

**THE APPLICATION AND REVIEW PROCESSES OF DISABILITY GRANTS
FOR DEAF ADULTS IN THE WESTERN CAPE: AN EXPLORATORY STUDY**

A Report on a Research Project

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ABSTRACT

This is an exploratory descriptive study. It is aimed at identifying and describing the multiple perspectives of Deaf adults and key role-players in the process of disability grant application and review for Deaf adults in the Western Cape. Specifically, this study describes the roles of each of the role-players, the communication issues that arise, attitudes and perspectives towards Deafness and disability and decision making criteria that are used in the disability grant application process. Semi-structured interviews were conducted with Deaf adults (15), doctors (7), Social Services clerks (2), social development workers (2), audiologists (2), and an occupational therapist (1). The interviews were coded and analysed. The roles of each of the key role-players are described. The Deaf adults reported communication difficulties at all stages of the application process. The doctors, however, did not report the same level of communication difficulty and were content to communicate with the escorts. The key role-players revealed different perspectives regarding Deafness and disability. The doctors had the main role of decision makers but due to lack of training and differences in interpretation of guidelines, decision-making was very inconsistent. As a consequence different doctors could make different decisions for the same applicant. Research and practical implications of the findings are outlined.

KEYWORDS: Deaf, disability grant, social security, Western Cape

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PREFACE

The researcher's personal experience as an audiologist has brought to light the difficulties that Deaf adults experience in application, review and appeal processes for disability grants and in maintaining such grants in the current system. The researcher works as an audiologist at a local Deaf organisation in Cape Town. The Deaf community organisation used is situated in Cape Town's southern suburbs. It is a non-governmental welfare organisation and was founded in 1987. Historically it served the needs of the Black and Coloured Deaf community in the Western Cape, but is now open to all races. It has an active Deaf membership of over a thousand and serves the greater Cape Town area. The Deaf organisation's practices are strongly based on a cultural / linguistic model of Deafness. It is an organisation *of* the Deaf, run by Deaf members. South African Sign Language (SASL) and Deaf culture form a central part of the organisation.

The organisation undertakes various social projects, including: Audiology, job creation, Social work, adult literacy, sign language teaching, Deaf awareness programmes etc. The Audiology project was started in 1995, and the researcher has been working as the audiologist since 2001. The Audiology project works within the organisation's strong linguistic / cultural model of Deafness. The Audiology project is designed to serve the Deaf community as well as those for whom private Audiology services are too expensive. The researcher has

observed that many Deaf people approach the organisation for a hearing test as 'proof of Deafness' either for a disability grant or for employment equity purposes. As the audiologist at the Deaf organisation, she has heard the frustrations of Deaf adults who have experienced difficulties obtaining and maintaining disability grants. However, the researcher was fairly ill-informed of the whole disability grant process. It is hoped that this study will shed some light on the disability grant process for Deaf adults in the Western Cape and provide an opportunity for all the role-players to voice their concerns and opinions.

In keeping with the move towards the social model of disability (Disabled People South Africa, 2001), the field of Audiology is slowly expanding from an impairment focus towards addressing issues of disability in South Africa. Thus the role of the audiologist is not only in the diagnosis and treatment of hearing impairment but also recognizing and addressing the societal barriers to full participation of Deaf and hearing impaired people in their communities and mainstream activities. As the audiologist at a Deaf organisation, the researcher has been greatly influenced by the linguistic / cultural model of Deafness. It is within this framework that the issues of interest in this study have arisen.

INTRODUCTION

This chapter introduces Deafness and disability within a South African context, outlining the different theoretical models of Deafness and disability. The chapter goes on to describe disability grants within the South African context, outlining various documents which have helped to shape the current disability grant process. The different role-players in the disability grant application process are introduced. Communication issues, attitudes / perspectives towards Deafness and disability and decision making criteria in the disability grant application process are then introduced.

This study is a qualitative exploratory descriptive study aimed at identifying and describing the multiple perspectives of Deaf adults and key role-players in the disability grant application and review processes for Deaf adults in the Western Cape.

Deafness and disability in a South African context

Communication is a vital part of understanding Deafness and Deaf culture. The natural language of communication for Deaf people is Sign language. Sign language is a genuine language with all the grammatical complexities of a spoken language and forms the cornerstone of Deaf culture and Deaf identity (Ross, Storbeck & Wemmer, 2004). Sign language allows Deaf people to communicate effectively enabling full participation in the Deaf

community. However, Deaf people often are isolated from the general hearing community because of communication difficulties (Ross et al, 2004). Deaf people have more difficulty in acquiring fluent spoken and written language. Lip-reading is a difficult skill, even for those with an acquired hearing loss, and is '*virtually impossible*' for the pre-lingually Deaf (Centre for Deaf Studies). Articulate speech is equally difficult, and only an estimated 20% of utterances of severely congenitally Deaf individuals are intelligible to the average listener (Ross, et al, 2004). Few hearing people speak Sign language fluently, and Sign language interpreters are very scarce in most environments.

There is a communication divide between the Deaf community and the general hearing population (Ross et al, 2004). It is, therefore, not surprising that communication has such a huge impact on nearly every aspect of Deaf-hearing interaction. Communication is central to nearly all aspects of life. Communication difficulties can lead to reduced employment opportunities, reduced access to information and facilities, and are even a significant factor in disability grant application.

There are widely differing estimates of the size of the Deaf population in South Africa (Glaser & Tucker, 2004). This is partly due to the different survey questions used. According to the Central Statistics Service, there were an estimated 4 million hearing-impaired people in South Africa; 402,874

were estimated to be profoundly Deaf. According the national census statistics from 1996 and 2001, there were 383,408 and 313,583 Deaf people in South Africa respectively (Stats SA). DEAFSA (1995) estimate 1.6 million people use South African Sign Language (SASL) as their first language. However, this estimate does not correspond with the census statistics for the profoundly Deaf.

The Deaf adult in South Africa has typically been schooled in special schools for Deaf children. In South Africa the inadequate school system has resulted in poor literacy skills, incomplete education and therefore, restricted employment choices. It is well documented worldwide that most Deaf adults have poor literacy skills, with the average reading age of Deaf adults at a grade 4 level (Conrad, 1979, Paul, 2001; Paul & Quigley, 1994, Rodda & Elweke, 2000). As a result of inadequate educational practices in South Africa, one in three Deaf adults in South Africa is functionally illiterate (DEAFSA, 1995). Many schools for Deaf children do not offer an academic course up to grade 12. As a consequence students are forced into choosing trades, which may ultimately limit their employment options. The Deaf adults interviewed in this study were generally above the age of forty. They grew up under the apartheid system and experienced the limited educational and vocational opportunities of the time. Many of them first applied for disability grants several years ago and have had to review or reapply for disability grants several times since then.

In South Africa there is a high rate of unemployment both nationally and in the Deaf community. Official unemployment in 2001 was estimated to be at 26.4%, with an expanded unemployment (including the informal sector) reaching 37% (Taylor Report, 2002). An estimated 70% of Deaf adults are unemployed (DEAFSA, 1995) and many who are employed are underemployed (Glaser & Tucker, 2004; Ross, et al, 2004). As a consequence of these circumstances, many Deaf adults who are unemployed, retrenched or poorly paid apply for disability grants.

Both in South Africa and internationally there exists a tension about whether Deaf adults are considered a cultural community or as people with disability. On one hand the Deaf community internationally presents itself as a cultural minority (Lane, 2002). On the other hand, in South Africa they are typically aligned with the disability sector - although there has been a shift towards political alignment as a minority group (Crawhill, 1995). The dilemmas around their identity and the perceptions of others complicate the disability grant processes. In recent years there has been a move to publicly present Deaf adults as a linguistic / cultural group, whereas for the purposes of the grant they need to be understood as people who are disabled. This tension needs to be understood within the broader context of contested perceptions of disability and Deafness. This study explores the issue of

disability grants and considers Deaf people from a variety of perspectives of disability and Deafness.

There are two main views of disability: the medical model and the social model. The medical model of disability is also referred to as the individual model of disability because it places the individual as central to disability. The individual experiences restricted access and opportunities as the direct consequence of his/her impairment. i.e.: the impairment causes the disability. For this reason Oliver refers to it as the 'personal tragedy' view of disability (Oliver, 1996). The solution to the problem of disability is to reduce the individual's impairment thus resulting in reduced restriction of activities. In the medical model the disabled person is the problem. Proponents of the medical model often do acknowledge the social exclusion experienced by disabled people, but they separate this from the harmful condition or impairment (Harris, 2000). The impairment / disability is viewed as causing the social exclusion, not visa versa.

Historically the medical model has been dominant and widely accepted as a common sense view of disability. Therefore, disability research and service provision has largely been housed in the medical setting. The World Health Organization's ICDH and the ICDH-2 frameworks are both based on an individual or medical model of disability in which the impairment causes the disability or social restrictions experienced by disabled people (Pfeiffer, 2000).

The medical model places the doctor as the expert. As a result the doctor is often the gatekeeper wielding considerable power over the lives of the disabled (Bircher, 2000). The doctor is considered the expert in disability, and therefore remains a critical role-player in the disability grant process. Research is generally done by non-disabled people researching disabled people.

The social model of disability is more recent and has emerged as a result of the disabled people's rejection of the medical or individual model of disability. It is argued from the perspective of disabled people. The publication of The Fundamental Principles of Disability by the Union of the Physically Impaired Against Segregation (UPIAS) in 1976 was a landmark in the beginning of the social model of disability.

"[Disability is] the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities." (UPIAS, 1976: 14).

"In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society." (UPIAS 1976: 14).

Unlike many other disability movements, UPIAS was comprised and led by people with physical impairments. They argued that disability is the result of society's imposition of restrictions and barriers on a person with impairment. Thus the disability occurs as a direct result or consequence of society's discrimination and is not the consequence of the impairment. Disability is seen as a form of social oppression and not a personal tragedy. Blame is shifted from individual to society. Thus the solution to the problem of disability needs to be socially, not individually, based.

The social model's claim that there is no causal link between a person's impairment and the social restrictions experienced by that disabled person; has been revolutionary in its influence on disability studies. Michael Oliver, who coined the term 'social model', has been a strong advocate of the social model emphasising the wholly social nature of disability and defining disability solely as the consequence of social oppression (Oliver, 1996). However, there have been some disagreements and criticisms from within the proponents of the social model. Crow (1996), French (1993) and Thomas (2004) criticise the social model in part for neglecting the personal experience of impairment, claiming that not all difficulties and barriers encountered are *entirely* socially created. i.e.: impairment does play some role in causing disability. However, Finkelstein and Oliver argue that it is important to stick to

the original UPIAS formulations of disability in order to further political strategy (Barnes, Mercer & Shakespeare, 1999).

Following these models of disability, Brueggeman (1999, in Rosen, 2003) describes three general perspectives on Deafness. The first, and most traditional, views Deafness as a pathology or a deficit. This perspective of Deafness is individually based and closely corresponds to the medical or individual model of disability. In some ways it is the easiest to understand, and has been the dominant view of Deafness. A pathology view of Deafness has been the basis of many charities and organisations for the Deaf. Levy (2002) argues that hearing impairment carries with it disadvantages and it is implausible to claim that all of these disadvantages stem from a social origin. I.e. at least some of the disadvantages are directly caused by the hearing impairment. Therefore solutions to the problem of Deafness lie with the individual not society. Research on Deafness and hearing impairment, within this view, is largely driven by hearing professionals, who not only conduct the research, but also set the research agenda. Disability grants are viewed as a necessary charity to those unfortunate people whose hearing-impairment prevents them from working.

Deafness can also be seen from a (social) disability perspective (Brueggeman's second perspective). This point of view corresponds to the social model of disability. It differs from the pathology perspective in that it

does not see the hearing impairment as the cause of the disability; rather the disability is created by society and imposed on the Deaf person. It recognises the hearing-impairment but argues that restricted access and isolation are the result of society's discrimination, not as the result of impairment. Thus, the solution to the problem of Deafness is to remove societal barriers that cause restriction, e.g.: having sign language interpreters available, having interpreted and sub-titled television. Finkelstein (1991 in Lane, 1995) is a strong proponent of viewing Deafness as a disability. He argues that Deafness has more in common with other disabilities than with the other cultural and language minorities. Research is highly influenced by the social model, believing that research on the Deaf should be emancipatory and participatory. Within this paradigm, disability grants are seen as necessary to compensate those people with hearing impairments because society has oppressed and discriminated against them by preventing them from fully participating in the employment sector.

In the third view of Deafness, Deafness is defined not by impairment, but by the use of sign language. Many Deaf people in South Africa do not view themselves as somehow deficient or disabled, but rather as a cultural and linguistic minority group (Aarons, 1995). Deafness is not viewed as an impairment or a disability; it is a minority, a language and cultural group which, according to Lane (2002), differs from disability groups in several ways. Lane (2002) argues that there is no such thing as impairment, merely

a difference from the norm that has been labelled by the troubled-persons industry (health professionals) as impairment. Thus Deaf people are not deficient; they form a minority group upon whom society places barriers or restrictions. This linguistic/cultural perspective argues that any social restrictions and disadvantages the Deaf community may face are a result of oppression and discrimination of Deaf culture (Harris, 1995; Lane, 1995). Thus, according to Aarons (1995), if sign language had more constitutional rights and better status, Deaf people would not be disabled. The solution is not to reduce Deafness (indeed, Deafness is seen as a good thing) but to improve the status of sign language, provide sign language in the schools and increase availability of sign language interpreters.

The cultural/linguistic view of Deafness complicates the issues of disability grants (or social security). If Deaf people were viewed as a cultural/linguistic minority group and not a disability, they would, therefore, not be eligible for disability grants. However, within the South African context, given the poor education and employment rates of Deaf people, the disability grant forms a vital lifeline to many Deaf people who would be without income. Indeed, for this reason some Deaf people, while viewing themselves as part of a minority linguistic group, have subscribed to the disability view of Deafness in order to gain certain rights and benefits (Lane, 2002). Many countries have special legislation enshrining the rights of disabled people such as 'The American's with Disabilities Act' (USA), 'The Employment Equity

Act' (RSA), The Social Assistance Act' (RSA). However, Deaf people would receive no such benefits as a minority linguistic group. In South Africa Deaf people are currently viewed within the pathology or disability models in terms of disability grants, employment equity, education etc.

The perspectives of Deafness are presented and debated by the various theorists. However, it is also important to understand how disability grant applicants, who may not be familiar with the theoretical debates, describe themselves.

Disability grants

South Africa is the only nation within the Southern African region with a social security system for people with disability (Hansen, Sait, Lorenzo, Ingstad, 2005). There were approximately 1,270,964 people receiving disability grants in South Africa in 2004; 123,807 of these people lived in the Western Cape (Swatz & Schneider, 2006). The number of people receiving disability grants has risen sharply since 1997 when there were 732,322 and 89,729 people receiving grants in South Africa and the Western Cape respectively (Swatz & Schneider, 2006). The disability grant system in South Africa has been in a state of flux since the inception of the new democracy in 1994. Several key documents have helped to shape the current disability grant process. These are discussed in chronological order.

The Disability Rights Charter of South Africa (DPSA, 1992) was drafted by disabled people and demands certain rights for people with disabilities. It addresses a wide range of issues such as non-discrimination, self-representation, education, employment, housing, communication etc. The charter claims that disabled people have a fundamental right to social security. Article 7 demands that the state *'provide security to disabled people who are without adequate income and all measures used to determine the adequacy of such income shall take into account additional costs incurred by them as a result of their disability'*. The demand for social security from the state should not be viewed in isolation but within the context of demands of non-discrimination and equal opportunities for education and employment. The Disability Rights Charter of South Africa set the scene for South Africa's post-apartheid disability strategy.

The decision in South Africa to afford people with impairments disability grants was further informed by the UN Standard Rules for the Equalisation of Opportunities for Persons with Disabilities (WHO, 1993) (of which South Africa is a signatory). According to the UN Standard Rules, *'states are responsible for the provision of social security and income maintenance for persons with disabilities'* (WHO, 1993). Rule 8.1 further clarifies: *'States should ensure the provision of adequate income support to persons with disabilities who, owing to their disability or disability-related factors, have temporarily lost or received a reduction in their income or have*

been denied employment opportunities.' While these standard rules are not compulsory, they provide a strong moral and political guideline for states to take action to ensure the equalisation of opportunities of persons with disabilities.

The Act 108 of the Constitution of South Africa (1996) affirms the right of everyone to social security if they are unable to support themselves, and requires the state to take reasonable measures, within its resources, to achieve those rights. Section 9 of the constitution also prohibits discrimination on the basis of disability. Thus South Africa has a clear legal responsibility to address the issues of social security and disability. This was directly addressed in the White Paper on an Integrated National Disability Strategy (INDS, 1997). In this white paper, government lays out its disability strategy and addresses the issue of social security. The White Paper accepts the social model of disability, seeing disability as a human rights issue. It specifically addresses issues of discrimination against people with disability and recognizes that people with disability qualify for affirmative employment opportunities within the private and public sectors because they have been unfairly discriminated against in society and employment. Disability grants are one avenue of addressing inequity for people with disability.

However, there are several challenges with regard to using a social model of disability as a framework for social security. These challenges are

not specific to South Africa but are recognised worldwide (Swartz & Schneider, 2006). In the social model there are no neat divisions between the disabled and the non-disabled. The social model considers disability as a social, not individual entity. It does not, therefore, lend itself to yes/no decisions as to whether a person is disabled or not. Disability is fluid and is dependant on the interaction between the person and the environment. Thus, the prevalence of disability can be changed by manipulating the physical and attitudinal barriers in the environment. This means a person may be considered disabled in one environment and non-disabled in another. The social model would argue that jobs, skills and training should be provided rather than disability grants (Swatz & Schnieder, 2006). However, this is a difficult ideal to implement when unemployment across the country is so high, education is inadequate and there is insufficient provision of basic assistive devices to those who would benefit. The social model is based on the assumption of a barrier-free society that is as equal as possible for all (Swatz & Schnieder, 2006). Within the context of South Africa, it seems impossible to create a barrier-free society when inequality (even among the so called 'non-disabled') is so widespread. Thus it is inevitable that provision of disability grants is required as a lifeline to people with disabilities. The challenge remains how to implement a social security system, which is individual in nature, within a social model framework.

The White Paper on INDS (1997) criticised the social security system in South Africa, as it related to disability grants, which was in effect in 1993. *'The present social security legislative framework, its administration and allocation systems; tend to be discriminatory, punitive, insensitive to the specific need of people with disabilities, uncoordinated, inadequate and riddled with high levels of fraud.'* (INDS, 1997: 52). Over the last decade the government has sought to redress some of these issues through various amendments. Specific criticisms, related to disability grants in South Africa, included:

- Assessment decisions are made by a single medical doctor, often with poor understanding into of disability and employment.
- Unsuccessful applicants are not given reason for being turned down.
- No effective appeal mechanism exists
- Definitions of disability vary and create confusion.
- The means test and other benefits discourage people from seeking employment and training.
- Pay points are often physically inaccessible.

These criticisms of disability grants in South Africa relate largely to the medical framework in which disability grants were based. In a move toward the social model of disability, WHO introduced the International Classification of Functioning, Disability and Health (ICF) in 2001. The ICF represents a world-wide shift in thinking from the medical model toward the social model of

disability. However, the ICF is still set within the medical / health disciplines. The ICF is an individual disability assessment which takes both the person and his/her interaction with the environment into account. Application of the ICF is still relatively new and it remains to be seen how effective it proves in assessing what is essentially a social construct. WHO's paradigm shift in disability adds further impetus to South Africa's disability strategy.

The Taylor Report of Inquiry into a Comprehensive System of Social Security for South Africa (2002) found that definitions of disability underpinning social security are "problematic". They are based largely on the medical model; don't take social and labour market barriers into account; undermine achieving full participation; and create a disincentive to work. The report recommended that *'Eligibility should not be based on the person's incapacity to work, as often their lack of work is due to the poor economic climate and prejudice in the workplace as opposed to their physical or mental inability to perform the job.'* (Taylor Report, 2002: 104). It recommends a needs-based assessment, which would replace the current means testing. The assessment would need to consider social, economic, physical and environmental factors in addition to the type and severity of disability or illness. It would focus on capabilities and potential for retraining.

The report made several recommendations regarding disability grants. Some of these have since been addressed. These recommendations included (amongst others):

- Revamp assessment forms.
- Utilise a multi-disciplinary panel for assessments.
- Develop clear eligibility criteria for assessors.
- Provide free healthcare to people with disabilities.
- Establish an appeal mechanism.
- Make provision for assistive devices.
- Broaden definitions of disability to include all types of disability (mental, physical, sensory and intellectual).

The South African Human Rights Commission Report (SAHRC, 2002): "Towards a Barrier-free Society", provided an overview of disability issues and current legislation as they related to disability in South Africa. The SAHRC used a social model of disability as a framework for evaluating progress in realising the constitutional rights of people with disabilities. The report focused on physical barriers but also highlighted the social and cultural barriers to equal participation in society. Since the birth of democracy in South Africa there has been much progress in legislating the rights of people with disabilities. However, the report concludes that there is still much progress to be made in terms of attitudes. *'Prejudice remains the greatest disability'* (SAHRC, 2002: 62).

The Social Assistance Act 59 of 1992 was assented to in April 1992 and given effect in March 1996. It is still in effect (April 2006). In this Act a disabled person is defined as *'any person who has attained the prescribed minimum age and is, owing to his or her physical or mental disability, unfit to obtain by virtue of any service, employment or profession the means needed to enable him or her to provide for his or her maintenance'* (Section 1). The Act was based on the medical model of disability. Medical assessments were conducted by medical officers, who, very often, were not trained in making assessments for disability grants. This was problematic, particularly where medical officers were scarce, such as in rural areas (Watson, Fourie & Andrews, 2006).

In 2001 Regulation 24(a) of the Social Assistance Act no 59 of 1992 was amended to enable assessment panels to make assessments for grants. Assessment panels may include a medical officer, but they do not have to do so. Membership of an assessment panel is flexible but panels, according to the regulations, should include: a senior security official, a rehabilitation therapist, a representative from the disability sector or reputable member of the community, and any additional members who may be relevant to a particular application. Assessment panels have been formally implemented in 3 provinces: Free State, KwaZulu-Natal and North West (Swartz & Schneider, 2006). The Western Cape did not formally implement assessment panels.

Assessment panels were introduced for a variety of reasons. It was hoped that assessment panels would facilitate equitable access to assessment, especially in areas where medical officers are scarce. It was also hoped that assessment panels would be more conducive to implementing a social model of disability. Assessment panels have the benefit of a richer contextual understanding of the applicant and the barriers they face. However, it is also difficult to achieve equity of the assessment process when panels are so context-rich and constructed differently in different areas (Swartz & Schneider, 2006). It was further hoped that assessment panel may be more successful at identifying so-called 'invisible disabilities' (such as Deafness, communication difficulties, mild brain damage etc), which may be overlooked in a brief medical assessment. Assessment panels have had a positive effect on the increase of the number of disability grant beneficiaries (Department of Social Development Progress Report, March 2003).

The Social Assistance Act no 13 of 2004 was assented to in June 2004 but has not yet come into action. When it does, a date will be published in the government gazette and the Social Assistance Act 59 of 1992 will be repealed. The Social Assistance Act of 2004 retains the same definition of disability used in the 1992 act and implements few significant changes in terms of disability grants. The regulations in terms of the Social Assistance

Act 13 of 2004 outline the eligibility criteria for a disability grant. Persons are eligible for a disability grant if they meet set criteria. This includes '*a valid medical report of a medical officer and the report specifies whether the disability is permanent or temporary...and as a result of the disability the applicant is certified as incapable of entering the labour market*'. Thus, the 2004 regulations appear to still be set within a medical framework.

The disability grant is one of several social grants administered by the Department of Social Development. These include: old age, war veterans, care dependency, foster child, grant-in-aid, child support, and disability grants. A person is eligible for an older persons grant if they are over 60 years and 65 years for women and men respectively. A person is eligible for a war veterans grant if they have performed naval, military or air force service in one of the specified wars and are over 60 years of age, or are unable to provide for themselves due to physical or mental disability. The care dependency grant is for the primary care-giver of a child under 18 years who requires permanent care or support due to a physical or mental disability. A foster child grant is for the primary care-giver to a foster child in need of care. A grant-in-aid is for a person who, due to a physical or mental disability, requires regular attendance by another person. A child support grant is for the primary care-giver of a child under the age of 18 years. At this stage there is no basic income grant and Deaf adults in need of social assistance would only be eligible for disability grants.

A person is eligible for a disability grant if the person is 'owing to his or her physical or mental disability, unfit to obtain by virtue of any service, employment or profession *the means needed to enable him or her to provide for his or her maintenance.*' (Social Assistance Act no 59 of 1992). The applicant must meet all the qualifying requirements of the Social Assistance Act no 59 of 1992.

The qualifying requirements in terms of the Social Assistance Act (1992)

- The applicant must be a South African citizen.
- The applicant must be a resident in South Africa.
- The applicant must be 18 years old.
- The applicant must comply with the means test.
- The applicant must submit a medical report that was completed by a medical officer who is in the service of the state, including a provincial government.
- The applicant must not refuse without good reason to undergo the necessary medical or other treatment recommended by a medical officer, medical practitioner, psychiatrist or an assessment panel.

Disability grants are currently administered by the Department of Social Development within each province. The eligibility criteria, including the means test, are determined at national level; however, the approach to

determining medical eligibility is determined at a provincial level (Whitworth, Wright & Noble, 2005). Three of the provinces have instituted an assessment panel, while others continue to rely on the medical officer as the sole decision maker (e.g. Western Cape). A new medical assessment tool was implemented in the Western Cape from 1 June 2004 to replace the old 'green' form (VR-T3). Stricter control measures have also been introduced along with the new tool. The green form had a very strong impairment focus and didn't address issues of Deafness or communication. However, the recent form has a section addressing communication and hearing loss (See appendix A).

Role-players in disability grant application process

The primary role-players in the disability grant application process (as outlined by the social assistance act) include: the [Deaf] applicants, medical doctors, and Social Services clerks. Secondary role-players depend on the specific context of the application process, but could also include: occupational therapists, audiologists and social development workers.

Deaf applicants are primary role-players in the current system of disability grant application, appeal and review. They are central to the whole disability grant application and review processes. There is no research into their experiences in disability grant application in the Western Cape.

The medical doctors are also primary role-players in the current system of disability grant application, appeal and review. Typically, their assessment is based on a medical examination of the applicant. Previously any medical officer employed by the state completed disability grant applications when necessary. However, in the Western Cape there has been a recent move by Social Services to employ doctors to do disability grant assessments. These doctors work from the local day hospitals and clinics but are separate from them. They only attend to disability grant assessments. There is no research in the Western Cape about the medical doctors' experience, about how they make decisions, consider reviews and appeals. It is, therefore, important to understand the experience of the medical doctor, who has historically been the powerful decision maker in the process, in order to understand the factors which influence the disability grant process.

Social Services form the official government controlled part of the grant application process. Their role is to assess the financial status of Deaf applicants and to complete the administration process. It is important to ascertain their experiences of the financial and administrative aspects of the process and to understand their specific experiences with Deaf applicants. Thus far their experiences have not been researched. Social Services can provide a more comprehensive understanding of the grant application process and the communication and decision-making issues that arise.

Secondary role-players are not always involved in the disability grant application process, but may be involved depending on the context. With the shift towards the social model of disability, the role of the audiologist is no longer only involved in the diagnosis and treatment of hearing impairment, but also recognizing and addressing the societal barriers to full participation of Deaf and hearing impaired people in their communities and mainstream activities. There is no literature on the role of audiologists with regard to disability grant assessments in South Africa.

Traditionally occupational therapists (OT) have been involved in disability grant assessments at work assessment units. There are four government work assessment units in the Western Cape. These units provide full evaluation of a person's ability to work by simulating real work settings. Based on this evaluation the OTs provide recommendations re: work placement, assistive devices, work place modification and disability grant qualification etc. There is no research in South Africa about Deaf people's experiences and communication difficulties with OTs at work assessment units.

Social development workers play a key role in the disability grant process for many Deaf applicants at the particular site of the study. They are employed by an NGO and are appointed to assist Deaf adults with many issues, e.g. integrating people into the Deaf community, finding employment

etc. In addition, they support Deaf adults in the disability grant application, review and appeal. Given their close association with the Deaf adult, and because they are Deaf themselves, they are likely to offer valuable insights into this process. There is no literature available on the types of difficulties they experience and how they manage such difficulties.

Communication Issues

Difficulties in access to healthcare for Deaf persons have been reported internationally (Iezzoni, O'Day, Killeen, Harker, 2004; Mohay & Kleinig, 1991; Steinberg, Barnett, Meador, Wiggans & Zazove, 2006; Ubido, Huntington & Warburton 2002). Deaf people have reported difficulties communicating with doctors and office staff, as well as accessing written information (Iezzoni et al, 2004; Sadler, Huang, Padden, Elion, Galey, Gunsauls, Brauer, 2001). Medical doctors often do not understand sign language and sign language interpreters are not available in a typical primary health care clinic in South Africa (Heap, Bloch, Chan, Jacobs & Mhlanga, 2005). There are only 33 accredited or trained SASL interpreters in South Africa (Heap et al., 2005). Interpreters save time and improve understanding between Deaf patients and health professionals (Heap, et al, 2005). A poor supply of interpreters results in communication problems between health care professionals and Deaf patients. These communication problems complicate the process of disability grant application. There is no research on

communication between Deaf persons and other role-players with regard to disability grants within South Africa.

Attitudes / perspectives towards Deafness and disability

There is as previously discussed, a wide spectrum of theoretical models/views about disability and Deafness. However, little is known about the attitudes/perspectives of Deaf adults and other role-players in South Africa toward these models/views. While South Africa has officially adopted the social model of disability (INDS, 1997), there is little research into how the social model has effected the different role-players in the disability grant application process.

Decision making criteria

Decision making criteria and processes with regards to disability grants remain relatively unexplored. Guidelines for assessment for disability grants have been developed by the Department of Social Services. However, it is unclear if these guidelines are used and how they are interpreted. It is also unclear how the decision-maker's perspectives on disability and Deafness influence his/her decision making.

There is limited literature investigating the experiences of people with disabilities in the application and review of disability grants in South Africa.

One study by Skeen (2002) reports on the experiences of people with aphasia applying for disability grants in the Western Cape. This study was an exploratory study in which key informants were interviewed regarding the disability grant process. Key informants included two people with aphasia and their families, a social worker, a medical officer, and district and administration officers. The study found that several barriers exist for individuals with aphasia in the disability grant system. These included: the continued use of the medical model, a poor knowledge and understanding by key stakeholders, as well as understaffing and time constraints. Although the social model of disability is advocated in South Africa (White Paper on INDS, 1997) it is the medical model that prevails on the ground. The study also found a poor understanding of aphasia as a disability and the resulting inaccessibility of the disability grant system to people with aphasia. In many ways the experiences of people with aphasia may be similar to Deaf people as they both have a less visible impairment that can result in considerable communication difficulties when adequate support is not available. The researcher was unable to find any published literature exploring the experiences of Deaf adults in the application and review of disability grants in South Africa. This provided motivation and impetus for this study.

Summary / conclusion

There are two main views of disability: the medical / individual model and the social model. Historically the medical model has been dominant,

however, recently South Africa has officially accepted the social model of disability (INDS, 1997). It is uncertain how this view of disability has influenced disability grants in South Africa. Both internationally and in South Africa there exists tension about whether Deaf people are considered to be a cultural minority or as people with a disability. The influence of these different perspectives of Deafness on disability grants is explored in this study. South Africa has a social security system for people with disability, which has been in a state of flux since the inception of democracy in South Africa. The social security system has been shaped by several key documents, both governmental and from disability groups. There are several primary and secondary role-players in the disability grant application and review processes for Deaf adults. Primary role-players include: Deaf applicants, medical doctors and Social Services. Secondary role-players may include: occupational therapists, audiologists and social development workers. The roles of each of the role-players are not well researched and need to be explored. Communication difficulties between Deaf and hearing people are common, resulting in decreased access to many services, including healthcare. No literature is available relating to the issue of communication with disability grant applications for Deaf adults. Thus the issue of communication in the disability grant process needs to be explored. Decision making criteria and processes with regards to disability grants also remain relatively unexplored – particularly with regard to Deaf adults.

METHODOLOGY

Aim

To identify and describe the multiple perspectives of Deaf adults and key stakeholders in the process of grant application and review for Deaf adults.

Objectives

1. To identify and describe the role of each of the key role-players.
2. To identify and describe communication issues in the grant application process.
3. To identify and describe each of the role-player's attitudes / perspectives towards disability grants for Deaf adults.
4. To identify and describe criteria used for decision-making around disability grants.

Study design

This study is a qualitative descriptive exploratory study of the Deaf adults and key role-players in the application, appeal and review of disability grants for Deaf adults. A qualitative research design was chosen because the research topic required in-depth study, using face-to-face data collection techniques within a natural context (McMillan & Schumacher, 2001). Qualitative research does not attempt to measure or statistically quantify a phenomena but rather to generate understanding and to learn about some

aspect of the social world that may be useful to that world. Qualitative research seeks depth of understanding into social phenomena and looks to answer the questions 'what, why, how, and under what circumstances?' (Henning, 2004; Ulin, Robinson, Tolley & McNeil, 2002). Thus qualitative research was appropriate for this research in order to gain a greater depth of understanding into disability grants for Deaf adults that could not have been gained by solely quantitative research. The study is descriptive in that it does not attempt to intervene, rather to describe phenomena accurately within a specific context (Durrheim, 1999). This study attempts to produce an intensive examination and a thick description of the issues surrounding disability grants for Deaf adults (Fouche, 2002). The study is exploratory because it attempts to make preliminary investigation into a generally unknown area of research (Durrhiem, 1999; Fouche, 2002; McMillan & Schumacher, 2001). There is very little research into disability grants for Deaf people in South Africa, thus this study aims to provide insight into this area, opening the way for further in-depth research. Exploratory research is usually preliminary, qualitative research which provides the foundation for further studies (Durrhiem, 1999; Fouche, 2002). In this research personal semi-structured interviews were used. Personal semi-structured interviews were chosen in order to investigate the perspectives of Deaf adults and key stakeholders because it allows for specific areas of interest to be targeted while still allowing for the individual nature of the experiences (van Vuuren & Marie, 1999). This study is does not make use of large-scale representative

sampling, but rather seeks to gain greater insight into this area through qualitative description.

The study is set within an interpretivist paradigm of research. The interpretivist paradigm recognises the subjective nature of reality and encourages the researcher to investigate multiple perspectives of a topic (Henning, 2004; Ulin, et al, 2002). While a single data collection modality was used for this study (semi-structured interviews), multiple perspectives were obtained from the different role-players involved. The interpretivist paradigm emphasises the importance of first-hand accounts and recognises both the participants and the researcher as active creators of meaning (Terre Blanche & Kelly, 1999). Semi-structured interviews are, therefore, appropriate within this paradigm of research because they allow participants to respond to questions spontaneously and naturally and become active partners in data collection (Terre Blanche & Kelly, 1999; Ulin et al, 2002). The intention of the research was thus to gain greater insight and understanding into circumstances and behaviours (Ulin, et al, 2002). Context is important within this framework (Terre Blanche & Kelly, 1999) and therefore no attempt is made to control or isolate phenomena from its context but rather provide rich detail of each role-player's perspective of disability grants for Deaf adults within Cape Town.

This study was influenced by the social model of disability. It was qualitative in nature and is set within an interpretivist paradigm which recognises the role and influence of the researcher and seeks to make known bias explicit. The researcher recognises that she is not neutral, but is considered to be a research tool, actively involved in creating knowledge. The researcher's own perspectives and bias on Deafness, disability and social welfare are acknowledged. The researcher is sensitive to the power relations between the researcher and the research population (Rabe, 2003).

Context of the study

This research study was initiated through the researcher's involvement with a Deaf organisation. This Deaf community organisation is situated in Cape Town's southern suburbs. It is a non-governmental welfare organisation and was founded in 1987. Historically it served the needs of the Black and Coloured Deaf community in the Western Cape, but is now open to all races. It has an active Deaf membership of over a thousand and serves the greater Cape Town area. The Deaf organisation's practices are strongly based on a cultural / linguistic model of Deafness. It is an organisation of Deaf people, run by Deaf members. South African Sign Language (SASL) and Deaf culture form a central part of the organisation. Many of its members were schooled at Dominican School for The Deaf in Wittebome, which is a traditionally Black and Coloured school for Deaf children situated in the Cape Town's southern suburbs. Thus, due to its location and historical roots, it

reaches only a particular sub-section of the Deaf community and its members are not representative of all Deaf adults in Cape Town. Also not all of the Deaf people at the organisation have applied for a disability grant.

The organisation undertakes various social projects, including: Audiology, job creation, Social work, adult literacy, sign language teaching, Deaf awareness programmes etc. The organisation also employs two social development workers, who are both Deaf. They are unique to the organisation and oversee many of the social projects such as: work placement, account queries, integration into the Deaf community and social issues awareness. The Audiology project was started in 1995, and the researcher has been working as the audiologist since 2001. The Audiology project works within the organisation's strong linguistic / cultural model of Deafness. The Audiology project is designed to serve the Deaf community as well as those for whom private Audiology services are too expensive. The Audiology project provides basic Audiology services such as hearing testing and hearing aid fitting. The researcher has observed that many Deaf people come for a hearing test as 'proof of Deafness' either for a disability grant or for employment equity purposes.

According to the 2001 census (Stats SA) there are 383,408 people in South Africa who reported a hearing disability. 18,965 of these people were from the Western Cape. It is unclear how many of these people with hearing

impairment use sign language. Participants in this research were recruited from a Deaf organisation and a Deaf hostel, thus sampling only a small section of the Deaf population in the Western Cape. The Deaf community organisation caters for the signing Deaf community. Not all of these Deaf people have applied for a disability grant. Thus only a specific section of the Deaf population was included in the study.

Participants

The primary role-players in the process of disability grant application and review include: Deaf adults, medical doctors at primary health care clinics, and Social Services clerks. Secondary role-players may also include: social development workers at local Deaf community organisations, occupational therapists (OT) at work assessment units, and audiologists. These secondary role-players are sometimes also part of the disability grant application process, but are not necessarily involved in every application or review.

Participant Selection Criteria

Selection Criteria for Deaf Applicants:

Deaf applicants selected to participate in the study met the following participant selection criteria:

- 1) Report having a hearing impairment. (Hearing was not formally assessed, but was reported by the participants. Hearing impairment is usually a characteristic of the Deaf community (Ross et al, 2004) and having an impairment is a requirement to qualify for a disability grant).
- 2) Identify with the Deaf community and use SASL as their primary means of communication, (this is a defining characteristic of the Deaf community as a cultural and linguistic group (Ross et al, 2004)).
- 3) Be over 18 years old (as this is a requirement to qualify for a disability grant).
- 4) Be a South African citizen (as this is a requirement to qualify for a disability grant).
- 5) Have applied for a disability grant as an adult. (This was to allow the Deaf adult's application and review experiences to be explored. Only disability grant applicants were included because disability grants were the topic of interest for this research.)
- 6) Be a voluntary participant in the study. (All participation was voluntary and informed consent was required of all participants in order to meet the requirements of the Medical Research Council).

Selection Criteria for Medical Doctor:

Doctors selected to participate in the study met the following participant selection criteria:

- 1) Have experience in disability grant application assessments for Deaf adults. (The researcher is only interested in medical doctors who have had experience in disability grant application assessments for Deaf adults because they can refer to their own experiences of assessments).
- 2) Work for the State as a qualified medical officer. (This is because a medical officer is required to confirm the disability for all disability grant applicants).
- 3) Be a voluntary participant in the study. (All participation was voluntary and informed consent was required of all participants in order to meet the requirements of the Medical Research Council).

Selection Criteria for Social Services Clerks:

Social Services clerks selected to participate in the study met the following participant selection criteria:

- 1) Worked at Social Services at the time of the study. (Social Services form part of the primary role-players in the disability grant application process as they are involved in processing all applications. Only current Social Services clerks were selected to ensure knowledge of the current disability grant system).
- 2) Have experience with disability grant applications for Deaf adults. (The researcher is only interested in social service clerks who have had

experience in disability grant applications for Deaf adults because they can refer to their own experiences of processing applications).

- 3) Be a voluntary participant in the study. (All participation was voluntary and informed consent was required of all participants in order to meet the requirements of the Medical Research Council).

Selection Criteria for Social Development Workers:

Social development workers selected to participate in the study met the following participant selection criteria:

- 1) Currently working at a local Deaf community organisation at the time of the study. (Social development workers are unique to this particular Deaf organisation. They are not involved with all disability grant applications but play an important role in assisting many Deaf adults with disability grant applications.
- 2) Have experience with disability grant applications for Deaf adults. (The researcher is only interested in social development workers who have experience in assisting Deaf applicants with disability grant applications and reviews because they can refer to their experiences).
- 3) Be a voluntary participant in the study. (All participation was voluntary and informed consent was required of all participants in order to meet the requirements of the Medical Research Council).

Selection Criteria for Occupational Therapist (OT):

The occupational therapist selected to participate in the study met the following participant selection criteria:

- 1) Currently working as an OT at a state work assessment unit at the time of the study. (While OTs are not always involved with all disability grant applications, OTs at the various state work assessment units are sometimes required to assess a person's ability to work and to provide recommendations regarding disability grant qualification. Only an OT currently employed at a work assessment unit was selected to ensure knowledge of the current disability grant system).
- 2) Has experience with disability grant applications for Deaf adults. (The researcher is only interested in OTs who have experience in assessing Deaf adults for disability grant applications and reviews because they can refer to their experiences).
- 3) Be a voluntary participant in the study. (All participation was voluntary and informed consent was required of all participants in order to meet the requirements of the Medical Research Council).

Selection criteria for Audiologists:

The audiologists selected to participate in the study met the following participant selection criteria:

- 1) Currently working as a qualified audiologist at the time of the study. (While audiologists are not always involved with all disability grant

applications for Deaf adults, they are sometimes required to assess an applicant's hearing impairment).

- 2) Have experience with disability grant applications for Deaf adults. (The researcher is only interested in audiologists who have experience in assessing Deaf adults for disability grant applications because they can refer to their experiences).
- 3) Be a voluntary participant in the study. (All participation was voluntary and informed consent was required of all participants in order to meet the requirements of the Medical Research Council).

Sampling Strategy

Purposive, convenience sampling was used to select individuals as representatives of the key role-players in the process. Purposive sampling was used because it allows the researcher to select particular participants who will be able to add valuable experiences and insight to the study (Schwandt, 2001; Strydom & Delport, 2002). Participants are selected not because they necessarily represent a larger population, but because they meet set selection criteria and are thought to be informative about the research topic (McMillan & Schumacher, 2001). Purposive, convenience sampling is a non-probability form of sampling and therefore more open to researcher and participant bias (Katzenellenbogen, Joubert & Karim, 1997; McMillan & Schumacher, 2001; van Vuuren & Maree, 1999). Findings cannot, therefore, simply be generalised to the greater population (Henning,

2004). Convenience sampling was used as participants were selected on the basis of being easily accessible (McMillan & Schumacher, 2001). Using purposive, convenient sampling provided the researcher with a smaller, information-rich sample. Due to the limited exploratory nature of the study all of the research participants were sampled from Cape Town. The Deaf organisation is situated in the Southern suburbs of Cape Town, and all the health professionals and the Social Services clerks sampled were from the vicinity. The study is, thus, set within an urban context and is not representative of the Western Cape as a whole.

Recruitment and Sample Size

In qualitative research there are no set rules for determining the sample size. Richness of the data is more important than representativeness. In-depth and rich data are more conducive to small samples (McMillan & Schumacher, 2001; Strydom & Delport, 2002). The number of role-players in the process influences the sample size in this study. The primary role-players involved in the disability grant application process formed the core of the participants. A few secondary role-players were also interviewed to provide further insight.

Deaf Participants:

The Deaf participants were recruited from a local Deaf community organisation and a local Deaf hostel using convenient, purposeful sampling. Because participants were recruited from a Deaf organisation and a Deaf hostel, only a specific subsection of the Deaf population in the Western Cape was sampled. Participants were recruited via word of mouth through key members in the organisation. It is important to get a balance between the new information that more participants can provide, and the financial and practical cost of conducting further interviews (Strydom & Delport, 2002). In order to allow sufficient in-depth interviews, without unnecessary data-collection, fifteen Deaf adults were interviewed.

Medical Doctors:

At first the researcher attempted to recruit participants from the Primary Day Clinics used by the Deaf applicants. This proved difficult as the usual doctors at the day hospitals are not involved in disability grant applications and have limited experience with disability grant assessments. Only one doctor was recruited to participate in the study this way. Contract doctors are usually employed to complete disability grant assessments. One contract doctor may assess disability grant applications at numerous day hospitals. Finally a list of 10 contract doctors working for Social Services in Cape Town was obtained from the relevant recruitment agency. Each doctor on that list was contacted and invited to participate in the study. Six doctors agreed to participate in the study. Due to the limited availability of doctors involved in

disability grants, and the time-consuming nature of the interviews, a total of only 7 medical doctors were interviewed.

Social Services Clerks:

The researcher approached the relevant manager at Social Services to identify clerks that may participate. The manager selected clerks who met the participant selection criteria. In total 2 social service clerks from one of the Social Services district offices were interviewed. There are 16 district offices in the Western Cape. Only 2 clerks were interviewed, because while they are primary role-players and are involved in every disability grant application, the clerks had limited time available for interviews because of their busy work schedule.

Social Development Workers:

There are two social development workers working at the local Deaf community organisation. Both were invited to participate.

Occupational Therapist:

One OT from a tertiary hospital work assessment unit was interviewed. Initially the research proposal did not include any interviews with OTs. However, through the course of the pilot study and some of the interviews it became apparent that some disability grant applicants were referred to work

assessment units. While this was not a common route for most of the Deaf applicants interviewed, it was felt that an interview with a work assessment OT could shed some light on the process. Only one interview was conducted as the OT is a secondary role-player and does not appear to be central to the disability grant process for the Deaf community in Cape Town. The researcher telephonically contacted an occupational therapist at the Work Assessment Unit at a tertiary hospital, who agreed to participate.

Audiologists:

Like the OT, the interviews with the audiologists were not included in the initial research proposal. However, the need to include them became apparent during the course of the pilot study. Only two audiologists participated in the study as audiologists are secondary role-players in the disability grant application process, and are not necessarily involved in every disability grant application. One audiologist was from a tertiary hospital and the other from a Deaf organisation. The researcher telephonically contacted the Head of the Audiology Department at a tertiary hospital, who agreed to participate in the study. The researcher also acted as a participant in the study by reflecting on her experiences as the audiologist at the local Deaf organisation.

Description of Participants

Deaf Participants:

All of the 15 participants had applied for disability grants as adults. Deaf participants ranged in age from 32 to 67 years. While all the Deaf participants had applied for a disability grant, these applications were not necessarily recent and some applicants had been receiving disability grants for several years. Twelve participants were successful and received disability grants. One participant was denied a disability grant. Two had applied but were still awaiting a response from Social Services. None of the Deaf participants had formal employment, but some worked in the informal sector when work was available. Two worked in job creation projects run by the Deaf organisation. All the Deaf participants (from whom information was available) were educated at Dominican School for the Deaf in Wittebome in Cape Town. Two of the participants completed part of their schooling elsewhere. All Deaf participants were interviewed at either the local Deaf organisation or Deaf hostel.

Medical Doctors:

Six of the doctors interviewed were employed by the Department of Social Services to do disability grant assessments. One doctor (Doctor 3) worked as a medical officer at one of the primary day clinics. Doctors 1, 5 and 6 were semi-retired doctors doing just disability grant assessments on a part-time basis.

Table 1:

Summary Table of Deaf Participants

Deaf	Gender	Age	School	Disability Grant	Current Employment
1	Male	44	Wittebome	Yes	None
2	Male	32	Wittebome & Nuwehoop	Applied	Sign language teaching
3	Female	45	* Data not available	Yes	None
4	Female	47	Wittebome	Yes	None
5	Female	63	* Data not available	No	Retired
6	Male	47	Wittebome	Yes	Casual labour when available
7	Female	33	Wittebome	Yes	Sheltered Employment
8	Male	59	Wittebome	Yes	None
9	Female	53	Wittebome	Yes	None
10	Male	67	* Data not available	Yes	None
11	Male	39	Wittebome & Chresway	Applied	Part time work at Deaf hostel
12	Female	55	Wittebome	Yes	None
13	Female	50	Wittebome	Yes	Sheltered Employment
14	Female	49	Wittebome	Yes	None
15	Female	47	Wittebome	Yes	Cleans church

Table 2:

Summary Table of Other Participants

Participant	Profession & Place of Employment	Gender
Doctor 1	Contract doctor employed by SS to perform DG assessments	Male
Doctor 2	Contract doctor employed by SS to perform DG assessments	Female
Doctor 3	Medical officer at Primary Care clinic	Male
Doctor 4	Contract doctor employed by SS to perform DG assessments	Female
Doctor 5	Contract doctor employed by SS to perform DG assessments	Female
Doctor 6	Contract doctor employed by SS to perform DG assessments	Male
Doctor 7	Contract doctor employed by SS to perform DG assessments	Male
SDW 1	Hard-of-hearing Social development worker at Deaf Organisation	Male
SDW 2	Deaf Social development worker at Deaf Organisation	Male
SS 1	Social Services clerk	Female
SS 2	Social Services clerk	Female
OT	Occupational Therapist at Tertiary Hospital	Female
Audio 1	Audiologist at Tertiary hospital	Female
Audio 2	Audiologist at Deaf Organisation	Female

Social Development Workers:

The social development workers (SDW) were based at a local Deaf community organization. Both the SDWs interviewed were Deaf and used SASL as their first language. However, SDW 1 had some residual hearing and was able to communicate verbally when required. The SDWs assist Deaf adults in a variety of areas including: grants, accounts, Deaf cards, integration into the Deaf community, interpreting disability grant applications etc. They are both male.

Social Services Clerks:

The two social service clerks were based at one Social Services district office. They are both female. No further personal details are presented to protect the participants' identity.

Occupational Therapist:

The Occupational Therapist had about 8 years experience working at a work assessment unit at a tertiary hospital in Cape Town. She is female. No further personal details are presented to protect the participant's identity.

Audiologists:

Audio 1 worked as an audiologist at a tertiary hospital in the ENT department. Audio 2 (who is also the researcher) worked as an audiologist at the local Deaf organisation. They are both female. No further personal details are presented to protect the participants' identity.

Pilot Study

Pilot interviews were conducted with 1 medical doctor, 1 social worker, 1 Social Services officer and 3 Deaf adults in order to develop and refine the interview schedule, and research processes, data capturing procedures and the analysis process. The sample size of the pilot study was kept small, as it served only to test the research procedures and not to generalise the findings (Strydom, 2002) and there were a restricted number of participants. A social worker was used to pilot the interview schedule for the social development workers as both the social development workers at the organisation were used in the main study.

Interview schedule development

Initially the interview schedule consisted of a few set questions focussing mainly on the each participant's role in the disability grant process, decision-making criteria, as well as the factors that facilitated and hindered the process, particularly with regards to communication difficulty.

Perspectives towards disability and disability grants were also probed. As the pilot interviews progressed, the participants raised new topics of interest. These were then included into the interview schedule and included topics such as: fraud, socio-economic needs, issues of fairness and justice. Thus the pilot interviews served to expand and refine the interview schedule. The interview schedule was also affected by the changing style of the interviewer. The schedule became less structured, consisting of guiding questions to be covered rather than set questions. Questions were more open-ended, and probed the participant's responses more deeply.

Process Development: Interview Style

The pilot interviews were useful in refining the interviewer's interviewing skill / technique. Initially the interviewer stuck closely to the set interview questions regardless of the participant's response. Interviews were extremely short, there were large areas which were unclear, and the interviews lacked the necessary depth / richness of information. Later the interviewer became more flexible, the participant's lead was followed and any unclear areas were probed and clarified. Thus the initial set interview questions became a more flexible topic-lead interview schedule. This was beneficial because it provided the participants with more freedom to express their own views and experiences. This resulted in a more equal relationship between the participants and the researcher and led to more information-rich data.

Interpreter

An interpreter was used when interviewing the Deaf participants. The same interpreter was used for the pilot study and the main study. The pilot study formed an essential part of training the interpreter for the main study. The interpreter was orientated to the aims of the study. The pilot interviews were then conducted and transcribed by the researcher. The interpreter then compared the transcription to the video recording of the interviews. This process of checking was useful to refine the interpreter's skill for the main study. From this checking it was identified that the interviewer was adding her own colloquial phrases such as 'you know'. These were later removed. The interpreter also added additional phrases to the Deaf person's response. For example: the participant signed 'yes' and the interpreter interpreted 'Yes, Deaf people are disabled'. The interpreter was requested to sign only what was signed by the participant.

Data Capturing Processes

In the pilot interviews the interpreter was not video-recorded. Only the Deaf participant was on camera. This caused some difficulty, as at times the Deaf participants did not understand a question that the interpreter asked. The interpreter would then rephrase the question until it was understood, and then interpret the participant's answer. This resulted in chunks of information

being lost off tape. Thus in the main study the interpreter was also included on camera. This allowed the exact phrasing of the question the interpreter asked to be recorded. She also verbalised the rephrasing of the question, which allowed the researcher to follow the interview.

Two transcribers independently transcribed the pilot interviews verbatim. The two transcriptions were then compared. When there was disagreement the tape was reviewed and consensus was reached. Most areas of disagreement were minor and inconsequential to the overall meaning of the utterances. However, some difficulties arose with the interviews with the Deaf participants. It was sometimes difficult to hear from the video microphone what the interpreter was saying if the Deaf participant was making a noise at the same time. Therefore a dictaphone was used in addition to the video camera in the main study in order to get a second audio recording.

Data Collection

Materials

Interview Schedules

Semi-structured interviews were used to collect data from each of the role-players. A semi-structured interview was used as it allows flexibility to probe and explore areas of interest that arise during the interview (Greef,

2002). The content of the interview was planned to keep the research focus and meet the research objectives. Questions were mainly open-ended to allow the participants maximum opportunity to tell their story (Greeff, 2002). However, some closed-ended questions were included depending on the topic and information needed. The interview schedule therefore served a support function. Three types of questions were used: main questions to guide the conversation; probing questions to gain greater clarity and depth; and follow-up questions to pursue implications of answers to the main questions (Greeff, 2002; Ulin, Robinson, Tolley & McNeil, 2002). The interview topics and questions were designed around the four research objectives. The researcher also attempted to elicit a chronological narrative of each Deaf participant's experience in applying for the renewal of a disability grant. Topics included: communication, the application process, the appeal process, maintenance and review of disability grants as well as perspectives towards Deafness as a disability. [See Appendix B for interview schedules]. Semi-structured interviews provide more rich data than structured interviews or a questionnaire (Greeff, 2002). Face-to-face interviews rather than a written response were preferred for Deaf adults because of the low literacy levels of Deaf people within the South African context (Aarons & Glaser, 2002).

Procedure

Deaf Participants and Social Development Workers

The local Deaf community organisation and hostel were approached for consent to recruit participants for the study. Participants were then recruited via word of mouth through key members of the community. Each participant was required to provide written informed consent individually. The interviews with the Deaf adults and social development workers were video-recorded and audiotape recorded to provide a full record of the interviews (Greeff, 2002). The researcher conducted the interviews using an SASL interpreter. The interpreter provided a real-time voice-over translation. This translation was then transcribed by the researcher and verified against the video-recorded data by the interpreter to enhance trustworthiness and rigour. The data was then coded and analysed. [More detail on data coding and analysis is provided later under management of data]. Member checking then took place where the main results of the study were then confirmed with the SDWs and a Deaf participant in brief interviews using an interpreter.

The time taken for interviews with the Deaf participants ranged from 11 to 43 minutes. There were communication problems between the researcher and the participant even though a SASL interpreter was used. Many times (across the different interviews) the researcher asked a question, the interpreter would then ask the question in SASL, but the Deaf participant would give an inappropriate reply indicating that he/she had not fully

understood the question. The question was then repeated, rephrased or explained by the interpreter until it was understood. This rephrasing was time consuming and even after much discussion, the questions were not always fully understood. Questions such as "Do you view Deaf people as disabled?" (which is fairly abstract), was particularly problematic for many of the Deaf participants. When the interpreter tried to explain the question further the meanings of the questions changed subtly. For example: "Blind people are disabled, and people that use a wheelchair are disabled. Do you think that Deaf people are also disabled?" As a result of these communication difficulties, much time during the interviews was spent on understanding and confirming basic factual information. The more complex, abstract topics of interest were more difficult to tackle.

The interviews with the SDW were longer (approx. 1 hour each) and communication through the interpreter was generally not as problematic. This may be because they were more familiar with the interviewer, as well as more familiar with the topics for discussion.

Medical Doctors, Social Services Clerks, Occupational Therapist & Audiologists

The participants each gave written informed consent to participate in the study. The interviews were then conducted by the researcher and were tape-recorded and transcribed. The researcher also reflected on her

experience as an audiologist and provided a verbal response to the interview schedule. This was recorded and transcribed into text. All the transcriptions were then coded and analysed. [More detail on data coding and analysis is provided later under management of data]. Interviews with the Deaf participants and SDWs were conducted first. These were followed by interviews with the Social Services, OT, doctors and finally the audiologists.

Research Setting

Except for the doctors, all interviews were conducted in a quiet room where there were few interruptions. The doctor's interviews were generally conducted on-site at the day hospitals where the doctors worked, except for Doctors 1 and 5 who were interviewed at their homes. The doctors interviewed at their homes were relaxed and the interviews were much longer. The interviews were private and there were few disruptions. Doctors 2, 3 & 6 were interviewed at their respective clinics after they had completed their assessments at the clinics. Once again the interviews were private and there were few disruptions. Doctors 4 and 7 were interviewed at their respective clinics during their working hours. At both clinics it was extremely busy and there were long queues of applicants waiting to see the doctors. The interview with doctor 4 was private with no interruptions, but was brief because she had people waiting to see her. The interview with Doctor 7 took place in his consulting room amid busy consulting, thus the interview was disrupted.

Management of Data

Data Transcription

The interview data was then independently transcribed into text by two different transcribers (the researcher and one assistant) and the texts compared to ensure accurate transcription of the data. (The assistant was a volunteer who transcribed all of the interviews and was briefed on the objectives of the study). When differences occurred a meeting between transcribers was held and consensus was reached. The data was transcribed word for word, and ungrammatical or incomplete phrases included verbatim (Ulin et al, 2002).

Data Analysis

The researcher transcribed the data verbatim from tape. This began the process of data immersion. The data was then read again so that the researcher was familiar with the content and had a sense of the data as a whole (McMillan & Schumacher, 2001; Terre Blanche & Kelly, 1999; Ulin et al, 2002). The data was then coded according to categories drawn from the research objectives as well as relevant emerging themes. Coding was done manually. Codes were written in the margins of the transcripts. A coding sort was then done in which similarly coded blocks of text were grouped together (Ulin et al, 2002). This took the text out of linear sequence, giving

the researcher a fresh look at the data, and allowed themes to become clearer (Terre Blanche & Kelly, 1999). The data was then reread in relation to the research question to identify emerging themes. This was a bottom-up approach and themes were generated from the data (Terre Blanche & Kelly, 1999). The researcher made use of peer debriefing to confirm and clarify the emerging themes (Katzenellenbogen, Joubert & Karim, 1997). The data was then recoded as overlapping themes became apparent and a coding sort repeated. Thus the coding system evolved as the researcher became more familiar with the data. The coded sort was then explored / elaborated one theme at a time to identify key concepts and discover relationships of subgroups (Terre Blanche & Kelly, 1999; Ulin et al, 2002). Data reduction then took place where the researcher attempted to stand back from the data and identify the central themes and relationships within the text (Ulin et al, 2002). Member checking was then done with a few participants to confirm the findings. The data was then re-examined in relation to the research objectives. Each objective was then addressed and the data represented via text. Data was represented raw as verbatim text, and was further elaborated on in the discussion.

Trustworthiness and Rigour

Trustworthiness and rigour concerns were addressed at all stages of the research. A number of steps were taken in the study to enhance trustworthiness and rigour. The topics and questions for the interviews were

preliminary and were subjected to peer-review. Topics were based on the research objectives. The interview schedules were then piloted and changed accordingly. All data was mechanically recorded in order to provide an accurate and complete record of the data (McMillan & Schumacher, 2001). The Deaf adults and the social development officer's interviews were conducted in SASL. Therefore, they were recorded using a video camera. The real-time voice over translation was recorded on both the video camera and audiocassette recording. The interviews with the doctor, OT, audiologists and Social Services representatives were recorded on audiocassette. All the data was then transcribed into text independently by the researcher and an assistant, and the texts compared to ensure accurate transcription of the data. The transcribers met and consensus was reached when differences occurred. A SASL interpreter was used for all the interviews with the Deaf participants and Deaf social development workers. In order to ensure the trustworthiness of the translation of the interviews conducted in SASL, the interpreter compared the voice over transcripts with the video tape recording and made any changes necessary.

In qualitative research credibility (referred to as internal validity in quantitative research) refers to the degree to which the explanations of phenomena match the realities of the world and are judged trustworthy and reasonable (McMillian & Shumacher, 2001; Schwandt, 2001). Thus credibility is the confidence of the truth or accuracy of the findings within a certain

context (Ulin et al, 2002; De Vos, 2002). In this study the issue of credibility is addressed by member checking and peer-debriefing (Lincon & Guba, 1985).

The researcher made use of peer debriefing at all stages of the process of design, data collection and analysis with several impartial colleagues, who had experience in qualitative research. Peer debriefing involves sharing ideas, getting advice and checking the dependability of ways of proceeding (Schwandt, 2001). It helps the researcher to understand her own values and how these impact on the research (McMillan & Schumacher, 2001). Thus peer debriefing can also enhance reflexivity.

Member checking was done with one of the Deaf participants and both social development workers who were easily contactable (Deaf 2, SDW1, SDW 2). It was not viable to contact the other professionals again. Member checking took place in a second interview conducted after data coding and analysis had been completed. The main findings of the study were discussed with the participants in order to ensure that the researcher's interpretation of what was said was confirmed by the participants as accurate. Member checking is a useful method for improving credibility and confirmability and ensuring trustworthiness of the findings (McMillan & Schumacher, 2001; Schwandt, 2001).

In qualitative research dependability (referred to as reliability in quantitative research) is the extent to which the research findings can be replicated, or rather the extent to which the research processes can be replicated because it may be impossible to replicate the results given changing circumstances (Ulin et al, 2002). Thus the researcher attempts to account for the changing conditions of the phenomena by providing a refined description of the setting. In the interpretivist paradigm of research, in which this study is placed, the continual construction of the social world is recognised and the concept of replication of results is problematic (De Vos, 2002). Thus dependability is ensuring that the process of enquiry was logical, traceable and documented (Schwandt, 2001). Like confirmability, dependability is addressed in this study by creating an audit trail (Lincon & Guba, 1985). Creating an audit trail involves maintaining a record of all data management techniques and decision (Kelly, 1999). In this study an audit trail has been created by collecting and storing the following information: raw data, data analysis codes, process notes and instrument development information.

Transferability in qualitative research corresponds to the concept of generalisability or external validity in quantitative research (De Vos, 2002). Generalisability is the ability to apply the research findings to a wider population. However, within qualitative research the context or setting of the study is of vital importance and the onus is on the reader (or person seeking

to make an application) to decide whether the conclusions of the study are transferable to other contexts (De Vos, 2002; Ulin et al, 2002). While conclusions from studies in one context may not blindly be transferred to another context, if careful account is taken of contextual factors, then lessons learned from qualitative studies can be transferred to similar settings as the results are conceptually rather than statistically representative (Ulin et al, 2002). The transferability of a study can be improved by triangulating multiple sources of data (Kelly, 1999; McMillan & Schumacher, 2001; De Vos, 2002). In this study, while a single modality of data collection was used (interviews), multiple perspectives were obtained from the different role-players involved. Thus there was triangulation of information sources. Transferability in this study was also facilitated by providing a thick description of the research participants, setting and process (Kelly, 1999). This allows the reader to make informed judgements about the transferability to other contexts. Therefore detailed descriptions of the process, interview settings, and participants were included.

Confirmability in qualitative research corresponds to the quantitative concept of objectivity (Ulin et al, 2002). In qualitative research this refers to the extent to which the findings of the study are due to the data and separate from some inherent characteristic of the researcher (De Vos, 2002). In quantitative research this refers to the maintaining distance between the researcher and the participants, and minimising the influence of the

researcher's values on the process and findings. However, this is not possible, or even necessarily desirable in most qualitative research. Within the interpretivist paradigm multiple perspectives of reality are recognised, and the researcher is seen as a valuable tool within the research process. Thus confirmability addresses whether the data accurately reflects the participant's experiences and helps to confirm the findings and implications (Ulin et al, 2002; De Vos, 2002). In this study an audit trail was left to allow other researchers to verify conclusions from the data (Lincon & Guba, 1985).

Reflexivity contributes to the confirmability of the results and is an important element in qualitative research (Schwandt, 2001; Seale, 1999; Ulin et al, 2002). Reflexivity is the '*process of critical self-reflection on one's biases, theoretical predispositions, preferences and so forth*' (Schwandt, 2001: pg 224). The researcher must recognise her influence and should undergo a process of rigorous self-scrutiny and disciplined subjectivity throughout the research process (McMillan & Schumacher, 2001). The researcher is recognised as a vital component of the research process. This is seen both in terms of the partnership with the participant that is formed to explore topics of interest, as well as being a research instrument herself, influencing how information is elicited (Ulin et al, 2002). Recognising the role of the researcher and undergoing self-examination is particularly important in this study as the researcher was also a participant. Thus the researcher recognises her own assumptions, biases and reactions that may influence

collection and interpretation of data. This research made use of peer debriefing and audibility to enhance reflexivity (McMillan & Schumacher, 2001).

Ethical Considerations

The research proposal was approved by the Faculty of Health Sciences Ethics (reference number 398/2004) [See appendix C]. There are four main ethics principles outlined by the Medical research Council of South Africa in 'Guidelines for Medical Research' (2003). Each of these ethics principles is addressed below.

Autonomy (Respect for Persons)

Respect for persons demands that each autonomous person should be given the freedom to act according to their own judgements. Each participant has the right to enter into research voluntarily and with adequate information. Respect for persons requires that each participant give informed consent. According to the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research informed consent involves three elements: information, comprehension and voluntariness (MRC, 2003).

These three elements were considered in this study. Informed consent was obtained from all participants before being included in the study. All participants in the study are adults and are considered competent to give

consent. According to Pollard (2002) relying on written consent with Deaf participants is inadequate, and for informed consent, conversations with participants are vital. Due to poor literacy levels in the Deaf community (Aarons & Glaser, 2002) consent was obtained either verbally (in SASL) for Deaf participants or in writing for other participants. Each participant was given an information sheet (which was also explained in SASL to all Deaf participants to ensure comprehension) before giving consent for the interview.

The information sheet [See appendix D] contained information on:

- The purpose of the study
- The research design and process
- Any expectations of the participants
- Any possible risks to the participant
- Any possible benefits to the participant
- Steps taken to ensure confidentiality
- Dissemination of results
- Voluntary nature of participation
- The right to withdraw at any time

Beneficence & Non-maleficence

Beneficence is the obligation of the researcher to do good. This is closely linked to the third ethics principle: non-maleficence, which is to do no harm (Katzenellenbogen et al. 1997; MRC, 2003). An assessment of the risks and benefits must be determined to ensure that the risks to the

participants are considered against possible benefits to the participants themselves and the greater community at large. This study did not provide any direct benefits to the participants. However, it is hoped that the local Deaf community and other role-players may experience some benefit from the knowledge gained in the study. The possible benefits of the study could include improved knowledge and understanding around the issue of disability grants for Deaf adults. This could lead to include improved assistance provided by Deaf community organisations to applicants for disability grants, and improved service by the State.

The possible risks in this study are minimal; however, there is always the risk of a breach in confidentiality. Anonymity among Deaf communities is particularly difficult because of the small close-knit communities and the need to video-tape interviews (Pollard, 2002). This risk was addressed by replacing all names with an assigned number given to each participant in the transcription process. The number of people who had access to the video tapes was limited to the researchers and the tapes will be destroyed after the study is concluded. In recognition of the potential risk that the interviews could cause a negative emotional response, referral to a social worker for professional assistance was available.

Justice

The principle of justice usually refers to the fair distribution of the benefits and risks of the research (Katzenellenbogen et al. 1997; MRC, 2003). The researcher must exhibit fairness in the selection of participants both individually and socially. Thus one population should not be exposed to possible risks if another population is to receive the possible benefits (Katzenellenbogen et al. 1997). In this study the participants are exposed to minimal risks and are not expected to receive any direct benefit from participating. However, the community, of which they are part, is expected to benefit from the research.

RESULTS AND DISCUSSION

The results and discussion are integrated within this chapter. Each research objective is presented separately. The data is presented as verbatim script in text boxes, as well as narrative descriptions in the text below the verbatim scripts. The verbatim script has been limited for readability and is provided as examples of the issues discussed. The verbatim text boxes are followed by a narrative description of the data and a discussion related to the particular objective. Short excerpts of the transcripts are sometimes included within the text to enhance understanding. The results are followed by a summary and discussion of the emerging themes and integration of the findings with the current literature. However, there is limited current literature available related to objectives 1 (description of roles) and 4 (decision making criteria). A brief summary is then presented for each objective.

Within each objective, primary role-players have been presented first, followed by the secondary role-players. The participants were each assigned a descriptive name and number (e.g. Doctor 1) which was used to identify the source of the verbatim text. It was felt that identifying the source of the verbatim text was useful to provide the reader with the range of differing opinions. Limited biographical information was provided about each of the participants to preserve participant anonymity. Names of places and people

in the verbatim text have been changed or removed to protect participant's identity. This study is an exploratory, qualitative study, and as such has not attempted to quantify the numbers of participants who raised any particular issue. The emphasis has been placed on exploring and describing the different issues raised, rather than quantifying how many participants raised them. When numbers are mentioned it is in an attempt to emphasise the extent of the issue, not measure it.

Description of Roles

Role of the Deaf Adults

Deaf 9: *"SDW1 helped me with the grant. And we went to the doctor to have an investigation. And then we went to the police station to get it approved. And then we went to [Social Services] to do some paper work. They asked me if I needed money and I told them that I don't have money for myself, and my husband and I are divorced. And I had to do fingerprints, and they told me that I was going to get my grant."*

Deaf 7: *"I went with my sister to [Social Services] and she just did everything for me."*

Deaf 4: *"No John handled everything."*

The role of the Deaf adult is central to the whole disability grant process. However, in practice this role is often a passive role and much of the responsibility for the process falls onto the shoulders of the Deaf person's escort. The Deaf adult simply follows the required process and collects the required documentation. The escort is often a social development worker from the Deaf organization, but can also be a family member or friend. Although they were present throughout the application process, the Deaf adults found it difficult to accurately describe the details of the application process or their role within this process. When an escort was present they played a passive role, and when some of the Deaf applicants applied without an escort present they had so much communication difficulty that they were unable to effectively complete the process.

Role of the Doctors

Doctor 1: "Lots of them come along saying that 'I am ill therefore I need money I need a disability grant' - well that's one set of circumstances; but a lot of them come and say 'I need a grant, I need money' full stop, then they will give you some weak reason why they want a disability grant. Then I try and explain to them, 'look there's a distinct difference between a disability grant for someone who is unable to work because of a disability' and a social grant which is something people get because they have no income and no ability to get one. It actually creates two sorts of channels and I am only dealing with the disability grants."

Doctor 6: *"I have a very strict record. The first time they come here and he is not sick and not uncomfortable or anything, I will refuse him the first time. I'd make him come back again."* [referring to all applicants – not Deaf specifically]

Doctor 5: *"I must say some of my colleagues are I think, sometimes, especially if they are inexperienced; there are two lots those who are inexperienced and those who have a certain attitude that will never change. And that is people don't want to work – that is the attitude of a number of doctors, so I am going to make this difficult for them to get a disability grant as I can. That is a real attitude of some of my colleagues. Others who are inexperienced are not aware of the socio-economic situation..."*

The doctor is essentially the 'gatekeeper' of the disability grant system. He/she is the decision-maker and has to assess who does and does not qualify for a disability grant on medical grounds. According to the guidelines *"only an applicant who as a result of impairment is unable to work is eligible for a grant. The medical certificate has to confirm that the person has a physical or mental impairment that limits or prevents the person from doing any work in order to maintain him or herself."* [See Appendix E for the guidelines in full]. The doctor's role is thus to diagnose and assess

impairment. The doctor's decision is final and is only reviewed by a panel during an appeal process.

The doctors were generally aware of their role as gatekeepers and thus the tremendous responsibility they held over the lives of disabled people. Doctor 1 (although he did not think he was making the final decision) was very concerned with how difficult the decision was and the implications of his decisions on the lives of desperate people. Doctor 1: *"It's sometimes very, very, you sit there and you think 'oh God now what do I do? What do I do? How do I overcome this problem here?' It's very difficult."* Doctor 5 was also acutely aware of the responsibility and was concerned with how inconsistent the process was. Doctor 5: *"We who are doing the assessments actually have the power to say yey or nay, which is a huge responsibility"*. Doctors 1, 5 and 6 commented that it was not a suitable decision for young doctors to make as they lacked experience.

Role of the Social Services Clerks

SS 2: *"I'm actually an admin clerk working with clients. At the moment I am doing processing."*

Deaf 2: *"They told me to fill in the form, I filled in the form. I waited for a man to approach me, went into the office. We negotiated. He asked me why I am applying. I told him I was disabled. He looked at me for quite some time and*

he told me to get up. He asked me can I jump? I jumped. He said 'no you cannot get a disability grant because you are physically able so. They told me. They said you can work so there is no disability grant... I didn't go to the doctor. It was in the department of Social Services in *****'

Deaf 5: "I did ask Social Services: must I go to the doctor? And the person said you don't have to because you look like you are in good condition."

The role of the Social Services clerks is to process the disability grant application and to assist the applicant where necessary. The Social Services clerk is based at the various district offices in Wynberg, Athlone, Belville etc. The Social Services clerk will administer the means test to ensure that the applicant meets the financial criteria for a grant. The means test is an assessment of the applicant's financial status. A sliding scale is used to determine the amount of money for which the applicant qualifies. The role of Social Services is essentially administrative. While the social service clerks do not have the decision-making power of the doctors, they do seem to act as gatekeepers to the disability grant application process. Deaf 2 and Deaf 5 both reported that they were not given the necessary forms and were turned away (before seeing a doctor) by the social service clerk who told them they were physically fit and thus did not qualify for a disability grant.

Role of the Social Development Worker

SDW 1: "The questions that come from the doctor I have to interpret, yes. But some doctors don't quite understand then I have to explain why the Deaf person is applying for the grant and what the Deaf person's background is, how they have become Deaf and so on and so forth."

SDW 1: I am a development worker. I also assist the Deaf with grants, with accounts as well. Such as bank accounts, any open accounts, such as Foshini, clothing, any other accounts. I am hard of hearing. I also help the Deaf with interpreting at private doctors, clinics, hospitals and so on and so forth.

SDW 2: "SDW1 is now focussing on grants. Only when SDW1 is out and then the client would come to me and then I would refer the client to SDW1. I'd take down their details, give them the information, tell them they must bring their ID or birth certificate, marital certificate and their accounts, their rates, if they have an account at the bank the they must bring that as well. So the Deaf person knows that they must bring everything at home and bring it back here to the [Deaf organisation]. And then they will meet SDW1... My role is, my work is getting ID cards, Deaf cards, referring to the social workers."

The social development workers (SDW) were based at a local Deaf community organization. Both the SDWs interviewed were Deaf and use SASL as their first language. However, SDW 1 has some residual hearing and was able to communicate verbally when required. The SDWs assisted Deaf adults in a variety of areas including: grants, accounts, Deaf cards, integration into the Deaf community, interpreting etc. SDW 1 took on most of the responsibility for disability grants, and SDW 2 only assisted when SDW 1 was not present.

The social development workers act as informants, providing the necessary information to the Deaf applicants regarding the application process. When a Deaf adult wants to apply for a disability grant with the assistance of the Deaf organization they can first approach the SDW. The SDW would then inform them what documentation they need to prepare (such as marriage certificates, bank account statements etc). During this application process the SDW acts mainly as an assistant and escort. The reason for a SDW assisting in the process is the communication and literacy difficulties faced by Deaf adults.

It appears as if the SDW acts more as a representative of the Deaf applicant, rather than just an interpreter. He seems to take on much of the responsibility for the interactions, explaining on behalf of the Deaf person. This was confirmed by many of the Deaf applicants interviewed. The role of

the SDW in applying for disability grants is merely to assist the Deaf person with the application. The SDW has no power to make decisions or even recommendations to the doctors and Social Services.

The SDWs are not officially recognised by the doctors or the staff at Social Services. The role of the social development worker is context specific to the Deaf organization and is informal and unofficial outside of the Deaf organization. When the SDW escorts the Deaf person to Social Services or to the day hospital he often has to wait for hours in the queue with the Deaf person. The SDW has to sit and wait with the Deaf person and cannot simply make an appointment, thus the SDW wastes a lot of time waiting in queues. He felt this was due to a lack of recognition and respect for him and his role from Social Services and from the doctors. A lack of recognition and respect for their role in the application process was further evident in the lack of communication from Social Services. The SDWs reported that they were provided with no training or guidelines from Social Services, and were not kept informed about changes in policy and procedure. However, SDW 1 reported that he had learnt a lot about disability grants from experience with Social Services and from their enquires.

Role of the Occupational Therapist

OT: *"The focus of the unit is to assess workability of people with disabilities. So the main focus of what we do is to see whether there is disability grant*

eligibility. Done mainly for the Department of Social Services with the doctors who work for them."

The occupational therapists at the Work Assessment Units are involved in assessing eligibility for a disability grant. OT work assessments are not routinely conducted on every applicant. The OT only assesses those applicants who have been specifically referred to the work assessment unit. There are four government work assessment units in the Western Cape. They conduct a 5 day long assessment of the person's ability to work in various environments. An assessment report is then sent to the referring party with recommendations for disability grant eligibility. The OT acts as an advisor to the doctors. She does not make the final decision but forwards recommendations to the referral source and the reasons for those recommendations. It is then up to the medical doctor to make the final decision.

Not everybody who applies for a disability grant will necessarily undergo a work assessment by the OTs. The OTs only assess those persons who are referred to them. Some doctors refer applicants more often than other doctors. The OTs from these work assessment units formerly also sat on the appeal panel. However, more recently the appeal panel has employed an OT for this purpose. The OTs at the work assessment units are no longer

involved in the appeal panel, but often assess applicants at the request of the panel.

Role of the Audiologist

Audio 1: *"Where we fit in? It is a difficult one because we know the whole system of disability grants is being under review. It is difficult in that we never get a clear directive from the department of health in terms of the procedure should be. So we have our own in-house procedure."*

Audio 2: *"I'm not sure what my role as an audiologist is supposed to be in terms of disability grants. At the moment it is purely impairment-based. I supply the hearing test, with no further recommendations – and I don't even hear what happens after that."*

The role of the audiologist is (among other things) to prevent, diagnose and manage hearing loss. However, the role of the audiologist within the disability grant process is not clearly defined. Both the audiologists described their current role within the disability grant application process as limited to defining and measuring hearing impairment. The audiologists made no decisions or recommendations as to who qualified for a disability grant, and were not asked to make any assessment of communication ability. The audiologist is not necessarily involved in the application process for every

Deaf or hearing-impaired person. The involvement of the audiologist depends on where the applicant starts the application process.

If the applicant goes to the ENT or Audiology department at the tertiary hospitals to apply for a grant, then he/she will automatically be seen by the audiologist at the hospital for a hearing test. The ENT doctor is the decision-maker in terms of disability grants and is responsible for completing the medical assessment form. The applicant is first assessed by the ENT doctor. Thereafter he/she is referred to the audiologist for a hearing test and a hearing aid fitting (if appropriate). From there he/she is referred to the Occupational Therapists at the Work Assessment unit. The OT will then make recommendation about eligibility for a disability grant and will make any other necessary referrals (e.g. training). The ENT will then make the decision and complete the medical assessment form. If the applicant goes through the local Deaf community organization then he/she will be tested by the on-site audiologist before going to the day hospital. Once again the audiologist is not involved in decision-making and does not provide any recommendations to the doctors. The Deaf person then takes a photocopy of their audiogram to the doctors at the day hospital. If the applicant goes directly to the day hospital then he/she is only sent to an audiologist for a hearing test at the doctor's discretion. If applicants go straight to Social Services they will be referred to their local day hospital for the medical assessment – thus only undergoing hearing tests at the doctor's discretion.

Summary / Discussion

Deaf adults are at the centre of the application process, yet seemed to play a passive role, bringing escorts along to represent them. The doctor would then communicate with the escort, largely ignoring the Deaf adult. The SDWs often escorted the Deaf adults through the application process. They seemed to act on behalf of the Deaf adult as their representative. The SDWs were considered beneficial to the process by all involved (doctors, Deaf, Social Services etc). Their role was informal and unofficial, but nevertheless important to those Deaf adults who used their services.

The doctors take the role of sole decision-maker and are the gatekeepers to the social security system. This role of doctors as the 'gatekeepers' in the disability grant system is a controversial one. Bircher (2000) argues that it perpetuates an individualising (medical) model of disability rather than addressing oppression at a social level. It locates the problem with the individual and draws a causal relationship between the impairment and the social restriction experienced by the individual. Thus the doctors continue to wield considerable influence over disabled persons' lives. By keeping health professionals / doctors in the role of gatekeeper of scarce resources, the disabled become trapped in a dependency-creating relationship. Even though health care may be only a small aspect of the lives

of the disabled, disabled people are dependent on the health professionals in almost every aspect of their lives.

The Social Services clerks have a mainly administrative role, processing the application and administering the means test. However, because they are the first contact that many applicants meet in applying for a disability grant, they also seem to take the role of initial gatekeeper – advising some people that they would not qualify for a grant.

The OT saw herself as an advisor to the doctors. OTs conducted a functional assessment of the applicant's work ability and then provided a full report to the referring doctor. The OT was not the final decision-maker but was aware of the influence of her recommendations on the doctor's decision. The audiologists did not have a clear idea of their role within the disability grant system. They were ill-informed about disability grants in general and were unsure of how their assessments were used. Thus, the role of the audiologist within the disability grant process appears to be impairment-based: the audiologist assessing just hearing loss. Neither of the audiologists interviewed were involved in assessing the Deaf person's ability to communicate effectively in different situation (the disability). The jump from hearing loss (individual impairment) to communication (social disability) is left entirely to the doctor.

Communication Issues

Deaf Adults

Interviewer: "Could you have coped without SDW 1 at the doctor's? Could she have understood you?" **Deaf 2:** "Never, never. I would have sat there for hours and hours on end doing nothing. When they call you Mr Smith, Mr Smith, luckily then maybe I would be able to understand the lip-reading, but you have to focus on everyone coming in calling your name. But when you are in the office then it is even more difficult because people speak way too fast. How am I supposed to understand? But luckily SDW 1 was there to help me, and to interpret for me."

Deaf 2: "I don't know SDW 1 just spoke and I just sat down and watched. All I had to do was sign, everything was stamped and SDW 1... what SDW 1 said to Social Services I don't know?... I didn't have any problems recently 'cause I just followed SDW 1 and left afterwards once the paperwork was done."

Deaf 4: "John handled everything" (communication with the doctor).

Most of the Deaf adults interviewed reported experiencing communication problems in the application process. These problems occurred in the waiting room as well as in the interviews with Social Services and with the doctors. However according to the Deaf adults these

communication problems are not limited to the application process but occur whenever a Deaf person is interacting with a hearing world. For example when catching a train or going to the bank. The main strategy mentioned to help bridge this communication divide was to bring an escort along. All but one of the Deaf adults were accompanied by an escort to Social Services and to the doctors. Escorts were often either social development workers or the hostel caretaker, but also included friends and family. The Deaf adults attributed the general communication success to the presence of the escorts, reporting that if the escort was not present they could not have managed.

It appears that these escorts took on much of the responsibility for communicating. The escort does not seem to act as an interpreter, but rather a representative of the Deaf person. Thus the escort talks on behalf of the Deaf person. The Deaf person therefore plays a much more passive role in the application process. Deaf 2 even commented that he did not know what was done at Social Service as the escort did all the talking and he just sat and watched. Even the Deaf adults, who felt that they communicated fairly well with the use of lip-reading, felt that it was necessary to bring along an escort. While an escort seemed to improve communication in the application process, it highlighted the Deaf adult's dependence. Only Deaf 6 preferred to do the application independently. He also reported miscommunication and relied on writing as a means of communication.

The impact of these communication difficulties on the disability grant process is uncertain. There are advantages and disadvantages to escorts representing Deaf persons in the application process. Deaf 2 reports that without an escort at Social Services he was unsuccessful in his application attempt. He did not even manage to get the application forms and was not sent for a medical assessment. The Social Services clerk asked him to jump. He jumped. The Social Services clerk turned him down on the basis that he was physically able. However, when Deaf 2 returned to Social Services with one of the social development workers as an escort, he reported that the whole process went smoothly and he managed to get the forms and information necessary.

Doctors

Doctor 2: *"I can, I can [communicate with the Deaf], especially if, like you point areas. You make sure the person sees you and you would say 'is it sore here?' You know and you actually can tell what the patient is trying to say as well. So it is not so difficult. But it always helps if there is someone, someone who stays with the patient, because they know the person better."*

Doctor 5: *"it [communication] is problematic... It is a problem, and I would think quite a few of my colleagues would find it very difficult indeed."*

Doctor 2: *"Firstly when you call them from outside they don't hear you, because you have a long queue of patients and you say so and so and you just shove the file underneath and you write there no response. And when you are getting out there, there is this one person who is waiting and you like what, and you actually find out that patient was here long before the other patients but with no escort to say it is actually her turn or you are calling this patient."*

Doctor 6: *"Sign language means? ... No, I haven't seen it no, definitely not. That would have been impressive if I had seen it. No"*

In general the doctors had different views to the Deaf adults and did not consider communication with the Deaf applicants to be particularly problematic. All of the doctors reported that this was because the Deaf person usually came with an escort, and they were able to get the information they needed from the escort. When an escort was not present they relied on writing to communicate.

One of the possible reasons that the doctors did not find communication issues particularly problematic is that they had different communicative expectations and their desire to communicate was different to that of the applicants. The doctors were generally content with relying on an escort to get the information necessary to make an assessment. They

appeared satisfied with the limited information communicated. Doctor 2 described that simple gesturing was sufficient to communicate.

While some communication difficulties were acknowledged by the doctors, most reported that they were easily solved by the presence of an escort. In contrast, doctor 5 acknowledged that communication was problematic and therefore she allocated more time for her Deaf patients and always confirmed that communication had been understood both ways, even when an escort was present. While reporting that she coped well with communication she considered that it may be problematic for other doctors. Most of the doctors reported that when an escort was not present, communication was still not problematic as they simply relied on writing to communicate.

In general the doctors reported very few communication difficulties with Deaf applicants. However, Doctor 2 reported that she had experienced communication problems in calling the Deaf person from the waiting room when an escort was not present. Doctor 6 also mentioned the added difficulties present when an additional language barrier exists between the doctor and the patient. Thus for an English/Afrikaans speaking doctor to successfully communicate with an isiXhosa speaking Deaf person is particularly difficult. None of the doctors mentioned the language barrier that

exists between a Deaf person using SASL and a doctor using a spoken language.

Most of the doctors reported seeing very few, if any, Deaf adults using SASL. A possible reason for this is that the Deaf people do not use sign language in the presence of the doctor. They accommodate the doctors by choosing to communicate verbally or through writing as best as they can, as they are aware that the doctor does not know SASL and there are no interpreters available. All the communication appears to take place between the doctor and the escort, without the Deaf person contributing to the discussion. This is, of course, a danger in all mediated conversations.

The doctors were not familiar with issues of SASL and considered Deaf people from a deficit perspective rather than as a linguistic minority. Doctor 6 was not even sure what sign language is. It is also significant to note that the doctors operated more from a medical model of disability, defining Deafness in terms of a deficit or impairment. This was evident in their choice of language describing applicants as 'patients' throughout the interview.

Social Services

SS 1: *"So it is very, most of the time it is not a problem. It's just sometimes when someone who is not probably interacting with an organisation who actually comes out of their own as a Deaf person, not having any assistance that is a bit difficult, but the others usually have someone there who is acting on their behalf."*

SS 1: *"Sometimes, you know, sometimes, some of them they don't prefer to write, they prefer obviously to lip read so you have to go really slowly. Some of them don't really listen to you, or shall I say look at what you are saying so it becomes difficult, because they are actually trying to speak to you, you know. And they can't really hear you so that's a bit of a, a little bit of a problem"*

Both Social Services clerks interviewed reported that communication with a Deaf applicant was difficult. SS 1 did not know any sign language and reported more communication problems. SS 2 had a personal interest in learning sign language through a friend of hers. She was not fluent in sign language but had 'picked up' a few signs from her encounters with Deaf people and through some books. When one of the social service clerks was struggling to communicate with a Deaf applicant, they would call on SS 2 to help.

SS 1 reported communication difficulties whenever the Deaf person was not accompanied by an escort. She tried to communicate using writing and relying on the Deaf person to lip-read. She considered that most Deaf people have enough basic literacy to communicate basic information. However, she reported that some the Deaf people preferred not to write and relied on lip-reading. SS 2 also reported miscommunication when the Deaf applicant came without an escort. When her limited sign language was not sufficient, she relied on writing to communicate. However, an escort accompanied most Deaf applicants to Social Services. The escort would then interpret for them and 'act on their behalf'.

Social Development Workers

SDW 2: *"But they haven't explained to the Deaf person what is going to happen. They don't explain to the Deaf person that it is only for 6 months and then they cut your grant. The Deaf person doesn't know. Even if the person had to read, because they are illiterate the Deaf person, they do not understand what the text is saying, because it says on the text they will cut the grant in 2006, but the Deaf don't know that because they just don't understand that, they just go and fetch their money and then all of a sudden their grant is cut. And then they are shocked because they have to go at the last minute."*

SDW 2: *"when you go to get your money the first time, because you've done all the paperwork, now you must fetch the money there is miscommunication. Where do I go to? I don't know where to go to firstly and they tell you to start there, they take a photo of you and then you get your money – the full amount. And then the next month you get a new card and you get the money."*

SDW 2: *"No, no not at all. We can communicate by sign language so it's no problem. If the person has lost his hearing or her hearing then we'd use writing as a form of communication. I had a hearing person come up to me, who has lost his hearing and when I wrote things down then the person couldn't understand, because maybe my wording wasn't English structured because sometimes I spell things wrong as well and sometimes I try to sign to the person, you know give them baby signing, but that was difficult."*

The SDWs viewed communication as a central issue for Deaf adults in applying for a disability grant. Their primary reason for assisting Deaf adults was to help bridge the communication breakdowns in both the process and the face-to-face interviews. Both SDWs reported that communication was problematic throughout the application process. No provision was made for interpreters at any time during the process. Communication difficulties did not just occur during the application process but were at the heart of disability grants for Deaf adults. The SDWs viewed communication difficulties as the

primary reasons for Deaf adults needing a grant. Communication breakdowns resulted in reduced access to training and employment opportunities, which in turn led Deaf adults to apply for grants. SDW 2: *"Deaf people don't have access, due to communication problems. So they should go for grants and they should be able to get a grant. ... Many Deaf people can't get access to jobs"*.

'Miscommunication' occurred whenever a Deaf person had to communicate within the hearing world, for example: at Social Services, at the police station, at the day hospital. This meant that the Deaf adult often did not understand what was required of him/her. Communication difficulties also were not just limited to one-on-one interviews but occurred throughout the process. For example: in the waiting rooms, in understanding the layout of Social Services and what they needed to do, in reading and understanding letters, and even in fetching the grant each month. SDW 2 commented that the doctors sometimes approve a temporary grant and the Deaf person does not understand that the grant is not permanent. He/she is shocked when the grant is suddenly stopped and then experiences miscommunication all over again when needing to reapply.

The SDWs reported that there were no communication difficulties between the Deaf applicants and themselves, as they both used SASL. However, SDW 2 reported communication difficulties between himself and

hearing people who had later become Deafened as they could not use sign language and were unable to understand his poor writing. The SDWs reported that not all Deaf adults come through them when applying for disability grants. Some Deaf prefer to do things themselves. However, he commented that communication was still problematic. When communication broke down they often resorted to writing. However, this was still problematic due to the Deaf person's poor literacy skills.

Occupational Therapist

OT: *"And even staff members in our unit struggle to get past the 'I cannot get them to understand me'."*

OT: *"With great, great difficulty and much frustration. We use the written word a lot. We use and hope that they lip read. When someone happens to be mute as well as Deaf. Then it is probably the most difficult. But often it is through a process of writing things down. And the client then either verbally responds or writes things down in response for us which takes makes the process that much longer. It is also very difficult when it happens to be a Xhosa speaking client. Because we, firstly I don't speak Xhosa. I do have an assistant who does so she helps us quite a bit. And then the old fallback position of any health professional who can't understand their client, or whose client can't understand them, is to get the family involved. So we will send a*

note home saying, asking the mother to come along or the wife to come along or somebody. And then kind of relying quite heavily on them."

Like the doctors, the OT reported assessing very few Deaf or hearing impaired people at Work Assessment, although she was not sure of exact numbers. She reported assessing only a few applicants who use SASL. She also commented that while some applicants may have a hearing impairment, it was not necessarily their primary diagnosis, but a complicating factor alongside another disability.

The OT acknowledged that communication was a significant issue in both the application process and the decision itself. She highlighted the language barrier that exists between a Deaf person using SASL and a hearing person using English. Nobody in the OT work assessment department could use SASL and there were no interpreters available. Like doctor 6, she also commented on the additional barrier that exists between a Xhosa speaking Deaf person and an English speaking OT. She relied heavily on the Deaf person's ability to read and write as well as lip-read, but reported that this was not always sufficient and they sometimes needed to have a family member escort them to the assessment in order to gain the information they needed.

It is interesting that the OT reported having much more communication difficulties with Deaf adults than the doctors. This is most likely because the Deaf adults had an escort to accompany them to the doctor, but not necessarily to the OT. The OTs may also have greater communication requirements as they conduct much more comprehensive work assessments than the doctors.

Audiologists

Audio 1: *"Well we have an audiologist who does sign quite proficiently so if I had difficulty then I would ask my colleague to come and sign and interpret if necessary because I don't have sign."*

The audiologists reported different communication experiences with Deaf applicants. In general the audiologist (1) at the tertiary hospital felt that communication with the Deaf applicant was not a big issue. She reported seeing very few Deaf people - most of the applicants did not use SASL. She managed to communicate verbally with most applicants, but another audiologist was available to interpret into SASL if necessary. However, audiologist (2) at the Deaf organization saw many Deaf applicants and reported that communication was, in fact, difficult due to the audiologist's poor sign language skills. The audiologist (2) relied mainly on her basic sign language skills but did need to call someone else in the organization to interpret when communication broke down. Writing as a communication

repair strategy was generally not successful due to the Deaf person's poor literacy skills.

Discussion

Several themes emerged regarding communication issues. The Deaf adults reported communication difficulties throughout the application process. These communication difficulties were not equally experienced by all those involved in the application process, with the Deaf adults reporting more problems than the doctors. An escort was often used to bridge the communication gap between the doctors and the Deaf applicants. However, this came at the expense of the Deaf adult's independence, highlighting the uneven power relations between the Deaf adults and doctors.

Communication difficulties were reported throughout the application process as well as in the face-to-face interviews with service providers. Other studies have also highlighted the communication divide between Deaf people and service providers. Ubido et al. (2002) surveyed Deaf women on their access to health care. Only 7% said that they usually understand what the doctor has said to them when they visit the doctor on their own. Communication problems in calling the Deaf person from the waiting room when an escort was not present were highlighted by both the doctors and the Deaf adults. These waiting room difficulties are well known and Ubido et al. (2002) reported that 76% of the Deaf women they surveyed reported

problems in the waiting room. Reeves & Kokoruwe (2005) interviewed 98 Deaf people on their access to primary health care and their preferred communication method. They found that for many of the patients who did not have their preferred communication support, communication was so limited that patient safety was put at risk. Many patients experience problems in making appointment, in the waiting room, and communicating with the receptionist. 54% expressed a preference for professional sign language interpreters in the consultation. Of those who preferred support, 64% preferred a professional interpreter over a family member or friend.

Communication problems were not equally experienced by all those involved in the process. The Deaf applicants experienced the communication breakdowns as significant. In contrast the doctors did not experience face-to-face communication with the Deaf adults as problematic because the Deaf adults were accompanied by an escort. The doctor seems to communicate mainly with the escort, not the Deaf person. This pattern of communication is similar to the findings of Kelsall (1992), who, in her survey of 100 Deaf mothers, found that the midwives would speak to the partner or interpreter rather than to the women themselves. Thus it seems that the escort appears to speak for the Deaf person rather than just interpret for them. This was further confirmed by one of the social development workers, who escorted many of the Deaf adults. He reported that he needed to step in and explain the situation to the doctor rather than just interpret.

There seems to be a communication mismatch between the Deaf adults and the doctors, with the Deaf adults reporting a communication breakdown and the doctors reporting few problems. Similarly Mohay & Kleinig (1991) reported that while they found a communication breakdown between the Deaf patient and their doctor in their study, the doctor was often unaware of the breakdown. Reeves & Kokoruwe (2005) also found that most General Practitioners (GPs) tended to overestimate their communication success, not appreciating the low literacy levels of the Deaf community, and overestimating the effectiveness of lip reading. Despite the use of lip-reading and writing, many Deaf patients reported that they still did not understand their GP.

The presence of an escort bridged the communication gap between the doctors and the Deaf adults to the satisfaction of the doctors. However, the Deaf adults were less satisfied with this solution as it came at the expense of their independence. The escorts took responsibility for the Deaf adult, acting on their behalf rather than merely interpreting. This resulted in a loss of independence and feelings of powerlessness by the Deaf adults. In the current disability grant process, the Deaf applicants do not appear to be independent and certainly do not display control over their lives during this application process. While the escort may have faithfully represented the Deaf person, it was at the cost of the Deaf person's independence.

Many people, especially health professionals, view independence as the ability of the disabled person to do things by themselves. Thus we value people who have overcome the odds and undertake self-care independently, even if it is more time-consuming and less effective. This view of independence reinforces the individual model of disability rather than the social model, locating the disability with the individual, not society. Consequently the disabled person is required to try to overcome their disability and function independently in mainstream society. It is the disabled person that is required to adapt to the mainstream, rather than society adapting to accommodate the disabled. Thus the Deaf person is encouraged to use hearing aids, learn to lip-read, speak, read and write in order to adapt to hearing society.

However, the disabled communities have started to reject this view of independence, claiming that the independence they seek is not the ability to do something without assistance, but the ability to make their own decisions and have control over their own lives (French, 1993). Thus, for the Deaf person, independence may have more to do with the availability of interpreters, than the ability to lip-read. This need for interpreters was identified by the Deaf adults. *"Independence according to Morris (1991) should mean that disabled people have control over their lives, not necessarily the need to carry out all activities of daily living."* (Bricher, 2000, pg 783). The solution to this issue of independence is not to attempt to do

everything alone, but to provide the support needed to allow each Deaf applicant to be in control of their own lives.

The communication breakdown further highlights the uneven power relations between the doctor and the applicants during the assessment. The doctor controls the consultation, while the applicant has little control over the direction or content of the consultation, and does not necessarily get an opportunity to fully present his/her case because of communication difficulties. This is particularly problematic when an escort is present as the Deaf person may not be consulted during the assessment. The doctor may feel that the communication is successful because he/she has gotten the necessary information to make a decision. However, these feelings of success may not be reciprocated by the Deaf person as their concerns may not have been addressed.

Most of the doctors were content with communicating with the escorts, or with the limited information exchanged by gesture and writing. This does raise questions as to the adequacy of such communication for any disability grant assessment. Is this limited type of gesture exchange really able to convey the complexities of the applicant's needs? Given that an estimated 66% of Deaf adults in South Africa are functionally illiterate (DEAFSA, 1995), it does, once again, raise questions as to the adequacy of such communication interactions. Deaf applicants reported that communication

was, in fact, a significant problem. This discrepancy in satisfaction with communication highlights the imbalance of power between the doctor and the applicant. Since doctors are satisfied to communicate with the escorts, there is little pressure or urgency for them to request that SASL interpreters be present during assessments.

Summary

The Deaf adults reported that communication was nearly always problematic, and their writing was not understood. Therefore they needed an escort to accompany them throughout the process. The medical doctor, however, considered communication generally adequate. They relied mainly on the escort, but were also satisfied with using gesture and writing to communicate. The Social Services clerks and occupational therapist also reported communication difficulties with Deaf adults. Once again they relied on the escort or used writing to communicate. One of the audiologists reported adequate communication with Deaf applicants as she had a colleague available with a good knowledge of SASL. The other audiologist reported more communication difficulties as her knowledge of SASL is not adequate. The social development workers reported good communication with the Deaf applicants using SASL. They seem to communicate on behalf of the Deaf applicant during the disability grant application process.

Perspectives on Disability and Deafness

Both in South Africa and internationally there exists a tension about whether Deaf adults are considered a cultural community or as people with disability. On one hand the Deaf community internationally presents itself as a cultural minority (Lane, 2002). On the other hand, in South Africa they are typically aligned with the disability sector - although there has been a shift towards political alignment as a minority group (Crawhill, 1995). The dilemmas around their identity and the perceptions of others complicate the disability grant processes. In recent years there has been a move to publicly present Deaf adults as a linguistic / cultural group, whereas for the purposes of the grant they need to be understood as people who are disabled. This tension needs to be understood within the broader context of contested perceptions of disability and Deafness. This objective explores the issue of disability grants and considers Deaf people from a variety of perspectives of disability and Deafness.

Deaf Adults

Deaf 11: Yes, I think Deaf people are disabled, because most people find it very difficult to get work, but there are a few who are lucky. Those who work at factories, those who work at Pick 'n Pay or at shopping centres. I have matric, but I find it really difficult to get a proper job. Is it because I am Deaf? So government should support the Deaf. That's what I think.

Deaf 5: No [Deaf are not disabled]... They're only Deaf because they cannot hear. Can see you, can lip read, they can do whatever they want to. Only some Deaf people are crippled.... I don't know why they put Deaf people within the disabled criteria.

Deaf 12: Some people want a grant and some people want to work, but if the work is closed how are we supposed to get work or go to work? Yes I want to work, but I stay at home, what am I supposed to do? What am I supposed to do? So that is why I come here to the [Deaf organisation]. It is 'cause all the factories are closing.

Many of the Deaf adults spoke of their difficulties in gaining access to the hearing world. This lack of access into the hearing world referred to a lack of access into the open labour market as well as other areas such as healthcare and entertainment. This is primarily related to communication issues but is linked also to the hearing world's perception of Deaf people. The Deaf adults had a strong perception that they were not accepted in the hearing world, and believed that they were considered to be stupid by hearing people. This perception was expressed directly and was also implied as the Deaf adults challenged the stereotype of being labelled stupid. The lack of acceptance of Deaf people within the hearing world, and the negative perceptions of Deaf people as stupid, also contribute to the discrimination against Deaf people and to reduced education and employment opportunities.

Deaf people viewed themselves as constantly struggling against discrimination, particularly in the work place. This exclusion from the hearing world leads to a lack of training and employment opportunities for Deaf people, which in turn leads to disability grant applications.

Deaf people applied for grants because they viewed themselves as isolated and discriminated against, rather than somehow abnormal or deficient. Their complaint was not about being unable to hear, but about being unfairly excluded and negatively judged by hearing people. They did not see themselves as incapable so much as excluded. Thus, they indirectly rejected a deficit view of Deafness. This is in agreement with many Deaf activists who have rejected the deficit view of Deafness (Lane, 2002). Thus the reason for applying for a grant was because of the exclusion and discrimination they faced, and not as the result of a deficit.

The Deaf adults' perspectives on Deafness and disability were varied. Four of the Deaf adults did not seem to understand what exactly was meant by "disability", and simply answered "I don't know" to the question "are Deaf people disabled?". The question is a highly abstract question and presumes that the person is familiar with the different theoretical views of Deafness and disability and has formulated an opinion. However, many of the Deaf people at grassroots level have not been exposed to the different arguments and

theories. The sign used for disability also complicates the question as it has definite connotations of physical impairment.

For those who were able to respond, more than half of the Deaf adults interviewed thought that Deaf people are disabled. Reasons for this explanation of disability were largely social, such as finding it difficult to get a job and wanting financial support from the government. Nobody thought that they were disabled solely because they cannot hear. They viewed themselves as disabled because they were socially disadvantaged in terms of employment and education opportunities and therefore in need of a disability grant. It must be remembered that the context in which this question was asked was during an interview about disability grants. It is interesting to note that they only considered themselves as disabled in terms of reduced access to society and did not align themselves with mainstream disability.

However, four of Deaf adults were adamant that they are not disabled and emphasized their abilities mentioning that hearing was the only thing they could not do. Deaf 9: "*No ... I am only Deaf!*" Deaf 2 expressed the tensions that surround the term 'disabled'. He was reluctant to categorically label Deaf people as disabled. Saying that while he did not 'feel disabled', he accepted being part of the disability world. He is highly politically aware and has been actively involved within the Deaf community. He was well versed with the different conceptual views of Deafness, and suggested that Deaf people

should be part of a language and cultural group as well as part of the disability world. His private and public views of Deafness as a disability differed. Privately he did not consider himself to be disabled, but publicly he identified with disability groups to advocate for rights and services, such as disability grants.

The Deaf adults were all in agreement that all Deaf people should be given a disability grant if they do not have a well paying job. The reasons given for this were largely social. They did not feel they should get a grant because they could not hear (and therefore considered incapable of work). They felt that they should get a grant because they struggle to find work given the disadvantages they face accessing a hearing world. The current economic situation combined with communication barriers and negative attitudes result in unemployment. For instance: several of the Deaf adults reported that they used to work in the factories, but now could not find employment due to retrenchments and factories closing down. Thus Deaf adults reinforced the idea of social disadvantage as a consequence of being Deaf.

The Deaf applicants found it difficult to find work and as a result needed an income for basic living expenses. The disability grant money was used for basic living essentials such as rent, food, electricity, clothing, transport etc. Only Deaf 2 mentioned using the grant for the special needs of

the Deaf people. He felt Deaf people should get grants because they need to pay for interpreters; they need communication resources such as cell phones and Teldem; and assistive devices such as lights switching on and off. All of these things help to improve access for a Deaf person into a hearing world but were overshadowed by their pressing survival needs.

Doctors

Doctor 5: *"So ja, in our climate they are definitely disabled, they are disadvantaged in a way that is difficult to recoup."*

Doctor 6: *"Of course they are disabled. They can't hear. We are supposed to be able to hear and see..."*

Doctor 4: *"Well they have got a disability, but I don't think they are as disabled as somebody who had got cerebral palsy, which I think they are disabled. It is just somebody with a disability, but they are not disabled. That's what I think"*

Doctor 2: *"You know, the reason I am saying yes, it is not that I am saying I believe they are [disabled], it is the way I or you know the way you react to someone, like if you pass someone who is in a – if you are going into a lift and there is someone in a wheelchair you stand to, you tend to stand back because you are giving way to this disabled person. You know what I mean?"*

I tend to have the same reaction to someone Deaf. ... it is not based on medical, it is on the way I know I look at the person. So I think I tend to have the view of a disabled person, but not that this person can't do anything for themselves, it is not like that."

Doctor 5: *"There are, I mean there are surely, I know of people who are Deaf who have worked effectively and people wouldn't want to do without them. But they had all the opportunities and the chance to develop to do that, the people who gave the jobs."*

Doctor 6: *"because these guys are simple. Some of them are very simple and they are not going to be able to manage these things [hearing aids]. But we try. I think the basic machine [hearing aid] is about as much as you can ask. If that is what you are trying to say"*

All of the doctors viewed Deaf people as disabled. However, the reasons for this conclusion varied considerably. Doctors 1 and 5 were more influenced by the social model and considered Deaf people at a disadvantage in our climate due to inadequate training, limited opportunities and other circumstances. Doctor 6, on the other hand, still clearly operated from a medical model. He had a strong deficit view and considered Deaf people as disabled solely due to their hearing impairment. In trying to understand the Deaf he imagined himself as suddenly not being able to hear. However, this

is just a physical attribute of being Deaf and does not include the rich language and culture of the Deaf community. As Lane (1995, pg184) comments: *"Hearing people led to reflect on Deafness generally begin by imaging themselves without hearing – which is, of course, to have a disability but not to be Deaf."* Despite this deficit model of Deafness, Doctor 6, while considering all Deaf people as disabled, did not think that all Deaf people should qualify for disability grants. Contrastingly Doctor 2, who also came from a deficit view of Deafness, said that she would grant all Deaf applicants a disability grant. Most of the doctors, however, had mixed feelings about disability and treaded carefully around the term disabled. While recognizing Deafness as an impairment, they were reluctant to categorically label a Deaf person as disabled, wanting to recognize the capabilities of the individual and the effect of training and work opportunities.

There is also an element of 'other' and 'anti-normal' that was clear in some of the doctor's attitudes towards Deafness and disability. However, this view seemed to be tempered by political correctness. Doctor 2 also discussed this uneasy balance in her thinking about disability, commenting that her personal and professional views may differ. She demonstrated an attitude of Deafness as 'anti-normal', while still being aware of political correctness in terms of labelling a person as disabled. There is a strong sense in which the dominant culture develops a dichotomy between normalcy (the features of the dominant culture) and 'other'. Any difference from the

world-view of normalcy is categorized as 'other' (Corker, 1998). Thus artificial social barriers are created which separate differences within society. For example Doctor 6: commented that "*People are supposed to be able to see, hear and smell...*" and anyone who differed from this idea of normalcy is 'other' or disabled.

The doctors viewed Deaf people as 'other', having a set view of normalcy against which they were compared. And even though some of the doctors tried to recognize the competencies of Deaf people, they still seemed to hold a personal view of Deafness as 'other' where Deafness is equated with deficiency rather than merely difference.

Despite this attitude towards Deafness as 'other' or anti-normal' there was a tendency by most of the doctors to recognise the Deaf person's competencies. Doctor 5 in particular acknowledged the talents of Deaf people, but was aware that they did not have opportunities to develop them and acquire skills. Thus she would approve disability grants for them on the basis of these reduced opportunities. Doctor 6, however, did not share in this view and reiterated the stereotype that Deaf people are 'simple'.

Social Services Clerks

SS 2: "*Most of, some of them [Deaf] are actually independent because there is a few of them who is independent, they work, some of them do work, I*

mean there is nothing wrong with the hands or whatever and some of them are employed. ... I am not so sure if everybody should get, I mean there is nothing wrong with , they are just Deaf, they are not, how shall I say, physically handicapped or whatever so. That is actually a difficult question if I think about it."

SS 1: *"I think, look, I would say, okay personally I think yes [Deaf should get a grant], because it is something most of them are born with you know and obviously in the open labour market it would be more difficult for someone with a disability to really get a job, but I don't think that it should just be singled out to say that they can't work as well, you know."*

SS 2 did not view Deaf people as disabled. However, she was not sure if they should qualify for a disability grant as some Deaf do work. SS 1 was also reluctant to label Deaf people as disabled. She thought of them as physically impaired but not part of the disabled community. However, she did think they should qualify for a disability grant because of a difficulty getting employment in the open labour market. She emphasised that this did not mean that Deaf people were incapable of work or were helpless or useless.

Social Development Worker

SDW 2: "Deaf people don't have access, due to communication problems. So they should go for grants and they should be able to get a grant. ... Many Deaf people can't get access to jobs"

SDW 1: "No, I call myself Deaf. But most of Deaf people say that I am not disabled I am Deaf. But most Deaf people know what being disabled means, being with blind people, to being in a wheelchair. The Deaf issue, that's just up to the Deaf person to use the word Deaf and not disabled."

SDW 1: "Deaf is different. Deafness is different because most Deaf people it's like they are hearing, but disabled you could see the person is disabled, but for the Deaf person you can't see that, you can't see that they are Deaf. For example many people ask you 'what the time is' and you look at them and you tell them - show them a sign that you can't really hear and they are shocked because they don't really know that you are Deaf. How can I help you, but they can't see that you are Deaf. When a person is blind they have an action and you can see that the person is blind because they either have a walking stick or the person is in a wheel chair. When it comes to a Deaf person the people see you as normal. When it comes to honking a horn, how does the person know that you are Deaf, they don't know. You can be walking across the road and the car wants to come through and they can be honking a horn and you could still be walking across the road as if nothing happened. So it is different."

Both SDWs agreed that Deaf people should qualify for a disability grant. They echoed that the reasons for this were mainly social. They felt that Deaf people did not have access to jobs and therefore needed a disability grant. They highlighted that this lack of access was due to communication problems and discrimination against Deaf people. SDW 2 commented that Deaf people are good workers but just cannot get access to jobs because of communication problems. Thus, they felt that it is because of this lack of access that they should qualify for grants, not because they are incapable of work.

The question: 'Are Deaf people disabled?' proved to be less clear cut. Both SDWs said that Deaf people are disabled. However, this was influenced by the context of referring to disability grants. On probing the issue further, it became apparent that both the SDWs did not see themselves as part of the disabled community, but rather part of the Deaf community. Nor would they refer to other Deaf people as disabled. SDW 1 viewed the issue as an individual thing to be decided by each person themselves.

This tensions expressed by the SDWs that surround the issue of Deafness as a disability, are similar to the tensions expressed by the Deaf applicants. While they accept Deafness as part of the disability world in terms of access to disability grants, they generally view Deafness as quite different

to other disabilities. This separation between Deaf and disabled is further highlighted because, unlike many disabilities, Deafness is not as easily visible. In this respect Deaf people can be seen as more 'normal' and may be considered less likely to need disability grants than those with more visible impairments.

Occupational Therapist and Audiologists

OT: *"To me disability is about how you are getting around in your world. How are you relating within your world, you know in your everyday life. And there are Deaf people who manage very well in that and therefore I wouldn't view them as disabled. And then there are people who don't manage very well and I may view them as disabled even though they may have the same level of Deafness. So it is about how they relate within their world to me".*

OT: *"So to me I think that... look I cannot generally say that all Deaf people are disabled or all Deaf people are not disabled. It is, to me it's an individual thing, and how they relate in their circumstance".*

Audio 1: *"I know at one stage Deafsa had a campaign saying the Deaf can do everything except hear. And a lot of my colleagues at that stage said well in that case why are we doing the disability grant story if ... Again I think it is very difficult. I think again so much of that depends on the educational recourses that the Deaf person has had access to, the kind of background*

they have come from in terms of socio-economic status. I think that they are huge worlds apart in terms of how you are born in this country and again I don't think you can make a blanket sort of thing".

Unlike the doctors, the audiologists and the OT displayed primarily a social model in their personal view of disability. While acknowledging that Deaf people have an impairment, they all stressed the role society has in creating the disability and were not willing to uniformly label Deaf people as disabled without taking each person's individual circumstances into consideration. The OT reported that Deaf people do have a reputation of being separated from the general disability population. They are seen as different from other disabilities. She commented that this seems to be perpetuated by Deaf people who seem to separate themselves from the broader population of people with disabilities. This can be seen locally as well as internationally; for example there are separate Deaf games and Paralympic games.

The audiologist (Audio 1) at the tertiary hospital reported that the Audiology department relies heavily on the WHO's classification of impairment and disability with regards to hearing loss. Only people with a 'disabling hearing impairment'¹ according to the WHO criteria would be considered candidates for hearing aid fitment due to the limited hearing aid

budget. These criteria would also influence her decision-making as to qualification for a disability grant. Thus, while she personally holds the social model of disability, it is the medical model that prevails in professional practice. Thus Audio2's personal and professional view of disability seemed to differ. This may reflect the difficulty of actually implementing the social model within a medical setting (i.e. at a hospital). Audio2 (at the Deaf organization) also expressed difficulty applying a social model to disability grant applications. She merely conducts a hearing test on each Deaf applicant, but makes no considerations or comments about communication ability or other social influences. The audiologists reported that they were only asked to test hearing impairment and were not asked to make any further assessments or recommendations.

Summary / Discussion

The Deaf adults and social development workers largely rejected a deficit view of Deafness, and generally did not consider themselves as having a disability. However, they thought they should qualify for disability grants due to their exclusion from the hearing world. Their exclusion was experienced as a lack of access to training and employment. They attributed this exclusion to communication difficulties as well as discriminatory attitudes towards Deaf people. The Deaf applicants represented an uneasy tension

¹ WHO: A 'disabling hearing impairment' means moderate or worse hearing impairment in the better ear with permanent unaided hearing threshold level for the better ear of 41 dB or greater, averaged at frequencies 0.5, 1, 2, 4 kHz.

between being considered part of the disability world and being considered as a minority language and cultural group.

This tension between being included in or separate from the wider disabled community has been around for a long time and has been debated throughout the Deaf world. Crawhall (1995, pg 5) interviewed a Deaf man (Kobus Kellerman – formally the vice president of Deafsa) about his views on Deafness and disability. He responded: *“For now, we act as a disability group to get our rights. In future, when more and more human rights for the Deaf are written down, we can move from a disability arena to being a minority language group. ... But we are caught between being a disability group and a language group. For so long we’ve relied on recognition as a disability group that there is an unbalance.”* Ten years down the line and this assessment could still apply to the Deaf community in South Africa today.

In many respects the Deaf community seems to need to strategically identify its self as a disability group in order to advocate its rights and needs. A person must be considered disabled in order to qualify for a disability grant. The guidelines for the disability grant assessment clearly state that language barriers are not a reason for awarding a disability grant. Therefore, if the Deaf community claims to be a minority language and cultural group with no disability, they would not qualify for a disability grant according to the current guidelines. There seems to be a fine balance between the Deaf community's

need for support and its desire for respect and equality within the broader hearing world.

Many different definitions of Deafness and disability have been proposed in disability studies literature. While the details of the various disability paradigms were not widely discussed by Deaf adults who participated in this research, many of the central issues were mentioned. Most of adults felt excluded from the hearing community and felt that they were disadvantaged in many situations, particularly in terms of employment opportunities. The reason for this disadvantage was not attributed to their hearing impairment, but rather to unequal access to information and opportunities and the discriminatory attitudes of the general hearing community. Likewise the reason for applying for a disability grant was attributed to this disadvantage and not to their hearing impairment. Thus, the Deaf adults seemed to subscribe to more of a social model of disability.

Currently most services for Deaf people are organized under a disability umbrella both in South Africa and abroad. Some countries have introduced legislation and guidelines aimed at addressing discrimination against people with disabilities in the workplace. Examples are: The Employment Equity Act (1998) and The Code of Good Practice on the Employment of People with Disabilities (2002) in South Africa; the American's with Disabilities Act in the USA; and the Disabilities Discrimination Act (1995)

in the UK. Such disability legislation results in a strong incentive to be classified as part of the greater disability community in order to promote Deaf rights. Some Deaf activists have used these disability acts as a platform to demand improved access, services and opportunities for Deaf people, such as making interpreters available in health care settings (Ubido et al. 2002). However, other activists argue that while many Deaf tolerate and even support the disability view of Deafness, in the end it undermines their overall struggle for equal access to society. *"The dilemma is that Deaf people want access and as citizens in a democracy have a right to access – access to public events, government services, and education – but when they subscribe to the disability definition in order to gain access, they undermine their struggle for other rights – such as education for Deaf children using their best language"* (Lane, 2002 pg 375). There was some ambivalence in strategy amongst the Deaf adults interviewed regarding Deafness as a disability. However, they all agreed that Deaf people should qualify for disability grants. In the case of disability grants, Deaf people need to be included with the broader disability community in order to qualify for grants, even though that may undermine their struggle for language rights.

In several countries people with disabilities qualify for social security benefits, such as a disability grant (in South Africa) or an incapacity benefit (in UK). Social security benefits further provide strong incentive for Deaf people to identify with a disability view of Deafness. To advocate a cultural view of

Deafness (which is the private view of many Deaf people) in the public arena, may place Deaf people at a further disadvantage, as they would no longer be protected under disability legislation. It is interesting, therefore, that despite these disadvantages, many Deaf people continue to aspire for equality and respect as a distinct culture and linguistic minority group.

Internationally Deaf people have campaigned to distance themselves from a disability label, claiming to be a minority language group (Lane, 2002). It is in the context of this minority group that Deaf people view their discrimination and oppression, much like the racial and religious discrimination of other minority groups. However, Finkelstein (1990) claims that Deaf people have more in common with other disability groups than other minority groups (such as racial and religious groups). He argues that it is, in fact, the individual/medical model of disability with its negative associations that they should be rejecting, not disability per se. The social model of disability, he argues, also rejects these negative associations of deficiency. The social model recognizes that Deaf people have a disability, but he attributes the cause of the disability to the discrimination imposed by society, not to the individual impairment. Thus, Finkelstein views Deafness as part of the disability sector (according to the social model), rather than a minority group.

Deaf people are not the only group of people rejecting the medical conception of disability. According to Finkelstein most people with a physical impairment also reject the label 'disabled' because of its negative associations. In recognition of their own self-worth and capabilities there is a sense in which each group views themselves as normal and everyone different as 'other' or 'disabled'. Thus Deaf people see themselves as normal and people who use wheelchairs as 'really' disabled. However, people in wheelchairs see themselves as normal and Deaf people as 'really' disabled (Finkelstein, 1993).

In South Africa there are benefits for Deaf people in being seen as a disability group rather than as a minority language group. This includes getting a disability grant. A disability grant has further benefits in that it allows the recipient access to free health care and access to free assistive devices from the State. Deaf people may also benefit from employment equity legislation promoting the employment of people with disabilities.

Attitudes of the health professionals varied and seemed to reflect the growing tension between the social and medical models of disability. While several of the health professionals in this study personally held to a social model of disability, it appeared to be largely the medical model that prevailed on the ground. Thus their practices were aligned along the medical model. A social model requires a radical change in perspective, moving the source of

disability from the individual to the society. This model of disability is conceptually counterintuitive and more difficult to quantify or measure. It is, therefore, harder to implement a disability assessment based solely on the social model (Swartz & Schneider, 2006). While the new disability grant medical assessment form has been influenced by the social model (in that it includes external social and contextual factors), it still falls short of many of the ideals of the social model.

The views of the doctors can be understood against this changing understanding of disability. Over the last two decades there has been a shift in perceptions of disability within the South African context (DPSA, 2001). Before this time a strong medical model of disability dominated. There has been a shift from the medical model to the social model of disability. This has been largely brought about by the disabled community itself (DPSA, 2001). The social model is now generally considered dominant in the academic world of disability. South Africa has theoretically embraced this model as set out in the White Paper on an Integrated National Disability Strategy (INDS, 1997). However this shift has been an uneasy one, and there has been concern that while the social model of disability may shape thinking in the academic world, it has been difficult to implement and it is the medical model that prevails on the ground (Oliver, 2004; Skeen, 2002). The doctors' differing views seem to reflect this uneasy tension.

Decision-making

Doctors

Doctor 5: "No, it's obvious. It's obvious, I don't need an Audiology report to discover that somebody can't communicate well. I talk to them. And I look at how they - I listen to how they communicate with the person who comes in with them. And some of them come in ready armed with a piece of paper and so on, and I can see that they are lip reading. I don't need special tests to tell that they can't hear well, and there are small things that you can do just to check that they are really Deaf."

Doctor 7: We normally take the people's word, I mean you can see, they can't hear. And I normally try and catch them out. I caught out few. They come in here with the escort saying they can't hear. And then I talk to them under here. I say I think she has not been at a school then suddenly she looks at her mother as if to say, what must I do now? Cause she did go to school. So little tricks like that. Its little tricks that you use if you don't have an audiogram, you must, you can't, I can send them to a doctor, but to get an audiogram you have to go to Tygerberg."

Doctor 4: "Because I strongly believe that Deaf people can work; cause I worked in England with a Deaf radiologist, and he's stone Deaf, he can't hear

a word and he works everyday of his life. So I really believe they can work. It's not an excuse not to work".

Doctor 7: *"They can take it out on you. Scratch your car, or shoot you on the way out here, things like that. They can be vicious about grants. It is like taking a toffee away from a child. You can't take a toffee away from a child. He will be upset. They are upset. And they can get very upset, why did the other doctor give me a grant and you don't. So normally we give the reviews always*

Several themes emerged from the doctors' interviews around the topic of decision-making criteria. The doctors' assessment strategies, attitudes, criteria and decision-making were strikingly inconsistent. This inconsistency among the doctors seemed to apply to almost every aspect of the decision-making process.

The basis on which the doctors made their decisions varied. Some of the doctors (Doctors 1, 2, 4, 6) relied on assessment of impairment and required some sort of proof that the applicant was in fact Deaf (a confirmation of the impairment). This usually took the form of an audiogram or a letter from a special school. However, when they got the audiogram none of them had set clear criteria for how they would use the audiogram to aid their decision. It appears as if they use the audiogram in conjunction with other

subjective criteria to make a decision. Doctor 7 admitted that although he would like an audiogram, it is a lengthy ordeal to go to the tertiary hospital for testing. So he generally gave a temporary disability grant without the audiogram, giving the Deaf person time to have a test done. He did not seem to be aware of the other referral sources that are available in the Cape Town area such as DCCT, The Association for the Deaf, GSH etc.

Doctors 3 and 5 did not require testing as they felt they were competent to make the decision for themselves and able to pick out the people who were not truly Deaf. Doctor 7 had similar sentiments about his ability to identify people who were not genuinely Deaf and used a variety of 'tricks' to identify those who were not really Deaf.

Doctor 4 made use of referrals to OT work assessment, considering the decision to be "*a team thing*". She was confident that the OTs at work assessment would not reject an applicant without first sending them for the appropriate skills training and development. However, according to one of the OTs at work assessment, no such training for the Deaf exists. The OT simply refers the applicant to the Deaf organisations, which refer the person for a disability grant. While all the doctors seemed aware of the work assessment units, not many of them made use of them for Deaf applicants. Some applicants were referred but it did not form part of their general decision-making criteria. Doctor 5 commented that she did not refer persons

to work assessment units because even if they were assessed as able to work, she was still concerned that no one would employ them. Doctor 2 complained that it is actually the responsibility of the day hospital to refer to work assessment if necessary. Doctor 4, however, reported that she would send most of her Deaf applicants to work assessment. She relied heavily on their recommendations, as she believed it was a team decision. In contrast, doctor 6 sometimes referred applicants to OT but did not always rely on their recommendations. Doctor 6: *"the OT's can go overboard in their assessment. And they also can most times feel that the person should get their grant. And you look at it differently."*

Not all of the doctors had received guidelines from Social Services. Some had received guidelines and found them useful, but others did not even know of the guidelines. As a result the doctors made inconsistent decisions based on 'instinct' and 'gut feel'. Doctor 5, who received guidelines, described the process as inconsistent and unfair. Doctor 5: *"And it is very much the luck of the draw as to whether a person gets [a disability grant] or not."* Doctor 2, who did not receive guidelines, was also concerned about this inconsistency. *"Because they also are confused now, one doctor will give a patient with the same diseases that I have declined And it only means that it is based on my gut feeling or that person's gut feeling to decide whether they go - so it is unfair for the whole community for one person for two people with the same diseases, one gets it and the other doesn't get it"*

and there no clear cut." However, Doctor 5, while concerned about the inconsistency of decisions across doctors, was very happy about the guidelines received from Social Services. Doctor 5: *"And Social Services give us quite nice guidelines now, I mean fair."*

One of the factors that may have contributed to such inconsistency of decision outcome is the lack of training. Six of the seven doctors interviewed were dedicated doctors employed by Social Services to assess disability grant applications. While some of the doctors had received brief guidelines, none of the doctors had received any training, and their interpretation of the criteria / guidelines differed significantly.

Work capability was viewed differently by the different doctors. Some of the doctors evaluated the applicants on the question 'Can this person compete in the open labour market?' Thus they considered not only whether the applicant would be able to do the job, but also whether they were likely to get a job in the open market given their disability. These doctors were more likely to give the Deaf applicants disability grants based on the applicants' lack of education and work opportunities caused by the hearing impairment. Thus, they considered the issue from more of a social model perspective. Other doctors asked 'Is this person capable of working in the open labour market?' These doctors generally decided that Deaf adults do not routinely qualify for a grant because they are capable of work. These doctors did not

take factors such as discrimination and work availability into consideration. They considered the decision from more of an impairment perspective.

Despite this inconsistency, all the doctors did, in fact, give some consideration not only to the impairment (Deafness), but also to the effect of social and economic factors. These included: education, work history, job opportunities, training, prognosis, compliance with treatment, age, literacy level, economic status, communication and speech skills etc. While social factors were given some consideration by all the doctors, it was clear that some of them were strongly grounded in a medical model of disability. Even though the doctors all tried to take economic and social factors into account, once again this was done in an inconsistent manner. The doctors had no specific training in this and the social and economic information gained from the disability assessment interview is sketchy at best.

The doctors had a lack of official information of the disability grant system on which to base their decisions. Therefore some doctors understood permanent to mean for life. Others understood permanent to mean that the grant is reviewed every 5 years and others thought that it was reviewed every year. Lack of official information was also evident in the financial issues around the DG process. Doctor 1 referred unsuccessful applicants for a Basic Income Grant (BIG), even though no such grant has been implemented in South Africa yet. Doctor 2 commented that she did not even know how

much a disability grant was each month. Not all the doctors were aware of who was responsible for making the decision to accept or reject an application. Doctor 1 and 7 believed that they merely made a recommendation and someone in Social Services made the final medical decision. This lack of knowledge of the process may have been due to the lack of training or because of the recent changes in awarding and administering grants.

The disability grant application guidelines mention that the doctor should consider whether hearing aids might benefit the applicant. However, the doctors were not always aware of the limitations of hearing aids. Doctor 1: *"Well you know quite a number of them can get some form of hearing aid and then of course then they don't need a disability grant, or they won't qualify for one because they will be able to hear and be the same as anybody else and they must go for a job."* Doctor 2: *"So for me that one he didn't deserve to get a grant because it only means that when he gets that hearing aid from [hospital] he is going to be just like any other person. You see, so it is someone who is really Deaf that I write a disability – that I approve a grant for."* Only doctor 5 seemed to be aware of the limitations of hearing aids. Doctor 5: *"The hearing aids often don't work that well, as you know."*

The disability grant assessment guidelines do not address the issue of transparency of the assessment, and doctors are left to decide on their own

transparency. Many of the doctors did not share with the applicants the outcome of their assessment. The applicants still were required to return to Social Services and then wait several weeks for a letter informing them of the decision. This lack of transparency was due to a genuine fear of intimidation that the doctors had towards some of the applicants. Only doctor 5 said that she shared and explained the results of her assessment with the applicant. She had some concern about intimidation but felt that the applicants had the right to that information. This intimidation affected not only the doctor's transparency with the applicant, but in some cases actually influenced their decisions. Doctor 7 admitted that he never denied a review for fear of intimidation, even if he found no reason for the grant. However, he did write a note on the application asking Social Services to make the final decision.

The doctors viewed their roles as decision-makers differently. Some doctors were far more likely to give disability grants in general than others, believing that most applicants have a genuine disability and are worthy of a grant. Doctor 5: *"Ja, they need it. Across the board they have a genuine reason and your particular field [Audiology] always."* Most of the other doctors, however, held the general view that the majority of applicants are not really disabled; only having social or economic problems and therefore not deserving of disability grants. Doctor 1, in particular, stressed that it was a social problem rather than a medical problem that led to the DG application. Doctor 6 was proud of his 'strict' record for both first-time applications and

renewals. Unless the person was obviously sick or uncomfortable he routinely rejected their first application, making them re-apply. It is not clear if this routine rejection for first-time applicants included Deaf applicants.

Social Services

The Social Service clerks were responsible for administering the means test to check that the applicant met the necessary financial criteria for a disability grant. They were not responsible for deciding who was disabled and qualified for a grant, they merely processed the application with the doctors' decisions.

Social Development Workers

SDW 2: "Some doctors decide yes we can give you a grant and some doctors decide no you don't need a grant. That's the doctor's role. I can't just tell the doctor, no that's not fair, that's his decision, but it is unfair. ... Some hospitals are good like the day hospital in X and the Y Hospital does not accept Deaf people to get a grant. So it depends on the doctor".

SDW 1: "Yes, but doctors, yes they give the grants to all the Deaf people, but if they are really sick and the doctor will usually give the Deaf person more years. Say for instance, three years or it depends on the doctor though. All the Deaf people who have grant, they have different years. So the grant usually has a limit or expires."

SDW 2: *"Yes we do help but the doctor decided at the end of the day. ... And because the doctor controls for which period, for what period of time the Deaf person gets a grant. I mean the Deaf person has children, that Deaf person has a hard time. At the end of the day the Deaf person has so much stress on his hands but it's up to the doctor at the end of the day."*

The SDWs confirmed the doctor's role as the primary decision-maker. While the SDW were not directly involved in decision-making, they reported concerns about the inconsistency or unfairness of the decision-making process. They felt powerless, at the mercy of the doctors and Social Services, whom they felt often discriminated against Deaf people and were not aware of all the factors involved in Deafness and disability. Another major concern for the SDWs was the inconsistency in awarding a temporary versus a permanent grant. They felt that Deaf adults should receive permanent grants. Once again they were powerless to influence the doctors' decisions.

Occupational Therapist

OT: *"Definitely, definitely. And sometimes you get to know who are the difficult doctors and who are the easy doctors. ... you work with the day hospital and you know that there is doctor A and doctor B. And you know that it is going to be easier with doctor A than doctor B. ... But there are doctors that are easier to persuade about a disability grant eligibility. And it goes both*

ways hey. Sometimes, I mean I know of doctors who routinely give everybody disability grants, even if they shouldn't be on disability grant. So they will... there are doctors who will easily grant the DG and there are doctors who will not easily grant the DG.

OT: "Look, in all honesty some of them [Audiology reports] don't make any sense to me. To us it is about function, sometimes we get Audiology reports, and if it is a [hospital] patient we will request the patient's folder and there will be this thing that have funny looking graphs and stuff on it. And I often don't know what those things mean. If it is relevant we will phone up the audiologist and say 'can you explain this to us?' But generally we will look at how the hearing impairment is impacting on function. And you can actually suss it out, you can suss out somebody's hearing quite well if you watch them work."

Once again, inconsistency in the process was a central theme around the topic of decision-making criteria. However, unlike the other medical professionals, the OT was well informed about the disability grant process. She had a copy of the guidelines and was familiar with the application, appeal and review process. The OT highlighted the inconsistency of decision-making by the doctors. Different doctors will make different decisions given the same applicant. The OT also commented that some doctors are more easily swayed by the social circumstances of the person than other doctors.

The OT does not make the final decision whether the applicant will be given a grant or not. The OT merely makes recommendations to the referring doctors. The doctors refer applicants to OT work assessment at their own discretion before making their decision.

Several factors influence her recommendations. She does not consider an Audiology assessment as necessary for her recommendation for a Deaf applicant, as the work assessment is essentially a functional assessment, not a medical one. Her task is to decide, "Can this person work?" She also comments that she does not necessarily even understand the Audiology report when it is present. Like the Social development workers, the OTs also viewed communication breakdowns as the central reason that Deaf people apply for disability grants. OT: "Because communication for the Deaf guy is probably his/her biggest ... obstacle." Communication was such an important issue for employers that it was difficult even to place Deaf people in supported workshops for the disabled.

The OT also considered economic factors, such as whether the Deaf person would be able to find work / get a job, not just whether they are capable of work. OT: "*And the other thing that comes into play, obviously big time, is the level of unemployment that you find.*" Although, she commented that this was much harder to motivate with the doctor. Work history and education also both have a strong influence on the OT's decision-making.

There are also other advantages to being on a disability grant, of which the OT was mindful. It allows one access to free health care and free assistive devices. It provides people with disabilities other advantages such as dial-a-ride and tax benefits. It is also an easy way of proving a disability when applying for employment in terms of employment equity requirements. Thus she reported that she considered all these factors in her assessment and decision-making.

The OT found that a disability grant assessment can be an emotionally difficult decision. Even though the OT is not the final decision maker, she was very mindful of the effect the outcome of the work assessment will have on the applicant. OT: *"And knowing that a lot of the people that we think shouldn't qualify for disability grant are probably not going to find work. That is hard too."* She was acutely aware of the applicants' expectations of a grant and their despair when the outcome was negative. The decision was particularly difficult when there were complicating factors or if the person was borderline and the decision could go either way.

The OT says that they are completely transparent with the applicant about the outcome of the assessment. The outcome of the assessment is explained to the applicant and they are counselled as to appropriate types of work and training where applicable. Unlike the doctors, she was not concerned about or influenced by intimidation.

Audiologists

Audio 1: "Because what is happening it is very inconsistently applied. If you go to one of our ENTs who is part-timer and works privately and likes to think he has got a big social conscience, you are going to get a DG whether you merit one or not on the grounds of hearing loss or anything else. You'll get it on social grounds. Now that is not our understanding of how disability grants work. So it is extremely inconsistent and there isn't any uniformity in how the system is applied. And as I say I think also folks I'm sure get them without even having had a basic hearing test. I am quite convinced that they do and I also do have kind of problems with that as well. In terms of how do you draw a line with regards to what is disabling or not in terms of a hearing loss?"

Audio 1: "So what I suspect is patients go to day hospitals. Doctor in the day hospital dishes out the form and the grant and they never actually get as far as a form and an assessment. Because we certainly, in this instance we would not have recommended or supported a DG application because the patient clearly doesn't warrant it."

Once again, inconsistency in the process, and a lack of knowledge of the process were central themes around the topic of decision-making criteria.

Audiologist 1 (at the tertiary hospital) reported that they have been given no guidelines or training from Social Services. As a result they have instituted their own in-house procedure. Audio: *"It is difficult in that we never get a clear directive from the Department of Health in terms of what the procedure should be. So we have our own in-house procedure"*. Applicants coming to the hospital's Audiology department have a hearing test and are fitted with a hearing aid if appropriate. They are then referred to the OTs at work assessment for a functional assessment. The doctor then makes the final decision based on the OT's and audiologist's recommendations. However, the doctors do not necessarily rely on the OT's or audiologist's recommendations, and ultimately the decision rests with the doctor. As a result, decisions are inconsistent and an applicant may get different decisions depending on the doctor responsible.

Also, not all applicants go through Audiology and OT at the tertiary hospitals, but can go through the Deaf organization or directly to the doctors at the day hospitals. Thus some Deaf applicants are awarded grants by the doctors at the day hospitals but the same applicants would probably have been declined had they gone through a tertiary hospital.

Audiologist 2 (at the Deaf organization) also reported that she did not receive any training or guidelines from Social Services. She was not aware of the disability grant procedure. She merely did an Audiology assessment of

Deaf applicants, who then took the assessment with them to the doctors. The audiologist received no feedback as to the outcome of the doctors' decision.

Despite more than 20-year experience in the job, audiologist 1 reported that she had had no communication with Social Services. They had received no guidelines or training from Social Services and had not even seen the current disability grant medical assessment form (white form). She was uncertain of how the disability grant application process works and did not know anything about the appeal process. Both audiologists reported that they would like to get a copy of the guidelines from Social Service and reported that they would appreciate future contacts and updates from them.

Summary / Discussion

The Deaf adults, doctors and health professionals all highlighted the human element of inconsistency in the decision-making process. Eligibility for a disability grant is no longer decided by a central group of doctors (Pensions medical officers), but by the medical doctors who actually assesses the applicant. This has some advantages because the doctor making the decision actually assesses the applicant. However, it also brings in a human element of inconsistency as each doctor may make different decisions.

None of the doctors received any training from Social Services. The guidelines for decision-making for disability grants had not been distributed to

all of the doctors involved. Of those doctors who have received the guidelines, not everybody interprets the decision-making criteria the same way. The guidelines are quite subjective and open to different interpretations. Some consider the guidelines to be impairment-based and make their decisions accordingly, trying to disregard social factors. Others interpret “*consider the global picture*” in the guidelines to mean that social factors should be considered.

It is not clear whether current economic realities like unemployment rates and work availability in a given area are taken into consideration when deciding on disability grant qualification. The current South African guidelines say that “*only an applicant who as a result of impairment is unable to work is eligible for a grant*” (Department of Social Services and Poverty Alleviation, 2004). “*Those who cannot find work because of unemployment*” would not qualify for a grant according to the guidelines. It is difficult to separate the effects of the impairment, the effects of discrimination, and the effects of the socio-economic situation on the employment of any given person. This is a debatable issue and proved to be a contentious point for the doctors as it greatly complicated their decision-making. Interestingly, Canada’s assessment for social security funding for people with disabilities clearly states that economic conditions such as unemployment rate and work availability are not to be taken into consideration.

In the guidelines [see appendix E for guidelines in full], section B6 addresses the issue of communication. While titling the section 'communication', it is only Deafness which is discussed. It is also interesting to note that the guidelines make no reference to other communication impairments such as aphasia and dysarthria, which may also limit a person's ability to compete in the open market. It is not clear whether the 'global picture' referred to is intended to apply to social factors.

B6. Communication

"Deafness: If a patient lacks effective communication skills with people other than family members, consideration is given for a grant. Consider communication skills, hearing aid and global picture. Look at whole patient. Language barriers are not a reason for disability."

The doctors themselves were acutely aware of the inconsistency in decision-making amongst themselves, recognizing that the same person would get different decisions if they went to different doctors. Several doctors commented that the process was 'unfair'. The OT and audiologists were also very aware of the inconsistency. The Deaf adults and social development workers were particularly exasperated at the inconsistency and perceived unfairness in the process. They felt powerless in the system.

The social development workers emphasized that there was not just inconsistency in deciding whether a grant was approved or not, but also in deciding the length of the grant. This was particularly problematic for Deaf people as they often had difficulties understanding the letter of approval and sometimes did not realize that the grant was only temporary.

University of Cape Town

CONCLUSION

The study concluded that Deaf adults tend to play a passive role within the application process. They are nearly always accompanied by an escort during the application process. The escort does not seem to act as an interpreter but rather as a representative on their behalf. While the escort does seem to facilitate the process, it is at the cost of the Deaf adult's independence. The Deaf adults reported communication difficulties at all stages of the application process. However, the doctors did not report the same level of communication difficulty and were content to communicate with the escorts. The key role-players revealed different perspectives regarding Deafness and disability. All the doctors viewed Deaf people as disabled, but their reasons for this differed. Most of the doctors were influenced by a medical model understanding of disability and Deafness, while the Deaf adults were more influenced by the social model of disability and linguistic / cultural model of Deafness. The tension between the different models of disability could also be seen in the differences of interpretation and implementation of the disability grant assessment forms and guidelines. The doctors had the main role of decision makers, but sometimes considered recommendations made by other health professionals. Due to lack of training and differences in interpretation of guidelines, decision-making is very inconsistent, and different doctors are likely to make different decisions for the same applicant.

LIMITATIONS OF THE STUDY

This study was exploratory in nature and aimed only to make preliminary investigation into disability grants for Deaf adults. This is a new area of research, and no previous studies on disability grants for Deaf adults could be found. As such this study aimed to provide insight into this new area and open the way for more in-depth research to follow (Durrhiem, 1999). This research was based on interviews of the key role-players in the disability grant processes. Because of the limited nature and purpose of the research, sample sizes were small and no other data collection modalities were utilized. Future research may benefit from a triangulation of data collection modalities. The scope of the study was limited, only addressing the research objectives. Other areas of interest around the topic of disability grants for Deaf people could be of importance if the topic were probed more openly.

The researcher had limited time available to complete the research study. This affected the nature of the data collection. The researcher was unable to follow the Deaf applicants through the application and review processes, thus interviews on the role-player's experiences were more feasible. The Deaf participants had applied for disability grants at different times over the last 20 years. During this time the social security system in South Africa has undergone much change. Thus the Deaf participants were of different ages (ranging between 32 and 63 years of age) and had

experienced different application and review procedures over the years. Some of the applicants have had to apply for grants several times over the years as their grants were reviewed. The participants were not certain how often grants were reviewed and reported that reviews were inconsistent. The participants were asked to describe their experiences related to disability grants and were not followed through the process for any length of time. It is difficult, therefore, to get an accurate picture of Deaf adult's experiences of the current/latest disability grant procedures.

This study targeted only one specific sub-section of the Deaf population in Cape Town. The researcher was particularly interested in the subsection of the Deaf population that actively participates within the Deaf community organization. Participants were purposefully sampled to provide value and insight to the research topic (Strydom & Delport, 2002). Participants were not randomly sampled and do not accurately represent the whole Deaf population in Cape Town. The findings of this research, therefore, cannot be simply generalized to *all* Deaf people in Cape Town.

The research was conducted by a novice researcher. The researcher conducted all the interviews. While the pilot study helped to refine the researcher's interview skills, the researcher's interview style and skills also changed over the course of the interviews. The researcher also gained information during the earlier interviews which was then included in

discussion points in the later interviews. Thus the interviews with the Deaf participants did not include all the relevant topics addressed with the health professionals, e.g. transparency of assessment results.

The interviews with the Deaf participants proved to be challenging. The researcher is not fluent in SASL; therefore an interpreter was used in the interviews. There were frequent communication breakdowns where the Deaf participant did not fully understand the question asked and responded inappropriately. The interpreter then rephrased the question until it was understood. This rephrasing sometimes subtly changed the meaning of the question and influenced the responses. Many of the questions asked in the interviews were theoretical or abstract in nature. The Deaf participants had a lot of difficulty understanding these questions, and they often needed to be rephrased and explained. This difficulty may have been due to difficulties interpreting the questions into SASL or may have been due to the Deaf participant's lack of exposure to the theoretical arguments. Because of these challenges experienced with the Deaf participants the depth of data collected was reduced. It was difficult to get in-depth data as much of the interview was spent on rephrasing and explaining questions.

Due to the non-availability of the participants (the health professionals and clerks had time constraints and many of the Deaf participants were difficult to contact again), the researcher was able to do member checking of

the results with only three of the participants (both SDWs and Deaf 2). Ideally to improve trustworthiness of the findings, member checking should be done with all of the different role-players.

This research study was originated and conducted by a hearing researcher. While Deaf adults were given the opportunity act as participants, no Deaf people were involved in the implementation or planning of the research. This does not meet the principals of emancipatory research. Emancipatory research aims to shed light on the social conditions, structures and processes which create disability, and to create a working dialogue between the researchers and the disabled communities. Traditional research has been heavily criticised by the disabled community for perpetuating the oppression of the disabled by individualising disability and creating the 'expert' researcher and the disabled 'victim'. These power relations between researcher and participants are particularly important in South Africa with its sensitive history of inequalities (Rabe, 2003). This makes it difficult for health professionals to find a place in relation to disabled people and the social model (Bricher, 2000). However, Barnes (2001) argues that it is important for researchers to place their skills at the disposal of disabled people and that one does not necessarily have to be disabled to do that. It is recommended that Deaf people are more involved in the planning and implementation of further research in this area.

IMPLICATIONS OF THE STUDY

This study was an exploratory study into an under-researched area. As such, while some practical implications are addressed, many of the recommendations are for further research.

Provision of Trained SASL Interpreters

Communication difficulties were described by the Deaf adults throughout the disability grant application process. As a result the Deaf Adults were nearly always accompanied by an escort. None of the Deaf adults used trained interpreters – instead they relied on friends, family members and prominent members of the Deaf community who had better speech communication. This resulted in a lack of privacy and a lack of independence for the Deaf adult. The communication difficulties described in this study has highlighted the need for trained SASL interpreters to be available within the disability grant process. Trained interpreters have been shown to save time and improve mutual understanding between Deaf patients and hearing health care staff (Heap et al, 2005). Reeves & Kokoruwe (2005), in their survey of access to primary health care for Deaf adults, found that nearly two-thirds of the Deaf patients who preferred support preferred the provision of a professional sign language interpreter over a family member or friend. They recommended that sign language interpreters should be routinely available at health care settings for those who desire it. Sign

language interpreters need to be trained professionals in order to deliver an accurate, professional and confidential service to the Deaf client.

As Deaf adults form such a small portion of the disability grant applicants, it would be impractical to have SASL interpreters available at every primary care clinic and social service district offices. Instead SASL interpreters could be available at a central point (perhaps a Deaf community organisation?), and could accompany the Deaf applicant to the various places by appointment. In some ways this is similar to the services provided by the social development workers at the participating Deaf community organisation. However, the SDWs are not trained interpreters and cannot perform the same level of service. They cannot always accompany the Deaf adult to the various places due to the time constraints of their job. They accompany the Deaf adult and tend to act more as a representative than an interpreter. Provision of professional trained interpreters would also provide an aspect of privacy, respect and empowerment to the Deaf adults within the disability grant system. Improved mutual understanding between professional staff and the Deaf applicants could also result in more appropriate, informed decisions regarding eligibility for disability grants. However, there is a severe shortage of SASL interpreters in South Africa (Heap, et al, 2005).

Watson, Fourie & Andrews (2006) highlighted some important factors for disability assessment in the South African context. They suggested that

the person being assessed should get a chance to "tell their story". The Deaf adults in this study got, due to communication difficulties, very little chance to represent themselves adequately in their disability grant assessment. Perhaps the provision of SASL interpreters would provide them with that opportunity.

There is insufficient provision for trained interpreters for any of the official languages at many of the primary health care clinics and Social Services local district offices. SASL users are one of several language and cultural groups at a disadvantage in terms of disability grant applications. While SASL is not recognised as one of South Africa's official languages, it enjoys some recognition under various disability charters and legislation. The Disability Rights Charter of South Africa (1992) article 14 on communication demands that *"disabled people shall have the right to communicate freely and measures to ensure the full enjoyment of this right shall include the ... recognitions and use of sign language for people with hearing and/or speech difficulties..."*. The Constitution of South Africa (Act 108, of 1996) provides the right of access to health care and freedom from discrimination on the basis of a number of grounds, including disability and language. The UN Standard Rules for the Equalisation of Opportunities for Persons with Disabilities (1993), of which South Africa is a signatory, further requires that States *"ensure the provision of assistive devices and equipment, personal assistance and interpreter services, according to the needs of persons with*

disabilities, as important measures to achieve the equalisation of opportunities" (Rule 4.1). These charters provide strong impetus for South Africa to recognise, respect and provide for the needs of Deaf people through the availability of sign language interpreters.

A longitudinal study of Deaf adults applying for disability grants with and without the use of a SASL interpreter would provide greater insight into its effectiveness of interpreters. The use of participant observation as well as interviews could also provide greater understanding of the practical workings of disability grant application. A study to determine the cost-effectiveness of interpreters would also be beneficial in motivating the availability of SASL interpreters at disability grant application processes. This needs to be examined in the light of reduced costs due to more time-efficient consultations with medical professionals and Department of Social Service staff.

Training and Guidance for Decision-Makers

The personnel involved in assessing eligibility for disability grants need to have more training and guidance in how to interpret and implement the eligibility criteria. The disability grant assessment tool needs to be reviewed, with input from the various disability organizations (including organizations of the Deaf). Consensus needs to be reached on interpreting and using the assessment tool. This would help to reduce the inconsistency between doctors in decision-making. Further training is also necessary to acquaint the

decision-makers with the social model of disability and its application to disability grants. Training should cover the assessment of less-visible disabilities such as Deafness, communication problems and traumatic brain injury. Research is also needed to determine if such training improves decision-making consistency.

Introducing Assessment Panels

While there is legislation paving the way for assessment panels [Regulation 24a of the Social Assistance Act no 59 of 1992, amended with effect from December 2001], medical officers are still the sole decision-makers in the Western Cape. It was hoped that assessment panels would solve several difficulties encountered by the medical officers. One of these difficulties was in identifying and assessing applicants with less-visible disabilities such as Deafness, aphasia, head injury etc. It was hoped that a panel comprising people with different backgrounds and expertise would be able to conduct a more thorough assessment. It was also hoped that a panel of assessors would provide more reliability to the assessments, which were reported by all of the participants in this study to be extremely inconsistent. The practicality and effectiveness of assessment panels to meet these and other goals (such as reducing corruption) needs to be assessed in the three provinces in which they have been implemented; and recommendations for the Western Cape and South Africa as a whole made accordingly.

Formally Recognise the Role of the Social Development Workers

This study has highlighted the important role that the Social Development Workers have played in the in the disability grant application and review processes for Deaf adults. The SDWs helped to bridge the communication gap between the Deaf adults and the other role-players in the disability grant processes. Many of the Deaf adults reported that the SDWs were essential, and they would not have been able to successfully complete the application process without them. The health professionals and Social Services clerks also commented on the important role played by the Deaf person's escort (often a SDW). Despite this informal recognition by all the role-players, the role of the SDWs was not formally recognized. The SDWs did not receive any information or training by the Department of Social Development. They were also unable to make appointments with Social Services or the doctors performing the disability grant assessments and had to wait hours in long cues when accompanying Deaf applicants. The effectiveness of the services provided by the Deaf organization (in the form of SDWs) could be greatly improved if the SDWs were formally recognized and received updated information and training from the Department of Social Services. If the SDWs were able to make appointments with Social Services and the doctors performing the disability grant assessments, this would also greatly improve the efficiency of their services.

Reduce Disabling Barriers in Society

In the current South African context, jobs are scarce in the country as a whole (Swartz & Schneider, 2006) and disability grants form an important life-line to disabled people. However, according to the social model, disability grants are not the only way of addressing long term economic hardship associated with disability. The social model considers disability to be a fluid, changing category. Thus, according to the social model the prevalence of disability can be increased or decreased by changing the environment (Swartz & Schneider, 2006). Environment changes could be physical or attitudinal or both. Thus if a Deaf person is considered to be disabled in one context, (due to educational, vocational and attitudinal barriers) he/she may be considered non-disabled in another context if these barriers are removed. Thus the long term implications of the social model are that changes should be environmental (such as providing skills and jobs) rather than providing disability grants, i.e. to reduce barriers that are disabling the Deaf person. Specific barriers identified in this study include: inadequate education, inadequate skills training, communication barriers, and attitudinal barriers. The state needs to consider channelling funds not only into providing disability grants, but also into reducing disabling barriers.

'Nothing About Us Without Us!'

The South African government has aligned itself with the social model of disability. In accordance with the implementation of this model, the current

disability grant processes have been the subject of much recent debate and have undergone many changes. It is important that the Deaf community and disabled community play an active role in these debates and decisions affecting their communities. Organizations of Deaf people have an important role at this crucial time in helping to create a 'barrier-free society'. *'Disabled people have the right to represent themselves in all matters that affect them in any way'* (SAHRC, 2002: 15). Therefore, the results of this study will be disseminated to the various Deaf and disability organizations for their consideration. This will include: DPSA, HSRC, DCCT, and DEAFSA.

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APPENDIX A: Disability Grant Assessment Form

PROVINCIAL ADMINISTRATION: WESTERN CAPE DEPARTMENT OF SOCIAL SERVICES AND POVERTY ALLEVIATION

MEDICAL REPORT: GRANT FOR DISABLED PERSON

First-Application

Re-application

Official Stamp
Date

A. PERSONAL DETAILS

- A1. ID Number _____
Surname _____ Full Names _____
Address _____
- A2. Highest level of education completed _____
- A3. Current Occupation _____ Previous Occupation _____
Date last employed _____ Where _____
- A4. Complaint/s as declared by applicant _____

A5. DECLARATION BY APPLICANT

I understand that the processing of this application may require that medical information concerning myself be made available to various staff members within the Departments of Health and Social Services. I hereby declare that I have no objection to disclosure of such information to the relevant officials.

APPLICANT SIGNATURE DATE

WITNESS SIGNATURE DATE

B. MEDICAL DETAILS

B1.

HEIGHT		DOMINANCE	
WEIGHT		BLOOD PRESSURE	

B2. FULL CLINICAL DETAILS TO SUPPORT ALL DIAGNOSES AND PROGNOSSES

Diagnoses	1.	2.	3.
Current Medical Treatment			
Stabilized	Yes No	Yes No	Yes No
Further management: (investigations, referrals to specialists work assessment, rehabilitation & specify facility where referred to)			
Medical prognoses (time expected till medically stabilized)			
Work prognoses: (Ability to work once medically stabilized)			

NOTE: Prior to referral to work assessment patient should have been diagnosed, medically stabilized and referred to rehabilitation including for issuing of assistive devices.

B3. CARDIO/RESPIRATORY FUNCTIONING

B3.1 Respiratory

What causes Dyspnoea? _____

Grade 1 Keeps up with peers on level not incline

Grade 2 (a) Unable to keep up with peers on level 1 km own pace

Grade 2 (b) Unable to keep up with peers on level 500m own pace

Grade 3 Breathless after walking a 100 meters

Grade 4 Breathless at rest

B3.2 Tuberculosis (consider 6 months if respiratory compromised)

B3.3 Smoker

YES	NO
-----	----

B4. DIABETES (*also refer to B2)

Target organ Involvement _____

B5. VISUAL ACUITY (Snellen Chart)

With Spectacles	Left	
	Right	

Without Spectacles	Left	
	Right	

B6. COMMUNICATION (hearing and speech impairment)

B6.1 Specify:

B6.2 Ability to communicate with people other than family members

YES	WITH DIFFICULTY	NO
-----	-----------------	----

Note: Consider referral for hearing aid or rehabilitative measures.

B7. EPILEPSY: (Also refer to B2.)

B7.1 Frequency per month: _____

B7.2 Collateral history:

B8. PSYCHIATRIC ILLNESS

(See Annexure A in guidelines)

Diagnosis:

B9. INTELLECTUAL DISABILITY (See Annexure B of Guideline)

Profound M.R. – IQ below 20 – 25 mental age below 3 years

☐

Sever M.R. – IQ 20 – 25 + 30 – 35, mental age 3 – 5 years

☐

Moderate M.R. – IQ 35 – 40 + 45 – 50 mental age 3 – 5 years

☐

Mild M.R. – IQ 50 – 70 mental age 7,5 – 10 years

☐**B10. COGNITIVE****B10.1 Orientation:** Time ☐ Y ☐ NPlace ☐ Y ☐ NPerson ☐ Y ☐ N**B10.2 Memory:** Short term ☐ Y ☐ NLong term ☐ Y ☐ N**B10.3 Concentration** ☐ Y ☐ N**Aggression** ☐ Y ☐ N**B11. CHRONIC CONDITIONS (consider specialist opinion)**

(I) Malignancies

(II) HIV/AIDS

B12. NEUROMUSCULAR / MUSCULO - SKELETAL**B12.1 Muscle Strength (Residual strength out of 5)**

ARMS	Left	
	Right	

LEGS	Left	
	Right	

B12.2 Muscle Tone

Upper limb	R	↑	N	↓	Lower limb	R	↑	N	↓
	L	↑	N	↓		L	↑	N	↓

B12.3 Co-ordination

C. ADDITIONAL INFORMATION***As determined by history and confirmed by selective examination.****C1. MOBILITY****C1.1 Independent** ☐ YES ☐ NO**C1.2 Assistive device/s: Indicate requires/uses**

Prosthesis	Requires
	Uses
Ankle foot	Requires
Ortosis	Uses

Walking	Requires
Frame	Uses
Wheelchair	Requires
	Uses

Crutches	Requires
	Uses
Boot/shoe	Requires
raise	Uses

C1.3 Patient can:

Crouch	Yes	No
Bend	Yes	No

Climb stairs	Yes	No
Tandem walk	Yes	No

C1.4 Use of Public Transport

	Taxi	Train	Bus	Motorcar	Pedestrian
Dependent					
Independent					
With escort					

C.2 PERSONAL CARE

Task	Dependent	Independent
Able to wash upper body		
Able to wash lower body		
Able to dress upper body		
Able to dress lower body		
Able to tie shoelaces		
Able to wash and brush hair		

D. RECOMMENDATION

D.1. Referred for specialist opinion?

Yes	No
-----	----

 Date of appointment

D.2. Name of Department and/or Institution referred to: _____

D.3. Grant to be administered by self

Yes	No
-----	----

 See note in guideline.

D.4. Disability

PERMANENT		TEMPORARY	6 months	7 months	8 months	9 months	10 months	11 months	12 months
DOES NOT QUALIFY									

If not qualify, give reason: _____

NAME OF MEDICAL OFFICER (in print): _____

REGISTRATION/PRACTICE NO: _____

SIGNATURE: _____

DATE: _____

OFFICIAL STAMP OF
FACILITY

DECLARATION:

1. I, the above-signed Medical Officer declare that the patient appeared before me and was examined.
2. All particulars furnished by me in this application are true and correct.
3. I realize that a false declaration will be regarded as an offence and is punishable.

APPENDIX B:
Interview Schedules
Deaf Adults

Age

DG application process

Have you applied for a DG before?

Tell me about what happened?

What difficulties did you experience?

How do you manage these difficulties?

What factors help to facilitate the process?

How could the process be improved?

Have you been to OT work assessment?

DG appeal process

Have you ever appealed the DG application?

What did this involve?

What was the result?

DG Review Process

How often does your DG get reviewed?

What does this involve?

Medical Assessment

Did you talk with the doctor?

How did you communicate with the doctor?

Did he/she examine you?

Did you have a hearing test?

Where?

Which clinic did you go to?

What clinic do you normally go to if you are ill?

Did anyone come to the clinic with you?

Communication

How did you manage communication with the doctor?

At social services?

What difficulties did you encounter?

How did you manage these?

What helped?

Personal

When did you become Deaf?

What school did you go to?

Are you married?

Is your husband / wife also Deaf?

Is he/she on a DG?

Work / Money

Why did you apply for a DG?

Are you working?

What work do you do?

Why not?

Have you worked before?

Why do you not have a job?

Poor skills?

Difficulty communicatin?

Lack of opportunity?

How much is the DG?

What is the money used for?

Is it enough?

Attitudes

Do you think all Deaf people should qualify for a DG?

Why / Why not?

Do you view Deaf people as disabled?

Do you have any further comments?

Medical Doctors

How long have you been involved with DGs?

Which hospitals do you service?

Have you had any experience with DGs for Deaf people?

Tell me about it

What is your role in the process?

Do you have any difficulties?

How do you manage these?

What facilitates / helps the process?

How do you communicate with Deaf applicants?

Who makes the final decision?

What is your decision-making criteria?

Do you have any difficulty making decisions?

Do you require an Audiology report?

Do you consider: previous work history?

Education and skills?

Signing vs. Oral Deafness?

Congenital vs. acquired Deafness?

Do you ever refer to Work assessment with the OTs?

Who?

When / why?

Do you usually take their recommendations?

Are you involved with the appeal process?

Review process?

How could the DG process be improved?

Should all Deaf people qualify for a DG?

Do you view Deaf people as disabled?

Do you have any further comments?

Social Services Officers

Welcome and thanks

Application Process

How does a Deaf person apply for a disability grant? What is the process?

Who is eligible for a disability grant? / What criteria must be met to be eligible for a disability grant?

Who makes the decision to approve the disability grant?

What is your role in the application process?

What difficulties arise in the process?

How do you deal with them?

Do you have any difficulties in communicating with the applicant?

Do you ever use an interpreter? Who? Does it help?

How could these be improved?

What facilitates the process?

How could these be expanded?

How much does the disability grant pay?

Appeal Process

How does the appeal process work?

Who is involved?

What is your role?

Maintenance and Review Process

How does the maintenance / review process work?

What is your role?

What challenges arise?

Do you have any suggestions how it could be improved?

Attitudes

Do you think all Deaf people should qualify for a disability grant? Why / why not?

Do you view Deaf people as disabled?

Do you have any further comments?

Social Development Workers

Welcome and thanks

Application and appeal process

How does a Deaf person apply for a disability grant? What is the process?

What is your role in the process?

What happens if the disability grant is approved?

What happens if the disability grant is rejected?

Are you involved in the appeal process?

Who is eligible for a disability grant? / What are the decision criteria?

Do you make any decisions about who is approved for a disability grant?

Who makes the final decision?

What difficulties arise in the application process?

How do you deal with them?

What factors facilitate the process?

Do you have any suggestions how these can be improved?

Maintenance and Review

How does the review / maintenance process work?

How are you involved?

What difficulties / challenges arise?

How could these best be addressed?

Attitudes

Do you think all Deaf people should qualify for a disability grant? Why / why not?

Do you view Deaf people as disabled?

Do you have any further comments?

Audiologists

Which hospitals do you service?

Have you had any involvement with disability grants for Deaf adults?

Describe?

How long have you been involved with DGs?

What is your role in the process?

Do you have any communication difficulties?

How do you manage these?

What facilitates / helps the process?

How do you communicate with Deaf applicants?

Who makes the final decision?

What is your decision-making criteria?

Do you have any difficulty making decisions?

How does the audiological assessment influence your decision / recommendations?

Do you ever refer to Work assessment with the OTs?

Who?

When / why?

Are you involved with the appeal process?

Review process?

How could the DG process be improved?

Should all Deaf people qualify for a DG?

Do you view Deaf people as disabled?

Do you have any further comments?

Occupational Therapist

How long have you been working here?

What do you do here at work assessment?

What would you do if a Deaf person was referred to work assessment, what is the process that they would go through?

How many Deaf adults do you see here at work assessment?

Are they mainly Deaf people who use sign language or people with acquired hearing loss?

Who refers applicants to work assessment?

Do you make any further referrals?

When you have completed your assessment, what happens next in terms of decision-making? Who makes the final decision?

On what criteria do you base your recommendations - specifically for a Deaf person?

Do you assess their ability to work or do you also consider their ability to get employment?

Do you have any difficulties communicating with the Deaf applicant?

What do you do to accommodate these difficulties?

Do you have any experience with the disability grant appeal process?

Who sits on the disability panel?

Do you have any problems with fraud? Explain.

How could the disability grant process be improved?

This process is specific to the Western Cape, is it different in other provinces?

Do you view Deaf people as disabled?

Do you think all Deaf people should qualify for a disability grants?

APPENDIX C
Ethics Committee Approval

UNIVERSITY OF CAPE TOWN



Research Ethics Committee
E53 Room 44.1, Old Main Building
Groote Schuur Hospital, Observatory,
7925
Queries : Xolile Fula
Tel : (021) 406-6492 Fax: 406-6411
E-mail : Xfula@curie.uct.ac.za

11 November 2004

REC REF: 398/2004

Miss C Mestern
Communication Sciences & Disorders

Dear Miss Mestern

THE APPLICATION, APPEAL, REVIEW AND MAINTENANCE PROCESSES OF DISABILITY
GRANTS FOR DEAF ADULTS

Thank you for submitting your study to the Research Ethics Committee for review.

It is a pleasure to inform you that the Research Ethics Committee has formally approved the above mentioned study.

Please quote the REC. REF in all your correspondence

Yours sincerely

PROF. T. ZABOW
CHAIRPERSON

APPENDIX D:
Consent Form / Information Sheet

UNIVERSITY OF CAPE TOWN



School of Health & Rehabilitation Sciences

Divisions of Communication Sciences & Disorders · Nursing & Midwifery
Nutrition & Dietetics · Occupational Therapy · Physiotherapy

Consent Form

Old Main Building · Groote Schuur Hospital · Observatory · 7926
Telephone: +27 21 4066401
Fax: +27 21 4066323

I am doing this research in partial fulfilment of my MSc degree. The purpose of this study is to explore the issues of disability grants for Deaf adults in the Western Cape. Interviews will be held with the key role players including: Deaf adults, medical doctors, social services officers and social development workers. Each interview is expected to last 30 - 60 minutes.

You will remain anonymous, and the personal information you supply will remain confidential. Your name and contact details are merely for the purpose of contacting you and will be destroyed once the data has been collected and you have received a report of the results. As a participant in the study you have the right to access your own records. Participation is voluntary and you have the right to withdraw from the study at any time.

Possible benefits of the study include improved knowledge around the issue of disability grants, which could lead to improvements in the disability grant application and review process. There are no personal benefits for participating in the study and there are no expected risks. No reimbursement will be provided for participating in the study, but transport costs will be provided.

Contact Details of the Researcher

Name: Carol Mestern

Tel: 021 715-9429 or 084-505-5678

Email: mstcar002@mail.uct.ac.za

Supervisor: Harsha Kathard

Tel: 021-406-6593

Email: hkathard@uctgsh1.uct.ac.za

I have been given the opportunity to ask any questions and have them answered.

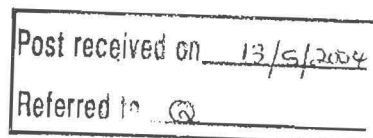
I hereby agree to participate in the study.

Name: _____

Signed: _____ Date: _____

APPENDIX E

Disability Grant Guidelines



Verwysing
Reference
Isalathiso

16/2/3

Navrae
Enquiries
Imibuzo

Telefoon
Telephone
Ifowuni

(021) 483-5004

Departement van Maatskaplike Dienste en Armoedeverligting
Department of Social Services and Poverty Alleviation
ISebe leeNkonzo zeNtlalo noNciphiso IwenNdlala



**TO: ALL OFFICE MANAGERS
ALL OPERATIONAL MANAGERS
ALL DIVISIONAL HEADS: SOCIAL SECURITY**

IMPLEMENTATION OF NEW MEDICAL ASSESSMENT FORM

1. BACKGROUND

Since December 2001 a steep increase in the awarding of disability grants occurred in the Western Cape Province. The rapid increase in the awarding of disability grants could be ascribed to the following factors:

- The Pension Medical Officer, who was responsible for the determination of disability and medical classification, has been abolished.
- Lack of uniform assessment tools and criteria.
- Lack of training for Medical Officers.
- A lack of monitoring mechanism to identify problem areas.
- Reviews in accordance with the current legislation.

2. ROLE OF "PENSION MEDICAL OFFICER"

From 1 December 2001 the Department retained the services of the medical pension officers to assist with the interpretation of medical reports completed by medical officers. The procedures in respect of this are the following.

- If the district office is unable to interpret the classification on the medical report, the report is then referred to the "pension medical officer" who interprets the information and provides the interpreted information to the district office to capture the information.
- In cases where the "pension medical officer" has reservation about a specific case, he/she may:
 - Inform the medical officer who completed the report in writing about his/her reservations;

14 Queen Victoria Road
Private Bag X9112
CAPE TOWN 8000
SOUTH AFRICA
FAX 27 21 - 483 5041

Queen Victoria Straat 14
Privaatsak X9112
KAAPSTAD 8000
SUID AFRIKA
FAKS 27 21 - 483 5041

2

Request officials from the Department to submit the medical report with the report of the "medical pension officer" to the medical officer; or

Request the medical officer to submit additional clinical information or specialist medical reports to clarify findings.

If the person according to the opinion of the medical officer does not qualify for a grant, then he/she must give reasons why the person does not qualify for the grant.

In the above procedure the "pension medical officer" is not allowed to make a classification or reject an application for a DG or CD.

3. IMPLEMENTATION OF NEW ASSESSMENT TOOL

In the Western Cape a medical assessment tool was developed in consultation with the Department of Health. Due to the problems/shortcomings of the current medical form (VR-T3) it has now been decided that the new assessment tool must be implemented at all the District Offices as from the 1 June 2004. The tool was already implemented at some of the District Offices.

It is also important that better control measures must be exercised with the issuing of the medical assessment forms. When District Offices print the forms it must be ensured that each District Office include on the form a unique identification, which must consist of an alphanumeric code (e.g. Wymb. that must then be followed a serial number starting from 1). A register must also be implemented to indicate to which person a specific medical assessment form was issued. The person must then signed that, the specific form was issued to him/her. The register must consist of the following headings:

- Numerical number of medical assessment form
- Name(s) of applicant
- Surname of applicant
- Identity number of applicant
- Address of applicant
- Signature of applicant
- Name and Surname of official who issued the form

Prior to the implementation of the new assessment tool District Office Staff must provide training to all the medical officers who are responsible for the completion of the medical assessment tool. The guidelines applicable to the new assessment tool must also be discussed with the medical officers who are responsible for the completion of the medical assessment tool.

Continued orientation in the use of the tool is required. Head Office will negotiate with the Department of Health that the previous medical pension officers be utilized for medical aspects/purposes. Officers from the District Offices of the Department of Social Services and Poverty Alleviation must provide training on the administrative processes.

On a quarterly basis District Offices must obtain a list of names and Health Professional Council registrations of all medical officers at the health facilities who are responsible for the medical assessments of applicants.

4. COLLECTION OF MEDICAL ASSESSMENT FORMS

In order to minimize alleged fraud and to protect medical staff a proper procedure for handing out (SEE PARAGRAPH 3) and collection of assessment forms is of the utmost importance. All District Offices must make the necessary arrangements with the health facilities in their respective areas for the collection of the completed medical reports. A pro-forma letter which must be given to the applicant after the medical officer have completed the medical report, as proof that the applicant was medically assessed by a medical officer, is attached in this regard.

5. PROCESS AND PROCEDURE FOR GRANTS FOR THE DISABLED AND CARE DEPENDENCY

The current policy is that a person can only re-apply for the award of a disability grant once the current disability grant has lapsed.

Medical assessments could only be done once the existing medical coverage has expired. A re-application for a grant for the disabled and care dependency grant can only be completed after the current grant has lapsed. Eg. Only if temporary medical coverage of six up to twelve months has expired. A social assistance application can only be taken down once a medical certificate was completed.

Invariably this cause the beneficiary to suffer financial hardship because the grant lapse and is only restored after the medical assessment (which is subject to long waiting periods) and re-/new application process is completed. It is thus of the utmost importance that these re-applications must be processed as soon as possible on SOCPEN. Social relief of distress may be awarded but must be deducted from the grant once the re-application was processed on SOCPEN.

6. NEW ASSESSMENT MODEL

An interdepartmental task team consisting of officials from the Departments of Social Services and Poverty Alleviation and Health was established. The purpose of the task team is to design a new assessment model for grants for the disabled and care dependency for the Western Cape Province. Whilst the task team is busy with its investigation, it is of the utmost importance that the above-mentioned measures be implemented by all the District Offices of the Department of Social services and Poverty Alleviation.

7. DOCUMENTS AND FORMS APPLICABLE

Attached, please find the following:

- New medical assessment form;
- Guidelines for grant for the disabled applications and

- Pro-forma letter that must be issued to applicants for grants for the disabled and care dependency

8. If any clarity is required, please feel free to contact me. Kindly acknowledge receipt of this letter.

Yours faithfully,



Director: Social Security and Disaster Relief

Date: 6/5/04.

University of Cape Town

PROVINCIAL ADMINISTRATION: WESTERN CAPE

GUIDELINES FOR DISABILITY GRANT APPLICATIONS

FOR ATTENTION: ALL HEALTH PROFESSIONALS

GENERAL INFORMATION

1. Social Assistance Act, No. 59 of 1992

A disabled person is any person who has attained the prescribed age of 18 and is owing to his or her physical or mental disability unfit to obtain by any virtue of any service, employment or profession the means needed to enable him or her to provide for his or her maintenance.

2. Amended regulation pertaining to above Act – 1 December 2001

He or she is a disabled person who has attained the age of 18 years and whose disability is confirmed by a medical report of a Medical Officer or by a report from an assessment panel: Provided that such shall only be valid for a period of three (3) months from the date of assessment: Provided further that the assessment has confirmed whether the disability is-

- I. Permanent in that the disability will continue for more than 12 months; or
- II. Temporary in that the disability will continue for a continuous period of not less than six (6) months or for a continuous period of not more than twelve (12) months, as the case may be.

3. A grant for the disabled can only be applied for on health reasons (medical diagnoses). A grant for the disabled can only be allocated if the health condition result in functional impairment, which prevents the applicant from gainful employment.

4. A disability grant is not designed to alleviate unemployment.

5. A distinction has to be made between:

- ⊗ Those who as a result of an impairment are unable to work.
- ⊗ Those who cannot find work because of unemployment
- ⊗ Those who do not wish to follow their treatment.

Only an applicant who as a result of impairment is unable to work is eligible for a grant.

6. The Medical Certificate has to confirm that the person has a physical or mental impairment that limits or prevents the person from doing any work in order to maintain him or herself.

- ⊗ Non compliance patients are not eligible.

- ⊖ **Impairment:** The alteration of normal functional capacity due to medical condition, assessed by medical means, after a diagnosis is established and appropriate and optimal treatment has been applied.

PROCESS OF APPLYING FOR A GRANT FOR THE DISABLED

- ⊖ The person who wish to apply for a grant for the disabled will present a referral letter that was issued by the Department of Social Services.
- ⊖ Medical reports will only be available from medical officers who are responsible for the medical assessments.
- ⊖ Upon completion of medical report, the applicant must sign the medical report and be issued with a receipt as proof that a medical report was completed.
- ⊖ The medical report remains in the possession of the medical officer.
- ⊖ An official from the Department of Social Services will collect all the completed medical reports at least once a week from the medical officer/health facility.

QUALIFYING REQUIREMENTS IN TERMS OF THE SOCIAL ASSISTANCE ACT

- The applicant must be a South African citizen.
- The applicant must be resident in South Africa.
- The applicant must be 18 years old.
- The applicant must comply with the means test.
- The applicant must submit a medical report that was completed by a medical officer who is in the service of the state, including a provincial government.
- The applicant must not refuse without good reason to undergo the necessary medical or other treatment recommended by a medical officer, medical practitioner, psychiatrist or an assessment panel.

DOCUMENTS THAT MUST ACCOMPANY AN APPLICATION FOR THE GRANT

- Official 13-digit bar code Identity document of the applicant and/ or his/her spouse.
- Proof of marital status.
- Proof of assets and income of the applicant and his/her spouse.
- A medical report from a medical officer.

ADDITIONAL INFORMATION

- All permanent disabilities may be medically reviewed after five (5) years.
- Temporary disability may be for six or twelve months and will be terminated after the period expired. These beneficiaries will need to re-apply for a grant.
- All beneficiaries are informed of the period for which they do qualify when the grant is awarded. Three (3) months prior to the expiry date the beneficiary will be informed in writing that his/her grant will be terminated and that he/she may re-apply for a grant if his/her medical condition has not changed.
- Patients must be rehabilitated whenever possible.

evaluation. If currently employed, pending boarding, a work site visit can be organized.

First application's – Medical Officer to indicate whether it is a first application, re-application. If re-application, the first application should be attached.

- A4.** History of complaints – pen sketch complaints and duration of illness. The patient's history in functional terms i.e. how long/far can the patient sit, stand or walk. Capacity to do domestic tasks or gardening and household activities. Capacity to use public transport independently and safely.
- A5.** The declaration must be completed by the patient and it will be appreciated if the declaration be explained to the patient.

B. Medical details

NB! Identification of applicant ensures that the Medical Officer is assessing the correct person.

Investigations – all relevant investigations supporting the diagnosis to be attached to the medical report.

- B1.** Height, weight, dominance and blood pressure must be provided.
- B2.** Clinical diagnosis & prognosis – a synopsis of the applicants health status. Verify the patient's history. Has he/she got the physical capabilities of doing the work and using public or own transport to get there?

COMPLETE APPLICABLE SECTION

NB! Eligibility for the grant depends on the severity of the impairment and to what extent it affects the person's ability as a whole. Conditions such as backache, single joint, arthritis, diabetes, coronary artery diseases, valve replacements, etc do not automatically ensure eligibility.

B3. CARDIO/RESPIRATORY FUNCTIONING

B3.1. Respiratory

- I. Dyspnoea – indicate the cause.
- II. Effort tolerance from grades 1 – 2 (b) to be considered in the global picture.
- III Tuberculosis – depending on his general health, consider 6-month grant and review. Patient must comply with treatment.

The number of acute episodes needs to be taken into account. Is the patient on maximum steroid therapy? Do peak flow and record as percentage of normal.

Cardio – vascular

- I. Frequent angina not responding to treatment coupled with target organ involvement – consider permanent grant.
- II. Stroke – If limbs are affected, considered 6 months grants refer for rehabilitation and review thereafter. Cognition may still improve over longer periods. Consider physical, communication and cognitive aspects

B4. Diabetes

- I. Consider grant only if target organ involvement.
- II. Amputation – **see mobility guideline**

Hypertension, diabetes, coronary artery disease is not an automatic right to a disability grant. Consider functional impairment.

B5 Visual acuity

- I. Refractive error – refer for glasses.
- II. Partial and total blindness with no education or skill competencies should be considered.
- III. Cataracts refer for surgery and give temporary grant for the disabled according to waiting list for surgery.

B6. Communication

Deafness: If a patient lacks effective communication skills with people other than family members consideration is given for a grant. Consider communication skills, hearing aid and global picture. Look at the whole patient. Language barriers are not a reason for disability.

B7. Epilepsy

Less than 3 seizures/month – consider globally. Note compliance with medication and substances, levels, maximum therapeutic medication and options. Note co-existence of mental retardation. (See B9) Consider type of occupation.

B8. Psychiatric illness

(See Annexure A attached)

PROCURATOR

There is a difference between a Procurator and Administrator. A Procurator has only authority to collect the grant on behalf of the beneficiary. The beneficiary might be unable to walk or wait long due to illness as verified from a Medical Officer. The beneficiary is still responsible for the use of the grant.

University of Cape Town

