

**The Social and Economic Effects of the Disability Grant for
People with Disabilities and their Households –
A Qualitative Study in KwaZulu Natal Province**

Christa Johansmeier

In partial fulfilment of the academic requirements
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School of Development Studies, Howard College Campus,
University of KwaZulu Natal, Durban.

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DECLARATION

I declare that this thesis is my own original work and that it is being offered here for the first time.

Ethical clearance for this study was obtained from the Higher Degrees Committee, Faculty of Humanities and Social Sciences, University of KwaZulu Natal.

Date: 08.10.2007

Name: C. Johannsmeier

Signed: 

ABSTRACT

People with disabilities (PWD) face physical and attitudinal barriers to participation in education, the labour market and development processes in general. The social model of disability views this exclusion as disabling and as caused by the way in which society is organised. Combined with the extra costs related to disability, this makes PWD more vulnerable to poverty, which is exacerbated by the fact that economic and social policies are often seen as being unrelated to each other. In South Africa with its high unemployment and poverty, there is a need for appropriate social assistance for PWD. Currently this is done through a means-tested cash transfer known as the Disability Grant (DG). Yet very little is known about the social and economic effects of the DG. The effects of the state Old Age Pension (OAP) have been well documented regarding, for example, expenditure patterns, utilisation of financial institutions, income-smoothing and household effects. This study aimed to explore whether these effects are similar for DG recipients, including the interaction with disability-related costs and intra-household decision-making processes. It furthermore aimed to explore the relationship between the DG and the labour market.

Using qualitative and participatory methods, this study involved people with physical, visual and hearing disabilities who are DG recipients, in eight urban and rural areas of KwaZulu Natal Province.

Findings highlighted the complex interactions between the DG recipients, their households, and the physical and attitudinal barriers they face. The grant is primarily used for basic needs (especially food), school expenses, and sometimes water and electricity. It is often consumed in households that have no other or very little income. This means often households remain poor and are vulnerable to financial shocks and debt to cover basic needs. The DG has sometimes contributed to shock mitigation (e.g. through stokvel or funeral policy contributions), but termination of DG for review was in itself a financial shock, necessitating going into debt.

The combination of poverty and high unemployment increases reliance on DG by PWD and their household. This interacts with physical and attitudinal barriers and

lack of education that hinder PWD from getting employed. Even though some PWD have expressed the desire to work, attempts have been frustrated by barriers faced and because of high general unemployment. This showed that employment of PWD, and possible disincentives to entering employment, must be understood within the current South African context, and that social and economic policies and their effects are inter-related.

The research process itself highlighted possible barriers to inclusion of PWD and gives recommendations for more inclusive research processes. The study concludes that while the DG may be one means to inclusion, disability cannot be relegated solely to a social assistance domain. Rather, an intersectoral and ‘twin-track’ approach is needed. Intersectoral refers to the collaboration between multiple government departments, private sector and disability organisations. ‘Twin-track’ refers to the need for programmes and services that are both ‘disability targeted’ (specific initiatives to empower PWD) and ‘disability mainstreamed’ (addressing inequalities between disabled and non-disabled people in all general development initiatives). This means that social and economic policies can become more interlinked, and that disability can be integrated into development programmes aimed at addressing poverty and exclusion.

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LIST OF ACRONYMS

ABET	Adult Basic Education and Training
CDG	Care Dependency Grant
CRF	Community Rehabilitation Facilitator
CSG	Child Support Grant
DG	Disability Grant
DoE	Department of Education
DoL	Department of Labour
DoSD	Department of Social Development (previously DoSW)
DoSW	Department of Social Welfare
DoT	Dept of Transport
DPOs	Disabled People's Organisations
DPSA	Disabled People South Africa
EEA	Employment Equity Act
FET	Further Education and Training
GiA	Grant in Aid
KZN	KwaZulu Natal (Province)
NGO	Non-governmental organisation
OAP	Old Age Pension
OSDP	Office of the Status of Disabled People
PWD	Person(s) with Disability/ People with Disability
ROSCA	Rotating Savings and Credit Association
SASSA	South African Social Security Agency

Introduction

People with disabilities (PWD) face physical and attitudinal barriers to participation in employment opportunities, education and development processes in general. The Social model of disability views this exclusion as ‘disabling’ and as caused by the way in which society is organized, making PWD more vulnerable to poverty and exclusion from the labour market. Current estimates for the proportion of the South African population with disabilities converge at five to six percent of the population, equating to around 2.5 million PWD in South Africa (DoSW, 1997; CASE, 1999; StatsSA, 2001) There is thus a need for appropriate policies and development services for this sector of the population, including appropriate social assistance within the South African context of general high unemployment and poverty. A current policy response is the means-tested cash transfer known as the Disability Grant (DG). The question is whether the DG is a developmental response that leads to pathways out of poverty and is able to mitigate the effects of social and economic exclusion.

The literature review will outline how PWD face exclusion and how this makes PWD more vulnerable to poverty, which is exacerbated by the fact that economic and social policies are often seen as being unrelated to each other. In South Africa with its high unemployment and poverty, there is a need for appropriate social assistance for PWD. Currently this is done through a means-tested cash transfer known as the Disability Grant (DG). While effects of the state Old Age Pension (OAP) have been well documented, very little is known about the social and economic effects of the DG. This study therefore aims to explore whether the effects of the OAP are similar for DG recipients, including the interaction with disability-related costs and intra-household decision-making processes. It furthermore aims to explore the relationship between the DG and the labour market. The following chapter will outline the methodology used, and this is particularly relevant to how such processes can be made more inclusive to PWD. Chapter 3 outlines the findings regarding the effects and interactions of the DG, while the Chapter 4 discusses the implications of this increasing social and economic inclusion of PWD. The chapter concludes with policy recommendations.

CHAPTER 1: LITERATURE REVIEW

1.1. Disability and development

Inclusion of Disability into Development

There is a growing policy emphasis on mainstreaming disability into development, yet in reality there is still widespread exclusion or marginalisation due to social attitudes and prejudice.

Nowhere has disability been adopted as a cross-cutting development issue and recent reports indicate that the most progressive disability policies...have not been carried through (Yeo, 2005:5).

Where disability has been addressed by development agencies or governments, it has typically been marked as a residual or social welfare category, rather than forming an integrated part of economic development policies, as has been evident in South Africa (DoSW, 1997). Before the 1990s, disability was mostly excluded from development policies and institutions, and PWD seen as passive recipients of, rather than full partners in, the development process. This has recently started to change, with governments, development agencies, financial institutions and NGOs increasingly making reference to disability as an international development issue (Coleridge, 1993; DFID, 2000; Yeo and Moore, 2003; Yeo, 2005). This gap has also been seen in South Africa where “paternalistic attitudes and a piecemeal approach to addressing the needs of people with disabilities have hampered their integration into society” (DoSW, 1997:53).

Development organisations frequently claim that they cannot work with such a specialist issue as disability, and there is often a lack of knowledge on how inclusion can be achieved, especially in a context of limited resources. To address this, specific steps are required to integrate disability into mainstream development processes so that PWD are seen as equal members of society (Coleridge, 1993; DFID, 2000; Yeo and Moore, 2003, Yeo, 2005). Inclusion, where PWD are able to achieve equal rights and opportunities, would contribute to poverty reduction as a whole, since without this it is unlikely that current development targets (such as the Millennium Development Goals) will be met. There may also be long-term financial costs of excluding PWD that may outweigh the

short-term costs of inclusion of PWD into current mainstream development initiatives (Coleridge, 1993; DFID, 2000; Yeo and Moore, 2003). Inclusion of disability into development and poverty reduction initiatives highlights the need to view disability not only as a social issue, but also in terms of economic development.

The relationship between economic and social policy

There are complex dynamics underlying the relationship between social and economic policies. There seems to be a tendency in policy-making towards ‘adding on social policies’, by focusing first on getting the macro-economic policies in place using market-based criteria, and only then adding on social policies in order to achieve socially desirable outcomes or to remedy inequality. However, this approach ignores the fact that “all macro-economic policies are enacted within a certain set of distributive relations and institutional structures” and that “all macro-economic policies entail a variety of social outcomes which need to be made explicit” (Elson and Cagatay, 2000:1348). This means that macro-economic policies and processes can in fact create inequalities and poverty. Examples of this include forms of economic growth that do not lead to employment growth, or do not enable the poor to be able to integrate into the economy, or adversely affect social provisioning for workers. One therefore should not see social and economic policies as unrelated – rather, a ‘transformatory approach’ is needed which includes the ability to mainstream social policy and rethink macro-economics (Elson and Cagatay, 2000). Social policy should therefore not be a ‘band-aid’ approach to alleviate the effects of economic exclusion. It also means that macro-economic policy cannot be viewed in isolation or as an end in itself, but rather needs to be assessed in the way in which it contributes to the social well-being of the population. This interaction between social and economic policies will be used in this study to evaluate policies related to disability.

Models of disability

One outcome of the discrepancy between social and economic policies is that disability often tends to be excluded from (or only added on to) the development policy-making process. How do the processes of exclusion come about and how can development policies be made more inclusive of disability? Different conceptual models are used to

understand approaches to disability. This research will be based on the social model of disability, which can be differentiated from the medical and charitable models.

The social model is useful in providing a framework within which the interactions between poverty, disability and development can be understood (Nagata, 2007). The social model does not view disability as an individual problem to be “cured”, but rather sees the problem as lying in society.

The social model of disability points to the ways in which people with impairments are excluded by the way that society is organized. It is the exclusion that disables people (Yeo, 2005:18).

The social model therefore starts from the point that inclusion of PWD is ultimately about removing barriers in society, which include physical barriers (for example, steps at the entrance to a building for a person with a wheelchair) and attitudinal barriers (for example fear of employing a blind person). It is often attitudes of fear, shame and rejection, together with the negative stereotypes commonly attached to disability that lead to social exclusion (DFID, 2000). Understanding such barriers places the onus for inclusion on changes at a societal level, rather than on the individual with a disability (Coleridge, 1993; Barnes and Mercer, 2004; Nagata, 2007). Usually barriers are socially constructed, but they may influence the economic status of PWD, making them more vulnerable to poverty and leading to exclusion from employment, education and development activities (Mitra, 2005).

The social model can be counterposed to the medical/individual model of disability, which views an impairment as an ‘abnormality’ which needs to be ‘corrected’, ‘cured’ or ‘overcome’. It sees the individual as alterable and the social environment as fixed and unalterable, and if a person does not fit into that environment, it is that person (not the environment) that must be made to change (Coleridge, 1993; Mitra, 2005). The social model is also differentiated from the charitable or institutional model which views the person with disability as a deserving recipient of charity, not able or worthy of full participation and dependent on care. Frequently this has meant that PWD are relegated to ‘special’ programs, and thus effectively excluded from mainstream development activities (Coleridge, 1993; Yeo and Moore, 2003; Philpott, 1995).

Using the social model enables one to view disability in terms of processes of exclusion and inclusion, with the aim of working towards greater social justice for PWD (Coleridge, 1993; Oliver, 1996; Burchardt, 2004; Barnes and Mercer, 2004; Mitra, 2005). This does not however, mean ignoring specific medical or individual interventions required to address specific disability concerns. Rather a twin-track approach is needed that recognises the need for both specific initiatives of empowering PWD, while simultaneously working towards the inclusion/mainstreaming of disability into all areas of development work (Philpott, 1995; DFID, 2000; Yeo and Moore, 2003; Nagata, 2007).

1.2. Disability, exclusion and poverty

Disability and labour market exclusion

The social model of disability views exclusion of PWD as caused by the physical and attitudinal barriers created by society. This is evident in South Africa despite a fairly comprehensive set of disability-related legislation and recommendations which include:

- Employment Equity Act (EEA) (1998) in which PWD qualify for affirmative employment opportunities in the public and private sectors, and in which Employment Equity Reports must be submitted to the DoL (SAHRC, 2002).
- Code of Good Practice on Employment of People with Disabilities (2002) which interprets the EEA and explains in more detail key aspects of disability in the workplace. It explains how discrimination can be avoided and equity achieved in all processes, from recruitment to termination (SAHRC, 2002).
- Technical Assistance Guidelines on the Employment of People with Disabilities (DoL, 2002), which provides practical guidelines in implementing non-discrimination and affirmative action. It defines ‘reasonable accommodation’ as “modifications or alterations to the way a job is normally performed and make it possible for a suitably qualified person with a disability to perform as everyone else” (DoL, 2002:14).
- National Building Regulations (1986, Part S) which describes accessibility of buildings to disabled persons e.g. signage, access to information, parking facilities, access into buildings, toilet facilities and office furniture (SAHRC, 2002).

In the South African labour market, exclusion of PWD from employment is the result of a number of interacting barriers, including a lack of accessible public transport to reach places of work; inaccessible buildings due to lack of application of the National Building Regulations; lack of skills training; lack of application and monitoring of the Employment Equity Act; loopholes in applying 'reasonable accommodation' and negative or discriminatory attitudes towards disability in all of the above, including in job application procedures. It is thus social exclusion and a discriminatory labour market, rather than the individual functional ability of PWD, that lead to their poor employment probabilities (Berthoud, Lakey and McKay, 1993; Moodley, 1997; EPRI, 2001a; DoL, 2002; EPRI, 2004; Seirlis and Swartz, 2006).

Exclusion from employment is also linked to exclusion from education and training opportunities, often due to the same barriers (accessibility and negative attitudes of parents, teachers and children). There is a lack of special schools in many areas and even when these are available the quality of education may be questionable. Little has been spent on supporting disabled learners in mainstream schools, teachers are not trained in inclusive education, and teachers struggle to cope with large classes. Thus neither special nor mainstream schooling is currently providing the quality education required. Limited education opportunities interact with prejudicial attitudes to decrease the chance of being economically active later in life (Schneider and Marshall, 1998; DoE, 2001; Batavia and Beaulaurier, 2001).

Even where PWD are employed, exclusion may be evident. In surveys of work arrangements in Australia, Canada, the UK and the USA, it was found that PWD may be under-employed relative to their level of training, have lower income levels, have less promotion prospects, are at greater risk to become unemployed and are more often in non-standard work arrangements (Elwan 1999; Emmett, 2006). The extent and nature of non-standard work-arrangements for PWD in South Africa is not well documented. Disability may also interact with other aspects of social disadvantage in South Africa, such as gender and race. Under Apartheid, access to health and education services were disparate, based on racial grounds (DoSW, 1997; Emmet and Alant, 2006). Thus African and Coloured PWD are less likely to have high levels of education, which in turn impacts

on employment probabilities (CASE, 1999; Emmet, 2006). While disability impacts on employment of both men and women, women have lower participation rates in the labour market, whether or not they have a disability. Internationally, disabled women are less likely to be employed than disabled men, and also earn less. Thus disabled women face a double disadvantage in the workplace (Emmet and Alant, 2006; Emmet, 2006).

Disability and Poverty

Exclusion of PWD is also evident in the fact that disability is closely related to poverty, both a cause and a consequence. Poverty increases the risk of disability, for example through lack of healthcare, poor nutrition, greater exposure to injuries or lack of knowledge about prevention. Disability also adds to the risk of poverty, for example due to the costs associated with the disability, discrimination in the labour market or exclusion from education. This means that PWD are more likely to experience discrimination that leads to financial difficulties and social and economic deprivation. PWD can be caught in a vicious cycle of poverty and disability, each being both a cause and a consequence of the other (Elwan, 1999; ILO, 2000; DFID, 2000; Yeo, 2001; Yeo and Moore, 2003; Mitra, 2005; Yeo, 2005; Emmett, 2006; Nagata, 2007). This is illustrated in Figure 1 and Figure 2 below (taken from Yeo and Moore, 2003:572).

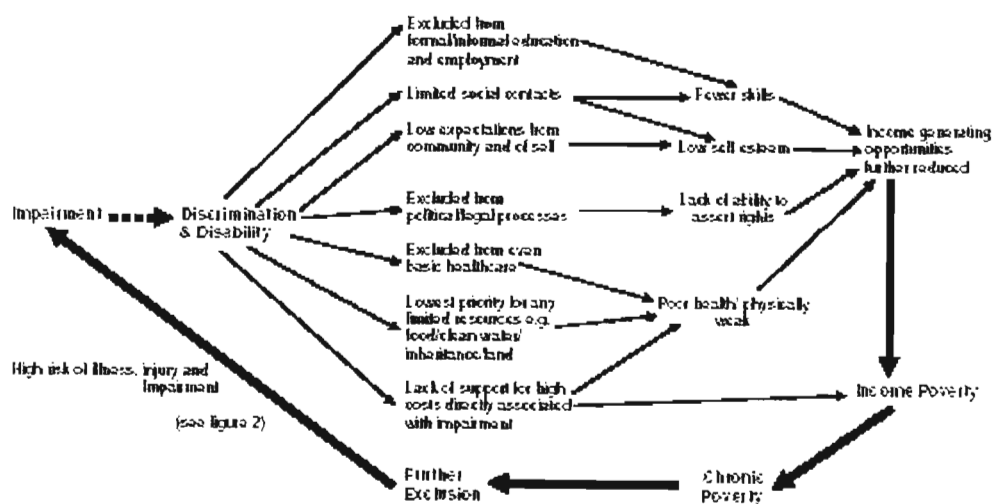


Figure 1. Disability/poverty cycle.

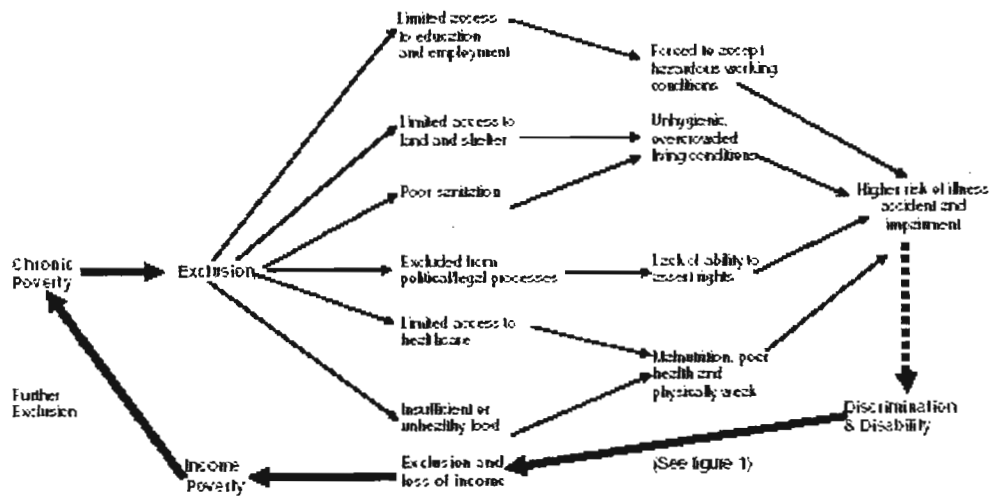


Figure 2. Poverty/disability cycle.

The diagrams show that disability and poverty are closely related, yet it needs to be acknowledged that not all impairments are poverty related.

It would over-simplify the issue to say that all disabled people are *always* among the poorest in a community or that the poorest are *always* most likely to get any form of impairment. However, a higher proportion of disabled people may experience severe and chronic poverty than the proportion of non-disabled people (Yeo, 2005:21).

A further contributing factor to the relationship between disability and poverty is the extra costs related to having a disability. For example, where public transport is inaccessible, it may compel PWD to use more expensive alternatives such as private adapted transport. Extra expenses may include attendant care services, assistive technology, rehabilitative equipment or devices, transportation services, housing and workplace modifications, interpreter or reader services, periodic medical or hospital visits, and many more. PWD thus often have financial burdens far beyond those of people without disabilities, both in developed and developing countries and even for people who are employed (Berthoud, Lakey and McKay, 1993; Schneider and Marshall, 1998; Batavia and Beaulaurier, 2001; Burchardt, 2004; Mitra, 2005; Zaidi and Burchardt, 2005; Emmett, 2006; Emmet and Alant, 2006). A number of countries provide a separate disability allowance to compensate for disability-related expenditures (such as

modifications, equipment, transport), irrespective of the work status of the person (Mitra, 2005).

Poverty not only affects the person with disability, but also the households or families that have a disabled member. Thus more of the population is affected than the PWD themselves. An estimated 16 percent of households in South Africa have a disabled member according to the 1999 October Household Survey (Emmett, 2006). Household members may spend time and resources supporting disabled family members or paying for disability-related costs, which may increase the likelihood of the household remaining poor. Families may be burdened by both out-of-pocket expenses as well as foregone earnings, and informal support is often uncompensated (Berthoud, Lakey and McKay, 1993; Altman, Cooper and Cunningham, 1999; Batavia and Beaulaurier, 2001; Mitra, 2005; Emmett, 2006).

Economic context of South Africa

The economic context of South Africa needs to be taken into account when looking at policies related to disability in South Africa. While the previous section indicated that disability is related to the incidence of poverty, Aliber (2001, as quoted by Yeo and Moore, 2003) argues that in South Africa the incidence of joblessness and poverty is so extreme, that unemployment rates are not much higher among PWD than the population as a whole. Thus in contexts of general poverty, PWD may share the general profile of the non-disabled poor, since “poverty is highly correlated with social exclusion, marginalisation, vulnerability, powerlessness, isolation and other economic, political, social and cultural dimensions of deprivation” (Dube and Charowa, 2005 as quoted by Yeo, 2005:19). In South Africa this is seen by correlations between other aspects of social disadvantage, where “interactions between poverty, gender, race and disability produce complex patterns of social inequality” (Emmett and Alant, 2006:453). Thus both disability and poverty are symptoms of the way in which society is organized, and both may marginalise and isolate certain groups of people (Yeo, 2005).

South Africa has high unemployment. Despite relatively rapid economic growth rates since 2000, unemployment rates have hardly changed, indicating that South Africa's

long-standing unemployment problem is likely to remain severe in the foreseeable future (Nattrass, 2006; DoSD, 2006b). High unemployment in the economy as a whole is a severe obstacle to improving the employment prospects of PWD (Moodley, 1997). This means that when there are a greater number of workers over number of jobs, employers can choose from a large pool of applicants, and PWD therefore compete with high numbers of non-disabled unemployed, putting them at a distinct disadvantage in the selection process, even where anti-discriminatory legislation is in place (Moodley, 1997; DoSD, 2006a). There is thus a mismatch between the premise of full employment available to all who can and want to work and the current reality of persistently high levels of unemployment (Nattrass, 2006).

1.3. Policy responses and effects

The United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (UN, 1993) sets out target areas for participation of PWD, which include accessibility, education, employment, social security, family life and personal integrity, culture, recreation, sports and religion. There are pre-conditions for this to take place (awareness-raising, medical care, rehabilitation and support services), but there are also implementation measures to increase participation: information and research, policy-making and planning, legislation, economic policies, co-ordination of work, organisations of persons with disabilities, personnel training, national monitoring and evaluation, and technical and economic co-operation. This highlights the need for wide-ranging and diverse policy responses to disability. The following section will focus on policies related to social security and social assistance for PWD.

Cash transfers as a socio-economic policy

Government-funded cash transfers is one method of social security provisioning. The role of cash transfers in the South African context needs to be explored, and how the provision of money, as opposed to other forms of service provision, affects the lives of PWD. The White Paper for Social Welfare (DoSW, 1997:31) defines social security as covering “a wide variety of public and private measures that provide cash or in-kind benefits or both, first in the event of an individual’s earning power permanently ceasing, being interrupted, never developing or being exercised only at unacceptable social cost

and such person being unable to avoid poverty”. Within social security, differentiation is made between a) private savings, b) social insurance (joint contributions by employers and employees), c) social relief (short-term crisis management) and d) social assistance (non-contributory and income-tested benefits provided to groups such as PWD, elderly people and unsupported parents and children who are unable to provide for their own minimum needs) (DoSW, 1997). Differentiation therefore needs to be made between social security and social assistance (a more narrow focus on providing assistance to the most vulnerable people in society who are unable to provide for themselves). In South Africa, social assistance has taken the form of grants/ cash transfers. This is underpinned by the South African Bill of Rights, which includes the socio-economic right to social security (Schneider and Marshall, 1998), and by the United Nations, which sets social security out as one of the target areas for equal participation of PWD (UN, 1993).

Cash transfers also need to be viewed from the perspective of the social model. One argument, as portrayed by Swartz and Schneider (2006:236), is that

within the social model, changes to society as a whole are emphasized with the broader goal of creating an environment which maximizes participation. Social 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.

In this view alternatives would involve providing skills, jobs and inclusion in mainstream development activities. This is, however, a controversial argument, since social grants have an important role to play in service provision to PWD, and could contribute to the removal of barriers described by the social model. Yet even this cannot take place without other disability-related policies and legislations (e.g. inclusive employment, education, health and development policies).

The Disability Grant

In South Africa, social assistance for PWD takes the form of a non-contributory cash transfer – the Disability Grant (DG). The DG is a means-tested social grant aimed at individuals who are poor and unable to support themselves through work due to their disability (adults aged 18-60 for women, 18-65 for men).

In April 2004, the total number of DG recipients was given as 1 270 964 (Treasury figures supplied to Swartz and Schneider, 2006:237). Women represented just over half of all DG recipients in October 2005 (DoSD, 2006b). There has been a marked rise in DG recipients over the past few years: from October 2001 to September 2004, the number of permanent DGs being disbursed increased by 143 percent, from approximately 400 000 to 970 000 (DoSD, 2006b; CASE, 2005). A number of possible reasons were identified for this marked increase, including: escalating poverty levels (i.e. including people that previously would not have applied, but now have no alternative forms of income), increase in proportion of awards for chronic illnesses such as HIV/AIDS, increased awareness of and better access to the social security system, possibly less rigorous review, and unclear guidelines about the severity of conditions (CASE, 2005; DoSD, 2006).

PWD eligible to receive the DG are defined within the 1992 Social Assistance Act as:

Any person who has attained the prescribed age and is, owing to his or her 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. (Government of SA, 2004:n.p.)

The DG is therefore a grant for adults who are unable to sustain themselves economically or are incapable of entering the labour market by reason of disability. In South Africa there are currently no state benefits to PWD who are in paid work, even if extra disability-related costs are incurred. Thus the South African DG is seen as an income replacement benefit for those with an inability to engage in paid work, as opposed to compensatory benefits that cover the extra costs of disability (CASASP, 2005; Mitra, 2005). The DG is designed with the clear expectation that those who in principle are capable of working should not be eligible.

The grant is not designed to compensate people for their disabilities per se, but rather to compensate them for the impact of their disability on earning potential. That people may be able and desire to work, but unable to find it, is irrelevant to the legislation (Nattrass, 2006:3).

Disability Grant and labour force participation

Any grant income provided to persons with certain characteristics (e.g. through means-testing) may influence an individual to take a certain course of action in order to secure that grant, usually rationally weighing up the costs and benefits of either gaining or losing the grant. Such incentives probably exist in most social security systems internationally, for example where people remain on unemployment benefits that are valued at more than the average minimum wage, or where a grant is seen as more secure than risking temporary employment (DoSD, 2006a).

In the interrelationship between the DG and labour force participation, it must be considered whether or not the receipt of the DG acts as a disincentive to seeking or keeping employment. The White Paper for Social Welfare (DoSW, 1997:32), acknowledges that “the means test has penalised and demotivated disabled people who have private savings, or who take up (generally lower paid) work, which often lasts only temporarily”. Moodley (1997) found that PWD are more likely to rely on the DG because of their exclusion from employment and that they may be discouraged from finding work due to its potential loss. In the words of one of his informants:

Employment is seen as a gamble that might later result in unemployment through layoff or firing with the loss of an otherwise guaranteed source of income. If the job does not work out, they may face long delays before they can receive government benefits again. (Moodley, 1997:57)

Moreover, because PWD often receive lower wages due to discrimination, and many job placements are only temporary, the DG may provide a more reliable standard of living (McLaren et al., 2003). “While little is known about the labour market impact of disability-targeted transfers in developing countries, it is important to recognize that the prospect of losing a disability transfer if one were to earn beyond a limit, can deter persons from disabilities from working” (Mitra, 2005:21). In contrast to other countries where there is gradual reduction in benefits as wages rise, the DG “is in effect, punishing the desired behaviour by withdrawal of support when a recipient enters the labour market” (Kerlin, 1993 as quoted by Moodley, 1997:58).

In South Africa unemployment among PWD is still high, yet many in this category indicate that they would like to have a job (DoSW, 1997). In South Africa only 0.7 percent of employed people have a disability (General Household Survey 2004, own calculations). There is, however, very little information on how many DG recipients would be able to work and in what type of work. Furthermore, little is known about current attempts by DG recipients to earn a supplemental income in addition to the DG. The current means test is only specific to the assets and income of a potential *applicant* but is not clear on whether getting any income over and above the DG *after* receipt will mean termination of receipt, and this has left many DG recipients wary to report any form of supplementation (Vorster, de Waal and de Koker, 2006).

The DoSD has recently published a discussion document on “Linking Social Grants Beneficiaries to Poverty Alleviation and Economic Activity” (DoSD, 2006b). The document is based on concerns about the sustainability of rising numbers of grant recipients, as well as concerns that there may be DG recipients who may be able to work. It acknowledges the lack of initiatives to help PWD/DG-recipients to enter into and remain in employment, and that the macro-economic growth in South Africa has failed to produce any significant growth in employment. It highlights the need for more research to “gain an understanding of what constraints and barriers beneficiaries experience in attempting to move to employment” (DoSD, 2006b: 9).

The socio-economic effects of cash transfers

Other effects of cash-transfers now need to be explored. While the effects of the State Old Age Pension (OAP) are well documented, it is the only other cash transfer to adults in their own right (as opposed for example to the Child Support Grant which is given to the adult caregiver of a young child, for the care of the child). It is not known if the DG has similar effects, since the presence of a disability creates issues that are qualitatively different to those of old age, making transferability of findings difficult. Where there are gaps in the literature regarding the effects of the DG, what is known about the effects of the OAP will be included. The household effects of the OAP enable us to pose questions about whether similar or different effects can be seen in the presence of a DG in the household.

Expenditure Patterns

In a national survey which profiled social security beneficiaries in South Africa, Vorster, de Waal and de Koker (2006) found that 77 percent of DG recipients indicated that food is the first item their money is spent on, and 59 percent indicated that food was also the item on which most of that money was spent. The survey also showed that 33 percent of DG recipients indicated payment for electricity and services as the second largest item the DG money is spent on, though this varied by province (due to large provincial differences in infrastructure delivery), with KZN recipients spending significantly less on electricity and services than other provinces. Other expenditure items included, in order of priority, clothes, funeral policy scheme, paying debt, paying accommodation or rent, school fees and sending remittances. Lesser items included medical expenses, buying building material, savings, toiletries, transport and paying someone to help at home. Schneider and Marshall (1998, based on three focus groups of PWD in Gauteng, Western Cape and Eastern Cape provinces) briefly mention similar findings, where DG recipients reported (not in order of priority) paying for groceries, supporting elderly parents, paying for medicines, and a few using it to further their own education, rent a flat, or assist in family members' education.

Eighty-four percent of DG recipients indicated that they did not need to pay someone to assist or take care of them. A negligible number indicated that they received the Grant in Aid (GiA) in addition to the DG (Frieg and Hendry 2002; Vorster, et al., 2006), despite some with more severe disabilities needing care and assistance at home. According to the Social Assistance Act (Government of SA, 2004), grant recipients are eligible for the GiA (approximately R200 per month) if they require full-time attendance by another person owing to their physical or mental condition. Many caregivers are not employed, "possibly indicating financial reliance of the caregiver on the grant of the person with disabilities" (Frieg and Hendry, 2002:17).

There are some similarities between spending by DG and OAP recipients. An EPRI study (2004) showed that spending in households that received these grants focused on basics like food, fuel and housing. In a small survey of poor households in the Eastern Cape receiving the OAP and Child Support Grant (CSG), all households reported spending the

majority on food (EPRI, 2002). Some of these households reported increased expenditure on medical, educational and funeral expenses. In a study of spending patterns of Zulu grandmothers who received the OAP, Moller and Sotshongaye (1996) found that most of the OAP money was spent on the most basic needs, especially food, although this varied by household and location, for example, urban areas paid more for electricity, water and rent. Most grandmothers mentioned expenditure on school fees, school uniforms and transport to school as important. There were, however, gender differences since females were more likely to spend their income to benefit children in the household (Moller and Sotshongaye, 1996; Case and Deaton, 1998; Lund, 2002; Keswell, 2003).

Household uses and effects

Social grants also need to be viewed in relation to household composition. Much of the South African population lives in large households and larger households are often poorer. This is often the case in three-generation or skip-generation households, where co-residency of extended families is not unusual (Edmonds, Mammen and Miller, 2001; EPRI, 2001b; Keswell, 2003). When there is a cash transfer, it is often used more broadly in the household, and “benefits that do exist are often used for purposes other than the income maintenance of the person for whom the payment is made. This is well documented for the OAP ... where payment into a household can support many different people within the household” (CASASP, 2005:40).

While the OAP has been shown to raise household income, some households still remain poor. The needs of a large household may ‘crowd out’ the personal needs of the OAP recipient because of income pooling or dilution. In some cases pensioners viewed themselves as poor or frustrated that their own needs were neglected in the interests of family welfare (Legido-Quigley, 2003; Moller and Sotshongaye, 1996). Conversely, the presence of pension income may ‘crowd in’ care, by ensuring the right of the older person to receive care and support, while also contributing to the provision of care to other household members (e.g. through nutrition and schooling expenses) (Lund, 2002; 1999; Legido-Quigley, 2003).

In contrast to what is known about the effects of the OAP, not much is known about the household effects of the DG. Schneider and Marshall (1998) mention that many DG recipients stated the difficulty in surviving with the money since it was mostly used to support both themselves and a number of others. It is not, however, clear whether and how the DG is distributed for use within the household, and this will be one focus of this study.

Decision-making processes

Households are seldom unitary decision-makers. There are intra-household processes of distribution such as income-pooling, forms of bargaining, decision-making and allocation. Therefore, who receives most benefit from a transfer will depend on the sharing rules within that household (EPRI, 2001b; Lund, 2002; Bertrand et al., 2003). It is not known how the status and care of PWD is affected by the presence of the DG. Vorster et al. (2006) show that 85 percent of DG recipients reported being the persons who collected the DG and managed the finances, while Frieg and Hendry (2002) noted that many DG recipients reported receiving assistance from the caregiver in collecting the DG and handling finances. "Evidence on intra-household income distribution and disability transfers is very limited" (Mitra, 2005:17). Similarly, while OAP-sharing is common, little is known about the process in which a household budget is drawn up and how the needs of individual household members are prioritised (Moller and Sotshongaye, 1996). There is some indication of gender differences where older men may have relatively more bargaining power within the household than women (Bertrand et al., 2003). Women with disabilities are said to face double discrimination, on the grounds of both impairment and gender (DFID, 2000; Emmett, 2006), but little is known about how, or if, this affects DG recipients.

Changes in household composition and formation

Edmonds, Mammen and Miller (2001) mention changes in household composition associated with the receipt of the OAP. There seem to be gender differences in this, where pension-eligible women often attract younger children under age five (possibly due to the practice of grandmothers often having the role of caring for young children), whereas for men, there seems to be an increase in older school-going age children. The

OAP also contributes towards orphan care when there is death due to HIV/AIDS in the middle generation.

Multi-generation households may also be induced by the presence of the OAP, as it may attract unemployed family members and “act as magnets for economically weaker persons” (Sagner and Mtati, cited in Edmonds et al., 2001:11). Where households receiving the OAP in rural areas attract younger unemployed members, this takes them out of proximity of job opportunities and therefore lowers job-finding prospects for them (CASASP, 2005; Klasen and Woolard, 2005). Conversely, Keswell (2003) argues that employment probabilities are enhanced for individuals who reside in those households, since access to pension income contributes to costs associated with seeking employment. EPRI (2004) estimates (from a number of regression models) that households receiving the OAP or the DG have labour force participation rates 13 to 22 percent higher than households that do not receive the grants. However, they comment that these findings may be inconclusive and do not prove causation. Not much is known about how the DG interacts with labour force participation or household formation, and this will be another focus of this study.

Financial institutions

Use of financial institutions is an important development issue since it influences the way in which households are able to cope with risk and vulnerability. Many lower income households are excluded from formal banking services or other means to cope with negative financial shocks. Understanding use of and access to formal and informal financial institutions and risk-management strategies is thus necessary to analyse poverty dynamics and the persistence of poverty over time (Ardington and Leibbrandt, 2004).

Moller and Sotshongaye (1996) find that the OAP enables contributions to savings clubs, burial society funds, and buying of furniture or appliances on credit. They note that some pensioners were able to open accounts, and pay for a wide range of goods and services in installments.

The OAP has also been shown to be associated with the formation of rotating savings and credit associations (ROSCAs), a common example of which is the 'stokvel' (one South African term for a rotating credit scheme). Keswell (2003) documents how in KwaZulu Natal, monthly payments into a stokvel coincide with the receipt of the OAP and that OAP receipt is a strong predictor of membership of savings clubs. He argues that participation in a stokvel is a less risky practice than using the money to start a business or using it to search for employment, and that it plays an important role in mitigating negative financial shocks, e.g. death of family member, injury, chronic illness, job loss, crop failure and destruction of property due to fire. The OAP thus plays a significant role in contributing to income smoothing (Edmonds et al., 2001; Keswell, 2003). There has been no documentation of whether the DG income is used for savings, whether it contributes to the formation of savings clubs, or whether it contributes to income-smoothing during negative shocks. Neither is it known if the DG is used to accumulate bank savings. Vorster et al. (2006) state that only about ten percent of DG recipients in the country have their grant paid into a bank account (as opposed to collecting it from a pay point), though this has provincial differences, the highest being in Gauteng (43 percent) and the lowest in KZN (only one percent). Thus not much is known about the utilisation of formal and informal financial services/ institutions by DG recipients, which will also be a focus of this study.

3.4. Research rationale and research questions

The effects of the OAP have been well documented, but it is not known if the DG has similar effects. The previous section showed that there are still remaining questions regarding, for example, DG expenditure, disability-related costs, utilisation of financial institutions, income-smoothing, household effects and intra household decision-making. What little is known about the DG draws from four mainly quantitative studies that have looked at the impact of the DG (Schneider and Marshall, 1998; EPRI, 2001a; EPRI, 2004; Vorster, et al., 2006). More research is clearly needed to understand the complex interaction between the DG and the labour market and to "gain an understanding of what constraints and barriers beneficiaries experience in attempting to move to employment" (DoSD, 2006b: 9). This will be explored in this study using the social model of disability, and by exploring the links between social and economic policy.

The research will aim to document the social and economic effects of the Disability Grant (DG) for PWD and their households, from the perspectives of PWD themselves.

Research questions include:

- What are the effects of the DG from the viewpoint and perceptions of PWD?
- What is the DG mainly used for (i.e. expenditure patterns) and are there specific disability-related costs?
- Does the use of the DG extend to the household and how does household composition and household formation interact with this?
- Does the DG have an influence on financial institutions utilised by PWD?
- Who or what controls decisions on the use of the DG?
- What is the status of PWD within decision-making processes?
- Does the DG pay for care or assistance of the PWD?
- Does the DG influence employment-seeking behaviour and labour-market access of PWD? How does the DG interact with PWD forming/having small businesses?

Taking the social model into account:

- Does the DG contribute to overcoming attitudinal barriers experienced by PWD?
- Does the DG contribute to overcoming physical barriers in the environment, and if yes, how?
- How does the research process reflect or overcome barriers to participation of PWD experienced elsewhere?

CHAPTER 2: METHODOLOGY

This chapter describes research methods used, focusing on obtaining qualitative information related to the research questions. It will elaborate on issues related to doing qualitative and participatory research with PWD.

Qualitative and participatory design

A qualitative methodology is effective in understanding social contexts from the point of view of the participants. This can be useful in disability studies since PWD are often marginalised, and such research gives them opportunity to voice their perspective on policies that affect their lives (Brink, 1991; Turmusani, 2004). There has been a recent move in disability studies towards “emancipatory” and “participatory” research designs.

Both these approaches support a move away from the traditional methods of studying disabled people as respondents only, and signal a move towards permitting respondents to have more participation and control of the research process (Turmusani, 2004:4).

While emancipatory research advocates for full and independent control of the research process by PWD, this may not always be possible on theoretical, contextual or methodological grounds (Turmusani, 2004).

My research study is based on a participatory model, which aims at participation and collaboration between researchers and PWD. The participatory method

implies that the role of the outside researcher is seen as that of an expert, although only in research skills, and that the local people or the target group, are the real experts in knowing their situation (Turmusani, 2004:8).

Nagata (2007) recommends the use of a participatory methodology, especially in research linking disability, poverty and development, which aim to increase people’s own analysis of their conditions and are used as part of triangulation of data (Pretty, Guijt, Scoones and Thompson, 1995).

Sampling

The sample included PWD residing in KwaZulu Natal Province, specifically adults with physical, hearing and seeing disabilities (using the 2001 Census definition of disability). Due to the limited scope of this study, people with intellectual disabilities or mental illnesses were not included, yet they are an important part of the disability sector, and a follow-up study should be done highlighting specific service needs for different categories of disability. For the purpose of this study it was assumed that a person who is currently getting a DG is “eligible”. I purposely aimed to avoid recent controversies about eligibility, assessment criteria and uptake, especially the extension of the DG to people with HIV/AIDS (studies looking into this are for example Kimani, 2000; CASE, 2001; Nattrass, 2006).

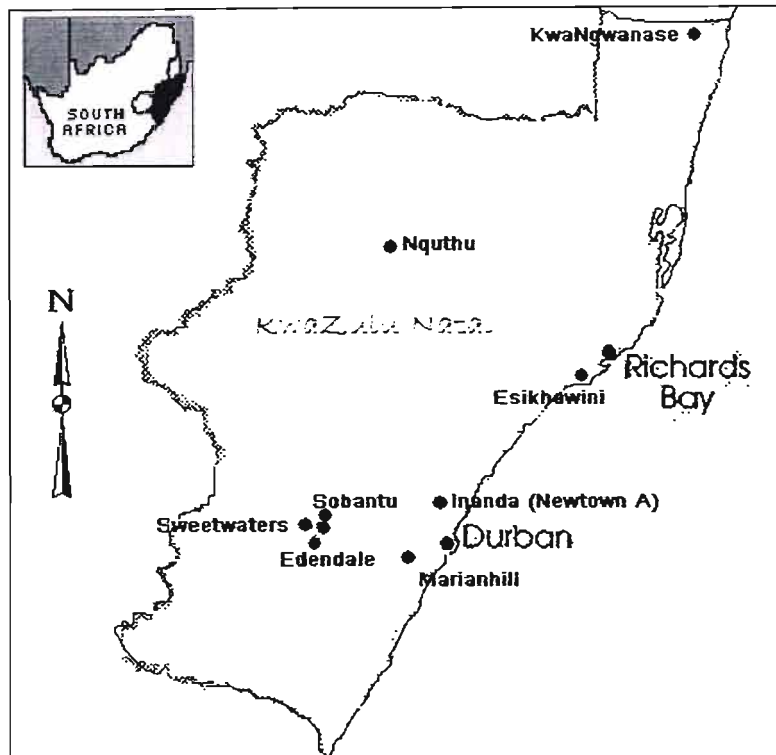
Non-probability quota sampling was used to ensure the inclusion of people with different categories of disabilities (hearing, seeing and physical disabilities), residing in urban, peri-urban and rural contexts in different parts of the province. Sampling aimed for equal representation of males and females, as well as focusing on Black/African DG participants, since 75 percent of DG participants fall into this category (Vorster et al., 2006) and it reflects the racial distribution of both the South African population and of PWD in general (StatsSA, 2001). Table 1 shows the characteristics of the sample, by area, type of disability and gender of participants.

Table 1: Numbers of participants attending focus group discussion, by area, type of disability and gender.

Area	Physical	Visual	Hearing	Male	Female	Total
Sobantu	8	-		6	2	8
Sweetwaters	6	-	-	3	3	6
Inanda	5	-	-	3	2	5
Nquthu (Pilot site)	6	-	-	4	2	6
KwaNgwanase	8	-	-	7	1	8
Marianhill	-	-	2	-	2	2
Edendale	-	8	-	4	4	8
Esikhawini	-	2	1	2	1	3
Total	33	10	3	25	13	46

Figure 3 shows the location of sample areas, which are a mix of urban and rural areas. Appendix 3 gives a more detailed description of each area.

Figure 3: Map of KwaZulu Natal showing location of sample areas



However, within this sampling frame, there was also purposive sampling of areas/communities where a Community Rehabilitation Facilitator (CRF) was working. CRFs receive a two-year training in Community-based Rehabilitation. I was involved as Occupational Therapist in the training of the CRFs, and so had contact with them and knowledge of their areas of work. After the training, CRFs are employed by a district Department of Health, hospital or NGO, and work with PWD on a regular basis. CRFs were involved as research assistants/facilitators and for identifying and inviting people with different disabilities residing in their area to participate in the focus groups. Use of CRFs aimed to increase access to and trust with PWD, and to ensure that any concerns raised at the focus groups could be followed up. CRFs acted as co-facilitators and translators from English to isiZulu during the focus groups. Two of the CRFs also did translation from English to sign language. CRFs received an orientation session, which

outlined the background, research questions, research process and their role. CRFs identified PWD in their area, based on representativeness of type of disability, age and gender. A limitation of this method, however, is that the participants had to be known by the CRF and were often selected based on convenience, e.g. people with a telephone, who were close to the CRF or able to use transport more easily. Few people with severe or multiple disabilities, or who were bedridden, were therefore included. Inaccessible or unavailable transport often affected practical arrangements and in many cases a private car had to be used to fetch people who were either unable to walk/get to public transport, or where public transport was non-existent or inaccessible.

Data collection

Data collection tools included focus groups, a participatory method, researcher's reflection and CRF interviews.

Focus groups

“Focus group research involves organised discussion with a selected group of individuals to gain information about their views and experiences of a topic” (Gibbs, 1997:1). Focus groups are suited to obtaining several perspectives about a topic, based on the ways in which individuals interact, agree, or differ about the topic (Gibbs, 1997; Bloor, Frankland, Thomas and Robson, 2001). Using focus groups is often also seen as a participatory method, since “having found voice, groups may develop an awareness of their common predicament and attempt a collective remedy” (Bloor et al., 2001: 94). However, this is not always the case, since there may be dominance by more powerful participants within the group.



The recommended number of participants ranges between six to ten people, as larger groups may yield less depth (Gibbs, 1997; Bloor et al., 2001). In this study the size of the group ranged from two to eight. Where only two to three participants were present, this was mainly due to organisational difficulties and adverse weather conditions. Venues varied, but were chosen because of centrality, access to transport and physical accessibility of the building. Usually this was a community hall, although in some cases it was a room at a library or a person's home. A recommended length for a focus group is up to two hours. In this study the length was usually up to three hours because of using participatory activities, translation from English to isiZulu, and in some cases sign language translation.

An interview schedule was used to outline topics that would be discussed in the groups (see Appendix 1). Discussions were started with either the participatory technique (discussed below) or with an open question on how the DG has affected the participants' lives. This was followed up with probing questions if topics did not come up spontaneously. In this way participants were open to bring in their ideas and understandings. Focus groups were taped and transcribed. During focus groups, notes were taken which included documenting group process, non-verbal behaviours and tone of voice.

Participatory technique

Four of the focus groups made use of a participatory technique, namely drawing a time-line, which is only one of many diverse diagramming/visualisation techniques that fall within a participatory design. Visual techniques are beneficial in promoting dialogue, in providing a focus for attention while discussing, in prompting discussion by both non-literate and literate people, in representing complex issues or processes simply and in stimulating peoples' memory about their past and present situations (Pretty, et al., 1995). In the time-line technique, individuals draw a line depicting their life, which marks significant life events, both positive and negative. Positive events are shown by the line going up, whereas for negative events the line is drawn downward. The result is a type of "graph" showing a line that may spike upwards or downwards at various life intervals.

Photograph 2: Drawing time-lines (urban area)



Photograph 3: Drawing time-lines (urban area)



While this method was useful in stimulating discussion, it did not always allow the discussion to cover all research questions, since feedback takes a long time. A second constraint was that such a visual method is not easily adaptable to people who are blind and may exclude them (Yeo and Moore, 2003). While the time-line activity has previously been adapted to a tactile method (using ropes and stones), I decided in this study not to use it in certain of the focus groups, for example those who had people who were deaf and blind, due to time constraints in using translators for both Zulu and sign language. A last weakness is that it is often difficult to translate this information into written form. Thus feedback and discussion was used to put the visual into written form, which was then included in transcription, coding and analysis. Thus some of the focus

groups were conducted without the time-line activity, which allowed more time for discussion on current life-situations and issues raised by the participants.

Reflective journal/contact summary sheet

Miles and Huberman (1994) highlight the need to have a form of self-reflection after each field contact. A contact summary was done after each field visit, using their proposed questions to guide reflection:

- What were the main issues or themes that struck you in this contact?
- Summarize the information you got (or failed to get) on each of the target questions you had for this contact.
- Anything else that struck you as salient, interesting, illuminating or important in this contact?
- What new (or remaining) target questions do you have in considering the next contact? (Miles and Huberman, 1994:53).

The reflection after the contact also included comments on process, interactions, my own reactions and remaining questions. This type of reflection increases self-awareness, highlights information gaps, helps to guide planning for the next contact, helps to summarise the contact, and aids in data analysis (Miles and Huberman, 1994; Rubin and Rubin, 1995).

Reflective interviews with research assistants/CRFs

After each focus group the CRFs who acted as research assistants/co-facilitators, were interviewed. They were asked what issues stood out for them, any new ideas not known before, or to confirm issues related to their experience of working with PWD. This was also used as a form of reflective dialogue, in which the research team exchanged ideas and reflected on the process and content of the group discussion.

Data analysis

Data were collected as transcripts of focus groups (including feedback from participatory technique and notes taken), transcripts of reflective interviews with CRFs and own reflections after each contact (including contact summary sheets). Content analysis was applied to the data in which pieces of data were classified, categorised and marked with

codes. Reflections and other remarks were also made in the margins of the transcripts as they were read (Miles and Huberman, 1994, Rubin and Rubin, 1995; Babbie, 2002). Codes were pre-determined (based on the theory and research questions), as well as created inductively, emerging from the data as it was read (also known as 'open coding') (Strauss and Corbin, 1990 in Babbie, 2002). This meant having a start-list of possible codes (keyed to research questions), but gradually adding emerging codes as well as revising, expanding or breaking down codes (Miles and Huberman, 1994; Hayes, 2000; Ulin, Robinson, Tolley and McNeill, 2002). Once the data had been thoroughly labelled with codes, these were clustered around themes relating to each other in a conceptual web (Miles and Huberman, 1994).. Summary of preliminary findings was given to participants to enable their feedback.

Verification of authenticity of data

Ulin et al. (2002) and Krefting (1991) list four criteria with which to establish trustworthiness of qualitative findings, namely credibility, transferability, dependability and confirmability. Credibility (portraying multiple and diverging perspectives) was increased through representative sampling, noting diverging perspectives during analysis, triangulation of data sources and methods, and reflective practices. Feedback of findings was given to participants through the community workers, so as to allow comment or verification of accurate representation of data. Transferability (application of findings to other contexts) was increased through detailed description of research context and participant characteristics, and noting whether findings were typical or atypical. Dependability (replication of study with similar subjects or context) was increased by recording a descriptive 'audit trail' of methods, and through triangulation. Confirmability (allowing external scrutiny of process and product) was increased by storing all forms of raw and process data (in this case in the University storage facility for five years), so as to create an 'audit trail' which will enable other researchers to review the analysis decisions (Ulin et al., 2002).

Ethical considerations and informed consent

My own experience as Occupational Therapist working for a disability NGO assisted in using appropriate facilitation of the focus groups, as well as appropriate and sensitive

interaction and handling of issues arising from the discussions. Where issues arose that required further intervention, these were appropriately referred to the CRFs or social workers employed in the study areas. My professional status, as well as being an “outsider” (being non-disabled, white, female) may have had an influence on the research process, for example creating either false expectations or fears. Therefore at the beginning of each focus group I tried to explain my role and intentions as openly as possible, for example, stating that I was not from a government department or a funding agency, and that the intention of the research was to make the voice of PWD heard, as well as make policy recommendations. My purpose during the focus groups was therefore to act as facilitator, allowing diversity of opinions. Research assistants (CRFs) were known to the participants, and since the CRFs’ work involves addressing disability issues, it would be beneficial for the participants to be open about any issues affecting their lives.

Informed consent was explained at the beginning of each focus group (including confidentiality, voluntary participation, withdrawal or refusal to answer). This was done verbally, though an agreement was signed (see Appendix 2 and 4). Permission to use photos was obtained from relevant participants.

Ethical clearance was obtained by the Higher Degrees Committee of the Faculty of Humanities and Social Sciences of the University of KwaZulu Natal (UKZN).

Ethical Considerations { informant

- My own experiences as Occupational Therapist working for a disability NGO assisted in using appropriate facilitation of focus groups as well as appropriate & sensitive

CHAPTER 3: FINDINGS

This chapter is an outline of the findings regarding the use of the DG, the interactions of the DG with the household, with poverty and with financial institutions, as well as the relationship between the DG and employment of PWD. The chapter will indicate whether the findings are in line with existing literature or whether they show different or new perspectives. Chapter four will then follow with a synthesising discussion that aims to draw broader links between the social and economic effects of the DG from the view of the social model of disability, with implications for inclusion of PWD in research, policy and development processes.

3.1. Expenditure patterns

While there was diversity in how participants described using their DG, there was a general convergence that the spending was mainly on basic household needs. The most frequently mentioned use of the DG was to buy food. There were a variety of other expenditure items, in differing combinations and the order in which they were listed. Table 2 lists the range of responses given by participants, in approximate order of frequency or perceived importance.

Table 2: Major expenditure items bought with the DG money

<p><u>Most frequently mentioned items</u></p> <ul style="list-style-type: none">• Food /groceries• Basic clothing• Paying school fees for own children or siblings (and other school-related expenses such as uniforms)• Rates, water, electricity (urban areas only)• Insurance – life and funeral cover policies• Toiletries (e.g. toothpaste, soap, feminine hygiene products etc)
<p><u>Less frequently mentioned items:</u></p> <ul style="list-style-type: none">• Disability-related costs: hired transport in absence of accessible transport; paying for assistance (e.g. pushing wheelchair, household tasks, accompaniment of a blind person)• Housing needs (rent or pay off government house; rural areas – build own house)• Paying for own further education• Furniture and household items (often a once-off expenditure, not recurrent)• Transport to clinic/hospital or medical expenses

Food and clothing

The most common response in all eight focus groups was use of the DG to cover food and basic clothing. In the rural areas KwaNgwanase and Nquthu, the money was primarily used to meet basic needs, especially food and clothing. This finding confirms quantitative results by Vorster et al. (2006), and findings on the use of the OAP on food (EPRI, 2002; Moller and Sotshongaye, 1996).

Educational expenses

The DG was very commonly used to pay for school expenses of children living with the DG recipient, and it was well documented in all areas, both urban and rural.

After the grant I was now able to take my children through school until Std. 10.
(Female, 48 yrs, physical disability, Inanda)

With the DG I can help my brothers and sisters by paying their school fees, especially now that my father has died. (Male, 33 yrs, physical disability, KwaNgwanase)

In one case it helped to pay for school expenses of the siblings as well as those of the person with disability.

I got my DG during high school. It helped me a lot to stay in school and paid for my brothers and sisters to go to school, because my father wasn't working. I pay the school fees. (Female, 26 yrs, physical disability, Nquthu)

While there has been brief mention in the literature on the use of the DG for family members' education (Schneider and Marshall, 1998), as well as through use of the OAP (Moller and Sotshongaye, 1996; EPRI, 2002), the present findings give a much more detailed documentation of how the DG gets spent on schooling for others. There seem to be no gender differences, as both males and females mentioned this. There were a few cases of using the DG to pay for their own education (e.g. FET college and ABET project), but in most areas this was not common.

Urban expenses: Electricity, water and rates

After food, other expenditure patterns varied according to location, the main differences being between urban and rural areas. In urban Inanda, Esikhawini and Sobantu the

majority of DG recipients mentioned electricity, water and rates as an expense, while in rural Sweetwaters, Nquthu and KwaNgwanase, these were not mentioned. In two urban cases this was the first expenditure item mentioned, highlighting the relative importance in their situation. Electricity as the second most important expenditure item was also mentioned by Vorster et al. (2006), who additionally highlighted provincial differences.

Housing

Housing expenses were not commonly mentioned. When they were referred to in rural areas, they were connected to building materials or fencing.

When I got this DG I was able to build a two-roomed reed house, because the house we were staying in before we were squashed, all sleeping together in the same room... The money wasn't enough to build the house quickly, but I was able to finish it over time. (Male, 31 yrs, physical disability, KwaNgwanase)

Three cases in urban areas (Esikhawini and Inanda) mentioned using some of the money to pay rent. Findings by Vorster et al. (2006), Schneider and Marshall (1998) and Moller and Sotshongaye (1996) seem to support the fact that rent is a relatively uncommon expenditure item. None of the participants mentioned the need to make disability-specific housing adaptations because of the disability, although this was not specifically probed for.

Medical expenses

Very few participants mentioned having to pay for medical expenses or medication or assistive devices (such as wheelchairs). This is probably because of the policy of free public health care and assistive devices for PWD, which seems to have made a positive impact.

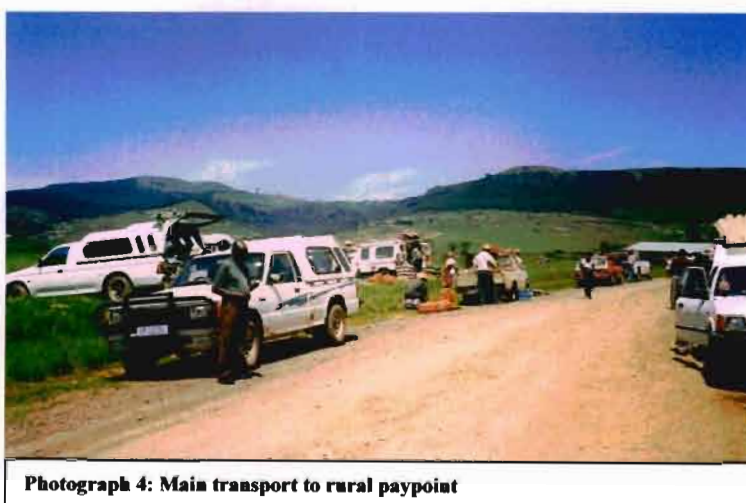
It is better now that the government has said that assistive devices are free. Before, I used to use some of the grant money to buy assistive devices. (Male, 29 yrs, physical disability/wheelchair-user, Inanda)

When medication was not available at a clinic, this was occasionally bought at a private pharmacy with DG money, similar to what Vorster et al. (2006) found, namely that medical expenses were a lesser expenditure item.

3.2 Disability-related costs

Transport cost with physical disability

Inaccessible public transport (especially buses and taxis) was mentioned frequently as necessitating expenditure on alternative means of transport. Sometimes it was not only the physical inaccessibility (e.g. step of bus or taxi too high), but also attitudinal discrimination (e.g. taxi drivers that were either unwilling to transport a wheelchair, or charged the person double fare because of it). Especially wheelchair-users mentioned transport being inaccessible and also people with a difficulty walking or using crutches who cannot walk far to reach the transport. When a private car was hired, this was at a disproportionately high cost as compared to public transport for example, where the local bus-fare was about R3, a similar trip in a private hired car cost between R50 and R200.



Transport to collect the grant from the paypoint was also frequently mentioned. This was evident from my own observations at the Sweetwaters pension point where no buses or taxis were used to reach the community hall. Only private cars and bakkies were hired, which could pick people up from home. Payment for transport is an even more serious issue in rural areas such as KwaNgwanase, Nquthu and Sweetwaters. All three these areas only have one main tar-road, and many homesteads are kilometres away, with only dirt or sand roads or small footpaths as access. Thus distance to public transport may again require extra expenditure, e.g. paying someone to push the wheelchair, especially in KwaNgwanase where the soft sand makes pushing one's own chair an almost impossible task.

In order for me to get a taxi I must go far with a wheelchair. So I must ask someone, like a neighbour, to help me. But they say: "For me to push you, you have to pay me something". If I say: "I can pay you R10", they say: "No, that's not enough, you must pay me R25". If you have to get to the taxi rank and maybe you need to ask someone: "Can you please help me into the taxi?", they say: "Then you must pay me R3 so I can go and buy a loose cigarette". So I have to pay many people to help me. (Male, 31 yrs, physical disability/wheelchair-user)

While the quantitative study by Vorster et al. (2006) mentioned transport as an expense, it only focused on access (distance and cost) to public transport by the household in general, and did not focus on expensive alternative transport. It has also not been documented previously how various community members (sometimes neighbours or passers-by) may be involved to give that assistance, and often at a cost.

Sighted-guide accompaniment with blindness

For many of the blind participants, a trip to town or a place such as a bank, police station, or welfare office means that assistance of a sighted guide is required. The person accompanying them could be a family member, neighbour, friend or stranger. Often it meant paying for transport of the assistant, but sometimes they also required a fee. There was a sense of being 'forced' to pay for such help, because if one did not, that person would not help again in future. Most blind participants were orientated to their home environment, moving around using a cane and independent in household tasks, but a trip to an unfamiliar environment required accompaniment of a sighted person. This person could also help with tasks such as collecting their grant, filling in forms, going to a bank, finding the right transport, crossing roads or shopping. It was also mentioned as a cost during the application (or re-application) process for the DG.

Every month I have to pay someone to accompany me to collect the grant, because if I don't do that, I can't go and get the grant. Even when I go to the bank, someone must accompany me. When I fill in a form... or go to the hospital, everywhere – I've got to pay for it...usually about R250 [per month] ... This month it is more, R450, because I had to go to the bank at Empangeni, the welfare office, eye clinic, because I was preparing to get my grant through the bank

account. So I had to go to-and-fro, to-and-fro, and every time I have to go with someone, pay for their transport and also giving them something, thanking them. Because if you don't give them something, next time they won't help you... I am actually independent at home. I can do cooking. It is only on the trips I take that I need help. (Female, 37 yrs, blind: Esikhawini)

The findings in this section highlight that assistance is often not needed in the home environment, provided by a family member (which has been the focus of other studies looking at caregiving needs e.g. Frieg and Hendry, 2002). This study shows that PWD require occasional assistance from a variety of people to travel outside the home environment.

Sign language interpreter with deafness

For a deaf person, a specific trip or task could necessitate paying for the services of a sign language interpreter.

I don't usually pay for someone to translate. But if I say go to the police, I pay transport for my friend who goes with me to translate, then maybe a small fee and some food for them – so I pay double transport money. (Female, 35 yrs, deaf, Marianhill)

Household assistance and caregiving

Many participants were independent in the home environment. There was however one situation where a single male with multiple physical disabilities had to pay for someone to help with household tasks.

I have to pay people to help me – even at home. I don't have a wife at home to help me, so I have to pay someone to clean the house. (Male, physical disability, Sweetwaters)

Few mentioned directly paying for caregiving services. Rather, there was a sense of increased independence on receipt of the grant and in now being able to buy things for themselves. Some participants relied on indirectly-paid help from family members for only some tasks, e.g. a wheelchair user in KwaNgwanase needed help to fetch water from the river because terrain was inaccessible. He did not directly pay family members to

help, yet they indirectly benefited from DG used for household expenses. This may link with findings by Frieg and Hendry (2002) that indicated that where PWD that needed care from a family member, this person was often not employed, indicating possible reliance on the DG. This links with findings by Vorster et al. (2006) who state that 84 percent of DG recipients did not indicate paying for care, though this excludes mention of unpaid care or indirect payment through contribution to household expenses. The findings of the present study, however, need to be viewed in terms of sampling that excluded people with multiple or severe disabilities, who may need full-term care.

3.3. Household interactions

Household composition

Many participants commented that the DG helps them as well as their family/household and is therefore often seen as a collective grant for household needs. While some showed satisfaction with the amount, many thought it was not enough to cover their needs as well as those of the household. This must be understood by looking at the household composition and how this affects the use of the money.

Income dilution and large households

The type of household that puts the most pressure on the DG money is a large household, in which the grant is the only source of income. This may interact with a context of high unemployment, where other adult members also rely on the grant. This was the case in a few multi-generational extended families with up to 11 members, who mentioned only buying food or basic items.

The money isn't enough because there are many in our family and I must support my siblings. We use the money to buy food, clothes, toiletries etc. We are eight in our family – my family is so poor and I have to carry all the burdens of this family using the grant. It is not easy. (Male, 31 yrs, physical disability, KwaNgwanase)

Even where another member of the household was working, this was usually in a low-paid position where they often earned less than the grant amount (usually between R250-R600 per month). In one household where the parents had passed away, the DG plus an

income of R250 supported a household of five siblings. Similarly, even in a household with other grant income, this must often be divided among a large household. An example of this is with a 41 year old female DG recipient from Nquthu who stays in a multi-generational household of ten people who depend solely on grants (1 OAP, 2 DGs and 1 CSG, with total household income less than R2500).

This mirrors findings on the use of the OAP to support the household (Edmonds et al., 2001; EPRI, 2001b; Keswell, 2003; CASASP, 2005). It also documents in greater detail the finding by Schneider and Marshall (1998) that the DG often supported others beyond the DG recipient. It shows various examples of income dilution due to large household size, even when the DG is pooled with other grant- or salary income. It corroborates findings that a larger household is more likely to remain poor despite the benefits received (EPRI, 2001b; Bertrand et al., 2003; Klasen and Woolard, 2005).

Older and younger children in households

Many participants stayed in households with their own children of differing ages (baby to adult), children both from before or after they became disabled. Sometimes grandchildren were living in the same house. Often the DG was used to support the children in the household, whether for food, clothes, or school expenses. In the case of younger children, the DG was often combined with the CSG, though in some households there were children eligible for the CSG who were still not getting it. When there are older or teenage children in the household who do not receive the CSG, it puts extra pressure on the use of the DG to care for these children.

I have a 17-year old son and 13-year old daughter. They go to school and the grant cannot meet all their needs, but it is still better than nothing... I need to take care of my family and on the other hand also take care of myself; it's difficult to balance the two. (Male, 46 yrs, physical disability, Inanda)

The role of parent combined with the role of DG-recipient was in some cases described as a 'breadwinner' role, especially where the DG was the only income.

I'm the breadwinner, I take decisions. I no longer stay with my mother and father.
(Female, 50 yrs, physical disability, staying with her five children aged 15-34 years)

The above findings show how the DG may support children in the household since both males and females of varying ages indicated expenditure to care for their children, similar to documentation of the child-supporting effects of the OAP (Moller and Sotshongaye, 1996; Case and Deaton, 1998; Lund, 2002; Keswell, 2003), though without marked gender differences.

Establishing an own household

In three cases the DG acted as catalyst that enabled the persons to move out and start their own family, and to move out into a separate house.

When I got this DG I was able to build a 2-roomed reed house, because the house we were in before, we were squashed all sleeping together in the same room. So now I was able to move out into my own house...I was now able to take two brothers in – one slept in the dining room the other in the other room. (Male, 31 yrs, wheelchair-user, KwaNgwanase)

The line went up when I got the grant, because now I could get a 'makhoti' (wife-to-be) to help me. I now have two children from her. (Male, 28 yrs, physical disability, Nquthu)

Not everyone, however, agreed that the DG made it easier to start out on one's own.

The money is not enough if you want to get married and have kids – it won't be enough to cover the needs of a family. (Male, 24 yrs, blind, Esikhawini)

Very little has been documented on how grants may lead to new and independent households being formed.

Impact of death

During the participatory time-line activity, death of a household member was described as a negative experience, often due to the loss of OAP, or wage income, or because of added household members, factors that increased pressure on the use of the DG. An older male from Sobantu described this as having “two families” that live off the grant, as he

sends money to his orphaned grandchildren (after his daughter died), as well as supporting his two adult sisters that stay with him. A 56 year old female with physical disability from Sobantu described the impact of the loss of the OAP at the death of her mother, with the added responsibility of orphaned grand-children after the death of her daughter.

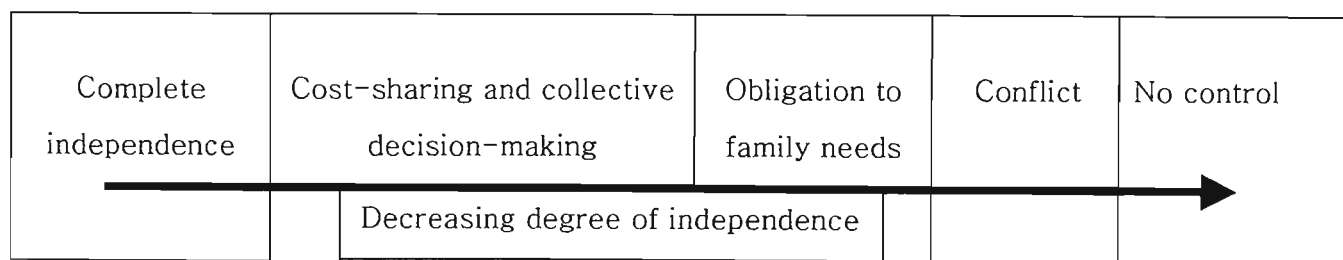
The OAP has been documented to be used towards the care of orphans due to HIV/AIDS (Edmonds et al., 2001; Legido-Quigley, 2003), but this has not previously been shown for the DG, as the above examples do. The effect of the death of an OAP recipient on the rest of the household is also not well documented, whereas above examples show how loss of the OAP puts added pressure on the use of the DG.

Household decision-making processes

DG use is influenced by the composition of the household, but this needs to be expanded by looking at the decision-making processes within that household. Moller and Sotshongaye (1996), EPRI (2001a) and Mitra (2005) all comment on the lack of research on intra-household distribution of grant income, and the relationships between the grant recipient and the household. There is some mention of OAP recipients being either primary decision-makers or being in a weaker position because of being elderly, and that there may be gender differences in this (Edmonds et al., 2001) – but there has been no documentation on decision-making processes of DG recipients and their household.

The following section will show how nuanced decision-making is. Decision-making processes can be placed in a continuum from complete independence, to no control, as shown in Figure 4.

Figure 4: Continuum of decision-making processes regarding DG use



PWD receiving the DG therefore had varying levels of control and involvement in the decision-making process on how to use that DG, and the continuum reflects a lessening degree of independence from left to right. Each block will now be described in greater detail.

Independent decision-making

Some DG recipients made an independent decision on how to use the DG.

I collect it myself. I am the one who decides 'I will give you so much'. They don't decide for me. (Male, 23 yrs, visual impairment, Edendale)

It's my money. I decide how to use it. (Male, 34 yrs, physical disability, Sweetwaters)

This type of response was frequently reiterated, often with a sense of being free from family interference or influence. In the time-line activity some mentioned the DG having the positive effect of increasing their independence, both in self-reliance and decision-making.

The line goes up when I got my grant, because I could manage to do things for myself. (Female, 41 yrs, visual and physical disability, Nquthu)

To me getting a DG is so helpful. Before I was getting it I was so frustrated. So now it is enough for me, because I can buy something for myself that I need. Maybe if I need some clothes, I can now buy it, or some other things for myself. It makes me feel I am independent, not always to ask my mum. (Male, 26 yrs, deaf, Esikhawini)

Similarly, a 37 year old female from Esikhawini who is blind, described how the death of her parents left her more vulnerable and dependent, while receipt of the DG after that helped her regain independence.

I have been blind since I was very young, two years old. I am living with my brother because my dad and mum passed away...I only got my grant years later in the 1990's. So before that everything was bought for me by my brother ... For a long time I kept quiet because I was shy. I didn't want to disturb my brother, because he was overloaded with his own family and children. I didn't want to be a

burden, so I just kept quiet and accepted whatever I could get. But there were a lot of things I would have liked to get for myself. Even education – I couldn't even mention going to school, so I have had no education till now. Because I wasn't with my parents I couldn't complain too much – I only had to take this and that. So after I got the grant, it helped me quite a lot.

Cost sharing and collective decision-making

Some described a more collective way of deciding how to use the money, often in a process of reaching agreement with others in the household. This usually meant talking to family members, or giving an agreed portion of the money to another family member who would then decide what to do with that contribution.

I live with my mother. We split the money into two. She takes half, then I take half. With my half I pay my school fees, and buy some things I need like toiletries or things like that. (Male, 20 yrs, blind, Edendale)

I take some money and give it to my brother, just to contribute something...The contributions that I make are out of my own will. They don't do anything or even ask for the money. They don't bother me. (Female, 37 yrs, blind, Esikhawini)

Four participants in Sweetwaters mentioned talking to their mother about how to use the money. The CRF commented that he thought it was better to talk to one's mother, since disagreements started with sisters or brothers, especially if the parents in that household had died.

I talk to and share things with my family ...I usually buy a few little things at the pension point, like meat, juice, etc. Then I bring the rest of the money home to my mother. (Female, 41 yrs, physical disability, Sweetwaters)

When there is another source of income in the household, particularly a salary or an OAP, this often leads to either the money being pooled and then used to cover all household expenses, or alternately the expenses were divided up among different household members.

I've got a brother, and my mother is getting the OAP. The pension goes for electricity and water bills, and I buy the groceries. My brother is working at the factory, so we can come together to support our family. It helps a lot. (Female, 46 yrs, epilepsy, Sobantu)

Obligation to family needs

For some the DG was used collectively, not so much out of mutual discussion, but because of an awareness of, and an obligation to, the needs of the family. Some mentioned that because no one is working in the household or the grant is the only income, they felt a sense of obligation to meet the family needs, but not necessarily out of coercion by other family members.

Sometimes I have to support a lot in the family because I have to buy some food and pay some rent for the house ... At my home they are not forcing me to buy some food, but they ask me to help them. I am willing to support them ... I have to help my mother because she helped me before. I can't let my mother down. (Male, 26 yrs, deaf, Esikhawini)

With the situation around the family, you are almost 'forced' to buy food, because that's the only money they have. You can't live with something if you see that your family needs something ... otherwise you will lose your family. (Reflection by CRF from Esikhawini)

Conflicting needs

There are also situations where decision-making was difficult, especially when there were differing expectations or conflicting needs. Sometimes this involved a parent voicing a different opinion on how the money should be used, but in other cases this led to a more severe family conflict.

Sometimes, but not always, they may force you to buy something. If you want to buy something for yourself, they can say: "No, today you don't have to buy that – you must buy something that we want". Now it is worse, because I have children and this money is not enough. (Male, 30 yrs, physical disability, Nquthu)

No control

Lastly there were a few situations where DG recipients described having no control over the DG money, and where there was possible abuse of the money by family members, combined with neglect of that person. It does not seem as if there are marked gender differences in cases of abuse, and it seems like vulnerability is more based on severity of disability. Lack of control was especially evident where a family member was collecting the DG on that person's behalf. Sometimes this happened where a parent was collecting the CDG (Care Dependency Grant) for their disabled child, and continued to collect it even after it changed over to the DG when their child turned 18 years old. In other situations it was more a case of family manipulation to gain control over use of the money. Two of the stories told by participants illustrate this.

[The grant] doesn't help me at all, because my mother is just using it and spending it all... I collect it myself, but my mother just takes all the money...she just decides for me. (Female, 25 yrs, blind, Edendale)

My mother takes all the money...I don't get anything because they even lock the room and hide the key. She doesn't even pay for a funeral policy. At one stage I left home and stayed somewhere else. Then I had to come back and ask my mother for forgiveness. My mother said: 'I'll forgive you if you take me to the welfare offices and sign that I'm going to collect the grant on your behalf'. Now my mother collects it for me from the pension point. She buys some groceries, but I get nothing, not even pocket money. (Male, 35 yrs, physical disability, Sobantu)

In these cases there was a short 'debriefing' within the focus group, as well as a referral to the CRF or, where necessary, a social worker. In reflection after the focus groups, some of the CRFs mentioned the concern that there may be other PWD, possibly those with more severe disabilities or mental disabilities, that were in abusive situations. As mentioned before, the sampling may have excluded these, and further research into this area of concern is needed.

3.4. Interactions with poverty

Context of poverty

Receipt of the DG also interacted with the experience of poverty, which was described by the majority of participants, either as directly related to their disability or to the general context in which they lived. In the participatory method, many described their life starting on a low point because the family was already poor and facing hunger or unemployment, thus indicating that poverty was prevalent, not just among PWD.

Even if you are not disabled, you experience difficulties. (CRF, KwaNgwanase)

Yet, despite the prevalent poverty, the findings also showed examples of specific interactions between poverty and disability, for example where poverty was a cause of disability through poor nutrition or poor health care (e.g. leading to TB of the spine, causing paralysis), and conversely, where onset of disability led to poverty through loss of a job (e.g. losing a job on the mines due to a physical disability). This supports literature on the links between poverty and disability (e.g. Elwan, 1999; DFID, 2000; Yeo, 2001; Yeo, 2005; Emmet, 2006; Nagata, 2007).

The receipt of the DG into such a context of poverty had either positive or negative perceived effects. The following sections will explore in more detail these interactions with DG receipt.

Ambivalence in perceived effect of DG – ‘staying poor’

In a context of prevalent poverty, participants described the effect of the DG as beneficial to a certain degree. It was not described as having a positive effect on the person’s life, because it did not allow them to exit poverty.

My family is so poor and I have to carry all the burdens of this family using the grant. It is not easy. (Male, 31 yrs, wheelchair-user, KwaNgwanase)

This was also evident in the participatory method, where initial receipt of DG was a positive experience (line went up), but usually shortly after that the line went down when

the money did not cover all expenses, or the family continued to struggle to meet their needs, or it did not allow a person to meet their aspirations of a better life.

This money helps us a lot but it is not enough to do everything. (Male, 29 yrs, physical disability, Sobantu)

The DG money is too small; it is not enough to think about the future. (Male, 38 yrs, physical disability, KwaNgwanase)

Improved lifestyle – exiting poverty

There was also evidence of those who were able to exit poverty on receipt of the DG, which was described as having a sense of an improved lifestyle, or now being able to live as normally as everyone else.

My family were happy to start getting money, because they knew for sure they could start getting rid of poverty. They knew their life could change because now they could get a bed, TV, some blankets and all those things. (Female, 41 yrs, physical disability, Sweetwaters)

The money also led to many becoming less of a burden on a family that was struggling as it is, and thus no longer needing to ‘beg’ from others.

I was told to apply, so that I won't have to worry people by asking for food and all those things...now things are just fine as I'm getting the grant. (Female, 34 yrs, deaf, Marianhill)

Before I got the grant, I was a burden to my family. But since I got it, I no longer need [financial] assistance – I'm no longer a worry to them. (Male, 50 yrs, physical disability, Inanda)

Experiencing financial ‘shocks’ – re-entering poverty

Exit from poverty after DG receipt did not necessarily mean protection from events or costs that could push them back into poverty. One reason for this financial vulnerability was the lack of savings as buffer. This left a household vulnerable to financial shocks – unexpected expenditure or loss of a source of income. With some, the termination of DG

income was a financial shock, due to the lapse of a temporary grant or a permanent DG that was unexpectedly terminated ‘for review’. This often negatively affected households, especially those where it had been the only source of income. Sometimes it happened unexpectedly, without a ‘grace period’ in which to reapply, and sometimes it happened repeatedly.

My grant was coming and going, coming and going [was cut and had to reapply], so it was only every time it came, that things were better. (Female, 48 yrs, polio, Inanda)

Loss of DG for review sometimes meant selling of previously-acquired assets or going into debt. The re-application process also meant paying money for transport to the nearest welfare office, and this was often costly, given the inaccessible transport situation, or paying for accompaniment.

I had to go and check often, and it costs money going to the welfare office every time. And if you are blind, you have got to pay for the person who is accompanying you. (Male, 24 yrs, blind, Esikhawini)

3.5. Financial institutions

The next section will look at transactions around the DG – how it is received, as well as how it is managed. It will also explore how the DG interacts with financial institutions in dealing with or buffering financial shocks. Getting and managing the DG may have cost implications, therefore analysis of the financial institutions that are involved in this can be helpful in understanding poverty dynamics.

Banks vs. paypoints

While the majority of DG recipients still collect their DG once a month at a mobile paypoint, a number have started to receive it directly into a bank account or are currently applying to do so. Vorster et al. (2006) found that KZN province has the lowest proportion of DG recipients who have the grant paid directly into a bank account. The findings below outline possible reasons for this, based on the perceived advantages, and disadvantages as well as issues of access to both methods of receipt.

Banking was described as advantageous when DG recipients don't need to travel far to a paypoint (especially where expensive alternate transport or accompaniment is needed). For some the cost of bank charges was still lower than the cost of collecting the DG from a paypoint. Banking is also convenient since the person does not need to attend the paypoint on a particular day, and can avoid the stresses that accompany waiting at a paypoint. Participants felt that bank charges were a disadvantage. Usually R20 is deducted on deposit of the DG, with subsequent charges per transaction. The high cost of banking is a development issue, since these costs will affect those in the lower income deciles to a greater extent. A number of people were in the process of applying for the DG to be paid directly into a bank account, but even the application process meant extra costs for transport or accompaniment. Some PWD did not have the knowledge about how to access or open a bank account.



Photograph 5: Social Security Agency vehicles at rural paypoint



Photograph 6: Wheelchair-user outside rural paypoint

A paypoint is advantageous in an area that has lack of banks. A rural area like Sweetwaters, for example, has only a small local shop, with no other facilities such as banks or ATMs other than in the city centre of Pietermaritzburg, which is about 40-50 minutes travel by bus, making it especially difficult for those unable to use public transport. Therefore most participants collected their DG at the paypoint at the community hall and travelled there with private hired cars. The disadvantage of paypoints includes many stresses, for example waiting for a long time in the queue, people pushing, lack of control of the lines, bribery of officials, not enough money available at the paypoint, or lack of consideration for those with a physical disability who cannot stand/wait for a long time.

I wake up in the morning to go as early as possible to stand in the queue...When I come, even at 6a.m., sometimes the pay-cars come late and sometimes the money is not enough, then you must come back tomorrow...Everyone is just pushing forward because they want to be the first. There are these people who should control the lines, but they are not able to do it properly. (Female, 37 yrs, blind, Esikhawini)

The security who look after the queue are very harsh. They don't care about your disability. When you ask for a line for people with disabilities, they tell you...to go back to the end of the line. If you want to go you must pay them R10...Others give the security R10 after they got their pay. I don't pay it. (Female, 41 yrs, physical and visual disability, Nquthu)

Savings

Lack of savings

Access to banks affects people's ability to save, which in turn affects the ability to deal with financial shocks. In areas where there are no banks or very few (or distant) ATMs, this was cited as a reason for not having any savings in a bank account. However, the more common reason for not being able to keep any savings was that the money was used up.

The money is too small for me to save anything... what is left is too small to even put R20 aside. (Female, 26 yrs, physical disability, Nquthu)

Some mentioned having considered opening a savings account, but realised that it would be useless. Others actually tried to put a small amount into an account, but found that as needs arose in the family, it necessitated withdrawing all the money.

Different forms of saving

Only two participants mentioned actually being able to save money in a bank.

I do have a bank account. Every month I try and put R100 to R200 into it. (Male, 20 yrs, blind, Edendale)

I usually take it home and decide how my expenses are ...If I have R50 left, I pay it into a Mzansi account. But I have to meet my needs first, before I have anything to save. (Male, 30 yrs, physical disability, Nquthu)

One person mentioned the possibility of having a savings arrangement at paypoint, where the 'Cornerstone' company deducts a certain amount directly off the DG amount, which was perceived as beneficial as it was deducted automatically.

Participation in a savings club or stokvel varied in different areas and different arrangements were evident. A common arrangement was a small informal group of neighbours who paid in R100 to R200 per month. This combined amount was paid out alternately to members on a rotating basis. Others were larger, slightly more formal arrangements where members paid in differing amounts and were paid out annually, some with bulk food.

I participate in two stokvels. The one separates or pays out at the end of the year. The second one is small, has only four members, where we take maybe R100 and give it to another member and rotate like that. The first one is also just within a group of neighbours. (Female, 38 yrs, physical disability, Sweetwaters)

I put money (R100) in every month so that at the end of the year I get bulk food back (e.g. 10kg bag of flour, rice, mielie-meel, sugar). (Female, 50 yrs, physical disability, Inanda)

This formation of and participation in savings clubs is similar to that of OAP recipients described by Keswell (2003) and Moller and Sotshongaye (1996). With DG recipients, there was mention of barriers to participation, for example being vulnerable to abuse (not being paid out), or not being able to communicate (in the case of sign language not being understood).

Savings by buying cattle was not common, but was mentioned in two of the rural areas, Sweetwaters and KwaNgwanase. There was mention of being able to buy cattle after receipt of the DG, but that this was an insecure form of savings.

When I got my grant ...I also bought cattle, because that is how we invest as a culture in our black community. I had six cows but then they were stolen. (Male, 36 yrs, physical disability, KwaNgwanase)

Another person invested in cattle while working prior to becoming disabled, but had to sell them when the DG was stopped for review. Whereas the EPRI (2002) study indicated that households receiving grants were less likely to sell assets such as livestock during times of financial shock, it has not been documented how loss or termination of the receipt of the grant is in itself a financial shock.

Debt, loans and credit

Opening accounts

Inability to obtain credit is another factor affecting access to financial institutions. There was very infrequent mention of participants being able to open an account with a shop once receiving the DG, and often DG recipients were denied formal credit from larger shops, as they could not show a payslip.

The amount we get is right – I'm not complaining about that. What I am complaining about is that when you go to one of the shops and want to open an account, the shopkeepers say no, because you are only getting a grant. (Male, 50 yrs, physical disability, Inanda)

This conflicts with accounts of the OAP that indicate increased ease in accessing credit because the OAP is seen as reliable income (e.g. Moller and Sothsongaye, 1996).

Informal loans with family or neighbours

Informal loans were more common than formal credit or accounts at shops. These were mostly in the form of borrowing small amounts of money from family members, neighbours or friends. This corroborates the quantitative findings by Vorster et al. (2006) which indicate DG recipients contacting family members outside the household or neighbours in times of financial difficulty.

Paying back these loans sometimes takes precedence on the day the DG is received.

[On grant day] I look at my budget, and my list of creditors that I need to pay back money I borrowed. Its not credit from big shops, its from small tuckshops

and neighbours...I first pay back all my debts. (Male, 50 yrs, physical disability, Inanda)

One reason cited for getting loans from friends or neighbours was the lack of access to formal loan companies.

They are not given the chance from the banks or loan companies because they are not working. The banks need you to come with a payslip. That's why they borrow from friends, family, neighbours. (CRF, Inanda).

This highlights the lack of access to formal financial services often experienced by people in the lowest income deciles described by Ardington and Leibbrandt (2004).

Loan companies

In a number of areas there is a private loan company (mostly Cornerstone) that arrives at the paypoint and seems to work in collaboration with the SASSA (although the extent of the relationship is not known). This seemed to be a common means to get a loan, although concern about certain coercive practices and spiralling interest was also mentioned.

There is a car always waiting for people ready to take loans...But also they don't explain to you how much they are going to take at the end of the month, together with interest. With the policies, they are taken right there at the paypoints. People are moving along the line saying 'Take it – have you taken one?' And you sit right there filling the forms. (Female, 37 yrs, blind, Esikhawini)

There is always a yellow car accompanying the paypoint and this car is waiting for you to take a loan ... If you loaned R500 plus interest, they will take it off the money you earn. That means you have to come back to them because now you don't have enough money. So why are these loan sharks allowed to come and coerce people? ...People end up becoming miserable. (CRF, Esikhawini)

These concerns regarding loan practices at the paypoint have not been well documented, although they have been mentioned in the media, but without follow-up. This may need further investigation.

There were other less-known loan companies or individuals (also known as *mashonisa*), using less formal, possibly more drastic ways of ensuring repayment, such as taking the person's card or ID book.

There are mashonisa working at the gate. They take money from people and sometimes also your card. Some people loan money from them. They keep your card until you can pay it back from your pension money, until you bring that money back. Sometimes they keep your ID. (Male, 45 yrs, physical disability, Nquthu)

Most participants in Nquthu agreed that these loans and the way that *mashonisa* operate is problematic, yet many took these types of loans (even if it was undesirable) because of the absence of alternatives.

They take your card in a way that everyone can see – it's terrible. There are no places or banks where you can get a loan, so there is no better way to get a loan. Maybe we need a place where people with disabilities can get a loan. (Female, 41 yrs, physical and visual disability, Nquthu)

This again reflects the lack of access to formal financial services often experienced by people in the lowest income deciles described by Ardington and Leibbrandt (2004).

Reason for loans

A common reason for needing a loan was to cover whatever monthly expenses could not be covered by the DG, or if the DG money ran out by the middle of the month. This practice, however, often resulted in a vicious cycle of debt.

If it is the middle of the month and your money is gone; you need to borrow money to support yourself for that time, till you get our next grant. (Male, 28 yrs, physical disability, Nquthu)

[The DG money is] all taken by the home needs... often they have to borrow. So by the time they get their next grant already they have borrowed, to cover up, because it doesn't cover their monthly expenses. (CRF, Inanda)

This mirrors findings on the OAP by Moller and Sotshongaye (1996), who noted that some pensioners saw going into debt as a necessary burden to meet the needs of the household.

Another common reason for debt was when temporary grants lapsed or permanent grants were unexpectedly stopped 'to be reviewed'.

It was stopped last year, for the whole year, to be reviewed. When it was reopened, they only back-paid me for two months, but not for the rest, so I had a lot of debt because I couldn't make it... So if the grant stops, the [funeral] policy collapses. It's a problem. So they must warn us before they cut the grant so we can have a chance to go and renew it. (Female, 56 yrs, physical disability, Sobantu)

This also indicates that the review process may have knock-on effects on other financial commitments, such as stokvels or insurance policies. The concern of both CRFs and DG recipients was the lack of warning, where in some cases the person arrived at the paypoint expecting to be paid, but instead received a slip telling the person to go to the nearest welfare office, or arriving at banks where the payment of money simply ceased without notification. Reapplication is often a costly process, requiring frequent visits to the welfare office, where transport and accompaniment may be very expensive.

Insurance policies

Insurance policies, specifically life and funeral insurance, were a very common expenditure item and also had relative importance in a list of expenditure items.

The first things that worry me are the funeral plan, and stokvel payments. After that, electricity. But the bulk of the money goes for food and some school expenses for the children. (Female, 50 yrs, physical disability, Inanda)

Where they were unable to afford such a policy, or family members didn't pay for it, this was seen as a cause for concern. In Sweetwaters all participants reported having some form of life or funeral insurance, ranging between R52 and R150 per month. Participants in Inanda and Esikhawini mentioned Cornerstone policies that are deducted at the pension-point. Similar to the loans mentioned earlier, there was concern about the

relationship between Cornerstone and the SASSA, and whether there was coercion or misleading in recruiting grant recipients to sign onto such a policy.

Many cited the cost of a funeral as a reason for taking a policy and not wanting to leave the family with financial burdens.

I do budget for insurance so that if I die, no-one suffers. (Female, 26 yrs, physical disability, Nquthu)

A CRF reflected that this is possibly related to the fact that many people, also younger people, are dying (related to HIV/AIDS) and that there is possibly coercion by family members who want to benefit from the pay-out of life insurance. The relative frequency of DG recipients having a funeral policy supports findings of Ardington and Leibbrandt (2004) that indicate a more equal distribution of funeral policies across income deciles, as compared to other financial services. Where they indicate that OAP receipt is a strong indicator of having a funeral policy, especially in rural areas, this is similar for the DG.

3.6. Employment/unemployment

Employment and unemployment of PWD needs to be understood in context of, firstly, the social model of disability which enables us to view physical and attitudinal barriers to the workplace, and secondly, the current labour market context in South Africa. Participants commented on both these aspects, which will now be described in more detail.

Barriers to work and employment

Inaccessible environments (physical barriers)

One reason for the difficulty PWD have in getting jobs are inaccessible environments, for example a building with no ramp access, no lifts or no accessible toilets for wheelchair-users. Participants in KwaNgwanase commented that most buildings in that area are still inaccessible including shops, the hospital buildings and the DoSD offices. In many cases, these physical barriers could be overcome with minimal and reasonable cost, yet many employers are not willing to pay this, especially where there are numerous other job applicants who would not require such measures.

It is not only workplaces that are inaccessible, it is also the inability to reach these workplaces, if they are far, combined with the inaccessibility and cost of transport or accompaniment.

There is nothing – no jobs. Only in town. And in this area there are no buses, so they [people with disabilities] cannot have transport to town. (CRF, Sweetwaters).

The findings mirror what has been said about lack of accessible transport and inaccessible buildings leading to exclusion of PWD from the labour market (Berthoud et al., 1993; Moodley, 1997; EPRI, 2001a; EPRI, 2004; Seirlis and Swartz, 2006). It also reiterates that exclusion is exacerbated by lack of application of ‘reasonable accommodation’, which are “modifications or alterations to the way a job is normally performed to make it possible for a suitably qualified person with a disability to perform as everyone else” (DoL, 2002:14).

Discriminatory attitudes (attitudinal barriers)

There are not only physical barriers to employment, but also (and often more so) attitudinal barriers. Discrimination by employers in the application process was commonly mentioned and three of the many examples will be given to highlight this.

They don't give us a job. They look at our disability and turn us away, saying: 'Come tomorrow!' ...You know, I'm an electrician, but they say: 'How can you climb a ladder?' ...I tried to get a job at that new building site for the mall. Then one of the guys told me: 'Because of your disability I can't take you'. I told him I can work but he said: 'No', so I decided to leave it. (Male, 30 yrs, physical disability – using crutches, Nquthu).

I tried to apply as a switchboard operator. When they hear I'm visually impaired, they turn me away, saying: 'How can you write things down?!'. (Female, 41 yrs, physical and visual disability, Nquthu)

[In the application process] they look down on us because we are disabled...they say: 'You're not fit to do this job'. (Male, 29 yrs, physical disability, Sobantu)

This discrimination affects self-esteem, which in turn discourages PWD to expose themselves to trying to find work. It also leaves PWD unsure about whether or not to state their disability on their Curriculum Vitae. On the one hand it is necessary to identify your disability so that reasonable accommodation measures can be put into place, and to allow companies to meet the percentage of their workforce designated for PWD. On the other hand, many of them felt that stating their disability severely hampered their chance to even get an interview, because of the reality of discrimination.

Discrimination is not only evident in the application process, but can also increase vulnerability and exclusion at the workplace.

I used to work at [company X] ...I had an Indian supervisor who was harassing me and there was no [sign language] interpreter to complain to the boss. I went to the boss to tell him this has happened, but the boss didn't understand what I was saying, so I decided to quit. I went to the police station to report the case, but nobody helped me because they didn't understand what I was saying, so I decided to stay at home now. (Female, 35 yrs, deaf, Marianhill)

Lack of education

Lack of education was mentioned very frequently in all areas as a reason for not being able to get a job. In the sample of 46 participants, eight had no formal education, ten had only primary school education, 28 had some high school education and seven completed matric (Grade 12). None had received any tertiary education, other than one who was currently attending a further education and training course. Those with no education mentioned the challenge of being illiterate and how this is a barrier to employment.

I tried [to apply for a job] at some of the shops, but failed because they are looking for literate people ...I only had a little bit of education, so I am illiterate. (Male, 28 yrs, physical disability, Nquthu)

Those with limited schooling or lack of particular skills-training also cited it as a barrier to employment.

It's not easy to find a job... Any job that you want you need education – even if you don't have matric you need a certain skill, then they will take you. (Female, 22 yrs, blind, Edendale)

This corroborates findings by CASE (1999) and Batavia and Beaulaurier (2001) that lower levels of education of PWD increases their chance of being economically inactive in later life.

The reasons for limited or lack of education of PWD in turn needs to be understood in terms of the barriers to education. In cases where onset of disability was during the schooling years, this often severely disrupted, or even terminated schooling. Secondly, the cost of education was described as a barrier, not only the payment of school fees for children, but also paying for high school or ABET as an adult (for those whose childhood schooling was disrupted due to disability). Lastly, negative attitudes and discrimination also play a role (e.g. when parents or teachers don't accept a disabled child at school).

Barriers to self-employment

Very few participants had made attempts to start their own business and those who had tried, complained of a high rate of failure. The most common attempt was to sell something like sweets or vegetables, but many faced related challenges such as lack of customers in an outlying area, family taking the profit or mismanaging it, or stock going rotten with lack of turnover. Others mentioned increasing competition because of large shops opening in town, or because many others sold similar products already. Those who hadn't been able to start something on their own, but wanted to, most often cited either lack of funds or lack of skills as the main obstacle. These are all factors that are not specifically related to the DG or to having a disability.

The DG was not seen as enough to invest in a business idea, as it was mostly used up for basic needs. Some participants in Inanda, Nquthu and Sobantu were part of support groups who wanted to start a co-operative, but mentioned similar challenges.

Some of us want to start our own business...there are many things we can do as a group, like handcrafts, but there is no funding to kickstart it. The grant is not enough to use any of it towards a business. (Male, 29 yrs, wheelchair-user, Inanda)

We could start a business, but we need skills training. (Male, 52 yrs, physical disability, Sobantu)

Some of these challenges have been mentioned by Moodley (1997), such as lack of access to credit, or inaccessible information/business training (though more detailed since it was a specific focus of that study).

Current context regarding unemployment

Disability-specific reasons and barriers were frequently given for not getting employment, but the context of high general unemployment was also mentioned in both peri-urban and rural areas. In rural areas, such as Sweetwaters and KwaNgwanase it was more severe.

In this [rural] area its especially difficult. It's not easy to get jobs. (Male, 57 yrs, physical disability, KwaNgwanase)

This general lack of employment opportunities in South Africa has been frequently documented (e.g. Moodley, 1997; Aliber, 2001 in Yeo and Moore, 2005; Klasen and Woolard, 2005; Nattrass, 2006; DoSD, 2006b). This means that PWD are contending with many unemployed non-disabled people, decreasing their chance of employment.

[People with disabilities] know that even if they were to look [for a job] they wouldn't be taken...[the reason for that is that] there is a lot of unemployment, of course! But if there are jobs that are coming, they first look at people who are not disabled, more than people with disabilities. (CRF, Inanda).

This disadvantage of PWD competing with large numbers of non-disabled unemployed has been documented by Moodley (1997), DoSD (2006b) and Nattrass (2006).

In this context, reliance on social grants is increased.

Especially in this [rural] area many people are very poor. Even if you are not disabled, you experience difficulties. People are willing to go direct to the welfare department because they want the DG...In this area not many people are working, so if a person is disabled and getting a DG, the members of the whole family are dependent on that money. So they say: 'Now you are receiving the DG, you have to support us!'. (CRF, KwaNgwanase)

This mirrors findings by Klasen and Woolard (2005) that indicate a large proportion of households with no labour market access, relying on social grants, especially in a context of high unemployment.

Aspirations of people with disabilities with regard to work.

Many PWD had a genuine desire to be meaningfully and gainfully employed, yet despair at the physical and attitudinal barriers faced, especially in a context of high unemployment. It is vital that the situations below be seen in the discriminatory context described in the previous section and quotes should not be taken out of context.

A number of participants, usually those aged between 20 and 40 years, expressed the desire to work, despite difficulties and frustrations faced (e.g. discrimination, inaccessible environments, lack of jobs, lack of education). A common reason given for wanting to be employed was the desire to earn more than the current DG amount, since this was not seen as enough to cover their needs and that of the household.

The job you can get will give you a better salary. So anything is better compared to the R820. (Female, 26 yrs, physical disability, Nquthu)

Employment was also seen as a chance for improvement, both in terms of learning new skills, but also the possibility of the salary increasing over time. This was similar for those wanting to start a business.

It's much better to work – you can learn many things. Also the grant stays at the same low level, whereas at least with a salary you have the chance of getting an increase. (Female, 34 yrs, deaf, Marianhill)

As young people, the grant is too small. But I'm trying to study further and start a business in order not to depend on this grant. (Male, 36 yrs, physical disability, KwaNgwanase)

A less common reason for wanting to work was related to the dignity and independence that come with working towards what you earn, rather than receiving the money as a 'hand-out'. There was also the desire to be perceived as being able to work, rather than being seen as a passive recipient.

I would take a job even if I would lose the DG. I want to get something for myself, something that I have worked for...I don't want something free, where you are waiting for it like a dog waiting for food...We must try and make the government see that we can do something. They must offer us something that will help us find our own money, instead of just giving us money. (Female, 23 yrs, blind, Edendale)

Some Edendale participants further mentioned that working for their own money would give them a greater sense of control and would also decrease the expectation of others to get part of that hand-out.

I want to work and earn my own money. Because people think when you get the disability grant, you didn't work for it, so you must also give them something of it. But if they know you have worked for it, they won't ask you for it. (Female, 22 yrs, blind, Edendale)

While the previous examples show reasons for wanting to work, some participants indicated being unable to work, or not seeing themselves able to move off the DG because of their disability.

I've never tried to seek for a job because I'm disabled. (Male, 33 yrs, severe mobility and communication impairment, KwaNgwanase)

I can't work because of my disability...Working in the garden maybe, or pushing a wheelbarrow, but that's not work! I can't do that anyway because I lack the strength and balance. (Elderly male, multiple physical disabilities, Sweetwaters)

There should therefore be a balance in considering the extent or severity of the individual impairments as a limiting factor, while on the other hand seeing this in balance with a limiting context.

Supplementing Grant Income

The desire to work or start a business is evident in those that have tried to apply for a job or start a business, or are currently attempting this. A few mentioned currently supplementing their DG income with a small amount of money, although this was not common. Evidence of supplementing the DG was seen in a 57 year old male with physical disability in KwaNgwanase who obtained sporadic income from forestry, and a

younger male in KwaNgwanase currently helping his brother run a charcoal business. One female in Sweetwaters was herself not able to start a business due to her severe mobility impairment, but the DG helped her family start a business buying and selling goats. Some participants in KwaNgwanase mentioned doing vegetable gardening, though this seemed to be on a subsistence level.

Employment while on the grant was uncommon. Two people in KwaNgwanase were on a DPSA (Disabled People South Africa) contract job to fix wheelchairs, but this seemed short term, as their additional stipend of R800 had recently been terminated. There was one example of someone receiving a reduced salary and half the grant amount until she had completed her training as a sign language teacher at a school for the deaf. This low incidence of DG recipients supplementing their grant with other income is in line with findings by CASE (2005) and DoSD (2006a), though as mentioned by CASE, there may be some degree of underreporting.

Understanding incentives/disincentives in context

In this section, possible incentives to either work or remain on the DG will be discussed. It is vital that this section is understood in relation to the context of discrimination and unemployment, and that participants' statements not be quoted out of context.

The first possible disincentive to DG recipients working is that they have faced so many obstacles, which have discouraged them from trying further. This includes physical and attitudinal barriers and the lack of available jobs in general. Two in Inanda mentioned being satisfied with having to continue receiving the DG because of high levels of unemployment and a discriminatory environment.

People getting grants are not willing to get jobs, because of the fear of losing the grant...they know, even if they were to look for a job, they wouldn't get it. So when they get a grant they feel they are O.K., because they know even if they were to look, they wouldn't be taken. (CRF, Inanda)

Especially in this area as many people are very poor...immediately after they got the DG, they have this fear that it is not allowed for them to get a job...they say: 'As we are receiving the DG, it is fine'. (CRF, KwaNgwanase)

This reiterates findings by Moodley (1997) who indicated PWD being more likely to rely on grants in a context of disadvantage and exclusion.

The second interaction between the DG and employment is the disincentive to take casual or temporary jobs. Participants stated not taking a temporary job because they would lose the chance of getting the DG again, as well as not being able to find any other jobs after that.

So if it's a permanent, professional job it is better, even if you would lose the grant. But not to be a casual worker. It means you have to go back and start renewing the grant again. (Male, 26 yrs, deaf, Esikhawini)

The grant is the basic thing I depend on. Even with casual work, it won't be enough to make it worth losing the grant. It should just be an additional thing – maybe R500 a month on top of the grant. (Male, 24 yrs, blind, Esikhawini)

This is a rational decision where applying for work is seen as a gamble or a risk that outweighs staying on the DG. The White Paper for Social Welfare (DoSW, 1997) made note of the fact that the temporary, and often low paid nature of work can demotivate PWD. Added to this is the fact that re-application in the case of retrenchment or unemployment may be tedious or impossible. Thus the degree of economic risk to enter the labour market interacts with the withdrawal of support as the recipient enters the labour market, to act as disincentive. This has also been documented by Moodley (1997), McLaren et al. (2003) and Mitra (2005).

The third interaction between the DG and employment is the comparison between the DG amount and the proposed salary. DG participants that have a desire to work often want to earn more than the current DG amount and would not take a job that paid less than that.

If it's the same amount as the DG, I won't take it. (Female, 26 yrs, physical disability, Nquthu)

If it were extra to the grant, I would take that job. (Female, 41 yrs, physical and visual disability, Nquthu)

There was also evidence that, even where another member of the household was working, this was usually in a low-paid position where they often earned less than the DG amount (usually between R250 and R600). This is also significant, since the possible wages, even for non-disabled workers, are significantly lower than the DG amount. Similarly, participation in public works programmes may be hindered by the fact that the earnings are about the same as (or less than) the grant amount and that the position is temporary.

CHAPTER 4: DISCUSSION – IMPLICATIONS FOR SOCIAL AND ECONOMIC INCLUSION

4.1. Linking social and economic policies with the social model of disability

The social model of disability states that integration and inclusion of PWD is ultimately about removing barriers in society, which include physical and attitudinal barriers. In various sections of the findings, reference was made to the barriers faced by PWD who are receiving the DG, and these are summarised in Table 3.

Table 3: Examples of barriers faced by people with disabilities

<i>Physical barriers</i>	<i>Attitudinal barriers</i>
<ul style="list-style-type: none"> ▪ Lack of public transport in general in rural areas, and lack of accessible buses and taxis (e.g. step into bus too high; taxi seat too high for a wheelchair-user) ▪ Inaccessible buildings (e.g. no ramp access; no accessible toilet) ▪ Lack of sign language interpretation (e.g. at banks, education institutions, the workplace) ▪ Lack of audio or tactile cues for blind people to cross roads, or lack of structured transport stops ▪ Water source (e.g. pump or river) not able to be reached by PWD ▪ Sandy or muddy roads: difficult to push a wheelchair in 	<ul style="list-style-type: none"> ▪ Employers discriminate against PWD in the job application process (e.g. turn the person away when they see they have a disability; don't see them as capable of doing the job even if they have the skills) ▪ Parents don't allow a child with disability to go to school ▪ Teachers don't allow a child with crutches into their classroom ▪ Taxi drivers that charge double fare for someone with a wheelchair, or don't allow that person into their taxi

These physical and attitudinal barriers interact with each other and may have various consequences for PWD. If the venue and transport are inaccessible, PWD may not be able to reach a meeting venue, and may therefore be excluded from the research process or a policy-making process. If there is discrimination in the job application process, PWD may not be taken, even if they have the necessary skills. If the transport system is irregular and the environment unpredictable, blind persons may need to pay for a sighted guide to accompany them. If the roads are sandy or muddy, a wheelchair user may need

to pay someone to help them. The negative attitude of a teacher or a parent may prevent a child from attending school, where lack of education will in turn affect employment prospects. Lack of sign language interpretation may mean lack of access to further education, or paying for a translator. Inaccessible bus entrances mean people with physical disability need to pay for alternative expensive private transport. Lack of adaptation of methods (e.g. visual methods for blind people, or lack of sign language interpretation) will exclude people from community development processes.

The above examples show that barriers in the environment or within society can lead to exclusion of PWD. Thus a social model perspective highlights that disability is not only an individual medical issue – rather, when changes are made in society (in people’s attitudes and in the environment), then PWD can be included. The onus for change therefore rests on society as a whole, and policies focusing on disability are therefore a cross-cutting issue that should involve multiple stakeholders, including, for example, the departments of transport, education and labour, as well as private sector stakeholders such as employers or chambers of business. It also highlights the importance of disability awareness-raising so as to challenge negative attitudes and discrimination.

This study showed how in some cases the DG money was used to overcome some of these barriers, for example: paying a taxi-driver double for the wheelchair; paying for a private hired car to take one to the hospital or to the paypoint; paying for a sighted guide as accompaniment for a blind person; paying someone to push the wheelchair on a sandy road; paying towards household groceries where family members help with household tasks such as fetching water; paying for a sign language interpreter to go with a deaf person to the police-station. Yet in many cases the cost of doing this was out of proportion to what a non-disabled person would pay to accomplish a similar task, e.g. paying up to R150 for a trip in a private hired car, as compared to the normal taxi fee of under R10; or paying up to R400 a month for sighted guide accompaniment. This means that the extra payments made to overcome barriers may mean a DG recipient is more likely to enter poverty, compared to a non-disabled person getting the same amount of money. Also, the findings showed that there is often income-dilution, where the DG is used collectively by a large household, especially in the absence of other forms of

income. This may limit the portion of the DG that can actually be used towards disability-related costs. Also, while the grant amount is in a sense used to overcome such barriers (e.g. by paying for private transport) – it may not detract from the role various departments have in making society more inclusive, rather than putting the onus for change back on the PWD.

There are also physical barriers that are beyond the scope of an individual person to change, e.g. a large building in town that only has steps or a narrow door at the entrance, and no accessible toilet; the public transport system (especially rural areas that use predominantly buses); lack of tarred or maintained roads in rural areas. Similarly, it is not the DG money that will change the negative attitudes of employers towards PWD in the application process, or change the negative attitude of a family member or teacher preventing a child with disability from getting an education. This highlights the need for specific and concerted and multi-sectoral efforts to remove such barriers in society. Removing attitudinal barriers is usually the more difficult, but could be possible, for example through workplace disability sensitisation, awareness raising, diversity training, or media awareness. Resources for such initiatives would either need to be specifically allocated, or funding reallocated (for example by the DoSD or DoL, both departments of which have made explicit their aim to increase employment and inclusion of PWD). This could be done in collaboration with DPOs (Disabled People's Organisations, e.g. Disabled People South Africa/DPSA or People for the Awareness of Disability Issues/PADI).

Understanding these barriers also contributes to understanding the exclusion of PWD from employment, which was described in the previous section. This helps to understand why certain PWD want to work, and may have tried to apply, but are not able to get employment. It is therefore not a matter of that individual person changing or adapting more, but rather there is a need to address physical inaccessibility and discrimination in society. While the DoL has the mandate to monitor target percentages of PWD employed by both government and large private companies (through the Employment Equity Act/EEA), the role of employers in addressing accessibility and discrimination (e.g.

through Chambers of Business or Corporate Social Responsibility initiatives) should not be minimised.

This is complicated in a context of high general unemployment and poverty, which was described in the findings. While the broader goal of the social model is to maximize participation of PWD (e.g. through skills and jobs), this becomes complex in a context where jobs are scarce in the country as a whole, and where access to education and employment is a general problem in large parts of the population. In such a context it becomes necessary to provide appropriate forms of social assistance. Such provisions should not, however, overrule former goals of inclusion of disability into mainstream development efforts.

This leads on to seeing the multiple links between social and economic policies. It has become clear that where macro-economic policies do not address the creation of employment, this has social ramifications, since high unemployment pushes PWD lower down in the job queue if having to compete with greater numbers of non-disabled job-seekers. It also has social effects on households, where non-disabled household members rely on the DG, especially where it is the only source of income for unemployed adults. Conversely, household composition may have economic effects, in terms of how that money is used. Thus the make-up of a family or household will affect its expenditure patterns, e.g. those with children in school pay for schooling expenses; bigger households, where the grant is the only income, may use it mainly for food. This in turn depends on what other income there is in that household and how this is used or combined. Decision-making may be different in a large household, in a context of poverty and high unemployment, as compared with a person staying alone. Similarly, the status and relationships in a household may make decision-making different for someone in a multi-generational extended family, or still staying with parents or having their own children.

Thus, macro-economic policies that deal with the labour market and economic growth, will impact on unemployment levels in the country, which in turn has economic implications on, for example, reliance on the DG and its use in the household, but also

has social effects in terms of how the decision-making is done within that household. Similarly, social consequences of disability, e.g. discrimination, have economic implications for PWD because of exclusion of PWD from employment. Also, social sector policies, e.g. education, affect employment later, or have economic implications because of the cost of tertiary education. There are thus multiple links between social and economic policies.

Without active measures to combat physical and attitudinal barriers to education, transport and employment, South Africa will not be able to reach the targeted number of PWD in employment as proposed by the Employment Equity Act. The number of unemployed PWD will in turn influence the number that rely on social assistance. Thus policies within different departments may affect each other and their relative amount of expenditure, for example, without accessible transport, PWD may not be able to reach health care facilities, or lack of accessible public transport may mean less PWD are able to reach employment opportunities offered by the DoL, which in turn will increase the number of PWD relying on social assistance. There are many other examples of interdepartmental interactions. This highlights the need to see economic and social policies as related. This will also inform the policy recommendations in the subsequent section.

4.2. Reflections on inclusive research

I want to make explicit some of the barriers and challenges that were faced to including PWD in the research process. While this study specifically aimed for participation of PWD, the actual experiences may highlight barriers to research or development processes in general, especially where there is not awareness about disability. It is therefore not only the actual 'data' collected that can be valuable in informing policies, but reflecting on the process can have important lessons for making development more inclusive, even for other vulnerable groups. While research is only one way in which people get their voice heard, it can be a metaphor for other types of inclusion.

Yeo and Moore (2003) state that PWD are often marginalised in development research (due to physical and attitudinal barriers in the research process), which means that PWD often lack the power and opportunity to exert influence on policy-makers. This exclusion of PWD from research may stem from a variety of sources.

Written surveys are generally inappropriate for those disabled people who have been excluded from education, or even for educated people with visual impairments, unless the surveys are produced in Braille. Many participatory methods are visually based, hence excluding people with visual impairments; oral discussions are inappropriate for deaf people unless interpretation is provided...disabled people may not physically be able to get to community meeting places. They may also be socially excluded from these places. (Yeo and Moore, 2003:577).

In this section, six aspects of inclusion of PWD in the research process will be discussed, as well as highlighting the possible factors leading to exclusion.

Severe disabilities and communication impairments

Sampling in this study aimed to include people with varying disabilities (physical, visual and hearing) and various degrees of disability. In reality, however, convenience sampling often took place, since those who were fairly independent and able to use transport to attend the focus group were more readily selected. This meant that people with severe disabilities, severe mobility impairments, those bed-ridden or unable to use transport were excluded or missed. Those with severe communication impairments were also not included (e.g. those with aphasia following a stroke or severe athetoid cerebral palsy), as the research process was very verbal (with interactions being taped). These are PWD who are possibly more vulnerable than those who actually attended, and it highlights the challenge of capturing the experiences and voices of those who do not have a means to communicate.

Accessible transport

Even those who were more independent and willing to attend the focus groups faced significant transport challenges. In some rural areas buses travel only on the few maintained sand roads and have a very high step and narrow entrance, making it unusable

for most PWD. Some participants could not walk very far or only with difficulty. Some taxis charge more for, or do not accept, wheelchair users. These challenges meant either fetching PWD with the researcher's car, or they had to pay for a private car to fetch them. This also highlights the potential for exclusion of people who cannot leave their house, cannot reach the main transport routes, or who face inaccessible public transport.

Accessible venues

During the planning of the focus group discussions, particular care had to be taken when selecting a venue, to make sure it would be accessible. Many buildings pose physical barriers to PWD. Some buildings (or even entire rural areas) do not have accessible toilets, especially when there are only pit toilets. Availability of accessible venues varied in different areas, with some having a library room, community hall or room at a clinic available, while in some areas it was decided to meet at a participant's house, also because this was more central in terms of transport.

Sign language interpreters

CRFs receive introductory sign language training in their course. This is enough to hold a basic conversation, but many of them did not feel confident enough to interpret a more detailed discussion. Where an alternate sign language interpreter was not available or too expensive, deaf people were not included, except in the two areas where there were CRFs who were confident in sign language (Esikhawini and Marianhill). This in part explains the poor representation of deaf people in the sample. Another factor may be the difficulty in making contact with those without cellphone access (to which a text message can be sent) and where a home visit may be too far. Even where there was a sign language interpreter, interpretation was often slow, and misunderstandings had to be clarified. The Esikhawini group included a mix of blind and deaf participants and needed English-isiZulu translation, which therefore necessitated the use of two translators.

Exclusion of blind people from visual participatory methods

Participatory techniques are in the majority very visual so as to enable inclusion of those not literate. Yet very little is said in participatory manuals on how these techniques can be adapted to PWD, specifically for those who are blind. Yeo and Moore (2003:577)

acknowledge that “many participatory methods are visually based, hence excluding people with visual impairments”. In this study the time-line exercise is a visual drawing of the person’s life, depicting high and low life events. This has previously been adapted to use tactile methods (such as by using string and stones), or by the person narrating while another drew the line. This, however, may detract from the purpose of such an exercise which is helping the participants to get a visual overview, so as to evaluate their own experience. In this study it was therefore decided not to do the time-line with blind people, but rather to have a more verbal interaction in which they could tell aspects of their life story. The experience, however, made it very clear how diagramming activities done in a community setting (especially methods such as mapping, venn-diagram or matrix) can exclude blind people.

Bias towards physical disability

The majority of the groups in the sample had physical disabilities (as opposed to visual, hearing or communication impairments). This could be valid since, for example, Vorster, et al. (2006) indicate that 30 percent of DG recipients gave physical disability as the main reason for getting the DG, as opposed to five percent each for visual and hearing impairments (and 33 percent specific illness, 22 percent emotional or intellectual impairment, and five percent combination of disabilities). Yet, this may also reflect a possible dominance of people with more outwardly visible impairments or those more easily able to communicate. Other reasons may include lack of proficient sign language interpreters or the need for sighted-guide accompaniment for blind people to reach the venue. In this study it was compensated for by doing one focus group specifically with blind people.

These different factors have implications for making other research studies, including larger national surveys, more inclusive. It poses challenges such as how to include home-bound individuals, or how to effectively incorporate sign language interpreters, or how to make community meetings more representative, while at the same time taking time and resource constraints into consideration. This also poses challenges on how to include other vulnerable groups such as women (who may have child-care and subsistence work),

the elderly (who may also have physical or hearing impairments), minority groups in remote areas, or employed people who are not often at home at times of survey.

4.3 Policy Recommendations

The research findings and discussion have made it clear that social assistance in the form of the DG cannot be seen in isolation from other intersectoral interventions to address the exclusion of PWD caused by physical and attitudinal barriers. While this has been a small study within KZN, it holds implications for national policy. The following are eleven recommendations that were identified as a result of this study.

Twin-track and intersectoral approach

Mitra (2005) and DFID (2000) argue for a 'twin-track' approach to disability interventions. This includes programmes and services that are 'disability targeted' (specific initiatives to empower PWD, e.g. rehabilitation, assistive devices, health care, counselling, support groups), as well as services that are 'disability mainstreamed' (addressing inequalities between disabled and non-disabled people in all general development initiatives). This means that disability is not relegated solely to a health or social assistance arena, but that it is integrated into development programmes aimed at addressing poverty and powerlessness (Philpott, 1995). This would mean keeping specific disability-related initiatives, such as free health care and assistive devices, therapy or counselling services. But it also means that various departments, e.g. transport, housing, education, local economic development, traditional affairs, sport and recreation, have a role to play in addressing barriers. Similarly, chambers of business, trade unions, large corporations, or other private economic institutions, cannot be excluded from playing a role.

Cash transfers and social assistance should be seen in conjunction with other disability policies. Social security is only one of the target areas set out for equal participation of PWD by the United Nations (UN, 1993). Other target areas for participation include accessibility, education, employment, family life and personal integrity, culture, recreation and sports, and religion. There are pre-conditions for this to take place (awareness-raising, medical care, rehabilitation and support services), but there are also

implementation measures to increase participation: information and research, policy-making and planning, legislation, economic policies, organisations of persons with disabilities, personnel training, national monitoring and evaluation, and technical and economic co-operation. This UN document views social assistance as one target area of participation for PWD, but it may also contribute to other areas of participation. It does, however, highlight that having cash transfers as a sole policy for addressing disability, would not be a comprehensive approach. In such an intersectoral framework, increasing employment of PWD (as proposed in policies by DoSD and DoL), would for example include providing adequate rehabilitation services, raising awareness of disability among employers, having accessible transport, having adequate education and training for PWD, considering the extra costs related to disability and adaptation in the workplace. Some aspects of the implications of such a comprehensive approach will now be elaborated on.

Barriers to employment.

The DoSD has recently produced a discussion document on “Linking Social Grants Beneficiaries to Poverty Alleviation and Economic Activity” (DoSD, 2006b) which is still open for comments in 2007. While this document is in general vague, it does recognise that there may be DG recipients who are able and want to work. It acknowledges that there may be PWD who want to work, but have not been able to work because of a discriminatory environment, as well as a context of general high unemployment. The proposed policy response (to “migrate beneficiaries to education, training, skills development and employment” – 2006b:10) is also vague and includes “a range of policies that include active labour market measures, skills development programmes, special employment and labour intensive development programmes and labour intensive government services” (2006b:7). It fails to acknowledge exclusion of PWD from current development programmes, or that the EEA has not contributed to reaching targeted numbers of PWD in employment. It does not mention a social model understanding of disability, which recognises physical and attitudinal barriers to employment. If the DoSD wishes to link DG recipients to employment or to starting small businesses, it needs to take into account the many environmental and societal barriers, particularly discrimination and a context of high general unemployment. It

cannot just focus on individual training or rehabilitation strategies for PWD, but needs to include a social model understanding into its policy.

Similarly, this needs to take inter-departmental effects into consideration, e.g. the effect of transport, education or financial services. To practically get interdepartmental collaboration is not easy, yet in this case it may mean initiating a consultative process between various government departments (especially DoL, DoE, DoSD and DoT), chambers of business or large employers, as well as Disabled People's Organisations (DPOs), so as to forge agreement about what actually should be built into a realistic policy for opening up entry into the labour market. It could be the role of the Office on the Status of Disabled People (OSDP) to do this, as has previously been recommended by Schneider and Marshall (1998:21), who state:

The OSDP has already recognised the need for interdepartmental collaboration. It has established an Interdepartmental Collaboration Forum (ICF), especially to facilitate an integrated and effective approach to disability. The aim of the Forum is to facilitate co-operation between various departments. It is a co-ordinating body to work on policy development, and not an implementing body. Being part of the Deputy President's Office means that it has some political authority when making recommendations around budgetary allocations.

While the role of the OSDP has been set out, it is not clear how far this has been implemented, since concerns about collaboration still remain.

Reasonable accommodation in the workplace

Where a work-environment is inaccessible, and there are slight adaptations needed, employers are mostly unwilling to bear the costs of financing these 'reasonable accommodation measures', despite detailed guidelines in the 'Technical assistance guidelines on the employment of people with disabilities' that was written to supplement the EEA and the Code of Good Practice for the employment of people with disabilities (DoL, 2002). It can be argued that the private sector is not the most appropriate mechanism to try to deal with these costs.

Market-based provision is largely inappropriate as a response to conditions of disability. This is for three reasons. First, markets respond to purchasing power

rather than to need. Second, markets are everywhere deeply embedded in social institutions of prejudice and discrimination. Third, firms comprising markets and competing in them cannot be expected, unaided by the state, voluntarily to add to their cost by adapting the workplace sites so as to accommodate disabled workers. (Harris-White, 1999, as quoted by Yeo and Moore, 2003:583).

This means that there may need to be a specific fund available (e.g. companies can apply through DoL for payment of measures to make a workplace more accessible), or that tax subsidies are given to companies that adapt their workplace.

Disability-related costs

The present study showed that assistance to PWD is often not needed in the home environment or is not necessarily given by a family member (which has been the focus of other studies looking at caregiving needs, e.g. Frieg and Hendry (2002)). Usually sporadic assistance was utilised from a variety of people (community members, sometimes neighbours or passers-by) to travel outside the home environment, which was often paid for. It is frequently assumed that ‘care’ within a community is provided by a family member, usually one person, and often a female, and it is on this premise that the Grant-in-Aid (GiA) is based. Yet very few participants mentioned that the GiA was received in addition to the DG, at the same time having high expenses for assistance outside the home. These needs differed between, for example, a wheelchair user who needed much assistance and a deaf person who needed very little.

It is therefore recommended that the means test or assessment procedure take the differential disability-related costs into account. “Providing estimates of disability-related expenditures allows policy-makers to assess the adequacy of the levels of means tests, and whether a different means test needs to be applied to persons with disabilities” (Mitra, 2005:27). There are also extra disability-related costs irrespective of employment status. Thus, even where PWD are employed, they may have extra costs, such as for transport or adaptive equipment in the workplace. This might mean having a ‘needs assessment’ as opposed to a means test, that would incorporate specific disability-related expenses of different types of disabilities, as well as the context. Such a ‘Needs Assessment’ would therefore link levels of functional capacity with socio-economic

factors, such as an economic profile of the area as well as other support mechanisms available (Schneider and Marshall, 1998). This would also clarify the concerns about GiA for accompaniment, pushing wheelchair, sign language interpretation etc., which are not usually done by a single family member.

Transport

Lack of accessible public transport is a major barrier, and has far-reaching social and economic consequences (e.g. ability to reach health care, a paypoint, or employment opportunities). It cannot be left to the DG amount to cover the extremely high cost of alternative transport. Nor is it feasible to expect changes to public buses, trains or roads to be financed by individual DG payments. Schneider and Marshall (1998:77) have similarly recommended that “some system has to be found to overcome the current dismal lack of appropriate and affordable transport”. The social model perspective implies that the onus for change in this area does not lie on an individual PWD, but should be with transport providers, such as the DoT or possibly large employers. Transport provision can in turn have implications for inclusion of PWD in all other areas (such as employment, education, health care, or reaching Social Development services). While there is a mandate to make public transport services more accessible in general, this would not exclude companies providing accessible transport as part of their Corporate Social Responsibility, or if working towards meeting equity targets.

Cost of education

The majority of households use part of the DG towards paying for the school fees and other related expenses for children in that household. The fact that DoSD expenditure is being used to pay for services that should be covered by the DoE alerts us to the fact that the DG as a policy cannot be evaluated separately from the context, and that policies may have interdepartmental implications. While it may be beneficial that the DG supports the education of children, it is not the explicit responsibility of the DG and should not detract from the DG recipient being able to meet his or her own needs.

Disincentive effects to DG recipients entering employment

The DG does not consider the type of labour market faced by PWD in South Africa and the degree of economic risk to enter. Complete removal of the DG stands in contrast to policies that advocate a proportional loss of disability benefits which are implemented gradually as a person with disability enters work, or a wage supplement to PWD in paid employment, which acts as a work incentive (examples of this type of wage supplement can be seen in countries in North America and Western Europe) (Moodley, 1997; Schur and Kruse, 2002). This assumes a sophisticated information management system, but this may become possible with the computerisation of information by the SASSA. The United Nations' 'Standard Rules on the equalization of opportunities for people with disabilities' supports the idea of wage supplementation.

Income support should be maintained as long as the disabling conditions remain in a manner that does not discourage persons with disabilities from seeking employment. It should only be reduced or terminated when persons with disabilities achieve an adequate and secure income. (UN, 1993:n.p.)

Another recommendation would be to consider a stand-alone benefit given to PWD based on their extra costs, and independent of their employment status. This could mean that a PWD who is employed is disqualified from the DG itself, but receives an employment related compensation for the extra costs related to disability (could be compared to a 'rural allowance' or 'uniform allowance' sometimes given with a salary package). This would also contribute to decrease the disincentive effect of losing the DG on employment. This stand-alone disability benefit is given in a number of countries (Mitra 2005).

Context of high unemployment

While many households without access to employment income rely heavily on grant income, this type of indirect provisioning may be inferior to direct support to the unemployed person (Klasen and Woolard, 2005). The role of the DG in households and in labour market participation, in the context of high unemployment and the absence of comprehensive social security was explored in this study. South Africa has very limited alternatives to disability benefits, in contrast to other countries with the alternative of

employment on one hand, and general social assistance benefits on the other (CASASP, 2005). It is therefore argued that broadening social security provision and making it more comprehensive, would address chronic poverty faced by many households that rely solely on cash transfers, yet remain poor because the household is large and supports unemployed adults or older children (EPRI, 2004; CASASP, 2005). The type and feasibility of a comprehensive social safety net in the South African context is contested, and the effect it would have on employment prospects for PWD is not known.

Swartz and Schneider (2006) emphasize the need to view the DG in the broader macro-economic context of South Africa:

With very high unemployment rates in South Africa, the context in which grants are awarded is vastly different from that in which the idea of grants was conceived. The concept of grants being available to people who, by reason of disability, are unable to support themselves financially is a good one. However, many people with disabilities, like many without disabilities, are unable to support themselves because of broader macro-economic factors – there are not enough jobs for South Africans. This reality places the disability grant system under enormous pressure, especially in the context of the HIV/AIDS epidemic, and raises questions about poverty relief and social security in South Africa, questions which go far beyond issues of disability. (Swartz and Schneider, 2006:243)

This re-emphasizes the fact that disability needs to be viewed within the context of poverty and high general unemployment in South Africa. Therefore, assessment of DG eligibility may need to be seen beyond the current criteria based on a medical diagnosis of functionality/ability to work. Schneider and Marshall (1998) recommend that assessment needs to move away from evaluating medical functional capacity only, but rather needs to include an evaluation of a range of needs and economic factors and hence developing a ‘profile of needs’ of the applicant. This profile should, besides the medical and financial indicators, also include indicators like disability-related costs, a socio-economic profile of the area and possibly vulnerability to discrimination. Their rationale for this type of profile is based on the fact that each disability creates a different set of needs and interacts with the context.

Financial services

The high cost of banking charges is a concern, especially to those in the lower income deciles. There is also still a general lack of banking services in rural areas. Also, banking services need to take possible barriers into consideration, e.g. ATM height, buttons, door access, height of counters for wheelchair-users. Another concern is access to credit by PWD and a general concern about the possibly coercive practices of the Cornerstone company that seems to work in relationship with the SASSA at paypoints. DG recipients reported feeling forced to make use of less reputable loan companies, due to lack of alternatives. What is needed is a safe and dignified place to get small loans or possibly 'financial literacy' and education about policies, loans, etc., so that people are not misled easily. This may mean lobbying the Financial Services Charter group, or utilising the new credit legislation, possibly through the formation of a civil society organisation. Lastly, the practices at paypoints may need attention, e.g. long queues, pushing and bribery, long time to wait for those physically weak or lack of sign language interpretation. This would be the responsibility of the SASSA to address such concerns.

DG review process.

The findings highlighted how termination of the DG without warning, especially of permanent DGs, for review, can have negative consequences. It was seen as a financial shock, especially when the entire household relied on it as income. This often meant resorting to short term coping mechanisms, such as debt or selling of assets, which had negative long-term consequences. Similarly, the costs of reapplication (e.g. transport or accompaniment) are high, especially where several trips to the welfare office must be made. Lastly, termination of the DG, even for a short time, has knock-on effects on other financial services e.g. the possible loss of savings or of a funeral policy. If DG receipt does need to be reviewed, this should be done with adequate notice (e.g. three months notice, given at the paypoint), and should not require more than 1-2 visits to the nearest welfare office. In this matter there should be collaboration between the SASSA and the DoSD, which will be assisted by streamlining electronic information systems being put into place.

Recommendations for further research

Finally, this study has identified areas for further research. First, it focused on DG recipients with physical, hearing and visual disabilities. A similar study is needed that focuses on people with mental illness, intellectual disability or multiple disabilities. This may highlight specific needs of different types of disabilities and expand the recommendations for making development processes more inclusive. By including people with more severe disabilities, there could also be further research on possible lack of control in decision-making and possible abuse of DG money of those who are in more vulnerable positions. Second, research about the care requirements of PWD is also needed, specifically the role of unpaid care by household members and the employment status of that caregiver. Not enough is yet known about whether such caregivers benefit directly or indirectly from the DG (e.g. through the DG contributing to household maintenance), and in cases of receipt of the Grant in Aid, how this is utilised. This leads, third, on to further research being needed regarding the employment-seeking behaviour of household members of a DG recipient, and how household formation is affected after the receipt of the DG (e.g. through attraction of unemployed family members). Lastly, gender differences in DG use, decision-making or employment opportunities can be explored more fully.

Conclusion

This section highlighted how physical and attitudinal barriers in the environment or in society lead to exclusion of PWD, indicating that change rests on policies focusing on disability as a cross-cutting issue that involves multiple stakeholders. Thus, while the DG may be one means to inclusion, disability cannot be relegated solely to a social assistance domain. Rather, an ‘intersectoral’ and ‘twin-track’ approach is needed. Intersectoral refers to the collaboration between multiple government departments, private sector and disability organisations. Twin-track refers to the need for programmes and services that are both ‘disability targeted’, with specific initiatives to empower PWD, as well as ‘disability mainstreamed’, in addressing inequalities between disabled and non-disabled people in all general development initiatives. This could be a means through which social and economic policies could become more interlinked, and that disability could thus be better integrated into development programmes aimed at addressing poverty and exclusion.

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APPENDICES

Appendix 1: Focus group interview guide

Examples of questions used in focus groups:

Can you tell me about how the DG has influenced or changed your life?

Can you tell me about how you use the DG? What are the type of things you usually buy or pay for with the DG money?

Who decides what the money will be used for?

If you decide, how do you decide what to use the money for?

Can you describe what life was like before you got the DG? (Probe: How do the people who you stay with treat you because of the DG? What difference would it make to them if you did not receive the DG?).

Can you tell me more about what happens on “grant day”? (This may be linked to expenditure patterns, decision-making, household status. It may also link the DG to local market formation, similar to the OAP).

Have you ever tried to find work while you are getting the DG? (Why/why not?) What happened to your attempt? Have you ever tried to start your own small business or get money in another way while getting the DG?

Appendix 2: Informed Consent Form

(To be explained by researcher before the beginning of the focus group which will then be translated into isiZulu or sign language by interpreter).

My name is Christa Johansmeier. I am doing research on a project titled “The Social and Economic effects of the Disability Grant”. This project is supervised by Professor Frances Lund at the School of Development Studies, University of KwaZulu Natal. Should you have any questions my contact details are:

School of Development Studies
Howard College Campus
University of KwaZulu Natal
Durban
4041

Tel: 033 345 5088.

Thank you for agreeing to take part in the project. Before we start I would like to emphasize that:

- your participation is entirely voluntary;
- you are free to refuse to answer any question;
- you are free to withdraw at any time.

The interview will be kept strictly confidential and will be available only to members of the research team. Excerpts from the interview may be made part of the final research report. Your name will not be used in the report, but we may use your disability, area of residence, age and gender as identifiers.

Please sign to show that I have read the contents to you.

----- (signed) ----- (date)

----- (print name)

Write your address below if you wish to receive a summary of the research report:

Appendix 3: Description of sample areas

Area	Description
Sobantu	Small peri-urban township. No own business area, but close to Pietermaritzburg city centre (5 min) and industrial area (Willowton) by taxi transport (i.e. possible access to employment, shops and banking if transport available and accessible). Fairly established township area with mostly 3-room brick houses with water and electricity. Majority have own vegetable gardens, giving it a 'village' feel.
Sweet-waters	Hilly rural area with mostly mud huts and no water/electricity. Settlements very spread out. Some subsistence agriculture. Closest town is Pietermaritzburg (40-50min by taxi) No shops/banks – very little employment opportunities. Only one tar road – rest dirt roads with limited bus transport. Some homesteads only foot access. Limited number of clinics and far from hospital. Prominent traditional leadership.
Inanda (Newtown A)	Large urban township area. Access to Durban and industries by taxi, but also has own business district. Close to N2 Highway. Fairly established and densely populated by small houses (sometimes with informal attachments) on small plots with water/electricity access. Most roads tarred.
Nquthu	Large sprawling rural area with large distances between homes. Approx. 50 km outside Dundee (Central KZN). One main tar road runs through area along which taxis operate, rest are semi-maintained dirt roads. Central business hub/ developing town centre around the hospital (limited ATMs, shops, taxi rank with informal traders, and new mall under construction). Taxi to services and shops in Dundee available but expensive. Very limited water/electricity provision in central area and along main road.
Kwa-Ngwanase	Deep rural area in northern KZN, at the border to Mozambique. Far distances to other towns such as Jozini. Strong traditional leadership and values. Primarily subsistence agriculture, though very sandy soil. Some access to fishing. Mostly mud and reed huts and settlements spread over a vast area. Only one main road is tarred, which gives access to hospital and small business district. All other roads only access by 4x4 because very sandy. Very far distances between homesteads, with large areas of uncleared bush remaining. Very limited electricity and running water – mainly from pumps and rivers. Eco-tourism in area, as well as tourist thoroughfare to Mozambique. Limited clinics with mobile points (up to one hour travel for health professionals).
Marianhill	Peri-urban area. Close to N3 Highway and Pinetown Industrial area, with access by taxi. Hilly with few tar roads. Prominent Catholic Mission station with St.Mary's hospital and various community projects, including school for the deaf. Small area of shops around taxi rank.
Edendale	Large urban township outside Pietermaritzburg, with regular taxi access to the CBD. Range of different types of housing from small brick houses to informal shacks, but most have water/electricity access. This area has a ABET community project 'Magaye' for blind and visually impaired people, which most participants of this focus group attended.
Isikhawini	Peri-urban township. Fairly established township area with mostly 3-room brick houses with water and electricity. Only limited local shops, but taxi access to Empangeni and Richard's Bay (including industries such as paper, aluminium). Main roads tarred, but subsidiary roads not maintained.

Appendix 4: Focus group attendance register

Name: _____ Date of Birth: _____ Male/Female

Type of disability: _____ Year became disabled: _____

Level of education: _____ Year got DG: _____

People in Household (live within same homestead/stand/house for at least 3 months in past year; share food together, share resources/income; excludes visitors)

Relationship to PWD (e.g. mother, brother, aunt, child)	Male/Female	Age

Other sources of income in the household : salary, remittance, other grants, small business income or any other?

Type of income	Approximate monthly amount