

DEAFSA

POLICY DOCUMENT

ON

EARLY IDENTIFICATION

OF

DEAFNESS

AND

EAR CARE

INDEX

	<i>Page no.</i>
PREAMBLE	1
VISION STATEMENT	2
GLOSSARY OF TERMS	2
PART ONE	2
1. INTRODUCTION	2
PART TWO	5
PART THREE	6
PART FOUR	8
GOALS	8
SHORT AND MEDIUM TERM OBJECTIVES	9
1. Policy	9
2. Research	9
3. Services	9
4. Awareness	10
5. Training	10
6. Funding	10
7. Networking	10
POLICY PROPOSALS	10
EXPECTED OUTCOME FOR A NATIONAL PROGRAMME FOR THE EARLY IDENTIFICATION OF HEARING IMPAIRMENT, DEAFNESS AND EAR CARE	11
0-2 YEARS	11
2-5 YEARS	12
Over 5 years	12
CONCLUSION	13
APPENDIX	14

The Deaf Federation of South Africa (DEAFSA), formerly the South African National Council for the Deaf (SANCD), subscribes to the Health for All objective, a Primary Health Care approach, and is committed to the Early Identification of Hearing Impairment, Deafness and Ear Disease and the provision of 'Ear Care' for all the citizens of South Africa.

The future of a child who is born with a significant hearing loss depends to a very large extent on early identification (i.e. audiological diagnosis before 12 months of age) followed by immediate and appropriate intervention. The emphasis of intervention early in the lives of deaf infants and children is on the development of communication skills, either signed or spoken language. Adults who acquire a hearing loss later in life need timely intervention in order to prevent any deterioration in their communication skills and to develop the appropriate communication strategies which are required to maintain their position in society and in the workplace.

The new political dispensation has inevitably brought a need for a re-evaluation of health policies and for the restructuring of health services. The National Health Plan, the National Plan of Action for Children and the proposed Policy for Maternal and Child Health emphasize the principles of health promotion and disease and disability prevention in order to ensure the health of the community at large, as well as rehabilitation for those with chronic diseases or disabilities. The role of persons with disabilities and their representatives in the formulation of strategies for the development of appropriate and acceptable services is now recognized. This is not only in the interests of persons with disabilities but of society generally. It is important that there should be timely and equitable services for all, especially for those who are either born with or acquire a disability. The Reconstruction and Development Programme (RDP) White Paper which was tabled and adopted by Parliament in November 1994, stipulates in its Chapter 7 the broad framework for a national comprehensive, and sustainable disability strategy. This should take place in consultation with persons with disabilities. The Integrated Framework for a National Strategy for Disabilities further extends these principles.

DEAFSA is committed to joint co-operation with government and other organizations in order to promote equitable health services and education opportunities, and in order to ensure a higher standard of living and full employment for persons with disabilities. In this way the necessary conditions for social, cultural and economic development and progress for persons with disabilities will be ensured.

This document is intended as a model for good practice and sets out in detail suggestions for ways in which a national plan of action for the Early Identification of Hearing Impairment, Deafness and Ear Disease might be organized by the Department of National Health and all the other relevant role players. Such a plan will ensure that the needs of the consumers of health services and the community at large but especially of those children and adults, who have a hearing impairment, will be met.

VISION STATEMENT

2

DEAFSA believes that timely services should be provided to those persons in the community who already have or who may acquire a hearing impairment. DEAFSA embraces the notion of creating an enabling environment that will facilitate the full participation of, and provide equal opportunities for, persons with hearing impairment at all levels of society, thereby encompassing human diversity and promoting maximum human potential.

GLOSSARY OF TERMS

Normal hearing is that level of hearing that falls within the 0 and 15 decibel intensity range of an audiometer.

Hearing loss indicates that measured hearing levels are outside of the 0 – 15 decibel normal hearing range. The categories of hearing loss are minimal, mild, moderate, moderately-severe, severe and profound.

Hearing impairment is the condition which results from the impairment of the sense of hearing to an extent that it interferes with communication and affects the social, emotional, educational and vocational aspects of the life of an individual.

The term *deaf* refers to a category of moderately-severe or greater hearing loss which affects the above aspects of life and renders a person dependent upon the visual sense for additional information for the purposes of spoken communication.

The term *Deaf* refers to those persons with a severe or profound degree of hearing loss whose mode of communication is Sign Language.

Ear disease encompasses any condition of the peripheral or central auditory system that affects the function of the sense of hearing.

Middle ear disease refers to otitis media, either in its acute or chronic form.

PART ONE

1. INTRODUCTION

Any policy for the Early Identification of Hearing Impairment, deafness and Ear Disease aims ultimately to facilitate the development of either oral or signed communication in those who are born deaf or become deaf early in life, or to conserve oral communication skills in those persons who lose their hearing later in life. The right of Deaf persons to choose Sign Language for themselves or their children as the preferred mode of communication should be respected as should the right of hearing persons to choose spoken communication for their deaf children. Sign Language has recently been officially recognized.

Policy regarding hearing impairment, deafness and ear disease should therefore address the needs of the following groups within society:

- The Deaf community;
- The deaf children of hearing parents;
- The hearing community at potential risk for acquired deafness - those persons whose occupations expose them to high levels of noise in industry and entertainment, the mines, and the military; those persons who are on ototoxic medication; those persons who suffer from frequent otitis media; those infants and children who are exposed to certain infectious diseases; those persons who are at risk for genetic and inherited conditions and syndromes;
- adults who are already hearing impaired, especially the elderly;
- the community at large.

The fact that there are so many groups for whom a policy of early identification is important, poses a challenge for the policy maker. A policy is needed that will incorporate both prevention and early identification of hearing impairment, deafness and ear disease and that will make provision for the habilitation and rehabilitation of deaf persons in addition.

There is a significant number of people in our society for whom such a policy will be important. Hearing impairment and deafness rank as the commonest forms of sensory deprivation. However one of the major constraints to the development of programmes for the prevention of hearing impairment, deafness and ear disease is the low profile that these issues have received to date (WHO: 1991). Some of the common causes of hearing impairment and deafness especially in the developing countries are mostly preventable (WHO: 1993). The extremely meager resources to support programme activities are a major constraint. Hearing impairment and deafness have far reaching effects on the development of language and communication skills. They also have an impact on social and economic factors with serious consequences for the quality of a person's life. This may also lead to dependence on the state for financial assistance and support, hence hearing impairment and deafness have cost implications for the state.

The following facts are pertinent to the problem:

- Hearing impairment and deafness affect at least 3 million individuals in South Africa.
- The average age of identification of young deaf infants in South Africa is around two years.
- Diagnostic facilities for the assessment of suspected deafness are located in a few of the major cities.
- There are five parent-guidance facilities in the whole country.
- Provision of technology is grossly inadequate to the underprivileged majority.
- Sign language has only recently been officially recognized and interpreter services are currently to a great extent, non-existent.

- Approximately 6000 children whose ages range between 3 and 21 years attend schools for the deaf.
- There are waiting lists for admission at many schools for the deaf.
- An estimated number of 16 000 Deaf learners of school-going age do not attend school, nor have they done so; they are mainly from rural areas, squatter camps and the disadvantaged socio-economic groups.
- It is estimated that 65% of deaf people are unemployed.
- It is estimated that 15% of primary school children have a hearing impairment as a result of otitis media.
- A significant number of adolescents and adults in rural areas suffer from untreated chronic otitis media.
- 90% of Deaf children are born to parents with normal hearing.

These facts and figures reflect the lack of accessible and available services for deaf people and to the community at large for the early identification of hearing impairment, deafness and ear disease from the health, welfare, education, transport, and labour sectors. They further highlight the magnitude and severity of the handicapping situations that confront those who are deaf or who suspect that they or their child may be hearing impaired or deaf. The formulation of policy to address the above problems is imperative.

Furthermore it is likely that profound deafness causes a yearly income loss to the state of several millions of rands given the above unemployment figures. The revenue to the state would therefore probably be considerable if an Early Identification of Hearing Impairment, Deafness and Ear Disease programme that generated better communication skills and hence better opportunities for employment, was introduced. In addition to the income savings of early identification and intervention, a significant amount could be saved in education and training expenses, and in personal expenses to the family and the deaf individual.

PART TWO

RATIONALE FOR A NATIONAL POLICY FOR IDENTIFICATION OF HEARING IMPAIRMENT AND DEAFNESS, EAR CARE PROGRAMMES, EARLY INTERVENTION AND MANAGEMENT FOR DEAF PERSONS:

There are many reasons for establishing a national policy for the early identification of hearing impairment and deafness, ear care programmes, early intervention and management. They are:

- Children pass through critical language learning stages between birth and 3 years, language stimulation during this period is essential for the development of communication (signed or spoken).
- There is a general lack of awareness and information regarding hearing impairment, deafness and ear disease.
- Primary health care professionals have little training in the early identification and management of hearing impairment, deafness and ear disease.
- There are inadequate resources as well as maldistribution of those few resources that are available for early identification, intervention and rehabilitation of disabilities; there is also limited utilization of certain resources, such as fully equipped schools, in underserved areas.
- Early identification and appropriate treatment which would prevent chronic ear disease and resulting hearing impairment, are often not available at the Primary Health Care levels of service and especially in the rural areas; referral systems are also not properly organized.
- The lack of national policy for the prevention and rehabilitation of disabilities has resulted in programmes for disability having a low priority.
- Training and education usually does not begin before a child reaches school age, especially amongst the disadvantaged and rural communities.
- Only a small proportion of persons with disabilities receive training and specialized education.
- Adult education training programmes for the Deaf are not available in the public or private sectors.
- Children are often incorrectly placed at a school due to the lack of a proper assessment prior to admission to school.
- Teachers, social workers, health professionals and co-workers in the health, welfare and education sectors at regional and district levels who could participate in an early identification programme, are not trained in the necessary skills.
- The implementation of legislation to protect workers from acquiring hearing losses in the occupational context is not adequately monitored.

- Despite significant advances internationally in technology for the deaf, this is not accessible to the majority of South African adults and children.
- There is a lack of co-ordination between government and non-government organizations (NGO's) in the field of disability.

PART THREE

GUIDING PRINCIPLES IN THE FORMULATION OF A POLICY FOR THE EARLY IDENTIFICATION OF HEARING IMPAIRMENT, DEAFNESS AND EAR DISEASE.

Infants and children with hearing impairments depend upon access to personnel screening and on adequate facilities for diagnosis, habilitation and the acquisition of oral or sign communication skills.

A basic ethical principle of screening and early identification is that resources and facilities for further management should be available and accessible. Therefore priority must be given to the strengthening of those parent-guidance facilities that already exist, or to the creation of additional facilities. Primary health care facilities should also be strengthened to provide the requisite services for the early identification of hearing impairment and deafness. A referral system between primary care levels and secondary and tertiary levels needs to be developed.

Adults with hearing impairments and deafness likewise do not have prompt access to facilities for assessment and management nor are adequate resources, including technology such as hearing aids, available for their rehabilitation. The strengthening of those facilities and resources that are already available must also be given a high priority and ways to extend services to disadvantaged and rural communities should be explored.

The additional **PRINCIPLES** that underpin the **PROVISION OF SERVICES** for the prevention, identification and management of hearing impairment, deafness and ear disease are:

- There should be sustained education of the public on issues regarding recognition of hearing impairment, deafness and ear diseases.
- There should be co-ordinated programmes for the prevention of hearing impairment, deafness and ear disease at all levels of service delivery and within health, welfare and education sectors.
- There should be a Primary Health Care system that is accessible to all, particularly those who live in rural areas and urban slums, for the identification and treatment of ear diseases that cause deafness.
- There should be effective Maternal and Child Health care and counseling services for both prevention and identification of hearing impairment and deafness.

- There should be a system for the early identification of deafness in infancy before the age of 12 months and available resources for adequate management of the system.
- There should be a multi-disciplinary team approach which follows the algorithm – specialists training trainers; trainers training workers; workers undertake screening; workers refer those failing to specialists; specialists ensure appropriate assessment and management thereafter in a suitable environment.
- There should be specialized services at facilities that are specially equipped for the assessment and diagnosis of deafness, e.g. Audiology and ENT services.
- There should be parent-guidance facilities which are attached to or are easily accessible from diagnostic centres; existing schools for the Deaf should be considered for this purpose as well as for serving the additional purpose of being a local community resource for providing information to the community about hearing health and ear care.
- There should be access to information about the Deaf culture, provided by the Deaf community and their interpreters, so that parents of Deaf children may make an informed choice re the mode of communication, oral or sign.
- There should be training programmes for all community health- and occupational health- nursing personnel who provide services at Primary Health Care level or in the mines, military and industries.
- There should be regular screening programmes in industry, the mines and the military for the identification of hearing impairment and deafness in the at-risk adult population.
- There should be concessions for the elderly and pensioners so that hearing aid technology is readily accessible and affordable.
- There should be screening programmes to monitor the hearing of any persons who are on ototoxic medication.
- There should be ready access to genetics services and counseling for persons who are at-risk for syndromes or inherited conditions that may give rise to deafness.
- There should be adequate training and re-training of medical, para-medical and other health care workers in the knowledge and skills needed for the early identification of hearing impairment, deafness and ear disease and the provision of “ear care” thereafter.
- There should be community participation and self- representation in any programme of rehabilitation.
- There should be acceptance of the procedure of self-referral to specialist services by persons who suspect that they or their children may have a hearing impairment.

PART FOUR

GOALS

THE FOLLOWING ARE THE GOALS FOR A NATIONAL POLICY FOR THE EARLY IDENTIFICATION OF HEARING IMPAIRMENT, DEAFNESS AND EAR DISEASE.

- To detect 80% of bilateral congenital hearing impairment in excess of 50 dB HL within the first year of life.
- To ensure that by 1 year of age 80% of infants will have benefited from screening procedures to identify deafness.
- To ensure that within four weeks of identification as “high risk” or of failing screening procedures, infants are referred for comprehensive assessment and management.
- To fit hearing aids within 4 weeks of confirmation of hearing loss in appropriate cases.
- To ensure that a multi-disciplinary team approach, which will incorporate members of the Deaf community, is endorsed by the relevant health, welfare and education authorities for the management of deaf infants.
- To ensure that training modules for the identification of hearing impairment, deafness and ear disease have been incorporated into the training curricula and programmes of primary health care, occupational health and school health personnel.
- To ensure that hearing screening of all children who enter Grade 1 at primary school is incorporated into the Early Childhood Development programme.
- To ensure that 80% of adults with hearing impairments have access to a comprehensive assessment facility and receive appropriate treatment, including fitting with hearing aid or alternative technology within four weeks of referral.
- To ensure that immunization coverage for those diseases that cause hearing impairment or deafness reaches 90%.
- To ensure that the appropriate authorities recognize that exposure of employees to noise levels above 85dBA in the workplace is hazardous and that they should therefore implement hearing screening and hearing conservation programmes.

SHORT AND MEDIUM TERM OBJECTIVES

1. POLICY

- Lobbying for the acceptance of this policy on Early Identification and Ear Care at all provincial levels.
- Development of guidelines by National and Provincial Health Departments for the provision of appropriate health manpower, hearing testing facilities and equipment, and hearing aid technology at all levels.
- Budgetary allocation of funds by Provincial Government to support the manpower, facilities and technology required at all levels.
- Development of guidelines by National and Provincial Departments for referral systems between the Primary Health Care facilities in a district, its regional hospital and the provincial audiologic diagnostic centres.
- Development of guidelines by the National Department of Manpower for hearing conservation programmes for industry, the mines and the military.

2. RESEARCH

- Baseline assessment of prevalence of Deafness and ear diseases in defined project areas involving targeted age groups; the development of a provincial and national data bank.
- Promoting and supporting research into the prevention and treatment of major causes of hearing impairment.

3. SERVICES

- Development or strengthening of provincial or regional infrastructure concerned with the identification of hearing
- Implementing infant screening programmes for the identification of hearing impairment prior to immunization at clinics in every district.
- Ensuring that there is at least one audiological assessment centre per region in each province.
- Ensuring that there are at least three parent-guidance centres per province.
- Encouraging the local development and production of appropriate technology for assessment of hearing and rehabilitation of Deafness.
- Developing culturally appropriate programmes in Specialised Education for Deaf children.

- Ensuring maximum coverage of children needing to be immunized against the target diseases of the Expanded Programme on Immunisations (EPI), and against mumps, rubella and meningitis.

4. **AWARENESS**

- Providing intensive Health Education Programmes to increase public awareness.
- Increasing and monitoring the awareness of local administrators, parents, teachers and others of the resources needed to provide services to the Deaf.

5. **TRAINING**

- Implementing training programmes for health care personnel in the identification of hearing impairment, Deafness and ear disease in infants and children and of “ear care” skills.

6. **FUNDING**

- Promoting the development of a system to support subsidized hearing aids to all children.

7. **NETWORKING**

- Improving co-ordination and monitoring of all services for Deaf children, those children with disabilities and children with special learning needs, both at central and local level.
- Extending collaboration and co-ordination between government agencies, NGO’s and organizations of civil society that are concerned with hearing impairment and Deafness.

POLICY PROPOSALS

THE FOLLOWING POLICY PROPOSALS ARE RECOMMENDED IN ORDER TO ACHIEVE THE STATED OBJECTIVES STATED ABOVE:

- Public education regarding hearing health care and deafness should be promoted via all communication media.
- Direct self-referral by parents to developmental screening centres should become part of clinic practice everywhere; parents who express concern about their infants’ or childrens’ hearing should be referred to diagnostic audiologic facilities.
- “At risk” infants should be monitored and the relevant risk factor should be recorded on the “Road to Health card.
- Screening of infants should be carried out at “Well Baby” or “Immunisation” clinics using parental questionnaires and developmental checklists to be implemented with an infant “Road to Health Card” at the 14 weeks and 9 months visits.

- Health professionals with appropriate training in Audiology should assume the responsibility for supervising hearing screening in pre-school children; infants and children who fail the screening should be tested at diagnostic centres by Audiologists.
- Hearing screening should be an integral part of the Early Childhood Development programme to take place as a routine part of the school entry assessment.
- General Practitioners should receive adequate training to enable them to make a precise and detailed diagnosis of ear diseases.
- Screening programmes should be monitored by Local Health Authorities and the results of such monitoring should be available for an external audit of the region.
- Adequate funds should be provided to each provincial and regional authority for the purpose of ensuring these facilities, resources and services.
- These programmes should aim to achieve as their acceptable standard the identification of infants with severe or profound bilateral hearing loss before 12 months of age.
- Within each district there should be a co-ordinator who is responsible and accountable for implementing and monitoring the hearing screening programme and who should also be accountable to the community for the screening programme.

EXPECTED OUTCOME FOR A NATIONAL PROGRAMME FOR THE EARLY IDENTIFICATION OF HEARING IMPAIRMENT, DEAFNESS AND EAR CARE

0-2 years

- 70% coverage of the infant population in all regions of the country by a screening programme that utilizes a high risk questionnaire at 14 weeks and a developmental checklist at 9 months for the purpose of identifying those infants with a high index of suspicion for hearing impairment or deafness.
- Sensitisation of policymakers and the community towards the programmes.
- Access to diagnostic facilities for further assessment of infants within four weeks of suspicion of a hearing loss.
- Creation of multi-disciplinary teams for the further management of Deaf infants, these teams to include Deaf adults and interpreters.
- Access to parent-guidance facilities within a maximum period of four weeks of identification of deafness.

- Development of at least four schools for the Deaf in rural regions as local resources for the community.
- Four weeks maximum delay in access to state audiologic facilities by hearing impaired adults.
- Improved hearing aid provision to adults receiving audiologic services through the state.
- Implementation of hearing conservation programmes in the mining industry and other high risk occupational environments.
- Strengthening the infrastructure by developing and initiating training programmes in administering the high risk and developmental questionnaires and in Ear Care for trainers of Primary Health Care personnel.
- Strengthening the infrastructure by developing and initiating training programmes for trainers of Occupational Health nursing personnel.
- Introduction of modules in Management of Deafness and Ear Disease in all Primary Health Care training courses.

2-5 years

- Endorsement of the above concepts regarding early identification, access to services and availability of resources, in a policy statement from the relevant National Departments.
- 80% coverage of the infant population by the High Risk and Developmental Screening questionnaire programme.
- Specific reduction of otitis media as a result of increased awareness of hearing impairment, deafness and ear disease in the community and through the training of personnel in the management of otitis media.
- Specific reduction in hearing loss acquired by adults who work in a noisy occupational environment, especially amongst mine workers.

Over 5 years

- 95% coverage of the infant population by the High Risk and Developmental Screening questionnaire programme.
- Parent-infant resources for the management of deaf infants whose parents are either Deaf or hearing in all the provinces of South Africa with financial support from the relevant National and Provincial departments.
- Extension of hearing conservation programmes to industries in addition to the mining industry.
- Reduction of ear morbidity and hearing impairment.

CONCLUSION

13

Hearing impairment is a major public health and social problem. Yet hearing loss is, in many cases, wither preventable or curable through relatively cost-effective methods that are applicable through the Primary Health Care system. In order to be successful an Early Identification of Hearing Impairment, Deafness and Ear Disease programme depends on the support of the government. Recognition should be accorded to the principle of respect for and recognition of the culture and language of all groups in South Africa and hence also to the Deaf culture and Sign Language. The Departments of Health, Welfare and Education particularly are urged to endorse these proposals.

Ear Care Infrastructure**FACILITY: LEVEL 1 COMMUNITY HEALTH CARE CENTRES**

- Community level (Outreach)
- Primary prevention

- Community health centres/clinics
- Primary prevention
- Secondary prevention

- Referral of identified problems is to Level 1 hospitals
- Secondary prevention

Personnel required:

- Primary level workers (including volunteer workers for health promotion purposes)
- Community Health Nurses
- Community Rehabilitation Workers
- General Practitioners

Equipment required:

- Infant high risk and developmental screening questionnaires
- Vaccines, MMR
- Basic ENT equipment for ENT examination
- Ear swabs
- Boric acid drops
- Sodium bicarbonate drops for cerumen management
- Saline for cleaning
- Teaching manuals
- Health education materials

FACILITY: LEVEL 2 HOSPITAL

- Secondary level
- Secondary prevention

Personnel required:

- ENT specialist
- Audiologist
- Speech-Language Therapist
- Audiometrician
- Community Speech and Hearing Worker
- Community Rehabilitation Worker

Equipment required:

- ENT equipment
- Acoustic immittance meter
- Paediatric screening audiometer
- Audiometer for air bone conduction tests and speech audiometry
- Sound treated test suite
- Sound level meter
- A mobile unit may be useful for outreach service delivery from the level 2 facility. It could be used for hearing screening or for health promotion purposes. Alternatively an existing mobile service unit that is already providing GOBIFFF could be used.

FACILITY: LEVEL 3 HOSPITAL

- Tertiary level (Level 3 referral)
- Tertiary prevention – habilitation and rehabilitation

Personnel required:

- ENT
- Audiologist
- Speech-Language therapist
- Social Worker
- Sign Language Interpreter
- Psychologist

Equipment required:

- ENT equipment
- Electronystagmography equipment
- Multifrequency immittance meter
- Diagnostic 2 channel audiometer with speakers and VRA system for free field testing
- Hearing aid test box
- Insertion Gain measurement system
- Calibration equipment and sound level meter
- Otoacoustic emission system
- Evoked Potential test system
- Sound proof double booth test suite

The author of this document is **Susan Swart** who was assisted in its compilation by

***Mmule Rakau
Cas de Lange***

***Brad McPherson
Johannes Swart***

***Chris Prescott
Laetitia King***

Use of, quotation from, or photocopying of the document in part or whole should be accompanied by an acknowledgement to the author since the content hereof forms the basis of an article due to be published during 1996.

DEAFSA

**THE *SWART* PROTOCOL
QUESTIONNAIRE**

ON

EARLY IDENTIFICATION

OF

DEAFNESS

AND

DISABILITIES

COMPLETION OF QUESTIONNAIRE

Before immunization of the child, the questionnaire must be completed by the nurse: in consultation with the mother/guardian.

All three questionnaires must be completed in respect of all children who come for immunization.

EVALUATION OF QUESTIONNAIRES

Questionnaire at 14 weeks of age:

Any **YES** answer constitutes a **FAIL**

Questionnaires at 9 months and 18 months of age:

Any **NO** answer constitutes a **FAIL**.

If the baby fails any single (one) failure question on a questionnaire, he/she needs to be referred to a centre (hospital) for proper **audiologic** testing and/or for developmental assessment at a paediatric assessment centre.

**DEAFSA PROTOCOL QUESTIONNAIRES ON EARLY IDENTIFICATION OF DEAFNESS
AND DISABILITIES**

14 WEEKS IMMUNISATION: HIGH RISK CHECK

	YES	NO
1. Was any member of your own or baby's father's family born Deaf?		
2. Were you seriously ill during your pregnancy? Did you receive any treatments, medicine or herbal medicine for this illness?		
3. Were there any problems during labour or delivery?		
4. Did baby struggle to breathe? (Apgar 0-4 @ 1, or 0-6 @ 5).		
5. Was baby jaundiced and put under lights? (Phototherapy).		
6. Was baby in an incubator?		
7. Has baby been ill and in hospital during the first 4 months?		
8. Did baby receive treatments or medicine while ill?		
9. Sister – is there any obvious abnormality of the head and/or neck?		

18 MONTHS IMMUNISATION: DEVELOPMENTAL CHECK

	YES	NO
1. Does your baby sing or use “baby words” and put words together?		
2. Does your baby understand when you ask him/her to show you three familiar things/objects (e.g. car, ball, dog)?		
3. Does your baby feed him/herself a biscuit (or rusk or piece of bread)?		
4. Does your baby climb up steps if you help him/her?		
5. Does your baby put blocks one on top of the other? Does your baby try to put the top on the Vaseline bottle?		
6. Does your baby play alone while you are busy nearby?		
7. Does your baby know what a brush, a car and a cup are used for?		
8. Does your baby copy your facial expressions or gestures.		
9. Sister – is there any obvious abnormality of the head and/or neck?		

Consensus Statement on Screening for Developmental Disabilities in the Pre-School Population

Children with developmental disabilities are those children who have difficulties seeing, hearing walking, writing, conceptualizing or performing any other functions outside of the normal range of children their age. Developmental Disabilities (DD) affect between 10-17% of South African children and their families.

Screening is a “brief assessment procedure designed to identify children who should receive more intensive diagnosis or assessment”. Current practice regarding screening for DD among pre-school children varies greatly, and families, communities and early child care workers do not have appropriate guidance for steps to be taken once a child has been identified as being at risk. The following has been drafted to guide practice on screening for DD among pre-school children.

BACKGROUND

1. There are constraining factors/barriers in the current system of health services (such as nurses’ increased workloads and lack of time) to implementing DD screening at the primary level of care.
2. There is a significant gap of time between the child’s age of 18 months and 5 years when health professionals often do not see children.
3. The current Road to Health Card model does not track milestones adequately.
4. In many parts of the country, health and education system interventions for children with DD are not available.

GENERAL PRINCIPLES

1. Screening for both major and moderate DD should be done, but only if it can be linked to appropriate interventions.
2. In general, screening should focus on parent and family involvement (particularly for children under the age of 2 years), the community and primary levels of care.
3. Screening for children *under the age of two* by families and community members (such as teachers, create workers, CHW’s and traditional healers) should focus on recognition and basic management of major physical, behavioural, sensory and mental DD.
4. Screening for children *above the age of two* by teachers, create workers, traditional healers, CHW’s and other community workers should focus on recognition and management of learning/developmental, mild physical, mild mental, speech and emotional/behavioural disabilities.
5. Screening for DD should form part of a continuum of management, including development of referral strategies and case management guidelines.
6. Health interventions to respond to DD should be guided by the principles underlying national health primary health care policy which include:
 - equitable distribution of health services;
 - equitable access to health care;

- Parent/family involvement and participation (family centredness);
- focus on prevention, promotion, curative and rehabilitation (comprehensiveness);
- use of appropriate technology/tools;
- Socially, linguistically and culturally acceptable methods and materials;
- multi-sectoral approach (integrated); for example for health, education and welfare; and
- developmentally appropriate.

SCHEDULE

1. Ideally, professionals should be able to respond to parents' concerns and needs about their child's development at any time. However, this has significant implications for training, and is not practical in South Africa at this time.
2. The schedule for DD screening at the primary level of care should be cost-effective, coinciding with other child contacts, such as at the child's nine month immunization visit.
3. Many DD problems (such as relating to motor perceptual, intellectual and behavioural) may be amenable to intervention during the period when a child is between 18 months and 5 years of age. Other alternatives should be used during this time to investigate a child's development. one possibility is interviewing parents during visits to family planning clinics.
4. Before birth, midwives should screen for DD risk factors at antenatal check-ups.
5. Mandating too many contact points for screening will cause confusion and may hinder screening efforts.

TOOLS

1. Tools used to screen for DD should:
 - Be valid, reliable, and evaluable for sensitivity, specificity, and positive predictive value;
 - Be acceptable to the person implementing the test, the family and the person receiving referrals;
 - Be easy to teach learn and administer;
 - Be administered quickly (i.e. in 5 minutes or less);
 - Be cost effective;
 - Have clear guidelines for referral;
 - Be developed with consideration of the context in which it is being used;
 - Be linguistically and culturally appropriate;
 - Be statistically reportable and useable; and
 - Place a minimal increase on nurses' workload.
2. Parent/caretaker questionnaires are cost and time-effective and are therefore often the most appropriate. These should form the basis of the essential package of DD screening services for children. However, if a questionnaire cannot be administered, a "hands-on" or "observation" tool should be available for alternative use.

INTERVENTIONS

1. Interventions must focus primarily on family and community education about recognition and management, particularly in areas where health and education system interventions for children with DD are not available.
2. Case management algorithms for different DD should be developed.
3. Intervention programmes should address the underlying causes of DD (e.g. parasitic infections).

PERSONNEL AND TRAINING

1. Any persons who have frequent contact with children should be utilized as key personnel for screening for DD. These persons include: parent/other caretakers, pre-school teachers, creche managers, community health workers, traditional healers, nurses and doctors. When available, other health personnel such as occupational therapists, physiotherapists and pharmacists, should be involved as well.
2. The media is a key strategy to inform parent/caregivers, child care workers and other lay people (including community health workers) about developmental milestones, basic detection of senses deficits and where to take children for screening.
3. In rural and underserved areas, parents of children with DD can play an instrumental role in supporting other parents of children with DD.
4. There should be an overall commitment in health, welfare and education systems to training caregivers and professionals about DD screening and intervention. Well resourced areas especially should be committed to supporting rural and underserved areas.
5. At the secondary level of health services, professionals (e.g. Advanced Clinical Nurses, Medical Officers and Therapists) should assess and diagnose.
6. Health and other professionals *in practice* should be given information about basic pathophysiology, developmental disability detection and options for management via adult distance learning programmes, short courses and workshops (that provide certificates).
7. Health and other professionals *in training* should be given information about basic pathophysiology, developmental disability detection and options for management via training modules for primary health care.

RESEARCH

1. Further data on the extent of DD in South Africa would support an impetus for more appropriate and accessible services; and would support planning. However, development of services should be the focus rather than research. Research and surveillance for DD should be built into services.
2. Data on DD should be incorporated into routine health information systems.
3. More research is needed to understand the cost-effectiveness of screening for DD and the effectiveness for particular disabilities. Research is also needed to determine the validity and reliability of particular screening tools.
4. Systematic reviews, meta-analyses and direct research are needed to determine the impact of screening on child and family well-being.

Finally, screening for DD should be viewed within the context of all problems of an area in order to determine its ranking as a priority issue.

This consensus statement is the product of the *Workshop on Screening for Developmental Disability in the Pre-School Population*, held June 12-13, 1996 by the Child Health Policy Group, Child Health Unit, University of Cape Town.

WORKSHOP PARTICIPANTS

Colleen Adnams, Child Health Unit, UCT
M Alexander, Cape Metropolitan Council
Linda Biersteker, Early Learning Resource Unit
Gerald Boon, Cecilia Makiwane Hospital
Dorothea Coetzer, Groote Schuur Hospital
Jacqui Couper, Manqguzi Hospital
Val Dekenah, Cape Town City Health Department
David Donald, Department of Education, UCT
Michael Hendricks, Child Health Unit, UCT
Karen Hofman, Child Health Unit, UCT
James Irlan, Department of Health, Durban
Lorna Jacklin, TMI for Child Health and Development
Marian Jacobs, Child Health Unit, UCT
Jane Kvalsvig, Health Services Research Council, Durban
Theresa Lorenzo, Department of Occupational Therapy, UCT

Mignon McCulloch, Child Health Unit, UCT
Neil McKerrow, Edendale Hospital
Chris Molteno, Department of Psychiatry, UCT
Mercia Naidoo, Cape Town City Health Department
Diane Nurse, EROS School
Leana Olivier, Department of Health, Western Cape
PG Pekeur, Cape Metropolitan Council
Alice Ravenscroft, University of Stellenbosch
Linda Richter, CERSA, Medical Research Council
Sandhya Singh, Department of Health, Kwazulu Natal
Janet Stanford, Medical Officer, Knysna
Vicki van Rensburg, Occupational Therapy, UWC
Carl Wicht, Child Health Unit, UCT
Alyssa Wigton, Child Health Unit, UCT

1

Meisels SJ, Provence S. *Screening Assessment, Guidelines for Identifying Young Disabled and Developmentally Vulnerable Children and their Families*. Washington, DC: Zero to Three/National Center for Clinical Infant Programs: 1989.