'Because I am disabled I should get a grant': Including disability in social protection programmes.

Marguerite Schneider Wamuldila Waliuya Stephen Barrett Joseph Musanje Prof Leslie Swartz

International Conference:

"Social Protection for Social Justice" Institute of Development Studies, UK 13–15 April 2011





'Because I am disabled I should get a grant': Including disability in social protection programmes

Marguerite Schneider¹, Wamuldila Waliuya², Stephen Barrett³, Joseph Musanje², Leslie Swartz¹

- 1. Department of Psychology, University of Stellenbosch, South Africa
- 2. Sightsavers International, Zambia and UK
- 3. Social Assistance Grants for Empowerment (SAGE) Programme, Social Protection Secretariat, Ministry of Gender, Labour and Social Development, Uganda

Presenting author: M Schneider E-mail: Margie who@mweb.co.za

Abstract

There is growing awareness of the importance of including disability in social protection programmes and, specifically, in targeting mechanisms for cash transfer beneficiaries. Current social cash transfer approaches (referred to as social assistance grants in Uganda and social cash transfers in Zambia) use either implicit (e.g. expecting disabled people to be in the poorest or most vulnerable households but not assessing disability as such) or explicit criteria (e.g. assessing for disability and allocating a weighting to a household with a disabled person). Furthermore, in South Africa there is a specifically targeted disability grant which requires a complex process of assessment to determine whether a person is eligible to receive the disability grant. Being disabled or having a disabled household member generates significant additional costs for the person and the household. These include transport for the person and their personal assistant, assistive devices, regular visits to health care facility, and extra care costs. These are both direct and indirect costs for the household. The cash transfer programmes targeting vulnerable households being developed in many African countries target households rather than individuals. In South Africa, historically and currently the disability grant is targeted to the individual but is used a de facto household benefit. This review paper briefly presents some of the experiences currently documented on social cash transfer schemes in South Africa, Uganda and Zambia to contribute to our growing understanding of how disability is included in targeting mechanisms and what the benefits are of cash transfers for people with disabilities and their households. The key themes discussed in the paper include: a) what cash transfers are used for by disabled people and their households and how this compares to households without any disabled members; b)findings from current targeting approaches on the benefits of and difficulties in including disability; c) the relationship of disability and chronic illness and how this is addressed in targeting approaches; and d) disability as a vulnerability factor in accessing services and the importance of providing services together with cash transfer programmes. A theme underlying all of these points will be the definition and measurement of disability, especially in relation to chronic illness, and how these are used in targeting and in monitoring and impact evaluations of social cash transfer schemes and service provision. The paper concludes with some thoughts on a comprehensive social protection programme that is inclusive of disability.

Introduction

There is growing awareness of the importance of including disability in social protection programmes and, specifically, in targeting mechanisms for social assistance grant¹ beneficiaries. In the last two years, for example, there has been a strong movement to include disability as an important consideration in realizing the Millemium Development Goals (MDGs) culminating in recommendations from the expert committee on the mainstreaming of disability within the MDGs (UN, report 2009).

Social protection programmes have focused on reducing vulnerability and creating safety nets for households who are at greatest risk of falling further into poverty. With the recognition that disability is an important contributor to poverty and that poverty itself is a contributor to creating or aggravating disability (Braithwaite & Mont, 2008; Yeo & Moore, 2003; Elwan, 1999), more attention is being focused on how to ensure that disability becomes a mainstream consideration in social assistance grants and in social protection programmes more generally (see AU Social Policy Framework, 2008/9). If the poorest households are targeted for a social assistance grants are households with disabled people automatically included in such programmes because of a high proportion being very poor?² If not then the way forward is to find ways of targeting these households. If yes, the way forward is to reinforce this process and collect information on disability to provide an on-going assessment of the impact of the scheme on people with disabilities and their households in the same way as information is collected on other vulnerability factors (e.g. women or child headed households). Disability becomes one of these vulnerability factors.

The aim of this paper is to raise critical issues in this endeavour starting with some discussion on defining disability, the relationship between disability and chronic illness, and the factors that make people with disabilities and their households potentially vulnerable. This is followed by a brief description of some current social assistance programmes and their inclusion of disability in three countries (Zambia, Uganda and South Africa) and presenting some of the points raised by the experiences of these three countries. The discussion focuses on the targeting process and the monitoring and evaluation of the benefits of these programmes. The paper concludes with the way forward in ensuring inclusion and mainstreaming of disability in social protection and, specifically social assistance schemes.

Defining disability

The UN Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006; Article 1) describes³ disabled people as including

 $^{^1}$ The terms 'social cash transfers' (term used in Zambia) and 'social assistance grants' (term used in Uganda) are used interchangeably.

² While the focus in this paper is the inclusion of people with disabilities in social assistance grant programmes targeting the poorest households, a number of questions remain on the inclusion of people with disabilities in a range of other social protection schemes, such as cash-for-work and other social pensions. Issues of access to information and physical access to the application location are important to consider. Furthermore, the extra costs of being disabled (care needs, payment for assistive devices, transport, etc.) are important considerations for disabled people who may be working but using a disproportional amount of their wages meeting these extra needs and, therefore, extracting less benefit from their earned income than a non-disabled person.

³ The convention does not in fact provide a definition of disability as this was a major point of discussion in the drafting. However, this description is close to such a definition.

those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

This broad definition sets out the different elements that make up disability highlighting the multidimensional and complex nature of this phenomenon. Of importance is to note that there is a health condition⁴ that is at the start of the disablement process but that this health condition does not equal disability. Disability is the consequence of living with a health condition and not the health condition itself. Thus HIV is not a disability but the numerous consequences of living with HIV are what lead to disability. Similarly, an amputation is not disability but the consequences of not being able to walk and all the other consequences stemming from that are disability. Furthermore, a person can have a chronic illness and not be disabled – usually if the illness is mild and/or is well managed and controlled through effective access to health care services.

The consequences of living with a health condition include the individual's activity limitations (e.g. difficulty walking, seeing, hearing, remembering and concentrating, communicating and self care) and the interaction of these activity limitations with the context in which the person lives. A child with moderate cerebral palsy who is provided with early assessment and intervention, a generally accessible and supportive environment and quality education will be able to build a significant capability set (Sen, 1999) for functioning as a fully developed person. The contrary will lead to a limited capability set and poor development of the person. However, both these groups of children will remain marginalized to a lesser and greater degree respectively because of stigma.

With later onset of disability, the capability set developed prior to becoming disabled will determine the impact of the disability. In a context of poverty, a person may already have developed a poor capability set (e.g. low educational achievement and limited work experience) and, hence, experience a more severe impact from the disability. For example, a manual and casual labourer would be heavily affected by a spinal cord injury resulting in quadriplegia compared to a highly skilled lawyer.

However, in all cases of what is seen as traditional categories of disability (Deaf, Blind, physically disabled and intellectually disabled), there remains a strong element of stigma which is minimally affected by the context in which the disabled person lives – marginalization and social exclusion remains a strong feature of disabled people's experiences. This is confirmed by a study on disabled people's experiences in Uganda: '...it is discrimination, rather than disability itself, which is at the heart of the exclusion experienced by disabled people thereby leading to a greater risk of poverty.' (Lwanga-Ntale, 2003).

Having said this, there is much that can be done to assist households with disabled members to become sustainable. Once a household is sustainable, the issue of stigma and discrimination can be addressed more effectively. The question is whether the social cash transfer programmes do include these households or are they excluded even at this level.

3

⁴ A health condition can be a chronic, progressive or acute illness (mental or physical); an impairment such as an amputation, deformity, or disfigurement; a disorder such as Down's Syndrome, autism, intellectual impairment; or a trauma such as a spinal cord injury or amputation. A health condition is not synonymous with being ill and requiring ongoing health care services for that health condition. Many health conditions (e.g. being blind or deaf from birth) require little medical intervention, but rather require a range of other services to ensure the full development of the blind or deal child.

While many of the problems experienced by disabled people are related to poverty and are not dissimilar to the experiences of their peers in the same communities, the problems associated with disability are compounded by poverty. The inability to pay for transport or repairs on a wheelchair means a disabled person is not able to go to the health care clinic or to go and buy food; disruptive behaviours, such as from a severely intellectually disabled adolescent or a mentally ill person, is difficult for others to understand and they shun both the person and his/her family. Social isolation becomes a real and a significant issue as it reduces the possibilities of support and access to opportunities. A stark and somewhat crude example is a non-disabled person who can scrounge a hand to mouth existence from searching in bins and waste dumps, while a blind, physically disabled or intellectually disabled person would find this difficult.

Disability is, thus, an important factor to consider in targeting of social assistance grants as part of a comprehensive social protection mechanism. It is imperative to understand the impact of disability on chronic poverty and the factors that determine that impact. The three main factors to consider are:

- Additional costs related to buying assistive devices, and paying (more than non-disabled households) for services such as transport, additional care and assistance, and medication. The cost of paying someone to do everyday task such as fetching water or wood, ploughing the fields or cooking meals is a cost associated with disabled people especially older people living alone.
- Additional care needs for household to meet (e.g. care needs required by a child beyond
 what is typical for a child of the same age with no disability, or an adult who is unable to
 care for him or herself.)
- Loss of social networks thus reducing access to support and to opportunities, such as livelihood opportunities.

A chronic illness is also a factor that makes a person and their household vulnerable. However, the main issue in this instance, are the additional costs of attending a health care service and loss of daily wage when attending the health care centre. The nature of a chronic illness is that it requires on-going access to health care for controlling the illness. If well controlled there should be no or limited activity limitations. Households living in poverty struggle to meet these costs in their monthly budgets and could become critically poor because of these costs (Goudge, Russell & Gilson, 2009a; Goudge, Gilson, Russell, Gumede & Mills, 2009b). There may also be some stigma associated with chronic illness, especially HIV/AIDS and TB, and Leprosy (in the few countries where there remain important incidence levels of the disease). In a longitudinal study of chronic illness and coping strategies used by households in rural South Africa (Goudge et al., 2009b) showed that 'cash transfers combined well with free health care to build resilience among some households. However, households without access to at least two strands of the social protection net [e.g. cash transfer + free health care] were impoverished by the direct and indirect costs of long-term illnesses.'

Criteria for eligibility for social cash transfers

The three countries discussed in this paper are Uganda, Zambia and South Africa. The criteria for eligibility for each of these countries in relation to disability is briefly described. The information presented in this and the following section is based on three pieces of work – one in each country. The first author was involved in all three of these pieces of work.

In Zambia, Sightsavers International's Zambian office has been involved at a national level with discussions on social protection. However, they observed that there were few data on the impact of the Social cash transfers on households with a disabled member as well as on the disabled individual (Marriott & Gooding, 2007). They then undertook a small mixed methods research study in two pilot sites (Kalomo and Monze) to obtain some evidence on this impact.

In Uganda the inclusion of disability as a criterion for eligibility for the social assistance grant necessitated the testing of a simple but accurate tool for assessing disability in very young children (0-5) years and older children and adults. The findings described below come from this pilot study.

The South African work was carried out over a period of a number of years and included developing assessment tools for the Disability Grant (DG) for adults and Care Dependency Grant (CDG) for children, and developing a proposal for policy options for social security for people with chronic illness.

Zambia

In Zambia the main criteria for determining eligibility of a household for a social assistance grant are being: a) critically poor (destitute) and b) incapacitated. The targets are households and not individuals. These criteria are set out by Schubert and Goldberg (2004) as follows:

- a) Critically poor or destitute households are defined as those households experiencing chronic hunger, under nutrition, begging, and in who are in danger of starvation.
- b) Incapacitated households are those where breadwinners are sick or have died; or where there are no able bodied person in working age, and only elderly, very young or sick people. The dependency ratio will be high in these households.

Typically people who are disabled are incapacitated resulting in loss of access to opportunities to earn a livelihood and maintain themselves (e.g. foraging for or growing food, fetching water and wood for cooking and self care). The link then with poverty is not difficult to surmise. Poverty in itself can lead to increased ill health, for example, when health care services are not affordable or one is in a state of poor nutrition. The spiral of disability to poverty to further ill health and disability is not necessary if the attitudinal, social, policy and built environments are such that access to services and to livelihood opportunities are fully inclusive for people with disabilities.

Schubert and Goldberg (2004) describe how households in Kalomo, a pilot site for the social cash transfer in Zambia, are classified in relation to the two criteria for eligibility – destitute and incapacitated. Figure 1 is an adaptation of that classification.

Table 1: Classification of households in terms of criteria of being 'critically poor' and 'incapacitated'

| | | Capacity and dependency ratio | |
|------------------|---------------------|---|--|
| | | Capacitated | Incapacitated |
| | | (low dependency ratio) | (High dependency ratio) |
| Poverty level | Moderate poverty | A. Some income and relatively good nutritional level; have household members for productive work - can respond to self-help oriented projects | B. Some income and relatively good nutritional level; Labour-constrained - unable to respond to labour based interventions |
| | Critical poverty | C. No income and poor nutritional level; have household members for productive work - could respond to self-help oriented project | D. No income and poor nutritional level; Labour-constrained - unable to respond to labour based interventions |

Given the description of ill health and disability and understanding the close relationship between disability, ill health and poverty, it is likely that most households who have a head of household who is disabled or have another disabled member, will fall in quadrant D. Thus, they are the households least likely to benefit from interventions other than a social cash transfer and, hence, are an important population sector to consider in social cash transfers.

The Zambian social cash transfer programme does not specifically assess disability or ill health in targeting the beneficiary households. However, reports on evaluations of the programme so far show that both of these factors are present in a number of households (Tembo & Freeland, 2007). The limitations of the data collected are that they do not record disability or illness status systematically making it more difficult to analyse by these characteristics. However most individual household files do contain information on this indicating that the information is collected and could be added to the formal database.

However, reports from the Community Welfare Assistant Committees (CWACs), who are responsible for doing the community based targeting of beneficiary households, indicate that they are very aware of the importance of looking at disability and chronic illness. Their comments were that, while disability and illness are important, they do not assess them specifically. Furthermore, having a disabled person in a household does not mean that the household is critically poor. They reported being able to assess disability and chronic illness easily as they know the community and meet people often and can observe their functioning on an on-going basis. The problem for Zambia is the change in targeting approach that will most likely be adopted in the scaling up of the scheme as community based targeting is too costly and time consuming. The correct assessment of disability and chronic illness then becomes more of a challenge. The social assistance grant is a household grant and focused on alleviating critical poverty. The amounts are in the region of USD15 per month paid bi-monthly.

Uganda

The social assistance grants for empowerment (SAGE) programme was started by the Ministry of Gender, Labour and Social Development in 2011 with support from DFID, Irish Aid and UNICEF. A four year pilot phase will see the project rolled out across 14 districts in Uganda reaching around 95,000 households and 600,000 individuals. The programme is part of a broader Expanded Social

Protection (ESP) programme which aims to embed social protection in national planning and budgeting systems through development of an effective policy and fiscal framework and capacity building of a range of government institutions. SAGE consists of two sub-components: an Old Age Grant for people aged 65 years and above and a Vulnerable Families Support Grant (VFSG) which targets households with limited labour capacity. The eligibility assessment for the VFSG includes a formal assessment of disability as part of an electronic birth registration exercise which is undertaken prior to targeting. The vulnerability of households is assessed according to the presence of simple vulnerability indicators including older people, children, people with moderate and severe disabilities and orphans with a composite score being calculated according to household composition. The highest scoring 15% of households are enrolled in the programme with changes in household composition – and subsequent eligibility - being monitored over time. It is expected that the VFSG will primarily target child-headed households, older people caring for children, older people living alone, households severely affected by disability and other households with limited labour capacity (e.g. single parents caring for a large number of children). Although simple disability assessment tools have been used by the Uganda Bureau of Statistics in the past, the challenge for the programme was to find a simple but accurate tool for assessing disability especially in very young children (0 – 5 years old). VFSG beneficiary households will receive UGX 22,000 per month (approximately US\$10) for a minimum of three years after which their eligibility will be reassessed.

South Africa

Historically, South Africa has had a well-developed social assistance programme including an old age grant, a disability grant for adults and a care dependency grant for disabled children, a foster care grant, and a child support grant (called the child maintenance grant until the mid 1990s when it was replaced by the Child support grant). These grants are all individually targeted and require a number of criteria to be fulfilled for eligibility, the main ones being a means test, an age criteria, and, for the DG and CDG, an assessment showing moderate to severe disability and need for extra care (in the case of children). The amounts paid are large relative to the amounts paid in other countries and to some of the minimum wages paid especially for casual work. The current amounts paid for the DG, CDG and Old age grant are around ZAR1080 (+ US\$154) per month paid monthly.

Key issues arising from these three programmes

This section reviews some key points arising from the three country contexts. These are divided into the impact of SCT (Zambia and South Africa), assessment and targeting of disability (Uganda and South Africa primarily) and the combination of service provision and social cash transfers.

Impact of social cash transfers

The studies undertaken in Zambia and South Africa show clear benefits from the cash transfer (Tembo and Freeland, 2007; MDSS and GTZ, 2007; Goudge et al., 2009b; de Koker, de Waal & Vorster 2006). Children are healthier and show better school attendance, instances of begging were reduced and use of health care services is increased for the beneficiary households.

When looking specifically at households with a disabled person in the Zambia study, these benefits are the same and allow people to sustain themselves effectively. One couple with HIV stated that it had saved their lives as they would have died without the social assistance grant. Of note in this study was that the majority of social assistance grant beneficiary households with a disabled

member were those where the head of the household was disabled. The fieldworkers struggled to find such households where the disabled member was not the head of the household. This has important implications for understanding the relationship between critical poverty and incapacitation (as defined by Schubert and Goldberg, 2004 – see above in table 1).

Clearly if the head of the household is disabled and that person usually has the main responsibility as the productive member, the impact on the overall level of poverty and incapacity level will be high. If another member of the household is disabled and the head of the household is capacitated to provide, the impact on the overall level of poverty is less pronounced. However, in this latter case there remain important costs to the household which may put the household into a moderately poor category (see table 1) with labour capacity and hence not eligible for the social assistance grant.

The major themes in relation to the impact for beneficiary households with a disabled member in the Zambian study were increased school attendance, better access to health care services and related to this improved health status, investment opportunities, increased sense of worth as person, greater inclusion and participation in the activities of the community. Some participants described how they are now able to attend church as they can pay their dues, become members of cooperatives and take part in voting for committees.

The South African study on coping strategies of households where members have a chronic illness, also showed that a combined access to a cash grant (DG or CDG or CSG or OAG) plus the access to free health care services provided the best coping strategies for households. Those households with only one of these two components of social protection struggled and often fell into critical poverty (Goudge et al, 2009).

Assessment and targeting of disability

Current social assistance approaches use either implicit (e.g. expecting disabled people to be in the poorest households but not assessing disability as such as noted in Zambia) or explicit criteria (e.g. assessing for disability and allocating a weighting to a household with a disabled person as noted in Uganda). Furthermore, in South Africa the DG and CDG requires a complex process of assessment to determine whether a person is eligible or not.

Assessment of disability for the purpose of social assistance programmes requires careful consideration. The social assistance grant programmes in Zambia and Uganda require an assessment that is quick and simple, while the South African context requires a more detailed assessment of disability in order to accurately target the Disability Grant and Care Dependency grant.

The Zambia study showed that the assessment of disability was a protracted set of observations by the CWACs but with no formal assessment. The types of difficulties identified would be the most visible ones where the activity limitations experienced by people are observable over a period of time. The Ugandan approach is to ask six questions on difficulties people have in six domains of functioning (one question per domain): seeing, hearing, walking and climbing stairs, remembering and concentrating, self care and communication. These questions are the Washington Group on Disability Statistics' Short Set of questions developed primarily for use on Census⁵. These questions move away from the traditional approach to measuring disability which tends to focus on types of

8

⁵ See Website for Washington Group on Disability Statistics for more information on the work and products of this group: http://cdc.gov/nchs/washington_group.htm

disability, such 'deaf, blind, crippled or mentally retarded', with response options of 'yes' or 'no'. The shift to asking about difficulties people have (rather than disability) and using a scale of four response options (no difficulty, some difficulty, a lot of difficulty or unable to do at all), provides a more inclusive and transparent measure of disability which gives both a profile of functioning and a more nuanced picture of the degree of severity. (Schneider, 2009a; Schneider, Dasappa, Khan & Khan, 2009b). Thus, these measures identify people who are elderly or who have chronic illnesses but who do not identify as being disabled, as well as identifying all people who do identify themselves or are identified by others as disabled. In brief, the questions asking about categories of disability are measures more of socio-political identity, while the questions asking about difficulties people have are measures more of functional status. And it is functional status that we are interested in primarily as this is what determines people's productive capacity, ability to access services and participate in normal social life.

The Ugandan Bureau of Statistics (UBOS) have been using the Washington Group Short Set on a number of surveys and have found them to good measures for the population aged 6 years and older, but not for the younger population. Thus, in addition to the use of these measures, a set of questions were collated from basic developmental milestones in physical and cognitive/communication development of children 0 to 2 years of age, and the Ten Questions Screening test (TQT). The TQT was developed and extensively tested in a number of low income countries and found to be accurate in identifying severe disability in children 2 to 9 years of age (Durkin et al, 1995).

The outcomes of the testing showed a good consensus between the description of the difficulties provided by the respondent (for themselves or for their children) and their responses on the questions. A number of borderline cases were noted where people described themselves as having difficulties but who reported 'no' or only 'some difficulty' on one or two questions. The majority of these respondents also reported having a chronic illness. The conclusion was that these people do experience problems in their day to day life not due to disability, but possibly due to the financial hardship of having to pay for on-going health care for their chronic illness.⁶

The outcome of the Ugandan pilot testing study was that the measures tested (Washington Group Short Set for children 6 years or older and adult, milestones and TQT) provided sufficiently accurate measures of disability for the purposes of eligibility for the social assistance grant. The measures for this purpose do not require the same level of accuracy as would be required when collecting data for national statistics on disability, for example, or for deciding on an individual rehabilitation programme. The reason for this is that the targeting of only 15% of households and, therefore, only the most severe disability, it is less important to have more accurate measures as severe disability is more readily identified. The use of the disability assessment measures is more useful in validating and documenting disability (e.g. for monitoring and evaluating the programme coverage in relation to disability) and weeding out the milder forms which we cannot be prioritized with a programme only reaching 15% of all households.

The South African assessment and targeting for the disability grant has historically focused on a medical assessment by a medical doctor. Not only does this require time and resources of doctors, but provides a very subjective assessment of functional status and tends to equate disability with

9

 $^{^{\}rm 6}$ The study did not collect sufficient data to be more conclusive on these possible reasons.

illness. This has lead in South Africa to a situation where people feel they have a right to the disability grant because they have a chronic illness such as diabetes, hypertension or HIV/AIDS even if they do not have any functional limitations (Swartz and Schneider, 2006; Schneider and Goudge, 2007; Leclerc-Madlala, 2006; Hardy & Richter, 2006). The outcome of this approach was one of the reasons for a large and unexpected increase in the number of people applying for and receiving the disability grant in the period 2002 – 2004 (C A S E, 2005). Efforts are currently in place to rectify the situation and target the DG more accurately. However, in order to more accurately target the DG a complementary sickness benefit should be provided for those people who have a chronic illness but who are not disabled (Schneider & Goudge, 2007). A sickness or chronic illness benefit would ensure that these people are not incentivised to remain ill (and functionally limited) in order to retain the DG, as they will receive a separate cash benefit that would encourage them to stay healthy and not become disabled.

The South African context provides a good example of what can happen when a specifically targeted and relatively high cash benefit is provided in a context of high poverty and unemployment. While still being a developmental intervention, it can become problematic and costly to the fiscus. In addition, such a specifically targeted benefit requires a careful and detailed assessment by skilled trained people – and these are in short supply in South Africa and even more in low income countries. The DG in South Africa remains the main source of benefit for the population aged 18 to 60 years, and, as such, became (and remains currently but to a lesser extent) a *de facto* poverty benefit rather than a targeted disability benefit.

In conclusion, the experiences in the three countries suggest that it is possible to assess disability reasonably accurately for purposes of a general poverty focused cash benefit, but that a specifically targeted disability benefit with quite a high cash amount does require more detailed and accurate an assessment to ensure accurate targeting. The targeting using a community based approach (as is the case in the sites of the Zambian study) provides a good assessment of disability but is not feasible when scaling up to a larger programme.

The need for assessment of disability in targeting for social assistance grants such as those in Zambia and Uganda is a question that remains unclear and would require more extensive research to answer. Further large scale survey research may show that it is not necessary to assess disability in a detailed manner as the very nature of the poverty-disability relationship means that many of the households who fall in the poorest sector of society are also households with a disabled or chronically ill person. Vulnerability of disability that remains socially unprotected leads to poverty. It remains, therefore, important to measure disability as one of the many vulnerability factors to better understand the poverty-disability-vulnerability relationship, and evaluate the effectiveness of social protection programmes in improving the lives of disabled people and their households.

Household versus individual targeting

The Zambian and Uganda social assistance grants are household benefits with the aim of benefiting the whole household. In South Africa the grants are individual benefits but have become *de facto* household grants (de Koker et al., 2006). This may be a factor in developing different approaches to assessing disability. In Uganda and Zambia, for example, the target is the household and the level of accuracy for disability assessment is only one of a range of household factors included in the

 $^{^{7}}$ Other reasons included the increase in AIDS sick (and hence disabled) people and fraud.

targeting. In South Africa, the individual targeting of the DG and CDG requires a detailed assessment of that individual with little consideration of the overall household characteristics. The CWACs in Zambia made that very clear when they said they take disability into account but that it is not all they take into account and certainly not sufficient in itself to make a household eligible.

Service provision and social cash transfers

One of the positive impacts of the social assistance gant noted in both South Africa and Zambia⁸ is the increase in access to education and health care services. This impact, however, can only be observed if the services are provided in an accessible manner. The debate about providing services or a cash benefit is a false one as social protection is effective when a range of interventions are provided. This was clearly shown by Goudge et al (2009b) where households who received only one component of a social protection (e.g. a social assistance grant OR free health care) were more at risk of falling into critical poverty than those households who accessed two or more.

When testing the pilot assessment tool in Uganda a number of examples were noted that highlighted the importance of providing not only cash transfers. One such case was that of an adolescent girl who is deaf and has been since birth or early childhood. The girl attends school and has been able to learn some basic arithmetic and writing. Her mother reports that she is able to do household tasks and is keen to learn. However, at 12 years of age she remains with only a rudimentary set of communication skills and language ability and will be seriously disadvantaged going into adulthood. She needed both a social assistance grant and services (access to a sign language teacher and specialized education) to enable her to fulfil her potential and protect her family from falling further into poverty as they met her needs. A cash transfer may help (as noted in the Zambian Study) to send a disabled child to a special school but this is usually far from home as a boarder. A number of other young children with cerebral palsy were seen with severe contractures and limited development. Again these children are in need of trained personnel (e.g. mid-level rehabilitation workers) who can provide some form of intervention in addition to their household receiving a social assistance grant. A third case was that of a 16 year old boy with a club foot who stopped going to school as it was too far and painful to walk to school. His lack of completion of basic schooling will ensure that he remains in the cycle of poverty rather than having any chance of getting out of it. If there is no public transport to get him to school then a social assistance grant does create the benefit of being able to pay for it and continue his schooling.

Health care services are important for all people. However, disabled people face significant barriers in accessing these services for reasons other than financial ones. A common example encountered is the role of stigma as a barrier where, for example, disabled people are denied access to reproductive health care or to voluntary counselling and testing for HIV (unpublished study on HIV and disability in South Africa). Disabled people are seen as sexually inactive and hence not in need of such services, while quite the contrary is true.

These examples highlight the additional barriers faced by disabled people and their families in accessing services. Households without a disabled person can use the social assistance grant to access schooling and health care, but the person with a disability may not have services to access or may be prevented from accessing those that do exist. The conclusion is that for a comprehensive

-

 $^{^{\}rm 8}$ It is too early to determine this for Uganda.

social protection intervention to be effective it should include both cash transfers and services particularly for disabled children and adults.

Conclusion and Moving forward

Social assistance grants are about social protection and ensuring a sustainable livelihood and are, thus, a key intervention for disability. Households with a disabled member should benefit in the same way as all other 'non-disabled' households. However, there are additional barriers that disabled people face that need to be addressed if they are to be full included and integrated in social protection programmes and in accessing social assistance grants. These barriers include, for example, inadequate access to information; inaccessible health care and transport services; creating livelihood opportunities that are not focused only on working age and non-disabled individuals; and providing complementary services such as access to assistive devices, inclusive education and rehabilitation services. If equitable service provision complemented by a social assistance grant is essential for households without a disabled member, it becomes even more so for households with a disabled member.

Mainstreaming of disability statistics at a national level and of disability assessment in targeting for social assistance programmes, more specifically, is the way forward. This not only makes disability information (e.g. the impact of disability on a range of social indicators) more visible but situates disability as one of a range of vulnerability factors (together with old age, female headed households, etc.) and not as a 'special case'. This approach may, it is hoped, lead to reduction on stigma towards disability as disabled people are less marginalized.

In conclusion, not all disabled people require a social assistance grant but may require assistance in other ways, such as accessible services, assistance with extra costs associated with being disabled, carer allowance, and so on. However, disability as an important vulnerability factor will guarantee that many households targeted for a social assistance grant will have a member who is disabled.

References

Braithwaite J & Mont D. (2008) Disability and Poverty: A Survey of World Bank Poverty Assessments and Implications. Social Protection Discussion Paper Series: paper 0805. World Bank, Washington DC; Available at http://siteresources.worldbank.org/DISABILITY/Resources/280658-1172608138489/WBPovertyAssessments.pdf

Charles Lwanga-Ntale. (2003) Chronic Poverty and Disability in Uganda. Paper presented at the International Conference: Staying Poor: Chronic Poverty and Development Policy. University of Manchester, 7th - 9th April 2003.

de Koker C, de Waal L, & Vorster J. (2006) *A profile of social security beneficiaries in South Africa*. Datadesk, Stellenbosch, report for Department of Social Development, Vol 1.

Durkin MS, Wang W, Shrout PE, Zaman SS, Hasan ZM, Desap P & Davidson LL. (1995) Evaluating a ten questions screen for childhood disability: reliability and internal structure in different cultures. Clinical Epidemiology, 48 (5), pp.657-666

Elwan A. (1999). Poverty and Disability: A Survey of the Literature. Social Protection Discussion Paper No. 9932. The World Bank, Washington DC. Available at

http://siteresources.worldbank.org/DISABILITY/Resources/280658-1172608138489/PovertyDisabElwan.pdf

Goudge J, Russell S, & Gilson L (2009a) Illness-related impoverishment in rural South Africa: Why does social protection work for some households but not others? <u>Journal of International</u> <u>Development</u>; Vol 21 (2): 231-251

Goudge J, Gilson L, Russell S, Gumede T, & Mills A. (2009b) Affordability, availability and acceptability barriers to health care for the chronically ill: Longitudinal case studies from South Africa; <u>BMC Health Services Research</u>, **9:**75

Hardy C & Richter M. (2006) Disability grants or antiretrovirals? A quandary for people with HIV/AIDS in South Africa. <u>African Journal of AIDS Research</u>, 5(1), pp85 – 96.

Human Rights Watch, 2010, "As If We Weren't Human": Discrimination and Violence against Women with Disabilities in Northern Uganda. Available at www.hrw.org

Leclerc-Madlala S. (2006). We will eat when we get the grant': negotiating AIDS, poverty and antiretroviral treatment in South Africa. <u>African Journal of AIDS Research</u>, 5(3), pp249 – 256.

Marriott A & Gooding K. (2007) Social Assistance and Disability in developing Countries, Sightsavers, 2007; Available at http://www.undp-

povertycentre.org/publications/cct/Social_Assistance_Disability_Gooding_Marriott.pdf

MCDSS and GTZ. (2007) Social Safety net project - final evaluation report, Kalomo social cash transfer scheme. Lusaka, September 2007. Unpublished report.

Schneider, M. (2009) The difference a word makes: Responding to questions on 'disability' and 'difficulty' in South Africa. Disability and Rehabilitation. 31(1), 42 - 50

Schneider M & Goudge M. (2007). Developing a policy response to provide social security benefits to people with chronic diseases. Human Sciences Research Council Unpublished report submitted to Department of Social Development.

Schneider M, Dasappa P, Khan N, & Khan A. (2009) Measuring disability in censuses: The case of South Africa. ALTER, European Journal of Disability Research. 3: 245 – 265

Schubert, B and Goldberg, J (2004). The pilot social cash transfer scheme: Kalomo District – Zambia. Lusaka, Zambia. Accessed on 24 January 2011 at

http://www.sed.manchester.ac.uk/research/events/conferences/documents/Social%20Protection% 20Papers/Schubert.pdf

Schubert B & Goldberg J (2004). The pilot social cash transfer scheme: Kalomo District – Zambia. Lusaka, Zambia. Available at

http://www.sed.manchester.ac.uk/research/events/conferences/documents/Social%20Protection% 20Papers/Schubert.pdf

Swartz L & Schneider M. (2006) Tough choices: The Social Mode of disability, social security and the challenges for implementation in South Africa.in B. Watermeyer, L. Swartz, T. Lorenzo, M. Schneider, M. Priestley (eds), <u>Disability and social change: a South African agenda</u>. Cape Town: HSRC Press

Tembo G & Freeland N (2007). Impact of social cash transfers on welfare, Investment and education in Zambia. 2007. Unpublished report.

United Nations (2009) The Millennium Development Goals (MDGs) and Disability. Message from the Secretary-General for the International Day of Persons with Disabilities. Accessed on 12 February 2011 at http://www.un.org/disabilities/default.asp?id=1470.

UN, (2006) Convention on the rights of Persons with Disabilities. Accessed on 30 August at www.un.org/disabilities/convention/conventionfull.shtml

Whitworth, A., Wright, G., and Noble, M. (2005), A Review of Income Transfers to Disabled and Long Term Sick People in Seven Case Study Countries and Implications for South Africa, Centre for the Analysis of South African Social Policy, Department of Social Policy and Social Work, University of Oxford, England

Yeo R & Moore K. (2003). Including Disabled People in Poverty Reduction Work: Nothing About Us, Without Us. World Development, Vol. 31, No. 3 pp.571-590,