extra costs such as nappies or specific food items to be covered. However, a criticism can be made that the amount of the grant cannot be adapted flexibly to the needs and requirements of its recipients. In addition, whatever the grant is used for, the system in which it is embedded as well as the way it is designed opens the door to fraud and elicits desperate attempts to access it. For example, interview partners speak of people who do not put their whole energy into rehabilitation after an accident or illness, do not seem to take their physiotherapy seriously, or do not take their medicine (e.g., antiretroviral medication in the case of an HIV infection) so that they will not recover and can thus continue receiving the grant. Also, some people pretend to have impairments while they are being assessed for the grant—but when they walk away from the hospital or office (and the people in charge of the assessment procedure see them leaving the building) there is no indicator of an impairment at all.

In addition, experts mentioned the fact that people borrow money because the grant is not sufficient, and highlighted the problematic situation that some persons with disabilities do not receive the grant, while others get it without fulfilling the assessment criteria. For some persons with disabilities, receiving a "special" grant is also an issue of criticism. Its existence can, however, also lead to people having negative views towards this group of persons, as persons with disabilities are seen as "better off" than the rest of the population due to their grant. A promising point of entry to react to this circumstance could be the twin-track approach described in the theoretical part of this thesis, which could be applied to combine two solutions: some form of social protection measure specifically for persons with disabilities, together with a "mainstream" approach towards social protection that benefits the whole population. Against the background of social exclusion and marginalization, a lack of basic provisions, as can be the case in South Africa, is especially serious for persons with disabilities.

Even though the system has undergone several changes, challenges remain on a variety of levels. Some are more system-related, including the requirements that have to be completed by applicants, the compliance with the disability definition, and the fact that many unemployed people who do not have any form of income try to access the DG (despite not fulfilling the criteria). It could be shown that the aspects of eligibility are not always easily applicable and that the application procedure can be a challenge. Even though the desire to belong to mainstream society is high, the reason for accepting the label of "being disabled" goes further than the solely monetary aspect of having some rand to spend; as (or rather if) access to the regular labor market is limited or inexistent, the grant can be considered a proxy and serves one of the purposes that paid labor is otherwise supposed to fulfill: independence. But barriers do exist regarding access to social protection, e.g., due to the requirement for ID documents. In addition, many interview partners argued that a person's living circumstances are not adequately taken into consideration in the context of the DG application process. Due to the existing criteria, for example, families with many household members but only one breadwinner do not receive the grant if that individual's income is above the threshold. In the specific case of South Africa, applications and their outcome are also dependent on those involved in the process, such as social workers and doctors. Aspects like these need to be taken into consideration when discussing the adequacy of social transfers (like the DG) for the improvement of the recipients' quality of life—and for those persons with disabilities (or families) who do not benefit from this social assistance scheme at all.[254]

The available social protection efforts need to be complemented with approaches aimed at achieving equal opportunities in the fields of education and labor. Several interview partners made the argument that persons with disabilities can make a valuable contribution—both socially and economically. In this regard, the costs and disadvantages of exclusion and the prerequisites for and benefits of inclusion need to be contrasted. Relatedly, DPO_II critically comments that *"having disability in a welfare focus places a lot of burden on a country. It places a lot of burden on the, on the country's fiscal thing. 'Cause if you have to look into national, what our government is paying out for Disability Grants, it's an astronomical amount of money"* (EX05, Western Cape). Later on, she highlights the importance of income-generating opportunities for persons with disabilities and states that in cases of poverty where the life of a person degenerates or does not improve, *"a grant is supposed to be a, a support mechanism. It's not supposed, you're not supposed to be the sole breadwinner, if you're the grant, you know what I'm saying? It should complement what exists in the house. It shouldn't be the sole income of a household"* (ibid.).[255] In addition, the human rights approach makes further efforts indispensable: Active citizenship, the exercise of self-determination to the highest possible extent and the respect for each individual's rights can be seen as fundamental for a just society. The topic of social justice is closely related to the question of equal participation and quality of life—especially if the latter is conceptualized in accordance with the CA. For Sen, as Graf (2011: 25) summarizes, each person's life has the same value, and every person is entitled to participate in development, irrespective of personal characteristics.

In order to expand agency and ultimately quality of life, the "unfreedoms" that people experience need to be removed. As could be seen in the analysis, these

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[254] As shown in the previous chapter (e.g., Ms. A's experience), reasons include review processes or the salary available to the applicant and/or his/her spouse.

[255] It is possible that the word "recipient" should have followed the words "if you're the grant," but this quote as it stands also equates a person with disabilities and his/her grant (similar to another example quoted previously), thus expressing a strong, unquestioned relation between the receipt of the money and disability.

can take various forms. A transition from the medical to the social model of disability, from sheltered workshops to inclusive and diversity-oriented employers, from organizations that only cater for one type of impairment to cross-disability organizations, and a social transition with advances in the level of implementation of existing legislation are all aspects that were mentioned in the interviews in this regard. In a variety of areas (e.g., labor, transport), external constraints need to be eliminated and accessibility needs to be established or extended. Against this background, the significance of conversion factors and people's personal background for the investigation of quality of life have been highlighted throughout this thesis—this is particularly important as far as the living situations of persons with disabilities are concerned. Variations were, for example, identifiable regarding the ethnic background of the respondents. The few white interview partners in particular seemed to have a larger reservoir of resources to draw on and were thus not (solely) dependent on the grant.

It could be that the DG does not adequately respond to the cultural diversity of South Africa or to factors like the role of the family, family cohesion, and household sizes. A clear difference becomes obvious between those who can use the grant for longer-term saving and those who need the money urgently. In the interviews, these were mainly black and coloured individuals and families. The research results thus underline that a "one size fits all" approach towards social assistance does not reflect reality, and the fact that the DG is only available as a lump sum should be reconsidered; the allegedly homogeneous group of persons with disabilities shares (only) three fundamental similarities: the disabling social and environmental factors that limit equal participation, the ascription of the disability status, and the limitations that (can) result from their own impairment experience[256] (Oliver 1996: 5, see subchapter 2.2 of this thesis). Apart from these similarities, the diverse living circumstances, socio-cultural backgrounds, and aims and ambitions that they have make the people interviewed a highly heterogeneous group.

8.2 Freedom to Act?

The CA has received criticism for being too individualistic, but the capability literature mentions "interpersonal variations" (Sen 1992: 27) with regard to the conversion of commodities into capabilities that are worth noting and should receive attention. Generally, conversion factors according to Sen's CA can be personal

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[256] This is not to say that the impairment should (again) be the center of attention but that, for many people, their impairment brings with it certain experiences (such as pain or restrictions to freedom of movement) that cannot be referred to external barriers.

(e.g., skills), social (e.g., social practices), or environmental (e.g., infrastructural aspects) (Robeyns 2005: 99). On the basis of the interview analysis, there are two major socio-cultural aspects that influence the interview partners' agency. These are disability experiences on the one hand and the interview partners' ethnic background on the other. The latter is particularly important considering South Africa's socio-cultural history. In many of the interviews, the respondents' personal disability experiences play a significant role regarding their professional as well as their personal life. Concerning the understanding of disability, it is not only the external reactions and views that are significant but also the impairments. This important aspect distinguishes disability from other diversity categories, as argued by Shakespeare (2013: 220). In this regard, positioning and self-narratives, two of the analytical heuristics Kruse (2011: 202; also 2014: 509 ff.) identified, are closely related. They provide information about the speaker's social position, how he or she wants to be seen by others, and how a person sees him- or herself. The positioning of the interview partners reveals information about their living circumstances and the factors that have enabling or disabling effects and can be counted as conversion factors. In addition, agency is a decisive element of the narrative construction of identity (Helfferich 2012: 16).[257]

In the interview analysis, it became obvious that the group of recipients is very heterogeneous and that "the typical DG recipient" does not exist. Interview partners, having varying disability experiences, are members of sheltered workshops, family members, South African citizens, male and female, mothers and fathers or daughters and sons, married or single, and people with different ethnic origins and language skills/mother tongues. In accordance with Sen's approach, a person can have various identities—including, e.g., being a man or a woman. This can become "important if women (or men) suffer from their female (or male) identity because their needs and interests are either neglected or not accurately *perceived* by other people" (Teschl/Derobert 2008: 126, italics in the original). The authors argue that two concepts of identification exist: the "social identity" (as a description of people resulting from group participation and identification) and a person's self-understanding. Whereas Sen "presents a view of a person who is capable of choosing and changing his[/her] group memberships and thus of differentiating [her- or] himself from the group" (ibid.: 127), Teschl and Derobert highlight that people's perspective and self-understanding might not correspond to the multiple identities they (really) have. Rather, they see themselves as coherent individuals from an "I"-perspective. On the basis of their arguments, Teschl and

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[257] Mutanga (2013) provides an interesting insight into the story of a South African student (Jane) and the way she understands disability. The title of his article, a quote from Jane ("I'm a university student, not a disabled student"), indicates how she deals with her impairment (epilepsy) and wants to be seen by others.

Derobert propose locating the aspect of “personal identity” within the capability space: “Any form of capability deprivation can then be seen not only as reducing a person’s well-being but also as impeding a continuous development of an individual’s personal identity” (ibid., see also p. 129).

The interview partners’ social situation and family background can fulfill several purposes, and it can be an enabling as well as disabling component of a person’s life. In accordance with Robeyns’ overview and the theoretical descriptions above, the social context shapes the way a person can convert goods and resources into functionings. In addition, the family can be a source of income and a provider of resources; thus one can assume that in some cases a strong influence on a person’s capability set can be traced back to the network of family and friends. Governmental support and service provision are not less important but are available to a lesser extent. A lack of state action regarding early childhood development and support for families with young children with disabilities became evident in the interviews with parents, especially those whose children are still very young.

The topic of disability and the living situation of children with disabilities were strongly related to family life and especially the mothers’ living situations (see also subchapter 7.3.4). It is decisive to note that the parents—mostly mothers—possess a strong repertoire of action that they use within their scope to pursue their goals. The fact that the mothers mainly speak about their own actions and not those of the fathers or other family members could stem from them being the interviewed persons. However, in most of the families, it was indeed the mother who took care of the child(ren) and had to deal with their concerns. In cases of children with disabilities, the mothers in particular experience practices of social stigmatization. As became evident from the interviews with parents, family life depends on the children with disabilities to a great extent and vice versa.

Many interview partners could only partially meet their own (and their families’) needs through the receipt of the grant. Some answers were thus characterized by even fear of the future, expressing a high degree of insecurity and lack of orientation. Of course, monetary aspects also play an important role, but, on an equal level, the necessity of support structures and governmental involvement beyond cash transfers became obvious. In line with a study published by the Centre for Social Development in South Africa (Graham et al. 2014: 7), the strong support networks that some persons with disabilities have in the household or family are clearly identifiable, although the data used by Graham et al. does not allow for conclusions regarding the quality and intensity of the support.[258] Most family support goes hand in hand with the absence of alternative support structures, and, in

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[258] Interestingly, the study also draws on the CA (in combination with the livelihoods model) as the theoretical and conceptual framework, thus supporting the arguments and choice made in this

cases where family support was not available, a negative influence on agency was also (or especially) noticeable—in the sense that people did not appear to be very strong and independent actors.

As became evident through the interview analysis, there are multiple forms of agency. Concretely, eight forms could be identified in the transcripts. They seem to be on a continuum from a rather high to a much lower level of independence and self-determined living. They were also related to the level of capability inputs and the interview partners' conversion factors. The eight aspects were

- self-determination: i.e., having the chance to actively shape one's life and make choices;
- cooperation and mutual support/collective agency—in the sense of becoming active agents on the basis of collaboration, working together/joining forces and/or receiving support from others;
- pragmatism: making decisions within the framework of opportunities;
- adaptation: adjusting one's behaviors and judgments so that a more positive evaluation of the situation becomes possible;
- outsourcing of responsibilities: making other people responsible for what happens;
- reliance on others: waiting for others to make the decisions/accepting that other people make the decisions;
- avoidance strategies: trying to avoid putting oneself in an uncomfortable situation, thus subordinating one's hopes and ambitions; and
- divine protection: believing that God or an anonymous agent will offer help at a certain point in time, to explain/compensate for a feeling of powerlessness.

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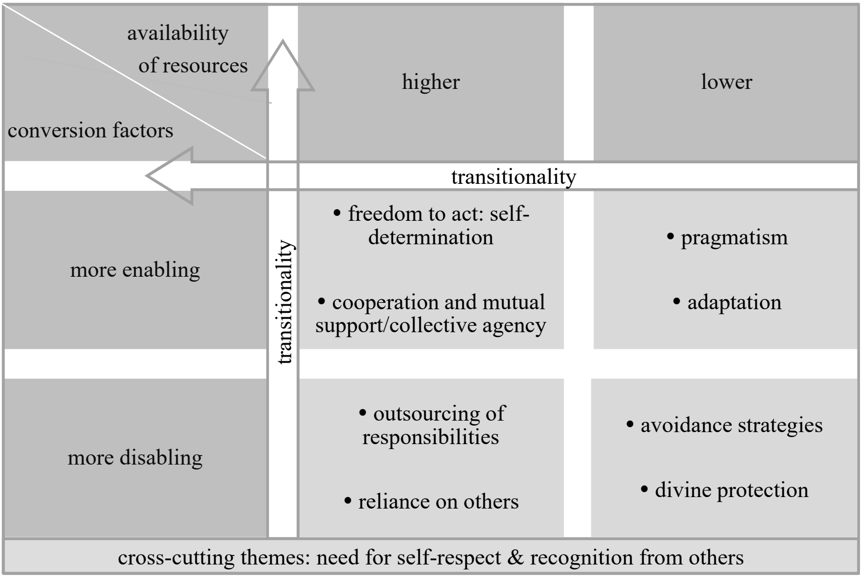
thesis. It is, however, used to contextualize the findings in a quality of life context rather than a well-conceived empirical application of the approach. The study also draws on aspects of emotional and subjective well-being.



availability of resources / conversion factors	higher	lower
more enabling	• freedom to act: self-determination • cooperation and mutual support/collective agency	• pragmatism • adaptation
more disabling	• outsourcing of responsibilities • reliance on others	• avoidance strategies • divine protection

cross-cutting themes: need for self-respect & recognition from others

Figure 28: Agency dimensions (on the basis of the interview analysis) (own overview)

The forms are not mutually exclusive in the sense that overlaps between the dimensions are possible, and several dimensions might be applicable for one interview partner. For example, regarding a specific aspect or living situation, an interview partner might express a lot of freedom to act, whereas concerning a different aspect, he or she relies on others.

In this regard, Crocker and Robeyns (2010: 85 f.) argue that

> "people exercis[ing] their own agency in deciding on and realizing their well-being freedoms (capabilities) […] are more likely to realize well-being achievements (functionings), such as a reduction of deprivation, than if they depend on luck or on the development programs that others provide. Moreover, when people make their own decisions, run their own lives, and make a mark on the world, this exercise of agency is often accompanied by a sense of satisfaction—a component of well-being achievement."

As became evident in the interviews, it does not necessarily seem to be decisive to be "able to perform activities for oneself without assistance, but […] being able to exercise control over whatever help is required in order to achieve chosen goals and objectives" (Evans/Atim 2011: 1442). Against this background, the reciprocal care relations (ibid.: 1441) and experiences of both the parents and the children with disabilities ("children" in this context does not necessarily mean that they are still below the age of 18) could receive further attention in future research. To a certain extent, the interviews have shown that external factors impose a restriction on the parents'—and especially the mothers'—agency.[259] The situation of siblings and other family members could not be focused on in this project but might also be worth investigating in further detail. Conducting more research on family structures and relationships could be a suitable means of addressing the above-mentioned claim that the CA is too individualistic. Focusing on the role of women in families and on care relations could also follow up on Nussbaum's (2000) and Robeyns' (2003) work on the CA and gender issues. In addition, the significance of personal assistance did not receive attention in this thesis but might be an interesting element when investigating the impact of social and disability policy on quality of life. Also, a stronger focus could be put on collective capabilities.

In addition to the forms of agency, the interviews revealed further aspects that were classified as "cross-cutting" and being in interdependence with agency, namely

- self-respect and
- recognition from others.[260]

Both can be understood as supportive of high levels of agency and as prerequisites for social participation and inclusion. On a theoretical level, these identified themes can be contextualized in the tradition of identity theorists; they take up concepts such as the "social self," which claims that selfhood is created through social interaction and relations with other people or the pragmatic view that "the self has two sides: it is both subject and object simultaneously" (Scott 2015: 5). The "self-respect" extracted from the interviews is closely related to what has been sugges-

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[259] Regarding the agency of women, see also Sen (1999: 189 ff.). Sen's argument on this topic can easily be transferred to the situation of persons with disabilities:
"The active agency of women cannot, in any serious way, ignore the urgency of rectifying many inequalities that blight the well-being of women and subject them to unequal treatment; thus the agency role must be much concerned with women's well-being also. Similarly, coming from the other end, any practical attempt at enhancing the well-being of women cannot but draw on the agency of women themselves in bringing about such a change. So the *well-being aspect* and the *agency aspect* of women's movements inevitably have a substantial intersection" (ibid.: 190, italics in the original).

[260] For a discussion on social recognition for a theory of justice, see Honneth (2004). On the importance of the recognition of unpaid work, see, e.g., Nierling (2012). In the interviews, this aspect was covered in the conversation with Mr. Q (PI12, Western Cape).

ted in the literature as being “self-esteem,” namely “the emotional aspects of identity, such as feeling accepted and valued” (ibid.: 7). G. H. Mead (e.g., 1967)[261] took up the differentiation between the “I” and the “me” as parts of the individual self and argued that the “I” (subject) can be understood as the “creative, impulsive agent of social action” (Scott 2015: 6), whereas the “me” (object) “stands for others in the community” (Mead 1967: 194) and reflects the perspective and view that others have. More concretely, the “I”

> “is something that is, so to speak, responding to a social situation which is within the experience of the individual. It is the answer which the individual makes to the attitude which others take toward him when he assumes an attitude toward them. […] The ‘I’ gives the sense of freedom, of initiative” (ibid.: 177).

And the “me,” according to Mead (ibid.: 178) “represents a definite organization of the community there in our own attitudes, and calling for a response, but the response that takes place is something that just happens” (for details, see also Mead 1967: 173 ff. and 192 ff.). In line with these theoretical considerations, it is thus not astonishing that the two above-mentioned themes could be derived from the interviews: “self-respect”[262] and “recognition from others.”

A variety of components can be considered to influence people’s agency (in accordance with Sen’s approach), among them the available resources but also, and to a greater extent, family and friends, as well as (other) supporting or disabling structures and the opportunities that society creates for an equal participation in social and economic life. Furthermore, it became obvious that changes in regard to the acceptance of persons with disabilities and their social inclusion seem to be taking place in South Africa (“transitionality”), but further efforts are needed in order to increase people’s capability sets: both through changes on the individual level (e.g., empowerment) as well as through social change (e.g., elimination of barriers). And the more self-respect and recognition from others they experience, the more their agency can be oriented towards an independent lifestyle and be perceived as “freedom to act.” The most positive statements regarding quality of life and life satisfaction were made by the interview partners with the most self-determined lifestyle (agency dimensions “freedom to act” and “cooperation and mutual support”): Mr. Q states that “*I’m a happy quad*” (PI12, Western Cape), and, as well as sharing what he “loves” (e.g., “*love my sports,*” “*love to be around people,*” “*love my family*” (ibid.), Mr. P confirms that “*my place is, it’s for me, I enjoy it*” (PI11, Western Cape). For both interview partners, the direct influence

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[261] The original volume was published in 1934.

[262] In this context, Beart (1992: 60) describes the differentiation “between self-reflection, self-control (or self-steering) and self-monitoring,” which will, however, not be taken up and discussed here (for details, see ibid.: 60 ff.).

of the DG is not the center of attention. Rather, they emphasize the opportunities they have to live their lives as independently and in as self-determined a manner as possible, to which the DG can definitely make a contribution. Other factors, however, seem to be equally important, and, as argued in the previous chapter, in many cases the DG is a valuable and necessary support, but it can only influence the interview partners' quality of life to a certain extent.

Receiving the DG can, on the one hand, offer the potential to be the sole breadwinner in a household/family, thus making persons with disabilities important and valuable for others (based, however, on monetary aspects). On the other hand, the DG sometimes contributes to the perpetuation of difficult family structures, e.g., if a person receives the grant but cannot decide on its use. Aspects of power come into play here. On a broader scale, power relations in society are worth noting as well. The following expert quote by DPO_II summarizes the presented aspects well: According to her, persons with disabilities

> *"can contribute towards our economy, can contribute towards our workforce. They can do that, they want to do it. But they have issues like accessible transport. You know, they have these kinds of issues. Or job creation, we're having those challenges. And, the more we can, if we can take someone out of the […] Disability Grant system, it'll actually help government. It alleviates the pressure on them to pay out grants. And we have to be realistic. What people receive for grant is what, one thousand and sixty rand a month. Can a person live with one thousand and sixty rand a month? It's, it's not, it's not, people do it, but in the worst conditions ever. You know what I'm saying? So, the grant […] is a support. But it's not an answer to all the problems. So, people who really need Disability Grants, if the more people we can take out of the Disability Grant system, who becomes part of minimal, meaningful employment, more money will be available to increase the grants for people who do really, really, really need it. Increasing their quality of life, you know what I'm saying? It's all about the quality of life of people. And to have, to receive grants of one thousand and sixty rand a month, doesn't do much for the quality of life of a person. You know what I'm saying? People just exist from, from day to day"* (EX05, Western Cape).

But there is still a long way to go: Both the literature and the data revealed that the implementation of relevant (mainstream) policies and the application of the legal framework do not adequately respond to the needs of persons with disabilities, and that policies and legal documents that focus more specifically on the situation of persons with disabilities, including the CRPD, are not fully implemented either.

9 Outlook

This thesis has dealt with the quality of life and living situation of persons with disabilities and their families in South Africa. Against the background of poverty and disability experiences, the main research focus lay on the South African social security system and its potential to promote social protection and inclusion for persons with disabilities in policy and practice. Particular attention was given to the DG, as well as the CDG, and the effects both can have for their recipients. This outlook contextualizes the findings with the theoretical considerations presented in the first chapters of the thesis and relates the results to the international discourse on social protection, poverty reduction, and inclusive development (with a specific focus on the need for and potential of inclusive social protection systems). The two subchapters focus on the following aspects:

- 9.1: The framework conditions that exist in South Africa, i.e., the political and legal background and also the social protection measures in place, are a basis or starting point for the improvement of the quality of life of persons with disabilities. However, shortcomings exist that still have to be addressed. On the basis of the South African experience, some general conclusions can be drawn regarding the access of persons with disabilities to social protection measures and inclusive social protection systems.
- 9.2: The answers that the interview partners gave confirm that the human rights approach is a suitable way to explore the topic of inclusion and underline the necessity of implementing the CRPD in practice – including the right to an adequate standard of living and social protection enshrined in article 28.

9.1 Lessons Learned from South Africa

As outlined, the South African legal and political framework does theoretically prepare the ground for a high degree of social inclusion and social justice, and provides for non-discriminatory and equal treatment of all population groups. The South African Constitution from 1996 in particular, which is very progressive in international comparison, sets the standards for a non-discriminatory legal framework. It was an important element of the process to end apartheid in South Africa. The Constitution is complemented by a variety of bills, acts, and also white papers

I. Bertmann, *Taking Well-Being and Quality of Life for Granted?*, Gesundheitsförderung - Rehabilitation - Teilhabe,
https://doi.org/10.1007/978-3-658-19812-1_9

that form the basis and framework for a variety of policy fields, including social policy. This is of specific importance as social injustices and gaps are still present today. In order to address poverty experiences and the income shortfall that can be experienced by persons with disabilities, the South African state offers a social assistance grant, which many interview partners in this research project had experience of.

A study by Graham et al. (2014) shows that only a small portion of all persons with disabilities receive the DG,[263] which leads to their conclusion that, in line with complementary efforts like the provision of assistive devices, "[m]ore work needs to be done to educate and support qualifying people with disabilities to access this means of income protection" (ibid.: 8). They describe the grant system for poor people and especially persons with disabilities as "a major positive programmatic intervention" (ibid.). However, at a later point their study reveals that the grant primarily fulfills the role of a poverty alleviation mechanism, in the sense of meeting basic needs rather than contributing to transformation (e.g., through the purchase of goods and devices that might promote independence and economic activity). This corresponds with the findings of this thesis that only in those cases where survival is secured through other means and support structures can be accessed or made use of does the grant contribute to enhancing the quality of life of its recipients.

A couple of general challenges can be identified that might be useful for other social protection systems. One of the main eligibility criteria of the grant that the interview partners and other persons with disabilities are confronted with is a rather medical definition of disability that does not reflect their complex and multifaceted living realities. The definition of disability can thus be seen as a critical element of social protection systems.[264] Furthermore, the fact that there is no other unemployment assistance available for the working-age population is a major problem in combination with the high unemployment rates among the South African population. In addition, the topic of fraud was mentioned repeatedly in the

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[263] The study mentions a figure of 10% in the sample but admits that this might be due to the amount of elderly people included in the sample and the possibility "that these people were not eligible for the disability grant because of their age and/or lower severity of difficulties" (Graham et al. 2014: 7, footnote 2).

[264] Graham et al. (2014: 38) assume that the comparatively low uptake of the Disability Grant might be due to the "complexity of defining disability," including a) the fact that people do not see themselves as "having a disability" according to the current definition, b) doctors or other officials might not consider them as having a disability, and c) that there is a lack of knowledge about the grant or its application procedures. On its website, SASSA (2015) regularly provides statistics on the number of grants awarded to entitled persons. The current information (as of June 30, 2015) mentions a figure of 1,106,425.

interviews. The way the application, decision, and payment procedures are organized (together with the lack of any other unemployment assistance) leads to the fact that people who do not qualify try to apply for the grant. On this topic, several interview partners spoke about an unauthorized receipt of the grant and mentioned the slogan of SASSA ("Paying the right social grant, to the right person, at the right time and place"), which seems to be difficult to fulfill.

As can be concluded from the literature and the results of the interview analysis, considering a revision of eligibility criteria and targeting mechanisms is just as necessary as considerations regarding a reform of the system in general. In addition, the amount of the grant is a debatable factor, and the personal living conditions of the recipients should also play a role as far as both the amount and the application procedure are concerned. If the attempt to achieve social inclusion and cohesion is to be taken seriously, the argument that this form of unconditional cash transfer might not be the most appropriate measure of social protection at all times must be addressed. Against the background that many people do not live on their own but are strongly integrated into a family/household, it is worth thinking about a social policy measure that takes the household more strongly into consideration. In any case, attention should be paid to the fact that the compensation that families and whole households offer, due to a lack of alternatives (e.g., regarding care work or financial compensations), is taken for granted as a substitute for inadequate structures.

The general problem of the South African system of social security is that disparities between richer and poorer members of society become obvious, "reinforcing and perpetuating not only the ever-present inequality, but also abject poverty in [the] country" (Olivier/Mhone 2004: 157). Whereas Graham et al. seem to want to continue with the use of the DG, it might be necessary to initiate significant changes in the system as it is—by either substituting or complementing the DG. Various South African scholars (e.g., Nattrass 2004) have argued in favor of a BIG in order to overcome the shortfalls of the current system. Their arguments range from the high rate of HIV infections to the fact that the full implementation of the current system[265] is very costly and yet leaves large numbers of South Africans without any benefits (Samson et al. 2002: 13). Furthermore, "these [i.e., existing; IB] grants provide for limited levels of income support" only, which is due to the amounts provided and also to the fact that "on average the said benefits [i.e., Child Support Grant, the Disability Grant, and the Older Persons Grant; IB] have to cover for five additional household members in African communities" (Olivier/Mhone 2004: 120; see also Samson et al. 2002: 7). Among other aspects, a BIG could help to overcome this and also reduce bureaucratic efforts. In addition,

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[265] What is meant here is "the assumption that all beneficiaries received the entire set of benefits to which they were entitled" (Samson et al. 2002: 10).

the topic of disability would then have a different meaning in the context of social protection. Others (e.g., Archer 2007), however, have also questioned whether a BIG is the right way forward or have at least raised concerns regarding such an initiative. Apart from the fact that determining the level of a BIG would be a difficult undertaking, the number of potential recipients alone makes the financial feasibility and affordability debatable. Many people are in need of social protection measures, but only a certain number of people (on the regular labor market) pay the taxes that contribute to the financing of specific social protection measures.[266]

The DG as it stands has both advantages and disadvantages. The aspect that it generally recognizes and addresses the additional needs of persons with disabilities can be evaluated positively. At the same time, a combination with a mainstream approach would be necessary to shift the focus away from disability as a welfare issue. The fact that a form of safety net is available at all for people who cannot find work on the regular labor market can be seen positively. However, the aspect that there is no general unemployment benefit for the working-age population in South Africa is a challenge and leads to problematic effects, such as the refusal of medical treatment and the deliberate acceptance of a bad health status in the case of an HIV infection—with the aim of qualifying for the DG. The need to combat unemployment among persons with disabilities (and all other members of society) and to reduce barriers towards working on the regular labor market thus becomes obvious.

The reinforcement of inequality on the basis of both poverty and disability is also worth noting. Terzi (2005), for example, highlights that labeling and categorization in general (both of which are done if a person's "disability" and "inability to work" have to be medically examined, as in the case of the DG application) can lead to stigmatization. On the other hand, offering a grant or other provisions that do not take into account the different specific needs of the various recipients is also problematic. The CA might be a framework of thought that could be used to identify alternative solutions and address the above-mentioned "dilemma of difference" (ibid.: 444; see also Robeyns 2003: 368). Rather than focusing on the medical condition of a person, his/her living situation and the available options need to be the center of attention, linking the provision of measures to the extension of a person's capability set. In this regard, Noll (2001: 25) highlights the key points of the "human development" concept as follows:

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[266] Regarding challenges that influence the establishment and the concrete design of social protection systems, such as "fiscal affordability" and potential "drivers of change" for this field in the upcoming years, see Devereux et al. (2015: 6).

> “Das ‚human development‘-Konzept legt nahe, Lebensqualität stärker über ‚capabilities‘ als über ‚commodities‘ zu definieren und unter anderem daran zu messen, inwieweit die Bürger einer Gesellschaft nicht als passive Empfänger von Wohlfahrtserträgen betrachtet werden, sondern als fähige und autonome Akteure agieren können, die ihre Lebensqualität im Kontext demokratischer Institutionen aktiv zu gestalten vermögen (‚empowerment‘).”[267]

As long as the DG does not have to be used to secure mere survival, it can lead to the enhancement of living standards and the improvement of quality of life. The grant has to fulfill two functions at the same time, which makes it worth reconsidering additional forms of social assistance or support. A twin-track approach might be a good starting point: on the one hand, addressing the issue of poverty among individuals with disabilities, and, on the other, taking into account special needs that persons with disabilities might have. Specific approaches in the fields of transport (vouchers for wheelchairs so that people do not have to pay twice when using buses) or healthcare (provision of adequate assistive devices and medicine if needed) are issues to be considered. In addition, the interview partners highlighted the need for accessible housing and sensitization regarding the inclusion of the requirements of persons with disabilities in public housing programs. Fittingly, Hilser (2014: 148) suggests a combination of basic income programs in combination with policies on economic, educational, and labor market aspects that prevent poverty and protect from risks in the life cycle.

Graham et al. (2014: 36) similarly argue that “policies aimed at enhancing access to employment and education for *all* people as a general poverty alleviation strategy should also benefit people with disabilities” (italics in the original). Furthermore, they highlight that persons with disabilities should also be targeted by gender equality strategies and those that promote racial equality. When it comes to persons with disabilities leading independent lives, the importance of participating in (mainstream) education, as well as gaining/exercising personal responsibility and autonomy, cannot be overstressed. In this regard, the DG offers the advantage that, once obtained, it can be used according to one’s own preferences—within the restrictions that the personal living situation (e.g., a big family with no further income) poses. It does, however, not take into account the different resource needs of persons with disabilities, thus ignoring the heterogeneity of this group of citizens. In sum, it can be seen as a starting point rather than the ultimate solution for the provision of inclusive social protection. On a more abstract level,

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[267] Own translation: “The ‘human development’ concept suggests defining quality of life through ‘capabilities’ rather than ‘commodities’ and it measures, among other things, the extent to which the citizens of a society are not seen as passive recipients of welfare earnings but can act as capable and autonomous players who are able to actively shape their quality of life in the context of democratic institutions (‘empowerment’).”

the focus on persons with disabilities as “objects” of social policy instead of active citizens and subjects needs to be overcome. With respect to social assistance, persons with disabilities are reduced to the one category of “disabled,” and additionally to the status of “being poor”—thus overlapping all other personal characteristics.

9.2 Approaching Inclusive Social Protection: Conclusion

In South Africa, a great deal of progress has been made, especially since the end of apartheid. As argued earlier in this thesis, the economic indicators and the legal and political framework of this BRICS country can be evaluated positively. Thus, reference was made above to Maschke’s welfare state-based typology, with its focus on rehabilitation, compensation, and participation, when describing different elements of South African disability policy. The participatory aspect, it seems, has to be strengthened in South Africa to make the existing rights a reality and to make further achievements regarding equality possible, e.g., in the field of labor and work. This could have a positive impact on people’s agency, reduce dependency on social protection, and encourage active citizenship. Political participation and inclusion in decision-making processes might be one suitable approach.

However, the interviews revealed that the South African disability rights movement is somewhat fragmented, which makes it difficult for it to exercise the watchdog function of holding the government to account. It still remains to be seen how the implementation of the CRPD will progress. In any case, the successful implementation of the CRPD requires the relevant provisions to be made in the fields of education, labor, health, and others.[268] Intersectional aspects and the interactions between disability and other diversity categories, e.g., gender or race, became obvious in this thesis. Taking into consideration that data is still limited, there is a great deal of potential for focusing on these issues on a broader scale and with other methodological approaches.[269] The topic of disability and old age, for example, was not focused on here, as the emphasis was on the situation of persons with disabilities of working age (and children).[270] Disability should be conceptualized as one diversity dimension, while understanding inclusive social protection

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[268] The 2014 Graham et al. study focuses on social capital (in the sense of support networks) and the fields of education, employment, and health in South Africa and provides recent data regarding the access of persons with disabilities to these fields. For education, for example, they note “[t]he fact that the education gap between people with disabilities and non-disabled people is closing” (ibid.: 8).

[269] E.g., intersectionality research.

[270] In South Africa, the level of the Disability Grant and the Grants for Older Persons are the same, and persons with disabilities who receive the DG permanently will automatically receive the

as a multidimensional topic that goes far beyond the provision of a single (or in the case of South Africa: two) unconditional cash transfer(s) for the group of "the disabled poor." Challenging social patterns and questioning common understandings of disability are therefore deemed necessary.

It is, to a large extent, a matter of responsibilities and the anchoring of the topic. For other countries, similar questions to the ones posed in this research project might be applicable: Is disability regarded as a "mainstream" topic? Or is it mainly regarded as a welfare issue? What is the legal and political framework? What are the demands that the state places on its inhabitants (e.g., principle of subsidiarity) and what governmental support is/will be offered? It is important to note that, despite all the advances that have been made, the South African performance in this regard cannot and should not be compared to any European welfare state, where the social, political, and economic circumstances would be very different. But it might be useful to take a look at elements of welfare states with different orientations and even more so to conduct further studies among countries in the Global South[271] in order to make comparisons between the various social protection frameworks that already exist and their effects on the living conditions of persons with disabilities. In this regard, interesting insights can be expected from the investigation of the effects of measures that are directed at the household level and measures that are—at least from their basic orientation—directed at the individual level.[272] If understood broadly, social protection measures can serve "as an instrument of social and economic transformation to redress conditions of injustice and exclusion that perpetuate poverty" (Tessitore 2011: 13). In addition, "if their objective is to strategically confront social vulnerability, programmes should explicitly aim at enhancing capability, agency, participation and freedom of choice" (ibid.). The South African DG and CDG can fulfill that aim to a certain extent but have to be complemented by additional efforts. Otherwise, they will not make a significant contribution to the enhancement of recipients' well-being and quality of life. And, as Esping-Andersen (1990: 22) argues,

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Older Persons Grant when they are old enough. But this grant can be obtained by all other persons over the age of 60 if they pass the means test and do not live in a state institution.

[271] The situation regarding the access to social protection for persons with disabilities in Peru and Tanzania has, for example, been the focus of a research study that was conducted by an international consortium commissioned by the German organization GIZ on behalf of the Federal Ministry for Economic Cooperation and Development (BMZ): The study reports and respective platform with further information can be found at: https://www.giz.de/expertise/html/16762.html (GIZ 2015).

[272] The South African Disability Grant is meant for the individual—however, as could be seen, in many cases it serves to cover the needs of more than one person or even the whole household. In contrast, the Brazilian "Bolsa Família" program has a household focus.

> “[t]he mere presence of social assistance or insurance may not necessarily bring about significant de-commodification if they do not substantially emancipate individuals from market dependence. Means-tested poor relief will possibly offer a safety net of last resort. But if benefits are low and associated with social stigma, the relief system will compel all but the most desperate to participate in the market.”

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