DEVELOPMENT AND VALIDATION OF A QUESTIONNAIRE AS A SCREENING TOOL FOR DEVELOPMENTAL DISABILITY IN 9 MONTH OLD INFANTS

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DECLARATION

I, CARL BRYCE WICHT HEREBY DECLARE THAT THE WORK ON WHICH THIS THESIS IS BASED IS ORIGINAL (EXCEPT WHERE ACKNOWLEDGEMENTS INDICATE OTHERWISE) AND THAT NEITHER THE WHOLE WORK NOR ANY PART OF IT HAS BEEN, IS BEING, OR IS TO BE SUBMITTED FOR ANOTHER DEGREE AT THIS OR ANY OTHER UNIVERSITY.

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ABSTRACT

In the past two decades major focus has been placed on child's rights, survival and development. This has occurred both on an international level and, since the inception of the Government of National Unity (GNU) in South Africa, nationally, provincially and locally through various development programmes.

Development in a child concerns the sequential acquisition of cognitive, motor and social skills. Adverse biological and environmental factors will have a major negative impact on a child's development. It is therefore crucial that children affected by these adverse factors are identified as early as possible, to prevent disability or facilitate intervention to ensure that they reach their maximum developmental potential.

The global prevalence for developmental disability (DD) is 7-10% of the population. The national prevalence for South African children is not known but a recent Disability Survey by the Department of Health in 1998 quotes 5.7% – 6.1% for the overall population. Developmental disability is therefore an important priority to be addressed, especially at the primary health care level. This has been highlighted in the White Paper on Integrated National Disability Strategy of the GNU in 1997.

The efficacy of intervention for developmental disabilities is debated. Scientifically this efficacy has not been proven unequivocally but there is consensus from parents, professionals and advocacy groups that early intervention is beneficial.

Taken that early identification is essential, screening is the ideal method in the South African context for detection of developmental disability. There are numerous screening tools used for this purpose which need to fulfil certain criteria to ensure effectiveness. Important issues around existing developmental screening tools have been: time taken to administer the test; reliability, validity and sensitivity; measurement methods; ease of administering; and applicable age range.

Questions which record parents' or caregivers' observations of their child's developmental skills have been used as effective screening tools for developmental disability. A large study which assessed prevalence of disability using a "Ten Question" format has been used extensively in Bangladesh and found to be effective.

A 10 question tool was developed to screen for developmental disabilities in 9 month old infants, the age of attendance at clinics for measles immunisation. The questions focused on the four areas traditionally tested in developmental assessments, namely speech and hearing, gross and fine motor, vision and personal/social functions. Other factors such as weight, head circumference, dysmorphic features and chronic illness were documented concurrently.

The 9 month screening tool in this study was tested at Site B Clinic (Khayelitsha) and Eastridge Clinic (Mitchells Plain) and extended to high risk clinics such as the Neonatal High Risk, Cerebral Palsy and Developmental Clinics of Red Cross War Memorial Children's Hospital. This was a prospective observational study.

235 9 month old infants were seen between the period September 1996 to January 1997. The interviews were conducted in Xhosa (53%), Afrikaans (28%) and English (19%). The questionnaire was administered to the parent or caregiver of each infant. This was followed by an examination and neurodevelopmental assessment of the infant.

On assessment 192 infants (82%) had no disability, 39 (16%) had developmental disability and 4 (2%) were at risk for motor disability. A further analysis of the 39 infants with developmental disability revealed that 25 (64%) were language impaired only, 2 (5%) were motor disabled and 12 (31%) were globally disabled (i.e. in both language and motor areas). Males and females were equally affected.

The results showed that the 9 month screening questionnaire is a valid tool for the screening for developmental disability. The overall sensitivity of the questionnaire was 97.7% (95% Confidence interval [CI] of 95.8 - 99.6) and specificity 88.5% (95% CI of 84.4 - 92.6). The positive predictive value was 65.6% and negative predictive value 99.4%. Only one infant who was at risk for motor disability was missed by the questionnaire.

On evaluation of the questions in specific areas (i.e. speech, hearing, motor, vision, squint), the numbers assessed were too small for meaningful analysis. As personal and social development involves motor, language and hearing skills, this area was not used on its own in the overall assessment of the infant, but those questions were incorporated into other areas of the screen.

Of concern was that a number of infants screened positive for DD on certain questions (e.g. language), but on assessment were found to have disability in a different developmental area (e.g. motor). In these cases the questionnaire identified the children with disability - but for the incorrect reason.

Certain issues would need to be addressed prior to implementation of the screening tool to ensure an adequate, appropriate screening procedure and prevention of falsely raising the expectations of parents. This involves personnel training, monitoring of screening, referral mechanisms, intervention once DD is identified and involvement of the family as a partner in the process.

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LIST OF ABBREVIATIONS

CHC	Community Health Centre
CHU	Child Health Unit of the University of Cape Town
DD	Developmental disability
DQ	Developmental quotient
GNU	Government of National Unity of South Africa
GSH	Groote Schuur Hospital (Cape Town)
IQ	Intelligence quotient
LBW	Low birth weight baby (<2,5kg)
MOU	Midwife Obstetric Units
NDA	Neurodevelopmental Assessment
NHRC	Neonatal High Risk Clinics
NMSQ	Nine month screening questionnaire
NPA	National Programme of Action for Children
PAWC	Provincial Administration of the Western Cape
PHC	Primary Health Care
PT	Preterm
SA	South Africa
RTHC	Road to Health Card
TQS	Ten Question Screen
UN	United Nations
WHO	World Health Organisation

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1. INTRODUCTION

The advent of several major Global Child Health Programmes in the 1980's and 1990's has served to increase international focus on child rights, survival with quality of life, and development.

Against this background, the South African Government of National Unity has identified child development as a key area for promotion of the well-being of children in South Africa (National Programme of Action for Children 1996). The Department of Health's National Plan of Action Working Document states that children, due to their youth and vulnerable developmental state, are disproportionately affected by poverty, homelessness, lack of clean water and sanitation and other environmental conditions.

The National Government has also made a commitment to various programmes which recognise the urgent needs of children.

These include:

- accepting the 1990 World Summit of Children's goals for survival, protection and development.

- ratifying the United Nations (UN) Convention on the Rights of the Child in the 1995.

- adopting the "first call for children", reflected in the statement that the needs of children must be paramount throughout the Reconstruction and Development Programme.

85% of the world's children with developmental disability who are under the age of fifteen years, live in developing countries. (Helander, 1993). Most of these children receive little specific health care. The situation is similar in South Africa, where children with chronic disability have been given little priority and health care services have focused mainly on the management of acute illness.

The new Constitution for South Africa states that children have a right to appropriate health care and education and that where problems of development or learning occur, these should be identified with provision of appropriate intervention where possible.

Within this context, developmental disability is a focus of concern which needs to be addressed through appropriate programmes developed at national, provincial and district level (Screening for Developmental Disability: Discussion document 1996). All aspects of child development need to be addressed within the primary health care approach.

2. LITERATURE SURVEY

2.1 THE NEED TO IDENTIFY CHILDREN WITH DISABILITY

A child's early years constitute a unique period for influencing development and supporting families. During the first four years the child has considerable adaptive potential to learn cognitively and socially. Adverse biological and environmental factors may limit learning attainment during this critical period with long term detriment to the child's development.

It is important to identify developmental disability (DD) in children, and if possible the causal factors as early as possible, so that adaptation to overcome or minimise the disability can be facilitated (Donald 1994). The benefits to children and families of early identification are well documented (Guralnick 1997).

2.2 PREVALENCE

The extent of the problem of developmental disability in children is not clearly established in South Africa. A national survey by the Department of Health estimated the prevalence of moderate to severe disability in the overall population to be between 5.7% and 6.1% (Schneider et al 1999). An earlier survey estimated the national prevalence of adults and children to be 12.4% (Department of National Population Development: Consensus 1993).

The global prevalence of DD is in the order of 7-10% of the general population and in developing countries, closer to 10% (WHO, 1982).

There appears to be little difference between these figures and the available national and regional prevalence figures in South Africa.

Reported motor disability rates vary: in rural Kwazulu, 8.6% of the entire population reported motor disability - this was confirmed in 5.2% (McLaren 1987); in rural Gelukspan 13% of the population reported motor disability (Cornielje 1992). The overall reported

disability rate in rural Gazankulu was 4.57% (Concha et al 1993) and in urban Alexandra it was 8.5% (Cornielje et al 1993).

These estimates do not include Learning Disability and Attention Hyperactivity Disorder in the school-going population, which is estimate to be as high as 10-15% in developed countries. Prevalence will also vary according to the definition and severity of disability, the age group, and method of identification.

2.3 INTERVENTION

The question "Is early intervention effective?" will be reviewed.

The most visible component of most early intervention programmes is the provision of information and services to families and children under auspices of a formal early intervention programme or through relationships with individual therapists (Guralnick 1997).

Have these programmes been able to prevent or minimise developmental problems from occurring for children at risk through preventative intervention? For children with established disabilities, have intervention programmes had a positive impact on the child and his/her family?

From a public policy perspective, parents, advocacy groups, professionals and policy makers have pressured for early intervention programmes and consensus is that early intervention does make a difference (Guralnick 1997).

However from a scientific perspective, due to various methodological problems, it has been difficult to establish unequivocally the efficacy of early intervention (Bricker, Bailey & Bruder 1984; Dunst 1986; Guralnick 1988, 1991; Simeonsson, Cooper and Scheiner 1982). Despite these concerns, the results of two meta-analyses (Casto & Mastropieri 1986; Shonkoff & Hauser-Cram, 1987) as well as more traditional reviews of effectiveness (Guralnick & Bennett 1987) support the opinion that early intervention

programmes are indeed effective, producing average effect sizes falling within the range of one half to three quarters of a standard deviation.

Many factors influence the outcome of the intervention, including the type of programme, the nature of the developmental disability (the type, severity and age at time of insult), duration of intervention and the psycho-social factors of the child and family.

There is no doubt that children with hearing, learning and motor impairment with normal cognitive function would not reach their maximum developmental potential without early identification and intervention. The opinion of various authors, that intervention does not improve developmental outcome prevails almost exclusively where all children and families have access to health care and social, financial and educational support. (McCarton et al 1997). Unfortunately in the South African context and especially in under-serviced rural communities, basic human needs remain unmet and the environment so necessary for nurturing children's development is one of deprivation.

Where intervention may have minimal impact on outcome, it is still important to identify the child so that social and emotional support be provided to the family to minimise the extra burden and to facilitate coping of other family members.

Once a child has been identified as being, or possibly being, developmentally disabled, it is essential for facilities to be in place for accurate assessment and intervention. It is therefore important that appropriate resources are developed at local, district and regional levels of care each with appropriate expertise for intervention and support of the child, family and community.

In South Africa with the present severe financial constraints for the development of new public sector services, lack of facilities and human resources is insufficient reason not to address the needs of children with disability. Rather these needs should motivate for provision of services by appropriate development and use of existing resources.

Intervention, no matter how basic and limited due to local constraints, should be provided within the capabilities of the district.

2.4 MONITORING FOR DEVELOPMENTAL DISABILITY

Developmental disability can be monitored by screening, surveillance, assessment or a combination of these methods. The method used for detection should be appropriate and available to health care resources.

The ideal health care situation, which facilitates monitoring of development over time, is where a child is followed up by the same health care worker or clinic. This continuity of care allows for detection of developmental problems through the process of surveillance.

Children who are identified as being biomedically or environmentally at risk for DD (e.g. preterm birth, complicated birth, previous meningitis), should be evaluated on an ongoing basis. This entails surveillance which can only be facilitated by a well resourced health care system.

With good surveillance, moderate to severe DD would be identified outside of screening.

However where a lack of resources restricts surveillance, screening would need to be undertaken to identify individuals who are at risk. Screening is aimed to detect disability in apparently healthy children in a primary care setting. Its major purpose is to separate children into high and low risk groups.

2.5 INTERNATIONAL POLICIES FOR MONITORING OF DEVELOPMENTAL DISABILITY

In developed countries, the issue of whether to screen for DD and how to accomplish this goal lacks consensus.

In 1988, the British Joint Working party on Child Health Surveillance emphasised the integration of health supervision which includes developmental monitoring within a comprehensive system of child health care (Dworkin 1989). The group concluded that there is no justification for a formal developmental monitoring programme on a repeated routine basis on pre-school or school aged-children. They emphasised the importance of

developmental history, observations of children and the importance of parents impressions and developmental concerns being addressed at health visits.

The Canadian Task Force on the Periodic Health Examination (1993) recommends the exclusion of the previously used Denver Screening Test from periodic health examinations of pre-school children. They also indicate that there is insufficient evidence to support either the inclusion or exclusion of other screening tests. They advise caution since problems exist with all current assessment tools and state that no interventions have conclusively been proven to be effective. (Feightner 1993).

The American Academy of Paediatrics Committee on Children with Disabilities (1994) recommends that all infants and children should be screened for developmental disabilities and suggest that primary care paediatricians be responsible. They do not make recommendations as to which instrument is useful, but indicate there is a need for the development of new, adequately validated screening tests (American Academy of Pediatrics 1994).

2.6 RATIONALE FOR SCREENING FOR DD IN SOUTH AFRICA

At present there are no national policies for developmental screening although development towards a national process is underway, through the Department of National Health. The Green Paper titled "Integrated National Disability Strategy of the Government of National Unity (GNU)" states that it is the responsibility of the GNU to initiate and plan adequate policies for persons with disabilities at national level, and to facilitate and support action at provincial and local level (Integrated National Disability Strategy 1996). In one province (the Western Cape), a programme of developmental screening will be implemented as policy in 1999.

A programme of action has also been established to address the issue of disability in the country. This focuses on setting up structures at national and provincial levels, establishing guidelines, integrating disability into the PHC approach, capacity building and monitoring (Integrated National Disability Strategy 1996).

Existing coverage for screening for DD in South Africa varies considerably from 90% in the Western Cape and Gauteng to nil in most of the other provinces. Figures were worse in the rural areas (Adnams C, personal communication 1996).

Implementation of a screening programme would provide the opportunity to identify gaps in service delivery and to address the unmet needs of children with disability. The benefits of implementing a screening service in South Africa are clear.

A Consensus Statement on Screening for Developmental Disabilities in the Pre-school Population was produced after a national workshop at the Child Health Unit, University of Cape Town in May 1996. This was developed by national participants involved in childhood development. The statement identified the needs for screening within local constraints and for research to aid formulation of policy and screening tools (Appendix 7).

2.7 SCREENING

2.7.1 General Principles

Several principles should guide the development and implementation of a screening process to ensure that it is effective.

Screening for DD should be done only if linked to appropriate interventions. Failure to do so serves only to increase unmet expectations of families and the community.

Screening should form part of a continuum of management, including development of referral strategies and case management guidelines.

The WHO has made recommendations for criteria that should be met by screening tools (Calman 1994). Considering existing constraints in the health service in South Africa, the Screening Tool Workshop Group devised a set of criteria based on the WHO recommendations, which would be appropriate to South Africa.

This group proposed the following criteria to be met by a screening tool for DD in South Africa (Consensus Statement 1996):

The tool should:

1. be valid, reliable, and able to evaluate for sensitivity, specificity and positive predictive value.
2. be acceptable to the person implementing the test, the family and the person receiving the referrals.
3. be easy to teach, learn and administer.
4. be administered quickly (i.e. less than 5 minutes)
5. be cost effective
6. have clear guidelines for referral
7. be developed within the context in which it is being used.
8. be linguistically and culturally appropriate
9. be statistically reportable and usable
10. place a minimal increase on nurses' workload.

2.7.2 Limitations of screening

Frackenburg et al enumerated common pitfalls in selecting adequate DD screening tests (Frankenburg 1988). These included the following:

1. Lack of quality control: The test result is invalidated because the screen is not administered in the prescribed manner. A related problem is that persons trained to proficiency may later begin to take shortcuts.

2. The assumption that a developmental screening test will identify all individuals who at some time later will manifest developmental problems: The two pertinent facts that are often overlooked include:
   - a child's development changes with time,
   - it may not be possible to assess the intactness of a child's more complex function at an early age.

3. The screening test was developed using non-representative samples to generalise about the use of the test in the general population.

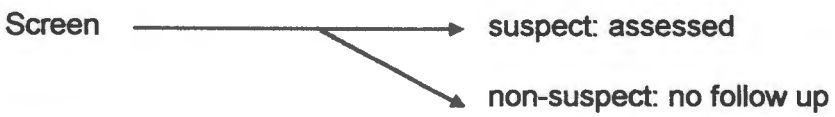
4. Screening tests lack specificity.

2.8 SCREENING MODELS

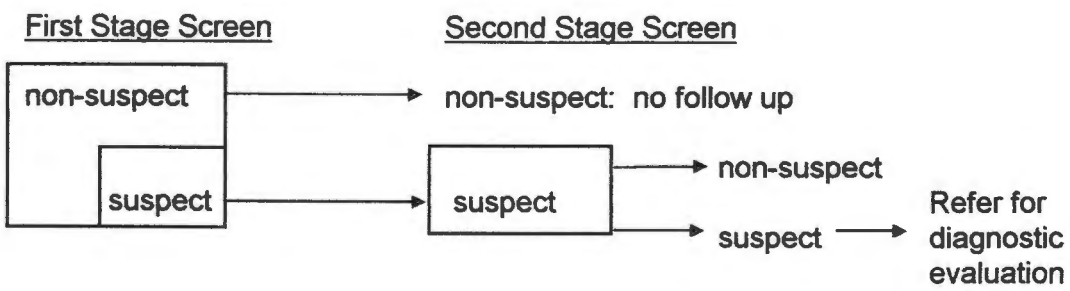
Screening should be conducted with a standardised test which has a known rate of detection if administered correctly (Glascoe, Martin et al 1990).

Various models have been proposed for the sequence of screening: (Frankenburg 1983)

- One stage screening:



- Two stage screening:



Even though the above is a proposal for a 2 stage screening, this could be applicable in the South African district health model:

- First stage screen:

  This would be done at primary level care.

- Second stage screen:

  This could include further screening and/or assessment undertaken at a secondary (regional) level of care by a developmental medical officer / general paediatrician.

Final stage of diagnostic evaluation:

This involves a detailed assessment which could be done at a secondary level (depending on resources) or on referral to a tertiary care level.

A developmental assessment traditionally involves evaluation in four main areas, namely gross motor, fine motor, language and personal/social. The comprehensive assessment of a child includes the above evaluation in addition to physical examination, investigations, diagnosis and management plan.

2.9 THE CONCEPT OF CARE GIVER DESCRIPTIONS

Certain types of clinical information, such as parent's opinions and concerns seem especially predictive of children's development and behavioural status. (Glascoe FP, Dworkin PH 1995). Research has focused on two broad types of clinical information that parents can provide: parent's appraisals, including concerns, estimations and predictions, and parents' descriptions, including recall and report.

2.9.1 PARENTS' APPRAISALS

These are the parents' evaluations and opinions of children's development and behavioural status.

1) Estimations

The ability of parents to estimate their children's developmental age showed moderate to high correlation, ranging from .53 to .93. Further studies of parental estimates of their

child's IQ, showed that estimates had a sensitivity of between 60 to 75%. The specificity in estimating IQ's that fell in the range of normal was consistently 100%.

The clinical applicability of most study findings were questioned for the following reasons:

i) All studies used populations at high risk for DD which may inflate the sensitivity and positive predictive value of estimations.

ii) Differences in wording made it difficult to compare studies.

iii) Parents need prompting and examples to offer age estimates, as parents did not think uniformly in terms of age estimates.

iv) Obtaining estimates across several developmental domains is necessary for identifying children with apparent difficulties.

v) More accurate estimates were given by parents who had higher education.

2) Predictions

Glascoe et al evaluated parents' prediction on how their children will function in the future. He concluded that parents overestimated how their child would function in the future - children with disability would function within the average range, whereas children who were developing normally, would function well above average.

3) Concerns

i) Emotional and Behavioural Concerns

Parents often have concerns about their child's emotional and behavioural status. In a study of children with behavioural and emotional problems, 70% were identified by

parents' concerns. (Glascoe FP, MacLean WE, Stone WL 1991). Mulhern et al evaluated parental concern of children who were referred to a developmental clinic for Attention Deficit Hyperactivity Disorder. 87% of parents identified concerns of symptoms of the syndrome (Mulhern S, Dworkin PH, Bernstein B 1993). This study documented true positives but no results were quoted for false positives as parents often voice concern about their child's behaviour which is within the accepted norm.

ii) Developmental concerns

Generally, parents attending a well baby paediatric clinic voice concerns about their child's mental development (Hickson et al 1983). In a study of 100 0-6 year olds, 20 had undiagnosed developmental problems of which 80% of their parents had developmental concerns. (Glascoe FP, Altemeier WK, Maclean WE 1989). Again there is no reference to the remaining 80 parents who voiced concern when there were no developmental problems on evaluation.

An interesting result from the latter study was that concerns about speech and language, fine motor or global functioning tended to reflect measurable difficulties, whereas concerns in areas of social, self-help and gross motor were not sensitive indicators of developmental problems (once neurological problems had been excluded).

2.9.2 PARENTS' DESCRIPTIONS

These are non-judgmental depiction of children's skills that do not involve appraisal or judgement and include recall and report.

1) Recall

Where parents are asked to recall events related to developmental milestones or child-rearing practices there is a thorough lack of reliability. On this basis, recall is not recommended for developmental screening. (Wenar C 1963, Robbins LC 1982).

2) Report

In contrast to parents' recall, a parent's description of a child's current skills is both reliable and valid.

i) Reliability

Phrasing of the question influenced reliability, and questions that were clearly and carefully written were answered more reliably than those which were vague and lacking in detail. (McGraw et al 1941). An actual qualitative measure would always be more reliable than a parental report.

ii) Validity

The issue of accuracy in parental reports seems clouded by conflicting conclusions. Several studies found that parental reports produced higher estimates of a child's skills in comparison to direct elicitation by a health professional. This may be as a result of a parent reporting on a skill whilst a child is busy acquiring it and demonstrates it inconsistently. The skill may not be reflected during an assessment (Blacher-Dixon et al 1981). This may be circumvented by asking whether the child demonstrates the skill "all of the time, some of the time, or rarely".

2.10 EVALUATION OF SCREENING TOOLS FOR DD

There are numerous instruments which can be used for screening of developmental domains in the areas of cognitive, gross and fine motor, speech and language, adaptive and psycho-social.

A comparative review by Glascoe FP, Martin ED and Humphrey S (1990) evaluated Screening Tests named in one of several texts on developmental screening (Appendix 8).

These tests were rated on the following dimensions:

i) developmental domains evaluated
ii) measurement methods: eliciting behaviour, observational methods or interviewing parents.
iii) test standardisation including reliability and validity, sensitivity (excellent if greater than 80%), specificity (good if > 90%).
iv) types of scores produced e.g. age equivalent, pass/fail etc.
v) examiner qualifications and training needs.
vi) miscellaneous factors e.g. non-sexist, quality of test stimuli.
vii) if pre-screening was an option.
viii) time and age data.

The screening tests compared by Glascoe were considered in the context of the following criteria that need to be fulfilled for use in the South Africa:

- Test takes <10 minutes to administer
- Age range needs to be applicable for < 2 years.
- Meet the criteria of valid and reliable
- Easy to learn and administer

Excluding the time criterion, half of the 19 tests rated by Glascoe et al would be unfavourable in the South African context. Taking time limit into consideration, only 2 tests would meet the South African screening criteria. These are discussed below.

2.10.1. The Infant Monitoring System (IMS)

This test uses parental reporting exclusively.
Five subtests assess communication, gross and fine motor, adaptive, and personal-social function at ages 4, 8, 12, 16, 20, 24, 30 and 36 months.
Parents complete the form according to specific behavioural skills of their child. This implies a need to be literate unless administered by a third person.
Administration and scoring takes less than 10 minutes.
The standardisation is good with high rates of sensitivity and specificity.

2.10.2. Denver Pre-screening Developmental Questionnaire (PDQ)

The PDQ uses a history/interview format.
It provides quick pre-screening of children between the ages of 2 weeks to 6 years.
The test takes 10 minutes to complete.
The test generates a single pass/fail/retest score.
Failing the PDQ, the full Denver Developmental Screening Test revised (DDST) needs to be administered which takes a further 20 minutes.
The standardisation sample is poorly described and sensitivity and specificity data may be artificially high as the test compares itself with the DDST. The detection rate is also low.

The PDQ was validated against the DDST for the age span of 3 months to 6 years. In 1155 cases parental responses agreed 93.3% with the DDST checklist. First stage screening revealed 31.2% suspected DD who required a second stage screen. (Frankenberg et al 1976)

2.10.3. The "Ten Question" Screen

The Ten Questions Screen (TQS) was designed to provide a rapid and cross-culturally useful tool for detecting several types of disability in two to nine year old children in communities where resources are scarce and formal services for disabled children may be unavailable. (Zaman et al 1990) (Appendix 6).

The questionnaire was used initially in Bangladesh and then extended for use in Jamaica and Pakistan.

The types of disability addressed were blindness, deafness, mental retardation, speech problems, epilepsy and movement disorders. No comment was made on how the questions were phrased apart from that they were direct questions concerning the child's development, abilities and general level of functioning. A result for the screen was positive if one or more response by a parent was reported as "yes".

In the initial survey in Dhaka, 2576 children were screened using the TQS. All children who screened positive and a random sample of those who screened negative were clinically assessed. The assessment included a medical history, observation of function, physical examination, neurological examination, testing of vision and hearing and a psychological evaluation of cognitive abilities and adaptive behaviour.

The outcome was that the TQS was sensitive for serious disabilities but that most children who screened positive were not seriously disabled. The authors concluded that it cannot function on its own as a case finding tool for epidemiological studies of serious disability or as a basis for referring seriously disabled children to rehabilitation services. However, it does function well as a screening tool for those who screen positive to be referred for definitive evaluation.

Analysis of the TQS revealed a sensitivity for serious disability of 100%, specificity of 95%, positive predictive value of 22%, negative predictive value of 100% and prevalence of 1,6%. If the case definition is expanded to include milder conditions of disability, the sensitivity drops to 31% with the positive predictive value doubling to 41%.

There was evidence of no significant age or gender bias for DD.

Of the TQS questions, hearing problems and unclear speech were the most commonly reported problems, whereas comprehension and learning problems were the least common. There was no evaluation of specific questions related to specific fields of disability but that the TQS was not found to be a useful tool for identifying the field of disability involved.

Further studies showed that the TQS was reliable, (but not with individual items with low prevalence) and was comparable cross culturally. (Durkin et al 1995) The reliability is the degree to which a measurement produces systemic variation.

Five methods were used to assess the original evaluation of the TQS.

The first two look at the screen as a single, global measure:

- test-retest agreement between overall screening results obtained on two occasions.
- evaluation of the internal consistency of the ten disability questions (items).

The remaining three involve analysis of the individual items:

- test-retest reliability.
- factor scores from a factor analysis.
- analysis of the item response process.

2.10.4. The "Susan Swart" Screening Tool for Detection of Hearing Loss

Ms Susan Swart, a speech therapist and audiologist working in Gauteng, developed a parental questionnaire which focused on hearing loss but included questions which detect other developmental disabilities.

The questionnaire was developed using the TQS as a guideline. (Swart, S. personal communication 1996). It is administered by nurses to parents of children presenting for their 14 week, 9 and 18 month immunisation. The Questionnaire has not been validated nor is there information available on sensitivity, specificity or cultural appropriateness.

A parent/caretaker questionnaire is a cost- and time-effective, appropriate screening tool. It should form the basis of the essential package of DD screening services for children. (Consensus Statement: Workshop on Screening for DD in the pre-school population 1996) However, if a questionnaire cannot be administered, a "hands on" or "observation" tool should be available for alternative use.

- In South Africa there is a need for questionnaires for parents and caregivers to be evaluated to assess if they are effective screening tools for detection of developmental disability in children.

3. HYPOTHESIS, AIMS AND OBJECTIVES

3.1 HYPOTHESIS

Questioning of parents or caregivers on their children's development at nine months of age is an effective method of screening for developmental disability.

3.2 AIM

3.2.1 To develop a questionnaire to be used as a screening tool for developmental disabilities in children who present for their 9 month immunisation.

3.2.2 To validate the questionnaire.

3.3 OBJECTIVES

3.3.1 To assess if the questionnaire identifies children with the following disabilities or impairments:

i) hearing
ii) vision
iii) speech
iv) motor disability
v) global developmental disability

3.3.2 To determine the sensitivity and specificity of the questionnaire and the individual questions.

3.3.3 To evaluate the structure of the questions.

3.3.4 To make recommendations for implementing a screening tool for the identification of 9 month old children with developmental disabilities.

3.4 DEFINITIONS

Development:

A progressive series of orderly coherent changes in skills and abilities, which can either involve structural differentiation or behaviour. Psychomotor development focuses on emerging motor, cognitive and social skills in infants and young children.

Screening Tool:

A method for detecting a described condition (here developmental disability) amongst a normal population. Its major purpose is to separate the population into high and low risk groups.

9 month old:

A child whose chronological age is between 37 and 44 weeks from date of birth.

Term pregnancy:

A baby born between 37 and 41 weeks gestation.
In calculating corrected age for the preterm infant, term was defined as 38 weeks gestation.

Corrected age:

The age of a child as calculated from her chronological age in weeks minus the number of weeks preterm if gestational age is known.

Definitions of impairment and disability:

There is a wide variety of terms concerning children with developmental problems, and a lack of clarity and agreement about their use in the field. Various authors have looked at these definitions from an individual or community perspective. There is now wide support for acceptance of definitions agreed to by disabled people's organisations. Impairment is considered an individual limitation whereas disability is 'the disadvantage or restriction of activity caused by contemporary social organisation which takes little or no account of

the people who have impairments and thus excludes them from participation in the mainstream of social activities'. (UPIAS 1976, Fincklestein 1993)

A child who has achieved developmental milestones less than that expected at his or her chronological age may also be termed developmentally delayed. Children with developmental disability will as a rule be delayed. However, children with delay will not necessarily be permanently disabled as the term delay implies that there can be catch up of development. To be consistent, only the terms impairment and disability are used in the study.

For the purposes of this study, the following World Health Organisation definitions are used : (WHO 1980)

Impairment :

Any loss or abnormality of psychological, physiological, or anatomical structure or function.

Developmental disability:

Failure of a function or skill or an inability to perform a function within the normal range for children of that age.

Developmental Quotient (DQ):

This is a figure derived by the division of the developmental age (numerator) by the chronological age (denominator).

Degrees of developmental disability (DD):

- Mild: DD in a field (or globally) with a DQ of between 50 - 75.
- Moderate: DD where the DQ is between 35 - 49.
- Severe: DD where the DQ is between 20 - 34.
- Profound: DD where the DQ is between 0 - 19.

Visual impairment:

Failure to follow a bright object held at 40 cm from the face through an arc of 180^0.

The assessment could not evaluate degree of visual disability.

Hearing impairment:

Failure to turn towards the sound of a rattle held at the level of the ears 50 cm away and at an angle of 45^0 behind the head. This was tested on both sides.

The child either passed or failed the test.

"At risk" for motor disability:

Those children who achieved the appropriate motor milestones for chronological age, but on neuro-developmental assessment had deviant signs for age.

Screening:

The presumptive identification of unrecognised disease or defect by the application of tests, examinations or other procedures which can be applied rapidly. It differentiates between those who probably do have the disease from those who probably do not. A screening test is not diagnostic.

Surveillance

The detection of deviations from the normal by means of screening, case finding and ongoing vigilance of an individual. (Kibel et al 1995)

Assessment

The evaluation of an individual to either confirm or refute an abnormality. In practice, this may involve a diagnosis, aetiology and plan for intervention.

Sensitivity and specificity:

Sensitivity is a measure of the ability to identify all positive cases, while *specificity* refers to the validity that only positive cases be included.

Predictive value:

Positive predictive value refers to the ability of the test to correctly identify true positives, while the *negative predictive value* refers to the proportion of screened negative cases which are truly negative.

These values are calculated as below:

	ASSESSMENT	
QUESTION	A (true positive)	B (false positive)
	C (false negative)	D (true negative)

Sensitivity: $\frac{\text{true positive}}{\text{true positive + false negative}}$

Specificity: $\frac{\text{true negative}}{\text{true negative + false positive}}$

Positive predictive value: $\frac{\text{true positive}}{\text{true positive + false positive}}$

Negative predictive value: $\frac{\text{true negative}}{\text{true negative + false negative}}$

4. METHODOLOGY

4.1 PHASE I: Developing the Nine Month Screening Questionnaire (NMSQ).

The "10 Questions" used by the "Rapid Epidemiological Assessment of Childhood Disability" study (Khan et al 1995) was used as a basis for development of the NMSQ. Within this framework, the questions of the NMSQ were developed in consultation with Speech Therapists and Paediatricians working in the field of Development.

(Appendix 1)

The questions were grouped into the following areas of development:

- Speech and hearing (questions 1-2)
- Gross and Fine Motor (questions 3-6)
- Vision (questions 7-8)
- Personal / Social (questions 9-10)

The questions focused on developmental indicators which should be achieved by an infant of 9 months in the gross and fine motor, and language fields. Direct questions were asked with regards to vision and hearing function to assess if the parent/caregiver had any concerns in those areas.

The questions were phrased in a manner so that an answer of "Yes" would imply that there was no disability or impairment. An answer of "No" would denote a concern by the parent and a need to evaluate the child further.

The more direct the question was in assessing a developmental area, the better the question and less chance of it being misunderstood. Where there was a possibility of a question being misunderstood, further standardised elaboration was added to ensure clarity.

The questions were developed in English and translated into Afrikaans and Xhosa. These questions were then translated back into English to ensure no discrepancies and where there was lack of clarity, the original English question was altered to ensure that each question could be translated backwards and forwards with no content change.

(Appendices 2-3)

The questions were then pretested amongst a group of parents who had 9 month old children to ensure that all questions were understood in each of the three language groups.

On choosing an appropriate sample size for the study, calculated on an estimated frequency of 5% of positive cases and a 95% confidence interval, revealed a figure of 1821. This number of children to be assessed was not feasible in the time available. The final sample size was therefore one of convenience until the number was large enough to effectively test the Questionnaire. The final sample population size was 235 children with the study period been September 1996 to January 1997.

4.2 PHASE II: Testing of the Questionnaire

4.2.1 Administration of the Nine Month Screening Questionnaire:

The questionnaire was administered to parents or regular caregivers of children between the ages of 37 - 44 weeks presenting for their 9 month immunisation which represented the study population. This was further expanded to 9 month old children attending "High Risk Clinics" (See 4.3).

Site B Community Health Centre (CHC) in Khayelitsha and Eastridge CHC in Mitchells Plain have the busiest "under 6" clinics in the Cape Metropole area and were used for the testing of the questionnaire. All children who presented at the clinic on routine immunisation days were included in the study. Each clinic was visited once a week during the months of October to November 1996 and in January 1997.

Two research assistants (one Xhosa speaking and the other Afrikaans speaking) were trained in administering the NMSQ. Both research assistants were from the local community and were not medically trained but had been caring for children who were disabled. They interviewed the parents or regular caregivers of children presenting for their 9 month immunisation and recorded their response on the questionnaire. The responses to the questions were graded as "Yes", "No" or "Unsure" if the parent was still unable to give an answer after further elaboration.

4.2.2 Assessment of the child

Each child then underwent a developmental assessment done by the author, a senior registrar in developmental paediatrics. This assessment tested the following:

- If the child:
  - followed a bright object through 180^0 arc.
  - orientated to a rattle bilaterally.
- Gross motor milestones (maximum level achieved was recorded)
- Fine motor milestones (" " " " ")
- Language (expressive) (" " " " ")
- Personal /Social milestones

(Appendix 4)

The fine and gross motor, language and personal/social scales were chosen from the Griffiths Mental Developmental Scales and have been previously validated. (Allan et al 1988).

Each child then underwent a Neurodevelopmental Assessment (NDA) to assess tone, motor development and primitive and protective reflexes. The results were recorded noting if any of these areas were deviant for a 9 month old infant. This assessment was also performed by the author. (Appendix 5).

4.2.3 Other information

Other information was collected from the clinic card, from the history or on examination.

- Birth weight, head circumference, gestational age and immunisation.
- Perinatal problems.
- Present weight and head circumference.
- History of any chronic illness.
- Signs of dysmorphic features on examination.

4.3 PHASE III: Expansion of the target group to include "High Risk Infants".

As initial analysis revealed that children attending the well baby clinics passed the NMSQ and had normal neurodevelopmental assessments, the questionnaire needed to be evaluated on a sufficient number of children who had possible developmental problems.

Infants who are at risk for developmental problems, identified by complicated perinatal history or by health care workers in the Health Services, are referred to various Provincial Administration of the Western Cape (PAWC) Clinics. These clinics include the Neonatal High Risk Clinics (NHRC) attached to the Midwife Obstetric Units, Neonatal Units at the maternity hospitals, and the Cerebral Palsy and Developmental Clinics at Red Cross War Memorial Children's Hospital. The author attended these clinics and did most of the assessments except for a small number at the NHRC. These clinics are staffed by paediatricians who used the identical assessments to identify any problems of development.

4.4 PHASE IV: Analysis of the data.

The data was collated and analysed using EPI info version 6.0.

A data sheet for capturing the assessment of each infant was devised to ensure that all developmental aspects were recorded and graded if problems had been identified.

Recording of the assessments was done blinded to the response to the NMSQ in order to ensure that the answers did not influence the analysis of the assessment.

For the appraisal of the assessment, gross and fine motor were evaluated separately, but analysed together as motor delay. As personal/social did not contribute separately to the overall evaluation due to overlap with motor function, it was not included in analysis of the questionnaire.

Dr Colleen Adnams reviewed all the assessment evaluations independently to ensure unbiased interpretation, and corrected any discrepancies.

The sensitivity, specificity, positive and negative predictive values of the NMSQ were calculated to validate the questionnaire. These were the major outcome measures.

4.5 CONSENT

Approval was granted from the Ethics Committee of the University of Cape Town Medical School to undertake this study.

Permission was obtained from the City Health Department, City of Cape Town to conduct the study at the Eastridge Clinic and from the Directorate of Health Services of the Cape Metropolitan Council for the study at Site B Clinic, Khayelitsha.

Prior to participation, all parents were informed verbally of the screening questionnaire and assessment and verbal consent was obtained.

4.6 BUDGET

All financial support was obtained from the Health Systems Trust. A statement of expenditure will be submitted on completion of the study.

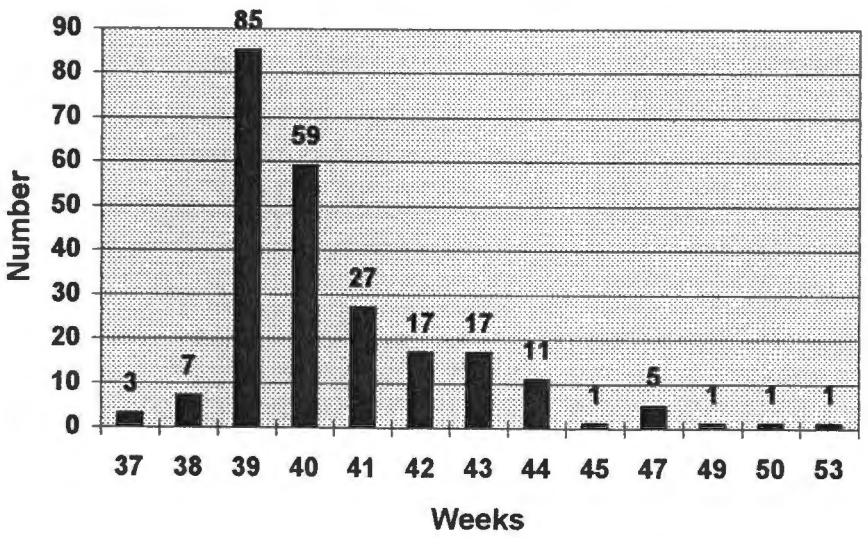
5. RESULTS

235 9 month old infants were screened and underwent neurodevelopmental assessments between the period October 1996 to January 1997.

5.1 AGE OF INFANTS

The age distribution is depicted in figure 5.1.

AGE DISTRIBUTION
Fig 5.1 (n=235)



5.2 AGE OF SUBGROUPS

The infants studied were divided into 3 subgroups according to chronological age. In the preterm subgroup (see 5.2.3), identified infants had a corrected age of less than 9 months at the time of the study. These infants may fail a 9 month screen in spite of having "normal development" for corrected age as catch up to the chronological developmental age may take up to two years.

5.2.1 Term:

207 term infants were between the ages of 37 and 44 weeks. Infants whose gestational age was not documented on the Road to Health Card were considered to be term and were included in this group (88% of total).

5.2.2 Preterm (9 months on corrected age):

9 preterm infants were older than 44 weeks on chronological age but were between 37 and 44 weeks on corrected age (i.e. more than 9 months old at the time of the study) (4% of total).

5.2.3 Preterm (9 months on chronological age):

19 preterm infants were between 37 and 44 weeks chronological age but less than 37 weeks on corrected age (i.e. 9 months old at the time of the study) (8% of total).

Table 5.1 Distribution of age subgroups

AGE DISTRIBUTION	NUMBER	PERCENT
Term	207	88%
Preterm (9 months corrected age)	9	4%
Preterm (9 months chronological age)	19	8%
TOTAL	235	

5.3 GENDER

There was an equal distribution of boys and girls in the sample group. See table 5.2.

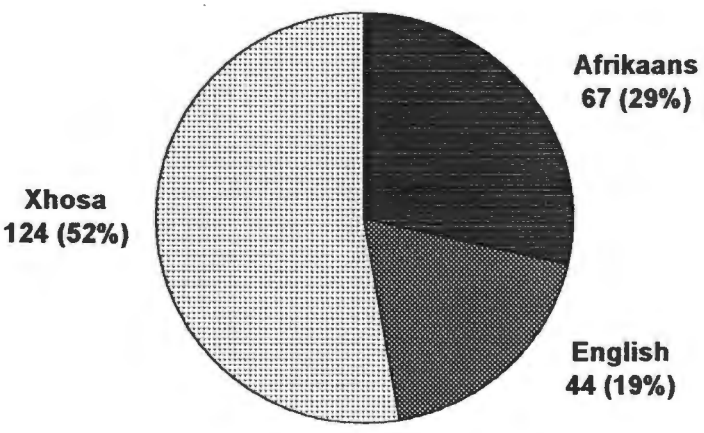
Table 5.2 Gender distribution

GENDER	Frequency	Percent
male	115	48.9%
female	120	51.1%
TOTAL	235	100 %

5.4 LANGUAGE

The questionnaire was administered in Xhosa in half of the cases (52.8%) reflecting those children seen at the busy Site B Clinic. Afrikaans comprised a further 28.5% of the interviews and was the language of the majority of caregivers and parents at the Eastridge Clinic. 18.7% of the interviews were conducted in English. See fig. 5.2. These figures do not reflect the demographic language distribution in the Western Cape.

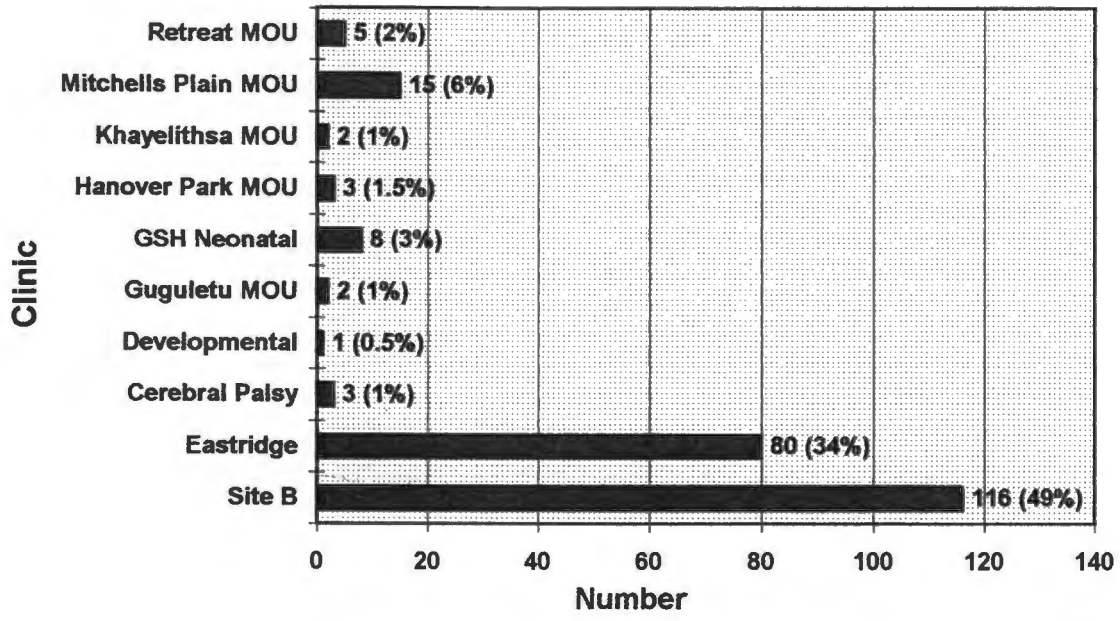
LANGUAGE DISTRIBUTION
Fig 5.2 (n=235)



5.5 CLINICS

Of the 235 infants who were assessed, 196 (83%) were seen at the routine 9 month immunisation clinics of Eastridge and Site B Clinics. 39 (17 %) were seen at the High Risk Neonatal follow up clinics at Groote Schuur Hospital (GSH) or the Midwife Obstetric Units (MOU'S) and at specialist developmental clinics at Red Cross Children's Hospital. See figure 5.3.

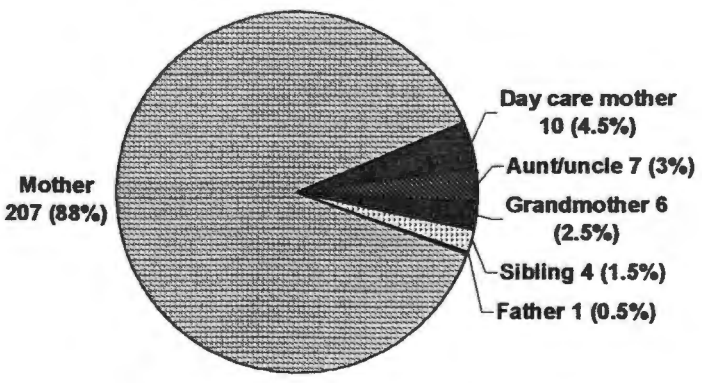
NUMBER OF INFANTS PER CLINIC
Fig 5.3 (n=235)



5.6 INFORMANT

The majority of the interviews (88.1%) were conducted with the infants' mothers. Where the child was in the care of another family member or day-care mother, all had been caring for the child for at least 1 month and therefore were familiar with the activities of the infant. The relationship of the informants to the infants is described in figure 5.4.

INFORMANT
Fig 5.4 (n=235)

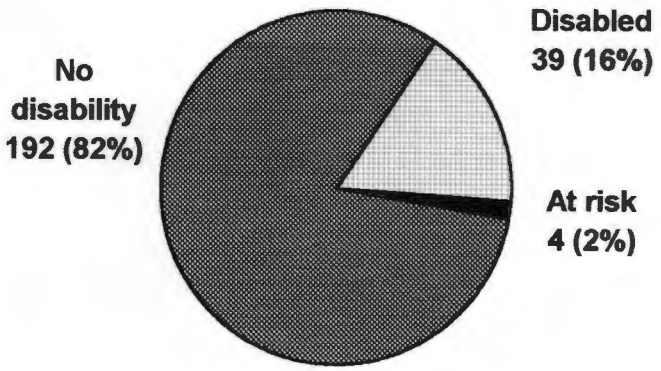


5.7 DEVELOPMENTAL DISABILITY ON CLINICAL ASSESSMENT

5.7.1. DEVELOPMENTAL DISABILITY/IMPAIRMENT

39 Infants (16 %) were assessed to have DD and a further 4 (2%) were assessed to be at risk for motor disability. These were infants who had achieved their milestones but on neurodevelopmental assessment had subtle signs of increased tone. They required further follow up.

FREQUENCY OF DISABILITY
Fig 5.5 (n=235)



5.7.2 DEVELOPMENTAL DISABILITY BY AGE SUBGROUPS

In the "Term infant" group, 207 infants, 30 (14%) were assessed to have DD with 2 (1%) assessed to be at risk for motor disability. (19 of the 207 infants were seen at the High Risk Clinics.)

In the "Preterm: 9 months corrected age" group, none of the 9 infants was identified to have DD. (8 out of the 9 infants had been seen at the High Risk Clinics.)

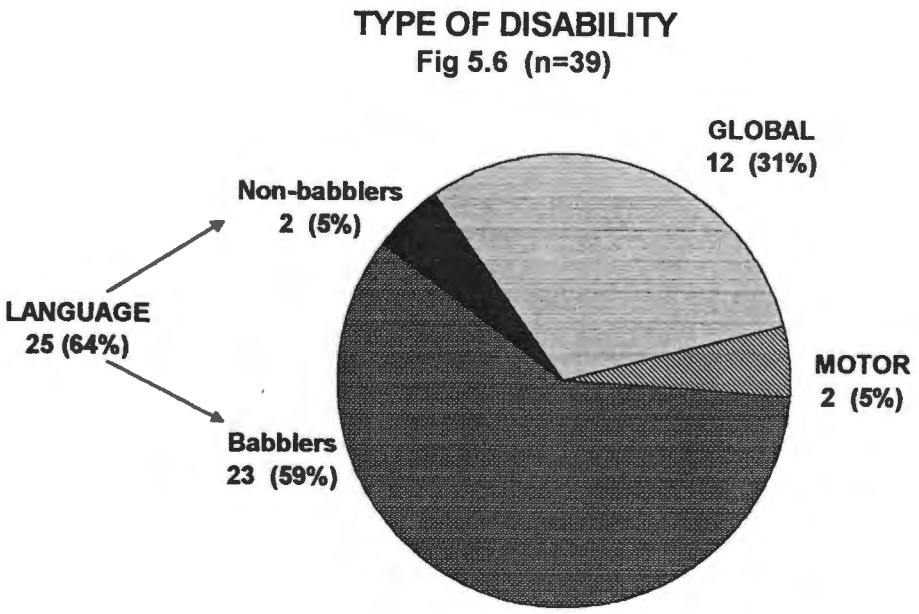
In the "Preterm: 9 months chronological age" group, of the 19 infants, 8 (42%) had no DD, 9 (47%) had DD and 2 (11%) were at risk and required further follow up. (12 out of the 19 infants had been seen at the High Risk Clinics.) See table 5.3.

Table 5.3 Developmental disability according to age subgroups

	Term	Preterm: 9mth chronological	Preterm: 9mth corrected
No disability	175 (85%)	9	8 (42%)
Disability	30 (14%)	0	9 (47%)
At risk	2 (1%)	0	2 (11%)
TOTAL	207 (88%)	9 (4%)	19 (8%)

5.7.3 TYPE OF DISABILITY/IMPAIRMENT

The type of disability detected on assessment is summarised in figure 5.6.



Language impairment constituted 64.1% of total DD on assessment. Of the 25 infants who had language impairment only, 23 were babbling and not vocalising "mama", "dada", or "baba" as per questionnaire. The remaining 2 infants had not reached the babbling stage. Thus infants who babbled and who were otherwise developmentally normal, constituted 59% of the infants with DD.

5.7.4 TYPE OF DISABILITY ACCORDING TO AGE SUBGROUPS

Table 5.4 shows the type of disability according to age subgroups.

Table 5.4 Type of disability according to age subgroups

	Term	Preterm 9 mth chronological	Preterm 9 mth corrected
Language only	21 (70%)	-	4 (44%)
Motor only	1 (3%)	-	1 (11%)
Global	8 (27%)	-	4 (44%)
TOTAL	30	0	9

(n=39)

5.7.5 DEVELOPMENTAL DISABILITY ACCORDING TO ATTENDANCE AT ROUTINE OR HIGH RISK CLINICS

Table 5.5 analyses DD according to attendance at the Routine Immunisation Clinics and the High Risk Infant Clinics.

Table 5.5 Developmental Disability according to Routine or High Risk Clinic

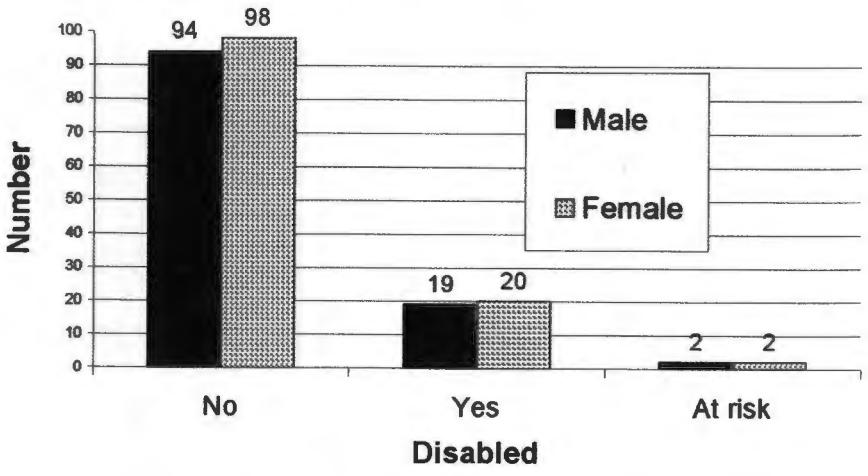
DEVELOP. DISABILITY	Routine Clinic	High Risk Clinic	Total
No	165 (84,2%)	27 (69,2%)	192
Yes	30 (15,3%) (Lang 24/Mot 1/Glob 5)	9 (23,1%) (Lang 1/Mot 1/Glob 7)	39
At risk	1 (0,5%)	3 (7,7%)	4
Total	196	39	235

Key: lang = language, mot = motor, glob = global (n=235)

5.7.6 DEVELOPMENTAL DISABILITY ACCORDING TO GENDER

There was no difference in DD between females and males. See figure 5.7

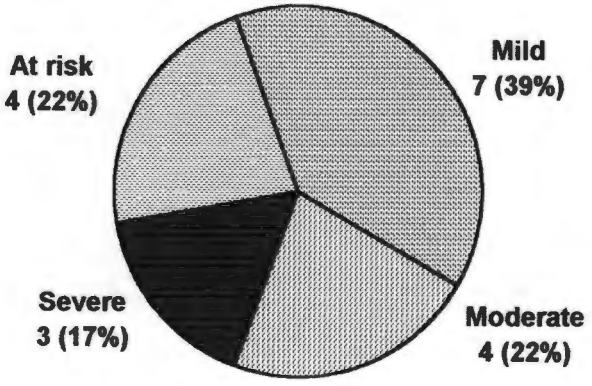
DISABILITY ACCORDING TO GENDER
Fig 5.7 (n=235)



5.7.7 FREQUENCY OF SEVERITY OF MOTOR DISABILITY

The degree of disability was only analysed for motor disability as language impairment was not captured in a format with a developmental quotient. See figure 5.8.

DEGREE OF MOTOR DISABILITY
Fig 5.8 (n=18)



5.7.8 DEVELOPMENTAL DISABILITY ACCORDING TO CLINIC ATTENDED

30 infants out of 196 seen at the Routine Immunisation Clinics at Site B and Eastridge were assessed to have DD (15%) whereas 12 of the 39 children seen at the Developmental or High Risk Clinics were disabled (31%).

5.8 OVERALL RESPONSE TO NINE MONTH SCREENING QUESTIONNAIRE

There were 170 infants whose parent or childminder responded "YES" to all the questions (i.e. no problem identified on history) and who had appropriate development on assessment.

In 64 of the infants, one or more of the questions was answered "NO". 22 of these infants did not have DD on assessment (false positives), 39 were assessed to be disabled (true positives) and 3 were at risk for motor disability.

Except for 1 infant who was considered to be at risk for motor disability, no children with disability were not identified by the questionnaire. See table 5.6.

Table 5.6 Overall response to questions of the NMSQ and assessment for DD.

QUESTION (1-10)	DEVELOPMENTAL DISABILITY			Total
	Yes	At risk	No	
Screen positive: Any "No" (i.e. problem)	39	3	22	64
Screen negative: All "Yes" (no problems)	0	1	170	171
Total	39	4	192	235

(n=235)

Overall sensitivity, specificity and predictive value of the NMSQ

i) Sensitivity: $\frac{42}{42+1}$ = 97.7% (95% CI = 95.8 - 99.6)

ii) Specificity: $\frac{170}{170 + 22}$ = 88,5% (95% CI = 84.4 - 92.6)

iii) Positive Predictive Value: $\frac{42}{42 + 22}$ = 65.6%

iv) Negative Predictive Value: $\frac{170}{170 + 1}$ = 99.4%

5.8.1 RESPONSE TO THE NMSQ ACCORDING TO CLINIC ATTENDED

Questionnaire response was compared to DD in the infants seen at the Routine Immunisation Clinics.

Table 5.7 Routine Clinics: Response to the NMSQ and assessment for DD

	ASSESSMENT			
	Disability	At risk	No disability	Total
Screen positive (answer "No")	30	0	17	47
Screen negative (answer "Yes")	0	1	148	149
Total	30	1	165	196

(n=196)

Sensitivity and specificity of the Questionnaire at the Routine Immunisation Clinics

i) Sensitivity: $\frac{30}{30+1} \times 100 = 96.8\%$ (95% CI = 89.0 - 105)

ii) Specificity: $\frac{148}{148+17} \times 100 = 89.7\%$ (95% CI = 85.4 - 94.0)

The response of the questions was compared to DD in the infants seen at the High Risk Clinics. This analysis was done to see if mothers who attended these clinics could have been "primed" to give the correct answer and therefore influence the sensitivity of the questionnaire.

Table 5.8 High Risk Clinics: Response to the NMSQ and assessment for DD

	ASSESSMENT			
	Disability	At risk	No disability	Total
Screen positive (answer "No")	9	3	5	17
Screen negative (answer "Yes")	0	0	22	22
Total	9	3	27	39

Sensitivity and specificity of the Questionnaire at the High Risk Clinics

i) Sensitivity: $\frac{12}{12+0} \times 100 = 100\ \%$ (95% CI = 96.9 - 103.1)

ii) Specificity: $\frac{22}{22+5} \times 100 = 81.5\%$ (95% CI = 69.3 - 93.7)

5.9 SPEECH AND HEARING

5.9.1 SPEECH

198 parents responded "Yes" to their child vocalising "mama", "dada" or "baba" indicating there was no language impairment (i.e. Question 1).

The assessment for speech impairment involved repeating a detailed question on the infant's language milestones. (Appendix 4 no 14).

34 infants were language impaired according to the questionnaire and the assessment.

A further 3 infants who were evaluated to be language impaired on the assessment, were not identified on the question. See table 5.9.

Table 5.9 Speech: Response to question 1 and language assessment

	LANGUAGE ASSESSMENT		
SPEECH DELAY	Delayed	Normal	Total
Yes (babbles or less)	34	0	34
No ("mama/dada")	3	198	201
Total	37	198	235

Sensitivity and specificity of the Speech Question

i) Sensitivity: $\frac{34}{34+3} = 91.9\%$

ii) Specificity: $\frac{198}{198+0} = 100\%$

5.9.1.1 SPEECH IMPAIRMENT ACCORDING TO AGE SUBGROUPS

In the "Term" group, of the 21 infants who had language impairment only, 20 were babbling and 1 infant was razzing only.

There were no infants with language impairment in the "Preterm 9 month corrected age" group.

In the "Preterm 9 month corrected age" group, of the 4 infants who had language impairment only, 3 infants were babbling only.

Table 5.10 shows language impairment according to age subgroups, and degree of language impairment in each.

Table 5.10 Language impairment according to age subgroups

	Term	Preterm 9 mth Chronological	Preterm 9 mth Corrected
Language only *babblers *other	21 (70%) 20 1	-	4 (44%) 3 1
Global *babblers *other	8 (27%) 5 3	-	4 (44%) 3 1
Motor only	1 (3%)		1 (11%)
Total	30	0	9

5.9.1.2 SPEECH IMPAIRMENT ACCORDING TO GENDER

In the group of infants with language impairment who were babbling only, there was no significant difference between males and females.

Table 5.11 Babbling according to gender

GENDER	BABBLERS	PERCENT
Male	13	57%
Female	10	43%
TOTAL	23	100%

5.9.2 HEARING

229 infants had normal hearing on Question 2 and on assessment.

3 infants had a "'No" answer and therefore a parental concern of impaired hearing. All 3 failed the assessment for hearing.

A further 3 infants whose parents were not concerned about their infants hearing, responded equivocally to the assessment. They will be followed up in 1 month.

Table 5.12 Hearing: Response to question 2 and hearing assessment

ON QUESTIONING	HEARING ASSESSMENT			Total
	Impaired	Equivocal	Normal	
Abnormal	3	0	0	3
Normal	0	3	229	232
Total	3	3	229	235

Sensitivity and specificity of the hearing question

i) Sensitivity: $\frac{3}{3+3} \times 100 = 50\%$

ii) Specificity: $\frac{229}{229+0} \times 100 = 100\%$

5.10 MOTOR

5.10.1 ANALYSIS OF THE MOTOR QUESTIONS

In the analysis of the motor questions, questions 3 - 6 were grouped together as they screened for both gross and fine motor development. If one or more of the answers were "NO" to any of these questions, this was recorded as a concern by the parent for motor problems.

203 infants had no problems identified on the motor questions or on motor assessment.

13 infants were identified on questioning to have motor disability, which was confirmed on assessment.

In 18 infants one or more of the motor questions were answered "NO" but none of these infants were assessed to have motor disability.

1 infant was not detected on the questionnaire and failed the motor assessment.

This is summarised in table 5.13.

Table 5.13 Motor disability: Analysis of response to motor questions 3-6 and motor assessment

QUESTION (3-6)	MOTOR DISABILITY YES	NO	Total
Screen positive (answers "NO" - problem)	13	18	31
Screen negative (answers "YES": no problem)	1	203	204
Total	14	221	235

Sensitivity, specificity and predictive value of motor questions for motor disability

i) Sensitivity: $\frac{13}{13+1} \times 100 = 92.9\%$ (95% CI = 91.2 - 94.6)

ii) Specificity: $\frac{203}{203+18} \times 100 = 91.4\%$ (95% CI = 89.6 - 93.2)

iii) Positive Predictive Value: $\frac{13}{13+18} \times 100 = 41.9\%$

iv) Negative Predictive Value: $\frac{203}{203+1} \times 100 = 99.5\%$

5.10.2 ANALYSIS OF MOTOR QUESTIONS 3 - 6

A total of 31 infants failed either one or more of the motor screening questions and/or the motor assessment.

Table 5.14 analyses the response to each of the motor questions and correlates each one with motor DD on assessment. Figures in bold italic indicate where the question confirmed either lack of a problem or identified that motor disability was present. (See Appendix 1 for the motor questions.)

Table 5.14 Correct response of motor questions 3-6 (in bold)

QUESTION	ASSESSMENT	Q 3	Q 4	Q 5	Q 6
YES (no problem)	***NO DISABILITY***	***16***	***12***	***13***	***7***
	Disability	5	11	0	5
NO (problem)	No disability	2	6	5	11
	DISABILITY	***8***	***2***	***13***	***8***

The accuracy of predicting the correct outcome was 84% in Question 5 (i.e. sitting unsupported) and 77% in Question 3 (i.e. using both hands to finger feed). See table 5.15.

Table 5.15 Accuracy of response to motor disability questions

	Q 3	Q 4	Q 5	Q 6
Correct response	24 (77%)	14 (45%)	26 (84%)	15 (48 %)
Incorrect response	7 (23%)	17 (55%)	5 (16%)	16 (52%)
(n = 31)	31	31	31	31

5.10.3 SENSITIVITIES/SPECIFICITIES OF EACH MOTOR QUESTION

The sensitivity and specificity of the motor questions with greater response accuracy (questions 3 and 5) were analysed individually. These results were compared with sensitivity and specificity of questions 3 and 5 in combination.

As these questions and corresponding assessments determined motor disability only, infants who were only language impaired were included with those infants who had no motor disability on assessment.

5.10.4.1 Question 5 (Does your child sit without support?)

Table 5.16 Motor disability: Response to question 5 and motor assessment

QUESTION 5	MOTOR ASSESSMENT		Total
	Disability	No motor disability	
Answer "NO" - problem	15 2 motor, 11 global 2 at risk	3 1 language 2 no disability	18
Answer "YES" - no problem	3 1 global 2 at risk	214 24 language 190 no disability	217
Total	18	217	235

Sensitivity and specificity of motor question 5 (Does your child sit without support?)

i) Sensitivity: $\frac{15}{15 + 3} \times 100 = 83.3\%$

ii) Specificity: $\frac{214}{214 + 3} \times 100 = 98.6\%$

5.10.4.2 Question 3 (Does your baby feed him/herself a piece of bread/biscuit?)

Table 5.17 Motor disability: Response to question 3 and motor assessment

QUESTION 3	MOTOR ASSESSMENT		Total
	Disability	No motor disability	
Answer "NO" – problem	9 1 motor 7 global 1 at risk	1	10
Answer "YES" – no problem	9 1 motor 5 global 3 at risk	216 25 language 191 no disability	225
Total	18	217	235

Sensitivity and specificity of motor question 3. (Does your baby feed him/herself a piece of bread?)

i) Sensitivity: $\frac{9}{9 + 9} \times 100 = 50.0\%$

ii) Specificity: $\frac{216}{216 + 1} \times 100 = 99.5\%$

5.10.4.3 Questions 5 and 3 combined

Table 5.18 Motor disability: Response to questions 3 & 5 and motor assessment

QUESTION 5 & 3	MOTOR ASSESSMENT		Total
	Disability	No motor disability	
One or both answers "NO" - problem	15 2 motor 11 global 2 at risk	4	19
Both answers "YES" - no problem	3 1 global 2 at risk	213 24 lang 189 no disability	216
Total	18	217	235

Sensitivity and specificity of Motor Questions 3 and 5 combined.

i) Sensitivity: $\frac{15}{15+3} \times 100 = 83.3\%$

ii) Specificity: $\frac{213}{213+4} \times 100 = 98.2\%$

5.11 VISION

5.11.1 VISUAL IMPAIRMENT

The analysis of Question 7 which evaluated following a moving object in front of the infant's eyes is shown in table 5.19.

Table 5.19 Vision: Response to question 7 and assessment for visual impairment

FOLLOWS ON QUESTION	VISUAL ASSESSMENT		Total
	Abnormal	Normal	
No	2	1	3
Yes	1	231	232
Total	3	232	235

Sensitivity and specificity of Question 7 (Does your baby follow a moving object?)

i) Sensitivity: $\frac{2}{2+1} \times 100 = 66.7\%$ (95% CI = 62.4 - 71.0)

ii) Specificity: $\frac{231}{231+1} \times 100 = 99.6\%$ (95% CI = 99.2 - 100)

5.11.2 SQUINT

The analysis of question 8 which evaluates the presence of a squint is shown in table 5.20.

Table 5.20 Squint: Response to question 8 and assessment for squint

ON QUESTIONING	SQUINT ON ASSESSMENT		Total
	Yes	No	
Yes	1	2	3
No	2	230	232
Total	3	232	235

Sensitivity and specificity of Question 8. (Do both your baby's eyes move well together?)

i) Sensitivity: $\frac{1}{1+2} \times 100 = 33.3\%$

ii) Specificity: $\frac{230}{230+2} \times 100 = 99.1\%$

5.12 PERSONAL/SOCIAL

Social interaction involves many functions such as seeing, hearing, motor and cognition. Response to questions 9 and 10 were therefore compared to the presence or absence of overall DD. This was analysed further by the developmental field involved.

5.12.1 Question 9: Playing games e.g. peek-a-boo, imitating hand clapping

Table 5.21 Playing games: Response to question 9 and DD on assessment

QUESTION 9	ASSESSMENT		Total
	Disability	No disability	
Answer "NO" – problem	7 2 motor 5 global	4	11
Answer "YES" - no problem	36 25 lang 7 global 4 at risk	188	224
Total	43	192	235

Sensitivity and specificity of Question 9 (Playing games?)

i) Sensitivity: $\frac{7}{7 + 36} \times 100 = 16.3\%$

ii) Specificity: $\frac{188}{188 + 4} \times 100 = 97.9\%$

5.12.2 Question 10: Does your child do the same things of other children of his/her age?

Table 5.22 Comparison with other children: Response to question 10 and DD on assessment

	ASSESSMENT		
QUESTION 10	Disability	No disability	Total
Answer "NO" – problem	14 1 lang, 2 motor, 8 global, 3 at risk	8	22
Answer "UNSURE" - ? problem	3 3 global	4	7
Answer "YES" - No problem	26 24 lang, 1 global, 1 at risk	180	206
Total	43	192	235

Sensitivity and specificity of Question 10. (Does your child do the same things as other children?)

i) Sensitivity: $\frac{17}{17 + 26} \times 100 = 39.5\%$

ii) Specificity: $\frac{206}{206 + 29} \times 100 = 87.7\%$

5.14 SUMMARY OF SENSITIVITY AND SPECIFICITY OF THE QUESTIONNAIRE

Table 5.23 summarises the sensitivity and specificity of the NMSQ overall, each question and motor questions in combination. The predictive values are also given where calculated.

Table 5.23 Summary of sensitivites and specifiicites of the NMSQ

QUESTION	SENSITIVITY	SPECIFICITY	POSITIVE PREDICTIVE VALUE	NEGATIVE PREDICTIVE VALUE
Ques 1-10	97.7%	88.5%	65.6%	99.4%
NMSQ at Routine Clinic	96.8%	89.7%		
NMSQ at High Risk Clinic	100%	81.5%		
Ques 1 Speech	91.9%	100%		
Ques 2 Hearing	50%	100%		
Ques 3-6 Motor	92.9%	91.4%	41.9%	99.5%
Ques 5 "Sitting"	83.3%	98.6%		
Ques 3 "Feeding"	50.0%	99.5%		
Ques 5 & 3	83.3%	98.2%		
Ques 7 Vision	66.7%	99.6%		
Ques 8 Squint	33.3%	99.1%		
Ques 9 "Playing"	16.3%	97.9%		
Ques 10 "Comparing"	39.5%	87.7%		

6. DISCUSSION

6.1 OVERALL USE OF THE 9 MONTH SCREENING QUESTIONNAIRE

Overall analysis of the NMSQ demonstrates that it is a useful tool for screening for developmental disability. The tool had a sensitivity of 97.7%. This is a high value and fits one of the major criteria for a good screening tool. Only 1 infant who was assessed to be at risk for motor disability and who had transient dystonia, was not identified by the questionnaire.

The specificity of the NMSQ was 88.5% reflecting a lower percentage than the sensitivity. Of the 235 infants screened, 64 screened positive on the questionnaire, of whom 22 infants had no DD on assessment (false positives). The remaining 42 infants were assessed to have some area of DD. Thus 22 out of 235 infants (9%) of infants would be referred for further evaluation unnecessarily. Alternatively 22 out of 64 infants (34%) who are referred for assessment will have no DD. This may be of concern as inappropriate referrals may add an extra burden to an already busy health service.

By reviewing the specific concerns elicited with the caregiver at the time of questioning, the number of infants who screen positive infants could be reduced. For example, the child whose parent who is concerned that the child is not sitting, but is doing so during the screen, or the child who does not follow, but does so on observation would be "screened out" and not referred.

The importance of having a tool that rather identifies all those with disability at the risk of including a manageable number of false positives is still a feature of a reasonable screening tool.

An issue of concern was that certain infants who screened positive in a particular field (e.g. vision), had no problems on assessment in that specific field but had a developmental disability in another field (e.g. motor) which was not elicited on the motor questions. In other words the disabled child screened positive but for the incorrect question. That is an inaccuracy but in the overall analysis the questionnaire still identified those children with DD.

6.2 SPECIFIC QUESTIONS

6.2.1 Speech

23 out of the 25 infants who had language impairment were babblers. They all had passed the hearing distraction test thus excluding deafness as a cause for their language delay.

The high prevalence of language delay noted in this study population, may reflect that the norm for this population is below that of the accepted gold standard developmental milestones for language acquisition for 9 month old infants.

According to a study by Capute et al (1987) the graph below (Figure 6.1) shows the range of babbling for the 10-90th centile to be 4,5 to 8,5 months (mean 6,3 months) and the range for dada/mama (indiscriminate) to be 5,5 to 10 months (mean 7,7 months). This study describes a population base from the United States. At present there is no available data on milestones of language development in our local population. Using the criteria from the USA and other developed countries, otherwise normal children in this study but are babbles are classified as language impaired. There is a need for normative language milestones to be developed for South African sub-populations.

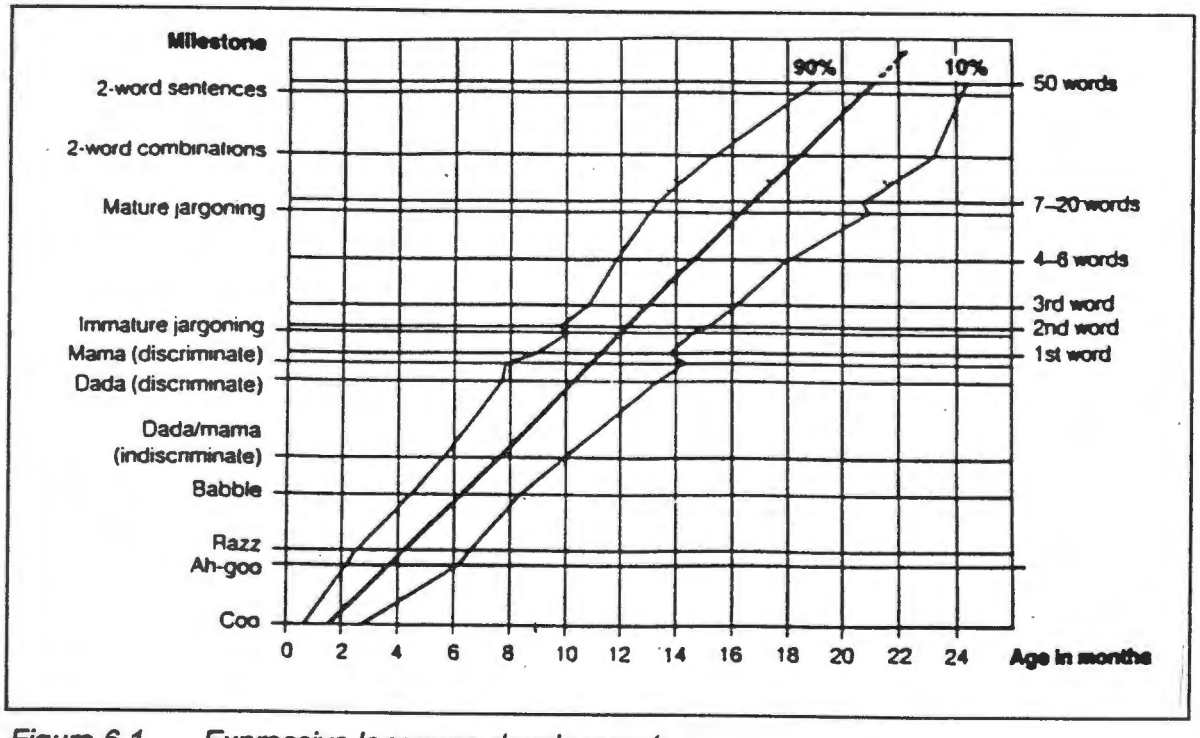


Figure 6.1 Expressive language development
Source: Capute AJ, Palmer FB, Shapiro BK et al

Possible error might have been introduced as a result of the difficulty caregivers had in recalling what sounds their infants made. Therefore the examiner needs to have a clear understanding of language milestones at nine months and of the descriptive terms babbling, razzing, cooing, etc., to ensure accurate assessment.

With regards to the 3 test languages, the words "mama/dada" are used ubiquitously and are therefore applicable to all three language groups. If another word is consistently used to address somebody, e.g. "tata", then that would pass for an appropriate language milestone for a 9 month old infant.

6.2.2 Hearing

The numbers of infants who had hearing impairment either on questioning (0), assessment (3) or both (3) were too small for statistical analysis.

The limitations of screening for hearing impairment have been well described (Robertson et al 1995). Hearing loss may be suspected in a child with lack of response to noise, speech delay, behavioural problems and recurrent ear problems. Only two of these manifestations were assessed in this study questionnaire, namely lack of response to noise (Question 2) and speech delay (Question 1). Robertson et al observed that the sensitivity of questioning may be affected by the fact that parents initially denied their observations of possible hearing impairment. The parents' denial was often compounded by false reassurance by health professionals.

The reliability of the Rattle Distraction Test has been questioned (Haggard 1990). Two testers are required in an environment with a noise level less than 30dB for an appropriate testing environment, a situation rarely obtainable in busy children's clinics. In support of these described limitations, the author generally found infants to be easily distracted by visual stimuli and therefore obtained inconsistent responses to the rattle.

Question 2 asks: "Does the child turn towards you when calling his/her name?" This question elicits a descriptive response from the parents which is more objective than asking an open ended question like "Does your child hear?". The latter question may be influenced by parental denial.

Screening for hearing impairment could easily and rapidly be undertaken by a questionnaire. Repeat questioning for hearing impairment at the 18 month screen and also screening children who are at risk for hearing impairment (e.g. recurrent ear infections, post meningitis, delayed speech development), should minimise those with hearing impairment who are not identified.

6.2.3 Motor Questions

One infant with motor disability was not identified by the motor questions. The infant's mother was initially unsure how to answer the question as her infant sat with support for short periods only. This infant also screened positive for language delay and thus was still identified by the questionnaire as having DD. On further evaluation, she was 8 weeks preterm and on neuro-developmental assessment, her development was appropriate once her age had been corrected for prematurity.

In a review by Allen et al (1997) several motor milestones were superior in predicting cerebral palsy in a high risk preterm population: sitting alone, crawling, cruising and sitting with arm support. This is followed by rolling. Later, walking is highly predictive of cerebral palsy. This milestone is achieved too late in normal children to be used to screen for cerebral palsy or other motor DD in the 9 month old infant.

Sitting unsupported is defined as sitting without using the arms for balance and being able to use the arms for play for at least one minute. The range of onset for this milestone is quoted from various studies:

Capute et al (1985): black females: 5.8 +- 1.2 months (1 standard deviation)
white males: 6.5 +- 1.2 months
overall range: 4.6 to 7.7 months

Lingam et al (1988): range: 5 - 8 months (25 - 90% of children)

Question 5, which asked about sitting, was the most sensitive question and correctly predicted the presence or absence of motor delay in 84% of cases. This supports the finding by Allen et al that sitting is a good indicator in screening for motor DD.

The reliability of using motor milestones for detection of DD is improved further if the infant's attainment of these milestones is observed in a sequential nature. Sequential observation pertains more to a system of surveillance and would not be applicable for use in a screening system.

In the study of preterm infants by Allen, infants who developed cerebral palsy, but did not demonstrate early delay of motor milestones, had mild cerebral palsy - generally hemiplegia or spastic diplegia. For this reason, questioning about abnormal quality of movement (e.g. using only one hand, dragging one leg when crawling) needs to be evaluated as an indicator of cerebral palsy. Question 3, which asks about non simultaneous finger feeding using both hands addresses this issue. This question also predicted a correct outcome in 77% of cases where there was a concern of motor DD on questioning or assessment.

Question 4, which enquires about asymmetrical arm or leg movements was only predictive of a correct answer for motor disability in 45%. Ideally this question should be evaluated on infants who have hemiparesis. Unfortunately in this study there were no infants with hemiplegia.

Question 6 assesses for either spasticity or hypotonia but unfortunately could not be phrased as a direct question about stiffness or weakness as a negative screen answer would be "No". The elaboration in parenthesis clarifies the question. The assessment confirmed a correct response to Question 6 in 48% of infants with motor DD. Respondents were occasionally concerned with weakness when their child was standing against objects ("the child would wobble and collapse"). Although the caregiver interpreted this as weakness, this is the beginning of cruising and is still appropriate development for age.

6.2.4 Vision

The number of infants with visual impairment was too small for meaningful statistical analysis. One mother was concerned that her infant was not following; one infant whose caregiver was not concerned, did not follow on assessment and in two infants visual impairment on questioning was confirmed on assessment.

Concern should be raised when the respondent replies that the infant only sees objects if held close by.

6.2.5 Squint

The number of infants with a squint was too small to evaluate Question 8.

One infant with albinism had nystagmus. The caregiver did not regard the infant's nystagmus as "eyes not moving together" but the infant failed question 7 due to poor visual acuity.

6.2.6 Personal/Social

Social interaction involves many areas of development which include seeing, hearing and cognitive function. The sensitivity and specificity of Questions 9 and 10 were determined individually for the presence or absence of DD. The field of DD was further determined for each positive and negative answer in both questions.

Question 9 had a low sensitivity (16.3%) and high specificity (97.9%) for screening for DD. Only half of the infants with motor delay were identified by this question whereas none of the infants with language impairment only were identified.

A point of concern is that a number of mothers had never played games with their child and therefore answered "NO" to this question. The lack of game playing would have negative implications for a child's personal, social and emotional development.

The sensitivity for Question 10 was 39.5% and the specificity 87.7%. In the group with language impairment only in Question 10, the caregivers did not report from their observations that their child's language development was different from other children.

Question 9 and question 10 identified 39% and 72% of infants with motor DD respectively.

A number of mothers were unable to answer question 10 as the infant was their first child or they had not observed other infants for comparison. This question may be more sensitive in screening the older child.

Of interest was that mothers of preterm infants with no DD, often answered "NO" as age correction for prematurity had not been taken into consideration in Question 10.

6.3 THE QUESTIONNAIRE

6.3.1 Structure of the questions

Various factors in the structure and administration of the questions are important to consider for future development of screening questionnaires.

The more direct the question the easier it was understood. Also the shorter the question the better (short and to the point).

Open ended questions are at risk of also been misinterpreted: e.g. "Does your child hear?". Instead the skill should be elicited by a description of the child's function in the area assessed. For example hearing, the question could be asked: "Does your child turn towards sound?".

If a specific word is used in the language in which the tool is administered to describe a milestone or behavioural activity, it should be used to enhance comprehension of the question.

6.3.2 Administering the NMSQ:

Valuable information other than that derived from the caregiver can be obtained from observation of the infant and caregiver during the screening process. This includes the interaction between mother and child, the physical appearance and motor and social activities of the infant.

The question should be asked exactly as worded in the questionnaire. The author's observation was that in the pilot phase of the study, during the training of the research assistants in administering the questions, they frequently elaborated on the question using their own interpretation. The incorrect interpretation of the question by the administrator resulted in the answer been unrelated to the actual screening question.

This problem would need to be addressed with adequate training.

Administering the questionnaire takes on average 2 minutes. The time taken is slightly longer when any questions needed to be clarified. As other screening tools take much longer (Appendix 8), the short time involved in administering this questionnaire is extremely advantageous.

6.4 THE ASSESSMENT

The developmental examination assessed locomotor, speech and hearing, and personal/ social function (Appendix 4). Except for hearing, indicators used in the assessment were taken from the Griffiths Mental Developmental Scales. The Griffiths Scales were developed in Great Britain for use with children 0-8 years of age. These scales were developed by observing children in their natural environments while engaged in their natural activities. This is one of the most widely researched tests available in the English language for the assessments of infants and young children today. (Allan, Luiz, Foxcroft 1988).

The Griffiths Scales were introduced in South Africa in 1977 mainly as a response to the need for an adequate assessment instrument for pre-school children. (Heimes 1983).

Developmentalists have suggested that development of different types of play and unfolding of language acquisition is a universal phenomenon and emerge in a regular fixed order in different cultures (Kagan 1991). The usefulness of the Griffiths Scales in the assessment of South African black Setswana-speaking (Mothuloe 1990), Indian (Bhamjee 1991) and white children (Allan 1988) has already been demonstrated but further studies indicated that item bias may hinder a national standardisation of the Griffiths scales for South African children (Allan et al 1988). These studies were all undertaken on 5 year old children.

Although these developmental scales are widely used in South Africa, the Griffiths Scales have not been validated for the under 2 year age group in this country. There is therefore a need to validate a culture free developmental assessment test for this age group.

Due to the time constraints of administering the full Griffiths Scales on each infant, certain pertinent indicators were selected.

Each infant also underwent a further developmental examination to support the initial test. This was the Infant Neuromotor Assessment (INA) which was developed for screening infants referred to high risk neonatal clinics within the first year of life. This test has been validated (Magasiner et al 1997) and is used in the neonatal follow up clinics of the Peninsula Maternity Services of the Western Cape.

The INA tests spontaneous movement, muscle tone, postural reactions and some primitive reflexes (Appendix 5). It comprises:

i) Spontaneous posture in supine, sitting and prone.
ii) Ellison's adaptation of Amiel Tison's measurement of tone. (Ellison 1984)
iii) The five postural responses of Votja: (Votja 1976)
iv) Four of Milani Comparetti's postural reactions. (Milani-Comparetti et al 1967)
v) Three of the primitive reflexes (Moro, grasp and asymmetrical tonic neck reflex) (Capute et al 1978)

All the developmental and infant neuromotor assessments in this study were performed by an experienced paediatrician with skills in the clinical diagnosis of DD. Ideally the

developmental assessment used should have been a validated gold standard. However combining both of these examinations provided an accurate assessment of each infant for developmental problems.

6.5 APPLICATION OF THE NMSQ FOR INFANTS WHO PRESENT BETWEEN THE SCREENING AGES

If screening for DD is to be administered to children at 6 weeks, 9 and 18 months and the pre-school age, a strategy will have to be developed for those children who present between those age periods.

Certain functions and activities such as hearing and seeing are maintained regardless of age. Where children present between the specified screening times, the questions asked can be identical to Questions 2, 7 and 8.

A basic knowledge of language milestones would be necessary especially with regards to screening for language delay. Screening motor development could involve questions about cruising, walking unaided and running. A check list of milestones would have to be developed for this purpose.

7. RECOMMENDATIONS

7.1 ADMINISTERING THE QUESTIONNAIRE

OBSERVATION of the infant during the interview is important as the interviewer can confirm or refute some of the caregivers answers to the questions.

Observe the following:

- the interaction between the mother and child.
- what sounds does she make? (language: question 1)
- does the baby listen to her mother's voice? (hearing: ques. 2)
- does the baby look and follow with no squint? (vision: ques. 7 and 8)
- does the baby grab and hold objects with either hand? (fine motor: ques. 3)
- does the baby sit unaided? (gross motor: ques. 5)

The question should be asked directly and succinctly. This decreases the possibility of misunderstanding.

The interviewer should ensure that the response to the question relates to what was asked. The reply could be about another concern not actually enquired about.

The respondent should be advised that if she is unsure about the question, she should ask for clarity.

The questions have been structured that an answer "YES" implies that there is no disability. In questions 3, 6 and 8, clarification of the question is written after the question in parenthesis. The administrator should be aware that a "NO" answer to the elaborated question may imply that there is no disability.

7.2 GUIDELINES FOR ACTIONS TO BE TAKEN TO ANSWERS OF THE SCREENING QUESTIONNAIRE

The action recommended for an infant who screens positive for DD may vary according to local resources as well as access to referral facilities for further assessments.

Question 1: Does your baby make a lot of speech sounds e.g. baba, mama, dada?

The infant needs to say only 1 of the following words: "baba, mama, dada". Ensure that the respondent is not confusing the question with babbling (playful repetition of consonant sounds e.g. "mamamamama")

If a child is babbling with no other "NO" answers, test the hearing to ensure hearing impairment is not the cause of language delay. If there is not hearing impairment, reassess the child in 1 month.

If the infant fails the above criteria, refer.

Question 2: Does your child turn towards you when calling her/his name?

A proviso should be that the parent should elicit the infants response to calling when she/he is out of the visual field of the child.

An answer of "NO" should indicate that the child should be referred for screening of hearing impairment. If you are able to conduct a Rattle Distraction Test, proceed to assess whether there is hearing impairment. If unable to do so or the child fails the distraction test, refer the infant for further auditory evaluation.

Question 3: Does your baby feed him/herself a piece of bread /biscuit (with both hands)?

It is important that the infant uses both hands to feed him/herself as lateralisation should not have occurred yet at this age.

The infant would not necessarily be able to use both hands simultaneously, but should use both with equal frequency.

Question 4: Does your child move the arms and legs the same on both sides?

The object of this question is to ascertain if there is asymmetry between the left and right side in either the upper or lower limbs or both.

Question 5: Does your child sit without support?

The infant should be able to sit for 1 minute without any arm or other support. If the answer to this question is "NO", observe the infant sitting and if this is possible, there is no need to refer the infant if this is the only question failed.

If this is not possible the infant should be referred for assessment.

Questions 3 and 5 are the most sensitive for motor delay and if these questions are not passed, the possibility of developmental problems are increased.

Question 6: Does your baby's arms and legs feel normal to you?

If the answer is "NO", enquire whether there is stiffness or weakness.

There may be positional or dynamic postural differences between the legs which could result in temporary soft tissue changes.

Ensure that there is no Congenital Dislocation of the Hips especially if the answer is "NO" to questions 4 or 6.

Question 7: Does your baby watch a moving object in front of his/her eyes?

A "NO" answer should be followed up by observing if the infant follows a brightly coloured object held at 1 metre away through 180^0.

Also observe for any squint. (See question 8).

There should be no nystagmus.

Question 8: Do both your baby's eyes move well together? (that there is no squint)

If the mother is concerned about a squint, use the reflection of a torch to assess if the reflection shines on symmetrical areas of the eye in all directions of movement.

Question 9: Does your baby play games with you? (e.g. peek-a-boo or imitates hand clapping)

Play is important for learning about social interactions. Caregivers may not have attempted to play peek-a-boo or imitating hand clapping. If this has not been attempted, the next step is to ensure that the child interacts with his/her parent and imitates playful actions.

Question 10: Does your child do the same things as other children of his/her age?

Parents may be unsure when asked this question if they have not compared their activities of their own child or if this is their first child.

Be aware of the respondent who answers "NO" and is comparing with infants who are ahead of their milestones e.g. cruising around furniture.

7.3 OTHER INFORMATION OBTAINED DURING SCREENING

The screening procedure can provide an opportunity to record other important information and observations.

The infant's weight and head circumference must be measured and plotted.

Dysmorphic features can be observed.

The immunisation schedule must be checked for previous omissions and measles immunisation given.

An enquiry should be made of the infant's diet.

7.4 RECOMMENDATIONS FOR FURTHER RESEARCH

There is a need for ongoing research to monitor implementation of the screening process and methods.

Further validation of this screening tool or other tools should be conducted involving larger numbers of infants. The assessment tool should be a validated gold standard in order to optimise the scientific analysis.

It is important also to ensure that South African screening tools are reliable and do not vary according to culture, translation or geographical area. This will have relevance when the NMSQ is translated into different languages.

7.5 RECOMMENDATIONS ON POLICY AND IMPLEMENTATION FOR DD SCREENING IN SOUTH AFRICA

There is a need to develop appropriate screening tools for the 1 month, 18 month and pre-school ages, the minimum times when screening should occur.

There is also a need for development of a policy for screening for disability both regionally and nationally.

Health care workers and other care givers who administer the screening, the assessments and the intervention should be identified and trained.

Guidelines for referral of children who screen positive should be developed within the district health model.

Intervention strategies should be identified within local resources.

Once implemented, evaluation of the screening and assessment needs should be done to ensure appropriateness and effectiveness.

The overall goal of detection and intervention of DD should be to integrate children into their communities wherever possible and to ensure that each child reaches her/his maximum developmental potential.

8. LIMITATIONS

8.1 The developmental assessment used was not a standardised test.

8.2 The numbers in the study group were small.

8.3 A few infants with mild mental handicap as well as infants who will develop learning disabilities at a later stage may not have been identified. However this reflects a limitation of all screening for developmental disability at an early age.

8.4 A repeat developmental assessment in the future would be ideal to assess long term developmental outcome of these infants. This was not possible in this study.

8.5 The screening test is done at a point in time and cannot predict development of DD at a later stage.

8.6 The NMSQ was validated only for infants between the ages of 8.5 and 10 months. Only certain questions would still be applicable for screening outside that age range. The questionnaire therefore would need to be altered for infants presenting between the recognised screening ages.

9. CONCLUSIONS

The 9 month Screening Questionnaire for Developmental Disability is a valid screening tool for developmental impairment and disability. The best time for its administration is when infants present for their measles immunisation.

Recommendations are made on administering the questionnaire, further research, policy and implementation.

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APPENDIX 1

QUESTIONNAIRE
9 MONTH DEVELOPMENTAL SCREENING

CLINIC:_____ DATE: d / m / y

NAME:_____ GENDER: M / F

D.O.B.:____/____/_____ AGE:_____

ADDRESS:_____

INFORMANT:_____ TELEPHONE:_____

SPEECH AND HEARING

1.	Does your baby make a lot of speech sounds e.g. baba, mama, dada	Yes / No
2.	Does your child turn towards you when calling her/his name?	Yes / No

GROSS AND FINE MOTOR

3.	Does your baby feed him/herself a piece of bread/biscuit. (with both hands?)	Yes / No
4.	Does your child move the arms and legs the same on both sides?	Yes / No
5.	Does your child sit **without** support?	Yes / No
6.	Does your baby's arms and legs feel normal to you? (that is there is no stiffness or weakness)	Yes / No

VISION

7.	Does your baby watch a moving object in front of his/her eyes?	Yes / No
8.	Do both your baby's eyes move well together? (that there is no squint)	Yes / No

PERSONAL/SOCIAL

9.	Does your baby play games with you? (e.g. peek-a-boo or imitates hand clapping)	Yes / No
10.	Does your child do the same things as other children of his/her age?	Yes / No

APPENDIX 2

VRAELYS
ONTWIKKELINGS EVALUASIE OP 9 MAANDE

CLINIC:_____ DATE: d / m / y

NAME:_____ GENDER: M / F

D.O.B.:___/___/_____ AGE:_____

ADDRESS:_____

INFORMANT:_____ TELEPHONE:_____

SPRAAK EN GEHOOR

1. Maak u baba babageluide, by voorbeeld baba, mama, dada? Ja / Nee

2. Draai u kind na u toe as u sy/haar naam roep? Ja / Nee

GROWWE EN FYN MOTORIESE BEWEGINGS

3. Kan u baba hom/haarself 'n sny brood of beskuit voer? (met albei hande?) Ja / Nee

4. Beweeg u baba se arms en bene die selfde aan albei kante? Ja / Nee

5. Kan u baba alleen sit **sonder** om sy/haar arms te gebruik? Ja / Nee

6. Voel u baba se arms en bene normaal? (dat daar geen styfheid of swakheid is nie) Ja / Nee

VISIE (SIEN)

7. Volg u baba 'n voorwerp wat voor sy/haar oe beweeg? Ja / Nee

8. Beweeg baba se oe altwee saam? (is die oe skeel?) Ja / Nee

PERSOONLIK/SOSIAAL

9. Speel u baba speletjies met u? (by voorbeld wegkruip of naboots handeklap) Ja / Nee

10. Kan u kind dieselfde dinge doen as ander kinders van sy/haar ouderdom? Ja / Nee

APPENDIX 3

UTHOTHO LWEMIBUZO
UKHANGELO LOKUKHULA KOMNTWANA OKWINYANGA EZI 9

CLINIC:_____ DATE: d / m / y

NAME:_____ GENDER: M / F

D.O.B.:_____/_____/_____ AGE:_____

ADDRESS:_____

INFORMANT:_____ TELEPHONE:_____

UKUTHETHA NOKUVA

1. Ingaba umntwana wakho uyizibiza izandi zamagama? (umz: baba, mama, dada) Ewe / Hayi

2. Ingaba umntwana wakho uyakujonga xa umbiza? Ewe / Hayi

INTSHUKUMO NOKUPHATHA

3. Ingaba umntwana wakho uyakwazi ukuzityela iqhekeza lesonka okanye iqebengwana? (izandla zombini) Ewe / Hayi

4. Ingaba umntwana wakho uyakwazi ukuhambisa ingalo nomlenze ngohlobo olunye macala omabini? Ewe / Hayi

5. Ingaba umntwana wakho uyakwazi ukuzihlalela? Ewe / Hayi

6. Ingaba iingalo nemilenze zomntwana wakho zivakala ziqhelekile? (aziqinanga okanye zibhetye-bhetye) Ewe / Hayi

UKUBONA

7. Ingaba umntwana wakho uyakwazi ukujonga into ehambayo? Ewe / Hayi

8. Ingaba amehlo akhe ahamba kakuhle omabini? (akalilo igxwemu) Ewe / Hayi

UBUQU UNXIBELELWANO

9. Ingaba umntwana wakho uyayidlala imidlalo nawe? (umz. ukulinganisa ukuqhwaba izandla) Ewe / Hayi

10. Ingaba umntwana wakho wenza izinto ezenziwa ngabanye abantwana abalingana naye? Ewe / Hayi

APPENDIX 4

ASSESSMENT

Age: _____mths

1. Weight: [ ][ ],[ ][ ] kg
2. COH: [ ][ ],[ ] cm
3. Length: [ ][ ] cm
4. Birth weight: [ ][ ][ ][ ] g
5. Birth COH: [ ][ ],[ ] cm
6. Gest. age: [ ][ ] wks

7. Is immunisation up to date? Yes | No

8. Are there any gross dysmorphic features? Yes | No
   If yes, describe:

9. Is there any chronic illness? Yes | No
   If yes, describe:

10. **Follows through 180^0 :** Yes | No
    Squint?

11. **Orients to bell / rattle:** Yes | No
    Left and right?

12. **Gross motor:** Quotient: mths Pass | Fail

    Prone extended arm support: 6 mths
    Tries vigorously to crawl: 7 mths
    Prone, pivots in circle using arms 8 mths
    Sits alone 1 minute: 8 mths
    Pulls to stand: 9 mths
    Crawls 9 mths

13. **Fine motor:** Quotient: mths Pass | Fail

    Shakes, waves, bangs objects: 6 mths
    Retains only 1 cube in each hand: 7 mths
    Strikes 1 object with another: 7,5mths
    Grasps ring by the string: 8 mths
    Retains 1 cube in each hand: 8 mths
    Mouthing exploratory (not obligatory): 9mths

14. **Language:** Expressive: mths Pass | Fail

    Ah-goo: 5 mths
    Razzing: 5 mths
    Babbling: 6,5mths
    "dada/mama" inappropriate: 8 mths
    "dada/mama" appropriate: 10mths

15. **Personal/Social:** Quotient: mths Pass | Fail

    Smiles, pats mirror image: 6 mths
    Drinks from a cup: 7 mths
    Plays peek-a-boo: 8 mths
    Holds and eats a biscuit: 9 mths
    Stranger anxiety: 9 mths

16. **REMARKS:** perinatal history, asymmetry etc

APPENDIX 5

INFANT NEURODEVELOPMENTAL ASSESSMENT

NAME: **DATE OF BIRTH:** **HOSPITAL NO:**

	MONTHS 1 2 3 4 5 6 7 8 9 10 11 12	COMMENTS
1) Supine lie	HEAD ASYMM / HEAD SYMM / LIFTS HEAD	
ANGLES		
2) Adductor	40° to 80° / 70° to 110° / 100° to 140° / 130° to 150°	
3) Heel to ear	80° to 100° / 90° to 130° / 120° to 150° / 140° to 170°	
4) Popliteal angle	80° to 100° / 90° to 120° / 110° to 160° / 150° to 170°	
5) Dorsflexion of foot	60° to 70° / 60° to 70° / 60° to 70° / 60° to 70°	
6) Scarf		
MONTHS	1 2 3 4 5 6 7 8 9 10 11 12	
7) Pull to sit	(a) (b) (c) (d)	
8) Sitting	(a) (b) (c) (d) (e) (f) (g)	
9) Prone lie	(a) (b) (c) (d) (e)	
10) Landau Response	(a) (b) (c)	
11) Axil hanging	(a) (b) (c)	
12) Vojta side tilting	(a) (b)	
13) Collis Horizontal	(a) (b) (c) (d)	
14) Hand grasp reflex		
15) Moro Response		
16) ATNR		
Protective Extension:		
17) Down		
18) Lateral		
19) Forward		
20) Backwards		

INFANT NEUROMOTOR ASSESSMENT

INA PROCEDURE (refer to diagram in Appendix 5)

Sitting on a caregivers lap / supine: Test eye following. Hands to mouth.

1. **Supine:** Head symmetrical = head turned to one side. Head symmetrical = head in midline.

   Angles: Infant lies supine with head in midline.

2. **Adductor Angle:** Examiner opens legs as far as possible. The angle formed by legs is measured.

3. **Heel to Ear:** Buttocks on the table. The legs are kept straight and moved towards the ear. When there is resistance to this movement, the angle formed from the table surface to legs is measured.

4. **Popliteal Angle:** Buttocks on the table. The legs are flexed to either side of the abdomen, until there is resistance. Then legs are extended. When there is resistance to this movement, the angle formed between the lower and upper leg is measured.

5. **Dorsiflexion Angle of the foot:** The knee is extended. The foot is flexed and the angle between foot and leg is measured.

6. **Scarf sign:** The examiner takes infant's hand and pulls arm across chest, until there is resistance. The position of the elbow is noted.

   (P.Ellison)

7. Traction is applied to arms until trunk forms and angle of 45 degrees with the examination plane. (a) Complete head lag with extended arms. (b) Moderate head lag. (c) Head in line with the trunk, the arms and legs are in flexion with the feet lifted. (d) The child actively flexes the head forward with strong elbow flexion. Knees go from flexion to extension.

8. (c) Extension down to lumbar 3. (g) Infant is able to rotate trunk sideways.

9. (b) Elbow flexion support. (c) Elbow extension support. Fisting in prone should cease at 3 ½ months.

10. (a) Head flexed, trunk curved. (b) Head, cervical and thoracic regions extended forming one horizontal plane (sometimes head slightly above horizontal). (c) Extension of head above horizontal. Full extension of trunk and pelvis.

11. Infant is held vertically with back to examiner. Examiner holds infant just below axillae with feet free of the table. (a) No head control with legs in loose flexion. (b) Legs in strong flexion. (c) Preparation for weight bearing with extended legs. Abnormal pattern is scissoring or stiff extension of legs.

12. Infant is held vertically with back to the examiner. Infant is tilted into the lateral horizontal position. (a) Moderate trunk flexion, Moro-like response in upper arm. Upper leg should flex with underlying leg extended. (b) Head and trunk righting, flexion of upper arm, flexion of both legs. Lack of trunk righting; stiff extension upper leg or both legs; stiff elbow extension or stiff elbow flexion with shoulder retraction are deviant signs.

13. Infant is in side lying with his back close to examiner. The examiner's hands grasp over shoulder and hip joints to prevent stretching ligaments. Raise infant just off table. (a) Flexion of lower leg and arm. (b) Lower arm elbow extended with hand partially open touching table. (c) Elbow extend, palm supports body weight. (d) Lower arm and leg down on table. Lack of trunk righting; stiff lower leg extension; lack of weight bearing on hand; stiff lower elbow extension or flexion with shoulder retraction are deviant signs.

14. **Grasp reflex:** Place index finger in palm from ulna side. Supine: grasp reflex should cease at 2 ½ months.

15. **ATNR** (asymmetrical tonic neck reflex): The arm and leg on the skull side should flex and on the face side extend. Can be assessed by turning head, or is observed when testing "following". This is not an obligatory response.

16. **Protective Extension – Down:** The child is held vertically and rapidly lowered. The infant should extend legs with abduction and external rotation to weight bear on flat feet. Persistent toe standing must be watched.

17. The child is placed sitting and is pushed sideways on one shoulder with sufficient force to make it lose balance. The opposite arm should abduct with extension of elbow and wrist to weight-bear. At 4 ½ months, prop sitting sideways is present.

18. The child is held vertically and tilted forwards to the table. The arms project forward with extended elbows, wrists and fingers.

19. The child sits and is pushed backwards. Both arms should extend backwards, although sometimes the reaction is only seen in one arm.

APPENDIX 6

THE 'TEN QUESTION' SCREEN

1. Compared with other children, did the child have any serious delay in sitting, standing or walking?

2. Compared with other children does the child have difficulty seeing, either in the daytime or night-time?

3. Does the child appear to have difficulty hearing?

4. When you tell the child to do something, does he/she seem to understand what you are saying?

5. Does the child have difficulty in walking or moving his/her arms or does he/she have weakness and/or stiffness in the arms or legs?

6. Does the child sometimes have fits, become rigid, or lose consciousness?

7. Does the child learn to do things like other children his/her age?

8. Does the child speak at all (can he/she make himself/herself understood in words; can he/she say any recognisable words?)

9. *For 3- to 9-year olds ask:*
   Is the child's speech in any way different from normal (not clear enough to be understood by other people other than his/her immediate family)?

   For 2- year olds ask:
   Can he/she name at least one object (for example, and animal, a toy, a cup, a spoon)?

10. Compared with other children of his/her age, does the child appear in any way mentally backward, dull or slow?

APPENDIX 7

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

Children with developmental disabilities are those children who have difficulties in seeing, hearing, walking, writing, conceptualising or performing any other functions within the normal range of children their age. Developmental disabilities (DD) affect between 10-13% 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."[1] 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. These guidelines have been developed with consideration of the fact that in many parts of South Africa there are children with significant needs, but there are not enough resources to respond to these needs.

SCREENING

1. Screening for both major and moderate DD should be done, but only if it can be linked to appropriate interventions.
2. 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.
3. 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.
4. Screening for children *under the age of two* by families and community members (such as teachers, crèche workers, CHWs and traditional healers) should focus on recognition and basic management of major physical, behavioural, sensory and mental DD.
5. Screening for children *above the age of two* by teachers, crèche workers, traditional healers, CHWs and other community workers should focus on recognition and management of learning/developmental, moderate and major (missed) physical, mental, speech and emotional/behavioural disabilities.
6. Screening for DD should form part of a continuum of management, including development of referral strategies and case management guidelines.
7. The current Road to Health Card model does not track milestones adequately, and could be revised to promote and document screening.

SCHEDULE OF SCREENING

1. The schedule for DD screening at the primary level of care should aim to be cost-effective, coinciding with other child contacts, such as at the child's nine month immunisation visit.

2. Ideally, health professionals should be able to respond to parents' concerns during any encounter. However, this has significant implications for training and is not currently realistic for South Africa.
3. Many DD which may be amenable to intervention (such as those relating to motor perception, intellect and behaviour) are missed because of a significant gap of time between age of 18 months and 5 years when children are not brought to health professionals for routine checks. Other alternatives should be used during this time to investigate a child's development.
4. Mandating too many visits for the sole purpose of developmental screening may be unrealistic.

TOOLS

1. Tools used by healthworkers to screen for DD should:

    - be valid and reliable;
    - 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; and
    - be socially, linguistically and culturally appropriate.

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 brief "hands on" or "observation" tool for use by healthworkers should be administered.

INTERVENTIONS

1. Particularly in areas where health and education system interventions are not available, interventions must focus primarily on the family 's and community's ability to recognise and manage DD.
2. Community-specific case management algorithms for different DD should be developed in relation to feasible interventions.
3. Health interventions to respond to DD should be guided by the principles underlying national health primary health care policy.
4. Intervention programmes should also address those underlying causes of DD (e.g., parasitic infections, malnutrition, and unsupervised births) which can be ameliorated and/or prevented with improved health care, and/or education.
5. Before birth, parents should be educated about normal development, how to recognise signs of DD, and what further steps to take should they arise.

PERSONNEL AND TRAINING

1. Persons who have frequent contact with children should be utilised as key personnel for screening for DD. These persons include: parents/other caretakers, pre-school teachers, crèche managers, community health workers, community rehabilitation workers, traditional healers, nurses and doctors. When available, other health

personnel such as health therapists, psychologists and pharmacists should be involved as well.

2. The media is key in terms of providing information to parents/caregivers, child care workers and other lay people (including community health workers) about developmental milestones, basic detection of sensory deficits and where to take children to determine if their concerns are justified.
3. In rural and underserved areas, parents of children with DD can play an pivotal role in supporting other parents of children with DD.
4. The health, welfare and education systems should be committed 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, other professionals (e.g., advanced clinical nurses, medical officers and health therapists) should be trained to provide assessment, diagnosis and referral for rehabilitation.
6. Health and other professionals *in practice* should be provided with information about basic pathophysiology, developmental disability detection and options for management via certificated adult distance learning programmes, short courses and workshops.
7. Health and other professionals *in training* should be provided with information about basic pathophysiology, developmental disability detection and options for management via training modules for primary health care within their curriculum.

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. Research is needed to determine the impact of screening on child and family well-being.

Finally, screening for DD should be based on local needs and priorities.

This consensus statement is the product of the *Workshop on Screening for Developmental Disabilities in the Pre-school Population*, held June 12-13, 1996 by the Child Health Policy Group, Child Health Unit, University of Cape Town. A proceedings document and a list of research questions also are in development. For more information, contact Alyssa Wigton, Child Health Policy Group, Child Health Unit, 46 Sawkins Road, Rondebosch 7700. telephone: (021)685-4103; fax: (021)689-5403.

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[i] 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.

APPENDIX 8

DEVELOPMENTAL SCREENING TESTS

Reference: Glascoe F.P., Martin E.D., Humphrey S. (1990)