THE COST OF DISABLING HEARING IMPAIRMENT IN SOUTH AFRICA

BY

MAGTELD SMITH

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EXTERNAL PROMOTER: PROF ALEX LUBET

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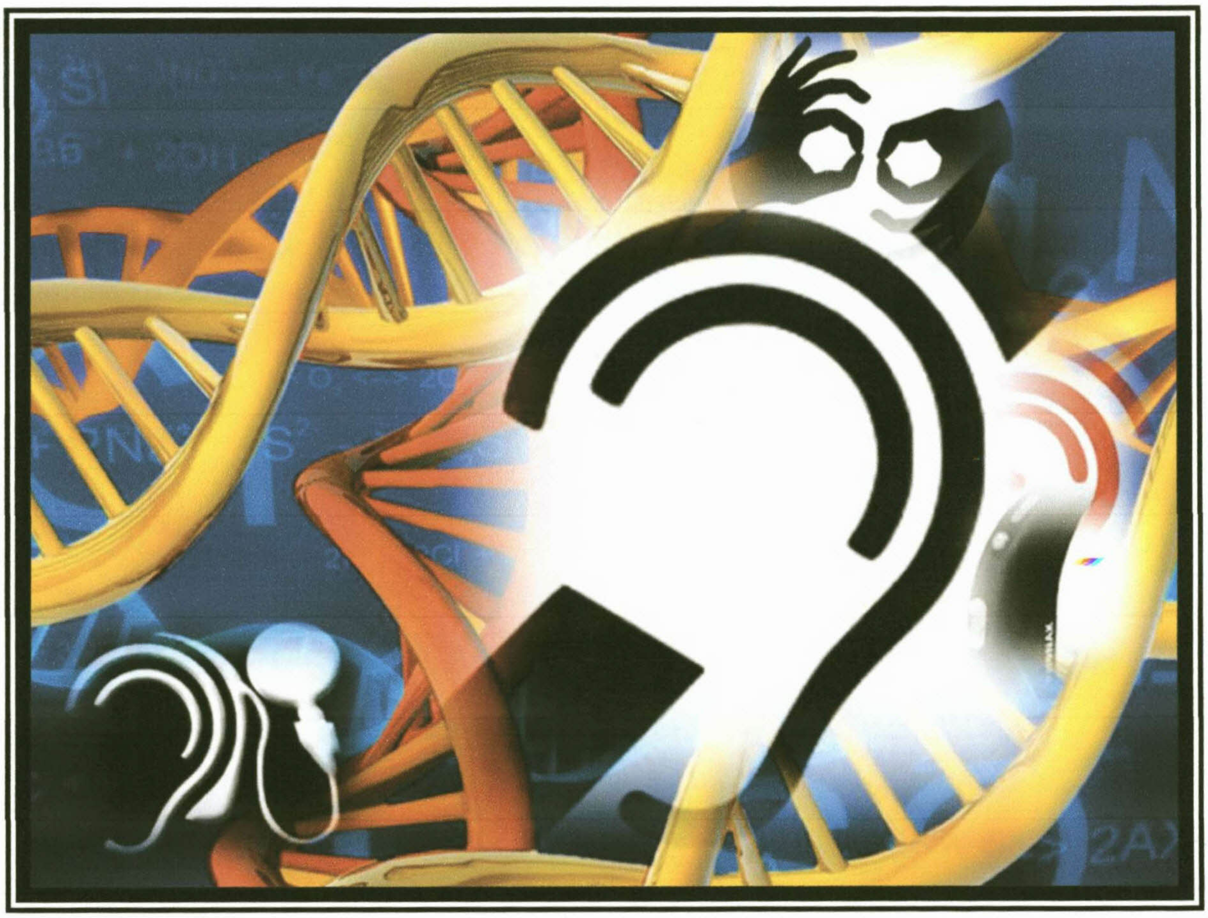

"Blindness separates us from things, but deafness separates us from people". - Helen Keller

DECLARATION

I declare that this thesis, which is submitted to the University of the Free State for the degree Philosophiae Doctor, is my own independent work and has not previously been submitted by me to another university of faculty. I hereby cede the copyright of the thesis to the University of the Free State.

Magteld Smith

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To the people with hearing loss in South Africa

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CONTENTS

INTRODUCTION AND CONTEXT

FIGURES

TABLES

History of deaf education in South Africa

Application of the International Classification of Functioning, Disability and Health with specific focus on disabling hearing impairment in legislation and policy in South Africa

TABLE

Socio-economic status of people with disabling hearing impairment in South Africa

TABLES

FIGURE

APPENDIX

The cost of sign language interpreter services in South Africa

TABLES

FIGURES

The cost of hearing aids in South Africa

TABLES

FIGURES

APPENDIX

The cost of cochlear implants in South Africa

TABLES

PAPER VIII 175

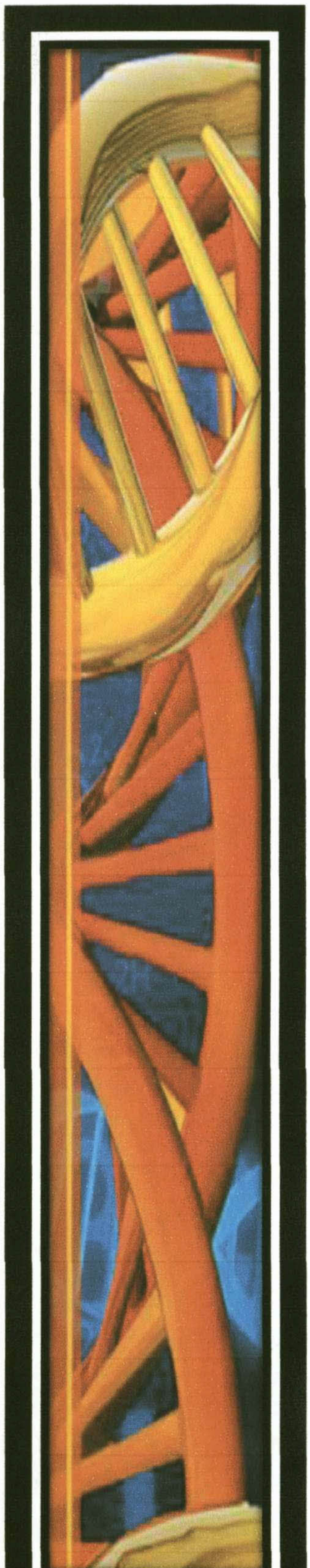
The costs of congenital genetic testing in SA

LIST OF ACRONYMS

AA	Annexure A
ABET	Adult Basic Education and Training
ASIC	Application specific integrated circuits
BTA	British two-handed alphabet
BTE	Behind the ear
CBC	Canadian Broadcasting Company
CLA	Criminal Law (Sexual Offences and Related Matters) Act
CSLHP	Council Speech, Language and Hearing Professions Board
dB	decibels
DBSA	Development Bank of Southern Africa
DEAFSA	Deaf Federation of South Africa
DHI	Disabling hearing impairment
DSP	Digital signal processor microchips
ENT	Ear, Nose and Throat
EU	European Union
FDA	US Food and Drug Administration
GEEMA	German Electrical and Electronic Manufacturers' Association
HI	Hearing impairment

HA	Hearing aid
HA's	Hearing aids
HIMPP	Hearing Instrument Manufacturers Patent Partnership
HPCSA	Health Professions Council of South Africa
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairments, Disabilities, and Handicaps
ICIDH-2	International Classification of Impairments, Activities and Participation
ITA	Income Tax Act
kHz	Kilohertz
MHSA	Mines Health and Safety Act
MSAA	Medical Schemes Amendment Act
NDH	National Department of Health
NHA	National Health Act
NLHS	National Health Laboratory Service
PSAP's	Personal Sound Amplification Products
PWDHP	People with disabling hearing impairment
R	South African Rand (ZAR)
SAMMD	South African Medicines and Medical Devices Regulatory Authority Bill
SARS	South African Revenue Services
SASL	South African Sign Language

SASSA	South African Social Security Agency
SATI	South African Translators Institute
SL	Sign language
SLI	Sign language interpreter
SLU	Sign language user
StatsSA	Statistics South Africa
SA	South Africa
SAPDH	South African Western Cape Provincial Department of Health
SASLI	South African sign language interpreter
UK	United Kingdom
UHG	United Health Group
UNC	United Nations Convention on the Rights of Persons with Disabilities
USA	United States of America
US$	United States Dollar
WHO	World Health Organisation



INTRODUCTION

AND

CONTEXT

1. INTRODUCTION

In April 1994, South Africa (SA) elected its first democratic government by majority poll. The end of apartheid was widely hailed as a miracle, and South Africa became a symbol of hope and possibility for the whole world, and particularly for those parts of the world that had recently entered the political upheavals of democratic transition. Many countries were perched on the threshold of something new, and South Africa seemed to embody all the promise of a new era, and caused all institutions under the previous apartheid system to change. Various new policies, legislation, and procedures had to be established to promote South Africa's new democratic image.

The Constitution of the Republic of South Africa (hereinafter referred to as The Constitution) of 1996 (Act no. 108 of 1996) completes South Africa's (SA) constitutional revolution. The Bill of Rights, section (s) 9(2) of The Constitution, guarantees equality and non-discrimination for persons with disabilities and limits the ability of government to pass laws or take actions that discriminate or infringe on human rights. Individuals must be treated equally, regardless of their race, national or ethnic origin, colour, religion, sex, age, or mental or physical condition. In addition it specifically provides that in order to achieve this objective, legislation that gives preferential rights to previously disadvantaged individuals may be promulgated.

The constitutional guarantee of equality must be interpreted contextually. This entails a historical understanding of the type of society that South Africa once was and against which The Constitution has set itself. The apartheid political and legal system was squarely based on inequality and discrimination. In the context of economic development in an environment with increasing global competition as well as a predominantly knowledge-based economy that is emerging with labour shortages, an aging population, and other environmental and personal factors, it is becoming evident that the participation of people with disabilities is increasingly essential for the individual and the collective well-being of our society and economic growth.

According to the World Health Organisation (WHO) sometimes, when special measures of this kind are adopted to redress the historical and continuing disadvantage suffered by members of a group, the measures are challenged by persons who do not belong to that group on the grounds that they are discriminatory (WHO, 2001). The WHO (2001b) warned developed and underdeveloped countries to ensure that any constitutional or legislative guarantee of equality makes it clear that special measures, mentioned in disability legislation, are lawful under the Constitution so that these are not subject to challenge under other equality guarantees by persons who do not have disabilities but who claim that their exclusion is a violation of their equal rights. Disability legislation is given high prominence in the disability classification scheme sponsored by the WHO. The WHO formulated the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) in 1980 (WHO, 1980).

According to Grimby & Gregory (1988), the ICIDH ran into swift trouble with social-model advocates, who argued the scheme still kept disability 'inside' the individual, insinuating that it belongs to and is caused within the person. Often critics claimed it did not pay sufficient attention to constraints in the external environment such as transportation barriers, job description, and negative public attitudes. The sharpest criticism of the ICIDH of 1980 was that disability is entirely a social or community product, and that features of the social, the physical, and the cultural environment are the sole causes of disability (Bower, 2000; Read, 2000).

By excluding medical causes, there were inconsistencies, overlaps, and omissions, and this diminished its appreciation in professional and scientific circles (Grimby & Gregory, 1988). The classification was subsequently amended to the International Classification of Impairments, Activities, and Participation (ICIDH-2) (WHO, 1997; WHO, 1999) and the title changed to the International Classification of Functioning, Disability and Health (ICF) in 2001 (WHO, 2001) as illustrated in Figure 1. Inconsistencies that plagued the first version were remedied (WHO, 1997) and have subsequently resulted in the ICF, a sophisticated classification that takes both medical and social factors into account. The ICF was officially endorsed by all 191 WHO Member States including SA as the international standard system to describe and measure health and disability on 22 May 2001 (WHO, 2001b).

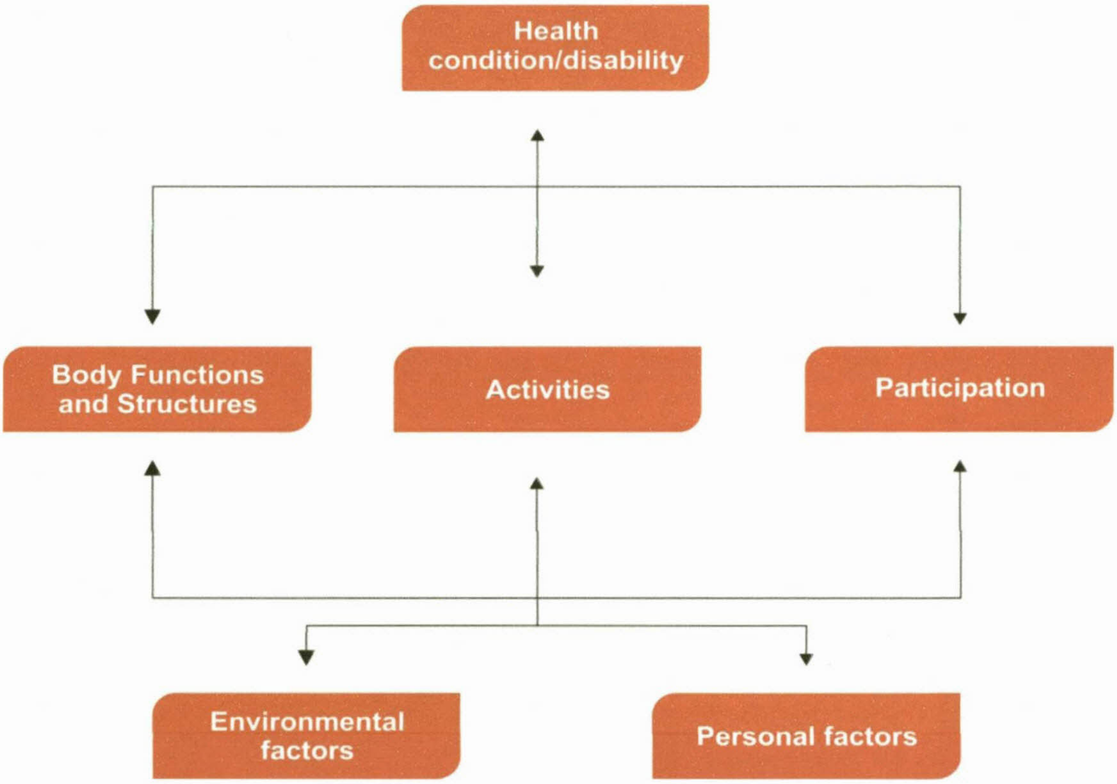
The overall aim of the ICF is to provide a standardised framework for the description of human functioning and disability as an important component of health. This framework was developed to encourage medical professionals and health statisticians to pay more attention to disability in client data and published statistics. Moreover, the title is indicative of a substantial change in the way one confronts oneself with the problem of presenting a unified language to describe the state of a person.

Collecting statistics on disability has proved problematic, mainly due to the confusion surrounding the definition and parameters of disability. This lack of clarity has served to confuse both the enumerators and those interpreting the data. Data collected in different countries are virtually incomparable from survey to survey, as different definitions and categories of disability are used with different cut-off points.

Observing the key words in this international classification, it is noticed that the term ‘disability’, once used in the 1980 version, has been substituted by ‘limitations to activity’, and that ‘handicap’ has been substituted by the phrase ‘restriction to participation’, and this indicates the positive developments implied. Other terms used are health conditions, impairments, contextual factors, environmental factors, personal factors. This builds up a model that focuses on activity at its centre, which can be more or less developed according to the personal situation of individuals but also according to the influence of their external environment. These were respectively defined as “any limitation or function loss deriving from impairment that prevents the performance of an activity in the time-lapse considered normal for a human being” (WHO, 1980). 'Handicap' is the disadvantaged condition deriving from impairment or disability limiting a person performing a role considered normal in respect of their age, sex and social and cultural factors.

The significant aspect of the ICIDH is that of being able to associate the state of an individual not only to structures and functions of the human body, but to link it to activities and participation in the social life of an individual. The ICF scheme is illustrated in Figure 1 and covers all aspects of human health, grouping them under the main 'health domain' inclusive of sight, hearing, walking, learning and remembering as well as those domains connected to the health domain, like mobility, learning and social life.

Figure 1: ICF framework and components



Source: ICF (WHO, 2001)

2. BACKGROUND TO THE RESEARCH PROBLEM

The researcher in her findings on Disability integration analysis in Government Departments in the Free State Province noted that at the time of the research in 2002 there were no standardised instruments and criteria in SA for determining disability, mainly because of different definitions (Smith, 2004) being used.

Cabinet has attempted to address these concerns by adopting the following more detailed definition of disability: "The loss or elimination of opportunities to take part in the life of the community equitably with others that is encountered by persons having physical, sensory, psychological, developmental, learning, neurological, or other impairments, which may be permanent, temporary, or episodic in nature, thereby causing activity limitations and participation restriction with the mainstream society. These barriers may be due to economic, physical, social, attitudinal and/or cultural factors". This definition of disability is based on the medical-social model (Republic of South Africa, Department Public Service and Administration, 2007).

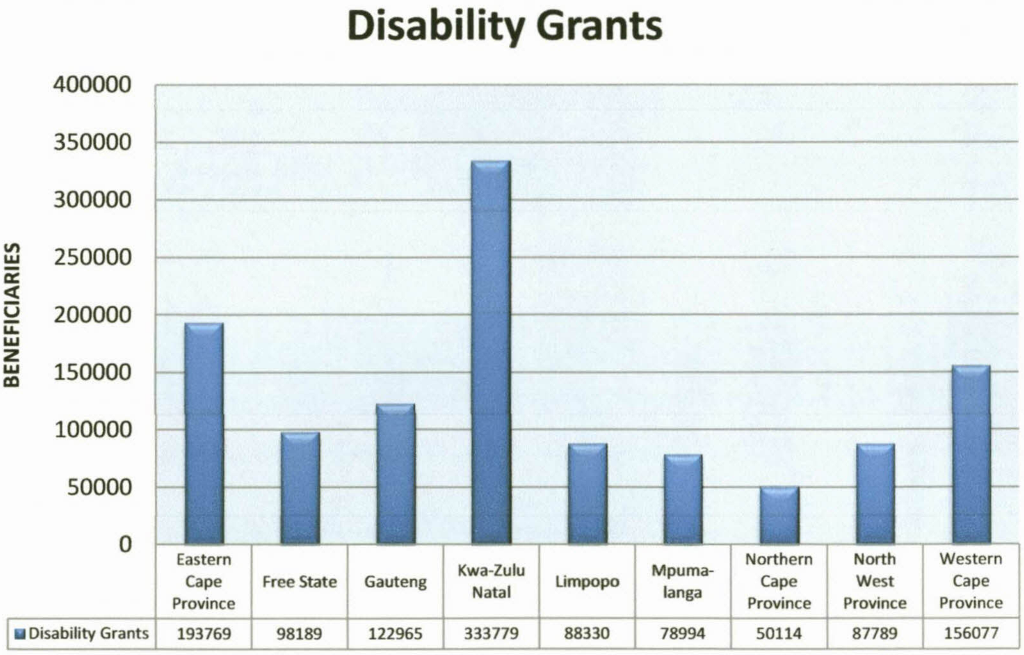
A study conducted by the Development Bank of Southern Africa (DBSA) (2005) revealed that the unemployment rate for people with disabilities on the open labour market in South Africa was estimated at 98 percent. The United Nations (2008) stated that in developing countries, 80 percent to 90 percent of persons with disabilities of working age are unemployed, whereas in industrialised countries the figure is between 50 percent and 70 percent.

According to the South African Social Security Agency (SASSA), the Disability Grant varies but the maximum amount that can be granted is R1 200.00 (US$120.02) a month (SASSA, 2012:6). A total of 1 388 969 million persons were registered receiving a disability grant. Disability grants can be granted if the applicant is over the age of 18 years and is not able to work because of mental or physical disability. Departmental spending has grown at an average annual rate of 16.8 per cent, from R9.9 billion in

2005/06 to R16.5 billion in 2008/09. The budget grows by 7.6 percent in 2009/10 to R17.1 billion and by an average annual rate of 9.6 percent over the Medium-Term Expenditure Framework (MTEF) period to reach R20.9 billion by 2011/12 (National Treasury of the Republic of South Africa, 2009:7,8,9,17). An amount of R1 583 424 660.00 has been paid out monthly at as June 2011 (SASSA, 2011).

Figure 2 provides a summary of disability grants beneficiaries by province. Kwa-Zulu Natal has the highest number of beneficiaries, followed by Eastern Cape and Western Cape respectively. The Northern Cape has the lowest number of beneficiaries.

Figure 2: Disability grants by province in South Africa



	Eastern Cape Province	Free State	Gauteng	Kwa-Zulu Natal	Limpopo	Mpuma-langa	Northern Cape Province	North West Province	Western Cape Province
■ Disability Grants	193769	98189	122965	333779	88330	78994	50114	87789	156077

Source: SOCPEN system (30 June 2011)

A major concern relating to the pervasive nature of invisible disabilities, such as disabling hearing impairment (DHI), is the economic impact (fiscal) on government. A household survey performed by Statistics South Africa (StatsSA) (StatsSA, 2011), indicated that compared to people with other disabilities, persons with DHI have the lowest education achievement level, lowest annual family income, lowest rate of persons in professional and technical jobs, highest rate of persons reporting that they were limited in performing their usual activity.

Although there are a number of different definitions for DHI, it refers to hearing shown by audiometry to be below levels for normal hearing. DHI is used in this study to refer to slight, mild, moderate, moderately severe, severe and profound hearing impairment levels in determined by medical tests. The different grades of DHI and their impact in performance on a person are presented in Figure 3.

WHO (2012) defines DHI as having permanent unaided hearing threshold in the better ear of more than 30 decibels (dB) in children aged up to 15 years, or more than 40 dB in adults at frequencies of 0.5, 1, 2, and 4 kilohertz (kHz). Classification of DHI ranges from 'no impairment' to 'profound impairment' according to the hearing threshold level.

Table 1: WHO grades of hearing impairment

	Receptive language	Expressive language	Activity limitation/participation restriction
Normal hearing (0-15 db HL)	Detects all speech signals	Normal range	None
Slight hearing impairment (16-25 db HL)	Misses up to 10% of speech sounds (e.g. Unvoiced consonants) especially in difficult listening situations	Mild language disability and speech problems	Inappropriate response to sound Learning difficulties Poor social interaction
Mild hearing impairment (26-40 db HL)	Misses 25-40% of speech especially in difficult listening situations	Mild language disability and speech problems	Inattention Learning difficulties Behaviour problems
Moderate hearing impairment (41-55db HL)	Misses 50-70% of speech	Moderate language disability and poor speech intelligibility	Learning dysfunction Significant social problems
Moderately severe hearing impairment (56-70 db HL)	Misses 75-100% of speech	Severe language disability and speech problems	Severe learning dysfunction Stigmatisation and possible social isolation
Severe hearing impairment (71-90db HL)	Misses up to 100% of conversational speech	Severe speech problems and language disability	Severe learning dysfunction Stigmatisation and significant social isolation
Profound hearing Impairment (90+ db HL)	Misses all loud speech sounds except vibrations	Visual cues essential for communication	Complete social isolation

Source: WHO Report of the Informal Working Group On Prevention Of Deafness And Hearing Impairment Programme Planning. Geneva, 1991

3. STATEMENT OF THE RESEARCH PROBLEM

One of the most common and neglected birth defects in developing countries is DHI, which can most severely impair and have a dramatic impact of the quality of the of the person with DHI. Moreover, DHI is one of the six leading contributors to the burden of disease in developing countries; along with ischemic heart disease, depression, and Alzheimer's disease (Mathers, Smith & Concha, 2000; Zahnert, 2011).

Ten percent of the world's population has some degree of hearing loss making DHI the most common disability in the world. The WHO (2012) published that in 2004 there were an estimated 275 million people in the world with DHI. Two-thirds of these are in developing countries (WHO, 2012). One quarter of DHI begins during childhood, and 80 percent of all hearing impaired people live in low and middle income countries. These percentages are modest compared to the prevalence level expected in the coming decades. Approximately 180 000 babies are born with or acquire permanent bilateral hearing loss within the first few weeks of life across sub-Saharan Africa every year (Olusanya, 2008).

A major concern relating to the pervasive nature of DHI is the economic impact on a person with DHI and on government (fiscal). Furthermore, statistics concerning the prevalence of DHI are constantly being revised because of a diversity of DHI definitions used. Authoritative figures on the size of the DHI population do not exist (Malange, 2011; Odhiambo, 2011; Smith, 2007). The incidence of DHI derived from a number of retrospective studies in SA (population about 50 million; birth rate 12-18/1000), is estimated to be about 17 born per day and 6 205 per annual birth cohort in 2011 (Hay, 2011) This estimate excludes children and adults who acquire hearing loss through infectious diseases, ototoxicity or noise-induced damage.

The WHO (2006) defines DHI as often life-long and sometimes life-threatening problems that may have profound effects on interpersonal communication, education, employment, social relationships, emotional and through stigmatisation beyond those experienced by their hearing counterparts. As stated by Stone (1987), "Hearing impairment strikes at the very essence of being human, because it hinders communication with others".

Likewise, Penniceard and Rabinowitz (1981) stated that even mild DHI can be a major disadvantage in a sound-dominated world and may have a detrimental effect upon development with psychological and social problems. Little is known about the health status of South Africans with DHI. Many studies have shown that hearing impairments can be seriously disabling and reported more high levels of depressive symptoms in people with DHI. (Theunissen, Rieffe, Kouwenberg *et al.*, 2011; Nachtegaal, Kuik, Anema *et al.*, 2009). A study examined by Baines, Patterson & Austen (2010) identified that people with DHI are considered to be at higher risk of suffering mental disabilities than hearing people. In a study of the historical overview of inpatient care of patients with mental disabilities with DHI, significant associations with anxiety, depression, loneliness, isolation and inactivity which is in fact part of the characteristics of a person with DHI (Pronk, Kramer, Davis *et al.* 2011; Tambs, 2004).

So far, over 332 genetic causes for DHI have been identified, moreover, almost 150 loci for nonsyndromic DHI alone have been mapped (assigned a chromosomal location), 57 for dominant DHI, 77 for recessive DHI, eight for X-linked DHI, and more than 54 genes have been sequenced and identified since 2009-2011 (Hildebrand, Morín, Meyer *et al.*, 2011; Hilgert, Smith & Van Camp, 2009). During 2012, new deafness genes have been identified, three syndromic, and six nonsyndromic and a total of 66 genes that have been sequenced and identified (Shearer & Smith, 2012).

In addition, DHI may be caused by factors in the environment, a combination of genetic and environmental factors or genetic factors alone and a large number of syndromes leading to hearing loss. According to Zahnert (2011), more than 400 syndromic forms of DHI have been described, although only the most common of these are likely to be seen in routine practice, for example, Waardenburg syndrome types 1 and 2, Treacher Collins syndrome, Branchio-oto-renal syndrome and Usher syndrome. In terms of non-syndromic deafness, genetically distinct forms of HI can rarely be distinguished from each other phenotypically and there is very little information regarding the contribution of individual genes to deafness generally.

Little research has been done on the causes of DHI due to high costs of genetic testing and a lack of trained professionals in South Africa (Kromberg *et al.*, 2012).

Persons diagnosed with DHI often require multiple medical tests to determine the exact cause of their DHI. Establishing a diagnosis of DHI is a critical component of the clinical evaluation of DHI persons and their families. If a genetic cause of DHI is determined, it is possible to provide families with prognostic information whether the HI will worsen over time, recurrence risks, and improved rehabilitation and habitation options based on what gene/s is affected. This outcome could assist with the choice of communication method such as, total communication, sign language or spoken language to contribute to the socio-economic status of the person with DHI to improve quality of life.

According to Smith (2011) from the Molecular Otorhinolaryngology and Renal Research Laboratories at the University of Iowa in the United States, diagnosing the exact genetic cause of DHI has always involved sequencing one gene at a time, a process that could take up to a year and cost roughly R9 000.00 ($1,000 US dollars) per gene. It would cost around R750 000.00 ($82 312.50 US dollars) to test all known deafness-causing genes using this approach. Traditional gene sequencing can only test one gene at a time, which makes the test expensive. It is for this reason that researchers from the Molecular Otorhinolaryngology and Renal Research Laboratories at the University of Iowa have developed a new test called OtoSCOPE that can screen all of the genes known to cause DHI in a single run, in one to three months and for about R14 116.50 ($1 500.00 US dollars) (Illumina, 2012). The Laboratory launched OtoSCOPE during September 2011 within the United States of America and has become the first laboratory in the world to offer genetic testing for all known DHI genes simultaneously, which will significantly increase efficiency and decrease cost.

There are a wide range of disabilities that people may experience in addition to their DHI. Approximately 40 percent of children with DHI have additional disabilities (Ardle & Bitner-Glindzicz, 2011). The aspects of responsibility and economic independence on a person with DHI has not been investigated in SA yet. While cumulative effect of an undiagnosed HI on children's social, cognitive, and language development can be determined, the economic aspect in the long term remains largely unquantified. A study conducted by Schroeder, Petrou, Kennedy et al, (2006) provides evidence of the annual health and societal cost of bilateral DHI in the preceding year of life at 7 to 9 years of age. Most children with DHI are educationally delayed by as much as three to seven years (Martin & Clark, 1996).

A survey of the available literature reveals that very little research has been conducted, particularly in the context of financial implications of DHI. There is no published research on the cost of DHI or the socio-economic status of a person with HI in SA. As health services and education reform are mandated by the Constitution, the primary responsibility for funding rests with government.

4. RATIONALE FOR THE STUDY

According to the South African Western Cape Provincial Department of Health (SAPDH) (SANPH, 2006) it is estimated that 1 in every 40 babies has a birth defect and 1 in 10 will develop an inherited disorder during their lifetime. Moreover, there is a wide range of disabilities that people may experience as a result of DHI. A framework for describing health and health-related states is the International Classification of Functioning, Disability and Health (ICF; WHO, 2001).

If undetected and untreated, it can lead to delayed speech and language development, learning problems, as well as social, economic and emotional problems (Northern & Downs, 2002:15).

5. ADDRESSING THE PROBLEM

The ultimate aim of this study is to measure the economic cost of DHI in SA by taking in account the WHO ICF model. The ICF will be used as measurement to assist and predict the economic cost implications by determine the socio-economic status of people with DHI and the direct cost of genetic testing for DHI, cochlear implants as a therapeutically interventional option for the first year, cost of hearing aids, and the cost of sign language interpreter services. In this model, disability and functioning are regarded as outcomes of interactions between an individual's health condition and contextual factors. Three levels of human functioning are classified by the ICF: functioning at the level of the body or body part (body functions and structures), functioning of the whole person (activities), and functioning of the whole person in a social context (participation).

6. ORGANISATION OF THE STUDY

In addition to this introduction and overview above, the study is presented as seven separate papers in which the analyses of the costs of DHI in SA, and the measurement thereof, are presented. Since the seven papers all revolve around the central theme of measuring the economic cost of DHI, some repetition will occur in the introductory discussions on background and context. Each of the papers nevertheless offers a quite different view on the cost of people with DHI in SA. Paper I gives a brief history of education for people with DHI. Paper II examines the application of the ICF with specific focus on DHI in legislation and policy in SA. The socio-economic status of people with DHI are presented in Paper III. Paper IV present the costs of the sign language interpreter industry in SA. Paper V presents the cost of the hearing aids industry in SA and Paper VI will present a cost-utility scenario analysis of the direct costs of cochlear implantation for the first year after diagnoses. Paper VII gives a review on the costs of genetic testing for congenital HI and an explanation why these tests are of cardinal importance for rehabilitation and educational placement for the child with DHI.

In order to do this, a combination of research methods were used, thus following for the collection of comprehensive and complementary data that provide a broader exploration of what the cost implications are of DHI in SA as it pertains to the research question: to determine the cost of DHI in SA.

Against this background, the primary objective of this study is to investigate the cost of DHI in SA using a theoretical and empirical approach so that resource and cost implications of interventions are utilised as well as the relative gain (quality of life) from their use could be determined in order to allow society to have informed choices.

7. CONCLUSION

A comprehensive literature review has revealed that there have been no previous published studies of the cost of DHI in SA with reference to the socio-economic status of people with DHI, the costs of genetic testing for DHI, the direct costs of cochlear implantation for the first year of diagnoses and intervention, or the costs of the sign language interpreter industry in SA which can be directly applied to the evaluation of the costs of DHI in SA.

In SA the study will be of intrinsic value, due to exchange of further information and research to be undertaken on how to improve the human quality of life of people with DHI and the economic burden on the person with DHI. This study will also lead to awareness of the importance of communication choice amongst people with DHI that could lead to a more productive human resource in SA.

8. REFERENCES

Ardle, B.M. & Bitner-Glindzicz, M. 2010. Investigation of the child with permanent hearing impairment. Archive of Disease in Childhood. Education and Practice Edition, 95(1), 14-23 doi: 10.1136/adc.2008.150987. London.

Baines, D., Patterson, N. & Austen, S. 2010. An Investigation Into the Length of Hospital Stay for Deaf Mental Health Service Users. *Journal of Deaf Studies and Deaf Education*, 15(2),179-184.

Bower, A. 2000. Inclusion and Special Educational Needs. *International Journal of Disability, Development and Education,* 47(4),427 – 30.

Development Bank of Southern Africa (DBSA). 2005. Unemployment rate for people with disabilities in the open labour market in South Africa. Pretoria: The Development Bank of South Africa.

Grimby, G. & Gregory, T.S. 1988. The application of the WHO handicap classification in rehabilitation. *Scandinavian Journal of Rehabilitation Medicine*, 20(3), 93-8.

Hay, C. 2011. 17 babies born deaf in South Africa daily. Media Release issued by: Colette Hay, the president of the South African Association of Audiologists. Available from <http://www.health24.com/news/Hearing_management/1-1239,65848.asp> [Accessed: 1 September 2012].

Hildebrand, M.S., Morín, M., Meyer, N.C., Mayo, F., Modamio-Hoybjor, S., Mencía, A., Olavarrieta, L., Morales-Angulo, C., Nishimura, C.J., Workman, H., DeLuca, A.P., del Castillo, I., Taylor, K.R., Tompkins, B., Goodman, C.W., Schrauwen, I., Van Wesemael, M., Lachlan, K., Shearer, A.E., Braun, T.A., Huygen, P.L.M., Kremer, H., Van Camp, G., Moreno, F., Casavant, T.L., Smith, R.J.H. & Moreno-Pelayo, M.A. 2011. DFNA8/12 caused by TECTA mutations is the most common identified subtype of non-syndromic autosomal dominant hearing loss. *Human Mutation*, 32(7), 825-34.

Hilgert, N., Smith, R.J.H. & Van Camp, G. 2009. Forty-six genes causing nonsyndromic hearing impairment: which should be analyzed in DNA diagnostics? *Mutation Research,* 681(2-3), 189-96.

Illumina. 2012. Pursuing Fast, Affordable Hearing Loss Screening. Eliot Shearer at the University of Iowa Carver College of Medicine is developing a method to simultaneously screen all 66 known deafness genes using the MiSeq® system. Available from: <http://www.illumina.com/documents/products/other/interview_eshearer.pdf> [Accessed: 12 November 2012].

Kromberg, G.R., Sizer, E.B. & Christianson, A.L. 2012. Genetic services and testing in South Africa. *Journal Community Genetic,* DOI 10.1007/s12687-012-0101-5.

Malange, S. 2011. [VeliM@sassa.gov.za]. 2011. Disability statistics. South African Social Security Agency. Email to: [Smith, M. smithm@ufs.ac.za]. 30 August 2011.

Martin, F. & Clark, J. 1996. Hearing care for children. Needham Heights, MA: Allyn & Bacon.

Mathers, C., Smith, A. & Concha, M. 2000. Global Burden of Disease. Geneva: World Health Organisation.

Nachtegaal, J., Kuik, D.J., Anema, J.R., Goverts, S.T. & Festen, J.M. 2009. Hearing status, need for recovery after work, and psychosocial work characteristics: Results from an internet-based national survey on hearing. *International Journal of Audiology*, 48, 648-691.

National Treasury of the Republic of South Africa. 2009. Estimates of Public Expenditure. ISBN: 978-2-621-38384-3. Pretoria: FormeSet Printers Cape (Pty) Ltd.

Northern, J.L. & Downs, M.P. 2002. Hearing in Children Fifth Edition. Philadelphia: R.R. Donnelley & Sons Company.

Odhiambo, A. [odhiambo@sassa.gov.za]. 2011. Disability grants and beneficiaries. South African Social Security Agency. Senior Manager. Email to: Smith,M. [smithm@ufs.ac.za]. 29 August 2011.

Olusanya, B.O. 2008. Priorities for early hearing detection and intervention in sub-Saharan Africa. *International Journal Audiology*, 47(Suppl. 1), S3-S13.

Penniceard, R.M. & Rabinowitz, A. 1981. Educational retardation and constructive hearing problems, 2nd ed. London: ILEA Schools Psychological Services, 3-18.

Pronk, M., Kramer, S.E., Davis, A.D., Stephens, D., Smith, P.A., Thodi, C., Anteunis, L.J.C., Parazzini, M. & Grandori, F. 2011. Interventions following hearing screening in adults: A sustematic descriptive review. *International Journal of Audiology*, 50(9),594-609.

Read, J. 2000. Disability, the Family and Society: listening the mothers. Buckingham: The Open University Press.

Republic of South Africa. 2007. Department of Public Service and Administration. Handbook on Reasonable Accommodation for People with Disabilities in the Public Service. Pretoria: Government Printer.

Republic of South Africa. 1996. The Constitution of the Republic of South Africa, Act no. 108 of 1996. Pretoria: Government Printer.

Schroeder, L., Petrou, S., Kennedy, C., McCann, D., Law, C., Watkin, M., Worsfold, S. & Yuen, H.M. 2006. The Economic Costs of Congenital Bilateral Permanent Childhood Hearing Impairment. *Pediatrics*, 117(4), 1101-111.

Shearer, A.E, Smith, R.J,H. 2012. Genetics: advances in genetic testing for deafness. *Current Opinion in Pediatrics*, 24(6):679-686.

Smith, M. 2004. *Disability integration analysis in Government Departments in the Free State Province.* Bloemfontein. University of the Free State.

Smith, R. 2011. The Sterba Hearing Research Professor and vice-chair of the Molecular Otorhinolaryngology and Renal Research Laboratories at the University of Iowa otolaryngology and pediatric otorhinolaryngologist with the University of Iowa Children's Hospital. Available from: <http://news-releases.uiowa.edu/2010/november/111610test-deafness-gene.html> [Accessed: 28 November 2011].

South African Western Cape Provincial Department of Health. 2006. Fact sheet on Birt Defects. Available from: <http://www.westerncape.gov.za/Text/2003/birthdefects.pdf> [Accessed: 11 January 2013].

South African Social Security Agency (SASSA). 2012. Fourth Quarter Indicator Report (01 January to 31 March 2012). Pretoria: SASSA.

Statistics South Africa (StatsSA). 2011. South African Statistics. Population censuses 1996 and 2001, and Mid-year population estimates, 2010 (Statistical release P0302). Pretoria: Statistics South Africa.

Stone, H.E. 1987. Adjustment to post-lingual hearing loss. In Kyle JG, ed. Adjustment to acquired hearing loss. Bristol: Centre for Deaf Studies.

Tambs, K. 2004. Moderate effects of hearing loss on mental health and subjective well-being: Results from the Nord-Trondelag Hearing Loss Study. *Psychosomatic Medicine Journal*, 66(5), 776-82.

Theunissen, S.C.P.M. 2011. Depressin in hearing-impaired children. *International Journal of Pediatric Otorhinolaryngology*, 75(2), 1313-1317.

United Nations. 2008. Employment of persons with disabilities. DPI/2486. United Nations.

World Health Organisation (WHO). 1980. International Classification of Impairments, Disabilities, and Handicaps. Geneva: World Health Organisation.

World Health Organisation (WHO). 1997. International Classification of Impairments, Disabilities, and Handicaps. Geneva: World Health Organisation.

World Health Organisation (WHO). 1999. International Classification of Impairments, Disabilities, and Handicaps. Geneva: World Health Organisation.

World Health Organisation (WHO). 2001(a). International Classification of Functioning, Disability and Health. Geneva: World Health Organisation.

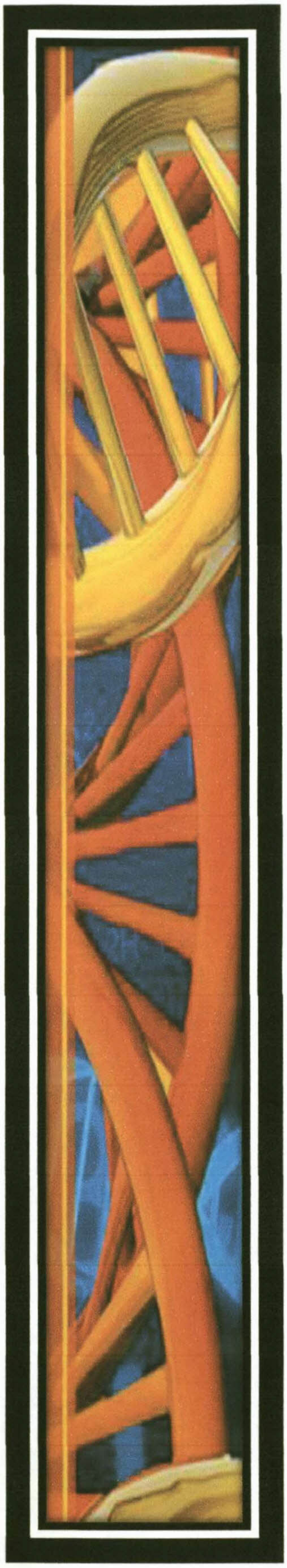
World Health Organisation (WHO). 2001(b). Fifty-Fourth World Health Assembly. Agenda item 13.9. WHA54.21. 22 May 2001. Geneva: World Health Organisation.

World Health Organisation (WHO). 2004. Report on informal consultation on epidemiology of deafness and hearing impairment in developing countries and update of the WHO protocol.Geneva: World Health Organisation .

World Health Organisation (WHO). 2012. Deafness and hearing impairment. Geneva: World Health Organisation. Available from:
< http://www.who.int/mediacentre/factsheets/fs300/en/> [Accessed: 15 March 2012].

Zahnert, T. 2011. The Differential Diagnosis of Hearing Loss. *Deutsches Ärzteblatt International*, 108 (25), 433-444.

PAPER I



HISTORY OF DEAF EDUCATION BEFORE THE END OF *APARTHEID* IN SOUTH AFRICA

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Abstract

This paper investigates the history of deaf education before the end of Apartheid in South Africa. The history in deaf education is of cardinal interest to understand the significant implications for curriculum and instruction. The field of deaf education is one that has a long history that parallels public education in South Africa. The Western Cape Province was one of the provinces that was on the forefront of education for learners with deafness and have become leaders in the field of special education. The paper chronicles the history of deaf education from 1863 to 1994. This study reveals that the deaf in South Africa have been underserved in education: that documentation of best practices is lacking, and that there is a need for the advocates and practitioners of eclectic approaches to deaf education in South Africa to share information and collaborate in order to chart the best future.

1. INTRODUCTION

The field of deaf education in South Africa (SA) is fraught with issues and controversies that, at times, seem to overwhelm it and keep it stuck in some unproductive ways. This seems to have been the case in the Western Cape Province, which had very early on in history established schools for the deaf. Some of these schools remained without secondary education when the first secondary school for the deaf was established in 1881 (Instituut vir Dowes Worcester, 1981).

Many of the traditional issues in deaf education such as communication philosophy, academic and political setting, and view of deafness as a culture can be seen as issues that prevented the history from being told. It is these issues that have kept schools from co-operating and working with each other, and instead encouraged competition and secrecy. The goal is neither to lay blame, nor to judge in any way, the educational methods and history that will be described herein. The objective is to describe the facts that have, heretofore remained buried.

2. METHODS

Qualitative empirical method was used through personal experience and data were obtained through fieldwork and collected between 1863 to 1994. Altogether, 18 deaf people born between 1927 to 1992, age 22 to 83 years, were approached and invited to participate in the study. A literature review was conducted on articles and books. In addition, research was conducted at the Western Cape Archives and Records of the Central Library in Cape Town and through on-site investigation of the archives of the De La Bat School for the Deaf in Worcester, Western Cape, SA, that this information is being made public here for the first time.

3. RESULTS

3.1 History of schools for the deaf in South Africa

It is significant that in 1863, the first school for deaf learners in SA was opened in Cape Town. Therefore, it is important to note that deaf education in SA is quite old. At first the school was called the Dominican School and later renamed the Grimley School for the Deaf. Bishop Thomas Grimley opened this school and brought nuns to Cape Town from Ireland. These nuns introduced the Irish Sign Language and it's variety of one-handed finger spelling (Erting, 1994). According to De Brún (2006), the origin of Irish Sign Language can be traced back to the eighteen century in France. Erting (1994), and Mesthrie (2002) stated that Cape Town became the first site for English-medium education for the deaf in SA.

A group of German Dominican nuns began educating deaf learners who lived in the Eastern Cape Province in 1884. Sign language (SL) based on the British two-handed alphabet (BTA) was permitted, although the primary method of instruction was English spoken language, and rather than German (Erting, 1994). Jessica Davis, a British deaf educator began a private school in Johannesburg for deaf learners during the 1920s, and in 1934, the St. Vincent's School for the Deaf was opened with the support of the Department of Education, by Minister Hofmeyr. Learners came from the former Transvaal, today Gauteng and Mapumalanga, East London, Durban, the former Rhodesia, today Zimbabwe, and other provinces. English spoken language was the method of instruction currently using total communication methods (Catholic Schools Office, 2012).

Many citizens with deafness of all ethnic groups attended school for short periods of time or not at all. After 1937, SA introduced compulsory education for all children with disabilities, including children with deafness (Republic of South Africa, 1937). White, Coloured (mixed-race), and Black learners were accommodated in the Grimley

School. After the law come into effect, the numbers of deaf learners increased, and Black and Coloured learners were transferred to Wittebome, a suburb of Cape Town. Black learners with deafness were established since 1937 (Erting, 1994). They brought with them Irish Sign Language used at the Grimley School, and this has been maintained in Wittebome to this day. The Wittebome SL has become the trademark of the Cape Town Coloured and White deaf community of the Cape Peninsula (Erting, 1994). However, churches established a number of special schools for deaf Black learners in SA.

In 1941 the first school for Black deaf learners, Kutlwanong was established in Gauteng Province. The medium of instruction was SL and after the Nationalist Party government came into power in 1948, a number of additional schools for Black deaf learners were established in the rest of the country's homelands. Diverse ethnic groups with different spoken language stayed in different homelands. Bartimea School for the Deaf at Thaba'Nchu in the former homeland Bophuthatswana, accommodated South Basotho's and Tswana's. The Thiboloa School for the Deaf in Witsieshoek, today QwaQwa, served South Basotho's. Setswana, South Sotho and Sepedi deaf learners were accommodated in the Kutlwanong in Rustenburg. St. Thomas for the School for the Deaf in King Williams Town in Ciskei, today part of the Eastern Cape Province, accommodated the Xhosas. Vuleka School for the Deaf at Nkandla, served the Zulu's, in the past Natal, today KwaZulu-Natal. The Venda and Tsonga deaf people were accommodated at the Tshilidzini School for the Deaf and isiXhosa at the Efata School for the Deaf in Transkei. In addition, the Sizwile School for the Deaf in Soweto and the Katlehong School for the Deaf in Spruitview, Katlehong, in the Gauteng Province. The Dominican School for Deaf Children in Hammanskraal was established by the Irish Dominican Sisters in 1962 after Black children were no longer allowed to attend school with Coloured children at the Dominican School for Deaf Children in Wittebome, Cape Town (Kleinschmidt, 2011).

In June 1881, Jan de la Bat opened the first bilingual school for Afrikaans-speaking learners with deafness in a rented room in High Street, Worcester, and English was taught as a second language (Instituut vir Dowes Worcester, 1981). Until 1905, learners with deafness and vision impairment were educated together at the Institute for the Deaf and the Blind in Worcester. Later that year, the Institute for the Deaf and the Blind was separated into two autonomous schools. Deaf learners came from the former Transvaal, the Free State, and Namibia, among other provinces. Over weekends the girls had to cook, bake bread, and churn butter, while the boys and Jan de la Bat collected vegetables by horse, and carted them from farms of the district. The boys went out to cut firewood in the afternoons, stacked on the cart of Jan de la Bat (Instituut vir Dowes Worcester, 1981)

Mr. Badernhorst became the principal of the Institute for the Deaf in 1953 after led by Dr. Gawie de la Bat for 70 years. Badernhorst undertook several educational visits to Europe and the USA to investigate and gain knowledge in the education of learners with deafness. In 1968, the school became a secondary school. The Matric Certificate which existed of six subjects, including Afrikaans and English was offered, and several learners completed various degrees at the University of Stellenbosch. With considerable effort on the part of education for the deaf learner, it was demonstrated that it is possible for children who are deaf to achieve good spoken language and literacy levels (Die Instituut vir Dowes Worcester, 1981; Akamatsu, Mayer & Hardy-Braz, 2008; Beattie, 2006).

Helen Keller was invited to SA by Rev. Arthur William Blaxall representing the South African National Council for the Blind and the National Council for the Deaf (Instituut vir Dowes Worcester, 1981). Keller, together with her friend and companion Polly Thomson via whom she communicated, visited the Institute for the Deaf in 1951.

The Institute for the Deaf was the first school to offer an academic matric certificate with the Auditory-Oral Method (AOM), today, senior matric certificate which is still the highest secondary qualification in SA.

Dr. Johan Hamilton became the principal in 1976, acquainted with the latest development in the field of special education after years of study and research, while associated with the University of Stellenbosch Child Guidance Clinic.

Accordingly, the AOM does indeed procure higher levels of educational success and assimilation into the hearing society for deaf individuals as illustrated from the history of the De la Bat School for the Deaf and other research (Convertino *et al.* 2013). Classrooms were equipped with the best technology available for those years consisting of microphones, and headphones. An induction loop system was installed in the school hall and used during assemblies, watching movies and guest speakers. All learners have worn analogue hearing aids with a 'T' setting. An induction loop is a cable that circles the listening area. It is fed by current from a loop amplifier. The amplifier gets its signal from a microphone placed in front of the person speaking or by means of a direct connection from a sound system (Instituut vir Dowes Worcester, 1981).

Several deaf schools were established between 1933 and 1988 for the Coloured (mixed race), Indian, and Black deaf communities, and were supported by the Department of Education (Erting, 1994). In 1954, Transoranje School for the Deaf was opened in Pretoria as another Afrikaans-medium school. Moreover, the first school for deaf Indian learners was opened in 1969 in Durban. The primary reason for this was because of the difference concerning religion and culture. Thereafter, the V.N. Naik School for the Deaf was opened in 1984 in Durban, thereafter, the Lenasia School for the Deaf, and Hearing Impaired, which also served independent states such as Lesotho, Botswana, Swaziland, and Mozambique, and MC Kharbai School for the Deaf in Lenasia, predominately an area for Indians (Kleinschmidt, 2011).

4. METHOD OF COMMUNICATION

4.1 Sign Language

SL is a visual language with its own grammatical rules, structures and syntax that uses manual movements to represent concepts. Some people consider SL to be the natural language of deaf individuals because they use visual and tactile input to compensate for the loss of auditory input. In addition, SL uses signs, classifiers, fingerspelling, facial expressions, body language, gestures, and miming to generate the language. It is also used by a group of people who include it as part of their culture, the 'Deaf Culture'. Through the schools for the deaf and the signing communities, there has been a continuity of signing tradition in SA for 131 years before the end of apartheid. SL was originated and related to Irish and British SL. The BTA was adapted for use as SL, and has become known as the Worcester Sign System.

Schools were established in different geographical regions, ethnic groups and religions and therefore, socio-historical conditions might have led to the emergence separate variety of SL dialects. SL was never oppressed or forbidden during the apartheid years. However, at the De la Bat School for the Deaf, SL was forbidden in the classroom, but was used freely outside the classroom.

4.2 Auditory-oral method

Classrooms were equipped with the best technology available for those years consisting of microphones and headphones. An induction loop system was installed in the school hall and used Spoken education ("auditory-oral method") for learners with deafness was favoured in the USA, Germany, and in some parts of Europe between 1878 and 1980, and most schools for learners with deafness in SA followed suit (Erting, 1994). As early as in the 1930s, Dr. Gawie De la Bat implemented the well-known residual hearing method (RHM) which had become the corner stone of all listening-based auditory-oral methods (RHM) in Worcester. Since the earliest history of the Institute for the Deaf, this method was supported and provided by the use of very basic sound amplification such as speaking tubes without electricity to amplify sound (Instituut vir Dowes Worcester, 1981).

4.3 History of residual hearing method in South Africa

The RHM of communication is that in which learners with deafness are taught to use facial expressions, body language, remaining residual hearing, speech reading, and speech to communicate. This method does not use any form of signing or fingerspelling. It may incorporate gestures such as those often used by hearing people like a gesture with thumbs up for 'very good'. The RHM does take extensive training and practice to master because a deaf person must compensate for the lack of auditory input and learn to rely on speech reading, speech, and residual hearing. However, only a few for deaf learners were taught the RHM. Additionally, intensive speech therapy by dedicated, qualified and trained educators with specific techniques, was offered. An example is blowing out candles and blowing bubbles to learn the "p" sound. Furthermore, learners following the matric senior certificate generally have strong academic curricula resulting in high achievement levels and more students who go on to complete higher and further education programs. Learners were placed to follow the matric certificate and learners with a technical interest were registered with the Technical College of South Africa completed up to a N3 qualification which is equivalent to Grade 10.

Ahead of his time, Professor Carel du Toit, an Otorhinolaryngologist from Cape Town, and Theodore Blumberg, whose daughter had been diagnosed with profound deafness in 1964 in East London. Both were determined to pursue a new system of teaching children with deafness and had a vision to start a programme for deaf children to develop their residual hearing to enable them to develop spoken language and enter mainstream education (Department of Otorhinolaryngology University of Stellenbosch, 2013). He undertook several journeys overseas to acquire information to develop a model for such a programme. Du Toit was influenced by the work of Edith Whetnall in the United Kingdom and Dr. Roskjawer in Denmark (Fry, 1973). In addition, he was particularly also influenced by the Central Institute for the Deaf in Missouri, United States of America (Central Institute for the Deaf, 2013). The RHM involved encouraging children with deafness to learn to listen and then speak, through a combination of technology and intensive language therapy. This method was also called names like 'Listen & Speak,' 'Listen & Talk'.25 The RHM was used and is defined by Estabrooks as the application and management of technology, strategies, techniques, and procedures to enable children with hearing impairments to learn to listen and understand spoken language in order to communicate through speech (Estabrooks, 1974).

Carel du Toit and Lynas (1994) and DeConde and Seaton (1997) were of the opinion that deafness in children without any residual hearing is rare. .The majority of profoundly deaf children have some residual hearing. In addition, Lynas argues that the residual hearing of most deaf children can be exploited by means of systems of amplification so that the brain receives sufficient input via the auditory channel for the development of spoken language (1994).

4.4 History of total communication

Roy Holcomb, born with deafness, and a fully qualified teacher for the deaf learner, became absorbed in 1967 with the concept of 'Total Communication'. Holcomb had intelligible speech and acceptable English. As a pragmatist, he was inspired by a supermarket slogan advertising 'Total Discounts'. The theory was that spoken language, SL and fingerspelling complement each other so that no deaf learner should be left outside the realm of understanding (Holcomb, 1972). Holcomb defined total communication (TC) as a prescriptive philosophy based on the individual communication-needs of children.

Accordingly speech, fingerspelling, and lipreading may be recommended for one child in a particular class, while speech and sign language may be suggested for another youngster in the same class (Holcomb, 1972). Before TC was defined or even completely understood, many schools in SA had adopted it. The main reason was apparently that a number of these schools had been for many years pursuing variations of this procedure, but had never had an appropriate name for what they were doing.

4.5 Learners with deafness in South Africa

More than 3, 000 learners with deafness attended schools for the Deaf during 1976 in SA (Sellers, Groeneveld & Beighton, 1976). The number of deaf learners in special schools were 3, 134 in 2007 (Education Management Information Systems, 2013). In 2012, the number of learners with deafness were 9, 190 in schools for the deaf, and 12, 324 deaf learners in mainstream schools (Education Management Information Systems, 2013). The consequence is that there could be about 131, 676 children with deafness that are not accounted for by the system. The Department of Basic Education stated that 6, 470 learners were accommodated in schools during 2011 count based on open institutions that submitted the survey forms (Department of Basic Education, 2013). Currently there are 47 schools for learners with deafness, and only 12 offer education up to Grade 12 (de Lange, 2012).

5. DISCUSSION

It is clear that SA has a colourful history by the use of SL and sound amplification which lead to the success of the AOM invented to help those with hearing disabilities. It was an innovative notion that held much promise for the future. The paradigm for deaf education in SA was much like what existed in the USA and in Europe in earlier times. The two ends of the communication spectrum for deaf learners prior 1994 were AOM and SL. However, the dispute comes when educators and academia who support each method define what is beneficial quite differently. Fundamental values lead those who advocate the AOM for deaf learners towards integration and educational benefits while those who support the use of SL focus on natural rights and social-emotional benefits.

In brief, those who believe the AOM is the most beneficial for deaf learners disagree with those who believe the most beneficial method is SL. Misinterpretations that SL is uniform and universal are still very widespread, but they're quite false. There are different dialects of sign languages that have arisen independently wherever there are significant numbers of deaf people together.

Currently, there are various schools for Black learners with deafness, each serving adifferent ethnic group or area, such as Tswana, Xhosa, Zulu, and Sotho. All these schools are making use of American fingerspelling and SL, and use different signs outside and inside the classroom (Department of Education, 2013). According to Erting (1994), all these schools have adopted English as an educational medium, and that further research on South African sign languages, particularly those of Black deaf communities, was attempted once, but this effort was rejected owing to its unscientific approach. Hearing people have made the final decision on what signs would be used in the classroom (Erting, 1994).

The communication debate between these two groups is important because, the method of communication used can affect the social and educational aspects of a deaf individual's life. Since the beginning, SL became a communication method for the deaf and was used extensively. However, the freedom to practice the newly accepted SL was stifled. The debate for the most beneficial communication method was kindled by the two extremes of deaf communication.

In addition, SL has grown as a coordinated and marketed movement and allowed deaf individuals to practice the natural rights of liberty, justice, and equality as stipulated in the Constitution. It is the belief of the Deaf culture and hearing individuals that finally had the liberty to choose and/or use a preferred method of communication while both communication options exist from the beginning. Many opinions as to the correct or most beneficial communication method for the deaf arose. Some chose to avidly support SL while others fought for the AOM. Still others tried to argue a combination of the two could be most beneficial. These combination methods include TC, Bilingual-Bicultural, and Simultaneous Communication (Schwartz, 1996).

However, these combined methods are not as highly debated as are the two clear-cut extremes. This is so because those who support SL truly value the benefits provided by it and the same is true for those who support AOM. Since the beginning of deaf communication until now, aspects such as law, opinions, technology, and educational modifications have formed the evolution and popularity of communication methods for the deaf. Currently, the debate over the most beneficial communication method for the deaf still wages on.

Since the beginning, the AOM has successful results, it can be understood why those who value education truly approve of the AOM. These benefits of AOM allow deaf individuals to reap the educational benefits and have a better chance for equal opportunities. Furthermore, the AOM also had new strategies and technology to assist in successfully educating the deaf.

Hamilton includes necessary services such as speech therapy, occupational therapists, audiology services, and special need education teachers to ensure and support educational success through AOM. Also, the development of technology has allowed for more deaf learners to access AOM, which in turn allows for easier access to educational information, and these technologies enhance the ability of deaf learners to use their residual hearing. All of these developments assist deaf learners in using the AOM to facilitate easier education. Because of the benefits received from the use of AOM, increasing access to it, and the importance placed on education by qualified educators in the field of deaf education, it is seen that the AOM can indeed be beneficial to deaf individuals.

Hamilton stated that developments for the language and hearing impairment include intensive diagnostic and prognostic evaluation by a professional team. Possibilities are presented to the parents and child, with whom the final decision of educational placement rests. Further growth in language and speech education is ascribed to advanced scientific equipment and increasing knowledge, e.g. of the brain. Home units and an after care section also supply increased differentiation. On the other hand, there is still the side of the debate supported by Pro-SL groups who do not disvalue education and assimilation, but instead highly value social-emotional benefits and the privilege to exercise human rights. These values held by Pro-SL groups stem from fundamental values affected by historical influences much as did the AOM supporters.

The evidence that verifies SL as a pathway for procuring social-emotional development, and the right to practice freedoms, is thus present for decades. Although this acceptance does come from a minority group, it comes whole-heartedly as conformity nor is educational status necessary.

Despite the overwhelming support for the benefits both AOM and SL can provide, the debate over the most beneficial communication method for deaf learners still exists. A solution to this debate has been long coming, and may never come, as the choice in communication methods for deaf learners largely revolves around the fundamental values held by each individual. Those who support AOM generally desire more holistic, educational benefits. Those who support the SL method of communication generally desire more individual, social-emotional benefits.

It is identified that the characteristics for general educators are also applicable to the same characteristics of teachers for learners with deafness. Furthermore, deaf education was not offered in the education and training curriculum for teachers, and were trained the skills necessary for the successful maintenance and development of the deaf learner at these schools. Moreover, the essence of teaching requires a deep and thorough understanding of the deaf learner. Archbold (2010) stated in brief that research involving such a low incidence diverse and 'challenging population' with large individual differences and a high proportion of additional disabilities can be problematic when the goal is to draw reliable conclusions.

6. CONCLUSION

To conclude, education for the learner with deafness in SA, has since the beginning of the 19th century been limited to a few learners with access to a few schools for the deaf. The debate regarding the most appropriate methodology for educating children with deafness has raged for more than 150 years and continues to be an emotionally charged issue. Overall, the research findings on efficacy of various communication styles and educational philosophies are inconclusive. Determining the most appropriate methods of enhancing language acquisition, expressive and receptive communication skills, and resultant educational achievement for children with deafness appears to be an issue of paramount importance.

Teachers were trained by highly skilled and experienced teachers at these schools concerning literacy, language, speech, audiology instruction, Deaf Culture, cognitive development and the identification of gifted, technical and practical learners with deafness. The article illustrates that deaf education involves a number of contextual and methodological conundrums which often render the direct application of findings to teaching and learning problematic.

Furthermore Hamilton argued that there is much confusion and ignorance in practice concerning the specific nature and function of special education for the learner with deafness. Furthermore, deafness itself is a complex phenomenon attracting the involvement of a vast range of professional service providers. The implications are inconsistent and not easily predictable for how any individual deaf child may develop and thrive (Hamilton, 1981).

To be deaf is in itself a challenge, including the age at which the hearing loss was diagnosed, prognosis, mental abilities, language development and potential to progress and educational achievements. In addition, domestic factors, socio-economic circumstances, and the attitude of the parents towards deafness. Furthermore, to evaluate these different aspects of the learner, a team of specialists is required and should be available (Hamilton, 1981).

There is a need for researchers and practioners to collaborate and co-operate on these matters in the future. It is clear that this article on the history of deaf secondary education using AOM, is not simply a pointless exercise in nostalgia, nor is it an attempt to turn back the hands of the clock. Rather, it is an opportunity to develop an appreciation for the mutual and differing contributions that have been made to the field of deaf education by the various secondary level schools and special education, that have existed and continue to exist in the commonwealth of deaf South Africans. The gap occurs where the issues of deaf education research and practice collide as two separate entities and remain separate till today. The challenge will be to unravel each communication method in order to re-shape a more integrated whole.

7. REFERENCES

Akamatsu, C.T, Mayer, C. & Hardy-Braz S. 2008. Why considerations of verbal aptitude are important in educating deaf and hard-of-hearing students. In: Marschark M., Hauser, .P.C., editors. Deaf cognition: Foundations and outcomes. New York: Oxford University Press.

Archbold, S. 2010. Deaf education: Changed by cochlear implantation? Paper presented at *Nijmegen: Radboud University Nijmegen Medical Centre.*

Beattie, R. 2006. Oral methods and spoken language acquisition. In: P.E. Spencer & M. Marschark, eds. Advances in the spoken language development of deaf and hard-of-hearing children. New York: Oxford University Press.

Catholic Schools Office. 2012. St Vincent school for the Deaf. Available from: <http://www.cso.za.org/stvin.htm> [Accessed: 22 March 2012].

Central Institute for the Deaf. 2012. A school where children learn to listen, talk, read and succeed. Available from: <http://www.cid.edu/Home.aspx> [Accessed: 11 March 2012].

Convertino, C.M., Marschark, M., Sapere, P., Sarchet, T. & Zupan, M. 2013. Predicting Academic Success Among Deaf College Students, *Journal of Deaf Studies and Deaf Education* 18, (4): 324-343.

De Brún, F. 2006. Belfast and the Irish language. Dublin: Four Courts.

DeConde, J. C. & Seaton, J. B. 1997. Educational Audiology Handbook. San Diego: Singular Publishing Group, Inc.

de Lange, D. 2012. Deaf not being heard, activists tell MPS. *Cape Argus*. Available from: <http://www.iol.co.za/capeargus/deaf-not-being-heard-activists-tell-mps-1.1215328> [Accessed: 18 January 2012].

Erting, C. 1994. *The deaf way: Perspectives from the international conference on deaf culture*. Washington, D.C.: Gallaudet University Press.

Department of Basic Education. 2013. Education Statistics in South Africa. Department of Basic Education.

Department of Otorhinolaryngology University of Stellenbosch. 2011. History - department of otorhinolaryngology. Available from: <http://www.docstoc.com/docs/71502418/History---DEPARTMENT-OF-OTORHINOLARYNGOLOGY> [Accessed: 11 June 2011].

Education Management Information Systems. 2007. Education Statistics. Available from: <http://www.pmg.org.za/minutes/20071108-education-management-information-system-emis-ensuring-quality-through-education-dis> [Accessed: 15 February 2011].

Education Management Information Systems. 2012. Education Statistics. Available from: <http://www.pmg.org.za/minutes/200121108-education-management-information-system-emis-ensuring-quality-through-education-dis> [Accessed: 11 October 2012].

Erting, C. 1994. The deaf way: Perspectives from the international conference on deaf culture. Washington, D.C.: Gallaudet University Press.

Estabrooks, W. 1994. Auditory verbal therapy for parents and professionals. Washington, D.C: Bell Association for the Deaf.

Fry, D. B. 1973. Acoustic cues in the speech of the hearing and the deaf. *Proceedings of the Royal Society of Medicine*, 66(10), 959-969.

Hamilton. J. 1981. 'Nuwe ontwikkelinge op die gebied van onderwys aan gehoorgestremdes'
[New developments in the field of education to the hearing impaired]', *South African Medical Journal,* 856-857.

Holcomb, R. K. 1972. The total approach. proceeding of the international congress on education of the deaf - Stockholm. Stockholm: Swedish Teachers Association.

Instituut vir Dowes Worcester. 1981. Instituut vir Dowes Worcester 1881-1981. Worcester: Worcester Printers.

Kleinschmidt, E. [ewk@xelatrading.co.za]. 2011. History of Deaf Education in South Africa. Email to: Smith, M. [smithm@ufs.ac.za]. 14 May 2011.

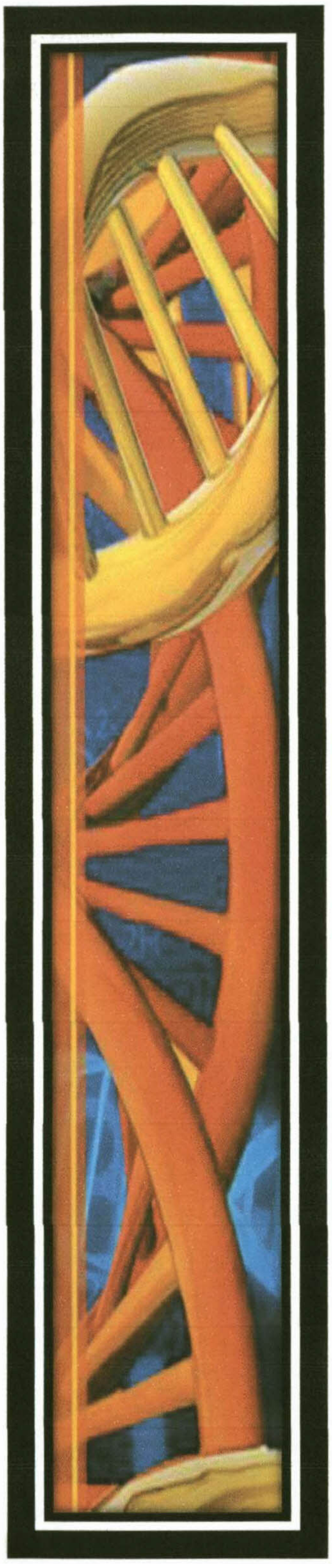
Lynas, W. 1994. Choosing between communication options in the education of deaf-children. *Journal of the British Association of Teachers of the Deaf,* 18, 141-53.

Mesthrie, R. 2002. Language in South Africa. Cambridge: Cambridge University Press.

Republic of South Africa. 1937. Deeds registries Act, Act no. 47 of 1937. Available from: <http://wced.pgwc.gov.za/documents/legislative_acts/act12-97.pdf> [Accessed: 28 February 2011].

Sellers, S., Groeneveld, L. & Beighton, P. 1976. Aetiology of Deafness in White Children in the Cape. *South African Medical Journal,* 1193-1197.

Schwartz, S. 1996). Choices in deafness (2nd ed.). Bethesda, MD: Woodbine House.



PAPER II

APPLICATION OF THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH WITH SPECIFIC FOCUS ON DISABLING HEARING IMPAIRMENT IN LEGISLATION AND POLICY IN SOUTH AFRICA

APPLICATION OF THE INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH WITH SPECIFIC FOCUS ON DISABLING HEARING IMPAIRMENT IN LEGISLATION AND POLICY IN SOUTH AFRICA

Abstract

Disability legislation faces two but potentially contradictory perceptions. Persons with disabling hearing impairment (DHI) are committed to eradicating discriminatory attitudes and practices, and are determined to remove barriers to communication and integration. Legislation should be aimed at breaking down these barriers, and be designed to assist persons with DHI to overcome stereotyped assumptions about their disability and ability. To achieve these goals, a common framework for describing functional status information is needed in order to make this information comparable and of value. The World Health Organisation's International Classification of Functioning, Disability and Health (ICF), which has been approved by all its member states, including South Africa (SA), provides a common language and framework to be used in legislation. This article analyses disability legislation in SA, with specific focus on DHI to determine the application and definition consistency. It finds that some legislation includes some elements of disability. This endeavour may have extensive implications for the development of law and public policy to supplement the ICF and the Constitution in South Africa.

1. INTRODUCTION AND BACKGROUND

This paper aims to present the results of a review on the application of the International Classification of Functioning, Disability and Health (ICF) with specific focus on disabling hearing impairment (DHI) in legislation and policy in South Africa (SA). In pursuance of this aim, relevant laws, regulations and policy statements issued in SA after 1994 are scrutinised. The term DHI is used to describe all individuals with hearing loss causing an impairment of functioning, regardless of their level of auditory impairment. The usage of terms such as deaf, socially deaf, and hard of hearing is subject to inconsistencies, and may embody a medical, psychological or social-cultural perspective (Calderon & Greenberg, 1977).

There is no separate disability legislation in SA. The World Health Organisation (WHO) is advocating a paradigm shift in how the world perceives and defines disabilities (WHO, 2001(a). An analysis of social protection and employment policies directed towards persons with disabilities first requires an answer to the question as to what constitutes a disability.

In 1980, an important breakthrough took place when the WHO developed the International Classification of Impairments, Disabilities and Handicaps (ICIDH), as the first conceptual framework of its kind to incorporate the influences of personal, social and environmental factors on persons with disabilities (WHO, 1980). The ICIDH was the first framework for analysing disability issues compatible with the emerging understanding that medical rehabilitation, assistive devices and personal assistance can reduce the functional limitations of persons with disabilities, and thus increase their capacity to take advantage of social and economic opportunities, and that social and environmental policies can alter the societal contexts of disability.

Previously, "disability" was regarded as a medical issue of a severe abnormality of a body structure or a loss or deviation of physiological function. The ICF combined these concepts into a comprehensive whole of multiple dimensions of human functioning, synthesising biological, psychological, social and environmental aspects. The newly proposed model, called the biopsychosocial model, synthesises the best of both the medical and social models on which ICF is based. Therefore, the ICF, first published by the WHO in 2001, created a standard language and framework for describing health and health-related states (WHO, 2002). In the case of the WHO, this is also in the acronym of the ICF, which replaces the acronym ICIDH, the International Classification of Impairments, Disabilities and Handicaps. Led by the WHO, the ICF is an attempt to improve our understanding of disability, and reflects the move from a static to a dynamic definition of disability. This has been underway for over twenty-five years. There are no published reports on the application of the ICF in SA.

The right of persons with DHI to health and rehabilitation services has been grossly neglected. Necessary health care and support services are frequently unavailable or inaccessible, while human rights abuses are often pervasive within services where they do exist. Despite progress in developing appropriate services, additional policy and legislative initiatives are a prerequisite for the realisation of the right to health for persons with DHI. A human rights approach, including participation, activities, environment, autonomy, dignity, inclusion, monitoring, and accountability should guide all relevant actions.

In an effort to improve the collection of disability data in developing countries, the United Nations Statistical Division formed the Washington Group on Disability Statistics consisting of representatives from member states and statistical agencies. The World Bank has provided support for this group to help arrange regional meetings, subsidise the attendance of developing country representatives and conduct field tests. First, in order to facilitate the gathering of basic disability information throughout the world, the group is guiding the process of developing a small set of general disability measures for use in censuses and sample-based national surveys. Secondly, the group is preparing recommendations for extended sets of survey items related to general measures that can be used as components of population surveys or supplements to speciality surveys. The ICF framework will be used to develop the measures.

In 2001, the 191 member states of the WHO, including SA, agreed to adopt the ICF as the basis for scientific standardisation of data on health and disability worldwide (WHO, 2002). As a result, the ICF serves as a powerful tool to address disability issues from clinical management to multidisciplinary research, legislation, policy development, and economic impact. The SA government sent a delegation of representatives to participate in the revision process.

2. METHOD

An analytic-comparative study of disability legislation with a descriptive focus was conducted, and an attempt was made to accurately portray the application of the ICF principles in disability legislation (Heywood, 2002). The approach to this study is deductive in that legislation will be utilised and applied to the definitions in disability legislation by means of the biopsychosocial model in the context of the ICF (WHO, 2001(b). Definitions of hearing impairment in legislation were analysed according to the framework provided by the WHO.

The discussion is exploratory in the sense that it explores the application of the ICF to the SA context with the aim of developing new insights into and understandings of the topic. The method of investigation relied mostly on a comprehensive literature review on the application of the ICF to SA legislation and consisted of books, journals, newspaper articles and internet sources. The study focused primarily on SA legislation by studying the relevant laws, regulations and policy statements issued after 1994 to illustrate the application of the ICF in SA disability legislation, with specific emphasis on DHI in the SA context.

3. LEGAL FRAMEWORKS IN SUPPORT OF DISABILITY LEGISLATION IN SOUTH AFRICA

Legal definitions of disability have been an issue of much international debate. Despite the efforts of the ICF, there is no universal international legal definition of disability. A study of the definitions of disability in various European Union (EU) countries has shown variations not only from country to country, but also within each country (Employment & Social Affairs, 2002). While there are similarities among the definitions of disability in some areas of social policy, definitions of legal disability in each country differ with respect to income maintenance, employment measures or social assistance with daily life activities. ICF combined these concepts into a comprehensive whole of multiple dimensions of human functioning, synthesising biological, psychological, social and environmental aspects. Therefore, ICF presents health and disability in a single spectrum. Traditionally, these areas were considered separately and at times polarised. However, a detailed analysis of the domains that make up health and disability shows that these two basic constructs are, in fact, different manifestations of the same domains of functioning such as vision, cognitive, hearing and many others. Despite the WHO's efforts, there is no universal international legal definition of disability, nor is there one in South Africa.

In international law, a number of international agreements refer to rules of a non-legal nature, respect for which is made obligatory by such references. Governments frequently wish to record, in writing, the terms of an understanding or arrangement between them without creating obligations that would be binding under international law (Mörth, 2004). While not binding under international law, a non-binding instrument may carry significant moral or political weight. Non-legally enforceable instruments are referred to as 'soft law', and such instruments are often used in international relations to establish political commitments (Goldmann, 2012).

It is suggested that the ICF be regarded as a treaty, since it is a basic principle of international law that a state which is party to an international treaty must ensure that its own domestic laws and practices are consistent with what is required by the treaty (Brownlie, 2008). In this instance, the ICF gives specific stipulations and general guidance on the measures to be taken (WHO, 2002).

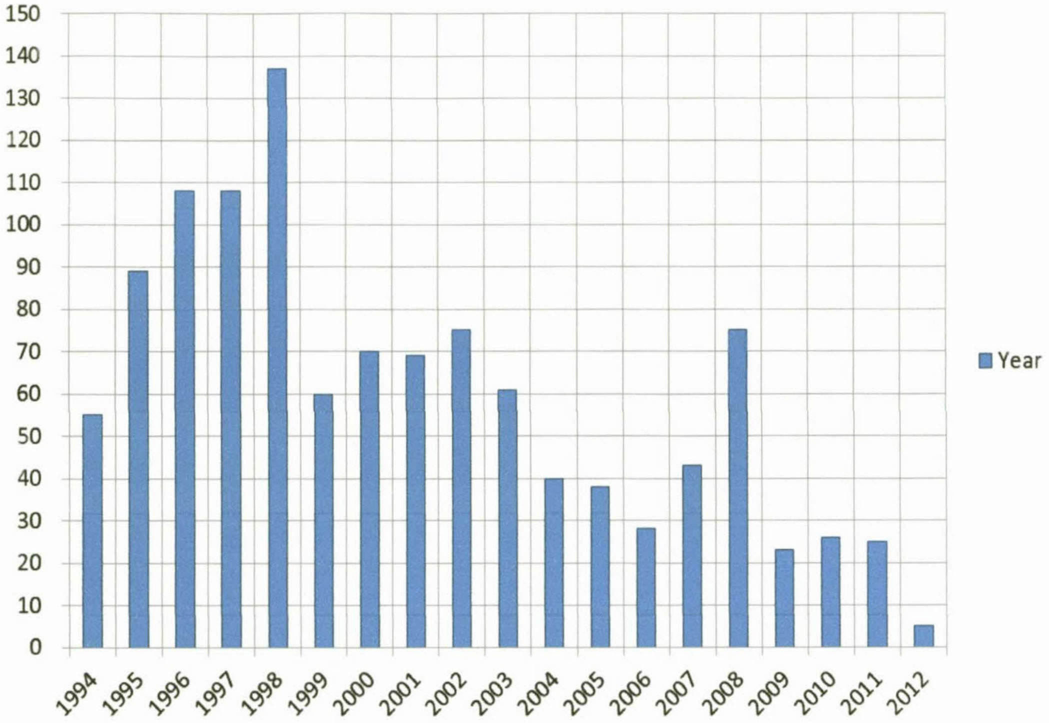
The United Nations Convention on the Rights of Persons with Disabilities (UNC) is an example of a treaty which entered into force on 3 May 2008 (United Nations, 2008). Although the UNC does not explicitly define disability, it considers that disability arises from a health condition in interaction with the environment. Parliament thus has a critical role in ensuring that the legislative measures required by the WHO and the UNC are adopted.

It is arguable that SA definitions of disability in legislation are closely aligned with the medical model. Definitions of disability in the SA context vary in relation to different legal purposes. The Social Assistance Act, 2004 (Act no. 13 of 2004) provides personal assistance benefits; for example, it may have a different target group of disabled persons than in discrimination law.

Therefore, eligibility criteria to classify impairment are based mainly on a person's medical status, with secondary attention given to environmental dysfunctions as incorporated, among others, in the Social Assistance Act, 2004 (Act no. 13 of 2004), the Compensation for Occupational Injuries and Diseases Act, 1993 (Act no. 130 of 1993), the Blind Persons Act, 1968 (Act no. 26 of 1968), the Income Tax Act, 1962 (Act no. 58 of 1962), the Income Tax Act, 1997 (Act no. 28 of 1997), the Medical Schemes Act, 1998 (Act no. 131 of 1998), Government Gazette (No. 2284 of 2001), Government Gazette, 2002(a) (No. 22209 of 2002), and Government Gazette, 2002(b) (No. 23718 of 2002). Since April 1994, 1135 Acts of Parliament have been issued, as illustrated in Figure 1. As a result, 17 pieces of the 1135 Acts contain words such as disability, disabled, deaf, Deaf, deafness, hearing impairment, and hearing impaired. Six pieces of this legislation are analysed according to the framework of the ICF namely;

- Impairments of body function;
- Activities, and
- Participation

Table 1: Total Acts of Parliament issued after 1994



Source: South African Government Information 2012

4. RESULTS AND DISCUSSION

This section critically analyses disability legislation with the application of the ICF and with specific reference to DHI. As a result of the concentrated lobbying activities of persons with disabilities and their advocates, key findings drawn from the analysis are briefly discussed. SA passed several laws aimed at protecting persons with disabilities.

4.1 Income Tax Act 58 of 1962

Expenditure prescribed by the Income Tax Act (ITA) of 1962, which is necessarily incurred and paid for by the taxpayer in consequence of a physical impairment or disability, is deductible in terms of Section 18 of the Act, subject to certain limitations. This Act came into effect on 1 March 2009.

Previously, persons with disabilities could only claim their total medical expenses not covered by their medical aid if they were 65 years and older, or if the ITA regarded them as handicapped. Prior to the recent changes, Section 18(3) referred to a "handicapped person" and was defined to the extent that some persons with a disability were excluded from being "handicapped". Disabled but not "handicapped" persons are afforded lesser tax benefit than "handicapped persons". These limitations in the ITA were restricted to persons with a disability who were not "handicapped".

The term "handicapped person" was narrowly defined, and covered five categories of persons, namely a blind person; a deaf person; a permanently disabled person requiring a wheelchair, calliper or crutch to move from one place to another; a person requiring an artificial limb, and a person suffering from a mental illness, as defined in Section 1 of the Mental Health Care Act of 2002. This meant that a person would have to have DHI to the point that s/he relied on sign language to claim all expenses, whereas a person requiring a hearing aid could not claim the expenses incurred in full.

In recognition of this, the ITA was amended in 2008 so that persons with disabilities can claim all expenses, medical or otherwise, to enable them to function more fully in their daily lives. These new deductions apply if the taxpayer concerned, the taxpayer's child or spouse has a disability. The ITA was amended to broadly replace the terms "physical disability" and "handicapped" by "physical impairment" and "disability", respectively, with effect from 1 March 2009. In addition, the word "impairment" is based on the definition of "disability" in Section 18(3) of the ITA and this is used in respect of all disabilities. Accordingly, the terms "hard of hearing", "Deaf", and "deaf" cannot be used.

The ITA defines a "person with a disability", as a person living with a "disability" as defined by the new legislation. This is a more widely accepted term and generally used in lieu of the term "handicapped person". The qualifying expenditure under Section 18 of the Act is not subject to a limitation if a taxpayer, his or her spouse or child is a person with a disability.

"Moderate to severe limitation" is defined as a significant restriction on a person's ability to function or perform one or more basic daily activities after maximum medical correction.

The prescribed list of qualifying expenses relating to physical impairment or disability and the diagnostic criteria for disability were published on 20 April 2010 (South African Revenue Services, 2010).

The amendment clarified which expenses the South African Revenue Services (SARS) would allow as a deduction; it also provides the list and the diagnostic criteria. The extensive but not comprehensive list of qualifying expenses identifies broad categories of qualifying expenses and provides examples of expenditure that can be claimed.

With respect to the diagnostic criteria, disability is viewed as an impairment to the body or mind that results in a moderate to severe limitation on a person's ability to perform daily functions. A person might be diagnosed with a permanent or temporary disability. In the case of a permanent disability, the diagnosis will be valid for five years and must be confirmed by a registered health practitioner at the end of that period, whereas a temporary disability diagnosis is valid for one year.

"Physical impairment" is interpreted as a disability that is less restraining than a disability defined as the restriction on the person's ability to function or perform daily activities after medical correction is below a "moderate to severe limitation". Qualifying expenses paid by a taxpayer in respect of a person with a physical impairment will still be deductible under Section 18(1)(d) of the ITA, but the quantum of the deduction will be limited to amounts in excess of 7.5 percent of the taxpayer's taxable income in the case where the taxpayer is below the age of 65. To claim the deductions, the person with a disability must be diagnosed and obtain a confirmation of his/her disability from a registered health practitioner in accordance with the criteria prescribed by SARS. To determine eligibility under Section 18(2)(b) of the ITA (as amended), the information required in order to comply the document, ITR-DD: "Confirmation of Diagnosis of Disability" is prescribed.

The diagnoses as defined by the ITA are divided into six categories, namely:

- Vision;
- Communication;
- Physical;
- Mental;
- Hearing, and
- Intellectual

The ITA refers to a "hearing disability" which is defined as the functional limitations resulting from a hearing impairment (HI). HI is a sensory impairment that will influence verbal communication between speaker and listener. It is an abnormal or reduced function in hearing resulting from an auditory disorder.

The list is structured in such a way that it broadly defines the category of allowable expenses and then provides examples of expenses that will be allowed under a specific category.

The definition given implies that impairment is a less severe disability than the one defined in the document. However, in the context of health, impairment is not defined in the same way as disability. WHO defines impairment as "any loss or abnormality of a psychological, physiological or anatomical structure or function", and as "problems in body function or structure such as a significant deviation or loss" (WHO, 2001a:10).

To the extent that alterations or modifications to assets are made to enable the person with disability to function or perform daily activities in both an efficient and safe (reducing the risk of personal injury) manner, the expenses incurred will be regarded "as necessarily incurred as a consequence of disability" and, therefore, allowable. The ICF provides a common language for describing the experiences of persons with DHI, as well as those experiencing a variety of other conditions, in terms of the impairment in body structure or function and the resulting limitations in the individual's ability to perform daily activities or participate in life. The ICF presents a clear framework, because it specifically incorporates contextual factors (environmental and personal) and demonstrates the potential impact of these factors on a person's overall experience of health.

4.2 National Health Act 61 of 2003

The National Health Act (NHA) of 2003, Section 73(2)(a) states that a "review of research proposals and protocols in order to ensure that research conducted by the relevant institution, agency or establishment will promote health, contribute to the prevention of communicable or non-communicable diseases or disability or result in cures for communicable or non-communicable diseases". Moreover, Section 25(2)(w) of the NHA states that the head of a provincial health department must, in accordance with national health policy and the relevant provincial health policy in respect of or within the relevant province, "provide services for the management, prevention and control of communicable and non-communicable diseases".

Section 39(2)(a) states that regulations relating to certificates of need "must ensure the equitable distribution and rationalisation of health, with special regard to vulnerable groups such as women, older persons, children and persons with disabilities" and (d) "must ensure and promote access to health services and the optimal utilisation of health care resources, with special regard to vulnerable groups such as women, older persons, children and people with disabilities", (e) "must ensure compliance with the provisions of this Act and national operational norms and standards for the delivery of health services".

The ICF is based on two important principles that have significant implications for how health services are conceptualised and structured. The first principle is universality, that is, the view that disability is a typical phenomenon of the human condition, affecting all individuals in some way and at some time in their lives. This is in contrast to the view of disability as a defining characteristic of specific minority groups. The second underlying principle of the ICF is continuity, or the view that disability in any area exists along a continuum, based on the interaction of the person, the health state, and the environment. This is in contrast to a view of disability as a categorical phenomenon, that is, something intrinsic to the person that s/he either does or does not have. The values that underlie the ICF include the dignity and worth of all individuals, the inclusion of persons with disabilities in society to the fullest extent possible, and the need for advocacy to provide persons with disabilities with the best opportunity to maximise their independent functioning.

According to Section 90(1)(d) of the NHA, assistive devices form part of health services "the development of an essential drugs list and medical and other assistive devices list". Section 25(j)(k)(l)(q)(r)(j) of the NHA provides regulations regarding (j) communicable diseases, (k) notifiable medical disease, (l) rehabilitation, (q) non-communicable diseases, and (r) health technology. Municipal health services include the (e) "surveillance and prevention of communicable diseases, excluding immunisations".

The NHA focuses strongly on local authorities adopting an enabling role, in partnership with the voluntary and private sectors. It also focuses on a more imaginative response to needs, rather than assessing people for services. This Act should be viewed, in conjunction with the ICF and other legislation, as managing or providing a range of services including hearing devices, interpreters and environmental aid provisions.

Rehabilitation is an important aspect of health and is defined by the NHA as "a goal-orientated and time-limited process aimed at enabling impaired persons to reach an optimum mental, physical or social functional level". ICIDH-2 was developed for application to various aspects of health. Furthermore, the ICF provides a framework to code a wide range of information about health such as diagnosis, functioning and disability, and reasons for contact with health services. It uses a standardised common language permitting communication about health and health care across a country in various disciplines and sciences. In a sense, it is a retrograde step and perhaps bodes badly for anti-discrimination legislation. The NHA has no joint plans on DHI services.

Furthermore, the ICF is particularly relevant to DHI, because it focuses on more than merely the observable characteristics of disorders. For DHI, the ICF supplements information on observable characteristics such as repetitions, prolongations, and misunderstandings that may characterise DHI with information about the overall impact of disorder including negative communication attitudes, shame, embarrassment, and limitations in an individual's ability to participate in society. In addition, the ICF allows the description of both impeding factors such as negative responses to a person's DHI and facilitating factors such as speech therapy, support groups, and an accepting environment. The application of the ICF in this Act will firmly enforce the notion of local authorities acting as enablers rather than providers, and will contribute to a mixed economy of social services and partnerships.

4.3 Medical Schemes Act 131 of 1998

The Medical Schemes Act No. 131 of 1998 was amended by The Medical Schemes Amendment Act (MSAA) No. 55 of 2001. Section 24, substitution (2)(e) of the MSAA promotes the right to equal treatment by stating that "the medical scheme does not or will not unfairly discriminate directly or indirectly against any person on one or more arbitrary grounds including race, gender, marital status, ethnic or social origin, sexual orientation, pregnancy, disability and state of health". The MSAA is, in fact, human rights legislation. One of the objectives of the Council for Medical Schemes in creating the Act was to protect and enhance the rights of the members, referred to as "beneficiaries", "at all times" (MSAA, 2001).

These rights may be championed or protected in two ways. First, by the registrar of medical schemes, who is empowered to conduct an inspection of a medical scheme "if he or she is of the opinion that such an inspection will provide evidence of any irregularity or of non-compliance with [the] Act by any person" or "for purposes of routine monitoring of compliance with [the] Act by a medical scheme or any other person". As amended, the MSAA (2001) also entitles the registrar to address to a medical scheme any inquiries related to "any matter connected with the business or transactions of the medical scheme".

The second is by the members themselves. In this regard, the MSAA affords the members the right to lodge a complaint with the registrar against a truant medical scheme. According to Section 43 of the MSAA, if the member is not satisfied with the outcome of the complaint, s/he may appeal to the Council for Medical Schemes. The MSAA also provides the member with a procedure that does not require the beneficiary to incur legal costs or formal litigation.

The rules of a medical scheme, which form the contract between the scheme and its members, are also regulated by the MSAA. What the rules may and may not contain is specified. These specifications are designed to protect members against discrimination. In addition, a medical scheme in SA operates as a 'non-profit organisation (NPO)', also known as 'Section 21 Companies' in accordance with the Non-Profitable Organisations Act, 71 of 1997. According to Section 31(a), an application for registration is R5 000.00 (US$500.00).

Prescribed minimum benefits are defined as benefits contemplated in terms of Section 47 of the MSAA, and consist of the provision of the diagnosis, treatment and covering of the health care costs of diagnoses and treatment pairs subject to limitations in Annexure A (AA), and any emergency medical condition.

An emergency medical condition means the sudden and, at the times, unexpected onset of a health condition that requires immediate medical and/or surgical treatment. If the treatment is not available, the emergency could result in serious impairment to bodily functions, serious and lasting dysfunction to organs, limbs or other body parts, or even death.

Code 905A in AA states that the diagnosis of acute and sub-acute meningitis requires "medical and surgical management". This means that a medical scheme may not refuse to pay for a cochlear implant if needed.

In 2003, the Board of Healthcare Funders wrote to its members to suggest that medical schemes volunteer to initiate a separate, shared fund to cater for specific rare conditions that usually create significant financial risk. Included on the proposed list of diseases was Gaucher disease, an inherited enzyme deficiency disorder, haemophilia, cystic fibrosis, cochlear implants, interferon-treated multiple sclerosis and chronic myeloid leukaemia. Gaucher disease was included as a prescribed minimum benefit and could cost between R600 000.00 (US$60 000.00) and R700 000.00 (US$70 000.00) to treat one individual. However, no discussion has taken place on the treatment and rehabilitation programmes for persons with DHI.

It was recommended that the concept be developed and that it would only be successful with the buy-in from the majority of the medical schemes. Shaun Matisonn, principal of Discovery Health, was of the opinion that such a fund might protect individual schemes from "adverse selection fallout". He mentioned that schemes are prevented from offering best practice care unless other schemes buy in, because if only a limited number of schemes offered treatment for particular expensive conditions, then all the sufferers of those diseases "flocked to that limited number of firms" (Board of Healthcare Funders, 2003). It is observed that inappropriate terms are used for cochlear implants such as 'a rare disease'; moreover, it is astonishing that reference has been made to a technology device and not DHI. According to the WHO (2006), "hearing loss, visual impairment and mental disorders are the most common causes of disability worldwide".

Moreover, it has become the norm not to exclude all impairments from the benefits of a medical scheme; however, medical scheme product designers are cautious about what they include and about the amount in the insured benefit portion of their scheme. Hearing devices, including cochlear implant devices and assistive listening equipment, whether introduced internally or not, as well as the maintenance of these devices, usually do not qualify for payment from insured benefits. The majority of medical aids pay between R4 000.00 (US$4 000.00) and R15 800.00 (US$1 580.00) for hearing aids per family annually. A limited number of medical schemes pay for cochlear implants, with benefits ranging between R55 000.00 (US$5 500.00) and R140 000.00 (US$14 000.00) per family annually, subject to prior approval.

The Council for Medical Schemes'(2011) 2010-2011 annual report revealed that the Council dealt with 863 more complaints last year (total 5351) than it did in 2009, when 4488 people complained about schemes. The highest number of complaints the Council received in 2010 were related to the prescribed minimum benefits (1749), followed by refusal to authorise treatment (272) and exclusion of conditions or benefits (87) (Council for Medical Schemes', 2011).

The MSAA refers explicitly to diagnostic groups without the framework of the ICF. The ICF definition clearly expresses the essential structure of the concept of disability as a result of an interaction between features of an individual with a health condition and features of the physical and attitudinal environment. In addition, the MSAA is restricted to specific groups, but is not flexible so that as resources become available, the threshold of disability can be adjusted so that more individuals can benefit from these resources.

The relationship of health and functional status information from the ICF codes for activities, participation, and the environment to ICD codes in predicting health care expenditures for persons with DHI is ignored. In addition, the analysis revealed that activities and participation within the context of the environment moderate the effect of physically disabling conditions on total health care expenditures for persons with DHI. The analysis used in an internationally recognised procedure for linking ICF classification codes and health care expenditures describes the relationship between total health expenditures and treats physically disabling conditions and function within the context of the environment.

The author argues that differences in conditions mean that expenditures are provided for all total, in-patient, ambulatory care, prescription medication, as well as dental and other medical care expenditures. The environment component of the ICF will contribute and ensure equality towards total health expenditure for persons with DHI.

An already complex industry has only now begun to embrace its newfound flexibility. The onslaught of managed care concepts and technology will raise the levels of complexity to new heights. Players will become more sophisticated, offering ever greater levels of service in order to survive. Furthermore, as the industry matures, an overall definition must be maximally inclusive and conceptually valid. The ICF adopts neutral language and does not distinguish between the type and the cause of disability – for instance, between "physical" and "mental" health. "Health conditions" are diseases, injuries, and disorders, whereas "impairments" are specific deviations in body functions and structures, often identified as symptoms or signs of health conditions (WHO, 2002).

4.4 Criminal Law (Sexual Offences and Related Matters) Act 32 of 2007

The Criminal Law (Sexual Offences and Related Matters) Act (CLA) defines a "person who is mentally disabled" as "a person affected by any mental disability, including any disorder or disability of the mind, to the extent that he or she, at the time of the alleged commission of the offence in question, Section (d) is unable to communicate his or her unwillingness to participate in any such act".

No provisions are made for persons with DHI and the provisions made apply explicitly to persons with mental disabilities. Legislation designed to protect persons with DHI from injury, ill-treatment or abuse refers to persons, in the main not themselves HI, who might be in a position, or who might take advantage of the condition of the HI, to cause them harm. Legislation which may be termed discriminatory in respect of the HI, though possibly for their protection as well, has been limited.

The ICF could play a vital role if used as an advocacy tool for the promotion of an inclusive and participatory approach in the fight against victimised persons with DHI, with a well-defined objective towards scaling down the Act to all vulnerable groups which will include all persons with different disabilities, whether visible or invisible.

Currently, there is no consistent data-gathering system in SA to document longitudinally the prevalence of childhood sexual abuse among children who are HI. If the prevalence of sexual abuse among this population is to be truly understood, additional steps must be taken to elicit consistent and widespread data-collection techniques from national organisations, and from the Departments of Social Welfare and Health. Understanding the prevalence of abuse is important to intervention and treatment. However, a problem with the system is the classifications used to identify children with disabilities and, in particular, those with DHI.

The CLA Section 43(a)(i) requires the registration of any person convicted of a sexual offence against a child or a mentally disabled person. Section 43 states that the register seeks to "protect" children and mentally disabled persons by "maintaining a record" of convicted offenders. Section 49(b)(i-iii) requires a limited amount of information concerning an offender. The register only requires the offender's name, address, identification number, passport number, and driver's license number. The register will outline the nature of the crime, including the date of the offence, the place of conviction, the case number and the court in which the trial took place. The provisions in Section 51(1)(a)(i) are lenient and the duration of the registration period is linked to the length (or potential length) of the offender's sentence.

The CLA states that persons sentenced to imprisonment or correctional supervision for between six to eighteen months are to be removed from the register after a period of ten years. Persons with sentences of six months or less may be removed after seven years. The level of confidentiality of the contents of the register is stipulated in Section 52(1), and will not be available to the public, but only those entitled to apply for a certificate will have access to the information contained in the register. Furthermore, the CLA makes it a criminal offence for anyone to wilfully disclose or publish information contained in the register, except as when necessary to give effect to the provisions of the CLA or when ordered to do so by a court (Section 52(3)(a-b)).

Government needs to consider the possibility that the register could violate the Constitution. Perhaps by curtailing the register's scope, Government hopes to avoid possible legal challenges. Chapter 2 of the Constitution is loaded with explicit and substantive rights. Several Sections might form the basis for a substantive attack on SA's sex offender register. Section 9(1) states that "[e]veryone is equal before the law and has the right to equal protection and benefit of the law". Section 10 states that "[e]veryone has inherent dignity and the right to have their dignity respected and protected". Section 12 states that "[e]veryone has the right to freedom and security of the person, which includes the right not to be treated or punished in a cruel, inhuman or degrading way". Section 14 states that "[e]veryone has the right to privacy".

In addition, the CLA does not prescribe penalties for at least 29 sexual crimes described in the legislation. The crimes include consensual sex acts with children and sexual offences against persons with mental disabilities. The Constitution states that the rights contained in the Bill of Rights "may be limited only in terms of law of general application to the extent that the limitation is reasonable and justifiable in an open and democratic society based on human dignity, equality and freedom, taking into account all relevant factors". The factors to be considered include "the nature of the right, the importance of the purpose of the limitation, the nature and extent of the limitation, the relation between the limitation and its purpose; and less restrictive means to achieve the purpose". In other words, SA courts will conduct a balancing test when faced with a law that infringes upon any of the rights contained in the Bill of Rights.

Individuals who need support services are usually more vulnerable than those who do not. Persons with mental health conditions and intellectual impairments are often subjected to arbitrary detention in long-stay institutions without right of appeal, in contravention of the CRPD (98, 99). Vulnerability – both in institutions and in community settings – can range from the risk of isolation, boredom, and lack of stimulation, to the risk of physical and sexual abuse. According to Goodstein (2010), the South African Government Information (2002) and Berke (2011), evidence suggests that persons with DHI are at higher risk of abuse, for various reasons, including dependence on a large number of caregivers and barriers to communication.

Contextual factors include environmental and personal factors that may have an impact on the individual with any disability. In addition, environmental factors make up the physical, social and attitudinal environments in which people live and conduct their lives, and are external to individuals and can have a positive or negative influence on the individual's performance as a member of society, on his/her capacity or on his/her body function or structure. Environmental factors focus on two different levels, namely

- Personal, including settings such as home, workplace and school. This level includes the physical and material features of the environment which an individual faces, as well as direct contact with others such as family, acquaintances, peers and strangers.
- Services and legal systems, referring to formal and informal social structures, services and overarching approaches or systems in the community or a culture, have an impact on individuals. This level includes components such as laws, regulations, formal and informal rules, attitudes and ideologies.

According to the ICF, environmental factors interact with the components of body functions, structures, activities and participation. One could almost assume that DHI and other disabilities are not a key factor in terms of child abuse, and that this Act does not represent the contextual factors of the ICF with the complete background of an individual's life and living.

4.5 Mines Health and Safety Act 29 of 1996

The Mines Health and Safety Act (MHSA) for noise regulation was introduced to increase eligibility for DHI according to specific measurements and classifications as required by the MHSA (Government Gazette No. 2284 of 2001).

In industries such as gold mining, in which the equipment generates noise greater than 85 decibels (dB), noise can cause irreversible hearing loss (Kahan & Ross, 1994; Franz *et al.* 1988; Crandell *et al.* 2004). The MHSA requires mines to implement hearing conservation programmes and to provide personal protective equipment to individuals exposed to such noise. The MHSA is based on the WHO's severity-level definitions for adult-onset hearing loss (WHO, 2001a).

There is an increasing need to accurately identify sound sources that may be dangerous, and to quantify the hazard or risk they potentially present. To date, research has primarily been directed at examining noise exposure in workplace environments (WHO, 2006; Neitzel *et al.* 2004:463-73; Monley *et al.* 1994:22). As a consequence, Neitzel *et al.* (2004) and Monley *et al.* (1994) addressed the problem; the focus has generally been on documenting the amount and level of sound received throughout an individual's working years, often with a specific focus on designated industries such as manufacturing, mining, transport and defence.

According to the ICF, these environmental factors comprise five different components: products and technology; natural environment; man-made changes to the environment; systems, and security policies (WHO, 2001).

A WHO steering committee is in the process of developing an internationally accepted, evidence-based, reliable, comprehensive and valid ICF Core Sets for Hearing Loss (Danermark *et al.* 2010).

4.6 Electronic Communications Act 36 of 2005

Regulations in respect of meeting the needs of persons with disabilities are stipulated in terms of Section 4(1) of the Electronic Communications Act (ECA) of 2005, and Section 2(h) of the Postal Services Act of 1998. The Act defines "persons with disabilities" as individuals who are limited in one or more functional activities. This may be seeing, hearing, communicating, moving, learning or other intellectual and emotional activities. The impairment may be permanent, recurring or transitory. It may be sensory, physical, cognitive or psychological.

Section 5(2)(e) of the ECA states that subtitles and sign language need to be provided to persons with DHI in television programmes. Section 10(1)(a) sets out the guidelines concerning specialised equipment for persons with DHI at no extra cost such as text phones. Two individuals with text phones can type directly to each other. Some text phones also have printers so that a physical record of a conversation could be on record to avoid misunderstandings. Landline phones are equipped with amplifiers, sms equipment and additional volume ringers.

The CEA goes beyond the medical model to take a much broader view of disability. These requirements are based on the ICF framework, namely body structure, function, individual activities and social participation, to make use of electronic technology in order to maximise communications to a full extent.

5. CONCLUSION

In the field of disability legislation in SA, the various terms used can be confusing and elicit controversy. Legislation without the framework of the ICF has become a pivotal issue, especially for persons with DHI. In most instances, with the exception of the tax domain, persons with disabilities have obtained little relief when seeking to utilise constitutional means to redress discriminatory conduct, in several contexts. This paper serves as a cursory analysis to a very complex area of the law. It is not meant to be utilised for comprehensive analysis. This study proceeds from the assumption that disability law should be designed in such a way as to enable policymakers to address the definition, activity, participation, environmental, and personal factors associated with disabilities. There is no doubt that this assumption requires further clarification, particularly since research reports and different definitions in SA legislation do not agree on any single definition for disability.

After 1994, interest in disability increased, but many new problems associated with disability emerged. Although conceptually simple, disability became quite complex when attempts were made to define it on all the different dimensions of disability, including DHI. SA legislation has a heavy, unbalanced and biased focus on persons with mental disabilities. The researcher is of the opinion that DHI is a simplistic view of the medical model that implies the presence of the pathology in a person with DHI, which a few physicians have the knowledge and skills to identify and refer the patient for appropriate rehabilitation.

There are clear benefits to using the ICF within the DHI context, although one should also recognise the challenge ahead, namely the direct and precise application of the ICF in specific settings. A critical appraisal of the ICF may emphasise three strengths. First, the involvement of consumers, institutions, organisations and government. All role players have an important role in the revision process. Secondly, universalism as a way to fight stigma and segregation. It is a powerful approach for understanding what persons without DHI and those with DHI think. Thirdly, the purpose of changing the environment, which is a very important component of the ICF. Environment is a separate list of items, to be coded in conjunction with the other components. In addition, environment is also a central part of the causal model underlying the coding guidelines. Moreover, the operationalisation of environmental factors could be challenging, especially considering the breadth of these factors in health care, education, and the workplace and the HI person.

It is suggested that the ICF and DHI interface be explored further, using empirical and qualitative studies and encouraging stakeholders' participation. The lack of classification of personal factors of the ICF in SA legislation may point to efforts to be undertaken in the future in order to further understand their impact on participation.

Hence, it is suggested that the role of contextual factors (personal and environment) in capturing important aspects of functioning be carefully investigated. Different perspectives can shape the understanding and practice of DHI. Therefore, an ideal definition in legislation should be an ''overarching'' of these perspectives. It is recognised that these differences in terms depend on the perspective. For example, DHI as a term may not fit well in the broad area of economic development. An inclusive conceptual definition will serve as a powerful organising force that could help unite the diverse stakeholders in the field of DHI.

It is for this reason that the ICF strongly and rightly critiqued this model and is currently regarded as a human rights violation of understanding and responding to the health and needs of the person with DHI. Furthermore, the medical model alone is clearly an unhelpful and potentially devaluing way of thinking about the person with DHI at either the individual or population level. Grant *et al.* (2005) argue that the medical profession has long been aware of the complex interaction of biological, psychological and social factors in the conditions they been treating and this has now been made explicit in what is termed the 'bio-psycho-social' model of the WHO.

It is within the framework of the ICF that the process of diagnosis and assessment of the health needs of an individual with DHI and the planning of rehabilitation services to meet their needs should take place. There is currently no medical school that teaches this model at any level of discipline in the medical field in SA.

6. REFERENCES

Berke, J. 2011. Health – Sexually abused deaf students. It happens internationally: 21 April 2011. Available from <http://www.deafness.about.com> [Accessed: 1 May 2011].

Board of Healthcare Funders. 2003. Finance and health. BHF proposes rare disease fund. *South African Medical Journal,* 93(3), 178-80.

Brownlie, I.Q.C. 2008. Basic documents in International Law, 6th ed. Oxford: Oxford University Press.

Calderon, R. & Greenberg, M.T. 1997. The effectiveness of early intervention for deaf children and children with hearing loss. Baltimore, MA: Paul H. Brookes.

Council for Medical Schemes. 2011. Annual Report 2010-2011. Available from <http://www.medicalschemes.com> [Accessed: 7 October 2011].

Crandell, C., Mills, T.L. & Gauthier, R. 2004. Knowledge, behaviors, and attitudes about hearing loss and hearing protection among racial/ethnically diverse young adults. *Journal of the National Medical Association,* 96(2), 176-86.

Danermark, B., Cieza, A., Gange, J., Gimigliano, F., Granberg, S., Hickson, L., Kramer S.E., McPherson, B., Möller. C., Russo, I., Strömgren, J.P., Stucki. G. & Swanepoel, D. 2010. International classification of functioning, disability, and health core sets for hearing loss: A discussion paper and invitation. *International Journal of Audiology,* 49(4), 256-62.

Employment and Social Affairs. 2002. Definitions of disability in Europe. A comparative analysis. European Commission.
Available from: <http://ec.europa.eu/social/BlobServlet?docId=2088&langId=en.>
[Accessed: 1 October 2012].

Franz, R.M., Schutte, P.C. & Kielblock, A.J. 1988. Research Report: Hearing and vision assessment services to the mining industry: A review from 1982 to 1987 with statistics for 1987. Johannesburg: Chamber of Mines of South Africa. Report No. 30/88.

Goldmann, M. 2012. We need to cut off the head of the king: Past, present, and future approaches to International Soft Law. *Leiden Journal of International Law,* 2012(25), 335-68.

Goodstein, L. 2010. Vatican declined to defrock U.S. priest who abused boys. *The New York Times.* Available from: <http://www.nytimes.com> [Accessed: 15 March 2011].

Grant, G., Goward, P. Richardson, M. & Ramcharan, P. 2005. Learning disability. A life cycle approach to valuing people. England: Open University Press.

Heywood, A. 2002. Politics, 2nd edition. London: Palgrave.

Kahan, E. & Ross, E. 1994. Knowledge and attitudes of a group of South African mine workers towards noise-induced hearing loss and the use of hearing protective devices. *South African Journal of Communication Disorders,* 1994(4), 37-47.

Monley, P., West, A. & Guzeleva, D. 1994. Hearing loss and industrial groupings, Western Australian noise-exposed workers. Shenton Park: Workcover Western Australia.

Mörth, U. 2004. Soft law in governance and regulation. An interdisciplinary analysis. Massachusetts: Edward Elgar Publishing, Inc.

Neitzel, R., Seixas, N., Goldman, B. & Daniell, W. 2004. Contributions of non-occupational activities to total noise exposure of construction workers. *Annals of Occupational Hygiene,* 48(5), 463-73.

Republic of South Africa. 1968. Blind Act, Act no. 26 of 1968. Pretoria: Government Printer.

Republic of South Africa. 1993. Compensation for Occupational injuries and Diseases Act, Act no. 130 of 1993. Pretoria: Government Printer.

Republic of South Africa. 1996. Constitution of the Republic of South Africa, Act no. 108 of 1996. Pretoria: Government Printer.

Republic of South Africa. 2007. Criminal Law (Sexual offences and related matters) Act, Act no. 32 of 2007. Pretoria: Government Printer.

Republic of South Africa. 2005. Electronic Communications Act, Act no. 36 of 2005. Pretoria: Government Printer.

Republic of South Africa. 2001. Government Gazette no. 2284 of 2001. Pretoria: Government Printer.

Republic of South Africa. 2002(a). Government Gazette no. 22209 of 2002. Pretoria: Government Printer.

Republic of South Africa. 2002(b). Government Gazette no. 23718 of 2010. Pretoria: Government Printer.

Republic of South Africa. 1962. Income Tax Act, Act no 58 of 1997. Pretoria: Government Printer

Republic of South Africa. 1997. Income Tax Act, Act no 28 of 1997. Pretoria: Government Printer.

Republic of South Africa. 1998. Medical Schemes Act, Act no. 131 of 1998. Pretoria: Government Printer.

Republic of South Africa. 2001. Medical Schemes Amendment Act, Act no. 55 of 2001. Pretoria: Government Printer.

Republic of South Africa. 2002. Mental Health Care Act, Act no. 17 of 2002. Pretoria: Government Printer.

Republic of South Africa. 1998. Postal Services Act, Act no. 124 of 1998. Pretoria: Government Printer.

Republic of South Africa. 1993. The Occupational Injuries and Diseases Act, Act no. 130 of 1993. Pretoria: Government Printer.

Republic of South Africa. 1997. The White Paper on Integrated National Disability Strategy. Pretoria: Government Printer.

South African Government Information. 2002. Sexual abuse in schools. Submission by the Department of Education to Task Group on Sexual Abuse in Schools. South Africa: South African Government: 11 March 2002. Available from: <http://www.info.gov.za> [Accessed:17 March 2011].

United Nations. 2008. The United Nations Convention on the Rights of Persons with Disabilities. 3 May 2008: United Nations. Available from: <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> [Accessed: 12 January 2012].

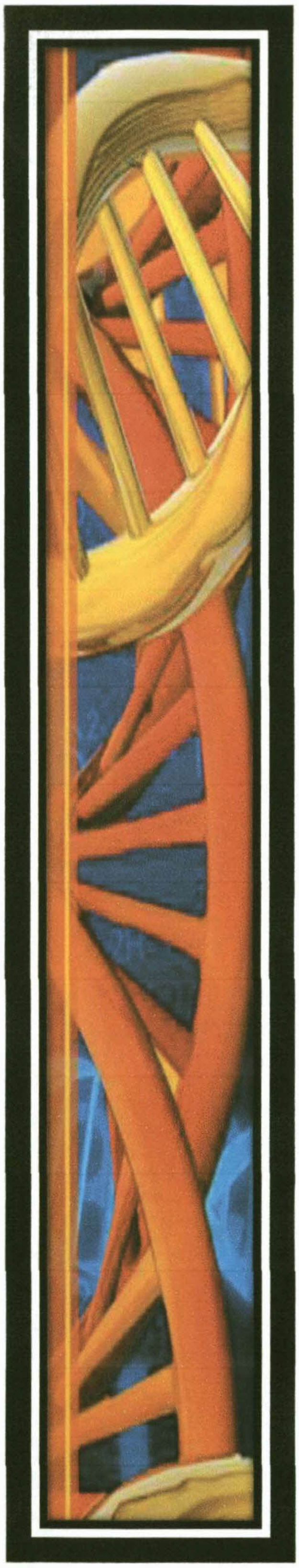
World Health ORGANISATION. 1980. International classification of impairments, disability and handicaps (ICIDH). Geneva: World Health ORGANISATION.

World Health ORGANISATION. 2001(a). International classification of functioning, disability and health. Geneva: World Health ORGANISATION.

World Health ORGANISATION. 2001(b). *ICIDH-2:* International classification of functioning, disability and health: final draft, full version. Classification, Assessment, Surveys and Terminology Team. Geneva: Classification, Assessment, Surveys and Terminology Team, World Health ORGANISATION.

World Health ORGANISATION. 2002. Towards a common language for functioning, disability and health (ICF). Geneva: World Health ORGANISATION.

World Health ORGANISATION. 2006. Prevention of deafness and hearing impairment. Word Health Organisation. Available from: <http://www.who.int/pbd/deafness/en/> [Accessed: 29 January 2011].



PAPER III

SOCIO-ECONOMIC STATUS OF PEOPLE WITH DISABLING HEARING IMPAIRMENT IN SOUTH AFRICA

SOCIO-ECONOMIC STATUS OF PEOPLE WITH DISABLING HEARING IMPAIRMENT IN SOUTH AFRICA

Abstract

Prior to the present study, systematic research on the socio-economic status of people with disabling hearing impairment (PWDHI) in South Africa was limited to a single 1978 survey of employment and job placement opportunities. This study is the first to report comprehensively on socioeconomic status and to attempt to portray fully the quality of life of adult PWDHI. Topics covered include marital status, causes of hearing impairment, additional disabilities, education, employment, use of assistive devices, and mental health. In nearly all categories, the socioeconomic status of PWDHI is at crisis levels, with extraordinary concern in the area of psychological distress. It is further noted that data from a larger geographic and socioeconomic representation of South Africans is needed and that the findings, though distressing, appear to be skewed positively because of a heavy reliance on digital media, and thus access to computers, in the surveying method.

1. INTRODUCTION

Data regarding the socio-economic status of people with disabling hearing impairment (PWDHI) as the sole focus are scarce, and, in South Africa (SA), with but one exception heretofore, limited to individual case studies. The first study published in SA, was conducted by the South African Human Sciences Research Council together with the Institute for Manpower Research (1978). Further research has not substantially increased our understanding of the situation of PWDHI.

Statistics on PWDHI are difficult to interpret because of a lack of an agreed-upon definition of and metric for determining disabling hearing impairment (DHI). There are particular reasons why the subjects of this survey are referred to by the terminology 'hearing impaired/hearing impairment/disabling hearing impairment/people with disabling hearing impairment' rather than 'Deaf/hard of hearing'. Because of differences of terminologies and metrics and also because the WHO grades of HI regard all degrees of hearing impairment as disabling, this study includes subjects with all degrees of HI.

The World Health Organisation (WHO) (2012) defines DHI as both complete and partial loss of the ability to hear. Hamilton (1981) stated that much confusion and ignorance exists in practice concerning the specific nature and function of DHI. DHI includes all the different kinds and degrees of hearing impairment (HI). There are a number of methods by which a child's average HI is calculated. The methods adopted will yield different results, and this can cause confusion when comparing PWDHI of both individuals and groups, unless complete assessments and medical histories are carried out (Hamilton, 1981; Gregory & Harley, 1991).

Furthermore, various factors need to be considered, including the nature and degree of the HI, the age at which HI has occurred, prognosis, mental abilities, ability to speak, hear and understand language, natural aptitude for speech reading, language development and speech development, the potential ability to progress, scholastic achievements, domestic factors, attitude of parents toward the disability, and socio-economic status (Hamilton, 1981).

Medical and social researchers engaged in DHI and HI research have paid little attention to the World Health Organisation's (WHO) framework of the International Classification of Functioning and Health (ICF). Research investigations related to DHI were, for the most part, descriptive in nature and often had only limited applicability (Swanwick & Marschark, 2010). The aim of this article is to describe the socio-economic status of people with DHI in SA.

2. PREVIOUS STUDY, *APARTHEID* ERA UNTIL 1994

2.1 Introduction: Findings of the previous study

The data presented here derive from the only published study on this subject, conducted by the South African Human Sciences Research Council, together with the Institute for Manpower Research, in 1978. The aims of this survey were: (1) to determine work opportunities for PWDHI, (2) to investigate the provision of effective occupational guidance to PWDHI; and (3) to analyse the professions of PWDHI.

2.2 Occupation and employer sector

Figures represented in Table 1 derived from the abovementioned study. The figures indicate 81 PWDHI registered with the Department of Labour, information obtained from the National Council for the Deaf, Trans-Oranje School for the Deaf in Pretoria, and St Vincent School for the Deaf in Johannesburg. The figures reflected the contrast between the range of occupations practiced by PWDHI, and that of the white population of SA as a whole. The largest proportion of PWDHI gainfully employed were in skilled, semi-skilled, and unskilled occupations with 54.3 percent. The table shows 20.9 percent in professional occupations, 24.7 percent in clerical occupations, and 27.7 percent in sheltered employment. Among the specific occupations listed, skilled, semi-skilled and unskilled, such as maintenance fitter, fitter and turner are most common. Most persons were employed by the private sector with 48.2 percent in contrast with 19.8 percent in the public sector. In all the occupations groups, the proportion from among PWDHI is less than for the general population, and in the remaining occupational groups not represented at all. According to the survey, most of the occupations practiced by PWDHI required a Grade 10 certificate of education, and consequently did not provide any challenge to the person's intelligence and ability.

Table 1: Number of deaf people in survey group by occupation and employer sector

Occupations	**No. of deaf**			
	Public	**%**	**Private**	**%**
Semi-professional and technical				
Computer data analyst			1	1.23
Computer operator	1	1.23	1	1.23
Display artist			1	1.23
Draughting assistant	1	1.23		
Draughtsman, learner draughtsman	2	2.47	2	2.47
Electronic technician/mechanic			1	1.23
Fingerprint expert	1	1.23		
Programmer (computer)			1	1.23
Pupil engineer			1	1.23
Quantity surveyor's assistant	1	1.23		
Technician tracer			3	3.70
Total	**6**	**7.41**	**11**	**13.58**
Clerical				
Bank sub-accountant			1	1.23
Clerk	1	1.23	6	7.41
Comptometer operator			1	1.23
Data typist/punch operator	2	2.47	3	3.70
Identity document printer	1	1.23		
Typist			2	2.45
Typist/clerk	1	1.23	2	2.45
Total	**5**	**6.17**	**15**	**18.52**

Skilled, semi-skilled and unskilled				
Boilermaker		1.23	2	2.47
Bookbinder	1		1	1.23
Cabinet maker		2.47	2	2.47
Carpenter/joiner	2		3	3.70
Checker/packer			3	3.70
Gauger			1	1.23
Hairdresser			1	1.23
High speed press operator			1	1.23
Journeyman			2	2.47
Maintenance fitter, fitter and turner			9	11.11
Moulder/operator			1	1.23
Operator		1.23	2	2.47
Printing/duplicating machine operator	1		1	1.23
Section leader (body shop)			1	1.23
Sewing machine mechanic			1	1.23
Sewing machinist		1.23	1	1.23
Sheetmetal worker	1		3	3.70
Water tank driver				
Welder			2	2.47
Woodworking machinist			2	2.47
Total	**5**	**6.17**	**39**	**48.15**
Grant Total	**16**	**19.75**	**65**	**80.25**

Source: South African Human Sciences Research Council, 1978

2.3 Discussion

According to the 1978 study, PWDHI were seriously underemployed. Maintenance fitter, fitter and turner, and clerk were common occupations. The primary reason for PWDHI being in low level jobs was the difficulty in communication between PWDHI and hearing people (South African Human Sciences Research Council, 1978). Because PWDHI were required to speech-read (sign language interpreters for the deaf in the workplace were nearly non-existent in SA), it took longer to understand instructions, and PWDHI were usually employed in occupations where work is repetitive, and few verbal instructions were needed. In addition, PWDHI were rarely trained as supervisors, and thus did not come in direct contact with the public.

According to Engelbrecht (1961), most PWDHI achieved only a Grade 10 certificate. Engelbrecht (1961) further stated that on the average, it took a PWDHI three to four years longer than the hearing child to achieve the same academic level, and therefore, they entered the labour market at an older age. As a result, enrolment at further educational institutions, which had no special needs facilities for PWDHI, presented more difficulties.

Vernon (1970) argued that there is no evidence that PWDHI are less intelligent than hearing people. Research findings have demonstrated that there is no difference between PWDHI and hearing people with regard to the capacity for abstract thought and reasoning (Vernon, 1970). Consequently, a large portion of the HI population found themselves in occupations that were beneath their capabilities and interests, unrewarding financially, and with low job satisfaction (Vernon, 1970; Engelbrecht, 1973). In addition, Engelbrecht (1973) stated that, "the deaf are known for their conscientiousness, reliability, application and concentration on the job".

2.4 Conclusion of the 1978 study

For all these reasons, underemployment of PWDHI presented a serious problem, and it was clear that skills should have been provided to enable the DHI workforce to compete on an equal basis with hearing people, in occupations more relevant to their abilities, in which there were prospects of promotion and achievement (South African Human Sciences Research Council, 1978).

It is also noted that all other schools for learners with DHI were not consulted, and they were thus not represented in this survey.

3. METHOD

The focus of the current study is to present the social-economic status of PWDHI in South Africa. The survey research was collected over a period of seven years. This study is an epidemiological observational population-based cross-sectional survey performed by means of a questionnaire in SA between 2005 to 2012.

Altogether, 3000 PWDHI between 1930 to 1991, age 21 to 80 years, were invited to participate in the study, and the questionnaire was designed in two versions, English and Afrikaans. Initially, 4251 names were collected, but 1251 could not be reached. The names of the participants were collected from the research on schools for the Deaf conducted by Ernest Kleinschmidt, a researcher with DHI. All schools for the deaf were approached to participate, and only one school's administration was up dated till 2005. In addition, friends of PWDHI, intensive research on articles in newspapers regarding PWDHI, Facebook, an online social network was also used to recruit participants and obtain their email addresses to email the questionnaire. The reason participants older than 21 years were invited to participate is because some people with congenital DHI take longer than 12 years to complete secondary education (Hamilton, 1981).

A total of 3000 questionnaires were sent out primarily through email. Two thousand two hundred ninety three people chose to participate and responded. The participants were primarily from the Western Cape, Gauteng, Mpumalanga, Kwa-Zulu Natal, and the Free State Province. They were specifically asked: (1) marital status, (2) personal history including diagnoses, (3) DHI according to causes, (4) additional disabilities, (5) education, (6) communication method, (7) assistive devices, (8) employment, (9) income; and (10) mental health. (The term "mental health," is used here as defined by the ICF, to indicate lack of psychological well-being: depression, anxiety, suicide ideation, and other distressed conditions. It is a category distinguished from the generic "mental disability."). Not all respondents completed the entire questionnaire, but all data supplied were utilized throughout the study, regardless of whether individual surveys were answered in their entirety.

4. FOCUS ON THE CURRENT STUDY

4.1 Results

4.1.1 Demographics

All respondents completed this section. The term "single" as used here means never married. The percentage of males is 56 percent compared with 44 percent females. Single males represent 50.6 percent, with 12.8 percent divorced, and 2.1 percent widowed. Among females, 48.1 percent are married, 27.5 percent single, 23.6 percent divorced, and 0.8 percent widowed.

4.1.2 Percentage distribution of DHI according to causes

Included in these figures shown in Table 2 is congenital DHI, who alone constitute 13.37 percent of all PWDHI. Congenital DHI includes, trauma and shock, 0.17 percent, prenatal exposure to drugs, 0.83 percent, perinatal asphyxia 2.37 percent, mother's exposure to measles 3.97 percent, and 2.9 percent head trauma/injury at birth. DHI resulting from a combination of diseases is 3.13 percent, and unknown causes 38.56 percent. Of the known causes of DHI, after congenital DHI, those that affect the middle ear are reported at 13.63 percent. Infections which involve the internal ear are responsible for 2.06 percent. Of DHI in which the internal ear is concerned, causes include, 1.13 percent for malarial fever, and mumps 0.93 percent. Infections which involve the auditory nerve are significant, 15.27 percent, and 13.67 percent are attributed to meningitis. Causes reported as affecting the brain center for hearing are negligible. Unknown causes of DHI, apart from congenital DHI, as already indicated, were reported at 38.56 percent and the balance of unknown causes is of miscellaneous.

Table 2: Causes of hearing impairment

Cause of hearing impairment	Number	%	Cause of hearing impairment	Number	%
Causes affecting the middle ear			*Combination of different causes*		
			Varicella	3	0.1
Scarlet fever	190	6.33	Medicine	39	1.3
Measles	154	5.13	Operation	30	1
Pneumonia	44	1.47	Trauma and shock	5	0.17
Influenza	21	0.70	Prenatal exposure drugs	25	0.83
Causes affecting the internal ear			Perinatal asphyxia	71	2.37
			Mother exposure to measles	119	3.97
Malarial fever	34	1.13	Head trauma/injury at birth	87	2.9
Mumps	28	0.93	Combination of disease	94	3.13
Causes affecting auditory nerve			Unknown	891	38.56
			Total	2293	100.0
Meningitis	410	13.67			
Tuberculosis Meningitis	2	0.07			
Typhoid fever	46	1.53			

4.1.3 Additional disabilities

Table 3 shows additional disabilities. The most frequent category is "not specified," at 8.98 percent, followed by epilepsy, 4.45 percent, unspecified orthopedic impairment, 3.88 percent, and vision impairments, 1.13 percent. The remaining disabilities are autism spectrum, cerebral palsy, diabetes mellitus 1, muscular dystrophy, osteogenesis imperfecta, spina bifida, Turner and Usher syndrome, for a combined frequency of 4.71 percent.

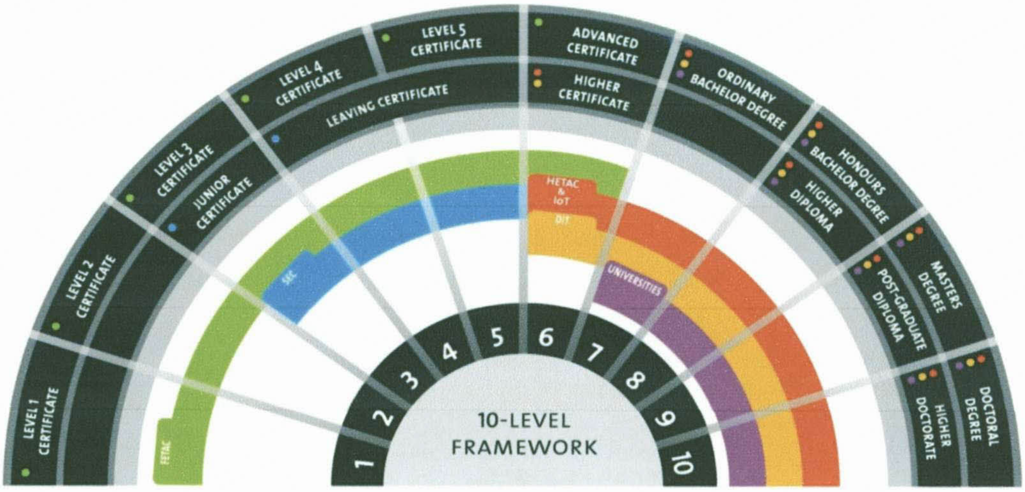
Table 3: Additional disabilities

Additional Disabilities	Number	%
Total known information	2293	100.0
No disability in addition to DHI	1762	76.84
Autism spectrum	34	1.48
Cerebral Palsy	4	0.17
Diabetes Mellitus 1	16	0.70
Epilepsy	102	4.45
Muscular Dystrophy	17	0.74
Orthopaedic impairments (not specified)	89	3.88
Osteogenesis imperfect	1	0.04
Spina Bifida	2	0.08
Turner Syndrome	22	0.96
Usher Syndrome	12	0.52
Unspecified	206	8.98
Vision impairment	26	1.13
Total	**2293**	**100.0**

4.1.4 Education

The introduction of compulsory education for all SA citizens between the ages of 7 and 15 in 1937, and in effect to this day, includes those with a disability (Republic of South Africa, 1937). The stated intent of this policy is that the rights of all children are protected, including children with special educational needs, by ensuring that 7 years of primary education and a further 2 years in secondary school are compulsory. In secondary schools there is a provision for a further 3 years up to Grade 12. The structure of the National Qualifications Framework (NQF) comprises 10 qualification levels (Republic of South Africa, 2008), as illustrated in Figure 1. Level 1 constitutes the General Education Certificate, which will be awarded after the acquisition of the compulsory schooling phase, pre-school plus 9 years to Grade 9, or it may be awarded through Adult Basic Education and Training (ABET). Levels 2-4 comprise: (1) senior secondary school up to Grade 12: (2) general and specific programs offered in the college sector. Level 5 comprises a Higher Certificate: (3) level 6: (4) Advanced Certificate or Diploma, level 7: (5) Advanced Diploma or Bachelor's Degree, level 8: (6) Postgraduate Diploma or Honours Degree, level 9: (7) Master's Degree, and level 10 a Doctoral Degree.

Figure 1: National Qualifications Framework



Source: South African Qualifications Authority 2008

Participants attend one of four types of schools: school for learners with DHI, public mainstream schools, private schools, and schools for learners with disabilities. All the participants in the survey have attended an educational institution to some extent. Of the participants, 12.6 percent obtained their education in public mainstream schools. Most of the participants attended schools for learners with DHI, 76.1 percent. Only 0.04 percent attended a private school, 8.4 percent went to a combination of public and DHI schools, and 2.8 percent attended schools for learners with disabilities.

4.1.5 Tertiary education

Tertiary education refers to Further Education Training Colleges (FET), Universities of Technology (UT), and Universities (UV). Only 23.9 percent have had FET qualifications, while 1.74 percent has attended UT, and for 5.23 percent graduated from UV. Of all the participants, 69.3 percent have no tertiary education, as shown in Table 4.

Table 4: Qualifications and occupations

NQF LEVEL	OCCUPATION Sample size: 2293	TOTAL	%
NQF 10	Biochemist	1	0.04
	Librarian/Researcher	1	0.04
Total		**2**	**0.09**
NQF 9	Librarian	6	0.26
	Physician	5	0.22
	Researchers various fields	10	0.44
Total		**21**	**0.92**
NQF 8	Chattered Accountant	3	0.09
Total		**3**	**0.09**
NQF 7	Accountant	27	1.18
	Architect	1	0.04
	Clinical Technologist	2	0.09
	Dentistry	9	0.39
	Educators	12	0.52
	Farmer/Agriculture	14	0.61
	Human Resources	5	0.22
	Nurse	8	0.35
	Pharmacist	5	0.22
	Radiography	2	0.09
	Social Worker	12	0.52
Total		**97**	**4.23**
NQF 6	Artist	61	2.66
	Computer Programmer	2	0.09
	Display Artist	4	0.17
	Graphic Designer	2	0.09
	Pastor	7	0.31
	Quantity surveyor	2	0.09
	Tourism guide	6	0.26
	Web designer	14	0.61
Total		**98**	**4.28**
NQF 5	Computer Technician	4	0.17
	Photographer	54	2.35
Total		**58**	**2.53**
NQF 4	Cosmetic and Beauty	73	3.18
	Data capturer	201	8.77
	Mechanic	31	1.35
	Plumber	85	3.71
	Police	16	0.69
Total		**406**	**17.71**

NQF 3	Apprentice mechanic	22	0.96
	Ballet dancer	7	0.31
	Builder	31	13.87
	Copywriter	5	0.22
	DSTV installer	3	0.1
	Fire fighter	8	0.35
	Gym instructor	10	0.44
	Hospitality	11	0.48
	Office Administrative	386	16.83
	Panelbeater	44	1.92
	Welder	188	8.2
Total		**715**	**31.18**
NQF 2	Bookbinder	52	2.27
	Cabinet maker	111	4.84
	Dog grooming	5	0.22
	Domestic workers	1	0.04
	Fitter and Turner	222	0.96
	Jewellery maker	17	0.74
	Nanny	1	0.04
	Nursery school assistant	26	1.13
	Painter	75	3.27
	Press operator	2	0.09
	Sheetmetal Worker	112	4.88
	Truck driver	35	1.53
	Upholstery	194	8.46
Total		**853**	**37.2**
Information not reported		40	1.74
Total		**40**	**1.74**
		2293	**100.0**

4.1.6 Highest qualification attained

PWDHI qualified for Level 10 are 0.09 percent, 0.92 percent for Level 9, Level 8, 0.09 percent, Level 7, 4.23 percent, Level 6, 4.28 percent, Level 5, 2.5, Level 4, 17.71 percent. Level 3 comprises the second highest percentage with 31.18 percent, and Level 2 the highest, at 37.2 percent. 1.74 percent have did not report (Table 4). Total Bachelor's degrees are 4.32 percent, 0.09 percent Honours, 0.61 percent Magister degrees, and 0.3 percent Doctorates. (Figure 1 shows international equivalencies of SA educational Levels and Degrees.) 94.77 percent have no university degrees. Information about the skill level required for an occupation was obtained directly from the NQF framework.

4.1.7 Employment

Table 4 gives the percentage distributions of general occupations for PWDHI, according to the NQF levels.

4.1.8 Communication method

PWDHI using spoken language as a means of communication in the workplace, comprised 92.0 percent (see Table 5). Sign language comprised 0.2 percent, note taking 0.13 percent, data capturing 0.0 percent, and 7.63 percent communication method unreported.

Table 5: Communication method at workplace

Communication method at workplace	Number	%
Spoken	2110	92.0
Sign Language interpreting	5	0.2
Note taking	3	0.13
Data capturing	0	0
Other	175	7.63
Total	**2293**	**100.0**

4.1.9 Assistive devices

Conventional methods for speech comprehension by the DHI rely heavily on vision. Table 6 revealed that 82.60 percent of the DHI population makes use of hearing aids, 2.09 percent received cochlear implants, and 15.3 percent make no use of assistive devices.

Table 6: Assistive devices

Assistive Devices	Number	percent
Cochlear Implants	48	2.09
Hearing Aids	1894	82.60
None	351	15.3
Total	**2293**	**100.0**

4.1.10 Income

Participants reported having jobs in 56 occupations totaled 2253, compared with 38 job descriptions in the 1978 study. The highest average salary income range was R3000 – R4999 (US$353.41-588.92, as of December 20, 2012)), representing 66.03 percent (see Table 7). 25.95 percent of the participants earn between R1000 – R2999 ($117.81-353.30, December 20. 2012) per month, as shown in Table 7. Included in the income of 22.72 percent of respondents are unemployed receiving disability grants of R1200 per month (US$139.73, December 22, 2012)

Table 7: Income

Income	Number	%
R1000 – R2999	595	25.95
R3000 – R4999	1514	66.03
R5000 – R6999	53	2.31
R7000 – R9999	16	0.7
R10 000 – R14 999	70	3.05
R15 000 or over	45	1.96
Total	**2293**	**100.0**

Table 8, also lists 62.93 percent of respondents employed and 14.35 percent were unemployed, not receiving grants.

Table 8: Employment status

Employment status	Number	%
Employed	1443	62.93
Unemployed	329	14.35
Disability grant	521	22.72
Total	**2293**	**100.0**

4.1.11 Mental health

According to Table 9, a total of 36.42 percent of respondents reporting experienced some form of physical or sexual abuse. About 92.0 percent of the participants are "suspicious about their environment," and at least 94.0 percent describe themselves as being dependent on hearing society for communication. A high percentage, 91.0 percent, reported that, in their experience, hearing people lack knowledge of DHI. 87.0 percent are "frustrated with their environment." A total of 4.55 percent visit a psychotherapist, but of these, 95.45 percent reported that the therapy was of no use at all.

Table 9: Mental health

Personal		Number	%
	Have you ever experience physical or sexual abuse?	835	36.42
	Are you suspicious about a hearing environment?	2210	92.0
	Are you dependent on hearing people in general?	2178	94.0
	Do you experience hearing people as knowledgeable about hearing impairment?	2087	91.0
	Are you feeling lonely?	1986	86.61
	Are you frustrated with a hearing environment?	1995	87.0
	Do you cry frequently?	191	8.33
	Do you feel depressed?	459	20.0
	Have you ever attempted suicide?	76	3.31
	Do you feel misunderstood?	1903	83.0
	Have you ever been to a therapist?	88	3.84
	Did the therapy helps you?	4 out of 88	4.55
	Did the therapy did not help you?	84 out of 88	3.66 95.5

4.2 Discussion

4.2.1 Medical

Entirely accurate statistics as to the causes of DHI are not available. The first and only previous study on DHI in SA, in 1978, included only 81 white respondents and was only a survey of occupations, without even income ranges or other socioeconomic indicators.

The current study includes data from 2293 individuals with DHI. The medical data from the survey confirmed the complexity of DHI, with 42.17 percent of causes unknown and 30 percent of children with DHI having an additional neurodevelopmental disability. Among known causes, many have practical public health and/or medical solutions. Some of these remedies were unknown, unavailable, or of only limited availability in SA during the times when some respondents were born DHI or became DHI.

Wide ranges of additional disabilities often face PWDHI (Van Naarden, Decoufle, & Caldwell, 1991; Guardino, 2008). In a study conducted in Atlanta, Georgia (USA), Van Naarden *et al.*, (1991) found that 30 percent of children with DHI had another neurodevelopmental disability, and most often, a mental disability. Other common disabilities identified in the same study are: autism, attention deficit disorders, learning disabilities, Down syndrome, Usher, Treacher Collins, Pierre Robin, and Turner syndromes. Additionally, coloboma, atresia, and genital hypoplasia were reported, to only mention a few. This is consistent with research done by Fortnum and Davis (1997), who found that just under 40 percent of children with DHI have an additional disability. Moreover, Fortnum and Davis estimated than 20 percent have as least two additional disabilities. According to Cone-Wesson, Vohr, Siniger, Widen *et al.*, (2000), vision impairment is prominent in addition to DHI.

The Gallaudet Research Institute (2008) conducted a survey to identify learners with additional disability. They found that learning disabilities, emotional disturbance, orthopedic impairment, deaf-blindness, and other health impairments are common in DHI.

Ewing and Jones (2003) emphasized that learners with multiple disabilities are often misdiagnosed or identified too late, with the consequence that learners are placed in inappropriate educational environments. Bundy, Lane, and Murray (2002) and Emmons and Anderson (2005) discussed learners with sensory disabilities with specific learning disabilities, such as dyspraxia, dyslexia, dyscalculia, and dysgraphia.

The extra burden of the second disability may be far in excess of what it would be for the single disability because DHI multiples the attendant conditions. Obtaining medical care for another condition may become a problem because communication with physicians is often difficult due to the compounding difficulty of multiple disabilities' impact upon effective communication. Those conditions which may, by themselves, be innocuous can become severely disabling when occurring in combination with DHI

4.2.2 Education, employment and income

The survey indicates that 37.2 percent have attained only NQF 2 and work in semi-skilled positions. 31.8 percent have attained NQF 3, with a somewhat higher level of job skills. Almost 70 percent of DHI are working in semi-skilled or skilled employment. By contrast, only 21 persons with DHI have Master's degrees/NQF 8 (0.09 percent), 3 have Honours/NQF 9 (0.09 percent), and only 2/NQF 10 (0.04 percent) have Ph. D.'s. This may indicate that the level of educational and professional attainment is primarily a function of disability, rather than ability. Those who achieve the highest NQF have become either researchers or accountants. An examination of individual survey responses indicated that the overwhelming majority of deaf professionals (NQF 7 and above) were employed within the hearing community (and using spoken language and written/digital communication), which suggests that their ability to advance the quality of life/economic status of deaf people in SA is constrained.

In addition, 66.03 percent, nearly two-thirds of PWDHI earn R3 000.00 to R4 999.00 (US$353.41-US$588.92) per month. Although this figure would indicate a higher-than-median income for SA (Monthly Earnings of South Africans, 2010), which does not align with the survey's results concerning level of education and type of employment, this may be attributable to a combination of the means by which the survey was disseminated (through email and Facebook contact) and the self-selection of those who responded, both of which point to a relatively high degree of financial wherewithal.

While the present study exclusively concerns SA, its findings as regards employment and (with somewhat less assurance, owing to the study's limitations) income are largely mirrored in a 2012 study from the US (Jung & Bhattacharyya, 2012), the latter also showing a decline in employment for PWDHI.

4.2.3 Communication method at work assistive devices

Among PWDHI, 92 percent use spoken language at work, Sign language accounts for 0.02 percent and real-time captioning 0.0 percent. This indicates that efforts to accommodate PWDHI in the workplace are virtually negligible.

4.2.4 Assistive Devices

Most of PWDHI, 82.6 percent use hearing aids. This indicates that total deafness is rare. All types of DHI may benefit from the use of hearing aids, regardless of degree of loss, age of the person with DHI, or whether the loss is unilateral or bilateral. Even in cases of severe DHI, hearing aids provide some degree of environmental sound.

4.2.5 Mental Health

These findings may be the subject of greatest concern with, for example, 36.42 percent of PWDHI reporting physical or sexual abuse, 92.0 percent complaining of "suspicion about a hearing environment," while 94.0 percent describe themselves as "dependent on hearing people in general." To make matters far worse, 95.5 percent of those who received therapy reported that it was of no help.

This is a toxic environmental combination, in which high numbers of WPWDHI simultaneously rely upon and fear – apparently with good reason – the hearing majority. Combined with contributing factors described above, this indicates a seriously imperiled sense of well-being for nearly the entire DHI community.

5. LIMITATIONS OF THE STUDY

This is the first attempt at a comprehensive study of PWDHI in SA. Because the study was solely the work of the author up until the final stages of analysis, the data was gathered over a 7-year period 2005-2012, during which time the demographics of the earliest respondents may have changed. The use of digital media to disseminate the survey oriented the responses toward the economically better-off, that is, those with computer and Internet access.

With a single exception, schools for learners with DHI either failed to keep data on their former learners or chose not to cooperate with this study. The one school that agreed to participate only had data through 2006 (though beginning in 1881); these were used in building the contact list. The lack of data from NPO's was an additional limitation.

Demographics on race would have enriched the survey in a country as diverse as SA. However, the need to utilize email and social media as the primary instruments of subject recruitment and which skewed the data in favor of people with access to computers – and thus to people of economic privilege. According to census data from 2010, Whites had by far the highest median earnings, followed by Indians/Asians, with Coloureds and Blacks earning significantly less (Monthly Earnings of South Africans, 2010). Surnames of respondents also point – though by no means with perfect reliability, as these often transcend race in SA – to a preponderance of White respondents. If even among privileged sectors of the population PWDHI are at such great relative disadvantage in all quality of life indicators and in particular in great psychological distress, a more representative survey might well indicate a crisis of even greater proportions.

6. CONCLUSION

This study attempts to establish better baseline data on PWDI in SA, in order to obtain a better indication of their socio-economic status. A comprehensive literature review has revealed that there have been no previous studies of the socio-economic status of PWDHI in SA. This study is the most detailed study on the socio-economic status of PWDHI in SA, although it was limited by a relatively small number of subjects of whom had access to internet using Facebook and electronic mail.

Further research is required to fully ascertain the relationship between hearing loss and socio-economic position. But even the current study offers compelling data indicating a critically high levels of socio-economic distress among PWDHI in SA. Improvements in public health, disease prevention, education, employment, assistive services and technologies are all urgently needed.

That the problems of PWDHI in the developed and developing world are so strikingly similar suggests both the need for further research worldwide and international collaboration in all DHI-related fields, both academic and applied, to improve people's socioeconomic status.

7. REFERENCES

Bundy, A.C., Lane, S. & Murray, E.A. 2002. Sensory integration : theory and practice. Philadelphia: Philadelphia: F.A. Davis.

Cone-Wesson, B., Vohr, B.R., Siniger, Y.S., Widen, J.E., Folsom, R.C., Gorga, M.O. & Norton, S.J. 2000. Identification of neonatal hearing impairment: infants with hearing loss. *Ear and Hearing*, 21, 488-507.

Emmons, P.G. & Anderson, L. 2005. Understanding Sensory Dysfunction. Learning, development and sensory dysfunction in autism spectrum disorders, ADHD, learning disabilities and Bipolar Disorder. London: Jessica Kingsley Publishers.

Engelbrecht, G.K. 1961. Die Dowe – die maatskaplike en ekonomiese posisie van die dowe in Suid-Africa, met besondere verwysing na hulle rehabilitasie. Cape Town: HAUM.

Engelbrecht, G.K. 1973. Employment Prospects for the Totally Deaf. *The Silent Messenger,* 39,19-23.

Ewing, K.M. & Jones, T.W. 2003. An educational rationale for deaf students with multiple disabilities. *American Annals of the Deaf, 148,* 267-71.

Fortnum, H. & Davis, A. 1997. Epidemiology of permanent childhood hearing impairment in Trent Region, 1985-1993. *British Journal of Audiology,* 31, 409-46.

Gallaudet Research Institute. 2008. Regional and national summary report of data from the 2007-2008 Annual Survey of Deaf and Hard of Hearing Children and Youth. Washington, D.C: Gallaudet University.

Gregory, S. & Harley, G.M. 1991. Constructing Deafness. London: Pinter Publishers Limited.

Guardino, C.A. 2008. Identifications and placement for deaf students with multiple disabilities: Choosing the path less followed. *American Annals of the Deaf,* 153, 55-64.

Hamilton, J.H. 1981. Nuwe Ontwikkelinge op die gebied van onderwys aan gehoorgestremdes. *South African Medical Journal,* 60, 856-858.

Jung, D. & Bhattacharyya, N. 2012. Association of Hearing Loss With Decreased Employment Income Among Adults in the United States. *Annals of Otology, Rhinology & Laryngology,* 121, 771-75.

South African Human Sciences Research Council. 1978. Careers for deaf persons with post-school qualifications. Pretoria: Institute for Manpower Research.

Swanwick, R. & Marschark, M. 2010. Enhancing Education for Deaf Children:
Research into Practice and Back Again. *Deafness and Education International,* 12,(4), 217–235.

Van Naarden, K., Decoufle, P. & Caldwell, K. 1991. Prevalence and characteristics of children with serious hearing impairment in metropolitan Atlanta. *Pediatrics,* 103, 570-75.

Vernon, M. 1970. Potential, Achievement and Rehabilitation in the Deaf Population. *Rehabilitation Literature,* 9, 258-67.

World Health Organisation. 2012. *Deafness and hearing impairment.* Available from: <Retrieved from http://www.who.int/mediacentre/factsheets/fs300/en/index.html> [Accessed: 29 5 March 2012].

Appendix 1

Date:

Method of interview:

☐ Face to face interview
☐ Email
☐ Post
☐ Facebook

MEDICAL-SOCIAL-ECONOMIC QUESTIONNAIRE

All questions contained in this questionnaire are strictly confidential

Definition: For the purpose of this survey, the term hearing impairment is used according to the World Health Organisation and includes all forms of hearing loss

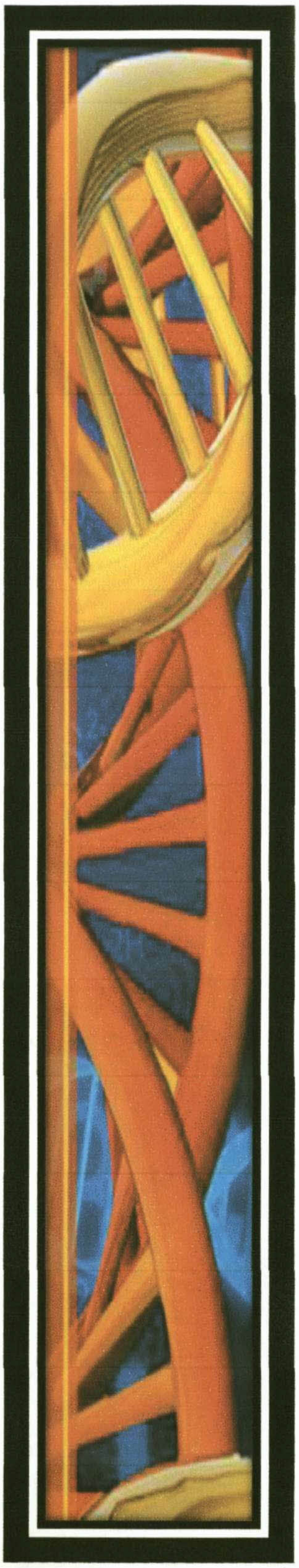
Name:	**Surname:**	☐ M ☐ F	**Age:**
Marital status:	☐ Single ☐ Partnered ☐ Married ☐ Separated ☐ Divorced ☐ Widowed		
Married partner:		☐ Hearing ☐ Hearing impaired	
Date of birth:			

PERSONAL HISTORY

Diagnoses of hearing impairment:	☐ Conductive ☐ Sensorneural ☐ Central ☐ Functional ☐ Mixed ☐ Genetic	
Age at onset of hearing impairment:	☐ Since birth ☐ Less than 1 year ☐ 1 to 3 years ☐ 3 to 5 years ☐ 6 to 18 years	
Do you have any additional disability?	☐ Yes ☐ No	
Additional disability diagnoses:		
Which kind of school/s did you attend?	☐ School for the deaf ☐ Public ☐ Private ☐ School for disabilities	
Mode of communication used?	☐ Spoken ☐ Sign Language ☐ Total communication	
What was the last grade of school you went to?		
Did you registered for tertiary education?	☐ Yes ☐ No	
Did you complete your study?	☐ Yes ☐ No	
What was the last qualification?	☐ Certificate ☐ Diploma ☐ BA ☐ Masters ☐ PhD ☐ Post PhD	
About your work:	☐ Employed	What is the name of title of your job?
	☐ Have you ever been layoff by work?	☐ Unemployed
	☐ Pensioner	☐ Disability grant
In what kind of sector is your work?	☐ Business/Private ☐ Corporate ☐ Public ☐ Self-employed	
What kind of work do you do?		
When your boss or supervisor wants to tell you something, which ways does he/she use most?	☐ Ask someone to tell you ☐ Speak ☐ Sign ☐ Fingerspell ☐ Gesture ☐ Write ☐ Cued speech ☐ Some other way: What?	
When you want to tell your boss something, which ways do you use most?	☐ Ask someone to tell him/her ☐ Speak ☐ Sign ☐ Fingerspell ☐ Gesture ☐ Write ☐ Cued speech ☐ Some other way: What?	
Do you make use of any assistive devices?	☐ Hearing aids ☐ Cochlear implant ☐ FM system ☐ Note taking ☐ Interpreter	
What is your income per month?	☐ R1000 – R3000 ☐ R3000 – R5000 ☐ R5000 – R7000 ☐ R7000 – R10 000 ☐ R10 000 – R15 000 ☐ >	
Is your boss or supervisor?	☐ Hearing ☐ Hearing impaired	

MENTAL HEALTH

Sex/abuse	Have you ever experience any form of verbally, physical or sexual abuse?	☐ Yes	☐ No
	Are you suspicious about a hearing environment?	☐ Yes	☐ No
	Are you dependent on hearing people in general?	☐ Yes	☐ No
	Do you experience hearing people as knowledgeable about hearing impairment?	☐ Yes	☐ No



PAPER IV

THE COST OF SIGN LANGUAGE INTERPRETER SERVICES

THE COST OF SIGN LANGUAGE INTERPRETER SERVICES IN SOUTH AFRICA

Abstract

This study assesses the direct cost of sign language interpreter services to a sign language user in South Africa. Fully understanding the costs requires an assessment of the extent of the benefits. To that end, the study considers not only fees for service and the income of interpreters on both an annual and per service basis, but also the degree of uniformity of vocabulary among South African Sign Language users and the quality of training and the process of certification with the profession of sign language interpretation. The study concludes that the cost of interpretation services is prohibitively high for nearly all potential users, that South African Sign Language has little uniformity of vocabulary, which lowers the value of interpretation services, and that the profession of sign language interpretation in South Africa has little oversight to guarantee an appropriate standard of service.

1. INTRODUCTION

Despite the importance of disability accommodations for many South African people with a severe or profound hearing impairment to enable them to participate in a predominantly hearing society, there is surprisingly no published research concerning the direct costs of sign language interpreting services, or their effectiveness in a working environment and educational setting versus other forms of accommodation, in particular captioning systems. The limited research in this area is reviewed by critically analysing the economic situation for a person with disabling hearing impairment (DHI) who operates within the "Deaf Culture" and whose disability accommodation of choice is South African Sign Language interpreter (SASLI) services. In accordance with internationally accepted practice, South African Sign Language (SASL) users making use of SASLI services will be referred to as "Deaf," that is, as members of the "Deaf Culture," rather than "deaf/disabling hearing impairment/hearing impaired." It must also be acknowledged that there are "speakers" of SASL who regard the language as part of their personal culture, but who make use of other disability accommodations in their public, educational, and professional lives, and who would regard the use of SASL in these capacities as an inappropriate imposition of their cultural practices upon others.

2. BACKGROUND

The United Nations Convention of the Rights of Persons with Disabilities came into force in May 2008. As a result, there is a growing awareness among policy-makers and development experts of the need to comprehensively address disability issues in their core activities, in this case, providing sign language interpreters (SLI) (United Nations, 2008).

The Constitution of the Republic of South Africa (RSA) of 1996 (Act no. 108 of 1996) completes South Africa's constitutional revolution. The Bill of Rights, section (s) 9(2) of the Constitution, guarantees equality and non-discrimination for persons with disabilities and limits the ability of government to pass laws or take actions that discriminate or infringe on human rights. Individuals must be treated equally, regardless of their race, nationality, ethnicity, origin, colour, religion, sex, age, mental or physical condition (RSA, 1996).

The incidence of DHI derived from a number of retrospective studies in South Africa (SA) (population about 50 million; birth rate 12-18/1000), is estimated to be about 17 born per day and 6 205 per annual birth cohort in 2011 (Hay, 2011). This estimate excludes children and adults who acquire hearing loss through infectious diseases, ototoxicity or noise-induced damage.

The World Health Organization (2012) defines DHI as often life-long and sometimes life-threatening problems that may have profound effects and impact on interpersonal communication, education, employment, social, emotional, and through stigmatisation beyond those experienced by their hearing counterparts. One study concludes that "Hearing impairment strikes at the very essence of being human, because it hinders communication with others". (Vaughn, Lightfoot & Arnold, 1981).

3. METHODS

This study examined internet resources and reviewed a published study and articles to determine the direct cost implications for a sign language user to hire a SASLI and the income for a SASLI. The assumption is that a professional person spends an average of four hours per day listening and in verbal communication in the workplace with others. The hours spent at primary, secondary, and tertiary education centres are much more than four hours per day.

4. RESULTS

According to the Deaf Federation of South Africa (DeafSA), the cost of a SLI in 2009 (DeafSA, 2013) versus fees in 2012 are calculated for 4 hours per day for 20 days a month as shown in Table 1 and 2.

Table 1: Sign Language interpreter fees in 2009

Working days of the week	**DeafSA 2009**	**4 hours**	**Total 20 days/month**	**Total 200 days**
Per hour/ maximum of 4 hours	409.20	1 636.80	32 736.00	R327 360.00
Daily fee	2 182.40		R43 648.00	R436 480.00

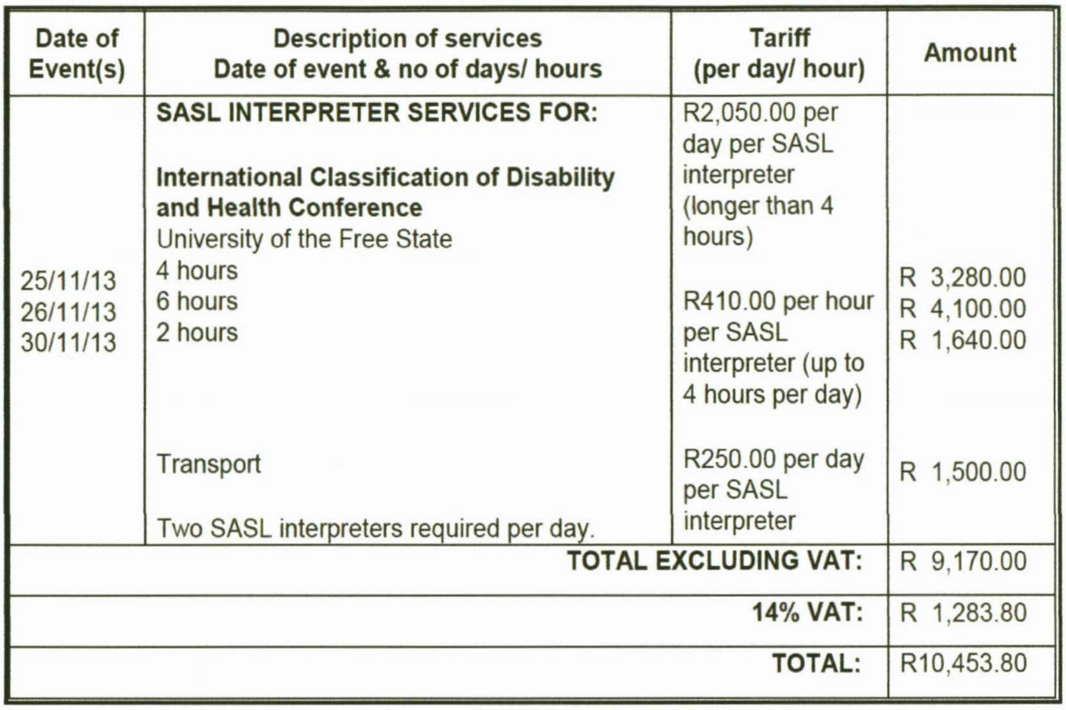
Table 2: Sign Language interpreter fees in 2012

Working days of the week	**2012**	**4 hours**	**Total 20 days/month**	**Total 200 days**
Per hour/ maximum of 4 hours	1 275.00	5 100.00	102 000.00	R1 020 000.00
Daily fee	6 375.00		127 500.00	R1 275 000.00

According to the results, the average annual salary for SASLI for 4 hours work per day for 20 days was R32 736.00 (US$3 437.15) in 2009. The income has risen almost 200 percent in 2012 to R102 000.00 (US$10 709.59) for the same period of time. However, the geographic region and industry in which the SASLI work can result in significantly higher or lower wages. These results are direct costs for the SLU.

Annual salaries of SASLI, though, are not the best indicator of costs to the SLU. The hourly rates an agency charges for services are even more revealing that the cost of SLI is prohibitively high for nearly all individuals with hearing impairment (Deaf Culture).

Figure 1: Sign Language interpreter fees for 2013



Date of Event(s)	Description of services Date of event & no of days/ hours	Tariff (per day/ hour)	Amount
	SASL INTERPRETER SERVICES FOR: **International Classification of Disability and Health Conference** University of the Free State	R2,050.00 per day per SASL interpreter (longer than 4 hours)	
25/11/13	4 hours	R410.00 per hour per SASL interpreter (up to 4 hours per day)	R 3,280.00
26/11/13	6 hours		R 4,100.00
30/11/13	2 hours		R 1,640.00
	Transport Two SASL interpreters required per day.	R250.00 per day per SASL interpreter	R 1,500.00
		TOTAL EXCLUDING VAT:	R 9,170.00
		14% VAT:	R 1,283.80
		TOTAL:	R10,453.80

Source: South African Sign Language Interpreting National Centre, 2013

Figure 1 is a quotation of costs from an interpretation agency for 12 hours of SLI over a period of 3 days at an academic conference. The amounts per day in the farthest right column are two times the number of hours times the hourly rate because (as indicated under "Description of services") the services of two interpreters are required. (SLI is physically taxing and this is the standard practice, both within and beyond SA). The total cost of R10 453.80 (US$1 090.96) for 12 hours' service is more than twice the median monthly income of a South African with hearing impairment.. The medium monthly earnings of white, black, Indian and coloured are R5 079.75 (US$530.12) (Statistics South Africa, 2010). Thus, the cost of interpretation is unimaginably high for an average Deaf person or their families.

Two additional interpreting agencies were contacted for quotations. Both declined, citing their inability to provide appropriately qualified interpreters who were adequately familiar with the topic of the conference (Katshwa, 2013).

5. DISCUSSION

5.1 Status of the Profession of South African Sign Language Interpreters

According to DeafSA, SASLI are accredited on a national basis with the South African Translators Institute (SATI). According to SATI (2013), the language profession is unregulated in SA. In addition, there is no legislation which requires any kind of registration for accreditation, or any examinations to determine the competence of a language professional, in this case, a sign language interpreter (SLI). Membership is on a volunteer basis with SATI. DeafSA reported in 2009 that seven of 151 SLI are accredited by SATI which is 4.64 percent. Furthermore, SATI has a practice test with guidelines However. the guidelines for a SLI are not shown on the website.

A total of 60 SLI's are registered with DeafSA on the basis of training which is 39.74 percent. On the basis on SASL fluency and experience, 30 (19.87 percent), and 54 (35.76 percent) who are without any form of training. Both DeafSA and SATI are registered as Non Profit Organisations (NPOs) in SA and therefore, registering is voluntary without any obligation for SLI's.

According to Dorothy Rasebopye (2010), a parent of a Deaf child who studied at the University of the Witswaterand, there was a unit for students with disabilities, that could provide a SLI. Lecturers refused to provide the student with any hardcopies of the lectures; in addition, no video-recording was permitted. Moreover, the SLI provided were not "subject-matter experts" in the field of her child's study, who thus had to hire a SLI at a high cost to enable her child to understand the lecturers and to enable her to participate during lectures. Rasebopye (2010) stressed that the needs of Deaf people need to be addressed to enable them to equally compete on an academic and economic level with hearing society.

With regard to the accommodation of students with hearing impairment, the website *Help for Lecturers* of the Disability Unit of the University of the Witwatersrand, Johannesburg (2013a) states the following:

> *"In dealing with a student who has a hearing impairment, the lecturer must first determine the nature and degree of disability and type of assistance the student usually employs. This is difficult if the disability is "hidden" and the student is reluctant to acknowledge it. Some indications of impairment may be the student straining to hear, loud or distorted speech, and consistent failure to respond. Once the disability is properly identified and discussed, classroom strategies and adjustments may effectively help the student function successfully in the classroom."*

This is clearly an untenable situation and a contradiction of the Disability Unit's own policy (University of the Witwatersrand, Johannesburg, 2013b). The Disability Unit of the University will already have "undertake[n] a **comprehensive assessment** [emphasis in the original] to determine whether the student has a disability that hinders educational access. It is an inappropriate and untenable expectation that a lecturer, regardless of topic, is expected or qualified to assume the responsibilities of either the Disability Unit or the student, who must be held responsible for his/her own studies and for seeking out the necessary assistance of the Disability Unit. It is the responsibility of the lecturer to deliver the content of the course and, when necessary, to accommodate the student with a disability according to the directives of the Disability Unit. Lecturers can not be expected to provide either diagnosis or counseling of a student.

Further, the expectation that the lecturer will function in the role of diagnostician is a violation of human rights (guaranteed in the South African Constitution, as cited above) and against the law that might affect any student. The lecturer, in nearly all cases is wholly unqualified to make a medical diagnosis, is herein being asked to act prejudicially upon a student, with the presumption, right or wrong, that the student has a disability. Any personal or even cultural idiosyncrasy might be flagged as a "disability" by the lecturer, with potentially serious negative consequences.

5.2 Non-Standardisation of South African Sign Language

Selzer (2010), both of whose parents are Deaf, argued that there is not a standarised Sign Language in SA. After an investigation of three different SASLI used in Parliament, only one of ten signs investigated was signed the same way by all three. It was found that no two parliamentary SASLI made use of the same sign for the same term in most cases. According to Selzer (2010:37)

> *"Only one of the 10 signs investigated in this study was signed the same by the two interpreters, while one other was signed very similarly. Sometimes there were slight differences between the signs used by the two, but at other times they used vastly different signs as equivalents to a particular English term."*

In addition, Kleinschmidt (2012) argued that each sign language in SA has different varieties and dialects, according to geographical region and ethnicity. Dialectical variation affects the production of signs and the use of vocabulary. A child with DHI may use a sign language dialect that has different items of vocabulary from the dialect of a television SLI. A White, Black, Coloured or Indian uses different vocabulary from each other. A person with DHI situated in Worcester will have a different dialect from a person with DHI from Durban.

According to Selzer (2010) however, the grammar of all dialects of SASL is the same, irrespective of users' age, ethnicity, or geographical region.

5.3 Lack of Written Form: Captioning as an Alternative

Selzer (2010) argued that equally important is that, like other sign languages, SASL does not have a written form (efforts have been made to create a written version of American Sign Language, but it is not in common use).. This attribute of sign languages (or lack thereof) is not a cost per se, but it is a factor worthy of consideration insofar as another option, real-time captioning, offers access to spoken text without the risk of loss of meaning through translation, as well as providing the Deaf/hearing impaired user with a print copy of the precise spoken text in its original language. This substantiates the argument for captioning as the best option, and for its being provided as the standard service for people with any form or degree of hearing impairment in SA.

5.4 Direct Costs of South African Sign Language Interpreter Services

The economic all aspect of DHI such as the costs of cochlear implants or hearing aids do not lend themselves well to comparisons with expenses in other countries such as the US and the United Kingdom, owing to radically different healthcare systems and economies. However, the structure of the provision of sign language services between SA and the US is strikingly similar (see Figure 1 and its subsequent explanation) and a comparison of costs is most revealing.

U.S. News & World Report (2013) stated that, in the United States (US), SLI's earned an average of US$44 160.00 (R391 553.47) and the best-paid earned an average of US$88,010.00 (R780 358.27) annually in 2011 and that SLI's should also expect an 'employment boom'. Moreover, by 2020, the Bureau of Labour Statistics in the United States projects a 42 percent growth in employment in this occupation, with a little less than 25 000 new positions (*U.S. News & World Report*, 2013).

According to Mari Magler (2013), Associate Director of Access Programs, Disability Services, University of Minnesota, the average rates for a freelance interpreter in the Twin Cities of St. Paul-Minneapolis (the capital and commercial center of Minnesota, 2010 population 3 280 000) were between US$38.00.00 to US$50.00 (R363.97 - R478.904), as of 22 May 2013) per hour. Thus, the costs of SLI in the US and SA are similar. The results are outrageous and shocking for a developing country. The comparison is even more troubling given that American Sign Language interpretation certification is kept to a high and uniform standard through the Registry of Interpreters for the Deaf (2013) that far exceeds the quality and uniformity of SASL interpretation, as described above.

6. CONCLUSION

Nearly 19 years after apartheid, not much progress has been made in terms of a standardised sign language in SA. A SASLI is not remotely affordable for a Deaf person in the long or even the short term and use of a SASLI is therefore not sustainable for all but the wealthiest individuals, an income cohort that includes few Deaf people. It will also not be realistic to expect health professionals, employers, government departments or organisations to pay these high costs for services for a Deaf person. Without any form of education in a written language, it is unimaginable that the Deaf person will come to his/her full potential in society. The focus in obtaining a good quality of life for Deaf people should be less on "Deaf Culture" than on the development of education such that they may compete equitably in society with the assistance of technology such as real-time captioning services. Without the use of such technology, as is common in the U.S., the Deaf person will remain isolated from all levels of society except "Deaf Culture." The Department of South African Sign Language in the Faculty of the Humanities of the University of the Free State (2013) states that:

> *"We teach SASL as a human language, we portray the Deaf community as a "linguistic minority" rather than a community with disability".*

While there is no denying the existence of Deaf Culture, which, by the definition above, includes all users of SASL, with no regard for whether they have DHI or not, it is not the responsibility of disability units to accommodate cultural differences. The expectation that disability units will accommodate DHI is tantamount to the (perfectly obvious) recognition that DHI is a disability, regardless of its association with cultural praxis.

It should thus be the responsibility and the best practice of disability units to provide technical accommodation and not translation services that it would never be expected to provide for any other "linguistic minority." Those concerned with education, employment, services, and quality of life for people with DHI need to consider the method of instruction and the lifetime costs and in the long run to live as economic independent citizens.

7. RECOMMENDATION

Due to the extraordinarily high cost of sign language interpretation services and the lack of a universally intelligible South African Sign Language, it is recommended that open and closed captioning services should be used in academic settings, classrooms for children and adults, courtrooms, health care services, micro and macro businesses and other environments. Captioning is also referred to as computer-aided transcription services and is known as "real-time captioning", or Communication Access Realtime Translation (CART) services, a professional service that can be delivered on location or remotely. The text produced by the CART service can be displayed on a computer screen of a notebook and is operates with blue tooth. Moreover, captioning is a service provided for people with hearing disabilities who use assistive listening devices, hearing aids, cochlear implants, sign language and lip reading and will benefit all deaf people's integration and participation throughout all aspects of life. Because captioning is a text display of words, positioned in such a way that it is open for anyone to see and read, and is considered passive assistance, it is a service that is there to use or ignore.

No one is labelled as needing open captioning with special equipment required at his/her seat. The captioner does not need to be seated next to the individual making use of this service, or as mentioned before, it can also be displayed on any display system and equipment.

In addition, Higbee (2003) stated that everyone who understands the language used in its written form can benefit from the presence of real-time captioning, which may therefore be regarded not as a disability accommodation for a few users, but as a Universal Design (or Universal Instructional Design) service, beneficial to all.

Based on statistics provided elsewhere in this thesis, there is a substantial market for captioning services, which could be very cost effective and a source of employment for people with excellent listening and typing skills. Furthermore, captioners are by far a more and effective service as note taking (note takers) and do not require knowledge of a certain topic or second (sign) language and, as previously noted, provide an universally useful service and not only a “disability service.”

8. REFERENCES

Deaf Federation of South Africa. 2009. Policy on the Provision and Regulation of South African Sign Language Interpreters. Available from: <http://www.DeafSA.co.za/index-1.html> [Accessed: 5 January 2013].

Hay, C. 2011. 17 babies born deaf in South Africa daily. Media Release issued by: Colette Hay, the president of the South African Association of Audiologists. Available from <http://www.health24.com/news/Hearing_management/1-1239,65848.asp> [Accessed: 1 September 2012].

Higbee, J.L. 2003. Curriculum Transformation and Disability: Implementing Universal Design in Higher Education. Available from: <http://www.myacpa.org/sc/scd/CTAD/ctad-a.pdf> [Accessed: 20 May 2013].

Katshwa, A. [deafconsultancy@gmail.com]. 2013. Re: Request a quotation for sign language interpreter services. Email to: Smith, M. [smit2073@umn.edu]. 25 January.

Kleinschmidt, E. [ewk@xelatrading.co.za]. 2012. Re: Different varieties and dialects of South African Sign Language. Email to: Smith, M.[smithm@ufs.ac.za]. 4 June 2011.

Magler, M.J.D. [magl0012@umn.edu]. 2013. Re: Sign Language Interpreters. Email to: Smith, M. [smithm@ufs.ac.za]. 22 May 2013.

Magongwa, L. 2010. Deaf Education in South Africa. *American Annals of the Deaf*, 155 (4), 493-496.

Rasebopye, D. 2010. A Parents Perspective on Deaf Education in South Africa. *American Annals of the Deaf*, 155 (4), 508-509.

Republic of South Africa. 1996. The Constitution, Act no. 108 of 1996. Pretoria: Government Printer.

Registry of Interpreters for the Deaf. 2013. Available from: <http://www.rid.org> [Accessed: 20 May 2013].

Selzer, M. 2010. *South African Sign Language used in Parliament: Is there a need for standardisation?* Unpublished master's dissertation, University of Stellenbosch, Stellenbosch, Western Cape Province, South Africa.

South African Statistics. 2010. Monthly earning of South Africans, 2010. Pretoria: Statistics South Africa.

South African Translators' Institute. 2013. Accreditation in South Africa. Available from: <http://translators.org.za/sati_cms/index.php?frontend_action=display_text_content&content_id=1739> [Accessed: 7 January 2013].

South African Translators' Institute. Practise test: guidelines. 2013. Available from: <http://translators.org.za/sati_cms/downloads/dynamic/sati_practice_test_2013_english.pdf> [Accessed: 7 January 2013].

U.S. News & World Report. 2013. Best Social Services Jobs. Interpreter & Translator: Salary. Available from: <http://money.usnews.com/careers/best-jobs/interpreter-and-translator/salary> (Accessed: 12 January 2013).

United Nations. 2008. United Nations Convention of the Rights of Persons with Disabilities. Available from: <http://www.un.org/disabilities/default.asp?navid=15&pid=150> [Accessed: 5 January 2013].

University of the Free State. 2013. The Department of South African Sign Language in the Faculty of the Humanities. Available from:

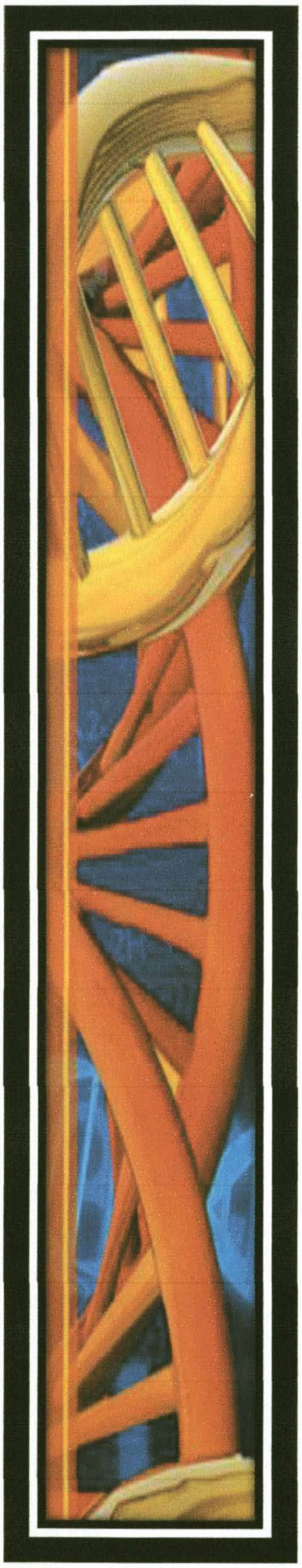
<http://humanities.ufs.ac.za/content.aspx?DCode=157> [Accessed: 20 May 2013].

University of the Witwatersrand, Johannesburg. 2013a. Disability Unit. Teaching students with hearing impairment. Available from: <http://www.wits.ac.za/prospective/studentservices/disabledstudents/11552/help_for_lecturers.html#hearing> [Accessed: 13 May 2013].

University of the Witwatersrand, Johannesburg. 2013b. Disability Unit. Policy Services. Available from: <http://www.wits.ac.za/prospective/studentservices/disabledstudents/11548/services.html> [Accessed: 13 May 2013].

Vaughn, G.R., Lightfoot, R.K. & Arnold, L.C. 1981. Alternative Listening Devices and Delivery Systems for Audiologic Habilitation of Hearing-Impaired Persons. *Journal of the Academy of Rehabilitative Audiology*, 62-77.

World Health Organisation (WHO). 2012. Deafness and hearing impairment. Geneva: World Health Organisation. <http://www.who.int/mediacentre/factsheets/fs300/en/index.html> (Accessed 28 February 2012).



PAPER V

THE COST OF HEARING AIDS IN SOUTH AFRICA

THE COST OF HEARING AIDS IN SOUTH AFRICA

Abstract

This paper concerns the cost of hearing products and services for people with hearing impairment in South Africa. For many years, the market in hearing aids and services was controlled by an oligopoly of six multinational firms based in the United States of America and Europe, who sold their products through on-site vendors, and kept competition to a minimum and prices quite uniform and stable. Challenges to this stable market have come from direct mail, online distributors, cheaper alternative devices known as Personal Sound Amplification Products, new manufacturers and distributors from countries including China and India, and even "telehealth in audiology." This complex situation is indicative of a large market, but has left HI consumers with a wide array of choices and inadequate disclosure of the necessary information to make them to best effect. Further, no option has even begun to address the problems of people with hearing impairment who are in extreme poverty.

1. BACKGROUND

Modern society desires a technological solution for every problem, even the physical. From human interest articles to science fiction television series, technology is presented as a way to overcome the frailties of the human body. In the case of hearing impairment (HI), technology provides early diagnosis through newborn hearing screening, sophisticated audiological testing, analogue and digital hearing aids (HA's), cochlear implants, bone anchored hearing aid (HA), brain stem implants and the development of implantable devices, and the possibility of hair cell regeneration to mention a few.

Technologies nowadays change at an ever increasing speed. Breakthroughs in technology and the ensuing emergence of new strong companies or the elimination of old flagships have led business people and researchers to speak of a new era in competition. Technological forces influence industries in several ways. Technological trends include not only new inventions that revolutionise and transform lives, but also can have a sudden and dramatic effect on an industry. These technological developments can significantly alter the demand for an industry's products, competitive prices, convenient accessibility and services.

In international business, one country's use of a new distribution method can make another country's products overpriced and non-competitive. If an industry continues to exhibit old methods of distribution, sales and structure instead of revitalising and engaging in fierce competition, it may affect and change an industry's products and services. The gradual painstaking improvements in methods and strategies, products, design, application, unemployment, old persons' grant of R1 260.00 (US$127.60) (South Africa Government Services, 2013), transportation and commercial base, will threaten and challenge old patterns in an industry. These changes impact the market for hearing technologies and thus the trend is applicable to the medical industry and thoughtful models of accessibility, affordability and implementation are needed.

The International Classification of Functioning, Disability and Health (ICF) of the World Health Organisation (WHO) introduced a new language and framework for disability in 2001 (WHO, 2001). Assistive Technology is, from an ICF perspective, an environmental factor that can facilitate participation. This new paradigm has been adopted by the United Nations (UN) Convention on the Rights of People with Disabilities, and member states such as South Africa (SA) are obliged to promote the use of assistive technologies suitable for persons with disabilities where there are barriers to accessibility (UN, 2006).

Furthermore, the WHO issued a report in 2010 concerning medical assistive devices and HA's, cochlear implants and FM systems were included (WHO, 2010). The report states that HA's, cochlear implants and affordable FM systems for students and quality low-cost behind-the-ear HA should be accessible and available to HA users.

All health professions have to be registered with the Health Professions Council of South Africa (Health Professions Act No. 56 of 1974). This Act governs all Health professions through the Health Professions Council of South Africa (HPCSA). The purpose of the HPCSA is to protect the public and guiding the professionals by a formal regulatory framework of the Health Professions Act. Furthermore, the HPCSA clearly defines the scope of each profession, which it mandates to register with HPCSA, and sets clear processes to be followed by the HPCSA (Health Professions Council of South Africa, 2013a). Therefore, all audiologists and HA acousticians are obligated to register with the HPCSA as speech, language and hearing professionals (Health Professions Council of South Africa, 2013b). It is however of cardinal importance to stress that audiologists and HA acoustician are not physicians, and all related diagnoses of HI should be performed by an otorhinolaryngologist.

2. INTRODUCTION

2.1 History of hearing aids

Most of the information on the history of HA's was obtained from the Bakken Library and Museum (BLM), Minneapolis in the United States (US) which has one of the most comprehensive collections of HA;s globally, as well as works on the history and nature of electricity and magnetism. The history of HA's are essential to understanding the HA industry. Some highlights relevant to this study will be mentioned.

The first published work on the treatment of deafness was written in the 1500s. Girolama Cardano, an Italian physician, philosopher and mathematician, published on bone conduction of sound and how sound may be transmitted to the ear by means of a rod or the shaft of a spear held between one's teeth (Wollock, 1996). The first work published on HA's was in 1588 by Giovanni Battista Porta. Porta described wooden HA's that were carved into the shapes of ears belonging to animals with superior hearing (The Bakken Museum, 2013). In 1812, Jean Marie Gaspard Itard, a French military surgeon turned otologist, developed a bone conduction hearing device. The speaker held the narrow end of a wooden rod between his teeth and the listener held the broader end against his teeth. During 1821, Itard invented a mechanical acuity meter, the sound source being a tuned copper ring (The Bakken Museum, 2013). Johann Heinrich August Duncker, a German optics manufacturer, patented the first speaking tube in 1819, which was a short leather-covered tube connected to a longer flexible tube, which could be between 1.52 meters (5 feet) to 3.05 meters (10 feet), and then to a large metal cup (The Bakken Museum, 2013).

In the United Kingdom (UK), Joseph Toynbee a surgeon, developed an artificial eardrum device consisting of a thin disk of vulcanized rubber affixed to a thin rod in 1854 (The Bakken Museum, 2013). The first full-scale manufacturer of a HA was Frederick Rein of London in 1800. Rein produced ear trumpets, hearing fans, and conversation tubes. These instruments helped amplify sounds, while still being portable. The first electronic HA was constructed after Alexander Graham Bell's telephone in 1876. The technology within the telephone increased how acoustic signal could be altered. Telephones were able to control the loudness, frequency, and distortion of sounds. These abilities were used in the creation of the HA, though Bell never registered a patent (The Bakken Museum, 2013).

The first patent registered for a HA in the US was by Edward Hyde in 1855 (The Bakken Museum, 2013). In 1935, Radioear Corporation introduced "The master hearing aid" that enabled a HA dispenser to test which combination of microphone and receiver provided the approximate gain and frequency response most useful for a given client. A HA having with those factors was made from the factory with which the seller had an exclusive contract.

In this first period, US distribution started with dealers normally marketing only products from one manufacturer. One example is Beltone established in 1940, which set up a national network of dispensing audiologists exclusively dealing with their own instruments by 1941 (Gerling & Taylor, 1997).

One of the first digital chips was created by Daniel Graupe, currently an Emeritus Professor of Electrical and Computer Engineering, Bioengineering and Neurology and Rehabilitation at the University of Illinois at Chicago. The digital chip, referred to as the Zeta Noise Blocker, routinely adjusted the gain in the frequency channels to help control high levels of noise. The chip was integrated in a number of HA's in the 1985 by Starkey Hearing Technologies, Siemens, Oticon, Phonak and Widex among others. In addition to the Zeta Noise Blocker, digital chips devoted to high-speed digital signal processing were developed and became available in 1982. By 1988, chips were produced in HA's. One of the major contributions of these chips was the ability to process both speech and other types of sounds in real time. Graupe is the holder of 26 US patents and of 12 foreign patents related to hearing technology.

Considerable research and development of hearing instruments and HA's were innovated by bioengineers, engineers, otologists, physicians and surgeons. This indicates that deafness is both a complex phenomenon and a disability and that there has always been a demand for hearing assistive devices to function at the highest possible efficiency within a hearing world cannot be overemphasised. This is particularly true in a context in which surrogates for hearing, in particular sign languages, are so emphasised in conversations by and about deaf people. Further research among deaf people to assess these needs and desired is a critical priority, in order to determine the best strategies for achieving social equity and the highest possible quality of life, particularly in terms of education and employment.

2.2 Hearing aid product

Hearing Aid devices resemble miniature public address systems. They are small, lightweight electronic devices, placed on the outer ear, within the ear canal, or behind the ear.

The microphone picks up the sound, the amplifier makes the sound louder, and the receiver (speaker) delivers the sound. Digital and analogue technology allows advantageous manipulation of sound in many useful ways. Some hearing devices are completely automatic, while others have user-adjustable controls, and all digital HA's are pre-programmed (Dennis, 2011).

Integrated microchips comprise the main components of a digital HA, and control signal processing. These microchips are extremely small and process several million transactions per second. Adaptation algorithms are installed on the microchips, which determine a particular hearing aid's digital signal transmission and performance range. The reputable manufacturers either use so-called digital signal processor microchips (DSP) or application specific integrated circuits (ASIC) microchips (Strauss, 2009). The primary difference between DSP and ASIC concerns the technology of the adaptation algorithm's programmability (e.g. new functions and programmes), and are of equal quality with regard to their application range and performance (Strauss, 2009).

3. HEARING AID INDUSTRY

Some of the leading hearing aid manufacturers that sell HA's such as Phonak Holdings, ReSound, US Holdings Inc., Siemens, Widex, Oticon to mention a few, are members of the German Electrical and Electronic Manufacturers' Association (2013). The German Electrical and Electronic Manufacturers' Association (GEEMA) provide members with detailed monthly information on their own sales volume and turnover. GEEMA also promotes research and development and use of innovative technologies by granting programs that accept research proposals technological, environmental protection, educational and scientific policy. This strategy establishes joint ventures, licencing and production agreements, patent pool, projects and alliances, development of shared fitting software and joint marketing (German Electrical and Electronic Manufacturers' Association, 2013).

3.1 Patent pool

Over more than a decade, the US company 3M has built a considerable portfolio of patents on signal processing technology related to programmable and digital hearing instruments. The generic character of these patents, applicable to assistive hearing technologies but other technologies as well, has threatened to block the development of new programmable and digital hearing instruments by others in the industry. Apparently, many hearing instrument companies were close to or actually did violate these patents, and in 1993 3M eventually sued ReSound for patent infringements (Bader, 2007).

As a solution to the patent litigation, ReSound, in Spring 1996, announced that it was about to purchase "certain assets" of 3M's hearing health activities, including research facilities and patents and patent applications (Tech Agreements, 1996; Bader, 2007). In August 1996, ReSound transferred the ownership of the 3M patents to a "Patent Partnership", called HIMPP (Hearing Instrument Manufacturers Patent Partnership) in order to purchase patents for the development of digital HA's from enterprises that do not themselves supply HA's and to make them available to all hearing aid manufacturers which is refers to third-party patent portfolio.

This patent pool was set up by ReSound and six other leading hearing instrument manufacturers, Danavox, Oticon, Phonak, Starkey, and Widex and Siemens (Bader, 2007). The purpose of HIMPP is to make a large patent portfolio available to all interested parties in the HA industry through membership in the partnership or through licence (Bader, 2007). According to Bader (2007) strategic patents that protect a particular instrument will not be pooled, but remain proprietary to the company which took out the patent.

The economics of patent pool arrangements are relatively complicated and not well explored (Nelson, 2007). Based on the research of Newberg (2000), from an anti-trust perspective, four factors may have caused the industry to set up the collaboration. The most important is probably an attempt to economise on contracting costs. It is very costly to set up licensing agreements. Therefore, the HIMPP solution limits the contracting costs to the initial formation of HIMPP, a modest and cost-efficient arrangement, granting all members all rights to use all 3M patents without any further negotiations or monitoring. The pooling agreement also eliminates the incentives to develop competing patents, economising expenditures. In addition, the industry increased its bargaining power through joining forces. The patent pool in this situation turns into a purchasing agreement, and thereby act as a "*lawful patent monopolist*" (Newberg, 2000). Finally, the partnership may engage in research activities that can produce new generic patents (Newberg, 2000). Therefore, the establishment of the HIMPP patent pool may contribute to the complex "competitive climate" in the HA industry (Newberg, 2000).

As shown in Table 1, Oticon, Phonak, Rexton, Siemens and Widex are European companies who have been active since at least as early as the 1950s and sometimes much earlier. Axon was established in China in 2002 and Audicus from the US in 2011. The structure of the industry seems relatively fragmented with a uniform character of ownership.

Table 1: Hearing aid timeline

Founding year	Start of production	Company name	Headquarter	Ownership
1904	1946	Oticon	Denmark	Private
1947	1947	Phonak	Switzerland	Private
1984	1984	ReSound	United States	Private
1956	1956	Rexton	Germany	Private
1847	1910	Siemens	Germany	Private
1963	1971	Starkey	United States	Private
1964	1964	Unitron	Canada	Private
1956	1956	Widex	Denmark	Private
2002	2002	Axon	China	Private
2011	2011	Audicus	United States	Private

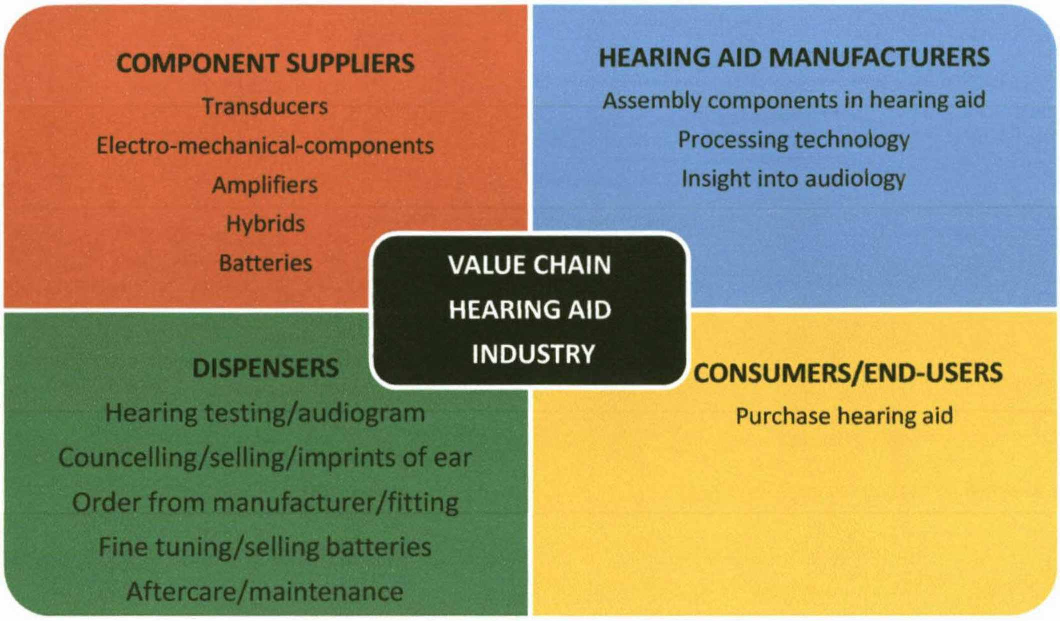
3.2 Hearing aid franchise and contract agreements

As previously noted, according to the manufacturers' websites, all of the above manufacturers offer franchise opportunities. According to Romo, Straus and Trigg (2012), the distinct competitive advantage that a franchise system may obtain is through a franchise supply chain of an industry. Moreover, a franchise represents opportunities for a positive impact to financial returns and a significant investment of capital. A hallmark of franchising is the ability of multiple outlets to operate under a common system and to offer uniform, products and services. According to the World Intellectual Property Organisation (2013):

> *"Franchising may be defined as a business arrangement which allows for the reputation, (goodwill) innovation, technical know-how and expertise of the innovator (franchisor) to be combined with the energy, industry and investment of another party (franchisee) to conduct the business of providing and selling of goods and services."*

The supply chain of the HA industry, starting from the downstream end with end-users (consumer), moving up-stream through dispensing audiologists and HA manufacturers to component suppliers and can be depicted as follows in Figure 1.

Figure 1: Supply chain of the hearing aid industry

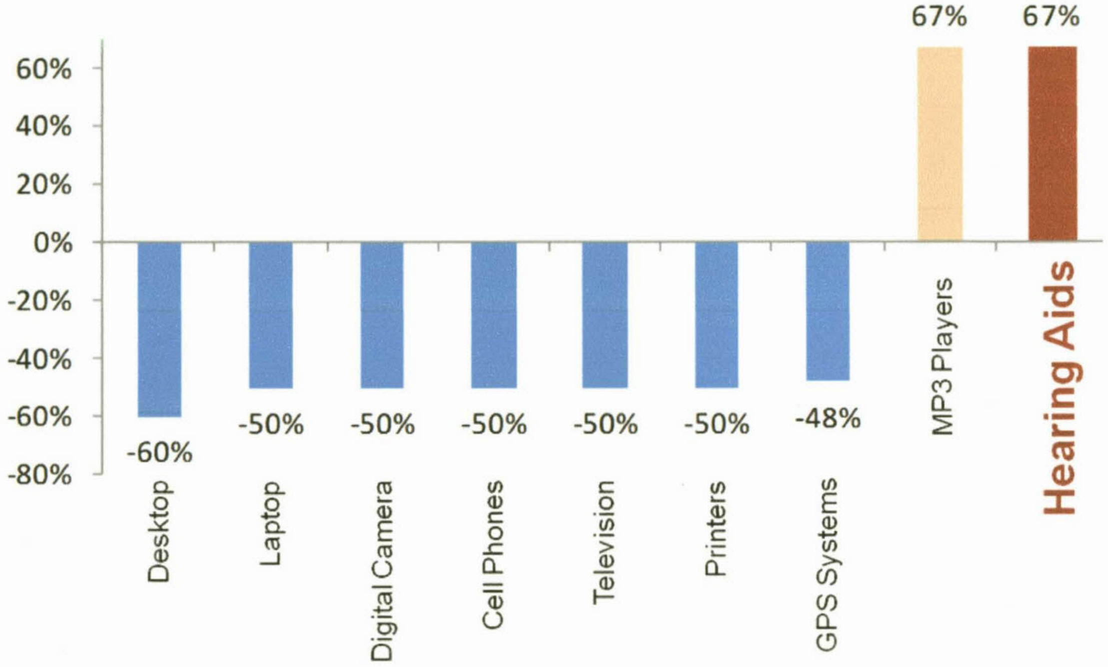


3.3 Hearing aid prices versus other electronic devices

Over the past decade, the prices of most electronic devices have dropped considerably. Common electronics products include digital cameras, notebooks, televisions and DVD players. Smaller components, streamlined methods of manufacturing, and new business models have all contributed to the overall decrease in price of everyday digital products with the notable exception of HA's. The average price of a HA with similar specifications has almost doubled in the past decade (See Figure: 2). This study does not take a price comparison between other medical devices such as pacemakers and catheters in SA due to the different electronic components of different medical devices.

Fourteen years ago, Humes (1991) found that this pattern could be attributed to the sense that the various HA products appear to be very differentiated, at least to non-technicians. Within the same product, technically HA's are more or less identical. However, what matters is that to dispensing audiologists of HA products appear to be different. That applies to design and technology, the accompanying services, the image created around them, and the means of distribution (Humes, 1999). If buyers are technologically well educated, competition tends to be much tougher, as illustrated in Figure 2 Thorough and reliable consumer reports on hearing instrument performance may move the competition in the same direction in the future as other technological products.

Figure 2: 10 Year price evolution: Hearing aids versus other electronic devices



Source: Survey by Audicus 2002-2012

Such an outcome contributes to a very common trend in free markets where consumers have substantial choice on where to obtain preferred products at lower prices. In addition, online business models offered consumers a far more economical alternative by which they could obtain the same product. Low cost manufacturing in China, streamlined production processes, and the commoditisation of components further accelerated this trend with the primary focus to offer consumers the best price and choice (Clarke, 2007).

Competition is one of the best ways to spur innovation, and that is certainly the case in the HA market, where recent technological developments are noticeably exciting manufacturers and dispensing audiologists, who believe the activity will lead to new or improved products. Clients referred by physicians to audiologists that treat patients with minor to severe HI are certainly most receptive to adopting new products that can improve upon existing treatments. The market for such devices is quite large. Obviously, this can make business endeavours in this area very attractive to manufacturers and dispensing audiologists.

4. SITUATION ANALYSIS

During April 2012, the University of South Africa (UNISA) group sponsored by the Starkey Foundation tested a total of 961 people for HI. The necessary fittings were made on the spot. Two hundred sixty five individuals were identified from among the 961, which constitutes 27.5 percent with HI, who were fitted with free HA's (UNISA, 2012).

The Centers for Disease Control and Prevention (2012) in the US have found that one in 25 people under the age of 45, and one in 10 people by the age of 60 will develop a hearing loss. McPherson and Swart (1997) estimated, during a 1997 review, that, conservatively, 20 out of 1000 children aged between five to 14 years had severe bilateral HI in the Africa Region [the authors' term, which is assumed here to mean the entire African continent]. This was primarily due to suppurative otitis media. However, it is almost impossible to obtain accurate statistics regarding the total persons with HI in SA.

4.1 Financial implications

For people with HI, the current prices charged for some of the HA's available in SA can often prove to be a severe financial obstacle. Depending upon the terms that are offered by a given client's medical aid schemes (medical insurance), most will cover the cost of a hearing test. The extent of costs covered by medical aid schemes towards a HA vary considerably, from R2 000.00 (US$200.00) to R12 000.00 (US$1400.00) per HA per family annually. As best can be determined at this time, no South African medical scheme will cover more than one family member per annum. Thus, costs range down from one HA partially covered to no assistance at all. However, some of the exclusive and very expensive medical aid schemes might be prepared to provide cover for up to R25 000.00 (US$2800.00) for only one member per family annually.

Statistics South Africa data from the General Household Survey (2010) shows that a relatively small proportion, only 17.6 percent of the individuals in SA, had medical aid coverage in 2010. Thus, the majority of South Africans, 82 percent, do not belong to a medical scheme. Ataguba and Goudge (2012) argued that in SA medical aid schemes are expensive, combining high costs with limited coverage to members.

According to van Zyl (2012), the Universitas Academic Hospital in the Free State Province received HA's supplied by a tender with Disability Rehab of R50 000.00 (US$5600.00) for the 2012 financial year. Despite the existence of a strong HA market, it appears that only a small percentage of the HI population in SA can afford to purchase a HA.

5. METHOD

There are currently no published studies on the cost of HA's in SA. Data were collected between 2011 and 2013. Data were obtained through fieldwork. The total suppliers identified included three dispensing audiologist practices in the Free State Province, one in Cape Town in the Western Province, and one in Johannesburg, Mpumalanga. In addition, a retail pharmacy group and two HA acousticians in SA were included in the sample. The dispensing audiologists were approached by the researcher, who requested confirmation of ownership of their practice and a general description of the HA's sold, functions of the HA and products recommended and offered, the costs of HA's, and estimates of expenditure to the customer on HA services. The data provided in this study were comprised of quotations and written notes. In addition, two HA users were approached to obtain information regarding the stages and the process of obtaining HA. Three on-line dispensing audiologists were investigated in SA by an intensive internet search as well as on-line dispensing audiologists in the US.

For comparison, eight hearing dispensing audiologists were visited in the US during 2012-2013. During 2011, two HA dispensing audiologists were visited in Zürich, Switzerland; three in Bergamo, Italy; one in Amsterdam, Netherlands, and two in Innsbruck, Austria. The UK was not included from the survey because the government supplies HA's and cochlear implants free of charge to its citizens, though an analysis was done of an on-line company in the UK that sells HA world-wide. Price comparisons were made between the various products and prices of the dispensing audiologists. A comparison was necessary to determine the cost difference of the same products in the international market versus the South African market since all the manufacturer head-offices are based where the product is manufactured.

Models of products with similar features were analysed, all in the middle range price, between R15 000.00 (US$1480.64) and R25 000.00 (US$2467.73). These were behind the ear HA's (BTE), with between 10 and 20 channels, as the number of channels varies by manufacturers. BTE HA's accounted for 70.8 percent of overall commercial sales in 2012, in the "key market geographies of the US, Canada, the UK, Germany, France, Italy, Spain, Japan, China, India, Australia and Brazil" (Pallarito, 2012). In the case of BTE HA, the HA is integrated into a case that is worn behind the ear. The ear fitting in the ear ensures that the HA has been put on correctly. Since the electronics are in the HA that is worn BTE, the ear fitting is considerably smaller than the otoplastic in the ear HA. The sound is transmitted to the ear fitting from the HA via a thin plastic tube. Due to the open construction of BTE equipment, hearing comfort is considerably greater than that of in the ear equipment, the reason the majority of HA users prefer BTE HA (Pallarito, 2012).

6. RESULTS

This study is not concern with the prices of HA's supplied to the State, due to numerous attempts to obtain this information regarding the different products and prices. All dispensing audiologists (providers) in SA were franchises of the different manufacturers as identified and owned primary by audiologists, with the exception of one dispensing audiologists owned by physicians, provided information on specific HA brands they sell, according to the franchise status or agreement with their suppliers/manufacturers. This author requested information from dispensing audiologists on the status of membership with a medical scheme. With or without a medical scheme, a quote was provided for a HA from the mid-range price segment upwards R15 000.00 (US$1480.64) - R25 000.00 (US$2467.73)(BTE)). New technological breakthroughs and all the distinctive features of a HA were over emphasised in all cases to justify the cost. Upon requests for lower priced HA's, it was emphasised that the performance of a HA in the price class between R5 000.00 (US$500.00) and R10 000.00 (US$1000.00) had limited features and thus was not encouraged. A 30 day trial period was offered without charged, and in case the total amount was not affordable, a one to two year agreement of paying-off in monthly installments was offered.

All dispensing audiologists kept their prices for products and services bundled, providing only information on the specific product they are recommending. Products offered were ReSound, Siemens, Unitron, Widex, Phonak, Rexton, Sonic, Starkey and Oticon in a similar price range for with similar, standard technology (See Figure 3). All the products analysed are digital programmable HA's, custom programmed by an audiologist using a computer with special software. The information in a consumer's audiogram is entered into the computer, and the HA are adjusted by computer to give the best possible hearing improvement. The HA can be reprogrammed or fine-tuned at any time and the consumer will be charged each time a consultation fee. These brands have proprietary and registered software and can only be purchased, programmed and repaired by the dispensing audiologist who sells the product. Therefore, the client becomes tied to a specific dispensing audiologist or franchise of a specific brand of HA for the life of the HA. The client loses the flexibility of having the option to make use of another dispensing audiologist. On this basis, it seems that the roster of franchises with subsidiaries represented by the current data would be indicative of the practices of all important players in the industry.

A cross-border price comparison between dispensing audiologists of the identified countries selling the same product with more or less the same features and price segment was analysed as shown in Figure 3.

Figure 3: Price and product comparison 2012/2013 between countries

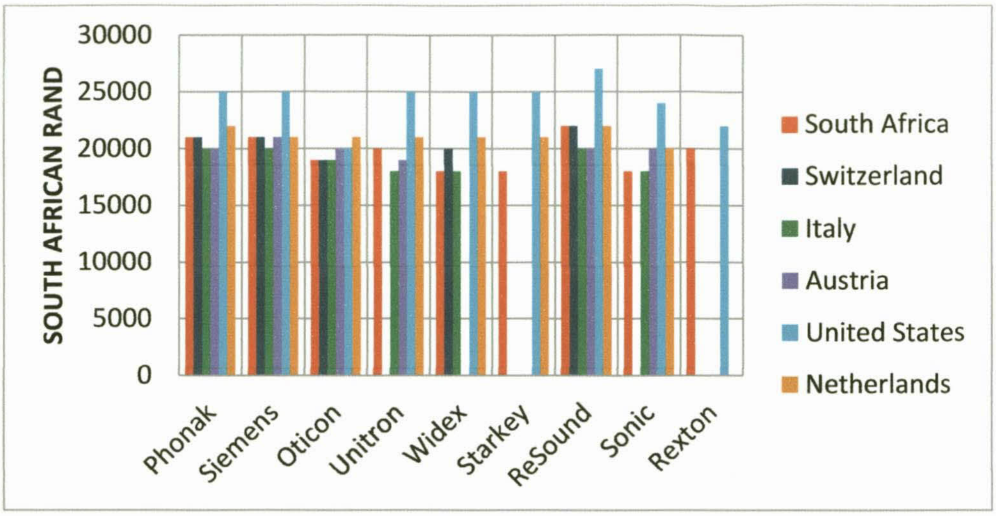
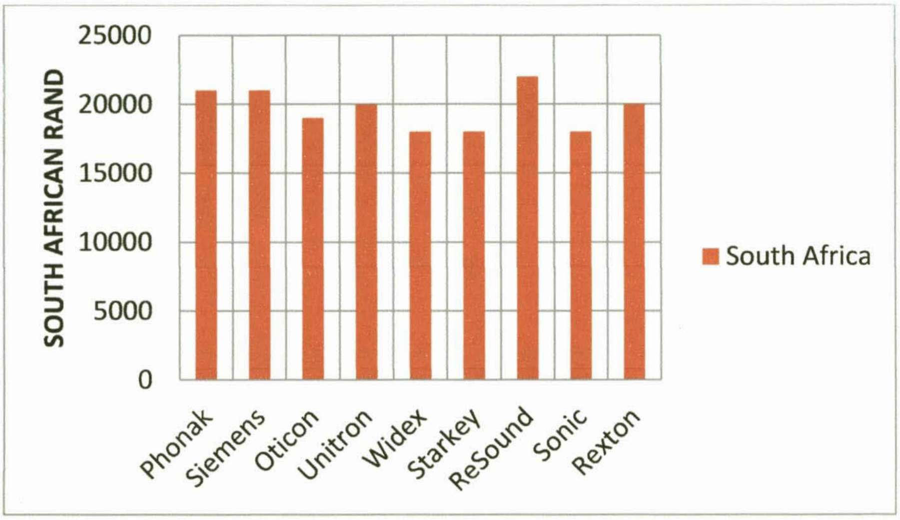


Figure 3 shows that prices of Phonak, Siemens, ReSound and Rexton are similar in all countries. The average price of a HA in these countries is R20 000.00 ($2000.00). Prices in the US are significantly higher than any of the other countries. While the countries represented in Figure 3 have very different economies and the HA industry is highly fragmented, insofar as no corporation has sufficiently large market share to dictate prices throughout, this chart nonetheless indicates great stability among prices from country to country. Therefore, the HA industry reveals a concentration that qualifies the industry as an oligopoly. It seems that the industry structure of manufacturers has stayed the same since the 1950s as illustrated in Table 1. The corporations that dominated the industry in the mid twentieth century are the same ones today.

Figure 4 illustrates prices from the different dispensing audiologists for HA's in SA. The data collected for this study indicates that dispensing audiologists sell products from one to three different manufacturers only. Even dispensing audiologists who sell from more than one manufacturer emphasise products from a single company. Despite a system of dispensing in which it is difficult for a customer to access the full range of products from all manufacturers, pricing is remarkably uniform from these dispensing audiologists.

The lack of competition at the level of on-site HA dispensing audiologist is illustrated in Figure 4. As illustrated in Figure 2, the outcomes are very similar to the international market. Moreover, it is shown that HA prices are similar across these countries, and supports the idea of an agreement between manufacturers and dispensing audiologists, whether through franchising or contracts. It seems that the structural conditions that support an oligopoly is parallel behaviour and impedes significant competition.

Figure 4: Product selling price comparison South Africa



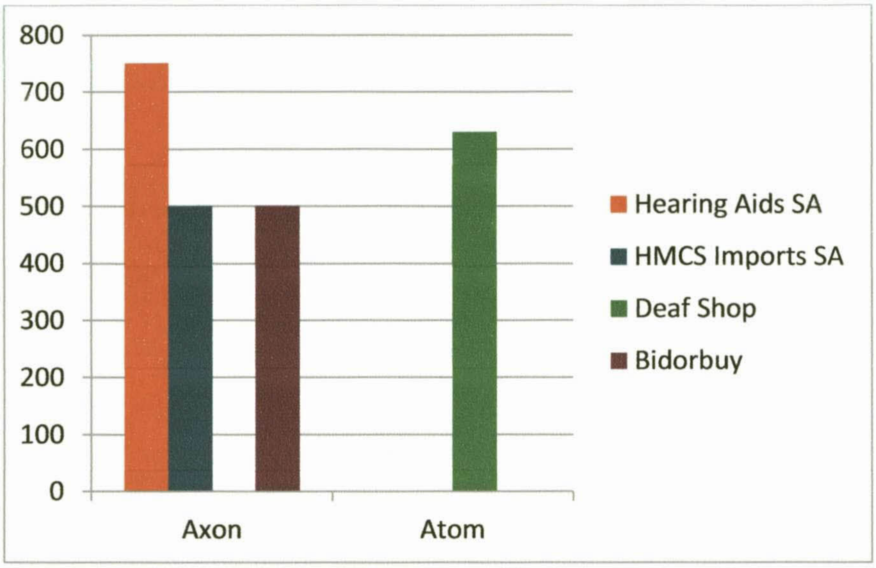
6.1 Online sales

Hearing aid manufacturers have a new distribution model by franchising and contract agreements with online businesses, selling older models in the average price class of R5 000.00 (US$500.00) direct to the consumer. On-site dispensers do not display these older products.

6.2 Newcomers to the hearing aid market in South Africa

In SA since 2011, pharmacies, retail shops and online dispensers began selling HA's. There are challenges taking place in the HA market that could spark some disruption in the future. Four Internet sites were identified as dispensers in SA. Hearing Aid SA (2013), HMCS Imports SA (2013), Deaf Shop (2013) and Bid or Buy (2013) provide consumers the opportunity to purchase a HA over the internet without any human contact as shown in Figure 5.

Figure 5: Online dispensers with prices posted online in Rand



Source: Hearing Aids SA, HMCS Imports SA, Deaf Shop and Bid or Buy (Accessed:27 May 2013).

One of the new comers is Axon Hearing Aid sells by HMCS Imports South Africa, and stated that there is no longer a need to travel any further than a computer to purchase a HA, with the added advantage of low costs, fully guaranteed by the manufacturer and returnable within 30 days (HMCS Imports South Africa, 2013). Hearing aid prices offered were between R500.00 (US$50.00) and R750.00 (US$75.00).

Axon Hearing Aid is a brand manufactured by Senlan Electronic Factory in China, founded in 2002 (See Figure, 6,7). Axon is selling by three of the four online dispensers in SA. The manufacturer supplies this product to agents and offers franchise opportunities. The average price for a HA is R500.00 (US$50.00). The product is registered in China, but the author could not obtain information regarding whether this product is registered with the United States' Food and Drug Administration (FDA). The FDA is a widely-accepted authority on product safety. Axon is available from Deal Extreme in the US for an amount of R130.27 (US$13.27) per HA, and is distributing to any country.

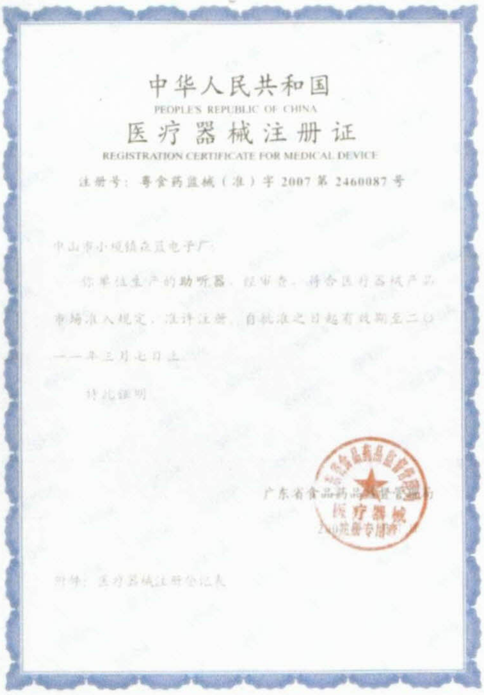
Figure 6: Trading registration certificate

中华人民共和国

医疗器械生产企业许可证

Source: Axon

Figure 7: Product registration certificate



中华人民共和国
PEOPLE'S REPUBLIC OF CHINA
医疗器械注册证
REGISTRATION CERTIFICATE FOR MEDICAL DEVICE
注册号：粤食药监械（准）字 2007 第 2460087 号

中山市小榄镇点亘电子厂：

你单位生产的助听器，经审查，符合医疗器械产品市场准入规定，准许注册，自批准之日起有效期至二〇一一年三月七日止。

特此证明

广东省食品药品监督管理局

附件：医疗器械注册登记表

Source: Axon

No confirmation could be found regarding whether this product is registered with the FDA, either. It is unclear whether it meets FDA guidelines for a HA. These certificates are only available in Chinese which is in general unknown to consumers in other countries.

A second newcomer to the SA market is Atom Hearing Aid, a product about which no specifics could be obtained online. Significantly, it could not be ascertained in which country this product is manufactured and no registration with the FDA could be obtained from the FDA's website on product registration.

6.3 Over the counter

According to Anderson (2013), The Council Speech, Language and Hearing Professions Board (CSLHP) of the (HPCSA) is taking legal action against Clicks Pharmacy Group, due to the fact that qualified nurses and not registered audiologists provide HA's. As mentioned in the background of this study, the purpose of the HPCSA is to protect the public and guide professionals by a formal regulatory framework of the Health Professions Act.

According to Fokazi (2013), the (CSLHP) is warning the public that certain retail pharmacies were selling amplifiers as HA's. The HPCSA stated that:

> *"In their advertising, hearing aids are dispensed by trained nurses. These nurses, who do not fall under the ambit of the HPCSA, are placing the public at risk by illegally administering treatment for clinically unproven hearing problems by supplying unprescribed amplifiers and are as such in breach of the law and also practicing outside their scope of practice."*

However, when the author visited a pharmacy outlet in 2012, the package indicated clearly on the label "amplifier". Moreover, the HA sold at that stage were an analog HA which do not need any programming. Furthermore, it is the opinion of the author that no 'prescription' is *legally* required to purchase amplifiers or a HA. Without additional legal proscriptions on such practices, an ill-informed and unsuspecting public in a developing country, often has little recourse but to rely upon inappropriately qualified service professionals who often dispense generic amplifiers, which may even physically damage the inner ear, as a much cheaper surrogate for HA's.

The "Medical Device Safety Argument" is supported by the South African Medicines and Medical Devices Regulatory Authority Bill (SAMMD) of 1998, Section 34 (1)(b) and read as follows:

> *"the Authority may, on application if the prescribed manner and on payment of the prescribed fee, issue to a manufacturer, importer, wholesaler or distributor of orthodox medicines, complementary medicines, veterinary medicines, or medical devices a licence to manufacture, import, act as a wholesaler of or distribute, as the case may be, such medicine or medical device, upon such conditions as to the application of such acceptable quality assurance principles and good manufacturing and distribution practices as the Authority may determine."*

The situation in the US is comparable but different in some important details. According to their websites, HA's are available over the counter at such major franchise outlets as Wal-Mart/Sam's Club, Costco, and Sears. Some outlets require an audiogram, but, if the customer signs the FDA waiver (Appendix 1), this requirement is waived.

6.4 International online sales:

In 2008, the US Food and Drug Administration published guidelines that attempted to distinguish between HA's and "Personal Sound Amplification Products" (PSAP's'). The Federal Food, Drug, and Cosmetic Act 21 of 1938, as amended in 2013, defines a HA under section 201(h) as:

> *"any wearable instrument or device designed for, offered for the purpose of, or represented as aiding persons with or compensating for, impaired hearing."*

This definition includes air and bone conduction regardless of how they are worn. Hearing Aids are subject to pre-market review and properly prescribed and used only with appropriate medical diagnosis. To purchase a HA without such diagnosis, one must sign a waiver (Ross, 2009).

According to Ross (2009), the FDA distinguishes PSAP's from HA's, in that they are *not regarded to address HI* (Emphasis is this author's.). The FDA regards PSAP's as amplifiers for non-HI "recreational use." However, copious online and television advertising for PSAP's implies otherwise, that is, that the devices are being sold for use with HI, although there are sometimes small print disclaimers to the contrary, denying that the devices are HA's. The industry is not legally obligated to make this important distinction. PSAP'S are cheap, as little as US$10.00 (R100.00), and widely available. Given the cost of HA's and the requisite services associated with them, it is easy to account for the popularity of PSAP's.

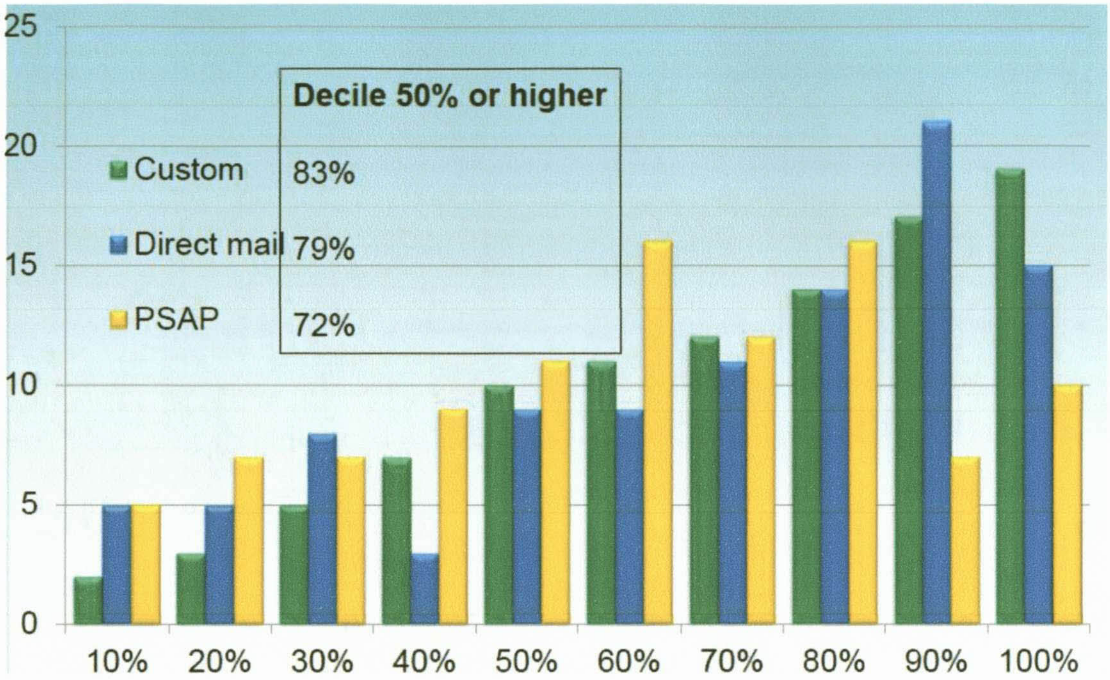
No PSAP examined by Ross (2009) included important HA features, such as noise and feedback management or directional microphones. Such features, along with audiological services are responsible for the high cost and the added value of HA's versus PSAP's.

The Hearing Industries Association urged the FDA to investigate some vendors for violation of FDA regulations and, if appropriate, send warning letters instructing violating parties to cease and desist marketing and/or distributing these products for not complying with FDA (Kirkwood, 2012).

Figure 8 indicates that 79 percent of HA and PSAP sales in the US were by direct mail dealers, such as Amazon.com and Ebay. In addition, 72 percent of purchases are PSAP's. This indicates that lower prices and ease of purchase are seen as important factors in the purchase of hearing products by many Americans. While economic circumstances may make such purchases the best or only available option, it is at the consumer's extreme risk.

The FDA waiver is required for online sales as well, in cases where the client does not supply an appropriate audiogram. However, not all online vendors comply with this requirement.

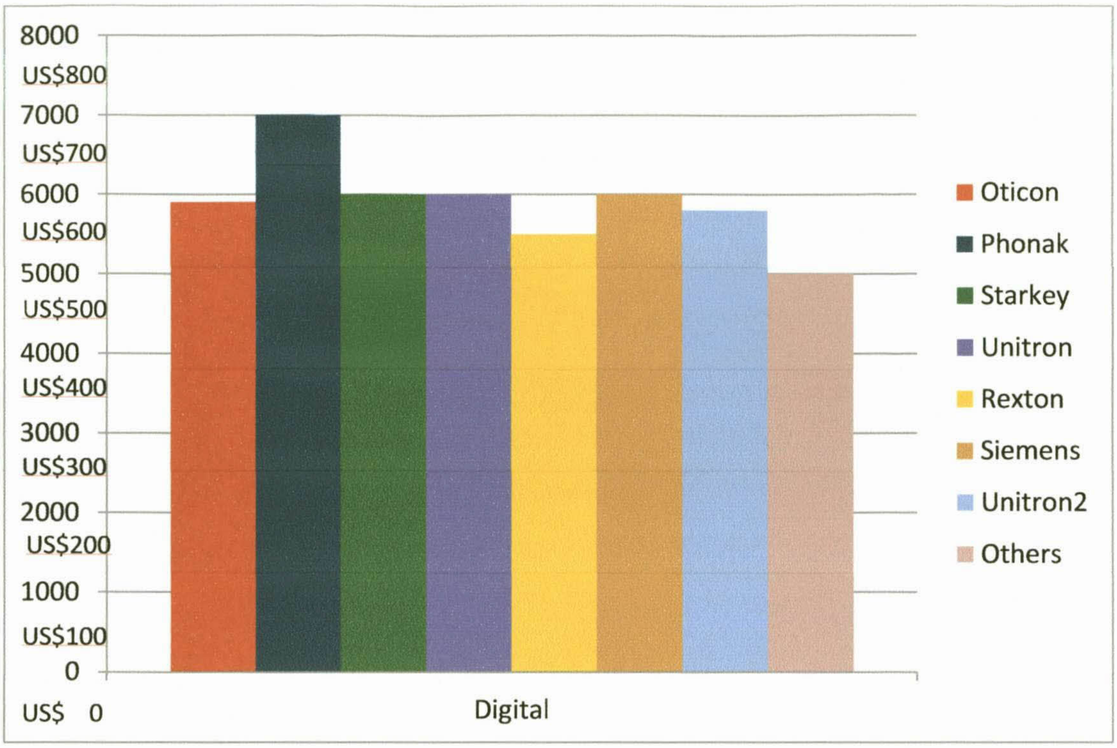
Figure 8: Market trends in the United States hearing aid industry



Source: Better Hearing Institute, (Accessed: 14 November 2012)

Figure 9 illustrates online distribution of brand name HA's and prices in US dollars US$) and South African Rand. In the US, the online distributors Wholesale Hearing Aids and Hearing Planet sell brand name HA's to customers with a 42 day trial period, during which time the product may be returned for a full refund. Prospective customers are required to supply an audiogram to these dispensers for fine tuning, having been given notice that all HA's, regardless of mode of vending, are initially pre-programmed. Upon receipt of the HA, the customer needs to obtain ear molds from an audiologist. In case the customer does not want to provide an audiogram, an FDA waiver form needs to be signed and sent back to the supplier. These are low-cost products, with a price range between US$100.00 (R1000.00) to US$700.00 (R7000.00) as shown in Figure 9. The lower prices may be attributed to older models, a lower number of technical features (such as only 8 channels, no remote controls, and no Bluetooth), the cost savings of online distribution, and the lack of an on-site audiologist to provide services. At the same time, some companies include five-year warrantees and supplies of batteries for the lifetime of the HA.

Figure 9: Online distribution of brand names in the hearing aid industry



Source: Hearing Aids Wholesale, 2013

6.5 International Companies

As the US Food and Drug Administration (FDA) stated:

"FDA does not "approve" companies, health care facilities, laboratories, or manufacturers. FDA does inspect product manufacturers to verify that they comply with good manufacturing practices."

However, the FDA (2013) stated that it is a great concern in the US as well that HA's are being sold without selection and fitting by health professionals. This is also a great concern in SA.

6.6 International online distributers of hearing aid brands

The international online distributors Hearing Planet (US) and Hearing is Believing (UK) sell the same expensive, high-quality products as audiologists with on-site vending outlets, at similar prices (Table 2). However, they do not provide audiological services (prices and rates of exchange as of 25 May 2013).

Table 2: Specific model comparisons

PHONAK	US	Rand	UK	Rand
Model	**Hearing Planet**		**Hearing is Believing**	
Audeo Q20	$1,849-$2,899	R18,667.32-R29,268.01	£1,595	R24,447.52
Naida Q90	$1,849-$2,999	R18,667.32-R30,227.60	£1,595	R24,447.52
WIDEX				
Clear440	$1,899-$2,999	R19,172.11-R30,227.60	£1,495	R22,914.76
Mind440	$1,899-$2,999	R19,172.11-R30,227.60	£1,450	R22,225.02
OTICON				
Ino Pro	$1,849-$1,949	R18,667.32-R19,676.91	£1,695	R25,980.28
ReSound				
Verso9	$2,399-$2,899	R24220.06-R29,268.01	£1,595	R24,447.52
Alera9 Wireless	$1,849-$2,799	R18,667.32-R28,258.42	£1,445	R22,148.38
UNITRON				
Quantum Pro 20	$2,899	R29,268.01	£1,595	R24,447.52
Max20 SP	$1,599-$2,699	R16,143.34-R27,248.83	£1,495	R22,914.76
STARKEY HA				

SoundlensIQ110IIC	$1,899-$2,999	R19,172.11-R30,277.60	£1,995	R30,578.56
Wi Series 110	$2,229-$2,999	R22,503.76-R30,227.60	£1,395	R21,382.00

Source: HearingPlanet

7. DISCUSSION

7.1 Hearing aid debate

Numerous television broadcasting companies in the US investigated and reported on the high costs of HA's. Geeser (2013) investigated the high prices of HA's, and reported that consumers had several concerns and questions in this regard. Consumers preferred to buy HA's over the counter for US$100.00 (R1 000.00) instead of between US$1 720.00 (R1 720.00) and US$7 000.00 (R70 000.00) per HA.

Moore (2013), a television journalist for the Canadian Broadcasting Company (CBC), investigated and reported on HA prices far higher than the production (actual) cost of a HA. Consumers can pay thousands of dollars for a single HA. The CBC investigation has found that the actual cost of making a HA averages around US$150.00 (R1 500.00). The figure was obtained from the operator of Audicus Hearing Aids (2012), an online company that distributes HA's direct from the manufacturer at a reduced cost to consumers around the world. Audicus president Patrick Freuler claims that he has broken out the cost of a typical HA, based on his own research with manufacturers. Freuler stated that:

> *"The typical cost to produce a hearing aid [is] anywhere between $50 to up to $200."*

Furthermore, Freuler argued that the price depends on how many features are within the HA, whether or not it has Bluetooth capability, or multiple channels and microphones. Moreover, the manufacturer sells the HA for US$400.00 (R4 000.00) to US$600.00

(R6 000.00) to a dispenser, who then sells the device for about US$2000.00 (R20 000.00). In addition, Freuler claimed that most of this price escalation happens at the dispensing audiologist practice and that services related to HA delivery are performed by audiologists and HA practitioners.

Prices at Audicus Hearing Aids range from about US$400.00 (R4 000.00) to US$600.00 (R6 000.00) per HA as illustrated in Figure 10.

Figure 10: Price Comparison, Canadian Broadcasting Company Study, 2013

	aSwing AUDICUS	Milo Phonak	Delta 4000 Oticon	Mind 220-M Widex
Price	$499	$1800	$2000	$2000
Digital Sound Technology	✓	✓	✓	✓
Speech Focus (Directional Mics)	✓	✓	✓	✓
Noise Reduction	✓	✓	✓	✓
Volume Control	✓	✓	✓	✓
Modern/Discreet Design	✓	✓	✓	✓

Source: Audicus.com, (Accessed: 1 June 2013)

The above price of US$499.00 (R5 000.00) includes consultations with Audicus's audiologists by phone or online. The price also includes a five-year warranty, and if consumers are not satisfied, the HA may be returned without cost. The comparison does not include specific models and does not attempt to match various models feature-for-feature. These are a very serious limitation. No consumer can rely on this data for that reason.

7.2 The role of an audiologist

Historically, consumers had few alternatives in purchasing HA in SA. Although competition is recognised as an important impetus for innovations and product launches, this does not in itself indicate that there is significant competition within the HA oligopoly. In terms of scale of economics, particularly from the point of view of maximising profits, the oligopolists of the HA industry are obstructing technical development by tacitly agreeing to forego such competition and by regarding technical developments of by a single member of the oligopoly independent of other members as being a contravention of oligopolist parallel behaviour. The hearing aid market practices oligopolist parallel behaviour in opposition to technological competition. Thus, the oligopolists restrain intra-group competition and ensure that no member corporations have a permanent competitive edge by way of introduction technical optimisations. The high level of intra-oligopoly market, product and price transparency supports this behaviour.

7.3 Costs of the audiologist

As part of the abovementioned CBC study, in response to claims by Audicus Hearing Aids, Andrea Richardson-Lipon, an audiologist based in Selkirk, Canada, does not dispute the above analysis (Moore, 2013). However, she claimed that HA prices include an essential bundle of services and stated:

> *"Depending on how long the warranty is, there's all the adjustments, all the cleaning.... That's all covered into the price. The hearing test, the fitting fees, everything is just all bundled. Hearing aids are more about service."*

The Society of Hearing Aid Acousticians of South Africa (2013) has 48 registered acousticians and sells HA's directly to the public. Though todays HA's are more sophisticated with additional channels, for most people with a mild to moderately severe hearing loss, they are arguably over-engineered. The additional channels do not significantly help those with moderate hearing loss. In other words, as stated, the technological improvements in HA's are not more affordable but less accessible.

HA's could not be purchased by consumers directly off the shelf in SA until 2011. In the past, audiologists recommended a certain type of HA to a potential buyer based on cost considerations and the severity of HI. This makes the supply chain of HA crucially dependent on dispensers who act as the middleman between hearing aid manufacturers and end-users.

The HA manufacturing industry is highly globalised and dominated by a few international firms, including Siemens, Widex, Phonak, Starkey and Oticon. For the inexperienced consumer, unbundling (separate pricing of goods and services) provides an enhanced range of price choices. The industry sells high-tech products that can range drastically in price.

As Kirkwood (2013) stated:

> *"The inconvenient truth is that all the major hearing aid manufacturing companies are in the retail hearing aid business, through ownership of hearing aid dispensing, audiology, and/or ENT practices. In addition, they own many of the buying groups and various web sites. These are all our direct retail competition."*

Rising healthcare costs and other factors have spurred consumers to seek the most affordable HA or PSAP on the market, and firms have increasingly competed on price (Kirkwood, 2013). Report Linker for Libraries (2012) found that this factor has led to the introduction not only of PSAP's, but even of very low-cost disposable HA's which have a non-replaceable battery and the prevalence of online hearing aid sales (Egolf, Kennedy & Larson, 1992). The results from this study have shown that though there are similarities in the organisation of health-care development there are variations in the type and extent of HA services provided. In addition, Harris *et al.* (2011) referred to the inequities in the health care system in SA with the focus only on Black South Africans, excluding people with disabilities which is also enshrined and protected under The Constitution of SA (The Constitution, 1996) applicable to the private and public sector.

It remains an open question whether online marketers will increase sales in SA. Hearing healthcare providers note that online marketers have been around for years but have had little overall effect on HA sales. That could change in the wake of United Health Group's

(UHG) attempt to offer HA citizens at sharp discounts on the Internet. The UHG is a diversified managed health care company headquartered in Minnesota in the US. The FDA banned the company's online hearing test in response to hearing healthcare industry protests, but consumers can still enter their audiogram results on United Health's site after being tested by a physician or hearing healthcare provider (Pallarito, 2012).

8. LIMITATIONS

Due to the brevity of the period of data collection in this study, it was not possible to ensure entirely consistent and comprehensive data, and consequently there may be slight variation in the factors included in the estimated cost of HA’s and services. A much more comprehensive study should be undertaken on the profit and turnover between manufactures and suppliers prices. As stated above, data on the costs for purchasing HA by a dispenser in SA are not readily available.

The solution to this debate concerning why HA’s have high prices is to obtain data on market share and price and sales figures from a variety of sources. Reliable data on market shares are not publicly available. Furthermore, to the best knowledge of the author, academic research of the HA industry in SA are non-existent.

9. CONCLUSION

The HA industry, in SA and worldwide, is complex. In SA, marketing models and distribution channels should be investigated through government enforcement of anti-trust (anti-monopoly) and fair trade laws. The “Medical Device Safety Argument” that has historically limited competition to a small number of corporations and dispensing audiologists are supported under the SAMMD. However, the argument is hollow in the context of non-medical devices and audiovisual products such as IPods, MP3 Players, Vuvuzela’s, video games capable of producing damaging sound levels and shown to induce hearing injuries (Swanepoel & Hall III, 2010; Vercelletto, 2013).

The current generation of such devices, along with the headphones and ear buds they utilise are potentially far more damaging to the ear than any HA ever produced. It is arguable that the HA industry utilises this rapidly eroding argument to justify the average price of R20 000.00 (US$2000.00) per HA that should sell for the R5 000.00 (US$500.00) to R8 000.00 (US$800.00) range if they followed the price trajectories of other consumer electronics. Barring unforeseen obstacles to competition, this could and should slowly change to a fairer and freer market. In much the same manner the over the counter retail HA industry has become a reality, so shall it be with the availability of HA's on the Internet.

Hearing Aid consumers in SA are still captive to a limited set of choices of products and services to a large extent, as there are clearly monopolistic elements operating in the country. The situation is slowly changing with the ability to shop internationally, along with the enforcement of fair trade laws and anti-monopoly statutes and litigation. As the market continues to change and new challenges to the conventional distribution system emerge, it is the opinion of the author that legislation should be changed so that dispensing audiologists should not only advertise their services but also the prices of products. More choice prices of products will contribute to competition and transparency.

Major retail companies have identified and discovered the profit potential of the HA industry and profit is one of the key ingredients that expand the field, and with it affordability and accessibility. The field needs to grow in order to further and increase HA market penetration.

As markets become freer, consumers more educated, hearing technology more standardised and choices abound, price levels in the hearing products industry should eventually see a similar downward trajectory. There are various HA companies and distributers making use of this direct model, eliminating the middleman, part of an ongoing trend to make HA's more accessible.

Investigation of competition on pricing and conditions in the market for HA's do not provide any clear evidence of significant competition within the oligopoly. The main reason for this evaluation is that HA manufacturers not only divided the market into different price segments at the start of digitalisation, but were also in a position to stabilise these price segments over time in spite of the considerable technical upheavals in the wake of digitalisation.

A great concern for the HA industry is the penetration of HA technologies manufactured and distributed by Chinese firms. Without evidence of US FDA approval, currently the best metric available, these products should be banned in SA, as it cannot be proven that they are safe and effective. In addition, the Health Professions Act and the HPCSA should clarify and strengthen its regulations and legislation over companies that illegally market HA's as PASP's. Without the SA equivalent of the US FDA, consumers will remain insufficiently protected.

Even the cheapest PSAP may be out of reach for the many South Africans in poverty. In addition, only six SA universities offer programmes in audiology, making for an urgent need for more trained professionals. The six universities are the University of Stellenbosch, University of Cape Town, University of Johannesburg, University of Pretoria, Medical University of Southern Africa and the University of Kwa-Zulu Natal. Further, the bachelor's degree in communication pathology (audiology) is only offered in Afrikaans and English, while training for speakers of SA's ten additional official languages is also a necessity. Although Swanepoel *et al.* (2010) argue that telehealth in audiology may provide a significant partial solution to this serious problem, this cannot be given credence. As this thesis has indicated throughout, even its own data gathering, despite a large *n* of respondents, was skewed toward the relatively well-to-do by a methodology that was heavily dependent of Internet access.

10. REFERENCES

AFA Balance & Hearing Institute. 2013. Medical Clearance for Hearing Aids Form. Available from: <theafainstitute.com/documents/MedicalClearanceforHearingAids.pdf> [Accessed: 17 May 2013].

Anderson, A. 2013. Council to clamp down on unregulated hearing-aid sales. *BusinessDaylive*. [23 April 2013]. Available from: <http://www.bdlive.co.za/national/health/2013/04/23/council-to-clamp-down-on-unregulated-hearing-aid-sales> [Accessed: 1 June 2013].

Ataguba, J.E. & Goudge, J. 2012. The Impact of Health Insurance on Health-Care Utilisation and Out-of-Pocket Payments in South Africa. Geneva Papers on Risk and Insurance. *Issues and Practice,* 37(4):633-654.

Audicus Hearing Aids. 2012. Hearing Aids Prices vs. Consumer Electronics. Available from: <http://www.audicus.com/blogs/hearing-aids-blog/6857818-hearing-aids-prices-vsconsumer-electronics?utm_source=Audicus+Updates&utm_campaign=be6cf66c01>
[Accessed: 1 June 2013].

Audicus Hearing Aids. 2013. Hear How Audicus Stacks up to the Competition. Available from: <http://www.audicus.com/pages/hearing-aids-comparisons> [Accessed: 2 June 2013].

Axon. 2013. Hear the World. Available from <http://www.axonchina.com/aboutus.php> [Accessed: 31 May 2013]

Bader, M.A. 2007. Strategic Management Of Patent Portfolios. Available from: <http://www.bgwsg.com/doc/patent%20portfolio%20strategie%20management%20nou2007.pdf.> [Accessed: 28 May 2013].

Better Hearing Institute. 2012. New Research from BHI for Promoting Your Practice. International Hearing Society 2012. Available from:

<http://www.betterhearing.org/professionals/material.cfm> [Accessed: 13 February 2013].

Bid or buy.com. 2013. Hearing Aids. Available from: <http://www.bidorbuy.co.za/item/100716101/Hearing_Aids.html> [Accessed: 27 May 2013].

Brande, V. 2011. The teen hearing loss "state of emergency". *The Hearing Journal,* 64(2), 4.

Centers for disease control and prevention. 2012. Data and Statistics. Available from: <http://www.cdc.gov/ncbddd/hearingloss/data.html>. [Accessed: 15 June 2012].

Clarke, E. 2007. From low cost to hi-tech. *Supply Management,* 12(3), 30.

Deaf Shop. 2013. Hearing Aids. Available from: < http://www.deafshop.co.za/> [Accessed: 22 May 2013].

Deal Extreme. 2013. Axon Hearing Aid. Available from: <http://dx.com/p/axon-hearing-aid-v163-4326> [Accessed: 28 May 2013].

Dennis, B.N. 2011. Component for a hearing aid and a hearing aid. *The Journal of the Acoustical Society of America,* 130, 3.

Federal Food, Drug and Cosmetic Act. 1938. Available from: <http://www.fda.gov/regulatoryinformation/legislation/federalfooddrugandcosmeticactfdcact> [Accessed: 23 May 2013].

Egolf, D.P., Kennedy, W.A. & Larson, V.D. 1992. Occluded-ear simulator with variable **acoustic** properties. *The Journal of the Acoustical Society of America,* 91(5), 2813-2823.

Fokazi, S. 2013. 'Get hearing aids from professionals'. ioLnews [25 April 2013]. Available from: <http://www.iol.co.za/news/south-africa/get-hearing-aids-from-professionals-1.1506165> [Accessed: 1 May 2013].

Geeser, M. 2013. 8 News Now. 2013. Hearing Aid Debate. Available from: <http://www.8newsnow.com/story/18634 10/hearing-aid-debate> [Accessed: 1 June 2013].

Gerling, I. J. & Taylor, M. 1997. Quest for quality and consumer appeal shaped history of the hearing aid. *Hearing Journal,* 50(11), 39-70.

German Electrical and Electronic Manufacturers' Association. 2013. ZVEI: Die Elektroindustrie. Available from: <http://www.zvei.org/Seiten/Startseite.aspx> [Accessed: 18 May 2013].

Harris, B., Goudge, J., Atagubs, J. E., McIntyre, D., Nxumalo, N., Jikwana, S., & Chersich, M. 2011. Inequities in access to health care in South Africa. *Journal of Public Health Policy, 32*, S102-S123.

Health Professions Council of South Africa. 2013a. Available from: <http://www.hpcsa.co.za/> [Accessed: 30 April 2013].

Health Professions Council of South Africa. 2013b. Available from: <http://www.hpcsa.co.za/board_speech_registration.php> [Accessed: 30 April 2013].

Hearing Aids South Africa. 2013. Hearing Aids. Available from: < http://www.hearing-aids-south-africa.co.za/> [Accessed: 23 May 2013].

Hearing Aids Wholesale. 2013. Wholesale hearing aids - free lifetime batteries. Available from: <http://www.hearingaidswholesale.com/> [Accessed: 8 February 2013].

HearingPlanet. 2012. *About HearingPlanet.* Available fromRetrieved <http://www.hearingplanet.com/about> [Accessed: 14 November 2012].

HMCS Imports South Africa. 2013. Hearing Aids. Available from: <http://www.imports-hmcs.co.za/hearing_Aids/hearing_aids.htm> [Accessed: 27 May 2013].

Humes, L.E. 1999. Dimensions of Hearing Aid Outcome. *Journal of the American Academy of Audiology,* 10:26-39.

Kirkwood, D. 2012. The hearing aid industry's inconvenient truth: A wake-up call for the independent practitioner. Available from: <http://hearinghealthmatters.org/hearingviews/2012/the-hearing-aid-industrys-inconvenient-truth-a-wake-up-call-for-the-independent-practitioner-3/> [Accessed: 28 May 2013].

McPherson, B. & Swart, S. M. 1997. Childhood hearing loss in sub-Saharan Africa: a review and recommendations. *International Journal Pediatric Otorhinolaryngoly,* 40 (1), 1-18.

Moore, H. 2013. CBC News. 2013. Hearing aid prices much higher than their actual cost [8 February 2013]. Available from: <http://www.cbc.ca/news/canada/ottawa/story/2013/02/07/mb-hearing-aids-cost-prices.html>[Accessed:3 March 2013].

Nelson, P.B. 2007. Patent Pools: an Economic Assessment of Current Law and Policy. *Rugters Law Journal,* 539-572.

Newberg, J.A. 2000. Antitrust, patent pools, and the management of uncertainty. Available from <http://www.ftc.gov/opp/intellect/020417joshuanewberg.pdf> [Accessed: 11 October 2012].

Pallarito, K. 2012. 2012 Hearing Aid Sales Predict Slow Start 2013. *The Hearing Journal,* 65(12), 14-16.

ReportLinker for Libraries. 2012. *Hearing loss industry brief report.* Available from: <http://academic.reportlinker.com> [Accessed: 1 March 2013].

Republic of South Africa. 1974. Health Professions Act No. 56 of 1974. Pretoria: Government Printer.

Republic of South Africa. 1998. South African Medicines and Medical Devices Regulatory Authority Bill of 1998. Pretoria: Government Printer.

Republic of South Africa. 1996. The Constitution of the Republic of South Africa, Act no. 108 of 1996. Pretoria: Government Printer.

Ross, M. 2009. The clever marketing of amplifiers. Available from: <http://www.hearingresearch.org> [Accessed: 12 May 2013].

Romo, G., Straus, R.J. & Trigg, S. 2012. Building an Effective Supply Chain and Distribution System. Los Angeles: 2012 American Bar Association.
Available from: <http://www.frostbrowntodd.com/assets/htmldocuments/Building-an-Effective-Supply-Chain-and-Distribution-System.pdf> [Accessed:19 November 2012].

South African Government Services. 2013. Old age pension. Available from: <http://www.services.gov.za/services/content/Home/ServicesForPeople/Socialbenefits/oldagegrant/> [Accessed: 3 June 2013].

Statistics South Africa. 2010. General household survey 2010. Available from: <http://www.statssa.gov.za/publications/P0318/P0318June2010.pdf.> [Accessed: 12 March 2012].

Strauss, W. 2009. A Study of IC Markets Driven by Digital Signal Processing Technology. Available from:
<http://www.fwdconcepts.com/DSP%20Silicon%20'09%20Table%20of%20Contents.pdf>
[Accessed: 14 November 2012].

Swanepoel, D.W. & Hall III, J.W. 2010. Football match spectator sound exposure and effect on hearing: A pretest-post-test study. *South African Medical Journal*, 100(4): 239–242.

Swanepoel, D.W., Clark, J.L., Koekemoer, D., Hall III, J.W., Krumm, M., Ferrari, D.V., McPherson, B., Olusanya, B.O., Mars, M., Russo, I. & Barajas, J.J. 2010. Telehealth in audiology: the need and potential to reach underserved communities. *International Journal of Audiology,* 49(3), 195–202.

Tech Agreements. 1996. Letter of Intent For Purchase of Certain Assets. Available from: <http://www.techagreements.com/agreement-preview.aspx?title=Resound%20-%20Letter%20of%20Intent%20For%20Purchase%20of%20Certain%20Assets&num=419654. [Accessed: 28 February 2013].

The Bakken Museum. 2013. History of hearing aids. Minneapolis, United States of America.

The Report Linker for Libraries. 2013. World Hearing Aid Industry Overview Report – market research report. Available from: <www.reportlinker.com/.../Global-Hearing-Aid-Market-Report-Edition.html > [Accessed: 16 May 2013].

The Society of Hearing Aid Acousticians of South Africa. 2013. How is your hearing. Available form: <http://www.shaa.co.za/Index.htm> [Accessed: 15 May 2013].

The World Intellectual Property Organisation. 2013. Franchising & Licensing. Available from: <http://www.wipo.int/sme/en/documents/franchising.htm> [Accessed: 13 March 2013].

Touchette, D. 2013. Paradise Hearing & Balance Clinics, Inc. Available from: <http://www.paradisehearing.com/pages/buyer-beware> [Accessed: 19 March 2013].

United Nations. 2006. Convention on the Rights of People with Disabilities. Available from: <http://www.un.org/disabilities/convention/conventionfull.shtml> [Accessed: 17 October 2013].

United States of America. 1938. Federal Food, Drug, and Cosmetic Act, Act no. 21 of 1938. Available from: <http://www.fda.gov/regulatoryinformation/legislation/federalfooddrugandcosmeticactfdcact/> [Accessed: 24 May 2013].

University of South Africa. 2012. CEDU, Inclusive Education & DCLD working with MEDIFIX / STARKEY to aid hearing impaired. Available from: <http://www.unisa.ac.za/cedu/news/index.php/2012/05/cedu-inclusive-education-dcld-working-with-medifix-starkey-to-aid-hearing-impaired/> [Accessed: 2 June 2012].

US Food and Drug Administration. 2013. Buying Medical Devices and Diagnostic Tests Online. Available from: <http://www.fda.gov/MedicalDevices/ResourcesforYou/Consumers/BuyingMedicalDevicesandDiagnosticTestsOnline/default.htm> [Accessed: 23 May 2013].

US Food and Drug Administration. 2013. Consumer Health Information. Available from: <http://www.fda.gov/downloads/ForConsumers/CONSUMERUPDATES/UCM143301.pdf> [Accessed: 23 May 2013].

van Zyl, N.R. [vanzylnr@hotmail.co.za]. 2012. Re: Gehoorapparate/Hearing Aids. Email to: Smith, M. [smithm@ufs.ac.za]. 17 June.

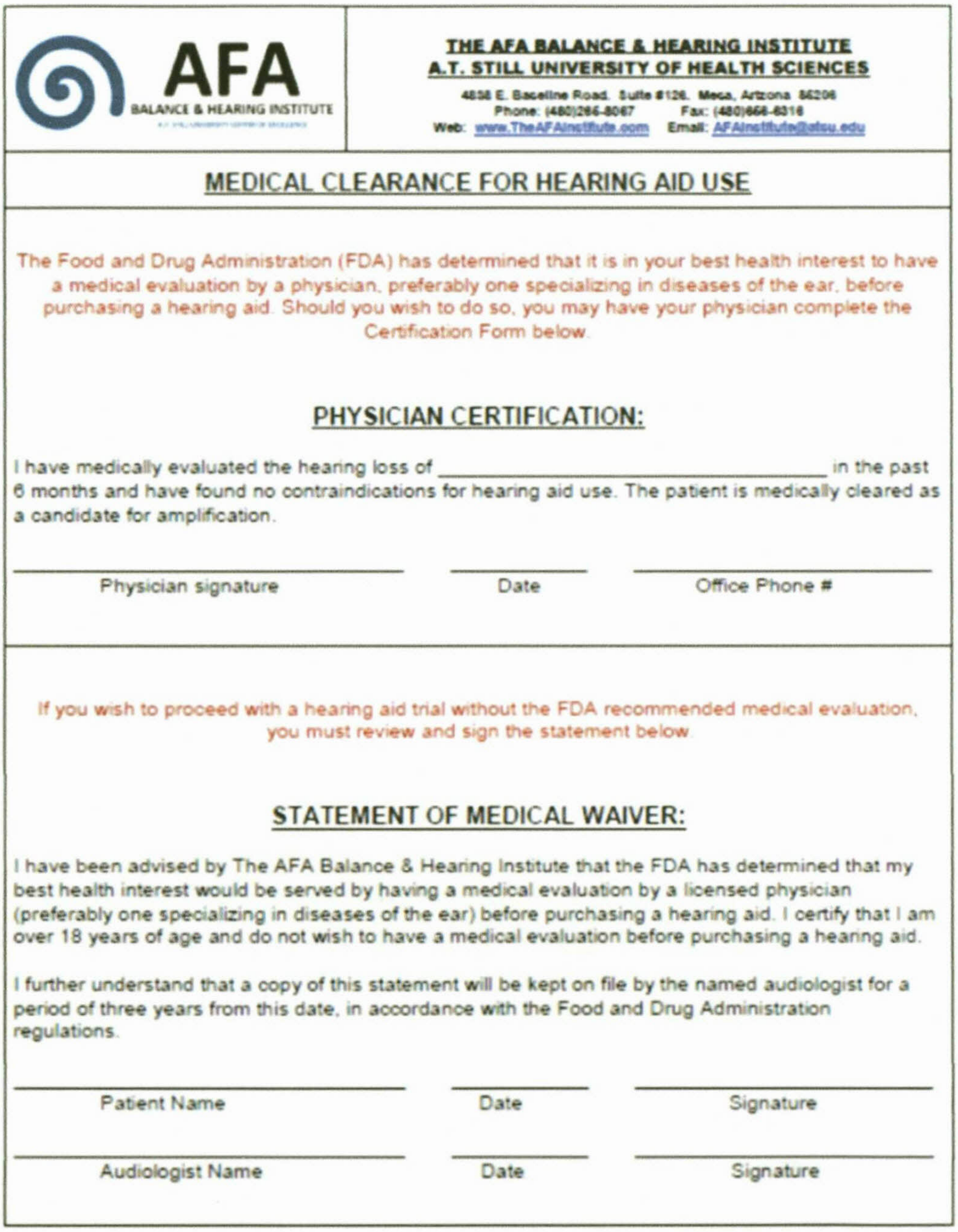
Vercelletto, C. 2013. Can my kid's noisy life-TV, video games, headphones-be harmful? *Parenting. School Years,* 27(3), 28.

Wollock, J. 1996. John Bulwer's (1606-1656) place in the history of the deaf. *Historiographia Linguistica* 23.1/2:1-46.

World Health Organisation (WHO). 2001. International Classification of Functioning, Disability and Health. Geneva: World Health Organisation.

World Health Organisation. 2010. MedicAl devices: MAnAging the Mismatch. Available from: <http://whqlibdoc.who.int/publications/2010/9789241564045_eng.pdf> [Accessed: 3 March 2013].

APPENDIX 1: FDA Waiver Form



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BALANCE & HEARING INSTITUTE

THE AFA BALANCE & HEARING INSTITUTE
A.T. STILL UNIVERSITY OF HEALTH SCIENCES
4838 E. Baseline Road, Suite #126, Mesa, Arizona 85206
Phone: (480)266-8067 Fax: (480)668-6316
Web: www.TheAFAinstitute.com Email: AFAinstitute@atsu.edu

MEDICAL CLEARANCE FOR HEARING AID USE

The Food and Drug Administration (FDA) has determined that it is in your best health interest to have a medical evaluation by a physician, preferably one specializing in diseases of the ear, before purchasing a hearing aid. Should you wish to do so, you may have your physician complete the Certification Form below.

PHYSICIAN CERTIFICATION:

I have medically evaluated the hearing loss of ________________________________ in the past 6 months and have found no contraindications for hearing aid use. The patient is medically cleared as a candidate for amplification.

Physician signature	Date	Office Phone #

If you wish to proceed with a hearing aid trial without the FDA recommended medical evaluation, you must review and sign the statement below.

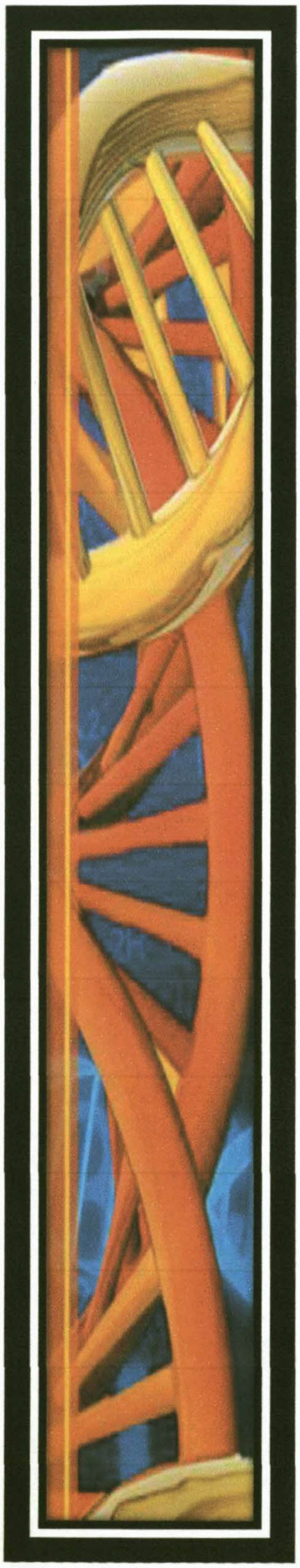
STATEMENT OF MEDICAL WAIVER:

I have been advised by The AFA Balance & Hearing Institute that the FDA has determined that my best health interest would be served by having a medical evaluation by a licensed physician (preferably one specializing in diseases of the ear) before purchasing a hearing aid. I certify that I am over 18 years of age and do not wish to have a medical evaluation before purchasing a hearing aid.

I further understand that a copy of this statement will be kept on file by the named audiologist for a period of three years from this date, in accordance with the Food and Drug Administration regulations.

Patient Name	Date	Signature
Audiologist Name	Date	Signature

Source: AFA Balance & Hearing Institute, 2013



PAPER VI

THE COST OF COCHLEAR IMPLANTS IN SOUTH AFRICA

THE COST OF COCHLEAR IMPLANTS IN SOUTH AFRICA

Abstract

This study assesses the direct medical costs of cochlear implantation in a person in South Africa. The direct costs included here are pre-operative visits, hospital expenses, post-operative visits, rehabilitation programmes, and maintenance over a one-year period. The mean cost was R354 244.33 (US$37 149.74) per person of the first year after implantation. The current transformation of financing of the healthcare system in South Africa requires detailed financial analysis and knowledge of the costs of technological interventions. The present economic situation and health legislation in South Africa, combined with the rapid evolution of cochlear implant technology, may make it possible to produce an affordable yet effective cochlear implant system. This paper discusses the cost of cochlear implants only in South Africa, although the social and economic factors are similar in many developing countries, where a low-cost, high performance cochlear implant system is needed.

1. BACKGROUND

The prevalence of acquired permanent bilateral disabling hearing impairment (DHI) is approximately 180 000 infants across sub-Saharan Africa every year (Olusanya, 2008). The incidence of DHI, a figure derived from a number of retrospective studies in South Africa (population about 50 million; birth rate 12-18/1000 per year), is estimated to be about 17 born per day and 6205 per annual birth cohort in 2012 (Hay, 2012).

While DHI may relate to abnormalities in the sound conduction system of the outer and middle ear, most severe DHI deficits in newborns and the elderly result from sensorineural abnormalities, particularly cochlear hair cells loss which limits the ability of the cochlea to convert sound vibrations into nerve impulses. This type of DHI is usually irreversible and has been treated with rehabilitation programmes involving hearing aids, sign language, and speech and language therapy. Amplification does not replace the function of lost cochlear hair cells and often cannot provide adequate hearing in the case of severe cochlear hair loss. If appropriate neural elements in the ear are intact and functional, it is possible to stimulate auditory nerve impulses with a cochlear implant (CI) to improve sound recognition (Blume, 1999).

Most devices are now approved for use in patients with severe to profound unilateral hearing loss rather than the prior requirement of a bilateral profound loss (Sampaio, Araûjo, Oliveira, 2011). In addition, criteria for candidacy for a cochlear implant are based on the history of hearing aid use on the ear to be implanted, the ability to use spoken communication, level of speech perception when using fully functional and appropriate hearing aids, motivational factors, realistic expectations, general health, and familial support. In most cochlear implant programmes, an ear that has been hearing impaired most of the life of the person, and has received little or no amplification for the duration of that deafness will not be considered for cochlear implantation. Of course, not all the aforementioned criteria will apply equally to all age cohorts. In particular, the candidacy of infants for CI, obviously the most apt candidates, will be determined on a more limited and obviously medical and quantifiable set of criteria. Otorhinolaryngologists with specific expertise and training in cochlear implantation are essential; CI is not a general qualification common to all practitioners.

From the early days of a single channel device, beginning in the US in 1961, to the present day, sophisticated, multichannel systems have been fuelled by the success of this technology (recognition (Blume, 1999).

Based on a series of studies showing safety and efficacy, multichannel cochlear implants were approved by the US Food and Drug Administration for use in adults in 1984 and in children in 1990 (Ramsden, 2004). The cooperative efforts among medical experts and facilities, manufacturers, and research laboratories throughout Austria, Australia, France, Spain, South Korea, China, and the United States, have resulted in major advances in this field in a relatively short period. Continued cooperation among medical and technological professionals will accelerate changes in this rapidly evolving field.

The first CI surgery in South Africa (SA) was performed in 1985 at Tygerberg Hospital, Stellenbosch University, Western Cape (Stellenbosch University, 2012). The numbers of cochlear implant manufacturers are growing; there are six manufacturers globally: Med-El, Cochlear Corporation, Advanced Bionics, Neurolec, Nurotron, and iEnjoy Sound. The three devices that are currently implanted in SA are Med-El, Cochlear Corporation and Advanced Bionics.

2. METHODS

The economic analysis here took into account only direct costs for a person with disabling hearing impairment (DHI) undergoing a unilateral CI. Data was collected from four patients' quotations, estimated hospital costs for 1.5 days and theatre costs calculated on 3 hours of surgery, from 4 private hospitals in Gauteng, Free State, and Western Cape Province.

Quality control of data was assessed according to The International Classification of Diseases (ICD-10D, H90.3) codes, and the guideline tariffs of medical schemes to calculate health care provider costs such as hospitalisation. Blood test costs were obtained from 2 pathology practices and audiology and speech tariffs from the South African Association for Audiologists. Maintenance costs such as insurance were obtained from 3 insurance companies. The average costs of a standard hearing aid, FM systems, and batteries were obtained from 3 private audiology practices and cochlear device agents. These data were used to determine the average cost of a person's CI procedure in one year during 2012 in SA. The cost analysis included candidate selection (preoperative assessment), implantation, rehabilitation, aftercare and maintenance cost covered 1 year of follow-up after implantation.

3. RESULTS

3.1 Candidate selection and evaluation

The mean cost per person was R354 244.33. The total cost of visits to health care practitioners was R4 530.28 as illustrated in Table 1. The patient is referred by a general practioner to an otorhinolaryngologist for a full medical history and physical examination. Extensive audiology testing is performed at a cost of R1 318.28. This cost is set by the Health Professions Council of South Africa (2013).

Table 1: Visits to health care practioners

Service	Unit price	Visits	Total
General Practioner	240.00	1	240.00
Otorhinolaryngologist	816.00	2	1 632.00
Audiologist	444.15	2	888.30
Speech therapist	429.98	1	429.98
Psychologist	670.00	2	1 340.00
Total			R4 530.28

Thereafter, a patient visits an otorhinolaryngologist for the second time for diagnoses and prognosis. Ideally, the patient (or, in the case of infants, the patient's parents) is referred to a psychologist for two sessions for evaluation to determine if the candidate will adopt and be committed to the lifelong rehabilitation of cochlear implantation. This psychological screening is the practice in some South African hospitals. The mean cost for medical examinations were R14 637.88 as shown in Table 2.

Table 2: Radiological and pathology evaluation and immunisation

Department	Procedure	Total
Radiology	CT/MRI	8 250.00
Audiology	Diagnostic audiological test	658.16
	Air conduction, pure tone audiogram	126.90
	Bone conduction pure tone audiogram	101.52
	Speech audiogram screening	42.30
	Visual reinforcement audiometry	338.40
	Speech therapy assessment	307.13
Pathology	Blood tests/terminal diseases and HIV/AIDS	3 842.17
	Immunisation Meningitis	971.30
Total		**R1 4637.88**

The mean cost of hospitalisation and theatre costs, excluding complications, was R48 416.80 as shown in Table 3.

Table 3: Hospital costs/Theatre costs

	Total
General Ward R3695.80 1.5 days	5543.70
Theatre fees R155.10 per minute @ 3hours	27 918.00
Theatre Medicine	14 955.10
Total	**R48 416.80**

The average cost of the implant device was R187 890.63., as shown in Table 4. The mean cost of the operation was R219 700.87.

Table 4: Operation costs

	Procedure	**Total**
Otorhinolaryngologist	Tympanomastoidectomy	4 078.24
	Cochlear Implant Surgery	3 580.52
	Exploration of facial nerve	2 330.58
	Cranioplasty	2 503.40
	Local skin flaps	1 925.90
	Muscle grafting to mastoid cavity without tympanoplasty	1 138.60
Cochlear implant device		187 890.63
Assistant fee		3 018.88
Anaesthesiologist		10 659.52
Audiologist	Consultation fee	444.15
	Implant test – four test modes	68.48
	Neural Response Telemetry	274.10
	Electrical Stapedius Reflex Thresholds – intra-operatively	178.08
Radiologist	X-rays	725.56
Pharmacy	Medicine	884.23
Total		**R219 700.87**

The post-operative costs were R2 036.46 as shown in Table 5, while the total cost of rehabilitation was R17 683.20 as illustrated in Table 6.

Table 5: Post-operative costs and cochlear implant mapping

Consultations		Total
Otorhinolaryngologist		422.15
Audiologist	Switch on consultation fee	444.15
	Electrode mapping 30min	411.06
	Implant test - four test modes	68.48
	Mapping session consultation fee 30min	211.08
	Electrode mapping 30min	411.06
	Implant test – four test modes	68.48
Total		R2 036.46

Table 6: Rehabilitation costs

Audiology	Mapping session consultation fee 30min	17	211.08
	Electrode mapping 30min		411.06
	Implant test – four test modes		68.48
Total			11 740.54
Speech therapy	30min	96	184.20
Total			R17 683.20

Maintenance and aftercare cost were R6 417.84 and the overall result of the cost analysis per an implanted individual was R354 244.33 as illustrated in Table 7.

Table 7: Maintenance

Insurance	12	5 822.52
Remote battery	2	160.00
Processessor battery	700.00 x 60 3 days 20 days 35.00p/d	12 775.00
FM system		28 481.32
Hearing aid for unplanted ear		15 732.00
Hearing aid batteries		1 200.00
Total		**64 170.84**
Grant total		**R354 244.33**

The current study analysed the cost of preoperative assessment, hospitalisation, implantation, rehabilitation and maintenance. The average implant-related and 1 year follow-up costs were R354 244.33 per person. The primary cost is the implant device. This study takes into account the main factors influencing costs, namely rehabilitation, and maintenance. This approach permits a robust economic analysis reflecting the reality of patient management.

4. LIMITATIONS OF THE STUDY

The study has some limitations. Quotations were without precise specification of services. Other quotations were specified with regard to health services and expenses. Owing to the necessarily limited size of its data base, the present study must be regarded as a pilot. Its findings must be regarded as preliminary, while establishing a methodology for further research. Ideally, with the broader use of cochlear implantation in SA, longitudinal studies will be developed to determine both long term costs and efficacy of the procedure.

5. DISCUSSION

As indicated, CI teams exist in a variety of different professional specialties. Speech therapy is part of rehabilitation and longer periods of therapy will generate a large portion of total costs. The CI team carefully evaluate each person individually, considering many factors, including the source of the person's hearing impairment, hearing ability, communication skills, and goals. Missing data were imputed from the results of clinical practice by parents of cochlear implantees or cochlea implantees themselves. In addition, valuable information was obtained from the cochlear implantees regarding rehabilitation and maintenance costs such as the lifetime of the use of batteries. Thus, rehabilitation programmes must be tailored to the unique needs of the individual cochlear implant recipient. This can result in hidden costs, unanticipated by patients and their families. While costs of any medical procedure and its follow-up are inherently not entirely predictable, many potential categories of follow-up costs are well known. It should be an essential part of CI counselling services to inform patients of these potential expenses as early as possible.

5.1 Cost of the device

It has been identified from the price quotations for the implant device that are provided to patients or their families that in most cases, they are not provided with choice options regarding different brands of implant devices. Devices have different functions and features and clinical practice should provide patients with a full range of device options and features. A specific device should only be suggested during candidacy, by identifying a reason that prompts the need for that particular device.

5.2 Associated Pathologies

None of the CI programmes had quoted costs for any pathological blood tests; these may result in hidden costs. Blood tests are of cardinal importance to identify any terminal diseases and/or HIV/AIDS, since a CI operation is not performed if any terminal diseases are identified in the blood test results. Meningitis vaccination was also excluded from the quotations. Carpenter *et al* (2010) states that individuals who have a cochlear implant are at increased risk for bacterial meningitis.

Bacterial meningitis after cochlear implantation remains a concern in the United States. More than 200 reported cases have occurred, and 10 percent of the cases resulted in death. Two types of bacteria have produced the vast majority of cases of meningitis after cochlear implantation: Streptococcus pneumonia and Haemophilus influenza type B. Because meningitis is unpreventable, there is an inevitable baseline incidence of meningitis (Carpenter *et al.:* 2010).

Therefore, during the evaluation phase, the patient must be counselled regarding the potential risk of meningitis, and the importance of appropriate and timely vaccination before undergoing surgery. It is not known how many cases of meningitis after cochlear implantation have been reported in SA.

5.3 Hospitalisation

Hospitalisation is required for a minimum of 1.5 days; therefore, high care, intensive care, and specialised intensive care for any complications that may occur during any operation were not included in quotations. Numerous studies have examined major post-operative complications associated with CI surgery, such as hard or soft implant device failure, infection, receiver or electrode misplacement, and vestibular disturbances (Migirov, Dagan & Kronenberg. 2008; Gosepath *et al.* 2009; Venail, Sicard, Prion, *et al.* 2008).

Studies also have examined minor complications, such as hematoma, transient facial paralysis, change in taste, tympanic membrane perforation, and skin infection at the surgical site (Bhatia *et al.* 2004; Wagner *et al.* 2010).

5.4 Rehabilitation: Audiology

Rehabilitation costs are the highest, as indicated in the tables. All the cochlear implant programmes in this study have indicated similar number of rehabilitation visits per year. Post-operative costs refer to those incurred during cochlear implant activation (switch on), and mapping performed by an audiologist. The activation of the CI occurs approximately four to six weeks after implantation surgery. The initial activation appointment is the first moment of hearing sound. However, activation does not always enable speech understanding. The initial sounds may sound like echoes: tinny, robotic or raspy. Each individual's perception of the sounds is different. It may take a while to adopt to sound and for the sounds to take on meaning. It is for this reason that follow-up programming is important to taking a CI to its fullest potential. This is a process and the complexities of the hearing pathway require that the hearing process unfold slowly.

At each appointment, the parameters of hearing will be re-evaluated and adjusted to make sure of the optimisation of the implant. Within the first year after implantation, there will be several mapping appointments. As the map stabilises, future appointments become farther apart. Mapping is never finished, it is an on-going process, and adjustments will need to be made periodically, even after many years of use. A CI is a lifetime commitment and mapping should be conducted on a six months or annual basis, depending on the individual experience for maximum benefit.

The "mapping" or "programming" of a CI is the process that sets the best parameters for an individual patient. Parameters, or the settings that define the map, establish the code that will be supplied to the receiver. This code consists of translations of the energies that make up sound. These include the coding strategy, the rate and duration of electrical pulses, the number of channels, the individual threshold levels and most comfortable or loud but comfortable levels. This requires an audiologist who is specially trained to judge the responses of the cochlear recipient responses to test signals to set the programme settings of the map.

Each CI manufacturer uses different names to describe various parameters, which can be confusing. It is important to understand how the individual parameters relate to one another and that some are programmed into the implant software and, thus, are not changeable. Since maps are customised and different techniques are used for each individual, they are unique to each person.

In addition, each appointment should include audiologic and speech perception. These test results are also useful in determining subtle decreases over time in the case of malfunctioning equipment. A standard check is run on the internal device by connecting the speech processor to the programming computer. The impedances of the contacts in the cochlea will be examined, establishing communication between the internal and the external devices. Impedances measure the ease of current flow through an electrical circuit, the cochlear implant electrode.

Thereafter, the audiologist examines every electrode, in order for the patient to ensure the volume of each is set similarly. Each electrode stimulates a different frequency range and is balanced to ensure that low pitches and high pitches are set at even loudness. Global adjustments can be made at this point to change the perceived volume and the sound quality can be tailored by emphasising pitches. Moreover, objective measures can be used to determine the approximate level of stimulation required for a neural response. Once a basic map is finalised, different programmes can be created for various listening situations by using a remote control. There are limitations to cochlear implant listening in various situations. The microphone will pick up all sounds, not just desired sounds. Background noise can never be eliminated completely since there is simply too much overlap between the characteristics of background noise and human speech. The brain will eventually learn to filter out the desired speech from challenging noise and the use of lip reading will help.

5.5 Rehabilitation: Speech Therapy

Regular appointments with a speech therapist are necessary with verbal rehabilitation. In most cases, lip-reading will always be a major part of communication even with the CI.

The implant can help make it easier to separate one word from the next in normal conversation. Hearing will never be normal with the CI, and the experience of each patient will vary from one another. Some patients will be able to recognise various amounts of speech without lip-reading, and may be able to make some use of a cell phone. Nevertheless, there is no way to predict beforehand whether the patient would be able to do this. Not every patient develops the same hearing abilities. The majority of patients benefit tremendously from speech therapy, which significantly improves their ability to communicate, though most still have communication problems in some situations.

5.6 Batteries

The primary maintenance costs are the batteries for the processor. It could cost a cochlear recipient up to R35.00 (US$3.46) per day if the CI is in use for 10-12 hours per day, and could cost approximately R12 775.00 (US$1 262.94) per annum. CI batteries are not manufactured in SA, but in countries such as the United States, United Kingdom and Germany. Battery life differs from manufacturer to manufacturer, though the average price is R700.00 (US$69.20) per 60 batteries, the average number needed for one month, which corresponds to product packaging. Audiology practices sell batteries, and prices are high in comparison with other batteries. However, competition is growing in SA, and well-known pharmacies are selling currently the same or equivalent quality batteries directly to the public for up to R300.00 (US$29.66) less for packages of 60 batteries. Competition will reduce battery expenses in future, which will benefit the cochlear implantee.

5.7 Hearing aids

For most cochlear implantees, it is recommended to wear a hearing aid in the unplanted ear. The reason for this is that the hearing aid can help "fill-in" those low frequency sounds that the implant may miss while conversely, the implant provides the high frequencies missed by the hearing aid depending on the hearing loss.

5.8 Medical Schemes (Medical Insurance)

Medical schemes are excluded from this study due to the variety of coverage. Currently, Discovery Health, the most favourable plan for implantees in SA, covers an amount of R155 000.00 (US$15 323.30) for one cochlear implant device, hospital and operation costs, while some others cover R80 000.00 (US$7 908.80), and others yet provide no coverage at all. Therefore, all patients with medical insurance will still need to pay some of the costs for a cochlear implant device out-of-pocket. The costs of two cochlear implant devices will be approximately R375 781.26 (US$37 149.74).

5.9 Repair Costs

Repair issues associated with CI such as the processor, cords/cables, microphone, coil, and external magnet are excluded in this study because manufacturers provide a 3-year warranty on the external components of the implants.

A study was undertaken by Kerr, Tuomi and Müller (2012,16-26) on the costs involved in using a cochlear implant in SA. The study is flawed in the sense that calculations were not adjusted for inflation over a period of 10 years. Furthermore, the database is limited to a single public hospital (Tygerberg) and the costs of a single cochlear implant manufacture. No investigation concerning pre-operative, hospital, theatre or post-operative costs were investigated.

Studies are needed which follow up implant recipients for longer use, standard measures for outcomes and quality of life impact, which record full information on known covariates of post-implantation and quality of life outcomes. There is a strong case for a national research registry of all cochlear implantees in SA. A larger database would enable better exploration of implant candidacy, including the relationship between hearing ability, timing of and age at implantation, and the presence of additional/complex needs, to key outcomes, to develop multi-criteria models which help predict the likely benefit profiles of individual candidates.

As illustrated, success of a CI not only depends on the device itself, but also rehabilitation and maintenance cost. It is clear that it currently requires a CI recipient be middle-to-high-socio-economic classes because patients of low socio-economic class might not even be able to pay for transportation, rehabilitation and maintenance cost to fellow-up visits. Given the limited funding from the government and medical health suppliers, it is unfortunate that surgeons have to deny patients access to cochlear implants because of their socio-economic status, even if the surgery and rehabilitation are offered free or at a minimal cost to DHI people in SA as a developing country.

6. CONCLUSION

This study is the first to estimate direct pre-operative, hospital, post-operative, rehabilitation, and maintenance costs over a one-year period of cochlear implantation in SA. All costs were examined on a representative national level. The costs of a cochlear implantation and aftercare require a detailed knowledge, not only for patients but also for the reform of the healthcare system in SA. These results can serve as a baseline as well as a framework for further cost-utility studies. Comparisons of the cost of cochlear implantation should be compared with other operations to define a "better quality of life" for all SA citizens.

Research has demonstrated that the benefits of early detection and intervention of cochlear implantation are well documented and known to greatly increase children with disabling hearing impairments' chances of developing their abilities to the fullest and enjoying a better quality of life (Fortnum, Marshall & Summerfield, 2002; Archbold & Donoghue, 2009; Fitzpatrick *et al.* 2009; Joint Committee on Infant Hearing. Year 2007, 2007).

Cochlear implantation is specifically designed to treat severe to profound bilateral sensorineural hearing loss. Cochlear implants have transformed the outlook for severely and profoundly deaf children by providing them access to spoken language and environmental sound, in some cases for the first time. In 2005, the WHO (2010) has warned cochlear implant manufacturers and suppliers not to exploit the situation of developing countries and urged governments that CI program be part of a comprehensive hearing loss prevention strategy within the national public health system. CI's should be provided and available for genetic deafness and adult onset, as well as presbycusis.

7. REFERENCES

Archbold, S. O. & Donoghue, G.M. 2009. Cochlear implants in children current status. *Journal of Paediatric Child Health*, 10:457-463.

Bhatia, K., Gibbin, K.P., Nikolopoulos, T.P. & O'Donoghue, G.M. 2004. Surgical complications and their management in a series of 300 consecutive pediatric cochlear implantations. *Otology & Neurotology*, 25:730-739.

Blume, S.S. 1999. Histories of Cochlear Implantation. *Social Science and Medicine*, 49:1257-1268.

Carpenter, R.M., Limb, C.J., Francis, H.W., Gottschalk, B. & Niparko, J.K. 2010. Programmatic Challenges in Obtaining and Confirming the Pneumococcal Vaccination Status of Cochlear Implant Recipients. *Otology & Neurotology*; 31:1334-1336.

Fitzpatrick, E., Olds, J., Durieux-Smith, A., McCrae, R., Schramm, D. & Gaboury, I. 2009. Pediatric cochlear implantation: How much hearing is too much? *International Journal Audiology*, 48(2):91-97.

Fortnum, H,M., Marshall, D.H. & Summerfield, A.Q. 2002. Epidemiology of the UK population of hearing-impaired children, including characteristics of those with and without cochlear implants, audiology, aetiology, comorbidity and affluence. *International Journal of Audiology*, 41(3):170-179.

Gosepath, J., Lippert, K., Keilmann, A. & Mann, W.J. 2009. Analysis of fifty-six cochlear implant device failures. *Journal for oto-rhino-laryngology and its related specialties*, 71:142-147.

Hay, C. 2012. 17 Babies born deaf in SA. Available from: [http://www.health24.com/news/Hearing_management/1-1239,65848.asp] <Accessed: 2 December 2012>.

Health Professions Council of South Africa. 2012. Protecting the Public and guiding the professions. Available from: [http://www.hpcsa.co.za/] <Accessed: 17 March 2012>.

Joint Committee on Infant Hearing. 2007. Year 2007 Position Statement: Principles and guidelines for early hearing detection and intervention programs. *Pediatrics*, 120(4):898-921.

Kerr, G., Tuomi, S. & Müller, A. 2012. Costs involved in using a cochlear implant in South Africa. *South African Journal for Communication Disorders*, 59(1):16-26.

Migirov, L., Dagan, E. & Kronenberg, J. 2008. Surgical and medical complication in different cochlear implant devices. *Acta Oto-Laryngologica*; 1:1-4.

Olusanya, B.O. 2008. Priorities for early hearing detection and intervention in sub-Saharan Africa. *Journal of the American Academy of Audiology*, 47(Suppl.1):S3-S13.

Ramsden, R. 2004. Prognosis after cochlear implantation. *British Medical Journal*; 328:419-420.

Sampaio, A.L.L., Araûjo, M.F.S. &, Oliveira, C.A.C.P. 2011. New Criteria of Indication and Selection of Patients to Cochlear Implant. *International Journal of Otolaryngology*, 1-13.

Stellenbosch University. 2012. Faculty of Medicine and Health Sciences. Division of Otorhinolaryngology . Available from:
[http://sun025.sun.ac.za/portal/page/portal/Health_Sciences/Otorhinolaryngology/history.pdf]
<Accessed: 12 September 2012>.

Venail, F., Sicard, M., Piron, J.P., Levi, A., Artieres, F., Uziel, A. & Mondain, M. 2008. Reliability and complications of 500 consecutive cochlear implantations. *Archives of Otolaryngology - Head and Neck Surgery*, 134:1276-1281.

Wagner, J.H., Basta, D., Wagner, F., Seidl, R.O., Ernst, A. & Todt, I. 2010. Vestibular and taste disorders after bilateral cochlear implantation. *Journal of European Academy of ORL-Head and Neck Surgery,* 267:1849-1854.

World Health Organisation. 2010. MedicAl devices: MAnAging the Mismatch. Available from: <http://whqlibdoc.who.int/publications/2010/9789241564045_eng.pdf> [Accessed: 3 March 2013].

PAPER VII

GENETIC TESTING FOR CONGENITAL HEARING LOSS IN SOUTH AFRICA

GENETIC TESTING FOR CONGENITAL HEARING IMPAIRMENT IN SOUTH AFRICA

Abstract

With recent progress in the identifications of genes for hearing loss, and a medical breakthrough by Richmond Smith at the University of Iowa, it is highly likely that genetic testing for hearing loss will become the cornerstone of diagnosis of hearing loss. Hearing loss is a complex process therefore; the causes of hearing loss are also complex. Linkage analysis in persons with hearing loss has revealed an overabundance of chromosomal locations linked to deafness reflecting the extreme heterogeneity of hearing loss. The overwhelming majority of cases of hearing loss in children are attributable to genetic causes. Understanding the genetic causes of hearing loss has important benefits such as, through improved language, mental health, education placement, communication choices, and employment prospects. The purpose of this paper is to analyse the situation and costs of genetic testing for hearing loss in South Africa.

1. INTRODUCTION

Hearing impairment (HI) is one of the most distressing disorders affecting quality of life. The impact is of considerable socio-economic consequence to the person with HI, his/her family and the community within which he/she lives (See Introduction, Figure 1.3, WHO grades of DHI). According to the World Health Organisation (WHO), in 2013 there were an estimated 360 million people worldwide with HI, with the majority are living in developing countries (WHO, 2013). During 1975, more than 3 000 learners with congenital and acquired HI were registered in schools for the deaf in SA (Sellers, Napier & Beighton, 1975).

Moreover, HI is one of the six leading contributors to the burden of disease in developing countries, along with ischemic heart disease, depression, and Alzheimer's disease (Zahnert, 2011).

In addition, Section 27 of the Constitution of South Africa (Act no. 108 of 1996), states that

> *"The State must take reasonable legislative and other measures within its available resources, to achieve progressive realisation of each of these rights."*

The Children's Act (Act no. 38 of 1985) gives effect to Section 28 of the Constitution; the Universal Declaration of Human Rights (1948); the Geneva Declaration on the Rights of the Child (1924); the Convention on the Rights of the Child (1989); and the African Charter on the Rights and Welfare of the Child (1999), among others. As a signatory to the United Nations Convention on the Rights of the Child, SA is required to provide health and welfare services for children disabilities. Article 23 Section 4 states

> *"States and parties shall promote, in the spirit of international co-operation, the exchange of appropriate information in the field of* ***preventive health care and of medical, psychological and functional treatment of disabled children*** [emphasis in the original] *including dissemination of, and access to, information concerning rehabilitation, education and vocational services, with the aim of enabling state parties to improve their capabilities*

and skills and to widen their experience in these areas. In this regard, particular account shall be taken of the needs of ***developing countries****"* [emphasis in the original].

Therefore, health and welfare is a basic right and this includes individuals with genetic disorders or birth defects including individuals with HI.

2. GENETIC EPIDEMIOLOGY OF HEARING IMPAIRMENT

According to Hilgert, Smith and Van Camp (2009), genetic causes account for approximately 80 percent of congenital HI in developing countries. These are nonsyndromic HI, usually profound, and have a genetic aetiology that segregates autosomal recessive inheritance. The remaining causes are attributed to factors such as prematurity, ototoxic drugs, and trauma. Almost 150 loci for nonsyndromic deafness alone have been mapped, 57 for autosomal dominant deafness, 77 for autosomal recessive deafness, and 8 for X-linked deafness.

Shearer and Smith (2012) have identified new deafness genes, three syndromic, and six nonsyndromic; a total of 66 genes that have been sequenced and identified. Shearer *et al.* stated that

> *"Mutations that cause deafness have been identified that affect almost every part of the organ of Corti: the cellular cytoskeleton – including actins (ACTG1) as well as actin-associated genes (TRIOBP and RDX); myosins (MYO7A, MYO15A, MYO6, MYO1A, MYH9, MYH14); cell–cell junctions (OTOA, CLDN14); cell–cell attachments (CDH23, PCDH15); gap-junctions (GJB2, GJB6); transporters (SLC26A4); and ion channels (KCNQ4). However, of the 102 reported NSHL loci, the causative gene has been identified for only 67, implying that at a minimum 34 percent of deafness genes have yet to be discovered."*

3. PREVALENCE OF HEARING IMPAIRMENT IN SOUTH AFRICA

The combined prevalence of congenital and acquired permanent bilateral HI is approximately 180 000 infants born across sub-Saharan Africa every year (Olusanya, 2008). According to Statistics South Africa (2001), 314 000 (0.7 percent) had a hearing disability in

2001. Census 2011 reported 3.5 percent of people with HI, which is 1.8 million out of a population of 50.59 million as of 2011 (Statistics South Africa, 2012). However, this statistic is not reliable since The South African Board of Audiologists estimates that 17 babies in SA are born deaf daily, a 6 205 per annum birth cohort in 2011 (Hay, 2011).

Using figures from Hay (2011), it can be calculated that 16.1 percent of babies in SA are born per annum with HI. This figure might be much higher, since infant hearing screening is only performed primarily in some private hospitals. There is no legislation in SA that requires that infant hearing screening must be performed. This estimate excludes children and adults who acquire hearing loss through infectious diseases, ototoxicity, trauma or noise-induced damage.

4. ADDITIONAL DISABILITIES ASSOCIATED WITH HEARING IMPAIRMENT

Wide ranges of additional disabilities often face people with HI (Guardino, 2008). Further, in a study conducted in Atlanta, Georgia in the United States (USA), it was found that 30 percent of children with HI had another neurodevelopmental disability, and most often, a mental disability (Van Naarden, Decoufle & Caldwell K, 1991).

The situation of mental health services for people with HI in SA is woefully inadequate. The health sector, especially the fields of psychiatry and psychotherapy need to understand that people with HI face the most life-threatening forms of discrimination. Mental health service providers may mistake cultural, language, additional hidden disabilities and communication issues for developmental delays, mental disabilities or even intellectual disabilities. People with HI with additional disabilities, mostly undiagnosed, face a health care system that is sorely inadequate and too often fraught with ideological and monetary battles between educators and other disciplines. Moreover, because people with HI are a low incidence population, health practitioners are typically unaware of the specialised needs and training required to work with this population, resulting in misdiagnoses and misperceptions of other conditions (Kitson, 2000).

Other common disabilities identified in the same study are autism, attention deficit disorders, learning disabilities, Down syndrome, Usher, Treacher Collins, Pierre Robin, and Turner syndromes. Other disabilities include coloboma, atresia, and genital hypoplasia. This is consistent with research done that reports that just under 40 percent of children with HI have an additional disability. Moreover, it is estimated than 20 percent have as least two additional disabilities (Fortnum & Davis, 1997).

5. RESULTS

5.1 Genetic testing for hearing impairment in South Africa

During 1972, the Department of Human Genetics of the University of Cape Town was established, followed in 1975 by the University of the Witswaterand in Johannesburg (Jenkins, 1990:732-763).

5.2 Previous studies in South Africa

According to Beighton, Goldblatt and Wallis (1987), more than 11 000 clients were examined with inherited genetic disorders. Furthermore, 6 000 clients from schools and institutions for learners with disabilities, were examined for HI, vision impairment, mental disabilities or physical disabilities. During 1975, 366 Coloured and Indian learners, aged from three to 19 years attending the Dominican School for the Deaf and Wittebome School for the Deaf in the Cape Province were examined (Sellars, Napier & Beighton, 1975). Of these, 20 percent had a genetic basis for their HI, 36 percent had an acquired HI, and in a further 44 percent it was cryptogenic. Specific genetic syndromes diagnosed in some of the learners, including Waardenburg's syndrome, Usher's syndrome, the possibility of Laurence-Moon-Biedl syndrome, Möbius syndrome, and Lewis's syndrome (Sellars, Napier & Beighton, 1975). In addition, undiagnosable genetic diseases included neurological and eye disease, stapes footplate and skeletal malformations (Sellars, Napier & Beighton, 1975).

A similar study screened 240 White learners of the Dominican Grimley School for the Deaf in Cape Town, and the School for the Deaf and Blind, today, the De la Bat School for the Deaf in Worcester (Sellars, Groeneveldt & Beighton, 1976). In 11 percent (26) of the learners, a diagnosis of a specific condition, of which HI is a component was made. Waardenburg, Pendred, Lewis, Treacher Collins, Marfan and Seckel Syndromes were identified. In addition, Tuberous sclerosis, X-linked deafness of Nance and deafness anhydrosis were reported (Sellars, Groeneveldt & Beighton, 1976). In 7.5 percent (18) an association with an additional clinical condition was made, however, which was not recognised and established as any other known syndrome.

Furthermore, a diagnosis of the cause of HI of a large number of the learners could not be identified. However, 18 percent (43) had HI relatives (Sellars, Groeneveldt & Beighton, 1976). Thirty four percent (82) of learners' HI was considered acquired. No genetic or acquired HI could be recognised in 30 percent (71) of learners. It was stressed that at that time of the study, undesignated genetic disorders could not be substantiated (Sellars, Groeneveldt & Beighton, 1976).

Winship and Beighton (2011) conducted a diagnostic survey of Indian learners with profound HI in the VN Naik School for the Deaf in Durban during 1987. Genetic syndromes which were diagnosed included Waardenburg, Alport, Pendred and Treacher Collins. At that stage Winship and Beighton (2011) stated that no studies were undertaken in molecular investigations that could be informative concerning familial HI. The above studies were the only two published in SA, whose sample constitutes only 0.01 percent of a population of 24, 728, 000 citizens in 1975 (Nation Master, 2013). In contrast, during 1983, Sellars and Beighton (1983) screened Indian 3006 learners with HI in schools for the deaf, and Waardenburg syndrome was not identified.

During 1986, a study has been done on inherited disorders in the Black population in Southern Africa (Beighton & Botha, 1986). It was found that the primary conditions were sensorineural HI, which accounts for at least 20 percent of HI, which were diagnosed in all ethnic groups, and included the Black population (Beighton & Botha, 1986). Waardenburg's syndrome was identified and the occurrences were particularly high in the black South Sotho ethnic group.

It is not clear in these studies how many genes and genetic loci have been identified to determine the underlying different syndromes associated with HI.

5.3 Genetic service facilities in South Africa

During 2012, there were four genetic service facilities in SA (Kromberg, Sizer & Christianson, 2012). Services are provided primarily by The National Health Laboratory Services (NHLS) to the University of the Witswatersrand, University of the Free State, the University of Stellenbosch and the University of Cape Town. Kromberg, Sizer and Christianson (2012) stated that only a limited number of nurses and doctors have been trained in primary health care settings in short courses to identify common birth defects and disorders. It has been estimated that 53.4 percent per 1 000 live births have a serious genetic congenital disorder (Christianson, Howson & Modell, 2006; Kromberg, Sizer & Christianson, 2012). In these studies, it is indicated that genetic testing for HI is excluded and the assumption is that it is not done or available at all in SA.

6. DISCUSSION

According to the Health Act (Republic of South Africa, Act no, 63 of 1977) genetic services are an inclusive part of the public health care system. In the existing National Policy Guidelines for the Management and Prevention of Genetic Disorder, Birth Defects and Disabilities the priority of medical genetic services are described (Department of Health, 2001). These provisions include services delivery prior to conception, during pregnancy, at birth, in infancy, childhood, adolescence, and in maturity. In addition, the manner in which these services should be delivered is covered at the various levels from primary to tertiary health services. The tertiary education and training of students and genetic health professionals at Universities are also addressed. However, recommendations that medical geneticists' and genetic counsellors' position vacancies should be provided, urgently, in the nine provinces, in order to offer the services, have not yet been acted upon, and most provinces still have no posts at all (Kromberg et al, 2012). Currently, four medical schools in the country have medical genetics professionals on their staff and medical genetics is integrated into a medical student's curriculum. There is at present no degree in genetic counselling offered at any university in SA.

McAllister, Dunn and Todd (2011) argued that financial resources from government for genetic services in SA are deprived partly due to other health priorities, particularly the HIV/AIDS and developing Tuberculosis epidemics. Conversely, also due to an element of ignorance concerning genetic services and their cost effectiveness and benefits for individuals, families and the community in general the general public are not aware of the hazards of an impairing condition and thus not demanding services. Genetic services are not widely marketed and therefore the benefits remain almost entirely unknown.

6.1 Qualified staff

According to Kromberg *et al* (2012), there are currently 11 medical geneticists, registered with the Health Professions Council of South Africa (HPCSA). Almost without exception, the permanent staff complement of the established medical genetic laboratories, departments and units have diminished over the last decade. Kromberg (2012) argues that in other specialties, it has resulted in loss of service capability and it has placed great strain on their ability to maintain standards. It has certainly resulted in the inability to deliver services to affected individuals at large. Accordingly, at present, equity and access to medical genetic services for the majority of the population remains an unachievable goal. Furthermore, Kromberg (2012) states that there may be a need for medical genetics to become a recognised speciality in South Africa, but until genetic departments are established in SA, this is unlikely to occur.

Moreover, few published studies could be obtained concerning genetic testing for congenital HI in SA, these, of course, not reflecting the major advances made in comprehensive testing by the University of Iowa group. According to Kabahuma *et al.* (2011), hearing loss was identified in GJB2 and GJB6. The four common mitochondrial mutations identified were, A1555G, A3243G, A7445G and T7511C. Human *et al.* (2009) studied 97 members of A South African family with the mitochondrial A1555G mutation on haplogroup LOd, the most common mutation associated with aminoglycoside-induced deafness.

Viljoen (2003), identified the need and opportunities for training health professionals in medical genetics. Therefore, a two year subspecialty training program in Genetic Counselling has commenced at the University of the Witwatersrand, Johannesburg in 2003. The prerequisite to register for this training was that the applicant be registered in Paediatrics, Obsterics and Gynaecology or Internal Medicine. Furthermore, it was also identified that there were a lack of finances and posts were limited for training. In addition, Beighton *et al.* (2012) report that the University of Cape Town also offers an MSc in genetic counselling.

Beighton *et al.* (2012) note that the lack of qualified genetics specialists leaves much of the population of SA without access to appropriate services. They make reference specifically to the role of genetics in cancer, diabetes and heart disease. While they do not reference HI, the research of the Iowa group makes clear the benefits of comprehensive genetic testing there as well. Without comprehensive genetic testing for HI, any chance of expanding diagnostic services for the development, proper diagnoses and right placement of the child with HI, the HI population and SA will be severely compromised.

6.2 Costs

This author has attempted to assess the costs for some of the syndromes associated with HI previously identified by the laboratory services from the NHLS and in the different departments in the schools of medicine. Due to lack of response from the agencies and offices in question and time limitations, the complexity of the funding structures in the various departments and because of the practice of cross subsidisation between clinical and laboratory research and service, this information could not be obtained. In addition, as stated before, currently routine genetic testing for isolated HI is not performed in SA. Could not find in the publish work to any reference to HI testing – it is an assumption.

Pinpointing the exact genetic cause of inherited HI has involved sequencing one gene at a time, a process that could take up to a year and cost an average of R9 000.00 ($987.75 US Dollar) per gene in the United States (USA). It would cost currently around R750 000.00 ($82 312.50 US Dollar) to test all known HI-causing genes using this method (The University of Iowa, 2012; Illumina, 2012). This method is known as Sanger sequencing, which was invented in 1977. Moreover, Sanger sequencing is a standard method for genetic testing and due to the low efficiency of the method, only 12 of the known genes could be tested. This is not only prohibitively expensive, but inconvenient, and time consuming for clients.

A new test, called OtoSCOPE (OS), was developed by the Molecular Otolaryngology and Renal Research Laboratory by the University of Iowa in 2011. OS uses a method called MiSeq and is able to screen all 66 known genes for HI simultaneously, making testing faster, more accessible and affordable. According to OS Genetic Testing (2013), the price for OS genetic testing is $1 500 US Dollar (R14 116.50) in the USA. It is currently not possible to purchase an OS machine, whose operation also requires a next generation sequencer, the specialised personnel to operate it, the consumables to run the genetic testing, and computers and software to do the analysis, among other factors. This laboratory is the only laboratory that can perform the total of the 66 genes discovered for this price and in a relative short time at this stage in the world. (Illumina, 2012). However, the laboratory is able to accept genetic samples for testing from anywhere.

Despite continuing and increasing limitations in financial resources, the academic departments of medical genetics at the Universities of Cape Town, Stellenbosch, Free State, and the Witwatersrand have managed to provide a limited, albeit diminishing service, and continue to do effective research in the field of genetic abnormalities. With declining resources, though, the future of genetic service and research in SA remains uncertain.

7. CONCLUSION

Kromberg *et al.* (2012) argued that, since the beginning, almost all activities in medical genetics, including service, research and development, and teaching and training, occur in academic institutions in SA. Some tests, primarily connected with laboratory services, also take place in the private sector. The continued undertaking of research and development and teaching and training, for the foreseeable future, will depend on the academic institutions, and are therefore dependent upon the relationship that will be developed and maintained between them and the NHLS.

Admittedly, given the disparity in the way that different medical genetic departments are structured and financed, it must be presumed that this future relationship would have to be negotiated with provincial health departments, which will be guided in these negotiations with universities. It seems that the manner in which medical genetic departments, units and laboratories are integrated into the NHLS can be expected to have significant consequences for their structure, functioning, staffing and financing (Kromberg *et al.* 2012). It will thus determine genetic units' ability to undertake research, development, teaching and training.

It was not possible to discuss specifics related to these issues without having details of the proposed relationship between the NHLS and academic laboratories. Given the precarious situation for medical genetics in South Africa, all of these aspects of academic endeavour will be essential to ensure the continued viability of medical genetics.

Kromberg (2012) argued that there is a lack of awareness on the part of both health professionals and the public regarding the available genetic services and their value, different ethnic groups particularly related to philosophical attitudes to health. Thus, the application of a standard protocol to the evaluation and diagnosis of all persons with HI is recommended. The clinical evaluation of the patient with HI is a multidisciplinary endeavor that includes participation by a clinical geneticist, otorhinolaryngologist, audiologist, pediatrician, speech therapist, educators, and some cases an occupational therapist and psychologists. Genetic testing should be the first test after medical history, physical examination and audiometry. It is of cardinal importance to make a genetic diagnosis that could preclude further invasive diagnostic testing. In addition, possible other medical conditions could be identified in time, and families could be informed and provide genetic counseling with prognostic prospects. Without a comprehensive genetic test for HI, the future will remain dark to the fullest development of the person with HI in SA.

8. REFERENCES

Beighton, P. & Botha, M.C. 1986. Inherited disorders in the black population of southern Africa. *South African Medical Journal,* (69):293-296.

Beighton, P., Goldbatt, J. & Wallis. 1987. Genetic disease in South Africa. South African Medical Journal, 72:766-769.

Beighton, P., Fieggen, K., Wonkam, A., Ramesar, R. & Greenberg, J. 2012. The University of Cape Town's contribution to medical genetics in Africa – from the past into the future. *South African Medical Journal,* 102(6):446-448.

Christianson, A, Howson, C.P & Modell, B. 2006. March of dimes global report on birth defects. March of Dimes Birth Defects Foundation, New York, United States of America.

Department of Health. 2012. National Policy Guidelines for the Management and Prevention of Genetic Disorder, Birth Defects and Disabilities. Available from: <http://www.info.gov.za/view/DownloadFileAction?id=70288> [Date access: 23 November, 2012].

Fortnum, H. & Davis, A. 1997. Epidemiology of permanent childhood hearing impairment in Trent Region, 1985-1993. *British Journal Audiology*, 1997:409-446.

Guardino, C.A. 2008. Identifications and placement for deaf students with multiple disabilities: Choosing the path less followed. *American annals of the deaf,* 64:153-155.

Hay, C. 2012. 17 Babies born deaf in SA.
Available from: <http://www.health24.com/news/Hearing_management/1-1239,65848.asp> [Accessed: December 2012].

Hilgert N., Smith, R.J & Van Camp, G. 2009. Function and expression pattern of nonsyndromic deafness genes. *Current Molecular Medicine*; 9:546-564.

Human H., Lombard D., de Jong, G. & Bardien S. 2009. A South African family with the mitochondrial A1555G mutation on haplogroup L0d. *Biochemical and Biophysical Research Communications,* 382(2):390-394.

Illumina. 2012. Pursuing Fast, Affordable Hearing Loss Screening. Eliot Shearer at the University of Iowa Carver College of Medicine is developing a method to simultaneously screen all 66 known deafness genes using the MiSeq® system. Available from: <http://www.illumina.com/documents/products/other/interview_eshearer.pdf> [Accessed: 12 November 2012].

Jenkins, T. 1990. Medical genetics in South Africa. *Journal Medical Genetics,* (27):760-779.

Kabahuma, R.I., Ouyang, X., Du, L.,Yan, D., Hutchin, T., Ramsay, M., Penn, C. & Liu, X. 2011. Absence of GJB2 gene mutations, the GJB6 deletion (GJB6-D13S1830) and four common mitochondrial mutations in nonsyndromic genetic hearing loss in a South African population. *International Journal of Pediatric Otorhinolaryngology*, 75:611–617.

Kitson, N. 2000. Mental health and deafness. London: Whurr Publishers.

Kromberg. G.R, Sizer, E.B & Christianson, A.L. 2012. Genetic services and testing in South Africa. *Journal Community Genetic,* DOI 10.1007/s12687-012-0101-5.

McAllister, M, Dunn, G, Todd, C. 2011. Empowerment: qualitative underpinning of a new clinical genetics-specific patient-reported outcome. *European Journal of Human Genetics*, (19), 125-130.

Nation Master. 2013. Population (1975) by country. Available from: <http://www.nationmaster.com/graph/peo_pop-people-population&date=1975> [Accessed: 20 April 2013].

Olusanya, B.O. 2008. Priorities for early hearing detection and intervention in sub-Saharan Africa. *The Journal of the American Academy of Audiology*, 47(Suppl.1):S3-S13.

OtoSCOPE Genetic Testing. 2013. Cost of genetic testing. Available from:
<http://www.healthcare.uiowa.edu/labs/morl/Gene_List_Complete.htm>
[Accessed: 5 January 2013].

Republic of South Africa. 2005. Children's Act, Act no. 38 of 2005. Pretoria: Government Printer.

Republic of South Africa. 1977. Health Act, Act no. 63 of 1977. Pretoria: Government Printer.

Republic of South Africa. 1996. The Constitution, Act no. 108 of 1996. Pretoria: Government Printer.

Sellers, S & Beighton, P. 1983. The Waardenburg syndrome in deaf children in southern Africa. *South African Medical Journal,* (63), 725-727.

Sellers, S., Groeneveldt, L & Beighton, P. 1976. Aetiology of Deafness in White Children in the Cape. *South African Medical Journal*, (50), 1193-1197.

Sellers, S., Napier, E. & Beighton, P. 1975. Childhood Deafness in Cape Town. *South African Medical Journal,* (49), 1135-1138.

Shearer, A.E, Smith, R.J,H. 2012. Genetics: advances in genetic testing for deafness. *Current Opinion in Pediatrics*, 24(6):679-686.

Smith, R. (richard-smith@uiowa.edu). 2012. Request: Price of OtoScope. Email to: Smith, M. (smit7304@umn.edu. 26 December.

Statistics South Africa. 2001. Census 2001: Stages in the Life Cycle of South Africans. Pretoria: Statistics South Africa.

Statistics South Africa. 2012. Census 2011: Highlights of key results. Available from <http://www.statssa.gov.za/Census2011/Products/Census_2011_Methodology_and_Highlights_of_key_results.pdf>, [Accessed: 1 November 2012].

The University of Iowa. 2012. New test can screen all deafness genes simultaneously. Available from: <http://news-releases.uiowa.edu/2010/november/111610test-deafness-gene.html> [Accessed: 18 November 2012].

United Nations. 1999. The African Charter on the Rights and Welfare of the Child. Available from: <http://www.childinfo.org/files/fgmc_AfricanCharterontherightsandwelfareofthechild.pdf> [Accessed: 15 November 2012].

United Nations. 1989. The Convention on the Rights of the Child. Available from: < http://www.un.org/cyberschoolbus/treaties/child.asp>, [Accessed: 15 November 2012].

United Nations. 1924. The Geneva Declaration on the Rights of the Child. Available from: < http://www.un-documents.net/gdrc1924.htm>, [Accessed: 15 November 2012].

United Nations. 1948. The Universal Declaration of Human Rights. Available from <http://watchlist.org/wordpress/wp-content/uploads/Universal-declaration-of-human-rights.pdf>, [Accessed: 15 November 2012].

Van Naarden, K, Decoufle, P. & Caldwell, K. 1991. Prevalence and characteristics of children with serious hearing impairment in metropolitan Atlanta. *Pediatrics,* 1991(103):570-575.

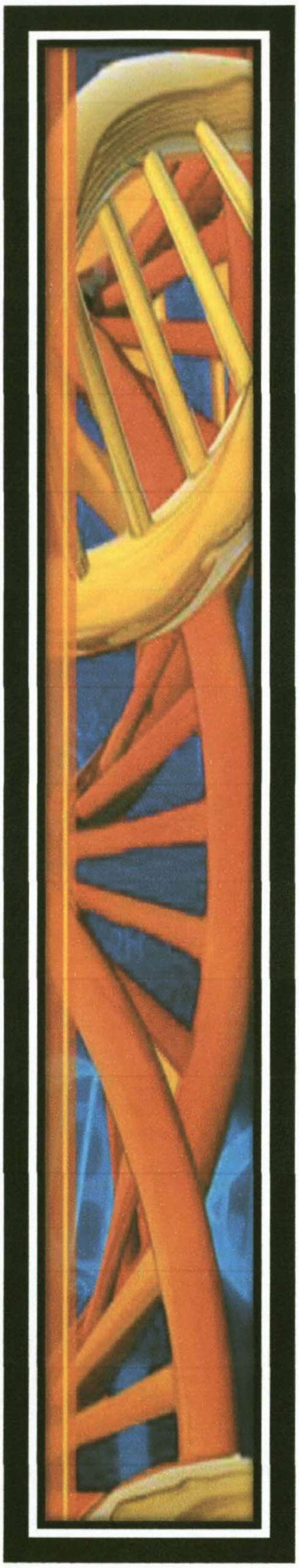
Viljoen, D. 2003. Need and opportunities for training health professionals in medical genetics. *South African Medical Journal,* 93(3):161.

Winship, W.S. & Beighton, P. 2011. Genetic disorders in the Indian community in South Africa. *South African Medical Journal,* (101):481-484.

World Health Organization. 2013. Deafness and hearing loss. Available from: < http://www.who.int/mediacentre/factsheets/fs300/en/index.htm> [Accessed: January 2013].

World Health Organization. 1991. WHO Report of the Informal Working Group On Prevention Of Deafness And Hearing Impairment Programme Planning. Available from: <https://apps.who.int/pbd/pdh/Docs/GRADESTable-DEFs.pdf> [Accessed: December 2012].

Zahnert, T. 2011. The Differential Diagnosis of Hearing Loss. *Deutsches Aerzteblatt International,* 108(25):433-444.



CONCLUSION

For persons with DHI, life in South Africa has always been and remains difficult. It seems that it shall remain so for the foreseeable future, unless significant changes are made to every aspect of living with DHI, including education, disability accommodation, sign language interpretation and real-time captioning services, to technical and medical enhancements of hearing by means of hearing aids and cochlear implants and diagnosis through genetic testing of congenital HI.

The economy and political situation of the country seem unlikely to be able to address all the challenges. It is also unclear whether there is the political will to do so, by making quality of life of persons with deafness a national priority. Although South Africa is by most measures a developing country and faces the typical democratic and economic challenges herein, it is unique among African nations in its world-class universities. These may yet hold forth the prospect for better addressing the problems of persons with DHI than other nations in its economic/developmental cohort and even offer potential models for the advancement of quality of life for the deaf.

Education may be the single most important factor in any person's achievement of success in life. Of course, this is no different for persons with deafness. And although there is a venerable history of deaf education in South Africa, it remains clear that people with DHI remain underserved and, further, that there is no consensus as to how they might best be served. Approaches to deaf education in SA remain highly eclectic and too little studied. What is clear is that literacy in English and the ability to communicate through speech are as valuable to South Africans with DHI as to their hearing compatriots.

It is also necessary that all persons with disabilities, including persons with DHI, have the benefit of legislation protecting their human rights. These protections must extend to all aspects of life and legislation must take into consideration both medical and social factors, both broadly understood. People with DHI may be particularly vulnerable to harm from others owing to challenges in communication. Current SA law as it applies to disability is complex and inconsistent with regard to definitions of disability, a problem hardly unique to the country. It is recommended that the United Nations' International Classification of Function (ICF), to which SA and all members are signatories, be employed to create consistency in law and policy that considers both medical and social aspects of disability in general and DHI in particular.

The need for more consistent and effective law, policy, and practice is borne out in the examination of the socioeconomic status of people with DHI in SA. In every measure of quality of life, people with DHI suffer demonstrably in comparison with the population as a whole. This is borne out statistically, with figures drawn from a large survey of people with DHI. Measures surveyed include additional disabilities, education (primary through tertiary), employment, communication and, perhaps most distressingly, mental health. Because the survey was primarily disseminated via electronic media, its respondents were demonstrably privileged in comparison to the large part of the population without ready access to the Internet.

Sign languages such as South African Sign Language (SASL) are a lifelong element of socialisation within "Deaf Culture." But "speakers" of SASL, both deaf and hearing, are a very small linguistic minority that, like other linguistic minorities in SA, needs to communicate in English to achieve a high standard of living. SASL vocabulary varies greatly among users, standards of certification for interpretation are loose, and costs of interpretation services are comparable to those in the United States, and thus highly unlikely to be affordable to individuals, companies, or agencies. Real-time captioning, which provides direct access to and a written record of spoken communication without concern for loss of content in translation, is clearly the preferable option, across all contexts outside of "Deaf Culture."

Cochlear implant devices have demonstrable benefits in enhancing quality of life for persons with DHI, improving, sometimes dramatically, access to spoken language and environmental sound. This study, though preliminary, indicates that the direct costs of all aspects of implantation, including surgery, hospitalization, rehabilitation and maintenance are prohibitively high for all but those with at least upper-middle class incomes. The World

Health Organization has strongly recommended that the technology and requisite accompanying services be made widely available across all income brackets in developing countries.

While law, policy, social practice and hearing technologies are all essential and morally imperative aspects of addressing the serious needs of persons with DHI in SA, it is also the case that DHI results from medical conditions, which may be addressed medically now or in the future. In particular owing to the value of early detection of DHI, genetic testing for congenital HI is an invaluable resource, though one that is underutilized in SA. There are few programs in SA in either genetics for physicians or in genetic counseling as a field in its own right and only very limited published research on the genetics of HI. The laboratory of Richard Smith at the University of Iowa (US) is now able to test for all 66 genes related to hearing impairment, with clear implications for SA and worldwide.

For many persons with DHI, hearing aids (HA) can be a practical technological means of enhancing hearing. Until recently, South Africans primarily purchased HA manufactured by six multinational corporations based in the US and Europe. HA's were sold by on-site vendors with audiologists on staff to provide services including testing and fitting. These manufacturers functioned as an oligopoly, who, along with dispensers, limited competition and innovation and kept prices uniform and stable.

In recent years, the market has begun to change in many ways, including the availability of direct mail and online vendors, simpler and less effective but far cheaper amplification devices called Personal Sound Amplification Products (PSAP's), and unregulated competition from new manufacturers in countries including China and India. It has even been proposed that online telehealth in audiology might lower costs. These changes have not made quality products and services more available, particularly to the economically disadvantaged.

The complexity and lack of transparency in the market, including limited and even deceptive information about hearing products has made the situation for consumers of hearing technologies even more difficult. In addition to the need to make quality HA's affordable to all South Africans with DHI, there is a need to expand the number of audiology programs in universities in order to train many more audiologists, who are able to provide services not only in English and Afrikaans, but in all eleven official SA languages.

Cochlear implant devices have demonstrable benefits in enhancing quality of life for persons with DHI, improving, sometimes dramatically, access to spoken language and environmental sound. This study, though preliminary, indicates that the costs of all aspects of implantation, including surgery, hospitalization, education and maintenance are very high, prohibitively so for all but those with at least upper-middle class incomes. The World Health Organization has strongly recommended that the technology and requisite accompanying services be made widely available across all income brackets in developing countries.

Disabling hearing impairment is a very expensive, perhaps the most expensive of disabilities. Every accommodation, however successful or not, to accommodate the challenges of deaf life, from sign language interpretation to cochlear implants, is visited upon a deaf population that can simply not afford the surcharges that society places upon their impairment. It is illustrated repeatedly here that persons with DHI in South Africa suffer disadvantages in every aspect of quality of life, whether material, in terms of lower income, or emotional, in terms of high rates of mental disabilities associated with emotional distress: depression, anxiety, and post-traumatic stress disorder. In a society that makes great claims and has great ambitions for equity among all its people, the quality of life for persons with DHI must be addressed across all fronts: law, policy, education, employment, and medicine.

To the best of this author's knowledge, this thesis is the first comprehensive national portrayal of the socioeconomic and medical situation of persons with DHI for any country. All aspects of life with DHI have been considered together, cohesively and coherently. This thesis can thus serve as a paradigm for the nationwide investigation of the complete socioeconomic and medical status of persons with DHI, and can serve as a model and inspiration for further, much needed research.

SUMMARY

This thesis examines the costs of disabling hearing impairment (DHI) in South Africa (SA). Its seven papers consider every dimension of life of persons with DHI. Their subjects are deaf education; socioeconomic factors; legislation; cost of sign language interpretation, cost of hearing aids; cost of cochlear implants; and genetic testing of congenital hearing impairment.

Utilizing a unique framework, the entire picture of deaf life for an entire nation is considered. The inevitable conclusion is that life for persons with DHI in SA is formidably challenging. Deaf education is insufficient, inconsistent in its methodologies with no effective research on best practices and poor outcomes, in particular regarding occupations and standard of living.

The study of socioeconomic factors was conducted primarily by means of a survey with 3,000 respondents. Among its findings are the frequency of multiple disabilities, low income, mental disabilities, particularly those associated with emotional distress, and sexual abuse. These factors indicate that persons with DHI in SA suffer some of the worst forms of social and economic discrimination.

While the Constitution of SA is among the world's most progressive, including the rights of persons with disabilities, it has yet to deliver on its promises. While there are laws such as those regarding employment and education that are applicable to persons with disabilities, there is little disability legislation per se. In SA, comprehensive disability legislation based on the medical-social model as manifested in the United Nations International Classification of Function (ICF) is needed.

While South African Sign Language (SASL) is central to the country's "Deaf Culture," it has not proven itself an effective disability accommodation that enables persons with DHI to communicate effectively with the majority hearing world, as is essential for success in education, employment, and the utilisation of services. There are problems

inherent in SASL itself, its lack of uniformity and sufficient vocabulary to communicate as needed in complex endeavors including education and employment. The cost of sign language interpretation services is beyond the reach of nearly all individuals, businesses, and agencies. Real-time captioning services are the best option for efficiency, accuracy, record keeping, and even utility beyond the deaf community as an element of Universal Instructional Design.

Hearing aids (HA) are widely used by persons with DHI. In SA, they are sold in an increasingly complex market where prices are prohibitively high for the economically underprivileged and information regarding the quality of products and services is far from transparent and sometimes even deceptive. An insufficient number of audiologists, especially those able to provide services in languages other than English and Afrikaans, makes access to quality HA's even more difficult.

The use of cochlear implants in SA remains limited at this time due to the reluctance of medical schemes and the lack of government support, despite the proven benefits of this technology. Currently, the technology is a realistic option only for people with upper middle class incomes or higher.

Recent research in genetic testing at the University of Iowa (US) has identified 66 genes relevant to hearing impairment. It is possible for physicians worldwide to access and employ this technology by sending samples to Iowa, but it appears to remain little known or unknown in SA. In addition, there is a need for more programs in medical genetics and genetic counseling.

Although this study concludes that the situation for persons with DHI in SA is extremely difficult, one hopeful factor is the presence of world-class universities. This thesis provides a comprehensive, nationwide model for further research within and beyond SA that can be utilized to improve the status of people with DHI.

OPSOMMING

Hierdie tesis ondersoek die koste van gehoorgestremdheid (GHG) in Suid-Afrika (SA). Die sewe artikels oorweeg elke dimensie van die lewe van persone met GHG. Die onderwerpe is die geskiedenis van dowe onderwys; sosio-ekonomiese faktore, wetgewing, koste van gebaretaal interpretasie, die koste van gehoorapparate; koste van kogleêre inplantings, en genetiese toetsing van aangebore gehoorverlies.

Die tesis maak gebruik van 'n unieke raamwerk, wat die hele konteks van die dimensie oor gehoorgestremd in SA dek. Die onvermydelike gevolgtrekking is dat die lewe vir persone met GHG in SA 'n formidale uitdaging is. Dowe onderwys is onvoldoende, teenstrydig is in sy metodes met geen effektiewe navorsing oor die beste praktyke en swak uitkomste, veral ten opsigte van beroepe en standaard van lewensgehalte.

Die studie van die sosio-ekonomiese faktore is hoofsaaklik deur middel van 'n opname met 3000 respondente. Onder sy bevindinge is die frekwensie van veelvuldige gestremdhede, lae inkomste, intellektuele gestremdhede, veral dié wat verband hou met emosionele nood, en seksuele mishandeling. Hierdie faktore dui daarop dat persone met GHG in SA verduur in sommige gevalle van die ergste vorms van maatskaplike en ekonomiese diskriminasie.

Terwyl die Grondwet van Suid-Afrika een van die wêreld se mees progressiewe wetgewing is, insluitend die regte van persone met gestremdhede, is dit nog te lewer op sy beloftes. Terwyl daar wette soos dié met betrekking tot indiensneming en opvoeding wat van toepassing is op persone met gestremdhede, is daar min wetgewing op persone met GHG. In SA, omvattende wetgewing vir gestremdhede wat gebaseer is op die mediese-sosiale model soos gemanifesteer in die Wêreld Gesondheidsorganisasie se Internasionale Klassifikasie van Funksie, Gestremdheid en Gesondheid is nodig.

Terwyl Suid-Afrikaanse Gebaretaal (SAGT) sentraal staan in die land se "Dowe kultuur," het dit nog nie bewys dat 'n effektiewe akkommodasie vir persone met GHG wat hul in staat stel om effektief te kommunikeer met die meerderheid gehoorde wêreld nie, wat noodsaaklik is vir die sukses in onderwys, indiensneming en die benutting van die dienste.

Daar is probleme inherent in SAGT, die gebrek aan eenvormigheid en die voldoende woordeskat om te kommunikeer wat nodig is in komplekse pogings insluitende onderwys en indiensneming. Die koste van gebaretaal interpretasie dienste is buite die bereik van byna alle individue, besighede, en agentskappe. "Real-time captioning" dienste is die beste opsie vir doeltreffendheid, akkuraatheid, rekordhouding, en selfs nut buite die dowe gemeenskap as 'n element van Universiële Instruksionele Ontwerp.

Gehoortoestelle (GT) word wyd gebruik deur persone met GHG. In SA, is hulle verkoop in 'n toenemend komplekse mark waar die pryse buitensporig hoog is vir die ekonomies minderbevoorregte en inligting oor die gehalte van die produkte en dienste is ver van deursigtigheid en soms selfs misleidend. 'n Onvoldoende aantal oudioloë, veral diegene wat in staat is om dienste te lewer in ander tale as Engels en Afrikaans, maak die toegang tot gehalte GT nog moeiliker.

Die gebruik van kogleêre inplantings in SA bly beperk in hierdie stadium as gevolg van die onwilligheid van die mediese skemas en die gebrek van die regering se ondersteuning, ten spyte van die bewese voordele van hierdie tegnologie. Tans, die tegnologie is 'n realistiese opsie vir mense met hoër middelklas inkomste of hoër.

Onlangse navorsing in genetiese toetsing aan die Universiteit van Iowa (VSA) het 66 gene geïdentifiseer wat oorsake is vir gehoorverlies. Dit is moontlik vir dokters wêreldwyd om toegang te verkry en hierdie tegnologie gebruik deur die stuur van monsters na Iowa, maar dit blyk dat dit minner bekend of algemeen onbekend is in Suid-Afrika. Daarbenewens is daar is 'n behoefte aan meer programme in mediese genetika en genetiese berading.

Alhoewel hierdie studie tot die gevolgtrekking gekom het dat die situasie vir persone met GHG in SA uiters moeilik en uitdagend is, is dat een hoopvol faktor die teenwoordigheid van wêreldklas-universiteite oor beskik. Hierdie tesis bied 'n omvattende, landswye model vir verdere navorsing binne en buite SA wat aangewend kan word om die status van mense met GHG te verbeter.

KEYWORDS

Disabling Hearing Impairment

South Africa

Hearing loss

Costs

Cochlear Implants

Hearing Aids

South African Sign Language

Disability Legislation

Genetic testing for hearing impairment

International Classification of Functioning, Disability and Health

SLEUTELWOORDE

Gehoorgestremdheid

Suid-Africa

Doofheid

Kostes

Kogleêre inplantings

Gehoorapparate

Suid-Afrikaanse Gebaretaal

Gestremde Wetgewing

Genetiese toetse vir gehoorgestremdheid

Internasionale Klassifikasie van Funksionering, Gestremdheid en Gesondheid