

# **Poverty and disability in Johannesburg**

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## Introduction

It is often difficult to ascertain how many people are living with a disability in South Africa, primarily due to a lack of awareness about certain types of disabilities (particularly learning disabilities); stigma that is sometimes associated with disability, and the fine line that exists between chronic illness and disability, particularly in relation to the disability grant in South Africa. In addition, as Schneider, Dasappa, Khan and Khan, (2009: 246) point out, “large differences in disability statistics are currently observed internationally due to a lack of consistency in what is being measured as ‘disability’.” Nevertheless estimates suggest that globally between 10% and 12% of the population is currently living with a disability.

Despite this, in South Africa, less than 1% of all people employed are people with disabilities (Progression, nd; Census, 2001; CASE, 1999). People living with disabilities are also less likely to be able to access social protection mechanisms and social networks of support. For this reason, many people who are living with a disability are also caught in a cycle of poverty. The mainstreaming of disability in the poverty reduction agenda is therefore an urgent development priority. During the 2000 United Nations Millennium Summit, former World Bank president James D Wolfensohn encapsulated this as follows:

*“Unless disabled people are brought into the development mainstream, it will be impossible to cut poverty in half by 2015 or to give every girl and boy the chance to achieve a primary education by the date.”*

It is for these reasons that the Centre for Social Development in Africa (CSDA), in partnership with Dr. William Rowland of the Thabo Mbeki Development Trust, undertook to conduct this research. The report focuses on the ways in which poverty and disability are linked and how each compounds the experience in an urban setting.

The research was conducted in eight of the poorest wards in Johannesburg and sought to understand how people who had indicated in a previous household survey that they were either living with a disability or were too ill to work, cope in a situation of poverty. The research sought to assess livelihood opportunities, access to education and health care, social networks and support as well as life satisfaction.

The data has been interpreted through a sustainable livelihoods perspective which seeks to understand the multi-dimensional nature of poverty and recommendations are made that are in line with a social development approach – the approach that dominates development policy and practice in South Africa.

The first part of the report provides a background to how disability is understood in South Africa today, and in particular points to the problems in terms of how disability is conceptualised in policy in relation to the Disability Grant. This section provides the national policy background to which this research hopes to contribute.

The report then moves on to deal with the conceptual issues arising from defining disability and poverty in South Africa. It points to the dominant ways of understanding disability theoretically with a particular focus on how the link between poverty and disability is understood. This is then followed by an outline of the methodology used.

The fourth section of the report deals with the findings of the data collected for this study. It provides insights into how people living with disabilities in Johannesburg's poorest wards make a living, their access to the disability grant, the social support mechanisms that they are able to access and their life satisfaction. This is then discussed in relation to the implications of the findings for understanding the link between poverty and disability from a livelihoods perspective. Finally, recommendations arising are presented in the final part of the report.

Although there is acknowledgement of the link between poverty and disability, very little academic work has been done to understand what the link might be and how both poverty and disability affect those who live with a disability in a resource poor setting. As Watermeyer et al (2006:3) note, “while South Africa is fortunate enough to have among its disabled population leaders, activists and campaigners who carry immense experience and knowledge of the nature of disability politics, a distinctly South African Disability Studies Literature is yet to emerge and develop.”

The intention of this study is not only to break new ground in terms of a better comprehension of how poverty and disability are linked, but also to provide evidence-based policy recommendations to national and local governments as well as non-governmental organisations working in the disability sector. Thus, the findings of this study are intended in some way to benefit the lives of those who so willingly participated in this study.

## **Chapter 1:        Disability in South Africa**

This report seeks to contribute to policy debates in South Africa in order to provide evidence to ensure that people living with disabilities are afforded better services and access to opportunities, thus strengthening their livelihood opportunities. In order to do this, it is important to understand what the policy landscape is with regard to disability in South Africa, and to analyse how disability is understood in the country. This section of the report seeks therefore to provide a background to how disability is understood from a policy perspective in South Africa.

It is generally accepted that disability in developing and developed contexts has different causes and is experienced rather differently. For instance, according to the WHO (1980), disability in developing countries stems primarily from malnutrition, accidents, communicable disease and congenital conditions, whereas in developed countries disability stems mainly from chronic disease such as arthritis, cardiovascular disease, mental illness, metabolic disorders and the consequences of alcohol and drug abuse.

South Africa, which is characterised by a high level of inequality faces a dual epidemiological profile – that is, it is faced with illnesses of overconsumption such as heart disease and diabetes, as well as illnesses of under-consumption and those exacerbated by poverty such as cholera and tuberculosis. In addition, high levels of crime and violence are associated with the added burden of injuries. With this in mind it is likely that the population has a diverse and extensive prevalence of disability and chronic illness.

The incidence of disability and impairment increases with age, and the numbers of people living with disabilities are expected to increase as a correlate of absolute population growth. In poor and deprived communities, a lifetime exposure to nutritional



inadequacies, unattended or inadequately attended health and injury problems, and a number of environmental risk factors imply that many people enter older age with chronic ill health and disability. Therefore, it is possible that, given South African society's particular epidemiological profile and its socio-political past, disability may be a particularly extensive problem in older South Africans (Joubert and Bradshaw, 2006).

Understanding how to best to provide services and support from a policy perspective therefore becomes more complex.

### **1.1. Disability and chronic illness in South Africa**

Understanding how many people are living with a disability is a difficult task. This is primarily due to changes in how disability is understood and measured. As Schneider *et al.* (2009: 246) note, "Large differences in disability statistics are currently observed internationally due to a lack of consistency in what is being measured as 'disability'." Research conducted by Schneider (2009) and Schneider *et al* (2009) demonstrates that differences in perceptions of disability exist both in terms of the line of questioning in attempts to measure the extent of disability, as well as in how the term itself is interpreted by people answering the questions. For instance, as Schneider notes (2009):

*"Narrow definitions of disability include people on the basis of questions such as 'Are you deaf, blind, crippled or mentally retarded' and variations of this question. ... These approaches produce small estimates of disability prevalence as they only consider people with severe disability and those who either identify themselves or are identified by others as 'clearly disabled.'"*

As will be discussed in Part 2 of this report, a broader definition of disability is increasingly considering the interaction between individual and environment but this is still to be factored into how disability is measured. For this reason, statistics from the

Community Survey (Statistics South Africa, 2007) and the last South African Census (Statistics South Africa, 2001) are unreliable. Currently work is being done by Statistics South Africa (StatsSA) in conjunction with experts in the field to change how disability is measured in such surveys, and in particular in the Census that is due to take place in 2011 (Schneider *et al.*, 2009).

Understanding disability is further confounded by the fine line that often exists between chronic illness and disability, particularly in relation to how these are understood with regard to the disability grant in South Africa. The South African social grants system includes a disability grant, which any person who is unable to work due to a disability is entitled to apply for. However, in a context of high levels of unemployment where people are desperate for an income, and where many people suffer from chronic illnesses including AIDS, many people with chronic illnesses, regardless of whether they may lead to a disability or not, attempt to claim a disability grant – either temporarily or permanently. This means that in the experience of many people who fall within the sample of this study the lines between disability and chronic illness may be blurred.

In addition to this, the Johannesburg Poverty and Livelihoods Study (JPLS) data, which was reanalysed for this study, focused on livelihoods and the factors that constrained this. In the dataset of the JPLS, chronic illness and disability are not separated out, making it impossible to differentiate between participants who were chronically ill and those who were disabled in sampling for this study (to be discussed further in Chapter 3). The blurring of the lines between chronic illness and disability in the policy landscape (at least in how the two are perceived by grant applicants) as well as in the dataset, provided reason for this study to focus on both disability and chronic illness.

## **1.2. The intersection of disability, chronic illness and poverty in South Africa**

As has been stated, in the common experience, the lines between disability and chronic illness may be blurred. A chronic illness is defined as illnesses that cannot be cured and that thus must be managed as a lifelong commitment. Where this illness is not managed well it may lead to functioning impairments such as loss of vision or limitations in physical activity. It is at this point that the chronic illness shifts from simply being a chronic illness to creating a disability, which is understood in the South African policy landscape to be “one or more moderate to severe activity limitations” (Schneider and Goudge, 2007: 10).

Physically a chronic illness, if properly managed should not lead to a situation in which a person is unable to work because of activity limitations. As such, people living with a properly managed chronic illness should have no reason not to be able to work or earn a living. However, the experience of poverty and unemployment in South Africa confounds the situation quite substantially.

South Africa has a comprehensive welfare programme that as Seekings (in Natrass, 2007: 179) notes, is “exceptional among middle-income and developing countries.” One aspect of this welfare programme involves providing disability grants to people with disabilities who are unable to work due to these disabilities. The assumption underpinning the grant therefore is that it is intended for people who are unemployed and unable to be employed because of their activity limitations. However, the grants system in South Africa, as it pertains to disability, also makes provision for people living with a chronic illness. As Schneider & Goudge note (2007: 4), “If a chronic disease has been controlled as far as possible, but the person remains with moderate to severe activity limitations, they are eligible for a disability grant.” Thus the criteria for receipt of the disability grant still technically call for the person to be living with a disability. However, in practice, because of a lack of clarity in the guidelines pertaining to how the

criteria for receipt of a disability grant are applied (CASE, 2005), many people with no activity limitations, but who are living with a chronic illness, have been awarded the grant. This is in some ways not surprising since “The ongoing high levels of poverty and unemployment confound this situation as people are desperate to find any form of income, and look to the disability grant as a means to do this” (Schneider & Goudge, 2007: 4).

This raises a number of issues pertaining to how disability is understood in South Africa. While disability rights movements are attempting to shift discourses of disability away from an illness focus, the experiences with the disability grant realign the understanding of disability with illness.

It is thus clear that there are specific debates and issues that are particular to South Africa and perhaps other developing nations when it comes to disability. There is, however, limited literature on disability in developing nations. Much of the literature considered in this report is international – developed in Europe and the USA. Research being done on disability in South Africa and developing nations is limited, for a number of reasons. Firstly, disability is not seen as a priority area for development. Secondly, lack of access to education institutions for many people living with disabilities means that many of those living with disabilities are not able to inform debates about disability. It is for this reason that research of this nature is so important.

### **1.3. The policy environment informing disability and chronic illness**

As has been mentioned, South Africa’s approach to development is framed by a social development approach, which seeks to enhance the capabilities of people to achieve and maintain livelihoods, through holistic interventions, and underpinned by a human rights approach. As a result, South Africa has a fairly comprehensive policy suite that

speaks to issues faced by people living with disabilities in the country. Since the 2009 election, the state has also created a new ministry – the Ministry of Women, Children and People Living with Disabilities – the main task of which is to deal with issues pertaining to these groups.

In 2009, the policy unit of the Presidency commissioned a review of policies pertaining to people living with disabilities. It noted that the social development approach to disability in South Africa acknowledges that disability is a result of a range of factors that contribute to institutional and structural exclusion for those living with disabilities. The human development approach recognises that people living with disabilities are of equal standing and are entitled to all the rights and responsibilities as all South Africans. This approach, enshrined in the South Africa Constitution, places considerable pressure on the state to ensure that people living with disabilities are afforded the necessary opportunities and support to participate in society on an equal footing, and to claim their rights and exercise their responsibilities.

#### **The disability movement in South Africa**

The period 1990 to 1994 was a heady time for the disability rights movement in South Africa. As participants in the liberation struggle, Disabled People South Africa (DPSA) was recognised as representing a sizable constituency of disadvantaged people with rights to be guaranteed under the Constitution of South Africa and with aspirations to be realised in the policies and programmes of government. Men and women living with disabilities were elected to parliament, and others were deployed to a host of public authorities covering virtually every aspect of the lives of people living with disabilities, from broadcasting to tourism, and ranging across the various commissions for human rights, gender, and youth. Also, an over-arching Integrated National Disability Strategy was put in place to deal with education and training, employment, social security, housing and environmental access as key components.

With all of this, the disability rights movement had by the early 2000s come a very long way from apartheid South Africa. Under the old dispensation, people living with disabilities were the most disadvantaged of the disadvantaged. The majority were subject to an inferior Bantu education. Services were strictly segregated, and such social assistance as was available was calibrated according to race. The number of workers living with disabilities entering the open labour market was extremely limited, especially in the case of black South Africans, and where jobs did exist at sheltered and protected workshops, starvation wages applied. Nevertheless, it is a remarkable fact that it was from that very generation of disadvantage that many of the leaders of the disability rights movement emerged.

Now, 15 years on from the birth of our new democracy, it is probably time to take stock of the situation. The question to be asked is this: to what extent have progressive legislation and the enlightened policies of government translated into change in the lives of people with disabilities?

Previously, the disability rights movement was opposed to research, the attitude being: "Stop counting us and do something!" Today, however, it accepts that the grounds for advocacy have to be evidence-based. Research has therefore become an essential tool for measuring progress in development and to discover how persons with disabilities feel about themselves and their circumstances. Their voice should, of course, also be heard in determining what is to be done with research findings to which they have contributed, true to the spirit of our universal slogan: "nothing about us without us!"

The constitution includes an anti-discrimination clause and names sign language as a language to be developed. In the early years of democracy in South Africa, the Reconstruction and Development Programme was extended to include people living with disabilities, and defined targets and mandatory quotas for employment equity and skills development were set. Government has also committed itself to financial support for small businesses run by people living with disabilities and to a procurement policy favourable to the disability sector.

In addition, policies that are aimed at protecting the rights and enhancing the opportunities of all citizens are available to be leveraged by those living with a disability to claim their rights. Such policies and frameworks include, amongst others:

- The Promotion of Equality and Prevention of Unfair Discrimination (PEPUDA)
- The Employment Equity Act 1998 (EEA)
- The Labour Relations Act
- The Admission Policy for Ordinary Public Schools of 1998
- National Plan for Higher Education
- White Paper on Social Welfare 1997
- The White Paper on National Strategy for the Development and Promotion of Small Business in South Africa 1995
- White Paper of Affirmative Action in the Public Service, 1998; and the
- National Skills Development Strategy (NSDS) 2001-2005 and 2005-2010

All of these policies are aimed at increasing access and opportunities for all people to ensure that they are able to develop sustainable livelihoods. They are intended to redress past inequalities and thus focus particularly on addressing the needs of the most marginalised and those that were previously disadvantaged under apartheid. They are thus readily available for people living with disabilities to leverage.

In addition to the above, the disability movement in South Africa has lobbied for particular policies and frameworks aimed at dealing with the challenges that constrain their ability to participate meaningfully in society. These include:

- Integrated National Disability Strategy (INDS);
- The Code of Good Practice on Employment of Persons with Disabilities
- Quality Education for All Learners: The Challenges of Addressing Barriers to Learning and Development
- White Paper on Special Needs Education

The policy framework for people living with disabilities is therefore quite comprehensive and holistic. Legislation has been put into place which requires that children living with disabilities that require special needs education are entitled to it, that there should be no discrimination of people living with disabilities when it comes to employment and that the inclusion of people living with disabilities in a company's workforce is counted in a positive light in terms of employment equity measures, that people living with disabilities are entitled to free healthcare and that they are able to access a housing subsidy. People living with disabilities are also entitled to receive the disability grant, provided they meet the requirements. The policy framework therefore makes extensive provision to facilitate access to the economy and to the means for survival in a holistic manner.

The policy framework for disability in South Africa should be celebrated. However, we also need to understand how these policies are being implemented and whether or not what they make provision for is in fact happening on the ground. One challenge that the Presidency's ten year review on disability (2009) noted is that the policies are not always coordinated and aligned, and often do not include monitoring and evaluation frameworks. This means that a major challenge still lies in the implementation of policy at the local level. It is for this reason that research of this nature is so important. It points to the ways in which coordination and implementation can be improved to

ensure that people living with disabilities and chronic illnesses are able to access opportunities to develop sustainable livelihoods.

#### **1.4. Challenges for people living with a disability in South Africa**

Despite the comprehensive policy landscape and the extensive work of the disability rights movement in South Africa, people living with disabilities still face a range of challenges that both compound and are compounded by poverty:

*“Despite the remarkable progress government has made in developing enabling legislation, transforming the state machinery and putting structures in place to be representative and responsive to the developmental needs of the People with Disabilities, the majority of People with Disabilities are still exposed to restrictive environments and barriers that continue to marginalise and exclude them from mainstream society and its social and economic activities” (Department of Social Development, 2009).*

The unfortunate truth is that persons with disabilities in particular remain among the poorest of the poor. Certainly, there has emerged a middle class of affluent and successful individuals living with disabilities, many of whom have rewarding jobs in the public sector. On the other hand, as this report demonstrates, at least in respect of Johannesburg, the lives of many people with disabilities are characterised by limited means, a lack of amenities and barriers to opportunities. These discouraging findings are, however, mitigated by more positive findings relating to family and community support, improved social assistance and the meaningful role often played by individuals in the life of their local communities.

Facilitating access to opportunities, spaces and the economy continues to be a challenge. This has serious consequences for the ability of people to participate meaningfully in community activities, to access health care facilities, and for children with disabilities to access education facilities (National Council of Provinces, 2008).



When it comes to accessing public institutions, physical access is not the only factor that needs to be taken into consideration. The Disabled Children's Action Group (DCAG), at a submission to the South African Human Rights Commission earlier this year, noted that children with particular disabilities, such as those who are deaf or blind, are not able to learn at public institutions as no assistive aids are provided, nor are teachers equipped to know how to effectively teach children with particular disabilities. In addition, there are very few schools that specialise in teaching children with particular disabilities. This means that many children with disabilities are in effect denied their right to education.

Access to employment opportunities is a further challenge. Despite the fact that affirmative action and employment equity policies, as well as the Broad Based Black Economic Empowerment Act call for the participation of people living with disabilities in employment and in empowerment deals, the effects of such policies have been fairly limited, particularly in relation to disabled people (Patel & Graham, 2010). Many lobby groups for people living with disabilities have complained that they have not been able to access government tenders as per the Preferential Procurement Act (National Council of Provinces, 2008), and employment levels of people living with disabilities continue to be significantly lower than those of non-disabled people. This may be due to lack of physical access to sites of employment, but issues of marginalisation and social exclusion no doubt also play a role.

The formal employment of people with disabilities in accordance with the Equity Employment Act is occurring at a slow and rather tedious rate. This is mainly attributed to the shortage and lack of appropriate skills and inadequate training among people with disabilities and a shortage of resources to support the employment of people with disabilities. The situation is compounded by the inaccessibility of transport, information and the built environment, contributing to the challenges people with disabilities face in an attempt to achieve sustainable livelihoods. Currently, the majority of people with disabilities are employed in protective and sheltered workshops as well as in various

income generating projects, most of which rely heavily on subsidisation and fundraising to maintain their existence. Additionally, these projects by their very nature perpetuate exclusion from mainstream economic activities and limit equal and meaningful participation of people with disabilities.

The issues of social exclusion and marginalisation (McClain, 2002) still seem to still be prevalent for people living with disabilities in South Africa and there still seems to be an attitude of pity towards people living with a disability, who are often seen as mere recipients of handouts and charity. In a 2006 submission to the Constitutional Review Committee, the South African Human Rights Commission flag the lack of tolerance and acceptance towards South Africans living with disabilities. They further note that there is a:

*“Lack of an adequate human rights culture of tolerance and acceptance; that intolerance is aggravated by a general lack of awareness and knowledge about the different types of disability, and the causes and ways of ensuring acceptance of persons with disabilities within communities; that there is still a presence of negative stigmas within communities associated with disability; that there is an invisibility of persons with disabilities in communities resulting in their specific and special needs not being adequately addressed; that this is further perpetuated by inadequate representation of persons in the work place; and that in terms of education there is a lack of integration of learners with disabilities into schools and also a lack of schools in many provinces for learners with special needs” (South African Human Rights Commission, 2006)*

The issue of marginalisation also has profound implications for the vulnerability to abuse of people living with disabilities. As Visser (2005) notes, women and children with disabilities remain the most vulnerable to abuse. In addition, people with disabilities – particularly people with mental disabilities – are most vulnerable with regards to HIV/AIDS, due both to abuse and lack of access to information (Smit, Myer, Middelkoop, Seedat, Wood, Bekker and Stein, 2006). Siyakha (2006) also highlights the particular

vulnerability of women with mental disabilities and explains the difficulties when it comes to them testifying in court.

Although South Africa has a disability grant in place, there are still challenges in terms of accessing the grant. One of the main challenges again relates to physical access where roads and buildings in villages are inaccessible for people with a disability, resulting in them having to rely on or even pay a non-disabled person to collect the grant on their behalf. Siyakha (2006) notes that the cost of disability, including medication and improved access to housing, are borne over and above the ordinary costs of living. While the disability grant should contribute to covering these costs, the grant is, in fact, often the only form of income in the household and is used for basic food and other needs.

A further challenge is the lack of services and programmes directed at persons with disabilities and a corresponding lack of awareness among persons with disabilities of the services that are available to assist (South African Human Rights Commission, 2006). There is minimal access, particularly for people with disabilities from previously disadvantaged groups, to a variety of sporting activities and facilities which cater for their needs. There is a problem of barrier-free access, and there is a lack of developmental programmes.

Access to care, rehabilitation and education services remain challenges. Many people living with severe disabilities in rural areas do not survive because of lack of supportive services and resources ([www.africandecade.org](http://www.africandecade.org)). This is something that the South African government has taken note of, stating in its policy on disability that:

*“The core developmental social services categories of promotion and prevention, rehabilitation, protection, continuing care and mental health and addiction and the levels of intervention; namely prevention, early intervention, statutory interventions and*

*reconstruction and after-care remain negligible” (Department of Social Development, 2009: 11).*

It is therefore clear that despite the extensive policy landscape intended to support people with disabilities, there is nevertheless still a gap between policy and experience. It is for this reason that further information is required in order to ensure that the challenges that people living with disabilities or chronic illnesses in some of the poorest urban areas are addressed.

## **Chapter 2:      Conceptualising the link between disability and poverty**

Disability has been defined in various ways and according to different models, with conceptions of disability evolving over time. People living with disabilities have increasingly shaped the way disability has come to be defined. Their involvement has led to a holistic understanding of the concept of disability. This is not to say that defining disability is necessarily easy, and the definition becomes even more challenging in the context of developing nations, as will be discussed in this section. Schneider (2006: 9) defines disability as “the outcome of the interaction between a person’s health condition and the context in which the person finds themselves.” The context includes both factors external to the person (such as the ways in which systems do not facilitate access for disabled people, social attitudes, discrimination) and those internal to the person (age, sex, education and skill level, personality).” She makes the point that health condition here refers both to a particular condition that may require medical intervention or assistance, but that this condition also exists as the precondition for being defined as different, in the same way that skin colour is the precondition for being defined as belonging to a particular race group.

Disability according to Schneider (2006) should also be understood by looking at levels of physical and personal functioning and how this interacts with environmental factors. For instance, a person living with a disability may have physical constraints to their activity. These constraints interact with the external social and physical environments which serve to either further constrain or facilitate interaction of the person living with a disability with their environment. Finally, personal functioning, which includes attitude, personality and communication contribute to how a person living with a disability may interact with the environment and can play a significant role in determining whether the environment will be constraining or facilitating.

Schneider's definition points to how various models of understanding disability are necessary for better insight into disability.

## **2.1. Conceptual models of understanding disability**

From a biomedical perspective, disability is understood as an illness or a "lack of" some kind of ability – an impairment. This model is often referred to as the individual model (Watermeyer et al, 2006) and is itself disabling – suggesting that the disability lies with the individual and that little can be done that will enable the person living with the disability to participate meaningfully in society. Stemming from this model, the philanthropic or welfarist perspective developed, where disability is understood to be a condition that, according to Disabled People South Africa (2008: 4), is "a tragedy or object of sympathy and charity. People with disabilities are therefore pitied, given handouts and cared for in separate institutions." This view of people living with disabilities can encourage dependency and isolation (Olson, Penna and Veith, 2004).

Nevertheless, the biomedical model does point to the issue of levels of functioning as discussed by Schneider (2006). As she notes disability is related to constrained physical functioning that may often be the result of underlying medical conditions. However, one of the key problems with the biomedical model is that it stops at only assessing the medical condition or physical challenge without taking into account the social perspectives of disability.

Through the advocacy of disability organisations, it became clear that biomedical perspectives on disability were inadequate and that they failed to acknowledge the fact that it is not the disability that is disabling but the social, political and physical environments that are disabling (Swartz and Schneider, 2006). As a result, definitions of disability have come to be more profoundly shaped by people living with disabilities through disability rights movements, leading to a greater understanding of disability and

the ways in which people living with disabilities are marginalised and disenfranchised. This influence has led to a more holistic understanding of disability with the British Council of Organisations of Disabled People (now the UK Disabled People's Council) defining disability as "the disadvantage or restriction of activity caused by a society that takes little or no account of people who have impairments and thus excludes them from mainstream activity." As DFID (in Harris and Enfield, 2003:11) note, "disabled people have long-term impairments that interact with environmental factors leading to social and economic disadvantages, denial of rights, and limited opportunities to play an equal part in the life of the community."

The social model has been criticised by some as undermining the very real limitations of the body that are experienced by a person living with a disability. As Arneil (2009:236) notes, "Feminist disability scholars theorizing the 'personal as political' argue that some versions of the social model tend 'to deny the experience of our own bodies, insisting that our own physical differences and restrictions are entirely socially created.'"

### **2.1.1. The systems model**

Nevertheless, taking into account the way the environment places constraints on the individual is important. Understanding how the environment affects people living with disabilities requires one to go beyond simply thinking about the physical environment. It is important to also consider how social systems and dominant discourses shape disability and how a person living with a disability operates in the social environment. A systems model understanding of disability enables one to understand that a person living with a disability enters into particular systems in society, already at a disadvantage because of how the systems or organisations use labels to organise people in order to operate optimally. By doing so, the abilities of a person living with a disability are overlooked in favour of focusing on the disability since it is the disability that challenges the system. As Michailakis (2003:214) explains in his article entitled "The systems theory concept of disability":

*“The individual is linked up to a specific system by means of that system’s specific codification ascribing a certain meaning to the particular individual’s condition (health–illness, working ability–inability, etc). The binary codification of the system becomes the attribute that colours the perception of the entire person. All other aspects of the person are ignored except those that fit the system-specific form of communication.”*

Thus at a systems level, a person living with a disability must overcome entering such a system at a disadvantage. But it is important to note that systems do not exist in isolation but rather interact with the broader environment. A systems approach to disability therefore encourages consideration of the dynamics “that can drive and accelerate (or constrain) the course of development by examining the synergistic influence of the characteristics of a person, and of the environment” (Llewellyn and Hogan, 2000:160 *authors’ emphasis*). Such a model encourages an assessment of the broader environment surrounding the person living with a disability. The systems model therefore encourages an understanding of how conditions of poverty limit the ability of a person living with a disability to such an extent that their disability places them at a severe disadvantage. As Llewellyn and Hogan (2000:160) note, “There is a de-emphasis upon the importance of objective testing and an emphasis upon real-life contextual research.” This study subsequently focused on speaking to people living with disabilities in settings of poverty in order to understand how their environment constrains or supports their abilities.

To gain as full an understanding as possible of the environment of people living with disabilities and chronic illnesses, it is necessary to consider not only their living environment but also their political environment. Arneil (2009) makes a case that points to how in modern political thought, people living with disabilities are almost always framed in a disabling way as either lacking autonomy or being dependent, which ultimately undermines their personhood and citizenship:



*“If the ‘rational’ citizen or ‘person’ at the heart of all these political theories is repeatedly constituted in direct opposition to the disabled ‘other’ who is defined as less than ‘normal,’ ‘irrational,’ outside the ‘usual’ way of being, only ‘potentially’ human, and governed by the principle of charity rather than justice, it is clear that to incorporate disability into contemporary political thought is not simply a matter of ‘including’ the disabled within existing norms or paradigms” (Arneil, 2009:229).*

From this statement it is clear that one also needs to take into account the political environment and conceptions of the self as citizen. The study aimed to include perspectives on the political environment and citizenship of people living with disabilities or chronic illnesses.

## **2.2. Issues and debates**

It is clear from the above discussion that defining disability is a complex matter, which becomes more complex when one considers what conditions might contribute to a person being regarded as disabled. Very often, disabled people are understood to include people who are deaf, or have visual and other sensory disabilities; people with physical impairments including paraplegia, cerebral palsy and the like; as well as mental disability. Society less often considers epilepsy and arthritis as well as other chronic illnesses, and psychological disorders such as depression, to be disabilities. Nevertheless, these could be considered to be disabilities. Add to this the rise in awareness of learning challenges that many children face, and it becomes clear that actual figures under-represent the number of people living with a disability.

It is also clear that disability is culturally defined. For instance, in some cultures, infertility and delayed menarche among women are considered serious impairments, while other cultures may base disability on appearance (such as albinism) (Buga, 2006). This also raises the issue of power and discourse. From a Foucauldian perspective, discourses apparent in language and practices serve to normalise or govern behaviour.

The Foucauldian perspective considers the act of defining disability as an act of “othering”; this perspective in addition to a medical focus on rehabilitation are in fact “practices that aim to create the normalized disabled person” (Turner in Handley, 2003:115). Thus, were one to consider disability from a post-modern perspective, the term disability may in fact be irrelevant, since every person is differently-abled, and disability, according to this perspective, is seen as having been shaped by individual and cultural perceptions.

### **2.3. Perspectives on poverty**

Understanding poverty today has moved beyond the notion of not being able to meet basic needs. Poverty can broadly be explained in terms of individual incapacities and structural forces. Public policy in South Africa is based on the assumption that the poverty of our people is the result of historical, political and economic forces within our society. Poverty reduction strategies are therefore aimed at breaking the structural forces that cause poverty through economic growth and human development. From a social development perspective, this involves enhancing the capabilities of individuals, households, and communities, and redistributive social interventions (Patel, 2005).

Any understanding of poverty in the world today, locally and internationally, has to include the perspectives of poor people themselves, that is, how they themselves interpret their situation. From this perspective, people are poor because they are unemployed, cannot read and write, and lack health care. Not possessing assets in the form of housing or land is a further factor, as well as the non-availability of services (water, electricity and transport). Social exclusion from political and economic processes also contributes to the cycle of poverty. To this must be added the psychological aspects of poverty: humiliation, inhumane treatment and the emotional strain of being poor, as well as deprivation factors – the understanding that conditions of poverty result in

vulnerability to exploitation and greater subjugation to structural forces that contribute to a cycle of poverty.

In South Africa, race and gender dimensions intensify poverty. Also, people move in and out of poverty throughout the life cycle. And then there are the “shocks” to which households are subjected when someone dies or becomes chronically ill, when someone loses a job, when an extra person moves in, or when economic changes such as price rises occur. Superimpose on this the disadvantage of living with a disability in such a community, and we begin to understand what living with a disability means to many South Africans.

Poverty of course goes hand in hand with development or attempts to reduce and eliminate poverty and raises questions as to how development is understood. Globally, development is seen as being a process of moving towards greater industrialisation, technological development and urbanisation. However, these processes have often gone hand in hand with greater levels of inequality and poverty, particularly in urban contexts. For this reason newer ways of understanding development have emerged.

## **2.4. Understanding assets and livelihoods within the framework of the systems model of disability**

The capabilities approach (Sen, 1999; Nussbaum, 2000) to development highlights the inherent potential of all human beings to meet their needs and goals and notes what factors might constrain these capabilities. The focus thus shifts from inabilities and deficits to assets and capabilities. This framing lens is used in this study to illustrate how in many instances the capabilities of people living with a disability are constrained, not by their disability necessarily, but by the environment in which they live.

The livelihoods approach to understanding poverty draws on the capabilities approach and demonstrates that in order to understand poverty and development, a multi-dimensional approach is necessary. The livelihoods framework focuses on the various assets that are available to households and how these are leveraged to ensure the survival of the household (Chambers and Conway, 1992) in difficult circumstances.

*“A livelihood is sustainable when it can cope with and recover from stresses and shocks and maintain or enhance its capabilities and assets both now and in the future, while not undermining the natural resource base” (Carney in Rakodi, 2002).*

This sustainable livelihoods framework (demonstrated in Figure 1 below) takes into account how assets that are available to individuals assist them to navigate various vulnerability shocks and trends that they have no control over (vulnerability context). It also takes into account the political structures and processes that facilitate access to assets and how they can be used to influence the vulnerability context. The interaction between the assets and the political context result in livelihood strategies that then produce livelihood outcomes such as increased income, health benefits, food security and the like and assist people to become more resilient to the vulnerability context.

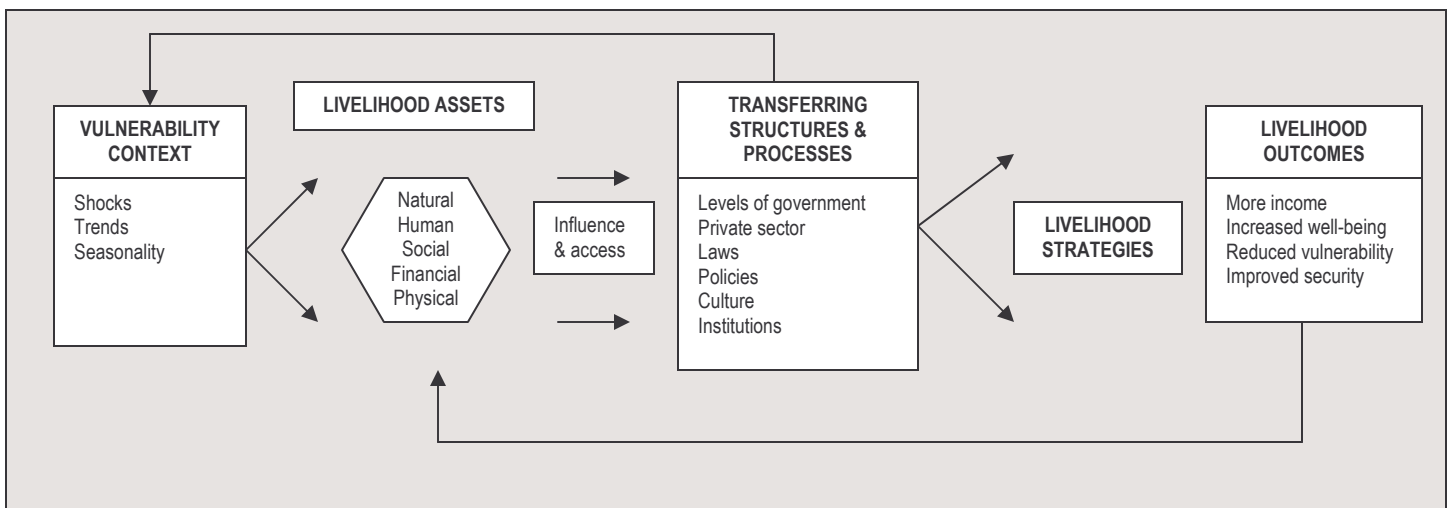


Figure 1: The DFID Sustainable Livelihoods Framework (adapted from Carney, 1999)

Understanding poverty and disability through an assets and livelihoods lens shifts attention to the ways in which people living with a disability contribute to the livelihoods of the household. This research points to some of the ways in which this happens.

However, the livelihoods perspective does not take into sufficient account the ways in which disability interacts with the systems to limit functioning. This interaction plays a significant role in influencing the ways in which assets that might be available to a person living with a disability can be leveraged for livelihood strategies. As this research will demonstrate understanding the livelihoods and systems nexus for a person living with a disability takes us a step closer in understanding the ways in which poverty and disability interact. This emerging insight is discussed in greater detail in Chapter 5 of this monograph.

In South Africa, development has come to be approached from a social development perspective (Patel, 2005), which seeks to increase the capabilities of all people, but particularly those living in poverty and other marginalised circumstances. The basis of the social development approach is a holistic approach to supporting people in achieving livelihoods. It therefore encourages a multi-sectoral approach to development and aims at creating conditions for development, rather than addressing lack of development in a remedial fashion. The livelihoods and systems nexus when viewed from a social development perspective assists us in making recommendations to influence the lives of disabled people living in situations of poverty.

## **2.5. Perspectives on the link between poverty and disability**

The link between disability and poverty is widely referred to in literature. As Emmet and Alant (2006:452) argue, disability is both the cause and a consequence of poverty, as

disability increases the risk of poverty while poverty creates the conditions for increased risk of disability.

A number of authors comment on the link between disability and poverty. The Department of Health (2004) make the general assumption that “We all know that disability and poverty are intertwined”, while other material points to more specific and definable connections between these two phenomena. “The high incidence of disabilities in the Third World relates to poverty and the environmental factors that underlie high levels of illness and accidents, the prevalence of unattended home births and the fact that selective abortion, which has reduced the number of children born with impairments in the West, is seldom available,” writes Ansell (2005: 15), who also acknowledges the impact of cultural views of disability and states that many African children living with a disability enter a cycle of poverty since, from a cultural perspective, they are considered to be burdens on their families.

Rouso (2006) refers to a circular relationship between poverty and disability and states that poverty in many instances is the cause of disability due to the lack of basic necessities such as food and medicine. The author states that disability can, in turn, perpetuate poverty due to the expenses that it entails.

Perhaps the most comprehensive study of disability undertaken to date is that of the Disability Knowledge and Research (KaR) Programme. Conducted between 2003 and 2005, the programme was jointly managed by the Overseas Development Group at the University of East Anglia and Healthlink Worldwide. Findings and broader lessons drawn from this programme are summarised by Albert (2005) as follows:

*“Studies conducted in both industrialised and developing countries show that people with disabilities generally have lower incomes than non-disabled people, have greater difficulty in accessing education, are at greater risk of social exclusion, and suffer considerably higher rates of mortality. The KaR Programme concludes that people with*

*disabilities are typically among the very poorest, experience poverty more intensely and have fewer opportunities to escape poverty than non-disabled people.”*

Despite the link between poverty and disability being seemingly obvious, there are very few studies that attempt to empirically establish this link, and in most cases the link appears to be assumed, rather than proven.

## **2.6. Responses to the disability-poverty link**

According to a Department of Social Development discussion document (2006:2) “There is a lack of proactive and deliberate strategies to link social group beneficiaries to opportunities for economic activity ... An intolerable proportion of able-bodied, poor South Africans and those persons with disabilities capable of rehabilitation continue to face particular barriers to entering into and remaining in and progressing in such employment. However, no known project of scale exists that provides rehabilitation and support towards employment for people with disabilities. Over 90% of the people with disabilities have low levels of general education and are unemployed. There are no public or private projects of scale geared at integrating people with disabilities into meaningful economic activity”.

Albert (2005) mentions that a disability and development team was established at the World Bank in response to the issues that emanated from the KaR Programme. Its members have been proactive in supporting research into disability and poverty and finding ways to get more disabled people’s organisations involved in poverty-reduction strategy papers as one of the new aid instruments. “They have also been pushing hard to get the tackling of disability issues recognized as essential for achieving all of the MDGs [Millennium Development Goals],” Albert (2005) writes

One of the collaborators on the KaR Programme, Yeo writes that the relationship between disability and poverty has often been referred to as “a vicious cycle” (Yeo,

2005). She argues, however, that this imagery obscures the similarities between the processes of marginalisation experienced by people living with a disability and poor people. She therefore argues, as is argued in this report, that disability and poverty are often “manifestations of the same processes”. Subsequently, if these commonalities are recognised, the need to build horizontal alliances between those living in poverty and people living with disabilities comes to the fore. Therefore, while the connections between disability and poverty might appear to be relatively straightforward, these linkages can in fact be very deceptively complicated. Hard statistical evidence is limited and sketchy. Yeo also raises some fundamental questions in terms of how the two concepts are understood and how this understanding convolutes the interrelationship. As has been mentioned above, this research demonstrates that understanding the link between the systems and livelihoods available to disabled people goes some way in explaining this relationship.

It should be kept in mind that disability and poverty are highly contested political concepts. Because different meanings are adhered to, role-players are often at cross purposes when debating these issues.

The KaR three-country study in Rwanda, Cambodia and India provides excellent case studies that highlight the social factors that make it more likely for poor people to contract impairments. These case studies also demonstrate why people with impairments are likely to become or remain poor.

People living with disabilities struggle to enter the labour market in all three of these countries. As Yeo (2005) explains: “Having a physical impairment makes it difficult to work in the agricultural sector, which dominates all three economies. Vocational training opportunities are limited, tend to be in urban areas and are not generally linked to gainful employment. Because they are seen as presenting a high risk, disabled people are also usually denied access to micro-credit schemes.”



In Cambodia, poor people tend to live near mined areas, are forced to use risky means of transport, have dangerous jobs and cannot access health care, resulting in minor illnesses or injuries that often become permanent impairments. Interestingly, the Cambodian research indicates the highest disability prevalence rate occurring in the least isolated villages with the best social and economic opportunities.

It is clear that poverty may contribute to the incidence of disability and that living with a disability may make a person more vulnerable to conditions of poverty. However, the relationship is not causal. There is a range of contributing or intervening factors that must be taken into consideration.

For instance the poor may face increased vulnerability to disability because of poor nutrition, lack of access to health care and education, and greater exposure to violence and unintentional injuries. This increase of vulnerability relates largely to environmental factors and disparities in economic, social and political power associated with being poor (Emmet and Alant, 2006).

According to Alcock (1999:181), people with disabilities are often unable to participate fully in society. This often leads to exclusion by structures within society that favour the 'able-bodied' thus directly excluding people living with disability and putting them at greater risk of poverty. Access to employment, for example, is greatly reduced due to restrictive hiring practices, often based on age and physical requirements. In South Africa, for instance, despite legislation encouraging the hiring of people living with disabilities, very little change has happened at the level of implementation. In addition, these requirements are often imposed on workers in lower socioeconomic status occupations, which people with disabilities are more likely to engage in. Unfortunately these occupations are often low paying and offer no job security. This means that those participating in these jobs are more susceptible to job loss (Haber, 1973; Alcock, 1999).

As people with disabilities are excluded from the labour market, and some of them are unable to work, they don't consider wages a reliable source of income. This would imply that many people living with a disability are reliant on social benefits as a source of income (Alcock, 1999).

In addition to the fact that people living with a disability often do not have access to wages, they face extra costs associated with their disability; for example, they need to provide for physical aids, medication, adaptations to the home, specialised transport costs and to pay for care (Wendell, 1989; Emmet and Alant, 2006). This means that people living with a disability may be doubly disadvantaged by exclusion from the labour market and having to bear the higher costs of living with a disability. As Wendell (1989) argues, this contributes to vulnerability to greater poverty.

According to Wendell (1989:105) and Emmet and Alant (2006:447), women with disabilities are more disadvantaged than men with disabilities as women have to struggle with the oppression of being women in male dominated cultures, and also face the further oppression in societies dominated by the able-bodied. In addition, as the South African Integrated Disability Strategy (Government of South Africa, 1997) argues, women with disabilities experience more discrimination than able-bodied women because their disabilities might prevent them from being able to live up to the cultural or societal demands and ideals of women, which mainly pertain to their roles as wives and mothers, in the community.

The oppression of women with disabilities in both developed and developing countries is evident. Studies undertaken in industrialised countries show that this group of women, compared to men, are at a disadvantage considering indicators for income, education, employment and employment opportunities. Women living with disabilities are not only less likely to be employed but also earn less than their male peers (Jans and Stoddard, 1999; Emmet and Alant, 2006).

Emmet and Alant (2006:452) further argue that in developing countries and among the poor the vulnerability of women is compounded, not only because of their poor position in the labour market but also because their parenting responsibilities and the division of labour in the home does not favour them. When a woman has to care for a family member with a disability, her vulnerability is intensified. Emmet and Alant (2006) add that the income and structure of households play a role on the bearings of disabilities and gender. Women with disabilities are also at greater risk of physical, mental and sexual abuse.

As has been mentioned before, the relationship between disability and other social problems, such as poverty and lack of employment, is exacerbated by social attributes such as gender and race. Haber (1973) asserts that the social attributes that restrict individuals or make them less adaptable tend to increase the likelihood of disabilities. For instance, Haber cites a study undertaken in the USA in the 1970s that showed that people living with disabilities (and particularly those living with severe disabilities) were older, had low levels of education and low-level occupational skills. This group also included a higher population of black people than the non-disabled population (ibid). It is likely that similar trends will be found in South Africa. In addition, South Africa's apartheid history has ensured that there is still inequitable access to education, employment and health care, making black South Africans more vulnerable to poverty as well as to chronic illness and disability.

Inequalities and disadvantages experienced because of gender, race, ethnicity, social class and socioeconomic status, and the cumulative impacts of these disadvantages often overlap to create extremes of deprivation and exclusion. Although poverty may be exacerbated by disability, living with a disability also means that people are more vulnerable to the effects of poverty. Therefore the goals of programmes and policies aimed at poverty reduction (such as the Millennium Development Goals) may not be

achieved without addressing the needs of people living with disabilities (Emmet and Alant, 2006), as these policies must take into account the high proportion of poor people living with disabilities (Haber, 1973), and this may require social action that integrates them into society by modifying the environment to support their full participation.

Based on the above discussion, it is clear that there is no simple causal link between poverty and disability. Such an assumption would be far too simplistic. Rather, the link between poverty and disability must be understood to be circular and multi-dimensional. A livelihoods approach to understanding this link, rooted in the social development and capabilities approaches to development, and the social and systems model lens of understanding disability is necessary to frame our understanding of this link.

## **Chapter 3: Research design and methodology**

In order to understand how poverty and disability interact in an urban setting, it is necessary to understand trends in terms of access to basic services and other social systems that provide for the well being of the population. However, it is also necessary to understand the day to day individual experiences of disabled people and how they are able to create livelihoods for themselves.

### **3.1. Research design**

For this reason a mixed-methods approach (Greene, 1999) was employed. This was used to ensure that statistically significant data pertaining to the conditions under which poor people with a disability live were generated in addition to qualitative in-depth data regarding the day-to-day life experiences of a poor person living with a disability. This allowed for triangulation of data and provided information that is rich and contextual, as well as significant for the sample.

The research design was framed from a livelihoods perspective, which is underpinned by an assets-approach to poverty (Sen, 1999). Questions posed were therefore intended to understand coping and resilience mechanisms in terms of livelihoods rather than focusing on deficits and challenges. That said, the ability of disabled and chronically ill respondents is obviously constrained by certain factors, which are also assessed.

### **3.2. Research method**

As has been discussed above a mixed-methods approach was used in this study. This involved re-analysing data that had been collected during the Johannesburg Poverty and Livelihoods Study (JPLS) that was conducted in 2007 by the CSDA (de Wet, Patel, Korth & Forrester, 2008); conducting a follow up survey with members of households who in the

2007 survey had indicated that they were either disabled or too ill to work; conducting semi-structured interviews with fifteen respondents; and conducting one in-depth interview which resulted in a case study of a particular individual who is disabled.

### **3.2.1. Reanalysis of the JPLS data**

In 2007, the CSDA conducted a study in eight of the poorest wards in Johannesburg with a view to assessing the livelihoods of people living in these areas. The wards were selected based on the Gauteng report of the *Provincial Indices of Multiple Deprivation for South Africa* (Nobel, 2001), which assesses levels of deprivation based on an index of deprivation which includes income and material deprivation, employment deprivation, health deprivation, education deprivation and living environment deprivation. A total of 1407 households were surveyed.

Within this data set 3.7% of households indicated that at least one person in the household was either living with a disability or was too ill to work. 19.6% of households that indicated that their circumstances included at least one person with a disability or chronic illness were from Alexandra, 15.2% from Doornkop, 14.2% from Orange Farm, 13.6% from Ivory Park, 13% from Riverlea, 11.7% from Phiri/Senoane, 8.5% from Jeppestown and 4.1% from Diepsloot (de Wet *et al.*, 2008).

The data generated from the JPLS data set was thus reanalysed to focus only on the households which indicated that at least one person with a disability or chronic illness was living in the household. This aspect of the study focused on access to basic services and predominant livelihood practices. Data from the reanalysis of this sample is referred to throughout the report as JPLS D/CI sub-sample. The data that was reanalysed was

also compared to the data for the general sample (referred to as full JPLS sample)\* and raised new questions that were probed in the new questionnaire.

### **3.2.2. Revisiting the households**

Because the JPLS study did not focus specifically on issues pertaining to disability, a new questionnaire was developed that probed certain issues arising from the reanalysis of the JPLS data. A sample of the JPLS households that included a person living with a disability or chronic illness was drawn for this next phase of the data collection. Of the 316 households from the JPLS data, 109 were randomly sampled and targeted for further analysis. The aim of this phase was to enquire about issues that had not been asked in the JPLS such as access to disability grants, support services, livelihood activities and social networks, and household decision making. Ultimately 93 participants were interviewed. Some of these respondents were themselves people living with disabilities or chronic illnesses; in the remainder of the cases, caregivers of the people with disabilities or chronic illnesses were interviewed. The data were analysed using the Statistical Package for the Social Sciences (SPSS). The findings pertaining to this dataset are referred to throughout this report as the new D/CI sample.

### **3.2.3. Probing the experience of poverty and disability further**

As has been mentioned above, using quantitative data to understand the link between poverty and disability is important but cannot interrogate the experiences of disabled people living in poverty. The study thus sought to gain greater insight by interviewing people living with a disability or chronic illness in these wards. Eight semi-structured interviews were conducted. These interviews focused on experiences of living with a disability, issues of participation and stigma, as well as self perception; in order to gain a better understanding of the lived experiences of someone living with a disability in a

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\* It should be noted that this overall sample also includes people with a disability or chronic illness. However, because the number of respondents with a disability or chronic illness in this sample is so small the effect on the overall sample responses is not significant.

poor community. These interviews were transcribed and analysed using Atlas.ti. A further in-depth interview was conducted with the mother of a person who had originally fallen into the JPLS dataset but had since moved to Polokwane for care. The interview data from this interview has been written up into a case profile, which profoundly illustrates some of the theoretical concepts arising from this study.

### **3.3. Limitations**

As with any study there are a few key limitations to this study which also point to areas for further research. Firstly, as has already been mentioned, the data generated from the JPLS study and reanalysed for this study did not differentiate between households in which a member was disabled and households in which a member was chronically ill. As such much of the data that is presented cannot be used to make distinctions between findings pertaining to chronically ill people and those with a disability. Secondly, the data that was collected in the follow up phase of the study did not seek to distinguish between types of disability based on severity or impact on functioning. Thus while categories of disability were asked for, the way the question was asked did not provide information on how severely the disability affected physical or mental functioning. Some of the findings such as those pertaining to types of livelihoods and community participation would have been enhanced had they been assessed by the extent of function limitation. Finally, the age of onset of the disability or illness was not assessed. As such questions pertaining to education could not be analysed by age of onset of disability. These limitations point to key gaps in our understanding that should be interrogated in future research.

### **3.4. Research gaps to be filled**

Apart from the above gaps that arise out of the limitations of this study there are a few other research gaps that would require a different research design and should be



considered as future areas for research. In order to enhance our understanding of the link between poverty and disability, a study that assesses the livelihoods of people living with a disability in poor areas as compared to disabled people from more affluent areas would give further insight. Secondly, a case study of a particular poor area in which disabled and non-disabled people are compared could also highlight features of the poverty and disability link that have not been unearthed in this study. Finally, our understanding of poverty and disability needs to be extended to rural areas of South Africa. A future study could therefore assess livelihood options for disabled people in rural areas.

### **3.5. Ethics**

All of the participants were given the full details of the research and were required to sign a consent form. They were also all guaranteed anonymity. The interviews were all conducted by trained researchers and social workers who participated in a training session before data collection. The training session focused on the aims of the study, clarified the instruments and prepared interviewers in terms of sensitivity to disability issues.

The CSDA is committed to ensuring that participants of its studies are not treated simply as objects of enquiry but that they are offered an opportunity to learn about the findings of the study. For this reason this monograph was launched at a seminar to which various disability organisations were invited. In addition, a summary document was prepared and sent to all participants. The CSDA also intends to use the findings to prepare a policy brief for government departments, particularly targeting the City of Johannesburg in which this study took place, in order to make some inroads in influencing the implementation of policies that are aimed at ensuring that disabled and chronically ill people are better able to access livelihood opportunities.

## **Chapter 4      Living with a disability or chronic illness in the poorest wards of Johannesburg**

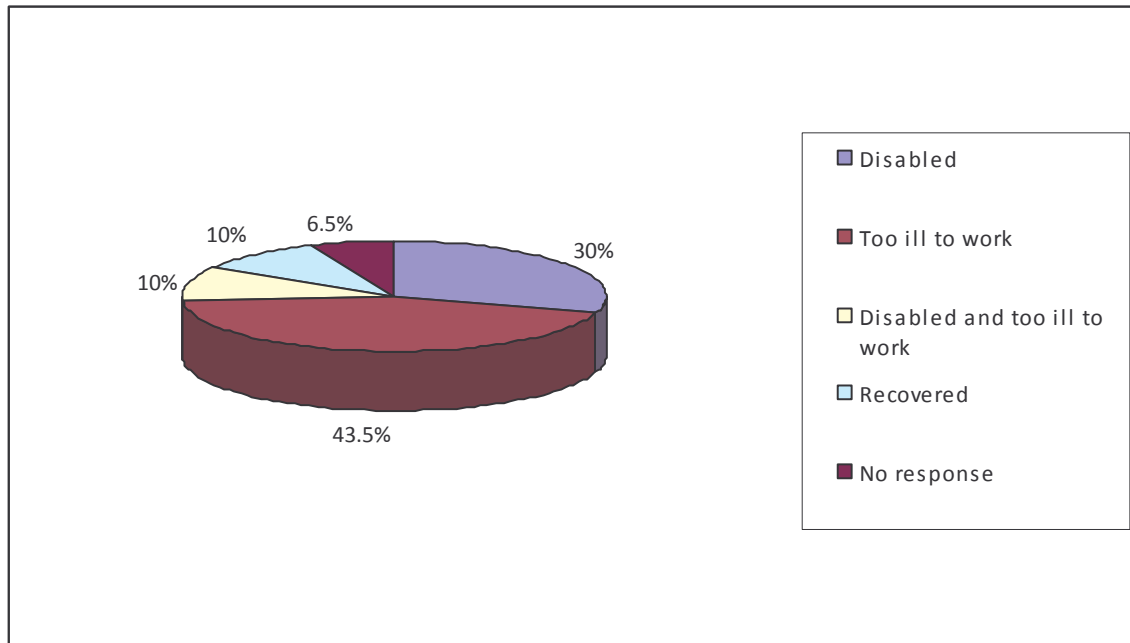
South Africans live in two very different contexts. On the one hand, 2% of the population lives in affluence – which equates to being employed, having plenty to eat, belonging to a medical scheme, enjoying the benefits of higher education, owning a house, and being part of a social network. On the other hand, 40% of the population live in poverty, with an income below the national poverty line, with some 25% of the population being ultra-poor, which means subsisting on less than R1 200 per month, or less than US\$2 per day. This translates into unemployment, inadequate health care, limited schooling and living in crowded and often insanitary conditions and social exclusion from political and economic processes. The overall unemployment rate (at the broad definition) for the country is in the order of 41%. The situation in Johannesburg is not dissimilar. There are wards characterised by incredible affluence situated alongside wards in which people struggle to survive.

### **4.1. Demographics of respondents**

As previously mentioned, the sample for this follow up study on poverty and disability was drawn from the 3.7% of households that indicated, in the Johannesburg Poverty & Livelihoods Survey (JPLS), that at least one person in the household had a disability or was too ill to work. Within this sample, the average age of respondents was 39 years. 16.3% of the respondents were 18 years or younger and 13% were 60 years or older. There were slightly more female (53%) than male respondents who indicated that they either have a disability or are too ill to work.

In terms of respondents' perception of their disability, 30% of the sample considers themselves to have a disability, while 43.5% are too sick to work, and 10% perceive themselves to fall into both categories. A further 10% were too ill to work at the time of the JPLS survey but felt that they had recovered by the time of the follow up study, and

another 6.5% answered on behalf of someone in the household who either had a disability or was too ill to work and could not answer the questions themselves.



**Figure 2: Disability and illness status of respondents in follow up study (new D/CI sample)**

As is indicated in the methodology section of this monograph, in the JPLS data, the type of disability or illness was not asked for. In the follow up study, the questions asking about type of disability were self reported and only broad categories of disability were accounted for. This means that other categories of disability such as emotional or learning disabilities, as well as the severity of disability were not accounted for. In addition, the onset of disability was not asked.

Although the type of illness was not asked for, certain respondents did indicate that they are suffering from, among others, asthma, arthritis and HIV. Furthermore, 33% indicated that there is more than one person with a disability or chronic illness in the household, while a larger proportion (66%) said there is only one person with a disability in the household.

### Meet Jacky Mthembu\*

Jack (Jacky) Mthembu is a young man of 28 years. A few years ago he started complaining of back pain that over time became debilitating. On certain days the pain prevented him from getting out of bed. Up until six months ago Jacky was living in the backyard room of a house. His sustained absences from work as a labourer in a workshop led to the loss of his job. For a while he worked on a casual basis – when he is not in too much pain - for various households and the company at which he used to be employed. The work he did involved manual labour – cutting branches, mowing lawns, lifting heavy materials and the like. For a long time Jacky did not know what was causing the back pain but he was concerned since it was threatening his ability to sustain an income. He had visited various hospitals and traditional healers without success.

A while later Jacky was no longer contactable. Various attempts to trace him led the research team to his mother who agreed to be interviewed. She revealed that the latest diagnosis was that Jacky had TB of the spine, which was causing the back pain. Just before this diagnosis, Jacky in desperation had visited a church which had promised to heal him. During the service someone had injected Jacky in the spine. His back pain became steadily worse until such a point as he was unable to walk. The TB diagnosis came hand in hand with more difficult news – the spinal injection carried out at the church service had hit the spinal chord, damaging the nerves, and leaving Jacky with no physical functioning from the waist down.

While nothing could be done to fix the spinal damage he was provided with a wheelchair and advised to begin DOTS treatment to deal with the TB. The family decided that it was best for him to go back to his rural home in Polokwane since relatives could take care of him and he would no longer need to pay rent in Johannesburg. Jacky is currently being cared for by his aunt and cousin in their home. They are unemployed but grow vegetables which they subsist on and which they sell to buy other food and household products. Jacky's mother who is employed as a domestic worker in Johannesburg sends a little money to the relatives in Polokwane each month to support the care of her son.

Besides his wheelchair Jacky has no other assistive aids and has not had access to the therapy that can guide him in how to cope without the physical functioning of the lower half of his body. He has no catheter or colostomy bag making the simplest acts of hygiene incredibly difficult. At the time of the interview, Jacky and his mother had not heard about the disability grant and did not know how to apply for it.

Jacky's experience has in many ways increased the vulnerability of the rural home, not to mention his own vulnerability. This experience does however provide key lessons about how poverty and disability interact.

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\* Not his real name

## 4.2. Access to basic services

The social assistance programme of the state, which includes grants, is also intended to ensure that people living in poverty are afforded access to basic services so that grants can be used for items other than those services that the state provides. From a livelihoods perspective, the government's commitment to providing basic services is one of the processes that interacts with the livelihoods assets available to people living in poverty since these services better enable people to use the assets and grants that they receive to reduce their vulnerability. It is therefore important to assess what kind of services people living with disabilities and chronic illnesses are receiving.

Although the households in this sample (JPLS D/CI sample) were drawn from eight of the poorest wards in Johannesburg, most of them (93, 4%) have access to electricity. However, it is clear that this is largely through pre-paid electricity meters as 85.1% of households with electricity stated that they did not receive electricity accounts from the City of Johannesburg, Eskom or City Power. These findings are to be expected as the City of Johannesburg's strategy in terms of ensuring access to electricity has been to install pre-paid meters in poorer areas, while households in suburban areas tend to receive electricity accounts.

The main type of energy used in the households of persons living with a disability is electricity. Compared to other sources of energy, electricity is the main source of power used for cooking, for lighting and for heating. Other energy sources commonly used for cooking and lighting are paraffin (10.4%) and candles (4.7%).

While 93.4% of the disabled/chronically ill subset of households who responded to the JPLS survey have access to electricity, only 26.6% of them access water from a tap in the household. It follows that water is less accessible than electricity in Johannesburg's

poorest communities. A large a proportion of the households (71.2%) obtain their water from a tap on the stand.

It therefore seems that to some extent the government's provision of basic services to poor households is beginning to make some inroads. Easy access to water – so critical for people living with a disability or chronic illness – still requires some attention. It should be noted that these services are not available free of charge and the presence of pre-paid electricity and water metres in many of the poorest wards, may actually serve to limit the ways in which livelihood assets can be used by people living with disabilities or chronic illnesses.

### **4.3. Type of dwelling and assets**

From a livelihoods perspective one of the key forms of assets is household assets including type of house and availability of land from which to grow some crops for subsistence and or for selling. It is therefore important to understand the household assets available to people who are living with a disability or chronic illness.

The most common type of housing in which people with disabilities and chronic illnesses (JPLS D/CI sample) reside is a formal house (53.5%), followed by 19% who reside in a backyard room/house. The most widespread building materials include brick/concrete for the walls (75.3%), galvanised iron/zinc for the roofs (71.8%) and cement/stone for the floors (61,4%).

A small number of the households including persons with a disability have a garden from which they are able to grow vegetables for subsistence and selling (17.4%). The most popular type of crops include vegetables (7.6%), flowers (7.3%) and fruit (3.2%). 1.6% of the households also keep livestock in the form of chickens and cows.

74.6% of the households surveyed have a working cell phone, 73.6% have a working TV, and just under 70% have a working fridge (67%) and a working radio (65%). Independent means of transport remains a problem. Only 12% have a car and 7% have a bicycle.

The experiences of people living with a disability or chronic illness in terms of type of housing, access to garden space and household consumer goods is very similar to that of the total JPLS sample. This demonstrates that the available household assets to people living with a disability or chronic illness are no different to those for people who are not disabled or chronically ill. What is different as will be demonstrated below is how people who are disabled or chronically ill are able to leverage these assets.

#### **4.4. Access to education**

Education affects the types of assets that an individual has access to as well as how an individual is able to leverage those assets for livelihood outcomes. It is well known that disabled people are less likely to have access to and complete their education (Albert, 2005; DSD, 2006). Findings from this research confirm this trend. According to the data from the JPLS study, in terms of highest education level achieved, 9% of the disabled and chronically ill respondents (JPLS D/CI sub-sample) indicated that they have a Grade 12 or matric qualification. This is significantly lower than for the general population within the JPLS survey, in which 33% of respondents indicated that they had a matric qualification (full JPLS sample). A further 23.1% (JPLS D/CI sub-sample) have completed some secondary education Grade 8 and Grade 10 respectively, significantly less than that the full JPLS sample in which 46% of respondents had some secondary education (full JPLS sample). Very few respondents (7.7%) have completed any type of post-matric or tertiary education, but this is a similar rate as for the general JPLS sample.

The research did not demonstrate whether the disabilities that people were living with were early onset or later onset disabilities. Earlier onset disabilities would have a more

profound effect on access to education than later onset disabilities. It is interesting to note that while disabled and chronically ill respondents didn't demonstrate significant differences in terms of access to household assets as compared to the general sample, in terms of education there are significant differences. This suggests that disabled people continue to face greater challenges in pursuing education. This is a key example of the ways in which disability interacts with the systems to constrain the ability of people living with a disability to leverage livelihood assets.

The follow up research sought to understand what some of the barriers to education might be for those who did not complete matric, and the success factors for those who did.

It should be noted that while many people with disabilities may face greater challenges in accessing and being supported in education, the major reason cited for leaving school before completing matric (47% of respondents) was that parents could not afford the school fees. A further 4% of respondents stated that they left school in order to support the family. Given the above finding – that people with disabilities are significantly less likely than their non-disabled counterparts to complete schooling, there seems to be a discrepancy between the reasons for leaving school. Since the respondents in the follow up study face similar socioeconomic circumstances to those in the JPLS study, it follows that inability to pay fees is likely to be a common reason for leaving school. And yet, far more disabled people left school for this reason than non-disabled respondents. Although some of these respondents (new D/CI sample) might have had later onset of disability, this does not explain the large variation. One possible explanation is that in situations of poverty, where inability to pay school fees might be a reason for leaving school early, if a disabled child is not coping at school and the school is unable to provide the assistance the child requires, it is more likely that the child with the disability will leave school than children without disabilities.



*“We could not afford to give him further education because we had financial problems.”*

There are, of course, other reasons often associated with poverty for not attending school. For instance, the quality of schools must be taken into consideration. Some noted that they kept failing the same grade as there were no adequate teachers and support. In many cases providing disabled children with the extra support and assistive aids they require to successfully navigate through school costs money that poor parents simply don't have. If this is not provided by the state, the reality is that disabled children may never be able to fully enjoy and access the schooling system.

Access to education is a clear example of the ways in which disability interacts with systems to hamper access. In situations of poverty many schools may not be equipped to provide the children they serve with the education that will assist them to leverage livelihood assets later in life, as well as schools in more affluent areas. However, the situation may be exacerbated for children with disabilities since schools, by and large, are not equipped to cater for their needs. 9.5% of the respondents of the second round of data collection noted that the schools they attended did not cater for their needs as a person living with a disability (new D/CI sample). A further 2% stated that they were too ill to go to school. Another reason for not completing school was a lack of focus due to a disability. Physical access was also noted as a key challenge. A quarter of respondents (new D/CI sample) explained that transport to school was difficult to access as a person with a disability, and 18% said the school was difficult to get around.

This points to the key role that support for children with disabilities in school plays. Those who had completed matric (new D/CI sample) noted a number of factors that had enabled them to complete their schooling, including support from the family (26%) and extra support from teachers (25%) and friends (13%). 77% of respondents who had completed matric (new D/CI sample) indicated that school was easy to access, and those who found it difficult to access (23%), said the main reason was because the school was

too far from their house. There is thus a need to mainstream disability at schools to ensure that young people with disabilities are able to develop adequate capacity to leverage assets for livelihood outcomes later in life.

The issue of education is a key example of the ways in which disability interacts with the system to compound the experience of disability and poverty. Educational status for the full JPLS sample is generally low, suggesting that ability to complete schooling is a challenge for most people living in the poorest wards of Johannesburg. However, the data demonstrates that the educational status of the disabled and chronically ill sub-sample, particularly with regard to completing matric, is worse. Many of the reasons for not completing school such as inability to pay school fees, are likely to be common across the JPLS sample and the disabled and chronically ill sub-sample. However, from a systems perspective, schools are designed primarily for people who are not disabled and there are thus few support mechanisms to assist those who are disabled or chronically ill as is evidenced in the data presented above. These people are thus far less likely to stay in school and complete their education. Disabled respondents who did complete their education attributed that to the support they received to do so. It is therefore clear that disabled people enter the system at a disadvantage since the system is not designed for their active participation. The system thus interacts with the disability to generate a greater disadvantage. The effects of this are profound when it comes to education since education is a key element of human assets that are available as a livelihood asset, as well as a factor that allows people to more effectively leverage other assets for their livelihood outcomes.

The physical and educational environment thus further precludes them from being able to access an education, which is crucial for later access to sustainable livelihood opportunities and consequently the ability to be self-sufficient. Addressing the whole school system and its ability to cater to all young people, as well as ensuring that young people with disabilities are provided with the extra support they require, will go along

way to enabling all young people, regardless of disability to achieve sustainable livelihoods. This demonstrates that the mainstreaming of disability should remain a key implementation consideration, particularly in respect of education systems.

#### **4.5. Health status, health care and specialised services**

In the JPLS survey, respondents were asked a battery of health questions. Almost a quarter of respondents (JPLS D/CI sub-sample) stated that they had been diagnosed with high blood pressure. Slightly less than this (23%) stated that they smoked at least once a day, and 12% indicated that they drank alcohol at least once a day.

The follow up study sought to better understand access to healthcare for those living with a disability or chronic illness. For the majority of these respondents (86%) (new D/CI sample) health care is accessed via a local clinic, while 7% of respondents go to a hospital, and even fewer (2%) use the services of a private doctor. 12% of respondents are able to see a medical professional once a week, and 11% see a health professional fewer times than once a year. 46% – roughly the number of people who are chronically ill and would require monthly medication – go to the clinic once a month. 56% of respondents said they find the source of health care easy to access, but just under half (41%) said it is difficult to access. The main challenges attributed to the difficulty in accessing health care are the distance from home to the health facility (47%) and transport being too expensive (18%). Far fewer respondents indicated their disability as being a particular barrier in accessing health care. For example, only 4% of respondents said transport is difficult to access due to their disability. One interviewee noted how the conditions of poverty that she lives in exacerbate her disability:

*“It is very difficult [to get to the clinic] because my feet are always swollen. Sometimes I walk using a stick. My grandchild also put me in a wheel barrow to take me to the taxi.”*

Another interviewee noted how onerous the travel expenses were in a situation where there was already limited income. The problem is exacerbated by a lack of adequate services and medication at the hospital, necessitating unnecessary expenditure by the people affected:

*“We hire a car to go for a check-up. When she [the household member living with a disability] is there, there is no medication, and she has to go the next day again. I have to hire other transport for her to fetch medicine.”*

Despite difficulties with getting to the clinic or hospital, and despite challenges with access to medication, it seems that the health care practitioners at the clinics are friendly and helpful. 82% of respondents explained they were satisfied with the staff assistance at the clinics, and a further 80% of respondents said the staff was friendly.

One of the key challenges facing people with a disability is lack of access to specialised services and assistive aids. This became clear during the interviews:

*“We do not have a wheelchair, so he tries to walk around very slowly.”*

*“There is nothing to keep him busy. No places for him to go. The TV is the only thing that helps.”*

Access to assistive aids and specialised services as well as basic healthcare must be a core priority if the livelihoods of the households of disabled people and those who are chronically ill are to be taken seriously. Take for example the case of Jack (Jacky) Mthembu outlined in the case profile above. The burden of care on his aunt and cousin is driven primarily due to his lack of access to the basic healthcare and the assistive aids that would make his interaction with the environment far easier. Currently Jacky does not have a catheter or colostomy bag. He does have a wheelchair, but there is quite a distance between the toilet (outside of the house) and the house, and the path to the

toilet is bumpy and narrow. The toilet itself is not large enough to accommodate a wheelchair. As a result, Jacky's aunt and cousin must share the responsibility of taking him to the toilet or cleaning up after him when he was unable to make it to the toilet. This severely limits Jacky's and his caregivers' abilities to effectively leverage the assets they have available to them for better livelihood outcomes.

Since ill health is one of the factors that contributes to a greater vulnerability context for poor households, being able to access health services is a fundamental component of facilitating resilience and reducing the vulnerability of poor households. This is even more of a priority for the households of disabled people since ensuring access to basic healthcare and especially assistive aids is one mechanism that can facilitate better interaction between a disabled person's abilities and the systems in which he or she must operate therefore making leveraging livelihood assets more possible for disabled people.

#### **4.6. Livelihood activities**

The JPLS data demonstrate that 80% of the households (full JPLS sample) had at least one economically active individual who was either formally or informally employed. From the follow up study it is clear that in most cases this household member is not the disabled or chronically ill person. The follow up study shows that 82% of respondents are unemployed, and the largest proportion (48%) stated that they are not involved in any significant livelihood activity (new D/CI sample). Of those who were involved in some form of livelihood activity, 15% of the sample indicated that they have some form of employment, 7.6% are involved in the care of a baby or child, and a further 7.1% are students or scholars. 5% indicated that they are domestic workers (new D/CI sub-sample of those involved in livelihood activities). There is a significant difference when compared to the JPLS data, which show that the most common livelihood activities amongst the poor are domestic work, factory work and office work. This suggests that

where a family member has a disability or is too ill to work, he or she may caring for children within the home in order to enable other family or household members to seek or continue employment. It also seems that where possible, people living with a disability or chronic illness will seek to bring in some money through activities that can be managed at or close to the home:

*“I sew doilies. As you see all this cotton lying around... I sew mats and sell them and buy food.”*

*“I sometimes go out and sell potatoes, tomatoes and onions. Then I will come back and share with my siblings.”*

Although the number of people who are employed is relatively small, it is interesting to note that those who are employed are predominantly in insecure employment, as might have been expected. For instance, of those employed 21% work full time and 71% are employed on a part-time basis. Only 14% work on a permanent basis, while 64% work on a contract basis, and just 7% of the respondents who work are self-employed (new D/CI sub-sample of employed respondents). 48% of the sample are currently looking for employment, 47% are not (new D/CI sub-sample of unemployed respondents). Interestingly, although it is commonly suggested that women with disabilities face greater challenges because of difficulties accessing the labour market based on gender *and* disability, the data show that in fact women in the sample are more likely to be employed than men. For instance, 16% of women stated that they are employed as opposed to 4% of men (new D/CI sub-sample of employed respondents). They are also more likely to be involved in more secure forms of employment. 28.6% of women who are working stated that they are working full time, and 20% noted that they are working on a permanent basis. None of the men who are working are working in full-time or permanent positions.

The majority (64%) of the employed respondents indicated they find it easy to get to work, whereas 29% have difficulties with transport. The most commonly used means of transportation are a mini bus taxi (58%), followed by a bus (25%), and 17% have a friend or family member who assists them with transport to work. In terms of the relationship with an employer, 33% of employed people with a disability report having a boss who is supportive. (new D/CI sub-sample of employed respondents).

Other activities respondents said they were involved in to support themselves and/or their households include, for example, fixing appliances, informally selling goods (such as sweets, clothes, fruit and vegetables), gardening or doing laundry for neighbours, being involved with various community projects, and sewing and craft work.

One of most significant ways in which people living with a disability or chronic illness contribute in terms of livelihood is taking care of household chores (including family responsibilities such as attending funerals) and children's needs in the home, thus freeing up other members of the household to seek and pursue employment. The interviewees noted this important contribution that is often overlooked and must be acknowledged:

*"I make sure that his house is very clean. I will even sweep the whole yard."*

*"Even if I am not well, I do something here at home. You can see from our yard, I like plants."*

*"I see him as a hard worker; he always gives a hand whatever we do here at home."*

*"Say there is a funeral around, he attends the night vigil but will always come back home. He will tell me he went there and ask if I will be going tomorrow or must he attend the funeral on behalf of the family. 'You are a builder,' he says. 'Go and work. I will attend on behalf of the family.'"*

The above data firstly demonstrates that it is important to consider the livelihood strategies that people living with disabilities or chronic illnesses are involved in and how these contribute to the livelihood outcomes of the household. The livelihoods framework may stop at assessing disability or chronic illness as a shock that might exacerbate the vulnerability context. However, it is also important to consider the capabilities of disabled people and those living with a chronic illness as significantly contributing to the overall livelihood outcome of the household. Secondly, it must be noted that for the majority of disabled people and those who are chronically ill living in situations of poverty, the types of livelihood activities they are involved in are by and large close to home or in the household. This demonstrates how individual abilities interact with the social systems and the environment to constrain the diversity of livelihood options for disabled people. Were the systems more conducive (such as public transport being more disability friendly) this might facilitate more livelihood options for disabled people.

It must also be noted that chronic illness and disability do exacerbate the vulnerability context of households, but only in so far as the social systems do not provide for and support households in which a member is disabled or chronically ill. The data demonstrate that in many instances a disability or chronic illness can affect the household's ability to gain income, particularly where support services for the person with the disability or chronic illness are not available and the burden of social care rests with the family or household. This issue came up strongly in the interviews. It transpired that taking care of an ill person or someone with a disability places constraints on the caregivers' ability to seek livelihood options:

*"I can't move around a lot because I look after my mother."*

*"If my son was not ill, I would still be working."*



*“She is someone who would like to live a normal life, but you have to keep on checking on her all the time. She must always be supervised.”*

This is most clearly demonstrated in the case of Jacky Mthembu discussed in the profile above. Jacky’s aunt and cousin are responsible for his care at every moment of the day. He needs constant supervision and must be cooked for, cleaned and taken to the bathroom by one of them. This severely limits their ability to go out and seek livelihood opportunities. However, should the social systems and processes be designed so as to recognise the need to support Jacky’s household the vulnerability context would to some extent be ameliorated. The disability grant is one mechanism that could alleviate some of the burden but up until the point of the interview Jacky and his family had not heard about the grant or how to apply for it. Should Jacky be able to easily access healthcare, therapy and guidance such as a catheter and information about how to cope with his disability and how to care for himself to some extent, this would lift the burden of care from his family, thus enabling both himself and his household to have greater abilities to leverage the assets available to them for more positive livelihood outcomes. Thus, disability and chronic illness need not significantly affect the vulnerability context of households, provided that disability is mainstreamed into the social systems so that disabled people and their households receive support that will assist them to continue using their livelihood assets effectively.

#### **4.7. Access to grants**

Within the communities in which the JPLS study was conducted, social grants are often the main form of income. From the reanalysis of the JPLS data for household in which at least one member was either disabled or too ill to work it emerges that almost 38% of households were receiving the old age pension, and a further 35% were accessing the disability grant (JPLS D/CI sub-sample). 19% also had access to the child support grant. A

worrying factor is that only 2% were able to access the care dependency grant, suggesting that awareness of this grant is still quite low.

When the households that were revisited for the follow up study were interviewed, the focus of the questions was on access to the disability grant in particular. A total of 39% of the respondents receive a disability grant, but of concern is that a larger percentage (59%) does not (new D/CI sample). This confirms the data presented above and suggests that uptake of the Disability Grant is between 35% and 40% for disabled people in the eight poorest wards of Johannesburg. Of all the respondents, 71% have heard about the disability grant, and despite only 39% accessing it, 56% of the respondents have applied for the grant. 29% of respondents have not heard of the grant, and, in total, 44% of those who have heard of it have not applied for the grant. 46% of those who do not access the grant were denied the grant due to not qualifying due to the nature of their disability. As suggested by the TAC (2009), there seems to be some confusion around what type of disability qualifies a person to receive a disability grant, and doctors tend to err on the side of caution. An interviewee who was interviewed on his brother's behalf noted their challenges with accessing the grant:

*“We really did not ask [why he did not qualify]. You know, these social workers treat people in the community badly. They just told us that he must go and work. As I told you, if a person is mentally ill, nobody takes him seriously. I just told myself that I will never go there again.”*

21% of people who tried to apply for the grant did not have the required documentation, and 5% have an income that is too high and therefore cannot access the grant. 21% of people who had not applied for the grant do not have the required documentation, with 7% not knowing where the offices are and 7% not having assistance as they do not know how to apply for the grant. It became clear that it may be difficult for persons with a disability to access the grant, particularly when a caregiver must apply for it on their behalf, suggesting that the bureaucracy associated with grant

application needs to be assessed in order to make it easier for caregivers to apply for and collect the grant on their behalf. This is particularly the case with temporary grants:

*“As you know the person has to stamp finger prints. If he is in hospital nobody can get it [the grant]. It gets to be closed. After some time you have to reapply. It takes time. As it is now we are still waiting for the paper work to be processed.”*

It is evident that a number of challenges must be addressed in order to increase access to the disability grant for those people who need it. Health professionals need greater clarity on the medical criteria that entitles a person to a disability grant. It is possible that many of the applicants were those with a chronic illness, and distinguishing between a disability grant and a chronic illness grant may resolve some of these issues, making it easier for those living with a disability to be correctly ‘diagnosed’ in order to access a grant. However, there are still challenges with awareness of the disability grant and particularly the care dependency grant, as well as the need for speeding up documentation processes to ensure that people who require the grant are able to access it.

A further concern is the means test. As has been noted, the income means test excludes certain people from accessing the grant based on their income. However, since living with a disability often brings related costs over and above day-to-day living, it is debatable whether the means test is actually useful in the case of the disability grant. Respondents to the follow up study were asked what they spent their money on. It is certainly clear from the data that the money gets used to cover basic household needs rather than being put towards any specialised care or access to assistive aids. On average for all respondents who were receiving the grant, 31% of the money is used for food and other essential items required by the respondent. 18% of the money is used for food and essential items for the household, followed by 13% for the respondent’s health care and 13% for water and electricity costs. Other uses include education for the household, health care for the household and transport (new D/CI sample). Although a

beneficiary of the disability grant may not receive any other grant, it is clear that households, in which there is at least one person receiving a disability grant, may also receive other grants, which may allow the disability grant to be used for extra care for the person living with the disability. 36% of the households receive other grants, with the majority of these households accessing the child support grant (53%) and the older persons grant (26%). However, 53% of the households (new D/CI sample) do not receive other grants, suggesting that the household is dependent on the disability grant.

In terms of accessing the grant, 61% of those who had applied for the grant found the offices easy to get to, and the remaining 32% said they had difficulty in locating the grant offices. 81% of the respondents who had applied for the grant were provided with all the necessary information, and 12% were not. 80% found the buildings easily accessible, and 74% found the officials at the offices to be friendly. 42% of the respondents who applied for a grant were helped by a government official, followed by 25% who were assisted by a social worker. Other volunteers, non-governmental organisations and church workers also assist people in applying for grants, but 8% of respondents who have claimed a grant had not received any assistance.

Receipt of the disability grant may affect power relations within the household for the person living with the disability. Interestingly, in the 2007-2008 JPLS study, 41% of disabled or chronically ill respondents noted that they were the head of the household, indicating that they are seen as the primary decision makers within the household. It seems that access to the grant may have something to do with this. The JPLS data show that 43% of the people who do receive grants have the responsibility of deciding what to do with the money on their own, and a further 15% shared the decision-making responsibilities with other members of the household including a parent (in 54% of the cases) or the children. In 25% of the households, the grant gets added to the household income. 18% of the respondents who received a grant did not get to decide what to do with the money.

Access to the disability grant is a fundamental mechanism for ensuring that disabled or chronically ill people and their household members are better able to leverage livelihood assets. The disability grant could be used to access much needed specialised services or assistive aids that would better enable the disabled person to interact with the systems that are often not disability friendly. In addition, the grant enables households to purchase items that might assist in building other livelihood strategies such as purchasing goods to resell. It is for these reasons that the issues pertaining to qualification for the grant and accessing the grant discussed above must be resolved.

#### **4.8. Social capital**

Social capital is a key asset that can be drawn upon for effecting livelihood strategies. For this reason the study sought to understand what social capital was available to disabled and chronically ill people and the households that they belonged to.

In the JPLS study, households were asked whether they had support that they could depend on. It is worrying to note that of those households where at least one member either has a disability or is too ill to work, the largest proportion (43%) stated that they had nobody they could turn to for support. This is very similar to the full sample for the JPLS in which 42% of households indicated that they had nobody to turn to.

In terms of emotional support, of those who stated they did have some form of support structure, for most (52%) this was other family members, followed by friends (42%) and neighbours (40%) (full JPLS sample). Religious organisations also play an important role, with 20% of respondents stating that they receive support from churches and other forms of religious organisations. Much the same pattern exists in terms of financial support but to a far lesser degree, indicating that within poorer communities, emotional support is far more likely to be available than financial support.

Although all of the households in the JPLS disabled/chronically ill sub-sample had at least one person that either had a disability or was too ill to work living within the home, only 27% indicated that they have had to provide a family member with special care. This most likely indicated a lack of access to special care services, rather than a lack of need for these services. Those who responded that they had needed special care indicated this was mostly for older persons or an adult with a mental disability, followed by babies and family members with physical disabilities. Besides family support, 31% of respondents said a social worker is the predominant form of support available to them, followed by someone from the church (22%), and a home-based carer from the community (15%).

There seems to be a fairly high level of social trust within the communities, from the perspective of those who responded to the follow up study (JPLS D/CI sub-sample). 79% of respondents stated that they feel as if they are part of the community, and 74% feel that they get along with their neighbours. 62% also feel that they can trust their neighbours. The vast majority of respondents (93%) said their families are a source of support to them, and a further 92% said their households are a source of support to them. These findings from the JPLS study were confirmed in the qualitative component of the follow up study.

*“My grandson is my mouth, my feet and hands and everything. He treats me so well that I sometimes feel for him. I think he is doing too much for me. He helps me so much when he is here at home.”*

The case of Jacky Mthembu also illustrates the importance of family as a source of support. Before his disability Jacky was independent, renting a backyard room from someone and paying rent from his own income. However, since his disability Jacky has had to rely on the goodwill of his extended family who provide care for him, and from his mother who contributes a little to the Polokwane household where he is staying.

It is clear therefore that there are strong social assets available to disabled and chronically ill people. This social capital is often the only form of support available to protect those living with a disability or chronic illness from major shocks of the vulnerability context.

Attitudes and perceptions about disability are also important to take into consideration when assessing social capital. From a systems perspective, as has been discussed in Chapter 2, social systems interact with individual abilities to influence how livelihood assets can be leveraged for livelihood outcomes. Attitudes and perceptions about disability, both from an individual and a community perspective, make up part of the social systems and therefore must be assessed. The study therefore sought to assess perceptions of disability and chronic illness. These perceptions were interrogated during the in-depth interviews.

By and large, attitudes towards people living with a disability or chronic illness in the community were seen to be positive and accepting by those interviewed. As is mentioned below, this seems to facilitate positive participation in community activities for people living with a disability.

That said, some interviewees did mention a few instances of stigma or negative attitudes:

*“You can see that when there is an occasion and a mentally ill person comes, then nobody takes notice of him or her. So that hurts us. Here at home we love our grandfather despite his illness. We don’t like people to make a fool of him.”*

Although community perceptions may not be driven by stigma and are not overtly negative, there is still a sense of pity towards those living with a disability. This is

particularly the case within the family or household where the dependence of the person living with a disability or chronic illness is most evident:

*“Before his illness we looked up to him, but that is no more. This sickness is like that. It just leaves you helpless.”*

The experience of Jacky Mthembu illustrates that when physical activity is limited, and especially when this affects mobility and self care, stigma may be greater. Jacky’s mother reports that Jacky is depressed predominantly because he hates being helpless and depending on others for his care. He worries about what others might think of him because he is unable to care for himself. He thus perceives stigma from the community and family that are rooted in his own expectations.

From a gender and cultural perspective, men are often seen as leaders within the household and the community and that this role is affected by disability or illness, leaving men to feel or be perceived as being emasculated:

*“His sisters respected him before. You can see he is unhappy because he is no longer as powerful as he was before.”*

*“It think it is difficult for us to involve him because nobody takes him seriously. He has nothing to contribute. I think that he does not like his condition because male people also want to lead.”*

*“He was the bread winner. It would be better if he was a female because we wouldn’t expect him to be the responsible one.”*

Jacky’s experience is overlaid with his own perceptions of gender expectations. Before his back injury Jacky was supporting himself and sometimes also sending money back to



his rural home. After his injury Jacky has become totally reliant upon his family and can no longer provide for himself or them.

Some of the interviewees also demonstrated a negative self-perception – one of being a victim and of being helpless. This would no doubt serve to discourage active participation in their communities.

*“I have stopped working. I did not want people to see me like this.”*

*“I feel useless.”*

*“She feels upset when sees other people being able to do ABC and she thinks she is not capable of doing them. Then you will see a decline in her state. She will feel like she is useless.”*

Perceptions about disability are key factors to take into account when it comes to livelihood strategies since they profoundly influence the ability of disabled and chronically ill people to leverage livelihood assets. For instance, a positive self perception means that there is greater likeliness of a disabled or chronically ill person to take advantage of livelihood assets and develop livelihood strategies outside of the home. The perceptions of community members also facilitate the success of livelihood strategies to some extent when they are positive.

This suggests that there is a need to continue education efforts aimed at reducing stigma that might be associated with certain disabilities and illnesses. It also means that efforts at building positive self perceptions, which may go hand in hand with physical therapy for people who are facing disability as a new phenomenon in their lives, should be a key programmatic goal.

## 4.9. Participation

Social capital relies in part on the social networks that people participate in. Understanding levels of participation therefore becomes important. In the follow up study, levels of participation were assessed. The results were by and large positive.

Respondents were asked what forms of community and social groups they were involved in and could respond to as many options as were relevant to them. A large proportion of respondents with a disability or chronic illness (40%) are part of a burial society, and 34% are part of a church group. 11% of respondents belong to a *stokvel* (a savings club), and 4% are involved in a support or political group. Only 3% of respondents are involved in a community-based organisation. In terms of accessing these activities, 37% of respondents walk, while 36% take a taxi. Lesser used methods of transport include using a bus or hitching a lift with a friend or family member.

The interviews provided great insight into the participation of those living with a disability or chronic illness, both at the household level as well as the community level. Within the household, 41% of respondents (JPLS D/CI sub-sample) to the JPLS conducted in 2007 to 2008 indicated that they were the head of the household. During the interviews it became clear that even where the person with the disability or chronic illness is not the head of the household, he or she maintains a level of authority in the household, particularly when they are older family members to whom younger members of the family defer for advice.

*“He is the uncle of our children. If the nephews and nieces are making rituals, we call him. He must be a part of all of us. He will answer in his own accord.”*

*“This is her house, and we consult her. We tell her before we do anything.”*

As the quantitative data show, those living with a disability or chronic illness still participate in community activities. From the interviews it is clear that this is in part facilitated by acceptance and assistance within the community. As some respondents noted:

*“When people see that you are mentally challenged, they tend to look down on you. But he is a likeable person. They all love him, and they send him around to do things.”*

*“These people (in the community) are treating me very well.”*

*“He is well supported by his friends. He is a people’s person. He is the most trusted person. People send him on different errands. He plays Lotto for them, and he won’t even take a cent. They pay him as they like, and it only makes him happier. He is very accurate. He will never mix people’s change.”*

This means that the contribution of people living with a disability or chronic illness continues to be valued at the community level and that exclusion at the social level does not seem to be a major problem.

That said, physical exclusion does seem to hamper people’s ability to participate meaningfully in their communities. Some of the interviewees noted not being able to get to community activities:

*“As you see me now, I am only able to go to the toilet and then I come straight back to the house.”*

*“I am not able to go anywhere. I stay here in the house and do my mats.”*

*“I stay here and get lonely and do not know what to do.”*

*“I always wish I had feathers to fly and go to church, but I don’t have them.”*

This inability to access community activities and participate fully in the household, as well as the dependency on household members can lead to frustration for the individual, as some of the interviewees noted:

*“I was a very active person. Now that I am ill, I work in the garden to keep myself busy. But I get frustrated staying here at home.*

*“I am frustrated. I get up every day, and I am not able to do anything. I can’t walk. My family has to wash me and feed me. It makes me feel bad.”*

From the interview data it seems that social barriers to meaningful participation are not problematic. However, the ability to fully participate in household activities and the dependency on other family members do pose problems and frustrations for people living with disabilities. This suggests that access to community activities may be more difficult for disabled people than it would be for those with a chronic illness. It is clear, therefore, that there is a need for assistance with physical access to community activities in order to facilitate better integration.

#### **4.10 Life satisfaction**

Respondents were asked to respond to a set of questions pertaining to their life satisfaction. Most felt very satisfied with their life with regard to their significant partner (34.5%), relationships with friends (57%) and the household relations (64.3%). There seems to be a positive correlation between the amount of support the respondents feel that they receive from friends and family and their feelings of life satisfaction. In relation to life satisfaction with regard to livelihood activities, 34% of respondents indicated they are not at all satisfied, followed by those who said they are only a little satisfied (26%). Only 15% of respondents said they are very satisfied.

This suggests that support and family relationships are positive for disabled and chronically ill people. But it does also demonstrate that in terms of livelihoods there are a range of mechanisms that if put into place could better facilitate the ability of disabled and chronically ill people to leverage livelihood assets. This may also contribute to greater life satisfaction with regard to livelihoods.

## **Chapter 5      Reframing the poverty disability link**

The findings presented above have been analysed using the livelihoods framework in conjunction with the systems approach to disability. The findings demonstrate that there are a range of factors associated with the social systems in which disabled people must function, which are predominantly designed with the able-bodied in mind. This therefore constrains their ability to effectively leverage livelihood assets for positive livelihood outcomes.

The ability or inability of a person to develop a sustainable livelihood for him or herself is as much a function of the social systems and processes as it is a function of individual ability and skill – something the livelihoods framework does not take into sufficient account. Here again, the systems model can be used to understand the link between poverty and disability. In South Africa, with its high unemployment rate, many people are constrained in their ability to access sustainable livelihoods, making them vulnerable. In this environment, people living with a disability are further disadvantaged, not as much by their particular disability, but by the environment in which they live. In addition to this, people living with a disability face physical barriers to developing a livelihood. For instance, as Michailakis (2003) notes, organisations cater for particular individuals (those without a disability), thus limiting the ability of a person with a disability to be integrated into the system. It thus becomes doubly difficult for a person living with a disability to develop a meaningful livelihood. But the systems model requires us to consider the individual interaction with the environment as well (Schneider, 2007). The data demonstrate that while many people living with a disability are involved in a range of community activities, there are also instances where respondents expressed feelings of helplessness and dependency. Such an attitude can also serve to further limit the ability of an individual to develop livelihood opportunities for him or herself.

This framework can also be applied to the situation of access to education and healthcare. The data pertaining to these aspects show that although access to good education and healthcare is a challenge for all people living in situations of poverty, for disabled people is even more so since the education system does not cater for children with disabilities and access to healthcare is particularly important to facilitate physical functioning. As such, mainstreaming disability in systems such as education and health become particularly important. Ensuring that these systems operate with disabled people in mind will go a long way to ensuring that disabled people are better able to leverage livelihood assets for positive outcomes.

A key finding of this study has been that most respondents are unemployed and predominantly dependent either on social assistance or on the support of family. However these respondents do play a vital role in either bringing in some form of income through self-employment, or by supporting the household in order to create space for other people in the household to seek employment. The value that this adds is not always visible or valued. In the same way that feminist writers have called for the recognition of the value that women add through activities related to social reproduction, there is a need to recognise that many disabled or chronically ill people living with disabilities are performing these social reproduction activities, regardless of gender, in their households. Caring for children or elderly members of the family, maintaining the household or the vegetable garden, and attending social commitments on behalf of the family are all activities that add value in so far as they facilitate the livelihoods of other members of the household.

In addition, many people living with disabilities in urban areas may be able to access livelihood opportunities within the community and from the household. Making handicrafts, growing and selling vegetables and other such activities may bring in some form of income into the household. Should there be possibilities to turn such initiatives into small or micro business opportunities, there needs to be greater awareness of the

existence of small business grants to people living with disabilities, and assistance from either social workers or the disabled people's movements to enable people to access this mechanism which can serve to enhance their ability to develop an income source.

Since social assistance, along with family support, is one of the main forms of survival and could contribute to the ability of a person to achieve livelihood outcomes, understanding accessibility of the grants is imperative. It has already been noted that there has been a significant increase in the number of disability grants being accessed since 2004. However, the data presented in this report suggest that more than half (61%) of people living with disabilities or chronic illnesses in the poorest wards of Johannesburg are not accessing the grant for a range of reasons including not meeting the requirements for the means test, lack of awareness of the grant and lack of documentation.

The grants system is framed within a social development and human rights approach. As such, even though the economic burden of making the disability grant more accessible might be a limitation, there is a need to think through how to ensure that all those eligible for the grant are able to access it. This may include awareness campaigns, streamlining of documentation and assessment processes, and greater clarity on the requirements to qualify for the grant. SASSA has had great success in rolling out the Child Support Grant to almost all children who qualify for it. Similar strategies may have to be employed to ensure that those who are eligible for the grant qualify for it.

However, before this can be done an assessment of the sustainability of the disability grant, in light of the fact that those with chronic illnesses are able to access it, is necessary. As Natrass points out (2007), the rapid increase in uptake of the grant is attributable predominantly to the number of people living with HIV and AIDS in the country. If the current system of qualifying those living with a chronic illness as well as those living with a disability for the grant remains, and goes hand in hand with increased



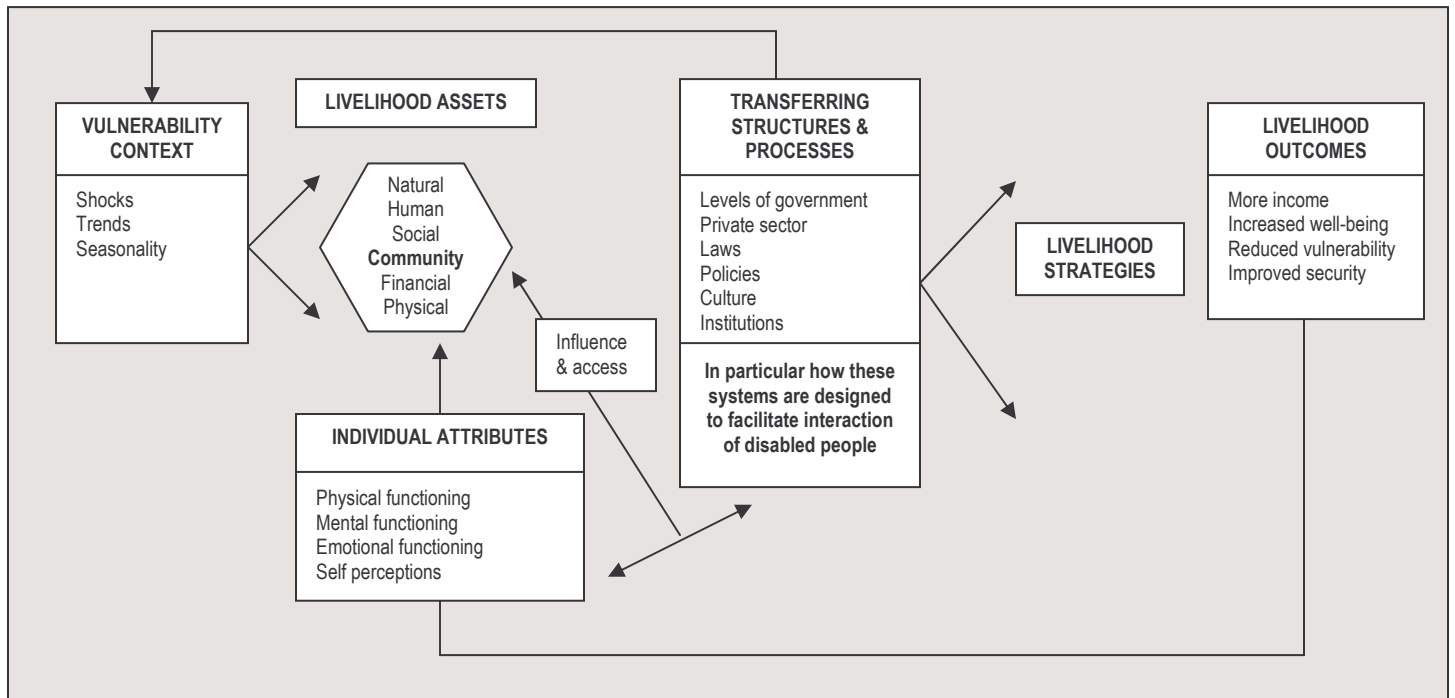
awareness, this may constrain the sustainability of the grant. As such, consideration must be given to the Chronic Illness Grant that has been tabled. In addition, an assessment of the underlying assumptions of the means test must be conducted. As Natrass (2007) points out, the disability grant, with its current means test does not actually intend to provide people with the extra support they require to meet the needs associated with their disability, but acts as a form of basic income for households. An assessment of the implications of these issues as well as recommendations regarding means testing, and clarity around criteria and the purpose of the grant is necessary.

It has also been noted that awareness of the Care Dependency Grant is currently fairly limited. One of the findings of the study was that where the person living with a disability or chronic illness required full-time care, the caregiver was particularly constrained in participating in community activities and in seeking employment. There is thus a need to increase awareness of the Care Dependency Grant and facilitate easier access for caregivers who may have to apply for and collect this grant. There is also no grant for adults who require permanent care although this has been advocated by organisations such as the Treatment Action Campaign.

The data show that although there is some involvement in community activities by people living with disabilities or chronic illnesses, this may be constrained by attitudes prevalent in communities, as well as by self-attitude. As mentioned many people interviewed noted their feelings of dependency and helplessness. In the political environment, as Arneil (2009) notes, people living with a disability may be defined as lacking and as dependent; perceptions of people living with disabilities or chronic illnesses as contributing citizens are thus undermined, which in turn may undermine the ability of disabled people to confidently seek livelihood opportunities

What the study demonstrates is that there is a need to take into account the way both individual ability and social systems interact to influence how a person is able to access

and leverage livelihood assets for better livelihood outcomes. Currently, the livelihoods framework does not take into sufficient account these aspects. The systems approach to understanding disability provides a better lens through which to understand how disabled people and those with a chronic illness have their livelihoods constrained. As such the livelihoods framework could be revised as follows:



**Figure 3: Livelihoods framework adapted using the systems approach to understanding disability and livelihoods**

The revision of this framework demonstrates the importance of taking into account the ways in which individual attributes such as level of functioning and self perception interact with the transferring structure and processes (the social systems), which by and large are designed to cater for the needs of people with particular levels of functioning, thus making the access of people with disabilities more difficult. A key asset that emerges from this research and which has been added into the livelihood assets is community assets which extend beyond social capital and also include the services and other support structures such as community organisations that play a very important

role for disabled people. How the social systems and the individual attributes interact profoundly influences the access to and ability to leverage livelihood assets to effect better livelihood outcomes. This highlights the importance of ensuring that the transferring structures and processes, the social systems, are designed in such a way that they work for all people regardless of ability so that all people are better able to leverage assets for their livelihoods.

In order to do this, as Arneil (2009) notes, at the level of political theory, a theory of interdependence must begin to shape our notions of citizenship. At the community level, interdependence must however be experienced and participation in community activities by people living with disabilities and chronic illnesses is vital to demonstrating their abilities to those who may label them as “disabled” or “ill” and those not able to see past those constructs.

## **Chapter 6      Recommendations**

Based on the findings and discussion presented above, it is clear that poverty and disability need to be understood within the context of a multidimensional or livelihoods approach to poverty and disability, which recognises that factors related to poverty constrain the ability of individuals living with a disability or chronic illness and that disability or chronic illness constrains the ability of a person to more effectively deal with situations of poverty. Understanding how the systems operating in society interact with individual abilities to enable or constrain access to livelihood assets emerges as an important starting point for describing the link between poverty and disability. This insight also highlights key recommendations that ought to be seen as priorities from a policy and programmatic perspectives in order to better enable disabled people and those living with a chronic illness to leverage livelihood assets for better outcomes.

As such the recommendations arising are framed through a social development approach that seeks a holistic response to issues of both poverty and disability that will strengthen the ability of people to exercise their capabilities in the pursuit of their potential. They are therefore pitched at the policy level as well as at the programmatic level but also include recommendations for further research.

### **6.1. Access to education**

Given that education builds the capabilities of people to leverage livelihood assets, ensuring that the education system is responsive to the needs of children regardless of ability emerges as a key priority area. There is thus a need to ensure that all young people are afforded the opportunity of good education that prepares them for life and work. This may require special needs education in separate schools where a disability limits functioning in the extreme. However, the number of schools catering for those with special needs will necessarily be limited and will thus not be accessible to all disabled children. In addition, most disabilities do not severely constrain the functioning

of people but do require that extra support is provided to make the interaction with the system easier.

Some recommendations arising are:

- Greater investment in education of teachers to be responsive to the needs of disabled learners
- Equipping schools with necessary resources and assistive aids to make the classroom and learning more accessible
- Ensuring that young people are able to access schooling even under conditions of poverty through flexible schooling hours that will allow for young people to work and study if necessary
- Ensuring that the curriculum builds a culture of tolerance with regards to differing abilities and teaches young people to make communities more disability friendly.

## **6.2. Livelihood opportunities**

While some disabilities limit functioning to such an extent that livelihood opportunities become almost impossible, for most disabled people, functioning does not severely limit functioning and being able to better access and leverage livelihood assets for better outcomes relies on changes in the system that would facilitate this. There is thus a need to enhance the system to ensure that people living with disabilities are better able to carve out sustainable livelihood opportunities. This will require:

- Ensuring that public transport is more disability friendly
- Continuing to build workplace awareness about disability and how to make the workplace more disability friendly
- Building greater awareness of the existence of small business grants available to people living with disabilities
- Equipping social workers and community development workers as well as disabled people's movements to enable people to access this mechanism which can serve to enhance their ability to develop an income source

- Recognising that disabled people may contribute to the livelihoods of the household by caring for other family members or taking care of household duties, thus enabling other family members to develop livelihood strategies
- Developing entrepreneurship or Small, Medium and Micro Enterprise (SMME) packages that are tailored for people living with disabilities

### **6.3. Social assistance**

The Disability Grant emerges as a key mechanism for building the capacity of disabled people and their households to survive and to develop livelihood strategies. More research is needed to understand exactly how the Disability Grant functions within households particularly in relation to exactly how it is used and how it shifts power dynamics within households.

Given how essential the Disability Grant is as a livelihood mechanism for many people living with a disability or chronic illness, there are a range of recommendations arising:

- There is a need to develop ways of ensuring that all those eligible for the grant are able to access it. This may include:
  - awareness campaigns,
  - streamlining of documentation and assessment processes,
  - facilitating easier access for caregivers of severely disabled people to apply for and collect the grant on behalf of the beneficiary,
  - greater clarity on the requirements to qualify for the grant,

Considering the implementation of the proposed Chronic Illness Grant may go some way to clarifying the eligibility criteria for the Disability Grants. There is also a need to increase awareness of the Care Dependency Grant for caregivers of disabled children, and consider proposals for a care grant for people requiring permanent and ongoing care.

#### **6.4. Participation and citizenship**

A key aspect of ensuring that people living with disabilities are better able to cope in situations of poverty is to facilitate greater access to community activities and social networks. Not only will this provide people living with a disability with further assets that can be leveraged in times of need, but it also facilitates greater awareness within the community environment about disability and the need to make public spaces and meetings more accessible.

- At the government level there is a need to ensure greater participation and visibility of disabled people in decision making and consultation processes such as the Integrated Development Planning process and in the local ward committees.
- At community level the disability rights movements can play a role in advocating for greater inclusion of people living with disabilities, not only in the movement but in community organisations and political parties.

## Conclusion

This study has demonstrated how disability and poverty are intimately linked. It is clear that there is no clear causal relationship between poverty and disability. What is clear from the findings of this report is that the situation of poverty, with its outcomes – including lack of livelihood opportunities and limited access to education – serve to provide disabling contexts in which a person living with a disability or chronic illness is less able to demonstrate his or her ability and reach his or her full potential. At the same time, from a social model perspective, people living with disabilities or chronic illnesses face further constraining social, political and physical environmental challenges. Thus, it is necessary to understand both poverty and disability through a multi-dimensional lens that acknowledges how a range of factors, including limited access to education and basic services compound both the problem of poverty as well as the impact on people living with disabilities. However a livelihoods approach also requires acknowledgement of the capabilities of people to create livelihoods and sustain households.

As a result, it is imperative that initiatives aimed at dealing with the delivery of basic services to all people, including those living with disabilities and chronic illnesses, remain an utmost priority. At the same time it is necessary to continue building a distinctly South Africa disability discourse that recognises the contributions of people living with disabilities in contributing to the livelihoods and survival of households.

But ultimately, a rethink of how our society and politics continue to see people living with a disability as 'other', constraining their ability to participate fully in society, is required. This will ensure that our political, social and physical systems change as people come to realise that to exclude people living with disabilities or chronic illnesses is to miss out on the potential meaningful contributions they can bring to society.



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