Evaluation of the Western Cape Province Developmental Screening Programme

In partial fulfillment of the requirements of a
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TERMS OF REFERENCE

This evaluation study was commissioned by the Maternal, Child and Women's Health (MCWH) Sub-directorate of the Provincial Administration of the Western Cape Department of Health and undertaken by the author, Lori Michelson. The study was completed under the supervision of Dr. Colleen Adnams (Child Health Unit) and Dr. Maylene Shung-King (Children's Institute), University of Cape Town and was supported by a grant from the Health Systems Trust.

In addition to this dissertation in partial fulfilment of the author's Masters of Philosophy degree in Maternal and Child Health, a number of other outputs of the research have included:

1. Full technical report for the Department of Health, including brief introduction and literature review, programme description, results on the current delivery of the programme, discussion of key issues and recommendations (completed)
2. Executive summary report for the Department of Health highlighting the above (completed)
3. Formal oral presentations to relevant stakeholders (commenced)
4. Relevant publications and conference presentations (two non-peer reviewed articles published and two conference presentations made to date)

In terms of the agreement between the MCWH Sub-directorate and the Children's Institute, the ownership of all outputs from this research study is that of the MCWH Sub-directorate. Appropriate academic presentations and publications may be made by the Children's Institute with prior approval from the MCWH Sub-directorate. Full acknowledgement of the MCWH Sub-directorate must be made in all written and verbal outputs, while the Children's Institute will be reflected as the primary researchers of this study. All other contributors will be appropriately acknowledged.

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ABSTRACT

This study evaluates the input, process and output parameters of the Western Cape Developmental Screening Programme in order to inform policy and practice regarding developmental screening in the province. The study describes the background, development and implementation of the screening programme and examines its current delivery, including the main enabling factors and barriers to implementation. In order to achieve the abovementioned objectives, a combination of predominantly qualitative and some quantitative data was gathered in stages from all levels of the health system (provincial, regional and district levels) using a number of different methods. In addition to documentary and literature reviews, information was gathered via structured interviews with key health managers at a provincial and regional level, a rapid facility survey and facility based assessments. Information gathered from interviews and focus groups was analysed thematically, while rapid facility survey results were analysed via EpiInfo. Despite numerous successes in its development and the overall awareness of the Developmental Screening Programme, developmental screening is not conducted uniformly across the province. Almost a quarter of primary health care facilities do not deliver any aspect of the programme and only one of nine facilities deliver according to protocol. This study concludes that despite the Developmental Screening Programme being a well-conceptualised and highly valued programme, its delivery has failed as a result of constraints within the broader health system. As previous evaluations of child health programmes have demonstrated, the overall transformation of the health system, organisation of service delivery at a primary health care level and gaps in human resource development and information systems impact significantly on the delivery of preventive service delivery for children. As official programmes for developmental screening are not conducted in any other provinces, the study results may also inform policy and practice on a national level.

ABBREVIATIONS

CHC	Community health centre
HRD	Human Resource Development
IMCI	Integrated Management of Childhood Illnesses
MCWH	Maternal, Child and Women's Health
NGO	Non-governmental organisation
PAWC	Provincial Administration of the Western Cape
PHC	Primary health care
PMTCT	Prevention of Mother to Child Transmission
PSNP	Primary School Nutrition Programme
RMR	Routine monthly report
UNICEF	United Nations Children's Fund
WHO	World Health Organisation

1. INTRODUCTION AND LITERATURE REVIEW

Within the health sector internationally, the monitoring and formal evaluation of health policies, programmes, services and interventions have historically not been conducted on a routine basis. This is a problem. Even in the United Kingdom, the National Health System has previously viewed research and development including programme evaluation as falling outside its core service delivery functions. There is however increasing recognition for health service evaluation to be embedded within the structures that are affected by and will make use of the information. Monitoring and evaluation should in fact be integral to any project planning cycle (St. Leger, Schnieden and Walsworth-Bell, 1992; Green, 1999; Jacobs and Kapuscik, 2000).

In South Africa, the need to monitor and evaluate health policies and programmes has been acknowledged in various national frameworks. Despite this, monitoring and evaluation rarely accompany policy and programme implementation. Furthermore, such evaluations are generally not undertaken by health departments themselves but rather by non-governmental organisations (NGOs) and university-based public health units (Shung King, 1998). While a wealth of new laws, policies and programmes have been introduced since the inception of the Democratic South Africa in 1994, there is a concerning lack of evidence regarding their merit and challenges faced in implementation. New legislation, policies and programmes continue to be developed despite the effectiveness of existing initiatives never having been systematically demonstrated.

The monitoring and evaluation of health services for children in South Africa is of particular importance. Children's health rights have been prioritised internationally via the United Nations Convention on the Rights of the Child (1990) and entrenched nationally in the South African Constitution (1996). The Reconstruction and Development Plan (1994), the White Paper for the Transformation of the Health System in South Africa (1997), as well as earlier drafts of the National Health Bill, give further indication of the government's strong commitment to the realisation of children's rights to health. Monitoring the Department of Health's ability to translate this political commitment to the "first call for children" into good quality health services for children is critical.

Child health service provision in the developing world has historically focussed on the treatment of leading causes of childhood mortality and morbidity. Similarly in South Africa, nutrition and childhood infections are prioritised in the development of policies and programmes. With increased curative caseloads at the primary health care (PHC) level and the additional burden of the HIV/ AIDS epidemic, preventive services such as screening activities accompanying routine immunisations and rehabilitation services for disabled children are neglected and under-resourced.

The purpose of this study was to inform policy and practice regarding developmental screening in the Western Cape and in South Africa. At a national workshop on developmental screening convened by the Child Health Policy Institute and held at the Child Health Unit, Cape Town, in 1996, the screening of young children to detect developmental disability was identified as a priority by key role-players in child health. Developmental screening has also been named as a key strategy for the prevention of disability (Office of the Deputy President, 1997; Department of Health, 2000). Despite this, the National Department of Health has not responded with a formal national developmental screening policy. Only the Western Cape Province responded to the workshop recommendations. This study therefore aimed at evaluating the only formal developmental screening programme in the country with a view to make recommendations to the Western Cape Department of Health which developed the programme. It was further envisaged that lessons learnt could be used to inform the development of a national policy and guide the implementation of an appropriate developmental screening programme throughout South Africa.

Disability as a universal term has been defined by the World Health Organisation (WHO) International Classification of Impairments, Disabilities and Handicaps (ICIDH, 1980) as "any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being". Developmental disability, in turn, refers to a child who has any difficulty seeing, hearing, walking, writing, conceptualising or performing any other function within the normal range for his/ her age (WHO, 1980; National Workshop on Screening for Developmental Disabilities in the Pre-school Population: Proceedings, 1996). In line with shifts towards conceptualising disability as socially constructed and not purely as a medical problem, WHO's International Classification of Functioning, Disability and Health

describes functioning, disability and other non-fatal health conditions with reference to the interaction between personal, health and environmental factors (WHO, 2001; Madden, 2001).

Global figures estimate that 85% of the world's disabled people live in developing countries (WHO, 1982). It is further estimated that 10% of the general population within this context are disabled. National Department of Health surveys conducted in South Africa in 1993 and 1999 have revealed overall disability prevalence figures for the country ranging between 5.7% to as high as 12.4% (Department of National Population Development: Consensus, 1993; Schneider et al., 1999).

The prevalence of childhood disability within the developing world is generally unknown. The most significant disability prevalence research was conducted in Bangladesh, Pakistan and Jamaica by Durkin, Khan and others in the early 90s. These studies (which formed part of the validation of the Ten Question Screen) reported prevalence rates of disability in children (two to nine years) ranging from 82/ 1000 to 152/ 1000. Confirmed rates, that is, where the disability reported by the family was confirmed by a professional, were slightly lower and ranged from 70/ 1000 children in Bangladesh to 94/ 1000 children in Jamaica (Zaman, Khan, Islam, Banu, Dixit, Shrout and Durkin, 1990; Thorburn, Desai, Paul, Malcolm, Durkin and Davidson, 1992; Durkin, Davidson, Desai, Hasan, Kahn, Shrout et al., 1994; Durkin, Wang, Shrout, Zaman, Hasan, Desai et al., 1995; Durkin and Khan, 1995).

In South and Sub-Saharan Africa, there is a paucity of data on the prevalence of childhood disability. National census results, which quoted childhood disability as approximately 1.5% in 1996, have been criticised for under-reporting (Guthrie, Berry and McClaren, 2003). Prevalence rates from a few smaller-scale studies in specific areas or sub-districts of the country appear to be more accurate in that they are comparable with the abovementioned developing country results. These local studies peg disability at approximately 6% of the childhood population within rural communities of South Africa. Table 1 below (adapted from Couper, 2000) provides a summary of these South African studies and overall childhood prevalence rates found.

Table 1: South African childhood disability prevalence studies and results

Study area	Researcher	Study year	Children's ages (yrs)	Confirmed rate/ 1000
Ntuze-ongonye, Kwazulu Natal	Irlam, J.	1996	2 – 19	33
Manguzi, Kwazulu Natal	Couper, J.	2000	0 – 9	60
Bushbuckridge, Mpumalanga	Kromberg, J.G.R. et al.	1997	2 – 9	64
Gelukspan, North West Province	Corneljie, H. et al.	1991	0 - 9	52

Source: Couper, 2000

It should also be noted that age-specific prevalence rates for children under two years were reported as 11/ 1000 in the Gelukspan study by Cornelie, Ferrinho and Gear (1991) and 20/ 1000 by Couper in the Manguzi sub-district of Kwazulu Natal. This suggests that approximately one third of disabled children in South Africa (two of the total six percent) are younger than two years of age. Discrepancies in prevalence figures are due to differing study definitions of disability and data collection methodologies. However, it can safely be assumed that developmental disability is a significant problem in this country.

There is international consensus that the early years constitute a unique period for influencing the development of children. The time from birth to four or five years is often referred to as the "critical period" for the acquisition of gross motor, fine motor and vision, speech, language and hearing as well as psychosocial skills (Venter, 1993; Billeud, 1993 in Louw, 1997; Guralnick, 1997 and Wicht, 1999). Understandably then, these early years are crucial for the identification of children with disability. It is well documented that through early identification, adaptations to minimise the disability can be facilitated (Committee on Children with Disabilities, 1986; Venter, 1993; Donald, 1994; Guralnick, 1997).

Despite agreement around the benefits of early identification, there has been some difficulty in scientifically proving the effectiveness of early intervention. This may be attributed to numerous methodological challenges. It was only in the late 1980's that studies by, amongst others, Casto and Mastropieri (1986), Shonkoff and Hauser-Cram (1987) and Guralnick and Bennett (1987) demonstrated convincingly that early intervention is indeed effective. As Guralnick (1997) asserts, "This first generation research has put the global question of whether or not early intervention is effective to rest". In countries such as the United States of America, state law now mandates the early identification and treatment of developmental problems (Committee on Children with Disabilities, 1994; Blackman, 1999).

Within the developing world, where poverty is rife, the benefits of early intervention have been equally if not more difficult to prove. Best practice models are often not documented by practitioners who are service rather than research and evidence-base driven. In these "third world" countries, socioeconomic and geopolitical conditions and a lack of infrastructure (including accessible services for disabled children) frequently inhibit the success of traditional early intervention initiatives.

While these constraints have been acknowledged, local child health practitioners do concur that early identification and intervention are critical for children with moderate and severe disabilities in South Africa (Molteno, 1996; Wicht, 1999; Adnams, verbal communication, 2003). It is argued that even where conventional therapeutic services are of less value, the exchange of basic information, guidance and emotional support to the family can have marked benefits. As Adnams (2003) further suggests, the simple provision of social security in the form of a child disability (care dependency) grant may often be a crucial starting point for the family to be able to facilitate a response to early intervention. Early detection of developmental disability even in these sub-optimal circumstances is therefore still a necessity.

Methods for monitoring child development and the identification of developmental disability vary considerably between and within countries. Even in developed countries such as the U.S.A., the United Kingdom and Australia, developmental monitoring lacks uniformity with an array of methods being practised. As Logan (1995) points out, "Policy statements (Dworkin, 1989; Feightner, 1993 and American

Academy of Pediatrics, 1994) reflect that even in developed countries, the situation of whether to screen for developmental delay and how best to accomplish this goal is ambiguous at best". Within this context, paediatricians are primarily responsible for examining the child's development and do so either via developmental surveillance, developmental screening, assessment or a combination of these approaches (Dworkin, 1989; Rossiter, 1993; Committee on Children with Disabilities, 1994).

In the United States, the Committee on Children with Disabilities (1994) recommends that all encounters with the child be used for observing and recording developmental status. This continuous, comprehensive approach, which involves more than just detection, is known as surveillance (Frankenburg, 1994). The committee also advises that specific screening tests including visual and hearing screens be carried out together with parental questionnaires and observations of the child in order to rule out delay or disability. In Australia, developmental assessment (comprehensive evaluation of child's development) is not often practiced routinely but rather on the basis of a clinician's suspicions or previous developmental screening test results where a problem was detected (Rossitter, 1993). The United Kingdom has also seen a shift from formal developmental screening to surveillance through primary prevention and "opportunistic" intervention (Hall and Elliman, 2003).

As developmental surveillance requires a high level of skill and thorough knowledge of child development, this approach has been more or less ruled out for developing countries (Casey, 1993; Simpson, 1997; Wicht, 1999). In South Africa, previous attempts at developmental surveillance have reportedly failed. Without a specific policy in place, the regular completion of milestones on the Road-to-Health Card in the Western Cape and the routine administration of a developmental milestones component at the Red Cross Children's Hospital outpatients department have both reportedly been unsuccessful (Molteno, 1996). The other disadvantage of surveillance is that those cases that do not present at the health facility, will not be detected.

The preferred method for developmental monitoring in many developing countries, including South Africa, is therefore developmental screening. Screening may be conducted on a mass basis which is expensive and may have a low yield or selective/ targeted in the case of the Developmental Screening Programme where children are

selected at specific ages for screening from a mass pool (immunisations). Developmental screening involves the detection of disability in apparently healthy children within the primary health care setting, separating children into high and low risk groups for developmental delay or disability (Casey, 1993; Simpson, 1997). Screening is usually conducted at a health facility and is intended as the first step in the identification and management of the disabled child (Guthrie et al., 2003).

A widely known screening test, validated in Jamaica, Pakistan and Bangladesh (see Durkin and Khan, 1995), is the Ten Question Screen. This tool involves the administration of ten questions to the caregiver which tap the key skills and abilities that a child should master between two and nine years. In South Africa, this and other screening tests including the Sheridan and Susan Swart's developmental screening tools, have generally been used for research purposes rather than in everyday practice in primary health care facilities. Couper (2000) used an adapted version of the Ten Questions Screen with an 11 point scoring system in her prevalence study in Manguzi, Kwazaulu Natal. The Denver Developmental Screening Test is the most widely used test internationally for screening while the Griffiths and Bayley Developmental Scales are most popular for developmental assessment (Olade, 1984; Rossiter, 1993; Committee on Children with Disabilities, 1994).

International criteria for screening have undergone much amendment since they were originally proposed by Wilson and Jungner in 1968 and are now well established.

Box 1: <u>International criteria for screening</u>

1. The condition to be sought should be an important public health problem
2. There should be an accepted treatment for cases identified
3. Facilities for diagnosis and treatment should be available
4. There should be a recognisable latent or early symptomatic stage
5. There should be a suitable test or examination
6. The test should be acceptable to the population
7. The natural history of the condition should be understood
8. There should be an agreed policy on whom to treat as patients
9. The cost of case-finding should be non-wastefully balanced in relationship to expenditure on medical care as a whole
10. Case finding should be a continuing process not a once and for all event

Source: Calman, 1994 in Logan, 1995

The above criteria concern not only the condition being screened for and the test used but also the broader programme context in which screening takes place. In terms of the condition criteria, the condition being screened for should be a significant health problem and the benefits of its early detection should be known. Furthermore, before screening can take place, there should be a full understanding of the condition which includes it natural history and the benefits of treatment in the early stages (Logan, 1995). Based on empirical evidence, it was agreed that developmental disability is indeed an important public health problem in South Africa and that there is sufficient understanding of its course and recognised benefit of early detection to warrant developmental screening (National Workshop on Screening for Developmental Disabilities in the Pre-school Population: Proceedings, 1996).

The test criteria for developmental screening proposed by Cochrane and Holland (1969) and Calman (1994) were unpacked and revised for the South African context at the 1996 National Workshop for Developmental Screening (Box 2).

Box 2: Criteria for developmental screening tools in South Africa

Tools should:

1. be valid and reliable
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 with consideration of the context in which it is being used
8. be linguistically and culturally appropriate
9. be statistically reportable and usable

Source: Jacklin, National Workshop on Developmental Disabilities, 1996

An additional principle highlighted by the national workshop group in support of the work of Glascoe and Dworkin (1995) was that parents or caregivers should play a pivotal role in developmental screening. Along similar lines as the Ten Question

Screen, caregivers should be involved in the screening process by being required to respond to questions posed by health workers regarding their child's development and indicate whether their child is delayed or disabled in any way.

Programme criteria for screening have perhaps come most under the spotlight and much debate has centred around these broader requirements for developmental screening in South Africa. Criteria, such as those outlined by Calman (1994, in Logan, 1995), emphasise the importance of screening not being a once-off event but rather on an identification and management continuum with screening or detection being the first step in the process. Screening should thus only be conducted where a response to case finding, that is services for the further assessment and management of developmental disability, is in place.

In South Africa, resources for the in-depth and comprehensive assessment and management of children identified with possible developmental disability are frequently unavailable. Developmental services and rehabilitation services are still predominantly based at a secondary and tertiary level and thus inaccessible to many of the children who would be screened (Integrated Provincial Disability Strategy, Western Cape, 2001; Power, van der Merwe and Dewar, 2003). Further barriers in the current South African health system to implementing screening for developmental disability include health workers' heavy workload and lack of time to carry out developmental screening at primary health care facilities (Child Health Policy Institute, workshop proceedings,1996). It can however be argued that this situation is a manifestation of inadequate government commitment to the development of rehabilitation services rather than a true "lack of resources" which is frequently claimed.

Whatever one's standpoint, these programme criteria have largely prevented the implementation of standardised developmental screening throughout the country. Despite the national prioritisation of developmental screening in 1996, the Western Cape has been the only province to take the process forward in developing and implementing the Western Cape Developmental Screening Programme. The majority of provinces continue to view developmental screening as a "luxury" where other child health interventions such as the Expanded Programme on Immunisation still

pose a great challenge. Developmental screening in these provinces is therefore conducted, if at all, sporadically, and using informal and non-standardised methods.

Jacobs and Kapuscik (2000) note that today's "post-modern" or "fourth generation" evaluation is characterised by two trends – firstly, targeted and detailed investigation of particular units or programmes and secondly, the assessment of broad systemic change in human services. In addition to documenting the background, development and implementation of the Developmental Screening Programme, this study aimed to investigate its current delivery in the Western Cape. It was envisaged that through the various quantitative and qualitative methods employed, the researcher would identify barriers and success factors in the programme which could be fed back to the Western Cape Department of Health. It was anticipated that the findings could be used to inform policy and practice regarding developmental screening at a national level.

It should be noted that in this study the Western Cape Developmental Screening Programme was not evaluated in isolation but rather within the prevailing and changing health care context in South Africa. By comparing findings with other recent Maternal, Child and Women's Health (MCWH) programme evaluations including evaluations of the Primary School Nutrition Programme (PSNP), Integrated Management of Childhood Illnesses (IMCI), the pilot implementation of Prevention of Mother-to-Child Transmission (PMTCT) and PHC services for HIV-positive children, this study looked beyond developmental screening and provides some insight into health systems and child health service provision as a whole.

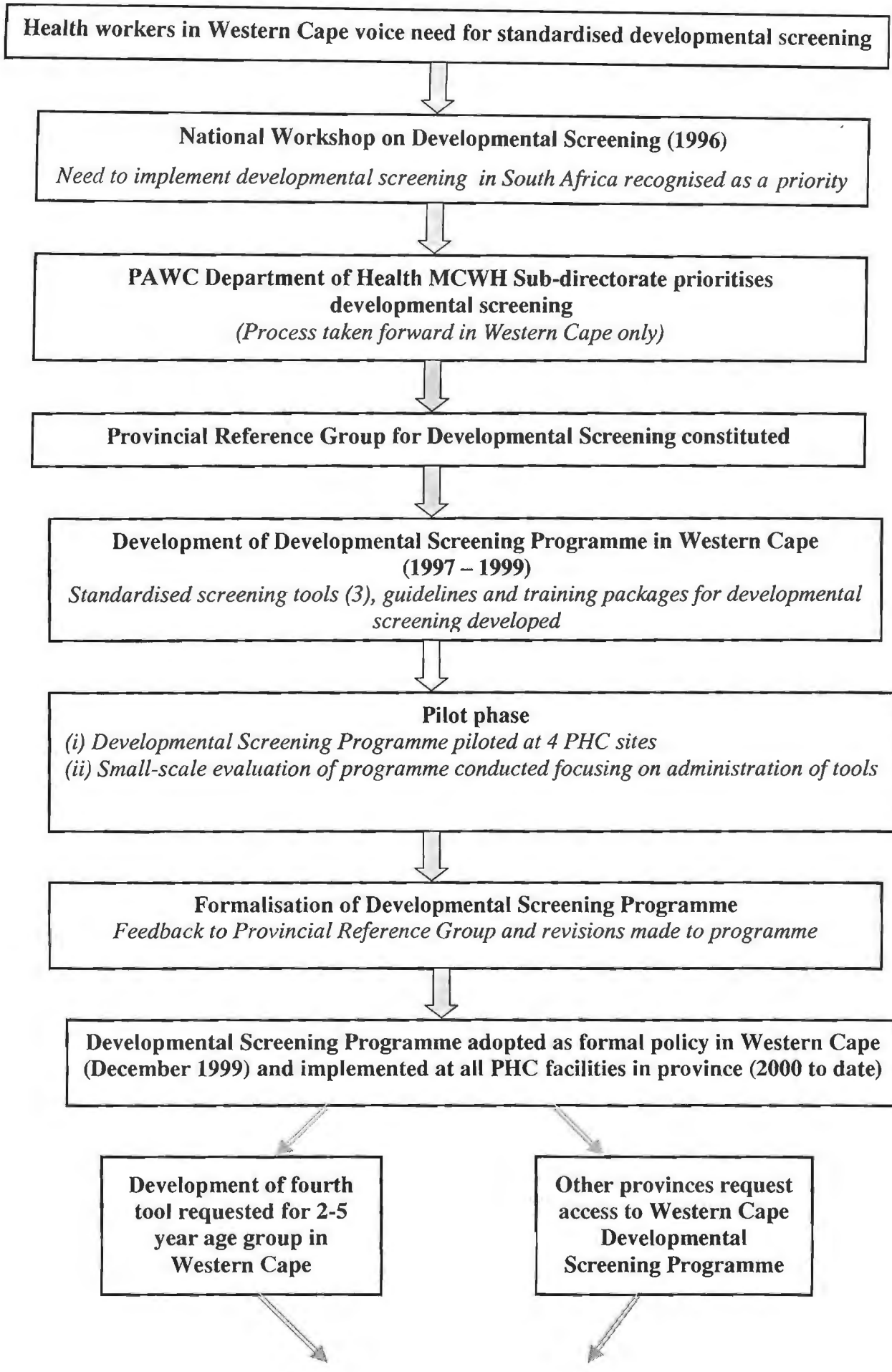
Fischer (1995) and Green (1999) explain that an evaluation may be carried out at the end of a particular activity (summative evaluation) or during the course of project implementation (formative evaluation). It is generally accepted that a comprehensive evaluation should consider the input, process, output and outcome parameters of a programme, service, policy or intervention (St. Leger et al., 1992; Fischer, 1995; Green, 1999; McConachie, 1999; Jacobs and Kapuscik, 2000). This formative evaluation explored the input, process and output parameters of the Western Cape Developmental Screening Programme. The overall outcomes of the programme were not investigated as this would require a long-term cohort study. The scientific validity and reliability of the individual programme tools were also not evaluated.

2. BACKGROUND AND DESCRIPTION OF THE PROGRAMME

According to Jacobs and Kapuscik (2000), "The systematic collection of information about project operations is the basis of all programme evaluation". This chapter details the background, development and implementation of the Western Cape Developmental Screening Programme. It is based chiefly on information gathered from secondary sources, such as programme documentation, rather than the result of primary investigations of the researcher which are presented in the Results chapter. Key health managers who participated in the programme evaluation provided additional information where required and are referenced below. This detailed description of the programme was deemed necessary to facilitate the reader's understanding of the programme evaluated.

2.1. Overview

The Western Cape Screening Programme for Developmental Disabilities in Pre-school Children is a standardised screening system to identify undiagnosed or unsuspected developmental problems in pre-school children. The programme was introduced as formal policy in the Western Cape Province in December 1999 (PAWC Department of Health and Social Services, Provincial Directive, Superintendent General, December 1999). Since this time, health workers at PHC facilities have been delivering this programme which involves the use of standardised screening tools to screen children when they visit the health facility for their immunisations at 6 weeks, 9 months and 18 months. In 2001 the MCWH Sub-directorate responsible for the Developmental Screening Programme commissioned the Children's Institute (with the author as primary researcher) to evaluate its implementation before expanding the existing programme. The background, description and implementation is depicted in Figure 1 and described in further detail below.


Health workers in Western Cape voice need for standardised developmental screening
National Workshop on Developmental Screening (1996)
Need to implement developmental screening in South Africa recognised as a priority
PAWC Department of Health MCWH Sub-directorate prioritises developmental screening
(Process taken forward in Western Cape only)
Provincial Reference Group for Developmental Screening constituted
Development of Developmental Screening Programme in Western Cape (1997 – 1999)
Standardised screening tools (3), guidelines and training packages for developmental screening developed
Pilot phase
(i) Developmental Screening Programme piloted at 4 PHC sites
(ii) Small-scale evaluation of programme conducted focusing on administration of tools
Formalisation of Developmental Screening Programme
Feedback to Provincial Reference Group and revisions made to programme
Developmental Screening Programme adopted as formal policy in Western Cape (December 1999) and implemented at all PHC facilities in province (2000 to date)
Development of fourth tool requested for 2-5 year age group in Western Cape
Other provinces request access to Western Cape Developmental Screening Programme

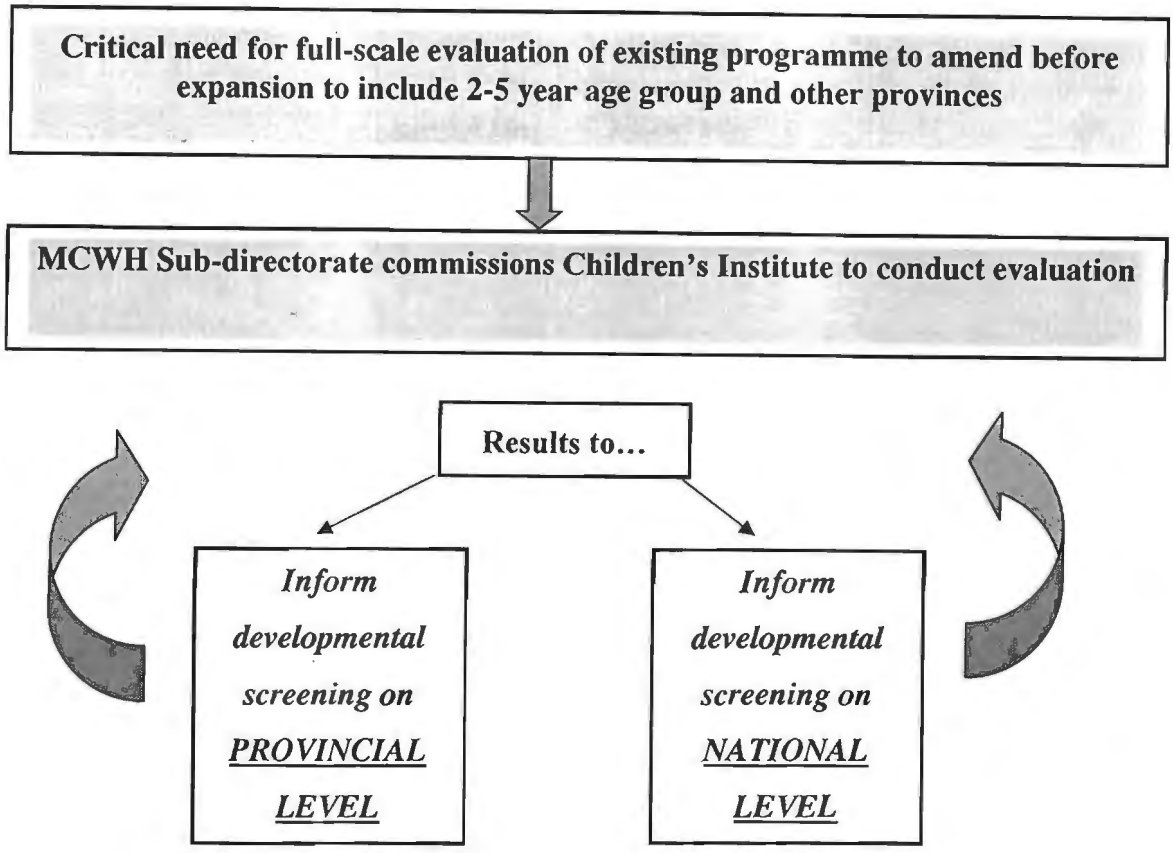


Figure 1: Implementation process of Developmental Screening Programme and need for evaluation in Western Cape

2.2. Background to the programme

2.2.1. Screening for developmental disabilities prior to the introduction of the Western Cape Developmental Screening Programme

Prior to the implementation of the Western Cape Developmental Screening Programme, screening for developmental disabilities was conducted by health workers but often in a random way and using instruments that were not necessarily standardised or scientifically reliable or valid. In addition, training packages and guidelines were frequently lacking, resulting in poor management of developmental disability in children (Provincial Directive, Superintendent General, Department of Health and Social Services, December 1999; Verbal Communication, Deputy-Director MCWH, PAWC Department of Health, 2002).

In 1993, for example, a national instruction was circulated to the provinces stating that screening should be done at birth, 3 months, 6 months, 9 months, 12 months, 15

months, 18 months, 3 years and 5 years, but no guidelines on how to conduct the screening or referrals were provided. Many health workers had also attended training in developmental screening at tertiary hospitals and institutions (e.g. Developmental Service, Red Cross Hospital; Carel du Toit Centre, Tygerberg Hospital) or other training sessions provided by academics in the field of developmental disabilities, from which they developed their own screening methods. As a result, screening for developmental disabilities was not empirically based and conducted in a non-uniform way (Verbal Communication, Deputy-Director, MCWH, PAWC Department of Health, 2002).

2.2.2. Need for and prioritisation of standardised developmental screening

From as early as the 1970s, the need for standardised developmental screening was voiced by health care workers. It was only in 1990s however that developmental screening came on to the child health agenda in the Western Cape at a regional and provincial level. In 1996 the Child Health Policy Institute convened a national workshop at the Child Health Unit, Cape Town, in order to urgently address the role of developmental screening and the feasibility of developing a standardised screening tool/s for this purpose in South Africa (Verbal Communication, Deputy-Director, MCWH, PAWC Department of Health; Developmental Screening Programme Training Packages, 1998, 1999).

At this National Workshop on Developmental Screening, consensus was reached that screening for moderate and severe disability should be carried out in line with comprehensive PHC service delivery. Such programmes should fully involve caregivers and be linked to appropriate interventions. This forum also outlined a proposed schedule for screening and criteria for the development of screening tools (Child Health Policy Institute, workshop proceedings, 1996).

2.2.3. Continuation of the process in the Western Cape and establishment of the Provincial Reference Group for Developmental Screening

Following the national workshop, developmental screening was prioritised as a priority within the MCWH Sub-directorate of the Western Cape Department of Health. The Western Cape Province was the only province to take this process forward. Other provinces were concerned that their PHC services were not sufficiently developed to introduce such a programme. As screening had been conducted previously in the Western Cape, local roleplayers from this province felt that screening could be achieved through standardisation of existing practices. (Verbal Communication, Deputy-Director, MCWH, PAWC Department of Health, 2002).

In taking developmental screening forward in the Western Cape Province, the MCWH Sub-directorate of the PAWC Department of Health set up a multi-disciplinary and inter-departmental Provincial Reference Group. The reference group was chaired by the Deputy-Director of MCWH and included representatives from the Chronic Care and Rehabilitation and Mental Health Sub-directorates of the Department of Health at a provincial level, regional health managers, the Western Cape Education Department, academic and child development service provision institutions, other centres and NGOs involved with children with developmental disability as well as health workers "on the ground" (PAWC Department of Health MCWH Sub-directorate, Letter to regional directors, December 1997; Summary Programme Report, August 1999).

2.2.4. Formulation of the goal, aims and objectives of the Provincial Reference Group

The initial goal, aims and objectives of the reference group, which first convened in November 1996, are presented in Box 3.

Box 3: Initial goal, aims and objectives of Provincial Reference Group

Goal:
To develop an integrated and co-ordinated system for the comprehensive management of childhood disability

Aims:

- To establish a system of early detection of developmental delay and disability in children under 5 years
- To develop a referral system for children with developmental delay addressing preventive, diagnostic and rehabilitative aspects of care

Objectives:

1. To develop screening tools for developmental assessment of children at 6 weeks, 9 months, 18 months and 3 years
2. To develop a referral system for children with developmental delay addressing preventive, diagnostic and rehabilitative aspects of care

(a) To do an audit/ situational analysis of services at each level of care
(b) Define services desirable at each level
(c) Identify relevant roleplayers and team members at each level
(d) Integrate and co-ordinate services available
(e) Develop regional referral patterns and support systems between each level of care
(f) To construct a regional data base/ resource directory to facilitate management

Source: Draft miscellaneous document, September, 1997

As can be seen from the aims and objectives, the reference group endeavoured not only to develop standardised screening tools but also to develop a referral system for children identified with developmental delay. In 1997, a provincial directive was issued regarding referral routes in the Western Cape, and thus the reference group's role in the development of a referral system for each of the regions came to be viewed more as a facilitatory function (See revised objectives in Box 4).

Box 4: Revised reference group objectives

Objectives:

1. To develop screening tools and guidelines for developmental assessment of children at 0 – 6 weeks, 9 months, 18 months and two to five and a half years.
2. To develop training packages for each of these screening tools.
3. To pilot these screening tools and to implement them with support to the districts.
4. To facilitate the development of a referral system in each region.

Source: Progress Report, May 1998

2.3. Programme Context

It is critical that the development and implementation of the Developmental Screening Programme is considered within the broader context of the health system in the Western Cape.

2.3.1. Location and prioritisation of the Developmental Screening Programme within PAWC Department of Health

The Developmental Screening Programme falls within the MCWH Sub-directorate of the Programme Development Directorate of the PAWC Department of Health. While the programme has been prioritised in that it has become formal policy within the province, it does not receive high priority within the Programme Development Directorate. Currently programmes such as those addressing HIV/ AIDS and TB receive the greatest focus at a provincial level. This has filtered through to a regional level where regional roleplayers have indicated that the Developmental Screening Programme is a low priority even within their MCWH Sub-directorates.

2.3.2. Developmental screening within the context of primary health care delivery in the Western Cape

The development and implementation of the Developmental Screening Programme has taken place during a period of much change and restructuring within the

Department of Health. In addition to the introduction of free health care for children under six years in 1994, the more recent shift towards the District Health System and the delivery of comprehensive, integrated services at a PHC level has had an enormous effect on health facilities, health workers and the services they deliver. These changes as well as the current emphasis on curative care have significantly influenced the delivery of preventive services including developmental screening. These issues will be discussed in further detail in the Discussion chapter.

2.4. Programme description

2.4.1. Vision, aims and objectives of the programme

Although objectives were established by the Provincial Reference Group for the development of the tools and training, no explicit vision, aims and objectives were formulated for the Developmental Screening Programme at the level of implementation. Furthermore, indicators and targets for the monitoring and evaluation of the screening programme were not defined.

2.4.2. Funding of the programme

In 1997 a private company formed a partnership with the Provincial Reference Group with an agreement to provide funding for the training component of the programme. A total of R80 000 was granted to the reference group from 1998 – 1999 towards the development of teaching and training materials (Provincial Reference Group, Letters to private company requesting funding, December 1997, November 1998).

2.4.3. Overview of the development, pilot and implementation phases of the programme

In accordance with the objectives outlined above, the development of screening tools guidelines and training packages commenced in 1997. Development and implementation comprised three phases:

- **Development phase**: Development of the core components of the programme

- **Pilot phase**: Pilot of the programme, including training, implementation and monitoring and evaluation at selected pilot sites
- **Implementation phase**: Formal implementation of programme across the province including regional training workshops culminating in the Developmental Screening Programme being adopted as formal policy in Western Cape.

2.4.4. Development phase

Based on observation of the PHC System, including health facility workloads, attendance patterns of children at health facilities and local and international research, the reference group decided to develop screening tools for the 0 – 6 weeks, 9 months and 18 months age groups. Screening would coincide with immunisation visits where attendance was notably higher. The feasibility of developing a screening tool for the 2 – 5 year pre-school age group was questioned. Issues addressed (1) children should already be identified before two years, (2) no immunisations were required between 2 – 5 years, (3) irregular clinic attendance at this age and (4) wide age range for which to develop a tool. Thus it was decided to focus on the development of the first three tools (PAWC MCWH Sub-directorate, Letter to regional directors, December 1997; Programme Training Packages, 1998, 1999). The 0 – 6 week, 9 month and 18 month screening tools, guidelines for delivery and training packages were developed sequentially from 1997 – 1999.

Components developed

Four core components were developed, piloted, reviewed and implemented as part of the Developmental Screening Programme. These included:

a) Standardised screening tools for screening at 0 – 6 weeks, 9 months and 18 months
b) Standardised guidelines to complement each of the three screening tools
c) Training packages to train staff on each of the three screening tools
d) Referral guidelines for referral of children identified via developmental screening for further assessment and management.

An additional component was later introduced and did not form part of the Developmental Screening Programme policy document:

e) Stimulation guidelines to assist health workers in providing information to caregivers on stimulating their children.

a) Standardised screening tools (See Appendix 1)

The three screening tools developed for the Developmental Screening Programme were based on existing local screening tools (that is, screening tools used previously in the province) together with additional input from other national and international tools and research in the field of developmental disability, for example, the "Ten Questions Screen Questionnaire" developed by Durkin and Khan (1995). The tools were developed so that they could be rapidly administered, were short, simple and easy to use and sensitive and reliable (PAWC Department of Health MCWH Sub-directorate, Programme Training Packages, 1998, 1999).

A physical examination was included in the screening tools at the request of health workers and to reinforce the idea of a comprehensive PHC approach. The focus of the tools however was on identifying developmental disability, covering all aspects of development i.e. gross and fine motor, language and hearing, vision, psycho-social development and mental health. Caregiver involvement and the notion that the "caregiver knows the child best" formed the foundation of these tools, with several previously used tests/ hands-on testing methods, such as the rattle hearing test using the Manchester high frequency rattle, being replaced by questions to the caregiver (Provincial Reference Group for Developmental Screening, Minutes, Seventh Meeting, 5 December 1997; Programme Training Packages, 1998, 1999; Verbal Communication, Deputy-Director MCWH, PAWC Department of Health, 2002). The tools were designed in such a way that they could be used as referral forms with space for health worker comments.

b) Standardised guidelines (See Appendix 1)

For each of the screening tools, a standard set of guidelines was developed in English and Afrikaans to assist health workers to administer the tools. Guidelines provided

health workers with information on preparing the clinic setting, equipment needed and administration of each item of the screening tool. Clear illustrations provided further guidance to health workers on physical examinations, observations and recording screening results.

c) Training packages

Training packages for each of the three tools were developed by the Provincial Training Task Team, a sub-group of the Provincial Reference Group. The training packages formed the basis of a six-hour workshop covering theoretical aspects of child development and screening, information on screening for developmental disabilities in the Western Cape Province (including formulation and implementation of the programme) and training on the content and administration of each tool (PAWC Department of Health MCWH Sub-directorate, Letter to regional directors, June 1998).

d) Referral guidelines (See Appendix 1)

At the request of the health care workers, guidelines for referral of children for further developmental assessment and management were developed. In these referral guidelines, referral points (e.g. medical officer, regional paediatrician, health therapist) for each abnormality or delay, were suggested. Each district and region was asked to identify their own specific referral routes in accordance with the provincial health policy for referral pathways and determined by their own health resources.

e) Stimulation guidelines

In addition to the core components of the Developmental Screening Programme, stimulation guidelines for health workers to provide caregivers were developed at the request of the health workers. The development of these stimulation guidelines (for each of the three screening ages) was co-ordinated by the regional Rehabilitation Co-ordinator in the Southern Cape/ Karoo with input from other therapists on the Provincial Reference Group.

2.4.5. Pilot phase

Pilot sites for the Developmental Screening Programme were chosen in consultation with roleplayers in the four health regions and approved by the regional directors. During the pilot phase of implementation, these pilot sites received training and continued support from the Provincial Training Task Team. Implementation at the pilot sites was formally monitored by an external evaluator. Based on the recommendations of this evaluator, together with recommendations made by health workers at the pilot sites and other stakeholders, the tools, guidelines and training packages were reviewed and finalised.

Selection of pilot sites

Four pilot sites with differing characteristics were selected.

1. Boland/ Overberg Region: **Grabouw Community Health Centre**
A rural town including mobile, clinic and private services.

2. Southern Cape/ Karoo Region: **Heidelberg Community Health Centre**
A rural health facility with a mobile unit.

3. Metropole Region: **Malibu Clinic**
An urban health facility with satellite facilities and a mobile unit.

4. Metropole Region: **Mzomomphle Clinic**
This pilot site was added in response to the concern raised by Provincial Reference Group members that the tools were not piloted in a Xhosa-speaking community in the region.

(Provincial Reference Group for Developmental Screening, Minutes, 7th meeting, 5 December 1997).

The programme was not piloted in the **West Coast/ Winelands Region** due to a lack of infrastructure in the regional office at that stage.

Training and support of health workers at pilot sites

Training and ongoing support of the health workers was provided by the Provincial Training Task Team at the selected pilot sites. This task team provided regular feedback to the reference group, regional directors and pilot sites, and in so doing contributed to changes and improvements in the training packages.

Although training is a regional and not a provincial function it was decided that the MCWH Sub-directorate at a provincial level and the reference group would provide the initial training via the task team in order to facilitate and introduce the programme to future trainers at a regional level. It was agreed that, following the initial training by the task team (during the pilot and early implementation phases), the Human Resource Development (HRD) Sections in each region would provide continuing in-service training on the programme.

Pilot phase monitoring and evaluation

Formal monitoring and evaluation was undertaken by an external evaluator during the pilot phase of the 0 – 6 week and 9 month Developmental Screening Tools (Programme Progress Report, May 1998; Programme Training Packages, 1998, 1999). This monitoring and evaluation focused predominantly on the tools and their acceptance and ease of use in the clinic setting.

Observation of developmental screening, evaluation of training and recommendations and interviews with professional nurses and caregivers were mostly positive. Tools and guidelines were reported to have met expectations and to be working well. Minor changes were suggested to improve the pilot tools, guidelines and training packages. These were subsequently incorporated into final drafts (Minutes, 12th Provincial Reference Group Meeting, 9 October 1998; Lavies, Report on monitoring and evaluation of the 0 – 6 weeks and 9 months Developmental Assessment Pilot Tool, July 1998, October 1998).

2.4.6. Implementation phase

Once the pilot phase of the programme was completed at the pilot sites, implementation was extended to all other facilities across the province. This initial implementation phase included the provision of two training workshops by the Provincial Training Task Team in each of the four health regions. Once all training workshops had been completed, a provincial circular was issued by the Superintendent General in December 1999 obliging health workers to deliver developmental screening at a PHC level.

2.5. Context for current evaluation

From early 2000, health workers at a PHC level throughout the province began delivering the Developmental Screening Programme with training provided by the HRD sections of the regional health departments. Already in the early stages, much interest was voiced by health workers and health managers regarding the development of a fourth screening tool for the 2 – 5 year age group. In addition, requests were received from other provinces for access to the existing screening tools. As no formal evaluation had been conducted regarding the implementation and delivery of the programme, the MCWH Sub-directorate and reference group took a decision to conduct an "audit" of the programme prior to commencing with the development of a further tool.

In March 2001, the MCWH Sub-directorate together with the reference group commissioned the Children's Institute (then Child Health Policy Institute) with the author as primary researcher to conduct an evaluation of the programme. The evaluation commenced in August 2002 on receipt of external funding.

3. METHODOLOGY

3.1. Purpose, scope, aims and objectives

Purpose

The purpose of this study was to inform policy and practice regarding screening for developmental disabilities in the Western Cape Province. Furthermore, it was envisaged that the findings of this research would be used to inform policy and practice at a national level.

Scope

This evaluation focused on the input, process and output parameters of the Developmental Screening Programme. Outcomes of the programme (i.e. in terms of the developmentally delayed child) were not evaluated as this requires a cohort study lasting at least five years.

This study did not examine the scientific validity and reliability of the three screening tools. This requires a separate study.

Aim

The aim of this research was to evaluate the implementation of the Western Cape Province Screening Programme for Developmental Disabilities in Pre-school Children.

Objectives

The objectives of this project were:

1. To document the background to as well as the development and implementation of the Developmental Screening Programme.
2. To describe the current delivery of the programme.

3. To determine barriers and success factors within the implementation process.
4. To make recommendations to the Western Cape Province Department of Health regarding the Developmental Screening Programme.

3.2. Definition of variables

In order to meet these objectives, the following variables were defined:

Table 2: Definition of variables to be measured

OBJECTIVE	VARIABLE TO BE MEASURED
1. Background, development and implementation of the Developmental Screening Programme	Why and in what context was the programme developed?
	Who initiated the process and who were the key role players?
	How and where is the programme placed within the Western Cape health system?
	How and over what time period was the programme implemented?
	What core and supportive components form part of the programme?
	What evaluation has taken place to date and why is this evaluation being carried out?
2. Current delivery of the programme	*What?* Components of the programme
	Where? Settings within which the programme is carried out
	Who? Personnel involved in the administration of the programme
	When? When each of the tools are administered
	How? The way in which each of the tools are administered
	How long? Administration time
	How many? Number of cases screened, identified, referred
	What next? Referral/ follow-up process
3. Barriers and success factors in implementation	Does the programme meet criteria for screening?
	What success factors are promoting implementation?
	What barriers are hampering implementation?

3.3. Study design

This health systems research project employed a descriptive study design.

3.4. Study area

This study was carried out at a provincial, regional and district level throughout the Western Cape Province. Investigations took place at the PAWC Department of Health, within the Metropole, Boland Overberg, Southern Cape/ Karoo and West Coast/ Winelands regional offices and at selected PHC facilities within each region.

3.5. Overview of methods

The data collection for this study constituted four stages, as outlined in the flow diagram.

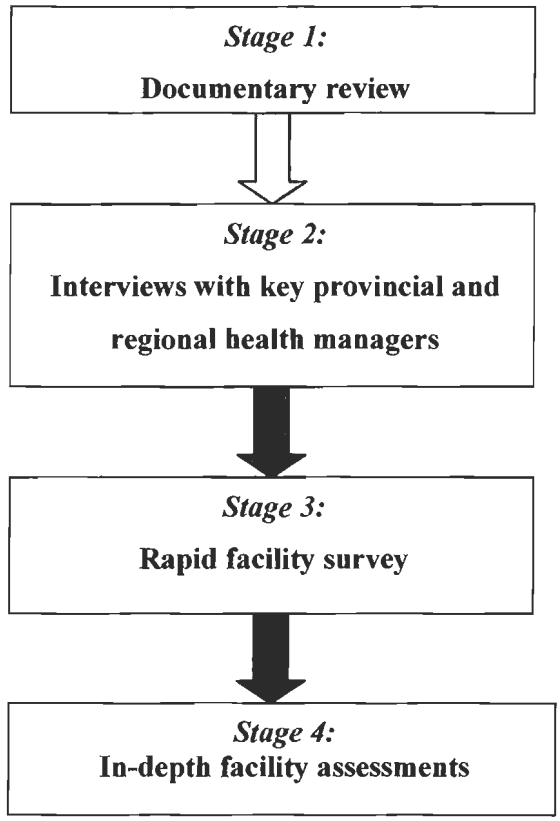


Figure 2: Stages of data collection

3.6. Sources of information and sampling

The sources of information and sampling during these four stages of data collection were as follows:

Stage 1: Documentary review

Sources of information:

The following written documentation was used to obtain information regarding the background, development and implementation of the Developmental Screening Programme:

- PAWC Department of Health Provincial Circular No. H159/99 dated 23 December 1999 including:
    - Policy statement regarding implementation of Developmental Screening Programme
    - Standardised developmental screening tools (6 weeks, 9 months, 18 months) and guidelines (for health workers on administration of tools)
    - Road-to-Health-Card and proposed method for record-keeping of screening results
    - Referral guidelines (for further assessment and management of children)
- Training packages for training of health workers on developmental screening at 0-6 weeks, 9 months and 18 months
- Discussion document on screening for developmental disabilities from National Workshop on Screening for Developmental Disabilities (1996)
- Report on monitoring and evaluation of the pilot phase of the implementation of the Developmental Screening Programme (Lavies, July, October, 1998)
- Summary programme reports (1998, 1999) compiled by Deputy-Director, MCWH
- Select letters from Deputy-Director, MCWH, to regional directors (1997, 1998)
- Select minutes of Provincial Reference Group meetings (1997 – 2002)

Sampling:

All documentation related to the Developmental Screening Programme was utilised during this stage of the research.

Stage 2: Interviews with key provincial and regional health managers

Sources of information:

- Deputy-Director of MCWH of the PAWC Department and the Chairperson of the Provincial Reference Group for the Developmental Screening Programme.
- Four regional MCWH or Rehabilitation managers (one from each of the four health regions in the Western Cape Province) integrally involved in the Developmental Screening Programme.

Sampling:

All designated provincial and regional health managers involved in the Developmental Screening Provincial Reference Group were interviewed in this study.

Stage 3: Rapid facility survey

Sources of information:

A random sample of all health facilities in the province was contacted telephonically in order to obtain a rapid overview of the delivery of developmental screening across the province.

Sampling:

A random 12% sample (n = 44) of all PHC facilities in the province was generated by computer using the MS Excel random number generator. The sample of 44 facilities was based on a hypothesis driven calculation made by a statistical consultant to ensure that the sample would be statistically representative. The random sample was stratified per region in order to obtain a proportional representation of facilities per region. Where facilities could not be contacted, a new random number (and hence facility) was generated.

Stage 4: In-depth facility assessments

Sources of information:

Of the telephonic survey sample, 20% of these facilities (nine PHC facilities of the 44 contacted telephonically) were earmarked for an in-depth facility visit. One Developmental Screening Programme pilot site and one non-pilot site within each of the four regions were selected. An additional non-pilot site in the Metropole was selected as a more typical facility within this region i.e. a large facility serving a densely populated township.

During these nine in-depth facility assessments, information was gathered from the following sources:

- Nurse managers, who provided information for the facility profile
- Clinical observation of health workers delivering developmental screening
- Interviews/ focus groups with health care workers involved with the delivery of the Developmental Screening Programme
- Exit interviews with caregivers
- Record reviews

Sampling:

Sampling of facilities

Pilot and non-pilot sites were selected in order to eliminate the bias of investigating the pilot sites alone. In this way the study would also be able to demonstrate whether the intense pilot input and training was effective. Pilot sites were matched with non-pilot sites in order that comparisons between the facilities could be drawn. Matching was based on the geographical location of the pilot site (urban, peri-urban or rural) and the concomitant socioeconomic characteristics of the district served. Each non-pilot site was located within a district similar to that of the pilot site but was not located within the same district to avoid the "spill-over" effects of the programme implementation from the pilot site. Matching was also based on the size of the facility

as measured by nursing staff complement to optimise comparability between facilities. Exact matches could not always be drawn.

Sampling of participants at health facilities

All nurse managers at the facilities visited were interviewed to obtain a profile of the facility. All developmental screening conducted during facility visits was observed by the researcher. All health workers involved with the delivery of the Developmental Screening Programme were interviewed individually or within focus group discussions. The number of health workers/ focus group participants was dependent on the number of staff available on the day of site visits and ranged from one to four.

The first available caregivers exiting from the developmental screening consultations were interviewed subject to consent. The number of caregivers interviewed was dependent on the number of developmental screens conducted and was subject to caregiver consent.

Clinic records were randomly selected for review of developmental screening entries.

3.7. Data collection

3.7.1. Procedure

In order to achieve these objectives, a combination of quantitative and quantitative data was gathered in stages from all levels of the health system (provincial, regional and district levels) using a number of different methods. In addition to documentary and literature reviews, information was gathered via structured interviews with key health managers at a provincial and regional level, a telephonic survey and facility based assessments. Data collection at health facilities included structured interviews with nurse managers to obtain a profile of the facility, clinical observations of developmental screening, interviews/ focus groups with health workers, exit interviews with caregivers and record reviews. The detailed data collection procedure is outlined in Figure 3:

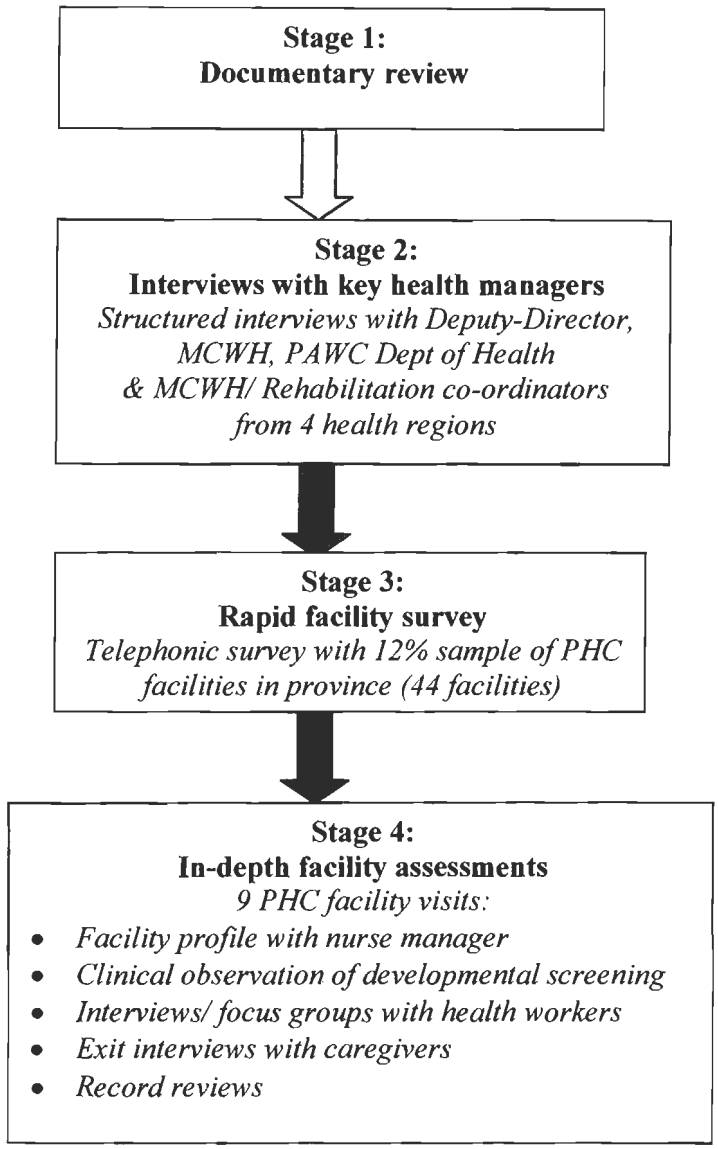


Figure 3: Detailed stages of data collection

3.7.2. Instruments

Data collection instruments used during the four stages of data collection included structured interview schedules, structured questionnaires for the telephonic survey, facility profile data capture forms, observational checklists, focus group guidelines, exit interview guidelines and record review data capture forms. These instruments were all piloted at a designated health facility prior to the commencement of formal data collection.

Stage 1 instruments

No structured instruments were developed for the documentary review. All relevant information from the documents was recorded and utilised for the documentation of the background, development and implementation of the Developmental Screening Programme.

Stage 2 instruments

Structured interview schedules: Interviews with provincial and regional health managers (Appendices 2a, 2b)

Interview schedules were developed for the semi-structured interviews (interviews using a structured instrument but allowing for varying clarification techniques and questioning) with key health managers at a provincial and regional level. Most questions were open-ended in nature allowing respondents to elaborate on any answers and reply in different directions. Ambiguous, multiple, leading and loaded questions were avoided. Summary questions were included at the end of each section to ensure that questioning was exhaustive. The content of the interview schedules encompassed the objectives and variables of the study with each schedule divided into the following sections:

1. Background, development and implementation of the Developmental Screening Programme
2. Current delivery of the Developmental Screening Programme
3. (Perceived) barriers and success factors in implementation.

The schedules for the interview with the provincial health manager and regional health managers differed slightly in terms of content. A number of additional questions regarding the background, development and implementation of the Developmental Screening Programme were asked of the provincial health manager while other relevant questions were asked of the regional managers e.g. Additional question posed to West Coast/ Winelands regional health manager: *"Why was there no Developmental Screening Programme pilot site in your region?"*.

Stage 3 instruments

Structured questionnaire: Rapid facility survey (Appendix 3)

A structured questionnaire consisting of 22 items to be administered over the telephone to health workers in the 12% facility sample was developed. A telephonic questionnaire was chosen over a self-administered questionnaire because of likely poor response rates due to communication problems (not receiving questionnaires) and time constraints at health facilities.

The format of the questionnaire was designed to facilitate maximum understanding by respondents by avoiding ambiguous or non-specific questions, including only one concept and no biased or emotionally laden words. Questionnaires were also prepared to keep administration time to a minimum. The questionnaire included multiple types of questions including fixed alternative questions (with yes/ no response or choice of three or four responses), scale items and a limited number of open-ended questions requiring specific factual information.

The content of the questionnaire related to the current delivery variables of this study. The questionnaire was divided into the following sections:

1. Awareness of the programme
2. Use of the tools
3. Appropriate use of the tools
4. Capacity to implement
5. Referral and follow-up
6. Statistics
7. Other comments

Stage 4 instruments

Facility profile data capture form (Appendix 4)

A standard data capture form was designed to obtain facility-related information from the nurse manager at each of the clinics and community health centres (CHCs) visited. This facility profile including both a service and staff profile with a focus on preventive services rendered (including developmental screening).

(d) Observational checklists (Appendices 5 and 6a, 6b, 6c)

Four observational checklists, i.e. a general health facility observational checklist and three developmental screening observational checklists for observation of developmental screening at 0-6 weeks, 9 months and 18 months, were developed for this study.

The health facility observational checklists included questions regarding the overall friendliness and child friendliness of the facility as well as the manner/ ease in which preventive services (immunisations and screening) were run within the facility. Notes were taken by the researcher and corroborated by the research assistant in response to these checklist questions.

Checklists for observation of the administration of the three developmental screening tools were developed based on the standardised developmental screening guidelines. These checklists made provision for the researcher to record which items in each of the tools were or were not completed by the health worker and were or were not administered in accordance with the guidelines. Checklists also allocated space for notes on screening time, other activities required of the health workers as well as any other general notes on screening observed.

(e) Focus group guidelines (Appendix 7)

Focus group guidelines for focus groups with health workers involved in the delivery of developmental screening at each of the facilities visited were devised, including topics for discussion to yield the following key information:

- Importance of developmental screening
- Implementation of the programme, with a focus on training
- Delivery of the programme
  - What did they like about it?
  - What did they dislike about it?
- Overall effectiveness of the programme – barriers and success factors
- Recommendations for improvement

Topics for discussion were posed via open-ended questions to encourage participants to talk freely and spontaneously, not only yielding information regarding the delivery of developmental screening but opinions and perceptions regarding the strengths of the programme and challenges faced.

(f) Exit interview guidelines: Interviews with caregivers (Appendix 8)

Exit interview guidelines for interviews with caregivers were developed in the same way as the focus group guidelines with a series of five prompt questions. This semi-structured approach was chosen over a structured set of questions in order to overcome cultural barriers i.e. to avoid caregivers responding only positively ("yes") to closed-ended questions. Interviews were conducted in the caregiver's home language by a research assistant.

(g) Retrospective record review data capture sheet (Appendix 9)

A data capture form was developed to record information on children who had failed the Developmental Screening Programme (i.e. identified as being possibly developmentally delayed) and follow them up at the next levels of care (referral points at secondary and tertiary levels of care). However, this form could not be used

in practice as facilities did not record children who have previously failed developmental screening and hence there was no mechanism for follow-up.

3.8. Pilot study

Prior to the commencement of the formal data collection, a pilot study of stages three and four of the research methods was carried out. The pilot study of stage three included the administration of the telephonic survey with one facility from each of the four health regions. Stage four included an in-depth facility assessment at a PHC facility in the Metropole Region (second Developmental Screening Programme pilot site in the Metropole Region) which was not to form part of the formal evaluation. The aims of the pilot studies were threefold:

1. To estimate the time required for each aspect of data collection, in particular the time needed to administer the telephonic survey questionnaire.
2. To familiarise the researcher with the methodology and research instruments, in particular the dynamics around conducting an evaluation at health facilities.
3. To determine whether any changes to the methodology and/ or research instruments were required.

Based on the findings of the pilot studies, minor changes were made to the research instruments. Some insights were also obtained into the constraints of once-off facility visits and logistics of collecting data within the busy clinic environment.

3.9. Data analysis

Stage 1 analysis

Information gathered from documentary reviews was recorded and included in the description of the background, development and implementation of the programme.

Stage 2 analysis

Tape-recorded interviews conducted with health managers at a provincial and regional level were transcribed verbatim and analysed thematically in order to extract both factual information regarding the background, development and implementation of developmental screening as well as perceptions and impressions regarding the current delivery of the Developmental Screening Programme. The procedure followed for this thematic analysis incorporated the work of three sources on qualitative data analysis: Patton (1990), Corbin and Strauss (1990) and Marshall and Rossman (1995) and is outlined in Figure 4.

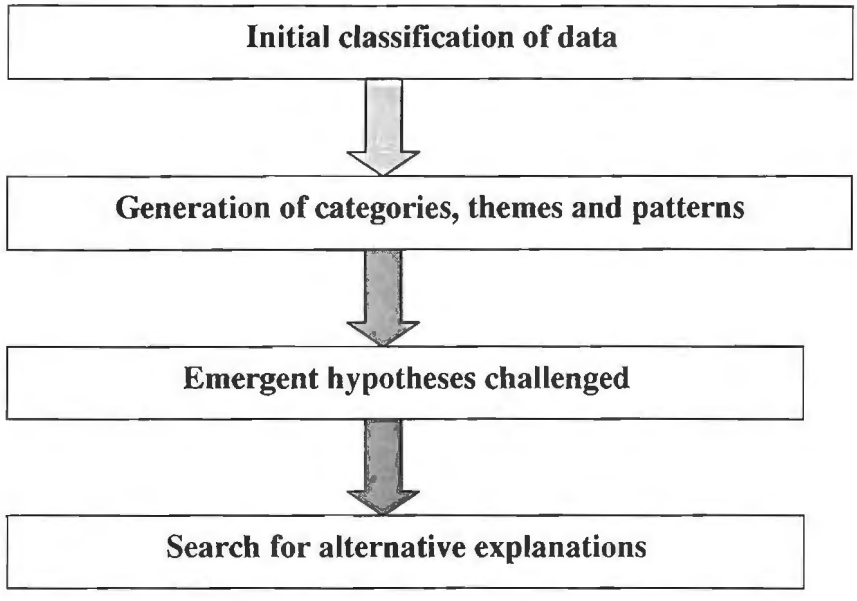


Figure 4: Stages of data analysis

Initial classification of data

Once all raw data were gathered and transcribed, the researcher studied each of the interview transcriptions, making comments in the margin. These comments included ideas and perceptions of particular observations, sentences and paragraphs. Each of these incidents, ideas or events were then given an identifying label. Incidents were then compared so that common phenomena received common names.

Generation of categories, themes and patterns

Once phenomena had been identified, groups or categories of phenomena were formed. Categories were provided with more abstract names but remained sufficiently transparent to reflect on the meaning of the raw data. Category sheets in MS Word were then set up and coded raw data from transcriptions pasted under relevant category headings. Categories were then examined for convergence and divergence to determine to what extent data were compatible within a particular category. Categories were also expanded by linking (bridging and surfacing) categories.

Emergent hypotheses challenged and search for alternative explanations

At this stage, data was searched in order to challenge the established hypotheses to find information that was not in agreement. When challenging these patterns, alternative explanations were sought, identified and described in order to demonstrate why a particular explanation was the most plausible.

Stage 3 analysis

Data collected via the telephonic survey were coded, entered into a MS Excel spreadsheet and then imported into EpiInfo (Version 6.04) for analysis. The statistical analysis was predominantly descriptive in nature and yielded important qualitative information and patterns regarding the delivery of the Developmental Screening Programme across the province.

Stage 4 analysis

Data collected from facility profiles, observational checklists and record reviews were summarised on summary and tally sheets to be presented in a descriptive fashion and examined for trends and patterns.

Data gathered from interviews/ focus groups with health workers and exit interviews with caregivers (all tape-recorded) were analysed using the same methods as for the analysis of interviews with health managers.

3.10. Procedure adopted to enhance and determine rigour of analysis

A number of methods were employed in this study in order to enhance and determine the rigour of the data analysis procedure. These were based on the methods proposed by DePoy and Gitlin (1994), Katzenellenbogen, Joubert and Karim (1997) and Jacobs and Kapuscik (2000), and are outlined below:

- **Reflexivity, subjective assessment of interview setting and data on characteristics of respondents**

Depoy and Gitlin (1994) and Katzenellenbogen and Joubert (1997) stress the importance of reflexivity or self-examination by the researcher to determine the effects he/ she and the environment have on data collection. They also encourage reporting on the characteristics of respondents (participants) to give an indication of the reliability of responses.

In this study, such notes were made during and after facility visits (in observational notes and transcriptions of interviews/ focus groups) e.g. regarding the researcher's relationship with the health workers and their willingness to provide information and the influence of clinic timetables and activities on the ability to conduct interviews and obtain information.

- **Triangulation**

Triangulation, a process whereby one source of information is compared to another, was used in this study to confirm and validate findings. Information obtained from interviews with provincial and regional health managers regarding current delivery of the programme, for example, was compared with quantitative data from the telephonic survey.

- **Peer review**

In addition to the abovementioned triangulation techniques employed, a research assistant who accompanied the researcher on all facility visits was able to perform a peer review function for data collected. Observations made by the researcher during facility visits were compared with those of the research assistant.

3.11. Limitations of the study

The inability to access information from the consumer population (i.e. the caregiver population) as well as information from record reviews, is acknowledged as a limitation of this study. It is also believed that the brief and once-off nature of the facility survey and site visits may have constrained the amount and quality of information gathered directly via discussions and observations of health workers.

3.12. Ethical approval and ethical considerations

Prior to the commencement of this research project, ethical approval was obtained from the Research and Ethics Committee of the PAWC Department of Health as well as the Ethics Committee of the University of Cape Town. Ethical approval from the Department of Health included permission to conduct the study within public health facilities. This was later confirmed with regional directors and relevant local authorities and health facility managers.

Written and verbal consent was obtained from all participants in this study. Privacy and confidentiality of participants was ensured. No patient details were recorded and staff anonymity was observed.

4. RESULTS

4.1. Sources of information

The results of this study detailing the current delivery of the Developmental Screening Programme and presented in this chapter are based on information from the sources described below:

(a) Key provincial and regional health managers interviews
(b) Rapid facility survey
(c) In-depth facility assessments
- Focus groups with health workers
- Observation of developmental screening by the researcher
- Exit interviews with caregivers
- Retrospective record reviews.

(a) Key provincial and regional health managers interviews

The provincial health manager interviewed for this study was the Deputy-Director of MCWH, PAWC Department of Health and the Chairperson of the Provincial Reference Group for Developmental Screening. The regional health managers who participated in this study are described in Table 3.

Table 3: Description of regional health managers interviewed

Region	Current position	Years on reference group
Metropole	Programme Manager, Comprehensive Health	1996 – 1999
Southern Cape/ Karoo	Rehabilitation Co-ordinator	1996 – present
West Coast/ Winelands	Deputy-Director, Comprehensive Health	1996 – 1999
Boland/ Overberg	MCWH Co-ordinator	1998 – present

(b) Rapid facility survey

Of the 44 facilities contacted for the rapid facility survey, 75% (n = 33) were PHC clinics and 25% (n = 11) were CHCs. The breakdown of facilities telephoned per

region was proportional to the total complement of health facilities per region. Almost 40% (n = 16) of the facilities contacted, for example, were in the Metropole Region which has the densest population and the highest number of health facilities (Table 4).

Table 4: Breakdown of facilities telephoned in each region

Region	Frequency	Percentage
Metropole	16	36.4%
Southern Cape/ Karoo	12	27.3%
West Coast/ Winelands	9	20.5%
Boland/ Overberg	7	15.9%
Total	44	100%

(c) In-depth facility assessments

The nine facilities where in-depth assessments took place served either an urban or rural population and varied in terms of patient load and staff complement. A facility description is provided in Table 5.

Table 5: Description of health facilities visited

Facility	Pilot/ non-pilot Site	Clinic/ CHC	Urban/ rural	Monthly patient load <5yrs	Prof. nurse complement
Metropole					
M1	Pilot	Clinic	U	618	2
M2	Non-pilot	Clinic	U	348	5
M3	Additional non-pilot	CHC	U	1355	6
Southern Cape/ Karoo					
SCK1	Pilot	CHC	R	503	5
SCK2	Non-pilot	CHC	R	784	4
West Coast/ Winelands					
WCWL1	Non-pilot	Clinic	R	755	3
WCWL2	Non-pilot	Clinic	R	596	6
Boland/ Overberg					
BOVB1	Pilot	CHC	R	627	14
BOVB2	Non-pilot	Clinic	R	591	3

Observation of developmental screening by the researcher

The researcher observed an average of three children screened at each health facility visited. At some health facilities more screens were observed, while at two facilities no screening took place during the visit. Other sources of information (including focus group with health workers and retrospective record reviews) were used to draw conclusions regarding the administration of the tools at these two facilities.

Focus groups with health workers

Health workers who participated in focus groups were predominantly professional nurses, although a number of staff nurses also provided information. The number of health workers who participated ranged from one to six.

Exit interviews with caregivers

Although the researcher planned to conduct interviews with caregivers exiting from their developmental screening consultations with health workers, accessing caregivers proved problematic. The few caregivers that were interviewed did not offer expectations regarding developmental screening as they were not informed of this service and/ or were reluctant to share information regarding the quality of service provision in general. Unfortunately, this source of information had to be discarded.

Retrospective record reviews

Difficulties were also encountered in the retrospective review of records of patients who had failed developmental screening. As health workers did not keep a register of children who failed developmental screening, they were unable to provide the researcher with records that could be used to track the referral and follow-up of these children to higher levels of care. Random clinic records were however examined to determine whether developmental screening was recorded at 6 weeks, 9 months and 18 months.

4.2. Awareness of the Developmental Screening Programme

The impressions of provincial and regional health managers interviewed for this study that a general awareness exists across health facilities regarding the Developmental Screening Programme were corroborated both by the rapid facility survey and the in-depth health facility visits. Findings from the telephonic survey revealed that 100% (n = 44) of health facilities were aware of the Developmental Screening Programme. Furthermore, all the facilities visited for in-depth assessments (n = 9), were aware of the programme, with the extent of awareness varying from facility to facility.

4.3. Extent of programme delivery

Provincial and regional managers expressed concerns that, although there seemed to be a general awareness of the Developmental Screening Programme, the extent to which developmental screening was delivered appeared to differ across facilities. These impressions were also confirmed by data gathered from the rapid facility survey and particularly from the in-depth facility visits.

The rapid facility survey revealed that the majority of facilities were delivering the 0 – 6 weeks, 9 months and 18 months screening tools. 95.5% (n = 42) of the sample of health facilities contacted telephonically reported that they were delivering the 0 – 6 week and 9 months screening tools, while 90% (n = 40) of facilities reported delivering the 18 months screening tool. Two of the facilities were not delivering the 0 – 6 weeks and 9 months screening tools, while two other facilities were not delivering the 18 months screening tool.

The in-depth assessment conducted at the nine selected health facilities revealed that seven facilities were implementing at least some part of the Developmental Screening Programme while the two remaining facilities visited were not delivering developmental screening at all.

Specific areas of non-delivery

The regional managers highlighted a number of problem areas where they believed the programme was not being delivered. The rapid facility survey confirmed that the Central Karoo District of the Southern Cape/ Karoo Region and the Caledon/ Hermanus District of the Boland/ Overberg had not implemented the programme. Additional problem areas, including the George and Mossel Bay Municipalities, were identified by the Southern Cape/ Karoo regional manager, but as they were not included in the rapid facility survey sample this information was not confirmed.

4.4. Who is delivering developmental screening?

The type or cadre of health worker as well as the capacity and training of staff in the Developmental Screening Programme was investigated.

4.4.1. Cadre of health workers conducting developmental screening

The rapid facility survey and in-depth facility visits revealed that developmental screening is primarily conducted by the professional nurse group. At one of the nine health facilities visited a staff nurse was responsible for developmental screening in collaboration with professional nurses who examined children who had failed the screen conducted by the staff nurse. At more than half of the facilities visited (n = 5) a nurse was assigned to preventive work including immunisations and developmental screening. Children attending facilities for immunisations were thus seen almost exclusively by these professional nurses.

4.4.2. Capacity of staff and training in the Developmental Screening Programme

Staff capacity

Results from the rapid facility survey revealed that an average of 3.2 health workers were delivering developmental screening per health facility telephoned. Some facilities had only one health worker delivering developmental screening, while

facilities with a larger infrastructure had up to six staff delivering developmental screening.

Findings from the in-depth facility visits differed slightly from the rapid facility survey in that fewer health workers were seen to be delivering developmental screening. An average of 1.8 health workers (professional nurses) were found to be delivering developmental screening per facility. In-depth facility assessments further revealed that the average total professional nurse complement per facility was 5.3. Hence, just over one third of professional nurses were engaging in developmental screening (See Table 6). The number of professional nurses delivering developmental screening in relation to the total professional nurse complement was dependent on the way in which service delivery was structured in the facility i.e. whether certain health workers were assigned to developmental screening (marked with "A" on Table 6) or whether all health workers carried out all PHC services.

Table 6: Professional nurse complement vs number professional nurses delivering developmental screening at health facilities visited

Facility	Total complement professional nurses	Professional nurses conducting developmental screening
Metropole		
M1	2	2
M2	5	1 (A)
M3	6	1 (A)
Southern Cape/ Karoo		
SCK1	5	2 (A)
SCK2	4	1 (A)
West Coast/ Winelands		
WCWL1	3	1 SN (A)
WCWL2	6	4
Boland/ Overberg		
BOVB1	14	2 (A)
BOVB2	3	3
Average	**5.3**	**1.9 (36%)**

Staff training

Both the rapid facility survey and the in-depth facility assessments investigated the training received by health workers in the Developmental Screening Programme. Data

were collected to determine what proportion of staff delivering developmental screening had received formal training and which training bodies had trained these health workers. Information was also gathered from health managers and health workers regarding their perceptions of training received.

Number of staff trained

Both the rapid facility survey and the in-depth facility assessments revealed that not all staff delivering developmental screening have received formal training in the programme. According to the rapid facility survey, of the 3.2 health workers delivering developmental on average in health facilities, an average of 2.6 health workers had received training (80%). In-depth facility assessments revealed that fewer health workers had received formal training – only 53% of staff (nine of 17 staff members).

Trainers

Data gathered from the rapid facility survey and in-depth facility assessment provided further information regarding the proportion of health workers trained by one of five trainers i.e. the Provincial Training Task Team, the HRD sections of the regional departments of health, local or district authority training departments , facility in-service training and other bodies (e.g. training on related programmes).

Table 7 and 8 indicate that the majority of health workers received training (especially initial training on the programme) from the Provincial Training Task Team. While 15 – 16% of facilities contacted telephonically for the rapid facility survey reported having received training from their regional HRD department, none of the facilities visited for in-depth assessments had received ongoing training from this body. The rapid facility survey did however reveal that the majority of HRD training had taken place in the Boland/ Overberg Region. Training by local or district authorities and facility in-service training were seen to have taken place, especially as mechanisms for ongoing training in the absence of input from the Provincial Training Task Team.

Table 7: Trainers reported by facilities telephoned and visited

Source of information	% of health workers trained by each body				
	Provincial Training Task Team	HRD	Authority training dept.	Facility in-service training	Other
Rapid facility survey results of initial training (n = 44)	59%	15%	-	21%	6%
Rapid facility results of ongoing training (n = 44)	40.5%	16%	3%	40.5%	-
In-depth facility results (n = 9)	78%	-	11%	11%	-

Table 8: Overview of staff training at facilities visited

Facility	No. nurses screening	No. formally trained	Trainer	Additional comments
Metropole				
M1	2	2	Provincial Training Task Team	Both professional nurses at M1 during pilot of programme. Staff nurse does immunisations only.
M2	1	1	Authority training dept.	Dedicated professional nurse for children (preventive and curative). Other 4 also trained by task team.
M3	1	0	-	Dedicated professional nurse for children, but has other functions e.g. PMTCT. Not trained in dev. screening and does immunisations only. 2 other PNs trained by task team (1 left M3, 1 acting clinic manager)
Southern Cape/ Karoo				
SCK1	2	2	Provincial Training Task Team	1 professional nurse screens on mobile, other at CHC. Professional nurse at CHC was member on Provincial Reference Group.
SCK2	1	0	-	Professional nurses rotate through preventive service delivery. Do not receive formal training.
West Coast/ Winelands				
WCWL1	1 (staff nurse)	1 (staff nurse)	Facility in-service training	Staff nurse dedicated to children formally trained by Sr. in charge who assists with cases who fail dev. screen

WCWL2	4	1	Provincial Training Task Team	Only Sr. in charge trained by task team. Other nurses not formally trained. No dedicated staff for children. Staff nurses involved in 9, 18 month screening.
Boland/ Overberg				
BOVB1	2	1	Provincial Training Task Team	Used to have dedicated professional nurse for dev. screening. Now nurses rotate through preventive service delivery. No formal training received. 1 professional nurse trained by task team assists with screening but she is also leaving BOVB1.
BOVB2	3	1	Provincial Training Task Team	Only Sr. in charge trained by task team. Other nurses not formally trained. Only received training packages.

Perceptions of health managers and health workers regarding training

Interviews with the provincial and regional managers as well as focus groups with health workers highlighted the following key aspects of training on the developmental screening:

Initial training by the Provincial Training Task Team

"When they finished the training they saw what the programme was all about – that it wasn't extra work it was actually easier to use – much more friendly for them."

The considerable input and training by the training task team was highly appreciated and valued by regional managers and health workers alike, especially in view of the fact that training is not a provincial function. Training by this body was very well received as highlighted by the comments above. Training by the Provincial Training Task Team was viewed as a major strength in the implementation of the Developmental Screening Programme and a factor which contributed significantly to whether the screening was delivered by health workers or not.

Training by the Human Resource Development (HRD) departments

"Training was done in the beginning by the provincial task team but unfortunately there has been no follow-up training"
"Then you sit with one single HRD person...it is humanly impossible for her to be on top of the nine sub-directorates and about 20 programmes"

The need for ongoing training in developmental screening was voiced by the health workers, however, as outlined above, little training was being conducted by the respective HRD teams. Many of the training manuals provided by the Provincial Training Task Team to the HRD teams had reportedly been mislaid. The Boland/ Overberg Region HRD team was reported to be the most active, as seen in the rapid facility survey. Provincial and regional managers commented on the difficulties within the HRD system which was seen as largely under-resourced.

Training by local or district authorities

"Otherwise there is nothing done internally to upgrade. Although we have a teaching department we rarely have sort of like seminars so that at least we know we are current or if there is anything else that is new it's added on or if we have questions that we can ask...at least we know we are abreast. So such things do not happen".

As seen from facility survey and assessment results, training by local or district authorities was fairly limited across the province. Comments from health care workers at health facilities highlighted this but there was a desire for ongoing training. Local authority training was very much dependent on the particular authority. In the Metropole Region, for example, some local authorities were identified as conducting training on developmental screening while others did not.

Facility in-service training

"Ons kry nou nie baie nie. Ons moet maar aangaan."
("We don't get much these days. We just have to go on")

"Ek het net ingeval maar nou actually hulle verwag nou eintlik die suster gaan my leer, maar sy't haar eie TB's so dis moeilik. Die mense wag vir haar so dan gaan jy maar aan."
("I just slotted in, but now they are actually expecting the sister to teach me - she has her own TB cases so it is difficult. The people wait on her so then you just proceed")

Health workers also highlighted the lack of formal facility in-service training regarding developmental screening, having to work out how to do screening based on the screening tools alone. This was especially problematic for professional nurses who rotated on to immunisation and developmental screening as seen from the comments above.

4.5. Delivery of developmental screening

4.5.1. Delivery in comparison with protocol

"I am just hoping that the tool is being used the way it should be which I have my doubts about." (Regional health manager)

As described above, the in-depth facility assessments revealed that seven of the facilities visited were delivering some aspect of developmental screening while two facilities were not delivering developmental screening at all. Further investigation at the nine health facilities visited revealed that, of the seven facilities delivering developmental screening, only one facility was delivering developmental screening according to protocol. Screening delivered in the remaining six facilities was found not to occur in accordance with standardised tools and guidelines.

Table 9 provides a breakdown of each of the nine health facilities visited.

Table 9: Delivery and appropriate delivery of Developmental Screening Programme at health facilities visited

Facility	Pilot/ Non-pilot site	Delivered?	Delivered according to protocol?
Metropole			
M1	Pilot	✓	✗
M2	Non-pilot	✓	✗
M3	Additional non-pilot	✗	✗
Southern Cape/ Karoo			
SCK1	Pilot	✓	✓
SCK2	Non-pilot	✓	✗
West Coast/ Winelands			
WCWL1	Non-pilot	✓	✗
WCWL2	Non-pilot	✗	✗
Boland/ Overberg			
BOVB1	Pilot	✓	✗
BOVB2	Non-pilot	✓	✗

Delivery of developmental screening at these six health facilities was seen to differ from protocol in one or more of the following ways:

- Not every child was screened at 6 weeks, 9 month and 18 months
- The full screen was not always completed (i.e. items were omitted)
- Items on the screen were inappropriately administered e.g. health workers altered wording when posing questions on tools to caregivers, inappropriate examples provided by health workers to clarify questions for caregivers, and/ or results of screening inappropriately charted.

Use of previously administered screening tools

The rapid facility survey and in-depth facility visits both showed that previous screening tools were still being used. These old screening tools were either used where the Developmental Screening Programme had not been adopted at all or in addition to the three newer screening tools. As older screening methods involved screening children at more frequent stages, old screening methods were used to screen children at "in between" ages i.e. at 6 months, 12 months, 3 years and especially 5 years. More detail is provided in Table 10.

Table 10: Rapid facility survey results of old screening tools used

Description	No. of facilities	Percentage
Old methods used only	1	2%
Old methods used at 6 months, 12 months, 3 years, 5 years complementary to Developmental Screening Programme	2	5%
Old methods used at 18 months in stead of Developmental Screening Programme, 5 years complementary to Developmental Screening Programme	2	5%
Old methods used at 5 years complementary to Developmental Screening Programme	10	23%

In-depth facility assessments revealed that health workers used old screening tools for the purpose of continuity. *"Kyk ons gaan mos deurlopend aan – dit is nie net die tool nie"*. (*"Look we just continue - it is not only the tool (that we use)"*).*"I think that we lose the baby between 2-5 and I use the green card because I like them to come back"*.

4.5.2. Delivery in relation to other child health services

The delivery of developmental screening in relation to the provision of other health services differed across health facilities visited for in-depth assessment. Three of the nine facilities visited were found to offer PHC services to children and adults throughout the day with few staff being assigned to particular areas of service delivery. Certain services (especially antenatal care, TB- and HIV-related clinics) still took place on certain days and times while comprehensive PHC was generally offered "around the clock". Children were not fast-tracked but waited among the general patient population for their immunisations and screening.

In contrast to this, six of the facilities visited for in-depth assessment were found to have health workers assigned to particular aspects of service delivery – either the delivery of child health services (n = 1) or, more specifically, the delivery of preventive services including immunisations and development screening to children (n = 5). At these facilities, well children coming for immunisations and screening were fast-tracked and did not have to wait amongst the general patient population to be seen by any one of the health workers. Delivery of (preventive) services for

children at some of these facilities occurred on a daily basis (n = 3), while at other facilities immunisations and developmental screening take place on certain days and/ or at specific times (n = 3) e.g. on a Monday (full day) only or Tuesdays and Wednesday mornings only.

At some facilities where health workers were assigned to particular services, some were permanently assigned to immunisations and developmental screening. At others, health workers rotated through the various services, spending periods (varying from a few months to two years) assigned to each service.

One facility visited had recently implemented a booking system with five children seen per hour for immunisations and developmental screening every day.

Comments from health workers and researchers' observations regarding assigning of staff, multi-tasking, staff rotations and booking systems

Focus groups with the health workers and observation by the researcher during facility visits revealed a number of **advantages of having staff assigned to specific functions:**

- **More organised and focused**

"Dis georganiseer, jy voel net meer georganiseer. Nou's jy besig met 'n siek mens, die volgende een kom in immunisering, die volgende een is 'n psigiatriese een... Ek meen jyself moet jou ook instel vir die dag."
("It is organised. You just feel more organised. The one minute you are busy with an ill person, the next one comes to be immunised, the next is a psychiatric case.....You have to tune yourself in to the flow of the day.")
"Ja, emosioneel kan jy dit nie verwerk nie en dis meer intensief ek meen as jy net mylpale die hele dag doen dan is jy ingestel en en dan gaan jy dit definitief doen."
("Yes, it is difficult to cope with it emotionally and it is a lot more intense – if you just do milestones the entire day then you are tuned in to it and then you will definitely do it.")

- **Better information provided**

"En daar word net baie beter voorligting gegee want jou voorligting wat jy gee is min of meer almal dieselfde, so jou kop werk net eenkant toe."
(*"And there is much better information given as the information you give is more or less the same, so your mind is just focussed in one direction"*)

- **Ownership/ responsibility taken by health worker**

"Kyk met die veranderings het hulle mos gesê alles moet mos poliklinieke wees, maar van die begin af het ons gesê as jy nie een ou die verantwoordelike persoon maak van jou dit of dat nie dan gaan niemand mos daarna kyk nie."
(*"With all the changes they told us that everything has to be comprehensive (polyclinics) but we told them at the outset that unless you make one person responsible, no-one will attend to it."*)

- **Establishment and maintenance of patient rapport**

"When we are dealing with people, the people must learn to trust somebody – that's one person. Now if there's somebody else whose on that room that she was you know. Now there is actually a problem."

Health workers further highlighted the **disadvantages of multi-tasking** i.e. being involved in the delivery of a variety of service rather than being assigned to specific services:

- **Inability to focus**

"Ja, it is because if you have to do four things at one time, your mind is not...you don't concentrate on one thing."

- **Quality of work not as good**

"So we don't actually concentrate on one thing, so we may miss one or two things"

Where assigning of staff was seen to be extremely positive, the **rotation of staff through the different services** was **not observed to work very well.** Where rotation of staff was in place, not all staff were motivated to carry out immunisations and developmental screening owing to lack of interest. When one health worker was asked if she enjoyed working with well babies, she responded *"Ek het nie 'n keuse nie - ons moet draai...". ("I don't have a choice - we have to rotate".)* Developmental

screening appeared to work best where health workers were permanently assigned to those and related duties such as perinatal care.

Health workers from BOVB1 highlighted some of the **advantages of having a booking system** which had recently been introduced at their facility. They indicated that it relieved the time pressures that they used to experience, allowing more quality time for patients. *"Nou met die nuwe sisteem gaan dit baie goed...Maar regtig met die afsprake het jy meer tyd". ("The new system is working extremely well. You actually have more time with an appointment system").* At M3, where a booking system was not in place, one of the health workers recommended, "*We should target on doing certain work for so many hours. I mean if we have to be with the patient for 15 minutes so if you are having 40 you must know when you are going to finish up."*

4.5.3. Administering of developmental screening

Setting required for developmental screening

During in-depth facility assessments, health workers were observed doing developmental screening in the clinic and, in one case, the mobile clinic setting. In all cases, screening took place in a separate room, however the extent to which privacy was ensured differed across facilities. In a number of facilities the door of the clinic room was left open during the developmental screening consultation. In one facility, two health workers consulted with two caregivers and their children in the same room. In some facilities, health workers experienced difficulties ensuring privacy owing to interruptions by other health workers and/ or patients. At one such facility, the health worker noted, *"And then the lack of privacy during that. You doing somebody and then there's someone coming, I need this, can you help me and they all expect you to help them."*

The extent to which consultation rooms were child friendly also differed dramatically between facilities. Some health facilities had dedicated "baby rooms" with brightly coloured walls bearing appropriate health education materials (including developmental milestones and head circumference charts). Other facilities did not offer private and/ or welcoming child and family centred treatment environments.

Equipment requirements

The Developmental Screening Programme Guidelines stipulate that health workers have the following equipment available in order to administer the screen:

1. Weighing scale and tape measure
2. Road-to-Health Card
3. Clinic records
4. Growth charts (weight and head circumference)
5. Otoscope (9 months and 18 months screen only)
6. Bean-sized object e.g. a crumpled piece of paper (18 months screen only)

In all facilities, the child's Road-to-Health Card and clinic records as well as growth charts were readily available in developmental screening consultations. In all facilities bar one, children were weighed by assistant nurses or nutrition counsellors prior to their developmental screening consultation. As a result, none of the consultation rooms where developmental screening took place had weighing scales. Head circumference measurements were however taken by health workers (a number of professional nurses also measured the child's length/ height although this is not obligatory) and thus a measuring tape was available in each consultation room. An otoscope was never required by health workers during site visits (otoscope is only used to rule out outer or middle ear pathology where children fail the language or hearing questions on screening tools) therefore it was not established whether these were available. Only one health worker made use of a bean-sized piece of crumpled paper to test the pincer grip on the 18 month screening tool.

Although the standardised guidelines for the Developmental Screening Programme do not stipulate that the health worker needs to have the relevant developmental screening tool available, a number of the health workers had the appropriate form on hand. "*Nee met die ondersoek ek hou die ding hier teen my muur en dan sal ek nou vra wat ek sal onthou en dan sal ek nou kyk of ek nou alles gevra het, of alles gedoen het.*" *("No, I keep the thing against the wall during the examination and then I will ask the things that I remember and then I will check if I have asked and did everything".)* Other health workers indicated that they knew the tool "by heart" and

did not make use of the actual tool. *"With the screening we know what to look for and don't use the tool physically. "I do know my tool. I ask questions and I observe".*

Procedure (prior to examination)

Procedures prior to examination, as outlined in the Developmental Screening Programme Guidelines, require the health workers to ensure that the caregiver is comfortably seated, explain the procedure to the caregiver, ask whether the caregiver has any concerns regarding the child, examine the Road-to-Health Card and wash his/ her hands. It was found that at the majority of health facilities, health workers did not follow these procedures. Caregivers on the whole were seated comfortably and Road-to-Health Cards examined (although not always in detail) but health workers rarely explained fully the procedure to the caregiver and mostly explained only that the child would be immunised. Caregivers were mostly not given the opportunity to voice concerns regarding their child. Only one health worker washed her hands prior to conducting each screen.

Use of tools

Administration time

Consultations observed varied from five to 20 with developmental screens taking on average ten minutes to complete. Screens completed in less than ten minutes were not conducted thoroughly. Consultations always incorporated additional management of the child and caregiver including information around growth, breastfeeding and nutrition, family planning, management of minor ailments/ conditions such as skin problems and nappy rash, deworming, colds and flu as well as discussion around immunisations and management of possible side effects. Maintenance of the umbilicus and teething were less common discussion points. Only one health worker provided caregivers with guidelines for stimulation and also addressed pre-school/ crèche placement with the caregivers.

Application of the screening tools

The thoroughness (extent to which all items/ full tool completed) and appropriateness (extent to which questions, examinations and observations carried with as set out in guidelines and in so doing, reflecting the correct meaning of each item) varied considerably across health facilities. Only one facility (SCK1) completed a full tool for each child according to the developmental screening guidelines, using appropriate questions and examples for clarifications of items misunderstood by the caregiver.

The majority of other health facilities did not complete the full developmental screening tool and/ or did not administer all items in accordance with the guidelines. Questions to caregivers were often worded differently thereby changing the meaning of the question e.g. "*If you say 'come to me', does your child come?*" instead of "*Does your child respond to simple commands or questions?*" Observations were frequently inappropriate e.g. tape measure used instead of bean-sized object to test pincer grip and questions used for clarification were sometimes inappropriate e.g. "*Does your child watch a moving object? Does he watch a car out the window?*" No set patterns in the items omitted or changed by health workers were noted. Physical examinations were generally always carried out by the health workers.

Table 11 provides a further breakdown of the facilities that appeared to be administering developmental screening in a thorough and appropriate manner. At some facilities, the appropriateness of screening was dependent on the health worker administering the screen and ✓/✗ has been used to indicate that sometimes tools are appropriately completed and other times not.

Table 11: Manner in which screening administered at health facilities visited

Facility	Thorough administration (Each tool completed fully)	Appropriate administration (Tool administered according to guidelines)
Metropole		
M1	✗	✗
M2	✓	✗
M3	✗	✗
Southern Cape/ Karoo		
SCK1	✓	✓
SCK2	✓	✗
West Coast/ Winelands		
WCWL1	✓	✗
WCWL2	✗	✗
Boland/ Overberg		
BOVB1	✓	✓/✗
BOVB2	✗	✓/✗

The lack of thorough and/ or appropriate administration of the developmental screening tools was not related to difficulties experienced by the health workers in delivering the tools. The only concerns voiced by health workers regarding the developmental screening tools were the following:

- **Hearing screening.** One health worker felt that a history of deafness or whether the child startles to sound does not tell whether child can hear or not.
- Some **difficulty with hip rotation.** *"Daai rotering om regtig te voel of hy gedislocate is of nie daai's nou bietjie van 'n probleem. Dis tricky.*
  ("The rotation that tells you for sure whether the hip is dislocated or not - that's a bit of a problem. It's tricky.")
- **Language barrier.** *"'n mens kan nie altyd so lekker die vrae vra nie".*
  ("One cannot always phrase the questions very well".)
- **Respondent is not always the caregiver.** *"As hulle nie weet wat daar aangaan nie dan sê ons vir hulle volgende keer stuur julle een wat weet wat daar aangaan."*
  ("If they don't know what is happening then we tell them to send someone next time who knows what is going on".)

Feedback to caregivers

Feedback to caregivers following developmental screening was usually restricted to the health workers informing caregivers that their child was growing well, although some health workers did mention development. No other information was provided to caregivers on the whole regarding child development and stimulation (except for the pilot facility in the Southern Cape/ Karoo Region, SCK1). In one case a child with Fetal Alcohol Syndrome was not discussed with the caregiver or managed further.

Recording of results

In accordance with Developmental Screening Programme Guidelines, health workers were required to record screening results in the child's clinic records and Road-to-Health Card. Health workers were only required to use the developmental screening form itself as a referral form when the child failed the screen.

During the course of in-depth facility assessments, health workers were observed to record developmental screening results in the child's clinic records. On reviewing a number of patient folders, however, screening results were not always recorded. Patient folders were also seen to differ across regions and facilities. One of the Metropole Region facility's records was found to include old screening tools for 9 months and 18 months.

Results of developmental screening were found to be recorded less frequently on the child's Road-to-Health Card, although health workers did allude to the importance of charting results to show caregivers their child's growth and development. At one facility (M2), a developmental screening form was completed for each child screened (sheet filed in the child's paediatric clinic records) and a second facility (BOVB1) completed a developmental screening form which formed part of each child's paediatric clinic records.

Findings of the in-depth facility assessments agreed with findings from the rapid facility survey which also indicated that developmental screening results are mostly

recorded in clinic folders but not always on the Road-to-Health Card, especially when the child passes the developmental screen. Further detail is provided in Table 12.

Table 12: Telephonic survey results of recording of developmental screening

Pass	Road-to-Health Card	Folder
Yes	61%	93%
No	39%	7%
Fail	**Road-to-Health Card**	**Folder**
Yes	80%	98%
No	20%	2%

Health workers perceptions of screening tools

Health workers were very positive about the tools and their administration, commenting on the following:

- **Layout**

"Die tool is wat my betref 'n baie oulike ding. Dis mooi uiteengeset met al jou mylpale"

("As far as I'm concerned, the tool is a very cute thing. It is set out well with all your milestones".)

- **Tools are quick and save time**

"So met die nuwigheid, het darem so bietjie van vermindering van werk gekom"

("With the new changes, the work has decreased a bit")

"Dis nie so baie tydrowend nie regtig waar nie."

("It does not take up so much time – truly")

- **Tools are practical and easy to use**

"Maar dis ook baie praktics die tool jy weet dis nie langdradige uitgerekte klomp vrae nie. Dis maklike, vinnige vrae."

("But the tool is also very practical you know, it does not have long tedious multiple questions. The questions are easy and quick.)

- **Content: comprehensive, addresses all milestones, questions good**

"Ek dink die vrae wat jy hier vra is genoeg dis nie moeilik nie."

"I think the questions are sufficient and not difficult"

"En hy dek alles, want hy't gehoor en spraak en al die bewegings."

"It covers everything as it has hearing and speech and all the movements"

- **Involvement of caregivers is perceived positively – yields more information, experience for caregiver positive and encourages their insight into child development**

"It is very good, because you pick up a lot of other things like the mother says this and that about the baby. And with those others you don't ask the mother you just do and you can leave out stuff."

"En vir die ma is dit ook baie gerusstellend, want sy sien jy stel belang. Jy kyk darem. Dit gee darem vir hulle die vrymoedigheid dan voel hulle volgende keer vryliker om te kom na die kliniek."

("It is also very reassuring to the mother, as she can see that you are interested. It gives them the liberty to come to the clinic next time")

- **Easy to identify developmental delay/ disability using the tools**

"Jy kan maklik agterkom wanneer is jou kind agter as jy volgens jou tool gaan".

("You can easily determine if your child is lagging behind if you assess according to the tool")

4.6. Referrals, feedback and follow-up

4.6.1. Referral points

Results from the rapid facility survey and in-depth facility assessments indicated that health workers made use of regional paediatricians, occupational therapists and other medical staff and institutions for referral of the child with suspected developmental delay. 30% (n = 13) of health facilities contacted telephonically reported referring to paediatricians, while 40% (n = 18) indicated that they make use of occupational therapists. It was observed during in-depth health facility visits that occupational therapists were predominantly used where they visited the facility on a monthly basis. Regional paediatricians were not used as referral points at many facilities due to the inaccessibility of regional hospitals where these services are based.

Most facilities were found via the rapid facility survey to make use of other referral points including the medical officer at their local day hospital, the district surgeon at the district hospital and the genetic screening programme. Numerous facilities (20%

of facilities contacted telephonically, n = 9) still referred directly to Red Cross Hospital – either to outpatients or directly to the Developmental Clinic. Again referral points used relate directly to accessibility of services as well as transportation routes. A breakdown of referral points used by health facilities where in-depth assessments were conducted is outlined in Table 13.

Table 13: Referral points of facilities visited

Facility	Referral points
Metropole	
M1	Regional paediatrician Genetic screening programme
M2	Red Cross Hospital Paediatric outreach service, district hospital Occupational therapist, nearby health facility
M3	Red Cross Hospital
Southern Cape/ Karoo	
SCK1	Occupational therapist, visiting 1/ month District surgeon
SCK2	Occupational therapist, visiting 1/ month Sessional medical officer, visiting daily ⇨ Regional paediatrician
West Coast/ Winelands	
WCWL1	District surgeon ⇨ Red Cross/ Tygerberg Hospital Occupational therapist, local special school Genetic screening programme
WCWL2	District surgeon ⇨ Tygerberg Hospital
Boland/ Overberg	
BOVB1	Occupational therapist, visiting 1/ month District surgeon
BOVB2	Occupational therapist, visiting 1-2/ month Regional paediatrician

Interviews with health managers and focus groups with nurses confirmed these findings. In the **Metropole Region**, regional managers and health workers reported that referrals were made predominantly directly to the tertiary hospitals, Red Cross Hospital or Tygerberg Hospital. The secondary level was generally missed out. *"If there is a developmental delay of any sort on any of the tools, they are either told to come back at a later stage or they are referred inappropriately directly to tertiary hospital without having been through any other channel."*

The health manager for the **Boland/ Overberg** indicated that, even in the rural regions, there is a tendency to refer directly to the tertiary hospitals. "*There is a*

tendency to refer directly to Rooikruis, Tygerberg, Groote Schuur, and just miss our secondary hospital. Unfortunately, there is a history of referring to tertiary level directly. The other thing is we have services at our secondary hospital but they are so fully booked." In this region, direct referrals to tertiary level occurred mainly from the Overberg where Red Cross and Tygerberg Hospitals are more accessible than the region's secondary hospital in Worcester. "*Especially again one of our regions are referring directly to the Metropole to our tertiary institutions because that is just the way that the ambulances drive. You'll find most of the times that there are more regular ambulances to the tertiary regions outside our region than inside our region."* Health facilities in the Boland were reported to still make use of regional paediatric services at secondary level.

Like the Boland/ Overberg, the **Southern Cape/ Karoo** health facilities made considerable use of occupational therapists in the region to refer children with suspected developmental delay/ disability. The implementation of the Developmental Screening Programme in the Southern Cape/ Karoo was driven by the occupational therapists in the region and specific referral routes including occupational therapists as initial referral points were reportedly developed for this region. These therapists therefore continued to receive most of the referrals together with the regional paediatrician. *" In actual fact what is happening is that even if the child goes through the pediatrician, she will then also refer to the Occupational Therapist."*

Although the rehabilitation service in the **West Coast/ Winelands** were reported to have developed considerably over the past few years, referrals to district surgeons at district hospitals have continued. Decisions on whether to refer on to the tertiary level were thus made by these medical professionals. Health workers did not seem to be aware of and/ or make use of occupational therapy services at or near their facilities.

4.6.2. Referral and waiting times

All facilities contacted telephonically for the rapid survey indicated that children identified with possible developmental delay were referred immediately after failing the screener. Interviews with health managers and facility visits including focus group with health workers, did however indicate that children were sometimes brought back

to the facility a second time to confirm the developmental delay before referring. Health workers were especially reluctant to refer immediately where services, such as the services of a visiting occupational therapist, were not readily available and transportation costs for the patient to the referral point were high. *"Yes, people are afraid to refer. Let her come back and I'll see if there's still a problem."* This reluctance to refer was attributed by one of the regional health managers as a lack of empowerment and confidence by nurses to make "diagnoses" and refer on. *" Nurses aren't very confident in their diagnoses or in their ability to recognise... I think it's the way we were trained. Never allowed to make independent decisions."*
The rapid facility survey, further revealed that patients waited between one and eight weeks for an appointment at the designated referral point, with the majority of patients having to wait one week only. The mean waiting time for appointments was calculated as 2.09 weeks, that is patients wait an average of 2 weeks for an appointment.

4.6.3. Referral forms

Developmental screening guidelines stipulate that children who fail developmental screening should be referred on the developmental screening form. It was however found via the rapid facility survey that 66% (n = 29) of facilities did not make use of this form but rather use their health facility letterhead and/ or memorandum to refer. Other standard internal referral forms or letters e.g. Red Cross Hospital referral form, were also reportedly used. This was confirmed by regional managers who indicated that few referrals are received by occupational therapists and regional paediatricians on standardised referral forms. *"We get few referrals on the standard referral form. Most people are still referring on little memos that accompanies the patient for things that should have been done on the tool."*

4.6.4. Record of referrals

Only one facility of the nine visited for in-depth assessment kept an additional register of children who failed the developmental screen (WCWL1). Through this list of folder numbers, the facility was able to recall folders and follow-up with referral

points regarding whether children arrived and were managed at these institutions. No other facilities kept such a register.

4.6.5. Feedback to health workers from higher levels of care

There was little consensus amongst the regional managers as to whether health workers receive feedback on cases referred following developmental screening. Impressions varied from *"There is definitely almost zero feedback from upper level downwards"* to *"There are I'm sure gaps where people are not properly informed"* to *"Ja. It depends on staff though but usually there is"*.

The in-depth facility survey revealed that feedback is almost always received from paediatricians and occupational therapists. The feedback from other referral points varied more. One third of facilities reported to receive feedback either sometimes or never from these other referral points.

4.6.6. Follow-up

Considering only one facility visited for an in-depth assessment had a record of children referred following developmental screening, health workers were seen to rely on caregivers returning with their children to the facility with feedback. Follow-up was however also reported to occur in smaller, rural communities where health workers *"know the patients and sees the patients and if patients gets lost somewhere along the line, even if she doesn't have the time to physically follow-up, she will follow-up the patient at the clinic."*

4.7. Children identified

Focus groups with the health workers at health facilities revealed that only a few children have been identified with a developmental delay or disability. *"Dit gebeur maar weinig, baie weinig"*. (*"It happens very very seldom".)* Health workers were however not able to provide figures on the number of children identified i.e. the incidence of developmental disability. Many of the problems which have been identified have been visible: physical abnormalities including undescended testicles, clubfoot, hydrocephalus, syndromes such as Down's Syndrome, Fetal Alcohol

Syndrome and other genetic disorders. Where developmental screening was implemented more readily and according to protocol, other more subtle problems including cleft palates and hearing problems had been picked up. A number of children did not have a developmental assessment (and, as a result, a more definitive diagnosis) as they did not attend their referral appointments. *"Baie van ons kinders het nooit gegaan as ons hulle verwys het nie, met ander woorde, hulle's nooit gediagnoseer as iets nie, maar hulle's definitief agter". ("Many of our children that we referred did not go – they were therefore not diagnosed, but they are definitely lagging behind.")*

4.8. Intervention for identified children

An important aspect of this evaluation was to determine the extent to which children identified with developmental delay actually receive further assessment and management i.e. to what extent there was response to the implemented programme.

A high proportion of facilities contacted telephonically for the rapid facility survey (95%) reported that children always received intervention. This is likely to be skewed as there is, as shown in this study, no formal mechanism for following up children who have been referred.

Provincial and regional managers acknowledged that there remains a shortage of resources for developmentally delayed/ disabled children to receive intervention across the province. *"I think we've got a shortage of resources for children, especially in the rural areas. That is a real problem".* Available resources, including occupational therapy services in some areas, were reported to be underused. *"Also, we do have mechanisms in place that our health care workers are not necessarily making use of".* Transport was also reported as a constraint to intervention especially in the vast Southern Cape/ Karoo and West Coast/ Winelands Regions.

Focus groups with health workers also highlighted the need for intervention to be easily accessible to patients. *"If they had nice things in place here you know locally and so on then it would be better, you could tell the mother the lady is coming on a Wednesday or she's coming here then you don't need to go there but to leave from*

here and go there she needs money, then we have to get the money." The need for intervention to be provided on a regular basis was also mentioned by health workers. *"In die verlede toe sy nog gereeld gekom het het dit goed gegaan." ("Everything went well in the past when she did come regularly.")*

Health workers also discussed how intervention needs to be accessible to caregivers to overcome financial and broader socioeconomic constraints. *"I understand when she says oh I can't, I've got four other children, how can I spend all this time running to Red Cross?" "And we have this whole range of behavioural problems and delayed development due to various factors, malnutrition the works, with the poor social circumstances and then you refer this child, this child needs money to get to these places, dedication by the parents...these things are just not in place".*

Health workers also identified caregivers' insight and cultural views of disability as factors which sometimes prevented caregivers taking their children for further assessment and intervention. *"Also what you see as a problem the mother doesn't necessarily see as a problem... And also like squints, you have to go to the ends to convince this women look this needs to be addressed and no my father and my grandfather, it's in the family...it's fine"*
"Ek het dan 'n dowe kind - 'n doof, doof, dowe kind van geboorte af opgetel en die ma stel glad nie belang om enige iets om daai kind in 'n plek te kry waar hy hulp kan kry nie. Hy moet nou al skool toe gaan en hulle stel geensins belang nie eens dat hy Worcester toe gaan nie. Alles gereel maar niks. Jy sien hulle dink dis ok hy verstaan alles."
("I diagnosed a deaf child - a very very deaf child from birth and the mother does not take any interest in sending the child to a place that can help him. He is meant to be at school already and they are not interested in him going to Worcester. Everything has been arranged, but no interest. They also think that he understands everything, you see.")

As there is no formal mechanism for following up children who have failed developmental screening, it was difficult to determine to what extent children were arriving at referral points and receiving intervention. Considering all these factors, it

is likely that approximately 50 – 60% of children received the intervention they require.

4.9. Monitoring and evaluation of programme

To date, other than the evaluation conducted during the pilot phase of the implementation of the Developmental Screening Programme, no formal monitoring and evaluation had taken place. Regional managers have acknowledged that their functions include monitoring and evaluation, however other than a few informal site visits and discussions with health workers, no formal monitoring of the programme had taken place. Regional managers also mentioned that they relied on the receipt of standard developmental screening referral forms by referral points to monitor implementation but this has also yielded little valuable information as many referrals were not occurring on this standardised form.

A criticism of the conceptualisation of the Developmental Screening Programme has been that monitoring and evaluation was not built into the programme. One of the regional managers reported that, as there were no clear objectives, indicators or targets set for the programme, monitoring was not possible. "*As a programme manager one has to back up answers to questions like that (coverage of a programme) with stats. My simple answer to that is that the monitoring and evaluation of the programme should have been conceptualised from the beginning and part of the operational objectives of the programme. We haven't got a target. We haven't got a system of going back to check that. That is a gap in the programme.*"

The only current mechanism for monitoring the delivery of the developmental screening is the Routine Monthly Report data on developmental screening, whereby facilities are required to keep a count of the following:

1. Babies examined 1st time before 6 weeks
2. Development assessments under 2 years
3. Referrals after developmental assessment under 2 years

Health managers in this study pointed out that the health information system in general has numerous problems. The Health Information Directorate at a provincial

level was reported as having little follow-up with the regions and significant gaps in statistics gathered at a district level exist. The current Routine Monthly Report data on the Developmental Screening Programme similarly does not provide valuable or meaningful information regarding the number of children screened or identified with developmental disability by the programme.

5. DISCUSSION AND RECOMMENDATIONS

5.1. Discussion

Disabled children in developing countries including South Africa have historically been marginalised and their needs are often unmet. Services for the prevention, identification and management (rehabilitation) of developmental disability, have received low priority and as a result been poorly funded and seriously under-resourced (van Niekerk, 1997; Guthrie et al., 2003). The initiative taken by the PAWC Department of Health in 1997 to develop and implement a formal screening programme to detect moderate and severe developmental disability at an early age was made in the above context. In South Africa, no national policy or guidelines on the detection of developmental disabilities have been forthcoming. This is in spite of national policy guidelines on how to respond to disability having been published (National Rehabilitation Policy, Department of Health, 2000).

The decision to develop and implement the Developmental Screening Programme in the Western Cape has been supported within the province by health managers and health workers alike. Requests have been made by service providers in health and early education for the development of a fourth screening tool for the 2-5 year age group and several other provinces have requested access to the current programme.

This study confirmed that health workers and health managers hold in high regard both the Developmental Screening Programme and the process undertaken in the development and implementation of the programme. The multi-disciplinary and inclusive nature of the Provincial Reference Group for Developmental Screening, specifically the high level of input from health workers "on the ground" as well as professionals from academic institutions, was believed to have facilitated the rapid and smooth implementation of the programme. The strong leadership, dedication and commitment of the MCWH Deputy-Director were acknowledged in driving the process. Similar findings were cited by Ogilvy (2003) where the MCWH Deputy-Director was described as demonstrating *"outstanding organisational, management and leadership skills"* in facilitating the development of the Policy and Management Guidelines for the Management of Survivors of Rape and Sexual Assault.

Epidemiological studies in South Africa estimate the prevalence of disability at approximately 6% of the childhood population within rural communities of the country (Corenljie, 1991; Irlam, unpublished; Kromberg et al., 1997 and Couper, 2000). The prevalence of developmental disability is thus comparable to other priority child health problems which contribute to infant mortality and under five mortality rates of 45 and 59 per 1000 live births respectively (Bradshaw, Groenewald, Laubscher, Nannan, Nojilana, Norman, Pieterse, Schneider, 2003). These include low birth weight (11.2%), malnutrition (4.3%), preventable childhood infections such as diarrhoeal disease (10.2%), lower respiratory tract infections (5.8%) and the escalating problem of violence and trauma against children (3.2%). Only the HIV/ AIDS epidemic is disproportionately high, accounting for 40.3% of all child deaths under five years. Despite competing priorities, the participants in this study unanimously voiced the need to conduct developmental screening.

International criteria for screening programmes (Wilson and Jungener, 1968; Cochrane and Holland, 1969; Calman, 1994 in Logan, 1995) stipulate that the condition screened for should constitute a significant public health problem. It would thus appear that the Developmental Screening Programme meets with this particular criterion based not only on the prevalence of the condition but also on the consequences of not identifying and responding to it. This includes both the impact on services and the severity of outcome for the disabled child. This notion is highlighted in the words of one of the health workers interviewed in this study. *"It is necessary because you may not know. It can be one (moderate or severely disabled child) in 100 but it will be good to pick up that one. You are helping that person to be able to be an abled person."*

In investigating the delivery of the Developmental Screening Programme, the strengths of the programme components themselves, in particular the three screening tools, were highlighted. It was evident that the three screening tools on the whole met with international test criteria. Health workers found the tools highly acceptable, describing them as practical and easy to use but sufficiently comprehensive to detect children with delay or disability. They also felt that the tools saved time and observation of screening in practice confirmed that each tool could be administered

quickly and effectively in less than ten minutes. Health managers and health workers alike felt that the tools were appropriate for use in the PHC context and were linguistically and culturally appropriate when administered in the caregiver's home language.

The scope of this study did not include the investigation of the scientific validity or reliability of the three screening tools nor an examination of the cost-effectiveness of the programme. A study of the gross and fine motor sections of the 9 and 18 month screening tools indicated high reliability on these sections on both tools (Dawson, de Klerk, Luther and Matschke, 2002). As the tools were based on other validated international screening tools, such as the Ten Question Screen, and developed by experts (including developmental paediatricians) in the field of developmental disability, it is likely that the other aspects of the tools are reliable and valid in identifying children with moderate and severe disability. Further studies would however need to be conducted to confirm the validity and reliability of other sections of the tools. This is important in view of poor sensitivity and specificity of many screening tests in general (Hall and Elliman, 2003).

Further research would be required to establish the cost-effectiveness of the Developmental Screening Programme. As the programme is not delivered via a conditional grant and as the national and provincial health budget statements do not present financial planning and expenditure data by child health programme or activity (Shung King, Vennekens-Poane, Michelson, Kaime and Ndlovu, unpublished), cost-effectiveness of the Developmental Screening Programme could be difficult determine. The delivery of the programme, however, does not incur expenses outside of the general costs in delivering PHC in that the same staff who deliver the Developmental Screening Programme, deliver all other aspects of PHC. In comparison to other forms of developmental monitoring world-wide, cost advantages include the simple methods used, the fact that children do not have to be sought out and the short screening time. Calculations of cost-effectiveness are however complex as numerous factors including prevalence and pick up rates as well as costs of training, response to detection and the price of missed detection, must also be considered.

Despite the high regard voiced of the Developmental Screening Programme and the overall awareness of the programme (100% awareness across all facilities in the Western Cape), delivery is occurring to a limited extent across the province. Results from this study revealed that almost one quarter of facilities in the province were not delivering any developmental screening. Of the nine facilities visited, only one was delivering the programme thoroughly and appropriately according to protocol. It is believed that these in-depth facility assessment results are more accurate than the rapid facility survey results, which seem to have painted a less realistic, more positive picture. Although the focus of Dawson et al's research project (2002) was on confirming the reliability of specific aspects of the screening tools, they too noted that in their study area within the Cape Metropolitan Region/ City of Cape Town, that health workers did not routinely conduct developmental screening.

The above findings are not unique. Recent evaluations conducted of other maternal and child health programmes, including the PSNP, Vitamin A Supplementation Programme, IMCI, services for HIV-positive children and PMTCT, have revealed that while there is generally an awareness of each of the programmes, coverage varied between and within provinces. Most of these studies also report the use of different guidelines and approaches in the implementation of these programmes despite formal provincial and national policies being in place (McCoy et al., 1997; Helen Keller International, UNICEF, Department of Health, 2002; Beardsley, 2003; Department of Health, 1999, 2000, 2001; Giese and Hussey, 2002; McCoy, Besser, Visser and Doherty, 2002).

An evaluation conducted in the Western Cape of the implementation of the policy and guidelines for the management of survivors of rape and sexual assault (Ogilvy, 2003) summarised that health workers *"clearly recognised the need for a policy on the management of survivors of rape and sexual assault, are aware of the policy and management guidelines, have it available in the health care facilities and furthermore consider it to be one of excellence...Although the policy supported by the management guidelines is highly regarded...the findings from the evaluation strongly indicate that the implementation has presented with numerous challenges and difficulties".*

Specific problems in the current delivery of the Developmental Screening Programme include screens not being completed thoroughly (with every child at all three ages) or being inappropriately administered (items not administered according to protocol). Health workers generally did not give adequate feedback to caregivers about their child's development, but focused on their child's growth. Caregivers and health workers commonly focus on physical growth more than cognitive milestones at the early stages of children's development (Shapiro, 1996).

Screening results were often not recorded as stipulated, both on the Road-to-Health Card and in the patient folder, and some patient folders contained old screening tools. This inhibited correct screening with the developmental screening tools. Many referrals were inappropriate with over 30% of children being referred directly to tertiary level, bypassing the secondary level hospital. Standard developmental screening referral forms were found to be under-utilised and follow-up of children referred for further assessment or intervention was infrequent.

Problems with referral systems have been highlighted by previous research in South Africa and other developing countries (Lachman and Stander, 1990; Power, Els, Zwarenstein, Lewin, Vundule and Mostert, 1997; Sanders, Kravitz, Lewin and Mckee, 1998; Shung King, 1998; Mathambo and Shung King, 1999; Department of Health, 1999, 2000, 2001; Siddiqi, Kielmann, Khan, Ali, Ghaffar, Sheikh and Mumtaz, 2001; Giese and Hussey, 2002). Difficulties have been shown to relate to lack of resources and infrastructure as well as poor management. These studies indicate that patients not only bypass lower levels of care on their own (i.e. arrive at higher levels unreferred), but that health workers also make inappropriate referrals to higher levels of care, especially tertiary facilities. Consistent with this study, unstructured referral letters and delays or lack of feedback from referral points were shown to exacerbate the problem.

Health workers in general did not experience difficulty with particular items on the developmental screening tools. They did however raise some concern about not always being able to communicate with the caregiver owing to language barriers and obtaining accurate information where the person accompanying the child was not the child's primary caregiver. The language divide between health workers and

consumers/ users is well documented. Strategies to compensate for this "language gap" have now become ritualised practices within the health setting and often allow for only sub-standard communication (Swartz, 1991; Kaschula and Anhonissen, 1995; Drennan, 1999). Fisch (2001) states that communication breakdown in health care is a *"multi-faceted problem that has to be conceptualised in a more global way than merely in the provision of interpreters, although this is clearly indicated."*

As detailed above, some facilities did not deliver the Developmental Screening Programme at all or made use of outdated, unstandardised screening tools, resisting the new policy. No distinct differences were seen between the delivery of the programme at pilot vs non-pilot sites, CHCs vs PHC clinics or between regions. Thus, the possibility that health facilities that received more intensive input during the implementation of the programme might provide more or better screening, was not founded. No common factors between health facilities identified not to be conducting developmental screening at all, were identified.

This study raises a number of issues. Amongst these are:

(i) Why are so few facilities implementing the Developmental Screening Programme as prescribed if it is valued by the Department of Health and health workers?

(ii) Why do some facilities deliver the programme, while others do not?

(iii) What are the underlying factors which enhance or hinder the delivery of the programme?

(iv) Do these factors differ from those identified in other MCWH programme evaluations?

This research study draws to a large extent similar conclusions that a number of other provincial and national programme MCWH evaluations have reached over the past six years (McCoy, 1997; Shung King, 1998; Mathambo and Shung King, 1999; UNICEF, Helen Keller International, Department of Health, 2002; Beardsley, 2003; Department of Health, 1999, 2000, 2001; Giese and Hussey, 2002; McCoy et al., 2002; Ogilvy, 2003). While each of the evaluations demonstrated numerous programme strengths and a few inherent programme-specific weaknesses, multiple challenges and barriers within the overall functioning of the health system were cited

as seriously hindering programme implementation. These studies have repeatedly shown constraints within the infrastructure of health facilities and their support systems (including drug supply, referrals, communication and transport) as well as major gaps in the Department of Health's formal operational systems including human resources and training, finance and health information. These gaps appear to be inherent challenges within health service provision which have been further exacerbated by the transformation process which has involved massive restructuring and policy reform.

This study did not examine the overall infrastructure of the health facility and major constraints in this regard were not identified as in other studies including the Evaluation of the Down-scaling of Red Cross Children's Hospital Medical Outpatient Department (Shung King, 1998) and the Interim Findings on the National PMTCT Pilot Sites (McCoy et. al, 2002). Lack of privacy and concerns regarding security at health facilities were however raised by individual health workers. The Developmental Screening Programme was also more successfully implemented in a child friendly health facility with a fast lane for immunisations and developmental screening. Where staff were dedicated to these preventive functions, screening was more likely to be delivered and delivered according to protocol. A booking system recently introduced at one health facility was also to have improved delivery of the programme.

These findings underpin the internationally recognised need to provide health care that focuses on the physical, psychological and emotional well-being of the child in accordance with the United Nations Convention on the Rights of the Child. The Child-Friendly Healthcare Initiative (Child Advocacy International, UNICEF, WHO) sets out preliminary standards for child-friendly health services (Southall, Burr, Smith, Bull, Radford, Williams and Nicholson, 2000). Amongst these recommended standards is the provision of a child friendly environment, previously defined by Mathambo and Shung King (1999) as "*an environment that is safe, pleasant and child-oriented where children are treated promptly and separately from adults*". The Child-Friendly Healthcare Initiative further stipulates that "*children should be cared for by professionals with training in their particular health and development needs.*"

Although the provision of dedicated services at dedicated times by dedicated staff is contrary to the "one stop shop" philosophy of the Department of Health, these factors contribute positively to the quality of delivery of services including developmental screening. Similar to the study conducted by Ogilvy (2003), this study showed that where dedicated health workers carried out immunisations and developmental screening services at set times, rather than seeing well children while simultaneously providing a range of other services, developmental screening was observed to run smoothly and in an organised fashion. Children were more likely to be seen quicker and receive better attention from a task-focused health worker.

The implementation of a booking system was cited at one of the health facilities visited in this study as aiding the delivery of preventive services including the Developmental Screening Programme. Although public health facilities are notorious for long waiting times, there has been little research to support the feasibility of an appointment system and the ability of such a system to reduce waiting periods. Preliminary research in South Africa (Berger, Wilson and Saunders, 1982; Mahomed and Bachmann, 1998) has shown that a simple appointment system can save time but due consideration of the logistics (e.g. patient flow) are required.

As the Developmental Screening Programme does not rely heavily on extensive support systems, constraints were identified only in terms of referral systems which related directly to transport difficulties. Similar to the findings of provincial (Lachman and Stander, 1990; Power et al., 1997; Shung King, 1998; Mathambo and Shung King, 1999), national (Department of Health, 1999, 2000, 2001; Giese and Hussey, 2002) and international studies (Sanders et al., 1998; Siddiqi et al., 2001) this study noted major problems with the referral system, including the lack of standardised referral protocols and feedback between levels of care. Referrals of children identified with developmental disability were further confounded by the lack of resources for further assessment and intervention together with transportation problems.

Other programme evaluations have reported barriers in other support systems, including the sporadic supply of drugs such as Vitamin A and other medicines required to carry out programmes such as the Expanded Programme on Immunisation and IMCI (Department of Health, 1999, 2000, 2001; McCoy et al, 2002; Giese and

Hussey, 2002.) Poor communication and overall management of health facilities, which were not investigated in this study, have also been cited extensively as hindering the delivery of key MCWH programmes (McCoy, 1997; Department of Health, 1999, 2000, 2001; Ogilvy, 2003).

The evaluation of the Developmental Screening Programme, as with all the abovementioned programme evaluations, highlighted major gaps in the Department of Health's formal operational systems including human resources and/ or health information. Breakdown in the financial system of the department including delays in processing funds and even corruption has also been noted (McCoy, 1997; Ogilvy, 2003).

Human resources have been defined as the bed-rock of a well functioning health system (Besser et al., 2002). As Lehmann and Sanders (2002) point out, "health care is a human system". Despite this, globally "there are far too many health systems paying lip service to the importance of human resources" (Martinez and Martineau, 1998). In South Africa, the National Assembly Portfolio Committee on Health has even acknowledged the "Department of Health's deficient strategy on human resources" (Sait, 2001).

Consistent with the abovementioned studies, this evaluation has identified numerous human resource constraints inhibiting programme delivery. Low levels of staff morale and motivation, lack of support and supervision and substantial gaps in training have been cited repeatedly as severely hampering programme implementation and consequently the quality of care provided at a PHC level. Although workloads (and what constitutes appropriate workloads) remain a highly controversial issue (Lehmann and Sanders, 2002), health workers in this study reported experiencing considerable pressures and frustrations as a result of low staff levels and increased workloads. As an interviewee stated *" So you find that as a sister, you can't actually do it properly - because you are rushing to finish that 100 patients that are outside."*

Health workers appear to be experiencing "transformation fatigue", a term coined by Lehmann and Sanders (2002). The move towards the District Health System in South Africa and the Western Cape has been burdened by numerous challenges. Frequent

changes in policy direction and the lack of consultation and poor communication about the introduction of a number of important new policies, in particular the free health care policies, have on the whole left health managers and health workers extremely confused, frustrated, demotivated, devalued and insecure (Khosa and McCoy, 1996; Gilson and Schneider, 2000; Bhunu, Kenyon and Leon, 2001; Kane-Berman, 2000 in Gibson, 2001; Magwaza, Cooper and Hoffman, 2002; Haynes and Hall, 2002; Klugman and McIntyre, 2003).

In this study, health workers translated their dissatisfaction into their inability to provide quality of care. "*It's complex, we are third world, we are seriously third world this countr. I mean there is no way we can claim to have such a wonderful health service because we don't*". A study conducted by Beardsley on the Vitamin A Supplementation Programme in the Western Cape (2003) showed and as related by Barron (2003), preventive and promotive aspects of health care in particular has taken a backseat to high curative workloads. "*Well, we do precious little preventive work. We try to prevent but I must say that the focus has actually shifted*". "*Ja, maar toet ons nog tyd gehad, met die pille wat ingekom het, jy weet kuratief dis (voorkomende diens) nou minder...* ". General dissatisfaction amongst health workers and high staff attrition rates are commonly reported (Bhunu, Kenyon and Leon, 2001; Lehmann and Sanders, 2002) and were alluded to in this study.

This study and previous studies have shown figures on the low numbers of staff trained to deliver child health programmes such as the IMCI, PMTCT and Vitamin A Supplementation. This evaluation revealed that only 53% of health workers delivering the Developmental Screening Programme had received training, while Beardsley (2003) reported that only 44% of staff has been trained in Vitamin A Supplementation in the Western Cape. Similar to the study of Ogilvy (2003), the significant contributions of the respective Provincial Training Task Teams in the initial training stages were essentially not sustained once this function was handed over to regional HRD teams, which significantly lack capacity. McCoy et al (2002) point out that this lack of ongoing training, support and supervision is detrimental to sustaining the positive impact of initial training especially in view of the rapid staff turnover and rotation of staff in many PHC facilities.

"Systems need to be in place in order to monitor, on an ongoing basis, the implementation of (health) interventions" (Giese and Hussey, 2002). This recommendation in the rapid appraisal of PHC services for HIV-positive children applies to all (child) health programmes but remains largely unheeded. The lack of monitoring and structures for monitoring of the Developmental Screening Programme emerged clearly from this evaluation. Routine Monthly Report data are inaccurately or inconsistently recorded (see also Beardsley, 2003) and largely meaningless, especially with targets for the Developmental Screening Programme not being set. Ogilvy (2003) asserts that statistics "are an additional burden to health workers already struggling with an excess of general clinical responsibilities." McCoy et al. (2002) conclude that "although the quality of data is improving...there is still a need to strengthen data capture, data management and programme evaluation".

In addition to challenges within formal operational systems, there also appears to be a lack of integration between systems. Programmes, such as the Developmental Screening Programme, are developed by the various sub-directorates within the Programme Directorate (e.g. MCWH) in isolation from other critical directorates, including HRD, Information Management and Finance (Ogilvy, 2003). In the absence of formal administrative integration (formal health districts) and even clear planning and guidelines for integration, these challenges are so vast that the implementation of a very sound and needed health programme, as in this case, is essentially impossible.

The lack of integration in the delivery of the comprehensive PHC package is also evident. Health workers are largely still coming to grips with the move away from dedicated service delivery to a one-stop "supermarket" approach. Curative care takes place at the expense of preventive programmes such as the Developmental Screening Programme and promotive aspects of service provision, for example, health education that should exist hand in hand with many interventions. In the case of the Developmental Screening Programme, information on child development and stimulation should go hand in hand as part of a comprehensive health care package. The immunisation coverage in this province has deteriorated with a massive 16% drop between 1995 and 1998 (SAVACG, 1995, Demographic Health Survey, Medical Research Council and Department of Health, 1998). This has implications for the Developmental Screening Programme which is linked to clinic attendances for

immunisations. Furthermore, although the government has committed to realising the rights of the disabled child and the delivery of rehabilitation services (Integrated National Disability Strategy, 1997; National Rehabilitation Policy, 2000), the elements of the comprehensive PHC service package required for delivery of a rehabilitative service to children with disability are still largely not in place (Department of Health, 2001).

The quality and quantity of comprehensive PHC provided has clearly deteriorated with critical components of the primary health care package being sorely neglected. This and other recent programme evaluations demonstrated that 80-85% of breakdowns in health care provision may be attributed to failures in system design and functioning. Systems changes are urgently required in order to achieve quality service delivery for children.

5.2. Recommendations

In light of the findings of this study, numerous recommendations relating to service, policy and research are proposed. These recommendations have been communicated to the Western Cape Department of Health MCWH Sub-directorate and the Provincial Reference Group for Developmental Screening and plans have been put in place to inform other key stakeholders at all tiers of the health system.

In terms of service delivery, it has been emphasised that broad health systems challenges need to be urgently addressed. Preventive service provision together with promotive services and rehabilitation should be strengthened to ensure delivery of a comprehensive, integrated PHC package. Referral pathways need to be clarified and each facility should be provided with explicit referral guidelines. Operational systems including HRD and Health Information should be strengthened and inter-departmental collaboration ensured in the development of all programmes. Staffing issues at a primary health care level, including poor staff morale, should be dealt with. All programmes must be regularly monitored and evaluated. To allow for this, objectives, targets and indicators should be set for all programmes and Routine Monthly Report data reviewed on a regular basis.

Specific problems with the Developmental Screening Programme itself should not be ignored. Aspects of inappropriate delivery, for example, the lack of communication of the developmental screening process and findings to the caregiver, inappropriate referral and lack of follow-up should be redressed. This could be achieved through revision and review of training and provision of ongoing support and supervision of health workers. A weakness of the Developmental Screening Programme is that it was developed without clear objectives and targets being set. A formal mechanism for ongoing monitoring and evaluation must be built into the programme. Finally, while it is recommended that the existing programme be improved and delivered, it is proposed that the development of the fourth screening tool for the 2 – 5 year age group should not commence until these programme-specific and health system improvements have been made.

With regards to **policy** development, it is emphasised that the existing policy on developmental screening in the Western Cape must be reinforced. Furthermore, the National Department of Health should be encouraged not to ignore this important aspect of preventive service provision and seriously consider developing a national developmental screening policy based on the current policy and recommendations made in the Western Cape.

Future **research** is encouraged to investigate the effectiveness of the Developmental Screening Programme as a screening tool. This should include an investigation of the scientific validity, reliability, sensitivity and specificity of the existing developmental screening tools. In an ideal situation, a randomised control trial could be conducted to determine in a rigorous way the effectiveness of the programme. A long-term case-control study should also be carried out to look at the long-term outcomes of children screened and detected via the Developmental Screening Programme. Finally it is highly recommended that in-depth evaluations of all child health programmes should be routinely conducted.

6. CONCLUSION

This study set out to document the background to as well as the development and implementation of the Western Cape Developmental Screening Programme. It also aimed to evaluate the current delivery of the programme with the purpose of informing provincial policy and practice regarding developmental screening being delivered at a primary health care level. It was hoped that the findings of this study could be used to inform national policy development and developmental screening practice throughout South Africa.

Thirdly, this study examined the barriers and success factors within the implementation process of the Developmental Screening Programme. The strengths were that the programme itself was found to be highly valued and regarded, comprehensive, user-friendly and highly appropriate for delivery at a primary health care level. Despite the positive attributes of the programme, its implementation is not in place satisfactorily. The challenges facing implementation are predominantly beyond the realms of the Developmental Screening Programme itself and lie within the broader context of health service provision and its systemic operations.

The Developmental Screening Programme needs to be considered within the context of years of extensive policy reform and significant restructuring of the health system in this country. The barriers to implementation should be understood within the broader framework of primary health care provision for children. Considering the high prioritisation of and dominance of curative services over the primary health care package (which is intended to be both comprehensive and integrated) it is not surprising that preventive and promotive services, together with rehabilitation, were found to be sorely neglected. The weaknesses and gaps within the health department's operational systems including human resources, training, health information and lack of commitment to resources, further paralyse the effective delivery of programmes such as the Developmental Screening Programme.

This study has provided an in-depth programme evaluation, which although an essential component of any health programme implementation, is rarely carried out in practice. It is believed that the findings of this research have presented relevant

information for future policy development in the neglected area of developmental screening. Within the broader health systems context, the results may also impact on service delivery for children as a whole. This process has already been initiated through written and verbal deliverables directly to the Department of Health who initially commissioned the study. The participatory approach adopted in this study as well as the methods of triangulation used ensure that its findings can be regarded with confidence.

The findings of this study would have been enhanced by incorporating the voice of the consumer – an important element of service audit. However, during the pilot phase of this research, interviews with caregivers yielded inadequate information and thus caregivers were regrettably not included as participants in the study. In future research however, especially when related to quality assurance, consumers should form an integral part of the research.

Another limitation of this study was the design of the rapid facility survey questionnaire. Although there are inherent limitations of a rapid and telephonic survey, it is felt that this stage of the data collection could have yielded further and more revealing qualitative results, had the questionnaire been designed using a more scientific and statistics based approach.

Finally, in order for unequivocal decisions regarding the continued delivery and further development of the Developmental Screening Programme to be taken, a study of the effectiveness of the screening tools as well as a focused investigation of patient records and outcomes, both beyond the scope of this study, would still need to be conducted.

In all human affairs there are efforts and there are results
and the strength in effort is the measure of the results
James Allan

APPENDICES

clinic stamp/address

DEVELOPMENTAL SCREENING TOOL: 0 - 6 WEEKS

(See guidelines for disclaimer)

Name of child:.....D.O.B:... .....

(D) indicates a possible Developmental problem.
Refer for developmental assessment

PHYSICAL EXAMINATION			
1.	Adequate weight gain	Yes	No
2.	Head circumference normal (relative to weight)	Yes	No (D)
3.	Fontanelle normal **If abnormal, may be medical emergency**	Yes	No
4.	General appearance normal	Yes	No (D)
5.	Skin and eyes normal	Yes	No
6.	Mouth and palate normal Sucking normal	Yes Yes	No No (D)
7.	Genitalia normal Testes descended in boys	Yes Yes	No No
8.	Hips normal	Yes	No
9.	Feet normal	Yes	No
QUESTIONNAIRE AND EXAMINATION			
	GROSS AND FINE MOTOR		
10.	Observe: Limb movements normal	Yes	No (D)
11.	Observe: Posture normal	Yes	No (D)
12.	Observe: Tone normal: Neck: Pull to sit Trunk: Ventral suspension Limbs: Limb flexion/extension	Yes Yes Yes	No (D) No (D) No (D)
13.	Observe: Moro reflex normal	Yes	No (D)
	LANGUAGE AND HEARING		
14.	Ask: Were both parents of the child born with normal hearing?	Yes	No (D)
15.	Ask: Does the child startle to sound?	Yes	No (D)
	VISION		
16.	Observe: Fixes (birth) and follows (6 weeks)	Yes	No (D)
	PSYCHO-SOCIAL		
17.	Ask: Does the child smile at you?	Yes	No
18.	Observe: Caregiver interacts well with child	Yes	No
	MENTAL HEALTH		
19.	Caregiver is coping. (Ask: How are you?)	Yes	No

Comment/referral:.....
.....
.....
.....
.....

Name: (PRINT) .....Signature:.....Date:.....

GUIDELINES FOR DEVELOPMENTAL SCREENING TOOL

Disclaimer: This tool has been developed and evaluated for use in primary health care services in the Western Cape Province. It is designed for use in conjunction with appropriate training. The Western Cape Provincial Developmental Screening Reference Group does not accept responsibility for use of the tool under other circumstances.

Stage: **0 - 6 weeks**

Setting: At home, at a clinic, satellite or mobile clinic in a warm room. Ensure privacy where possible.

Procedure: Explain the procedure to the caregiver.

The baby's caregiver should be invited to observe.

Examine the Road-to-Health card to identify high risk factors:
- antenatal history
- birth
- follow-up at other health facilities

Wash hands before commencing procedure.

Fully undress the baby and lie him/her on an examination surface.

Equipment:
Weighing scale
Tape measure
Road-to-Health card
Clinic records
Growth charts (weight and head circumference)

Administering the screen:

Note: In premature babies, correct for gestational age by subtracting the number of weeks born early from the actual age. Example: A baby that is 8 weeks old, but is born at 34 weeks gestation (instead of 40 weeks) is considered to be only 2 weeks old. (40 – 34 = 6 weeks, thus: 8 – 6 = 2 weeks)

Test number:

Physical Examination/Observation:

1. Weight: Plot the weight on the growth chart. Progressive fall off in weight from the birth centile indicates inadequate weight gain.
   The newborn baby loses weight during the first three days. The baby should begin to gain weight from the fourth or fifth day of age and regain birthweight by the seventh to tenth day.

2. Head circumference: Plot the head circumference on the growth chart. Head circumference and weight should be on similar centiles.

3. Fontanelle: The fontanelle in a normal baby is flat or slightly depressed. Note - crying can cause the fontanelle to bulge in a normal baby.

4. Dysmorphism: Observe for dysmorphic features in body shape, face, ears, hands and feet. Dysmorphism means abnormality of the physical structure (i.e. malformation) of a single or multiple parts of the body. Characteristic patterns of malformations may be recognised as syndromes, for example Down Syndrome or Fetal Alcohol Syndrome.

5. Skin: Examine the baby's entire skin including back and buttocks. Exclude jaundice, anaemia, rashes and mottling. At this age these signs may indicate septicaemia.
   Refer to the Johnson and Johnson pamphlet, "Common Skin Conditions in Infancy".

   Eyes: If held upright most babies will spontaneously open their eyes. Exclude conjunctivitis, jaundice and conjunctival pallor. Conjunctival pallor may be a sign of anaemia.

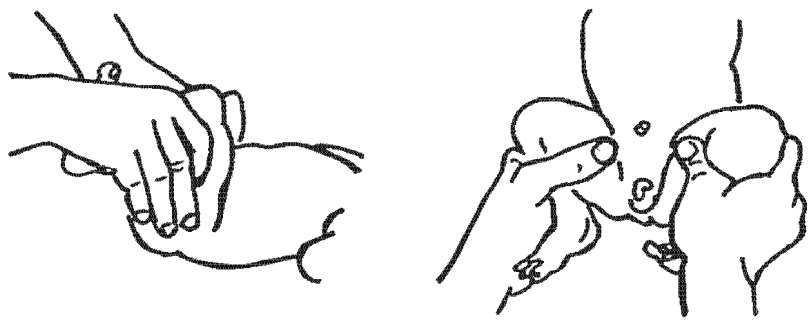
6. Mouth and palate: Look for cleft lip and/or palate and oral thrush. Feel for submucosal cleft palate. Small submucosal clefts may not affect sucking.
   If the baby does not suck well on your finger ask the caregiver if the baby sucks well. If there is any doubt observe the baby feeding.

7. Genitalia: If a male's testes are not in the scrotum, test for retractile testes by stroking firmly downwards from the inguinal area to the scrotum.
   Exclude phimosis (in boys) and nappy rash. White mucoid vaginal discharge in girls may be normal - if necessary reassure the caregiver.

8. Hips: The baby lies supine with the feet towards the examiner.

   - Grasp the child's legs placing the examiner's
     - middle finger of each hand on each outer hip
     - thumbs on each inner side
   - Half abduct each leg
   - Lift each leg up from the back with the middle finger
   - Push backwards with the thumbs

   This will identify an unstable hip which clicks into, or out of the hip socket.



Testing for dislocation of the hips

9. Feet: Exclude clubfoot. A temporary postural defect can be reduced by bringing the ankle and foot to a neutral position. A clubfoot (talipes) is a fixed abnormality and cannot be put in the normal position. Refer early if clubfoot is suspected.

Questionnaire and Examination:

Gross and Fine Motor

10. Limb movements: Exclude asymmetry or decreased movements. Observe the baby's spontaneous movements during placement on the examination surface, undressing, and the examination.

11. Posture: Observe the baby's posture during the examination. Normal posture includes some flexion of the limbs.

12. Tone:

Pull to sit:

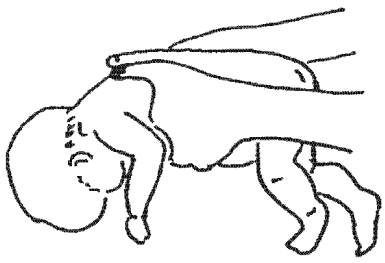
The baby lies supine. Hold the baby at the wrists and pull to the sitting position. Observe the extent of head lag. The normal newborn infant may have complete head lag. At 6 weeks there may be some, but not complete head lag.

Ventral suspension:

- Hold the baby in a prone position
- Support the baby's chest and abdomen
- Observe - extension of the trunk and neck
  - flexion of the arms and legs.

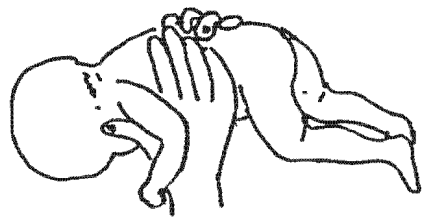
Normal newborn

- some head control
- some trunk curvature
- hips flexed
- preterm: - less head control
  - more trunk curvature
  - less hip flexion



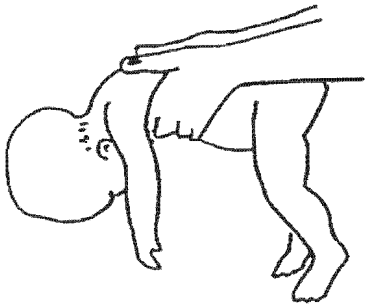
Normal 6 week old

- head is held up
- some hip extension
- knees flexed
- elbows flexed



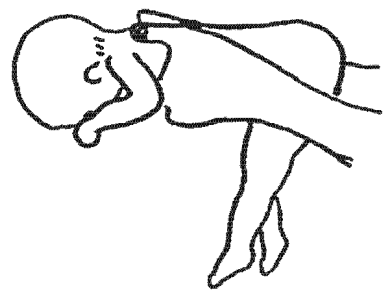
Abnormal: low tone (floppy)

- poor head control
- marked trunk curvature
- limbs hang



Abnormal: Increased tone

- neck and trunk extended
- hands fisted
- elbows flexed
- scissoring of legs or increased flexion of hips and knees



Limb flexion:

With the baby lying supine, gently flex and extend the limbs. Observe for skin flexure cleanliness.

13. Moro reflex: Hold the baby supine, supporting the head with palm of one hand. Lift the baby's head and then gently and quickly lower the supported head for about 4 cms. The baby should extend the arms and open the hands, followed by flexion to the midline. Observe for excessive, decreased or asymmetrical arm movements.

Language and Hearing

14. This question is to determine if either parent of the baby was born deaf. If a baby's parent is born deaf, there is a high chance of congenital deafness in the baby even if the examination suggests the baby can hear. If so, refer the baby to your regional specialist centre for hearing assessment.

15. Hearing: Ask the caregiver if the baby startles to loud sound. If there is any doubt clap hands loudly out of sight of the baby. Observe for blinking, startle reactions, or cessation or change in physical activity (for example stopping sucking, change in respiration rate).
Note: Caregivers may be in denial about their child's hearing impairment.

Vision

16. Move a brightly coloured object across the baby's gaze. Observe the baby's eyes. The baby should follow by 6 weeks.
Note: Caregivers may be in denial about their child's visual impairment.

Psycho-Social

17. Smiling: Ask the caregiver if the baby smiles at her. The baby should smile by 6 weeks.

18. Infant-caregiver's interaction: Observe the quality and appropriateness of interaction of the caregiver and the baby.

Attachment bonds (bonding):

- are feelings of emotional closeness between parent and child
- are necessary for normal emotional development of the baby
- may not occur immediately

- It is best to assist the caregiver who is struggling to relate to her baby's needs assistance as early as possible.

- Observe whether the caregiver is able to respond appropriately to the baby. For example, does she show interest in her baby : is she able to smile, stroke, talk to her baby? Does she soothe the baby when it shows distress? Does she handle the baby with confidence and care?

Mental Health

19. Caregiver's mental health: Ask about symptoms of distress, anxiety and depression in the mother.

    The "Baby Blues":
    - are experienced by 80% of mothers
    - occur 2 – 4 days after birth
    - are characterised by rapid mood changes, tearfulness, anxiety and irritability linked to hormonal changes
    - resolve within 2 weeks

    Post Natal Depression:
    - occurs in 30% of mothers across all cultural groups
    - presents within one month after birth
    - may persist if untreated
    - use the Johnson and Johnson checklist to identify post-natal depression and manage and/or refer accordingly
    - depression in most mothers resolves with psychological support only, but some mothers may require medication as well.

    Post Natal Psychosis:
    - occurs rarely
    - refer for urgent psychiatric management

PAWC : Department of Health
MCWH Sub Directorate
1999

JOHNSON AND JOHNSON CHECKLIST FOR POST-NATAL DEPRESSION

Ask: The baby's fine, how are you?

Does this sound familiar?

"I'm so irritable..."

"I feel like crying all the time...'

"I'm so tired, I'm exhausted..."

"I'm not coping..."

"I worry all the time..."

"I'm scared – I feel panicky at times..."

"I feel so lonely..."

"I feel ashamed and guilty..."

"I sometimes think of hurting the baby..."

"I don't know who I am anymore..."

"I don't sleep the way I used to..."

"I don't eat the way I used to..."

"I don't want sex anymore..."

These are normal feelings, but if you are experiencing a few of these feelings a lot of the time, you may be suffering from

POST-NATAL DEPRESSION

DEVELOPMENTAL SCREENING TOOL: 9 MONTHS

(See guidelines for disclaimer)

clinic stamp/address

Name of child:.....D.O.B:... ... .

(D) indicates a possible Developmental problem.
Refer for developmental assessment

PHYSICAL EXAMINATION			
1.	Adequate weight gain	Yes	No
2.	Head circumference normal (relative to weight)	Yes	No (D)
3.	General appearance normal	Yes	No (D)
QUESTIONNAIRE AND EXAMINATION			
	GROSS AND FINE MOTOR		
4.	Ask: Does the child sit without support?	Yes	No (D)
5.	Ask: Does the child move all his/her limbs equally?	Yes	No (D)
6.	Ask: Do the child's arms and legs feel normal to you? (with no stiffness or weakness)	Yes	No (D)
7.	Ask: Does the child feed him/herself with a piece of bread?	Yes	No (D)
	LANGUAGE AND HEARING		
8.	Ask: Does the child make speech sounds (e.g. ma-ma-ma, da-da) or try to copy your sounds?	Yes	No (D)
9.	Ask: Does the child turn towards you when you call his/her name?	Yes	No (D)
	VISION		
10.	Ask: Does the child watch a moving object?	Yes	No (D)
11.	Ask: Do the child's eyes move well without squinting?	Yes	No (D)
	PSYCHO-SOCIAL		
12.	Ask: Does the child prefer to go to familiar people than to strangers?	Yes	No
13.	Observe: Caregiver interacts well with child.	Yes	No
	MENTAL HEALTH		
14.	Caregiver is coping. (Ask: How are you?)	Yes	No

Comment/referral:.....

.....

.....

.....

.....

Name: (PRINT) .....Signature:.....Date:.....

GUIDELINES FOR DEVELOPMENTAL SCREENING TOOL: 9 MONTHS

Disclaimer: This tool has been developed and evaluated for use in primary health care services in the Western Cape Province. It is designed for use in conjunction with appropriate training. The Western Cape Provincial Developmental Screening Reference Group does not accept responsibility for use of the tool under other circumstances.

Stage: **9 months,** for example when the child presents for the 9 month immunisation

Setting: At the clinic, satellite or mobile clinic.
Ensure privacy where possible.

Procedure: The child's caregiver should be seated comfortably.

Explain the procedure to the caregiver and ask whether she has any concerns about the child's development.

Examine the Road-to-Health card to identify high risk for developmental problems from:
- birth history
- birth to 6 weeks screen
- previous follow-up and illnesses

Wash hands before commencing procedure.

Place the child on a suitable surface e.g. examination couch or floor whilst interviewing the caregiver, in order to observe the child's movements and behaviour.

Equipment: Weighing scale, tape measure, otoscope.
Road-to-Health card
Clinic records

Administering the screen:

Ask questions 4 - 12.

If a caregiver does not understand the question, demonstrating the activity with your own movements where possible.

If there is any doubt about an answer to any of the questions, refer to the guidelines for suggested observations/examinations for that test item.

If still in doubt, refer for further assessment.

Note: In premature babies, ***correct for gestational age*** by subtracting the number of months born early from the actual age. A child who is 9 months old, but is born at 32 weeks gestation (instead of 40 weeks gestation - i.e. 2 months premature), is considered to be only 7 months old. (40 – 32 = 8 weeks = 2 months, thus: 9 – 2 = 7 months).

Test number:

Physical Examination/Observation:

1. Weight: Plot the weight on the growth chart.

2. Head circumference: Plot the head circumference on the growth chart. Head circumference and weight should be on similar centiles.

   If the head circumference is inappropriately small, or has progressively fallen from the birth percentile, refer for developmental assessment.
   If the head circumference has progressively increased from the birth percentile, **refer stat to exclude hydrocephalus.**

3. General Appearance: Observe for dysmorphic features in body shape, face, ears, hands and feet. Dysmorphism means abnormality of the physical structure (i.e. malformation) of a single or multiple parts of the body.
   Characteristic patterns of malformations may be recognised as syndromes, for example Down Syndrome or Fetal Alcohol Syndrome.

Questionnaire and Observation:

Gross and Fine Motor

4. Sitting: The child should sit unaided, without any support e.g. cushions, for at least one minute and be able to use the hands for play and eating. In order to sit unaided a child needs good trunk and neck control.
   If in doubt: Observe the child sitting.

5. Limb movements: Observe for asymmetry of movements in the child's limbs. Decreased movement on one side may indicate hemiplegia.

6. Limb tone: If in doubt: Observe for abnormal posture (for example limbs abnormally flexed or extended, hands fisting) and examine for floppiness or spasticity.

7. Feeding: If in doubt: Give the child an object that can be held in one hand. A child of 9 months old usually takes objects to the mouth.

Language and Hearing

8. Speech sounds: Absence of speech sounds indicates a developmental problem, for example deafness, emotional problems or mental handicap.

9. Turns when called: If the answer is 'No', examine both ears with an otoscope.
   If wax, foreign bodies or pus *are not* present, refer for a diagnostic hearing test.
   If pus, wax or foreign body *are* present this may be the cause of hearing loss. Treat the cause or refer to MO and repeat otoscopy in 2 weeks.
   After 2 weeks if the answer is still 'No' on repeating the question, refer for a diagnostic hearing test.

Vision and Squint

10. Vision: If in doubt: Observe whether the child makes eye contact or follows an object moved in front of him/her.

11. Squint: If in doubt: Observe for squint. Note: Wide epicanthic folds can mimic a squint.
    Sudden onset of squint may indicate a serious condition such as a tumour, and require urgent referral.
    For non-acute squint refer as per regional policy.

Psycho-social

12. Prefers familiar people: Infants interact differently with caregivers and strangers within their first few months, but begin to show a consistent preference for their primary caregivers at about 8 - 9 months of age. At this stage, the infant tends to look warily at unfamiliar people or strangers, resists being handed over to them by a caregiver and looks for or moves towards their caregiver when a stranger approaches.

13. Caregiver's interaction: Observe whether the caregiver responds appropriately to the child's behaviour. For example, does she respond calmly and caringly when the infant signals his/her needs? Does she

show interest in the child? Is she interested in the child's play? Does she watch out for potential situations of danger for the child?

Caregivers who consistently ignore, become annoyed with or seem unaware of how to respond to children's needs, may be unable to respond to them because of inadequate parenting skills or psychiatric or psychological difficulties.

Note: In a short interview it may be difficult to observe the above thoroughly, for example, the baby may be tired, ill or teething and resist the caregiver's attempts to soothe him/her.

Mental Health

14. Caregiver's mental health: If in doubt: Refer to the Johnson and Johnson checklist for post-natal depression.
    Note: The caregiver's mental health has a profound effect on an infant's development. Refer to the 0-6 Week Developmental Screening Mental Health notes.

DEVELOPMENTAL SCREENING TOOL: 18 MONTHS

(See guidelines for disclaimer)

clinic stamp/address

Name of child:.....D.O.B:... ... .

(D) indicates a possible Developmental problem.
Refer for developmental assessment

PHYSICAL EXAMINATION			
1.	Adequate weight gain	Yes	No
2.	Head circumference normal (relative to weight)	Yes	No (D)
3.	General appearance normal	Yes	No (D)
QUESTIONNAIRE AND EXAMINATION			
	GROSS AND FINE MOTOR		
4.	Ask: Does the child walk unaided?	Yes	No (D)
5.	Ask: Does the child move all his/her limbs equally?	Yes	No (D)
6.	Ask: Do the child's arms and legs feel normal to you? (with no stiffness or weakness)	Yes	No (D)
7.	Ask: Does the child grasp a bean-sized object with pincer grip?	Yes	No (D)
8.	Ask: Does the child drink out of a cup unaided?	Yes	No
	LANGUAGE AND HEARING		
9.	Ask: Does the child respond to simple commands or questions? (e.g. show me your foot/nose; where is mommy?)	Yes	No (D)
10.	Ask: Does the child use 3 recognisable words?	Yes	No (D)
11.	Ask: Does the child turn towards you when you call his/her name?	Yes	No (D)
	VISION		
12.	Ask: Does the child watch a moving object?	Yes	No (D)
13.	Ask: Do the child's eyes move well without squinting?	Yes	No (D)
	PSYCHO-SOCIAL		
14.	Ask: Does the child play alone in your presence?	Yes	No
15.	Ask: Does the child come to you when needing assistance?	Yes	No
16.	Observe: Caregiver interacts well with child.	Yes	No
	MENTAL HEALTH		
17.	Caregiver is coping. (Ask: How are you?)	Yes	No
18.	Observe: Child's emotions and behaviour appear normal.	Yes	No

Comment/referral:.....

.....

.....

.....

.....

GUIDELINES FOR DEVELOPMENTAL SCREENING TOOL: 18 MONTHS

Disclaimer: This tool has been developed and evaluated for use in primary health care services in the Western Cape Province. It is designed for use in conjunction with appropriate training. The Western Cape Provincial Developmental Screening Reference Group does not accept responsibility for use of the tool under other circumstances.

Stage: **18 months,** for example when the child presents for the 18 month immunisation

Setting: At the clinic, satellite or mobile clinic.
Ensure privacy where possible.

Procedure: The child's caregiver should be seated comfortably.

Explain the procedure to the caregiver and ask her whether she has any concerns about the child's development.

Examine the Road-to-Health card to identify high risk for developmental problems from:

- birth history
- birth to 6 weeks and 9 months screen
- previous follow-up and illnesses

Wash hands before commencing procedure.

Place the child on a mat, or the floor whilst interviewing the caregiver, in order to observe the child's movements and behaviour.

Equipment: Weighing scale, tape measure, otoscope.
Road-to-Health card
Clinic record
Bean-sized object (e.g. a crumpled piece of paper)

Administering the screen:

Ask questions 4 - 15.

If a caregiver does not understand the question, demonstrate the activity with your own movements where possible.
If there is any doubt about an answer to any of the questions, refer to the guidelines for suggested observations/examinations for that test item.

If still in doubt, refer for further assessment.

Note: In the 18 months screen, *do not correct* for gestational age in children who were born prematurely.

Test number:

Physical Examination/Observation:

1. Weight: Plot the weight on the growth chart.

2. Head circumference: Plot the head circumference on the growth chart. Head circumference and weight should be on similar centiles.

   If the head circumference is inappropriately small, or has progressively fallen from the birth percentile, refer for developmental assessment.
   If the head circumference has progressively increased from the birth percentile, **refer stat to exclude hydrocephalus.**

3. General Appearance: Observe for dysmorphic features in body shape, face, ears, hands and feet. Dysmorphism means abnormality of the physical structure (i.e. malformation) of a single or multiple parts of the body.
   Characteristic patterns of malformations may be recognised as syndromes, for example Down Syndrome or Fetal Alcohol Syndrome.

Questionnaire and Observation:

Gross and Fine Motor

4. Walking: The child should be able to take at least 10 steps unaided.
   If in doubt: Observe the child walking.

5. Limb movements: Observe for asymmetry of movements in the child's limbs. Decreased movement on one side may indicate hemiplegia.

6. Limb tone: If in doubt: Observe for abnormal posture (for example limbs abnormally flexed or extended, hands fisting) and examine for floppiness or spasticity.

7. Pincer grip: If in doubt: Demonstrate a pincer grip to the caregiver and/or observe the child grasping a bean-sized object (e.g. a piece of paper crumpled up to the size of a bean).
8. Drinks from cup: The child should be able to drink out of a cup unaided. This item assesses the child's fine motor ability and psycho-social development (ability to conduct simple tasks independently). If the child still drinks only from a bottle, encourage the caregiver to introduce use of a cup.

Language and Hearing

9. Simple commands: If in doubt: Ask the child to show you his/her foot or nose. A child of 18 months might not necessarily show you his/her foot, but might respond by looking at the foot. If the child is shy, he/she may respond to the caregiver asking the question

10. 3 recognisable words: These words should have meaning (e.g. mama, ball, bye-bye). The words do not need to be phonetically correct but must be used consistently to indicate the same person or object. The absence of words may indicate a developmental problem, for example deafness, emotional problems or mental handicap.

11. Turns when called: If in doubt: Call the child's name and observe his/her response.

If the answer is 'No' to the language and hearing questions, examine both ears with an otoscope.

If wax, foreign bodies or pus *are not* present, refer for a diagnostic hearing test, or, if the child turns to sound but cannot point to his/her feet/nose and say words, refer for developmental assessment, as this may indicate mental handicap.

If pus, wax or foreign body *are* present this may be the cause of hearing loss. Treat the cause or refer to MO and repeat otoscopy in 2 weeks.

After 2 weeks if the answer is still 'No' on repeating the questions, refer for a diagnostic hearing test and/or developmental assessment as appropriate.

Vision and Squint

12. Watches moving object: If in doubt: Observe whether the child makes eye contact or follows an object moved in front of him/her.

13. Squint: If in doubt: Observe for squint.
    Note: Wide epicanthic folds can mimic a squint.
    Sudden onset of squint may indicate a serious condition such as a tumour, and require urgent referral.
    For non-acute squint refer as per regional policy.

Psycho-social

Note: These questions may not be answerable if the child's attendant is not his/her usual caregiver.

14. Plays alone: Toddlers vary in the closeness to, and amount of attention they need from their caregivers, particularly in the presence of new places and people. If not tired, hungry or ill, the average toddler shows interest in exploring the assessment room in the presence of his/her caregiver, rather than being disinterested in his/her environment, clinging to the caregiver, or being fearful or aggressive.

15. Comes when needs assistance: The child's exploration of his/her environment should be balanced by the need for closeness to the caregiver. Look for signs of bonding and response to the caregiver, e.g. showing things to the caregiver; caution when the caregiver points out dangers (plugs, sharp objects) or returning to the caregiver for physical contact. The toddler should not ignore, or show fear or aggression towards the caregiver.

16. Caregiver's interaction: Observe how the caregiver interacts with the child, how the child is held, handled and spoken to. Caregivers who consistently ignore, become annoyed with, or seem unaware of how to respond to children's needs, may be unable to respond to them because of inadequate parenting skills or psychiatric or psychological difficulties.

Mental Health

17. Caregiver's mental health: The caregiver's mental health has a profound effect on child development. Ask about post-natal depression and assess whether this has resolved or whether symptoms persist. If in doubt: Refer to the Johnson and Johnson checklist for post-natal depression.
    Refer to the Mental Health notes: 0 - 6 weeks developmental screening guidelines.

18. Child's mental health: In a short interview it may be difficult to assess the child's mental health thoroughly – for example the child may be tired, ill or teething, and resist caregiver's attempts to soothe. Children vary greatly, but excessive behaviours in the child may point to potential psychosocial difficulties. Where toddlers are observed to cling and cry excessively; appear depressed; are overactive or are negative or non-responsive to parental interventions, ask for the caregiver's view of the child's behaviour. This may establish whether the caregiver has realistic expectations of the child and whether the child's behaviour is difficult to manage.

COMMUNITY BASED INTERVENTION PROGRAMME: FOR 0 – 2 YEARS
DEVELOPMENT SCREENING FOR THE WESTERN CAPE PROVINCE

ABNORMALITY	IMMEDIATE INTERVENTION	INTERVENTION BY WHOM	REFERRAL
Inadequate weight gain	• Counseling	• Primary health care worker	• Nutritionist • Medical officer • Regional paediatrician
Head circumference (too big/too small)	• Counseling • Support and reassure • Referral	• Primary health care worker	• Medical officer • Regional paediatrician
Abnormal fontanelle	• Emergency referral	• Primary health care worker	• Medical officer • Regional paediatrician
Abnormal appearance / dysmorphism	• Family history and high risk behaviour NOTE! e.g. abusive behaviour • Counseling and support	• Primary health care worker • Genetically trained Professional nurse (3 day course)	• Medical officer • Regional paediatrician • Human geneticist
Conjunctivitis (exclude Opthalmia neonatorum)	• Swab with lukewarm salt water • Refer, if needed	• Primary health care worker • Health advisor / Community Health worker	• Medical officer • Regional paediatrician
Abnormality of mouth and/or palate Abnormal sucking	• Treat local causes (e.g. thrush) • Supportive feeding • Refer immediately	• Primary health care worker, • Health advisor • Community health worker • Support group	• Speech/health therapist, e.g. Occupational therapist • Medical officer • Regional paediatrician

ABNORMALITY	IMMEDIATE INTERVENTION	INTERVENTION BY WHOM	REFERRAL
IPS Congenital dislocation	• Double nappies • Refer	• Primary health care worker • Health advisor • Health care worker	• Medical officer • Regional paediatrician • Orthopedic service
ub-feet	• Refer	• Primary health care worker • Health advisor • Health care worker	• Medical officer • Regional paediatrician • Orthopedic Service
ROSS & FINE MOTOR Abnormal limb movement Abnormal tone	• Refer • Home exercise programme • Touch and message	• Primary health care worker • Health advisor • Health care worker	• Medical Officer • Regional paediatrician • Health therapist
NGUAGE AND HEARING Suspected abnormal hearing in baby Either parent deaf	• Refer	• Primary health care worker • Health advisor • Health care worker	• Medical officer • Regional paediatrician • Audiology assessment service
SION Suspected visual impairment Blindness	• Refer	• Primary health care worker • Health advisor • Health care worker	• Medical officer • Regional paediatrician • Opthalmological Service • Institute for the Blind (Worcester)
YCHO-SOCIAL / MENTAL ALTH Inappropriate interaction Maternal depression Psychosis	• Offer support and child care information • Refer	• Primary health care worker • Health advisor • Health care worker	• Medical officer • Mental health service • Social service

The above mentioned recommendations for referral should be seen in context with the Provincial Health Plan and the Screening Guidelines provided for each developmental screening tool.

Appendix 2a

Structured interview schedule: Interview with provincial health manager

Name of informant:	_____
Current position:	*Deputy-Director, MCWH, PAWC Department of Health*
Date of interview:	_____

BACKGROUND, DEVELOPMENT AND IMPLEMENTATION OF THE DEVELOPMENTAL SCREENING PROGRAMME (DSP)

1. What is your role in the DSP in the Western Cape?
2. What was the international, national and provincial context in which the DSP was initiated in the Western Cape?
3. What is the present status of the national developmental screening initiative?
4. How is the DSP currently viewed in terms of priority within the Department of Health at a provincial level?
5. What are the financial implications of the DSP for the Department of Health and what are the ongoing cost implications?
6. Johnson & Johnson were the primary funders of the programme, including funding of training. It is unusual for a private company to sponsor a Department of Health initiative. Could you comment on how this was received by role players at all levels.
7. What do you feel worked well in the development of the DSP? *(e.g. academic input)*
8. In retrospect what would you have done differently in terms of the development of the DSP?

Training:

9. What training was developed for the implementation of the DSP?
10. How was this training carried out? (Who did the training, who was trained, how many staff trained, when, over what time period?)
11. What feedback did you receive regarding the training?
12. Can you summarise what monitoring and evaluation of the DSP has taken place to date and what some of the major findings have been?
13. What do you hope that this evaluation will achieve?
14. Do you have any other comments regarding the background, development and implementation of the DSP?

CURRENT DELIVERY OF THE PROGRAMME

1. To your knowledge, to what extent are all primary health care sites delivering the DSP?
2. What is working well with the delivery of the DSP?
3. What problems with the delivery of the DSP have been identified to date?
4. How is DSP training currently being carried out in the province?
   (Who is training, who is being trained, what training package is being used, how many staff are being trained, disparity across regions?)
5. Correct referrals and follow-up are essential to the DSP. Has referral and follow up of cases been taking place according to protocol and how effective have these aspects of management been?
6. To what extent do you believe children who are identified with developmental delay through the DSP are receiving appropriate intervention?
7. Do you have any other comments regarding the current delivery of the DSP?

BARRIERS AND SUCCESS FACTORS IN IMPLEMENTATION

1. What has the response been by health managers at all levels to the DSP?
2. What has the response been by health workers in the community to the DSP?
3. What has the response been from the national office and other provinces to the Western Cape Developmental Screening Programme?
4. What do you feel have been enabling factors promoting the development and implementation of the programme at a provincial, regional and district level?
5. What do you feel have been the barriers hampering the development and implementation at a provincial, regional and district level?
6. To what extent is the DSP meeting its desired outcomes?
   (Prompt with specific outcomes)
7. What improvements do you feel are required at this stage in order for these outcomes to be improved?
8. Do you have any other comments regarding the barriers and success factors in the implementation of the DSP?

Appendix 2b

Structured interview schedule: Interview with regional health managers

Name of informant:	_____
Current position:	_____
Region:	_____
Date of interview:	_____

BACKGROUND, DEVELOPMENT AND IMPLEMENTATION OF THE DEVELOPMENTAL SCREENING PROGRAMME

1. What is your role in the DSP in your region?
2. What was the situation in your region in terms of developmental screening prior to the implementation of the DSP?
3. How has the situation changed since the implementation of the DSP?
   (Has the situation improved or worsened and how?)
4. How is the DSP currently viewed in terms of priority in your regional office?

Training:

5. How was the DSP training carried out in your region? (Who did the training, who was trained, how many staff trained, when, over what time period?)
6. What feedback did you receive regarding the training?

7. What do you hope this evaluation will achieve?
8. Do you have any other comments regarding the background, development and implementation of the DSP in your region?

CURRENT DELIVERY OF THE PROGRAMME

1. To what extent are all primary health care sites in your region delivering the DSP? *(Explore which areas DSP is not working and why.)*
2. Can you summarise what monitoring and evaluation of the DSP has taken place in your region to date?
3. What is working well with the delivery of the DSP in your region?

4. What problems have been identified in the delivery of the DSP in your region?
5. How is DSP training currently being carried out in your region?
   (Who is training, who is being trained, what training package is being used, how many staff are being trained?)
6. Correct referrals and follow-up are essential to the DSP. Has referral and follow up of cases been taking place according to protocol and how effective have these aspects of management been?
7. To what extent do you believe children in your region who are identified with developmental delay through the DSP are receiving appropriate intervention?
8. Do you have any other comments regarding the current delivery of the DSP in your region?

BARRIERS AND SUCCESS FACTORS IN IMPLEMENTATION

1. What has the response been by health workers in the region to the DSP?
2. To what extent is the DSP meeting its desired outcomes?
   (Prompt with specific outcomes)
3. What do you feel have been enabling factors promoting the development and implementation of the programme in your region?
4. What do you feel have been the barriers hampering the development and implementation of the programme in your region?
5. What improvements do you feel are required at this stage in order for these outcomes to be improved?
6. How do you think your region's experience of the DSP differs to that of the other health regions?
7. Do you have any other comments regarding the barriers and success factors in the implementation of the DSP?

Appendix 3

Structured questionnaire: Rapid facility survey

Survey #: _____

Name of facility: _____

Health region: _____

Health district: _____

Type of facility:

Primary care clinic	*Community health centre*

Type of DSP facility:

Pilot site (Phone and visit)	*Non pilot site (Phone only)*	*Non pilot site (Phone and visit)*

Telephone number: _____

Contact person: _____

A. Awareness of programme

1. Do you know about the Developmental Screening Programme?

Yes	*No*

B. Use of the tools

1. Which of the Developmental Screening Tools do you use in your facility?

0 – 6 weeks	*9 months*	*18 months*
Yes/no	*Yes/no*	*Yes/no*

2. What other tools for developmental screening do you use in your facility?

_____

C. Appropriate use of the tools

1. Do you screen every child that comes for immunisation at:

0 – 6 weeks	9 months	18 months
Yes/ no	*Yes/ no*	*Yes/ no*

2. When you screen, do you complete the full tool for each child?

Always	*Sometimes*	*Never*

3. Tell me more about how you complete the screening (If always, probe how do screening, is sometimes/ never probe reasons for lack completion and what parts completed/ not)

_____

_____

4. Where do you record results if child passes the screener?

RTHC	*Patient folder*	*Other* _____
Yes/no	*Yes/no*	*Yes/no*

5. Where do you record results if child fails the screener?

RTHC	*Patient folder*	*Other* _____
Yes/no	*Yes/no*	*Yes/no*

D. Capacity to implement

1. Have you been trained in delivering the Developmental Screening Tools for:

0 – 6 weeks	9 months	18 months
Yes/ no	*Yes/ no*	*Yes/ no*

2. Who were you trained by?

Prov task team	*Regional HRD*	*In service training*	*Other* _____

3. How many staff including yourself are delivering the Developmental Screening Tools?

_____

4. How many of these staff have been trained?

_____

5. Who else has trained staff?

Prov task team	*Regional HRD*	*In service training*	*Other* _____

E. Referral and follow-up

1. If a child fails developmental screening, are they referred immediately?

Yes	*No*

2. If not, what is the waiting time (in weeks)? _____

3. On what form do you write your referral?

DSP referral form	*Facility letterhead*	*Memo*	*Other* _____

4. If the child fails developmental screening where do you refer?

Regional paediatrician	*Visiting O.T.*	*Other* _____
Yes/no	*Yes/no*	*Yes/no*

5. Do you receive feedback on referrals?

Regional paediatrician			*Visiting O.T.*			*Other* _____		
Always	*Stimes*	*Never*	*Always*	*Stimes*	*Never*	*Always*	*Stimes*	*Never*

6. Do children with developmental delay receive intervention?

Always	*Sometimes*	*Never*

7. If sometimes or never: What happens to children if don't receive intervention?

_____

F. Statistics

1. What data do you keep on immunizations and developmental screening?

RMR - immunisations	*RMR – dev screening*	*Records of failed screener*
Yes/no	*Yes/no*	*Yes/no*

G. Other

1. What other comments do you have regarding the developmental screening programme at your facility?

Appendix 4

Facility profile data capture form

Name of facility: _____

Sr. in charge: _____

Phone : _____

Fax: _____

Date of visit: _____

1. What patients do you see at the facility? (Children and/ or adults, health children only?)
2. What is your facility patient load? (Approximate statistics)
3. What services are provided? (preventative, curative, rehab, services for adults)
4. What time is allocated to the different types of services?
5. What does your clinic timetable look like? (days and times of clinics, what services provided when?)
6. When are immunisations and screening done?

Staff

1. What is your staff complement? (numbers and ranks, including support and visiting staff)
2. What staff do immunisations and screening? (numbers and ranks)
3. Which of these staff have been trained in the Developmental Screening Programme?
4. Who trained them and when?
5. Were you sr. in charge when Developmental Screening Programme introduced?
6. Are you involved in service delivery including immunizations and screening?

Appendix 5
General health facility observational checklist

Name of facility: _____ Date: _____

Does the facility appear to be friendly?

- Friendly environment
- Friendly staff
- Quota system
- Waiting times

Does the facility appear to be child friendly?

- Separate waiting area
- Separate consultation rooms
- Dedicated staff for children
- Triage system where children prioritised

Do immunizations and developmental screening run smoothly overall?

- Fast lane for immunizations and screening
- Other

Appendix 6a
Observational checklist: 0 – 6 week screening

Name of facility: _____ Date: _____

Caregiver number: _____

Relationship to child: ___ Mother

___ Grandmother

___ Aunt

_____ ___ Other (specify)

Health worker: _____

Rank: _____

Fluent language/s: ___ English

___ Afrikaans

___ Xhosa

_____ ___ Other (specify)

Home language: ___ English

___ Afrikaans

___ Xhosa

_____ ___ Other (specify)

Tools used (check one):

0 – 6 weeks	9 months	18 months

Description of facility for screening in relation to clinic facility:

_____

_____

Start time: ___h___

End time: ___h___

Availability of equipment in the screening room:

___ Weighing scale
___ Tape measure
___ RTHC
___ Clinic records
___ Weight chart
___ Head circumference chart

Availability of material:

___ Appropriate Developmental Screening Tool
___ Guidelines

6 weeks: Did the health worker...	YES	NO	N/A
Prior to examination			
1. ...ensure caregiver comfortably seated			
2. ...explain the procedure to caregiver			
3. ...ask the caregiver whether she has any concerns about the child			
4. ...adequately examine the Road to Health Card (RTHC)			
5. ...wash her hands			
Examination			
6. ...weigh the baby fully undressed			
7. ...plot weight on RTHC			
8. ...measure head circumference			
9. ...plot head circumference on chart			
10. ...examine the child's general appearance			
11. ...examine baby's entire skin (incl. back and buttocks) and eyes			
12. ...examine mouth and palate			
13. ...examine genitalia			
14. ...examine hips (test for dislocation)			
15. ...examine feet (for clubfoot)			
...observe...	**YES**	**NO**	**YES***
11. ...limb movements...			
12. ...posture...			
13. ...tone... (Neck: pull to sit, Trunk: Ventral suspension, Limbs: Limb flexion/ extension)			
14. ...moro reflex...			
...ask the question...	**YES**	**NO**	**YES***
15. Were both parents of the child born with normal hearing?			
...observe...	**YES**	**NO**	**YES***
16. Vision: ...fixes (birth) and follows (6 weeks)			
...ask the question...	**YES**	**NO**	**YES***
17. Does the child smile at you?			
...observe...			
20. Caregiver interacts well with the child			
...ask the caregiver...			
21. How are you?			

* Question asked but meaning altered. Write in new meaning.

Additional examinations performed by health worker

- _____
- _____
- _____
- _____

Additional questions asked by health worker:

- _____
- _____
- _____
- _____

Result of assessment:

Pass	Fail

Item/s failed (if applicable): ___

Referral made: _____

Did the health worker ...	**YES**	**NO**	**N/A**
Referral and feedback			
22. ...make an appropriate referral?			
23. ...give adequate feedback to the caregiver?			
24. ...complete the RTHC?			
25. ...complete the referral form?			

Appendix 6b
Observational checklist: 9 month screening

Name of facility: _____ Date: _____

Caregiver number: _____

Relationship to child: ___ Mother
___ Grandmother
___ Aunt
_____ ___ Other (specify)

Health worker: _____

Rank: _____

Fluent language/s: ___ English
___ Afrikaans
___ Xhosa
_____ ___ Other (specify)

Home language: ___ English
___ Afrikaans
___ Xhosa
_____ ___ Other (specify)

Tools used (check one):

0 – 6 weeks	9 months	18 months

Description of facility for screening in relation to clinic facility:

_____

_____

Start time: ___h___

End time: ___h___

Availability of equipment in the screening room:

___ Weighing scale
___ Tape measure
___ RTHC
___ Clinic records
___ Weight chart
___ Head circumference chart

Availability of material:

___ Appropriate Developmental Screening Tool
___ Guidelines

18 months: Did the health worker...	YES	NO	N/A
Prior to examination			
1. ...ensure caregiver comfortably seated			
2. ...explain the procedure to caregiver			
3. ...ask the caregiver whether she has any concerns about the child			
4. ...adequately examine the Road to Health Card (RTHC)			
5. ...wash her hands			
Examination			
6. ...weigh the baby fully undressed			
7. ...plot weight on RTHC			
8. ...measure head circumference			
9. ...plot head circumference on chart			
10. ...examine the child's general appearance			
...ask the question...	**YES**	**NO**	**YES***
11. Does the child sit without support?			
12. Does the child move all his/ her limbs equally?			
13. Do the child's arms and legs feel normal to you?			
14. Does the child feed himself with a piece of bread?			
15. Does the child make speech sounds or try to copy your sounds?			
16. Does the child turn towards you when you call his/ her name?			
17. Does the child watch a moving object?			
18. Do the child's eyes move well without squinting?			
19. Does the child prefer to go to familiar people than to strangers?			
...observe...			
20. Caregiver interacts well with the child			
...ask the caregiver...			
21. How are you?			

* Question asked but meaning altered. Write in new meaning.

Additional examinations performed by health worker

- _____
- _____
- _____
- _____

Additional questions asked by health worker:

- _____
- _____

- _____ • _____

Result of assessment:

Pass	Fail

Item/s failed (if applicable): ___

Referral made: _____

Did the health worker ...	YES	NO	N/A
Referral and feedback			
22. ... make an appropriate referral?			
23. ... give adequate feedback to the caregiver?			
24. ... complete the RTHC?			
25. ... complete the referral form?			

Appendix 6c
Observational checklist: 18 month screening

Name of facility: _____ Date: _____

Caregiver number: _____

Relationship to child: ___ Mother
___ Grandmother
___ Aunt
_____ ___ Other (specify)

Health worker: _____

Rank: _____

Fluent language/s: ___ English
___ Afrikaans
___ Xhosa
_____ ___ Other (specify)

Home language: ___ English
___ Afrikaans
___ Xhosa
_____ ___ Other (specify)

Tools used (check one):

0 – 6 weeks	9 months	18 months

Description of facility for screening in relation to clinic facility:

_____

_____

Start time: ___h___

End time: ___h___

Availability of equipment in the screening room:

___ Weighing scale
___ Tape measure
___ RTHC
___ Clinic records
___ Weight chart
___ Head circumference chart

Availability of material:

___ Appropriate Developmental Screening Tool
___ Guidelines

18 months: Did the health worker...	YES	NO	N/A
Prior to examination			
1. ...ensure caregiver comfortably seated			
2. ...explain the procedure to caregiver			
3. ...ask the caregiver whether she has any concerns about the child			
4. ...adequately examine the Road to Health Card (RTHC)			
5. ...wash her hands			
Examination			
6. ...weigh the baby fully undressed			
7. ...plot weight on RTHC			
8. ...measure head circumference			
9. ...plot head circumference on chart			
10. ...examine the child's general appearance			
...ask the question...	**YES**	**NO**	**YES***
11. Does the child walk unaided?			
12. Does the child move all his/ her limbs equally?			
13. Do the child's arms and legs feel normal to you?			
14. Does the child grasp a bean-sized object with pincer grip?			
15. Does the child drink out of a cup unaided?			
16. Does the child respond to simple commands or questions?			
17. Does the child use 3 recognisable words?			
18. Does the child turn towards you when you call his/ her name?			
19. Does the child watch a moving object?			
20. Do the child's eyes move well without squinting?			
21. Does the child play alone in your presence?			
22. Does the child come to you when needing assistance?			
...observe...			
20. Caregiver interacts well with the child			
...ask the caregiver...			
21. How are you?			
...observe...			
22. Child's emotions and behaviour appear normal			

* Question asked but meaning altered. Write in new meaning.

Additional examinations performed by health worker

- _____
- _____
- _____
- _____

Additional questions asked by health worker:

- _____
- _____
- _____
- _____

Result of assessment:

Pass	Fail

Item/s failed (if applicable): ___

Referral made: _____

Did the health worker...	YES	NO	N/A
Referral and feedback			
22. ... make an appropriate referral?			
23. ... give adequate feedback to the caregiver?			
24. ... complete the RTHC?			
25. ... complete the referral form?			

Appendix 7

Focus group guidelines

Name of facility: _____ Date: _____

TOPICS FOR DISCUSSION:

How big is the problem of developmental disability in children this community?
What types of disability have you come across?

What do you understand to be the purpose of the DSP?
What are your feelings on screening children for developmental delay?

(What is the understanding of the health workers regarding the purpose of the programme? Do the health workers feel we should we be screening? How important is developmental screening and the programme to them?)

How did you experience the introduction of the DSP at your clinic?

(How was the introduction of the DSP experienced by the health workers, what training did they receive and how effective was it? How competent do the health workers feel in delivering the DSP?)

You are all involved in carrying out the DSP on a daily basis...
What do you find easy or like about delivering this programme?
What difficulties do you experience in delivering this programme?

Do you feel that the programme is effective/ fulfills its purpose?

(What are some of the other major barriers and success factors? Are children being identified and do they receive the necessary follow up assessment and intervention?)

What do you feel needs to be improved to make this programme work?

Notes regarding group dynamics:

e.g. level participation , active/ passive/ dominant participants etc.

_____

_____

_____

_____

_____

_____

_____

Key points that need to be determined in this discussion include the health workers' perceptions and feelings regarding:

- Importance of developmental screening
- Implementation of the programme, with a focus on training
- Delivery of the programme
  - What do they likes about it?
  - What do they dislike about it?
- Overall effectiveness of the programme – barriers and success factors
- Recommendations for improvement

Appendix 8
Exit interview guidelines: Interviews with caregivers

Name of facility:
Caregiver number:
Date:

1. Tell me what happened in your appointment with the nurse.

2. What did she explain to you about your child's growth and development?

3. What did the nurse say will happen with your child after today?

(If child passed screener, when must she come back. If failed, where is child being referred, when etc. What other advice was she given e.g. regarding stimulating her child?)

4. What did you like about your consultation with the nurse?

Enough time spent, nurse's skills, understand everything, happy with information received

5. What could have been better in your consultation?

Appendix 9
Retrospective record review data capture sheet

Name of facility:

Name of patient:

Clinic folder number:

1. Primary health care facility

Patient folder number: _____

Developmental Screening Tool used

0 – 6 weeks	9 months	18 months

Item/s failed/ reason for referral: _____

_____

Date referred: _____

Referral point (place referred to): _____

Appropriate referral? _____

Management completed prior to referral:

_____

_____

Additional comments:

_____

_____

_____

_____

2. Referral point #1

Name of facility: _____

Level of facility: _____

Folder number: _____

Referral received?

Yes	No

Type of notification with referral:

DSP referral form	Facility letterhead	Memo	Other _____

Date of receipt of referral: _____

Reason for DNA: _____

Health professional who received referral:

Regional paediatrician	Visiting O.T.	Other _____

Management completed:

_____

_____

Feedback sent to referral source?

Yes	No

Additional comments:

_____

_____

3. <u>Referral point #2</u>

Name of facility: _____

Level of facility: _____

Folder number: _____

Referral received?

Yes	No

Type of notification with referral:

DSP referral form	Facility letterhead	Memo	Other _____

Date of receipt of referral: _____

Reason for DNA: _____

Health professional who received referral:

Regional paediatrician	Visiting O.T.	Other _____

Management completed:

Feedback sent to referral source?

Yes	No

Additional comments:

8. REFERENCES

Academic publications

Barron, P. (Health Systems Trust, South Africa) (2003). The challenge of rolling out antiretrovirals. Health-E.www.health-e.org.za.

Beardsley, J. (2003). Are opportunities for Vitamin A supplementation being utlized in the Western Cape Province of South Africa? Unpublished report. Child Health Unit: Cape Town.

Berger, M.; Wilson, T.D. and Saunders, L.D. (1982). Queuing and patient flow at Soweto polyclinic. *South African Medical Journal*, 10(6), 547 – 570.

Bhunu, F., Kenyon, C. and Leon, N. (2001). Voices of health facility managers. In Health Systems Trust (Ed.) *South African Health Review*. Health Systems Trust, Durban.

Blackman, J.A. (1999). Developmental screening: infants, toddlers and preschoolers. In Levine, M.D.; Carey, W.B. and Crocker, A.C. (Eds.). *Developmental Behavioural Pediatrics*. 3rd ed. Philadelphia, PA. WB Saunders, 689 – 695.

Bradshaw, D.; Groenewald, P.; Laubscher, R.; Nannan, N.; Nolijana, B.; Norman, R.; Pietserse, D. and Schneider, M. (2003). *Initial Burden of Disease Estimates for South Africa, 2000.* Cape Town: South African Medical Research Council.

Calman, K. (1994). Developmental screening in the NHS. *Journal of Medical Screening*, 1, 101 – 105.

Casey, P.H. and Sanson, M. (1993). A pediatric perspective o developmental screening in 1993. *Clinical Paediatric Phila*, 32(4), 203 - 208.

Casto, G. and Mastropieri, M.A. (1986). The efficacy of early intervention programs: a meta-analysis. *Exceptional Children*, 52, 417 – 424.

Child Health Policy Institute (1996). *Workshop on Screening for Developmental Disabilities in the Pre-School Population: Proceedings, Child Health Unit, Cape Town, June 1996.*

Child Health Policy Institute (1996). *Workshop on Screening for Developmental Disabilities in the Pre-School Population: Reference Materials, Child Health Unit, Cape Town, June 1996.*

Cochrane and Holland (1969). Cited in Hall and Elliman. No reference provided.

Committee on Children with Disabilities (1994). Screening infants and young children for developmental disabilities. *Pediatrics*, 93, 863 - 865.

Committee on Children with Disabilities (2001). Developmental surveillance and screening of infants and young children. *Pediatrics*, 108, 192 - 195.

Corbin, J. and Strauss, A. (1990). *Basics of Qualitative Research: Grounded theory procedures and techniques.* Newbury Park: Sage.

Cornielje, H.,; Ferrinho, P and Gear, J. (1992). Results and methodological problems of a community survey of developmental delays in rural African children under 37 months of age. *SA Family Practice,* December, 575 – 581.

Couper, J. (2000). *Prevalence of Childhood Disability in Southern Africa*. Fogarty Maternal and Child Health Workshop, Durban, August 2000.

Couper, J. (2002). Prevalence of childhood disability in rural Kwazulu-Natal. *South African Medical Journal*, 92(7), 549 – 552.

Dawson, L.; de Klerk, D.; Luther, J. and Matschke, A. (2002). *A quantitative descriptive study to determine whether the gross and fine motor section of the PAWC Western Cape Developmental Screening Tool is reliable for the ages of nine and eighteen months*. Submitted to the Department of Occupational Therapy, University

of Cape Town in fulfilment of final year requirements for the Degree of BSc Occupational Therapy.

DePoy, E. and Gitlin, L.N. (1994). *Introduction to Research: Multiple Strategies for Health and Human Services*. St. Louis: Mosby.

Donald, D. (1994). *Children with special educational needs. The reproduction of disadvantage of poorly served communities in childhood and adversity*. A. Dawes and D. Donald (Eds.). David Phillip Publishers, Claremont.

Drennan (1999). Organisational factors affecting the provision of language services in mental health care. In m. Erasmus (Ed.) *Liaison Interpreting in the Community* (pp. 109 – 122). Van Schaik: Cape Town.

Durkin, M.S. and Khan, N. (1995). *The "Ten Questions" Screen.*

Durkin, M.S.; Davidson, L.L.; Desai, P.; Hasan, Z.M.; Shrout, P.E. et al. (1994). Validity of the ten question screen for childhood disability: results from population based studies in Bangladesh, Jamaica and Pakistan. *Epidemiology*, 5(3), 283 – 289.

Durkin, M.S.; Wang, W.; Shrout, P.E.; Zaman, S.S.; Hasan, Z.M.; Desai, P.; and Davidson, L.L. (1995). Evaluating a ten questions screen for childhood disability: reliability and internal structure in different cultures. *Journal of Clinical Epidemiology*, 48(5), 657 – 666.

Dworkin, P.H. (1989) 'British and American Recommendations for Developmental Monitoring: The Role for Surveillance'. *Pediatrics*, 84 (6): 1000-1009.

Feightner, J.W. (1993). *Pre-school Screening for Developmental Problems*. The Canadian Guide to Clinical Preventative Health Care. The Canadian Task Clinical force on Periodic Health Examination.

Fisch, M. (2001). *Interpreting Practices in Health Care: An Investigation of Differences across Trained and Untrained Interpreters in initial Assessment*

interviews, within the field of Speech-Language and Hearing Therapy. Unpublished Masters in Speech Pathology. University of Cape Town.

Fischer, F. (1995). *Evaluating Public Policy*. Nelson-Hall Publishers: Chicago.

Fischer, R.M. and Fitzgerald, M.T. (1987). A family involvement model for hearing-impaired infants. *Topics in Language Disorders, 7(3),* 1 – 18.

Frankenburg, W.K. (1994). Preventing developmental delays: Is developmental screening sufficient? *Pediatrics, 84 (4)*, 1000 – 1010.

Gibson, D. (2001). Negotiating the new health care system in Cape Town, South Africa: five case studies of the acutely chronically ill. *Medical Anthropology Quarterly*, 15(4), 515 – 532.

Giese, S. and Hussey, G. (2002). *Rapid appraisal of primary level health care services for HIV-positive children at public sector clinics in South Africa*. Children's Institute and Child Health Unit, University of Cape Town.

Gilson, L. and Schneider, H. (2000). The impact of free maternal health care in South Africa. In Berer, M. and Ravindran, TKS. (Eds.) *Safe Motherhood Initiatives: Critical Issues*. London: Reproductive Health Matters.

Glascoe, F.P. and Dworkin, P.H. (1995). The role of parents in the detection of developmental and behavioural problems. *Pediatrics, 95(6),* 829-836.

Green, A. (1999). *An Introduction to Health Planning in Developing Countries*. 2nd edn. Oxford University Press, New York.

Guralnick, M.J. and Bennett, F.C. (1987). *The Effectiveness of Early Intervention for at-risk and Handicapped Children.* Academic Press, New York.

Guralnick, M.J. (1997). Second-generation research in the filed of early intervention. In M.J. Guralnick (Ed.) *The Effectiveness of Early Intervention*. Paul H Brookes Publishing Co.

Guthrie, T.; Berry, L. and McClaren, P. (2003). *Social Security Assessment Tools for Children with Chronic Health Conditions: A Review of the Literature*. Children's Institute and DART.

Hall, D.M.B. and Elliman, D. (2003). *Health for All Children*. 4th edn. Oxford University Press, Oxford.

Hall, W; Haynes, R. and McCoy, D. (2002). *The Long Road to the District Health System. Legislation and Structures for the District Health System in South Africa: An Appraisal at August 2002*. Health Systems Trust, Durban.

Haynes, R. and Hall, W. (2002). District health systems and local government developments. In Health Systems Trust (Ed.) *South African Health Review*. Health Systems Trust, Durban.

Health System's Trust (2000). *South African Health Review*. Durban.

Helen Keller International, UNICEF and Department of Health (2003). National Assessment: Vitamin A Supplementation Program September – October 2002. Helen Keller International.

Irlam J. (1996). *A Rural disability Prevalence Study in KwaZulu-Natal*. Unpublished report.

Jacobs, F.H. and Kapuscik, J.L. (2000). *Making it Count: Evaluating Family Preservation Services*. Tufts University, Medford.

Jacklin, L. (1996). *Tools available for assessment*. Workshop on Screening for Developmental Disabilities in the Pre-school Population. Child Health Unit, Cape Town, June 1996.

Kaschula, R.H. and Antonissen, C. (1995). *Communicating Across cultures in south Africa: Towards a Critical Language Awareness.* Hodder & Stroughten: Johannesburg.

Katzenellenbogen, J.M.; Joubert, G. and Karim, S.S. (1997). *Epidemiology: A Manual for South Africa.* Cape Town: Oxford University Press.

Khosa, S. and McCoy, D. (1996). "Free health care" policies. In Health Systems Trust (Ed.) *South African Health Review.* Health Systems Trust, Durban.

Khosa, S. and Thomas, E. (1995). "Free health care" policies. In Health Systems Trust (Ed.) *South African Health Review.* Health Systems Trust, Durban.

Klugman, B. and McIntyre, D. (2003). The face of decentralisation and integration of health services: experiences from South Africa. *Reproductive Health Matters*, 11(21), 108 – 119.

Kromberg, J.G.R.; Christianson, A.L.; Manga, P.; Zwane, M.E.; Rosen E. and Venter, A. (1997). Intellectual disability in rural black children in the Bushbuckridge district of South Africa. *Southern Africa Journal of Child and Adolescent Mental Health*, 9 (4): 2-11.

Lachman, P.I. and Stander, I.A. (1990). Patterns of referral to Red Cross War Memorial Children's Hospital, Cape Town. *South African Medical Journal, 78*, 404 – 408.

Lehmann, U. and Sanders, D. (2002). Human Resource Development. In Health Systems Trust (Ed.) *South African Health Review.* Health Systems Trust, Durban.

Lavies, D. (July 1998). *Report on monitoring and evaluation of the 0 – 6 weeks Developmental Assessment Pilot Tool.* Report for PAWC Department of Health. Cape Town.

Lavies, D. (October 1998). *Report on monitoring and evaluation of the 9 months Developmental Assessment Pilot Tool.* Report for PAWC Department of Health. Cape Town.

Logan, S. (1995). Early identification of impairments in children. In Zinkin, P. and McConachie, H. (Eds.). *Disabled Children & Developing Countries.* London. Cambridge University Press.

Louw, B. (1997). *Guidelines for Speech-Language Therapists and Audiologists: Early Communication Intervention.* SASLHA Ethics and Standards Committee.

Madden, R. (2001). The International Classification of Functioning, Disability and Health (ICF). Australian Institute of Health and Welfare. www.physioth.unimelb.edu.au/symposium/madden.pdf.

Mahomed, H. and Bachmann, M.O. (1998). Block appointments in an overloaded South African health centre: quantitative and qualitative evaluation. *International Journal of Health Care Quality Assurance*, 11(4), 123 – 126.

Magwaza, S.; Cooper, D. and Hoffman, M. (2002). *The Delivery of Integrated Reproductive Health Services at District Levels.* Health Systems Trust, Durban.

Marshall, C. and Rossman, B. (1995). *Designing Qualitative Research.* Thousand Oaks: Sage Publications.

Martinez, J and Martineau, T. (1998). Rethinking human resources: an agenda for the millennium. *Health Policy and Planning, 13(4)*, 345 – 358.

Mathambo, V. and Shung-King (1999). *An Investigation into Primary Level After-hours Services for Children in the Western Cape Metropolitan Region.* Child Health Policy Institute, University of Cape Town.

McConachie, H.R. (1999). Conceptual frameworks in evaluation of multidisciplinary services for children with disabilities. *Child: Care, Health and Development*, 25(2), 101 – 113.

McCoy, D. (1996). *Free Health Care for Pregnant Women and Children under Six Years: An Impact Assessment.* Health Systems Trust, Durban.

McCoy et al (1997). *An Evaluation of South Africa's Primary School Nutrition Programme.* Health Systems Trust, Durban.

McCoy, D., Besser, M., Visser, R. and Doherty, T. (2002). *Interim findings on the National PMTCT Pilot Sites: Lessons and Recommendations.* Health Systems Trust, Durban.

Molteno, C. (1996). *The need for developmental screening in the pre-school population.* Workshop on Screening for Developmental Disabilities in the Pre-school Population. Child Health Unit, Cape Town, June 1996.

Morris, G. (1999). Improving quality of services. *South African Health Review.* Health Systems Trust: Durban.

Ogilvy, D. (2003). *Evaluation of the Policy and Guidelines for the Management of Survivors of Rape and Sexual Assault.* Report for PAWC Department of Health. Cape Town.

Olade, R.A. (1984). Evaluation of the Denver Developmental Screening Test as applied to African children. *Nursing Research*, 33(4), 204 – 207.

Patton, M.Q. (1990). *Qualitative Evaluation and Research Methods.* London: Sage Publications.

Power, M., Els, R., Zwarenstein, M., Lewin, S., Vundule, C., and Mostert, J. (1997). Most patients attending a "walk-in" clinic at Red Cross War Memorial Children's

hospital could safely be managed at primary care level. *South African Medical Journal, 87(1),* 36 – 41.

Power, D.; van der Merwe, B. and Dewar, R. (2003). *Survey of Child Health Services in the Western Cape Province.* Cape Town, South Africa.

Rossiter, E.J.R. (1993). The use of developmental screening and assessment instruments by paediatricians in Australia. *Journal of Paediatric Child Health,* 29, 357 – 359.

The South African Vitamin A Consultative Group (SAVACG) (1995). *Children Aged 6 to 71 Months in South Africa: Their Anthropometric, Vitamin A, Iron and Immunisation Coverage Status.* Isando, SAVACG.

Sait, L. (2001). Health legislation. In Health Systems Trust (Eds). *South African Health Review.* Health Systems Trust, Durban.

Sanders, D.; Kravitz, J.; Lewin, S. and Mckee . (1998). Zimbabwe's hospital referral system: does it work? *Health Policy and Planning, 13(4),* 359 – 370.

Schneider, M.; Claasens; M., Kimmie; Z.; Morgan, R.; Naicker, S.; Roberts, A. and McClaren, P. (1999). *We also Count! The Extent of Moderate and Severe Reported Disability and the Nature of the Disability Experience in South Africa.* Summary Report. Community Agency of Social Enquiry. Researched for the South African Department of Health.

Shapiro, B.K. (1996). Neurodevelopmental assessment of infants and young children. In A.J. Capute and P.J. Accardo (Eds) *Developmental Disabilities in Infancy and Childhood.* 4th edn. Paul Brookes Publishing Co.: Baltimore.

Shonkoff, J.P. and Hauser-Cram, P. (1987). Early intervention for disabled infants and their families: a quantitative analysis. *Pediatrics,* 80, 650 – 658.

Shung King, M. (1998). *An Evaluation of the Down-scaling of Red Cross Children's Hospital Medical Outpatient Department in the Western Cape Metropolitan Region.* Child Health Policy Institute, University of Cape Town.

Shung King, M.; Abrahams, E.; Giese, S.; Guthrie, T.; Hussey, G.; Irlam, J.; Jacobs, M. and Proudlock, P. (2000). Child Health. In Health Systems Trust (Eds). *South African Health Review.* Health Systems Trust, Durban.

Shung King, M.; Vennekens-Poane, A.; Michelson, L.; Kaime, T. and Ndlovu, N. (2003). The right to health . In J. Streak (Ed). Idasa Children's Budget Book. Idasa: Cape Town.

Siddiqi, S; Kielmann, A.A.; Khan, M.S.; Ali, N; Ghaffar, A.; Sheikh, U. and Mumtaz, Z. (2001). The effectiveness of patient referral in Pakistan. *Health Policy and Planning, 16(2),* 193 – 198.

Simpson, H. (1997). *Child Development Monitoring in the Western Cape: Acceptability and Potential benefits.* Summary of findings of dissertation submitted in partial fulfilment of Masters in Community Health, Liverpool School of Tropical Medicine.

Southall, D.P., Burr, S.; Smith, R.D.; Bull, D.N.; Radford, A.; Williams, A. (2000). The Child-Friendly Health Care Initiative: healthcare provision in accordance with the UN Convention on the Rights of the Child. *Pediatrics*, 106(5), 1054 – 1064.

St. Leger, A.S.; Schnieden, H. and Walsworth-Bell, J.P. (1992). *Evaluating Health Services' Effectiveness*. Open University Press: Philadelphia.

Swartz, L. (1991). The reproduction of racism in South African mental health care. *South African Journal of Psychiatry*, 21(4), 240 – 246.

Thorburn, M.; Desai, P.; Paul, T.J.; Malcolm, L.; Durkin, M. and Davidosn, L. (1992). Identification of childhood disability in Jamaica: evaluation of the ten question screen. *International Journal of Rehabilitation Research*, 15(3), 262 – 270.

Van Niekerk, A. (1997). Traumatic spinal cord injury among youth. In: C. de la Rey, N. Duncan, T. Shefer and A. van Niekerk. *Contemporary Issues in Human Development: A South African Focus.* South Africa: International Thomson Publishing.

Venter, A. (1993). Screening for developmental delay in general practice. *CME*, 11(7), 1263 – 1276.

Wicht, C.B. (1999). *Development and validation of a questionnaire as a screening tool for developmental disability in 9-month old infants.* Unpublished Masters Degree in Medical Paediatrics and Child Health. University of Cape Town.

Wilson, J.M.G. and Jungner, G. (1968). *Principles and Practice for Screening of Disease.* Geneva. World Health Organisation.

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

World Health Organisation (1982). *Report on an inter-regional consultation in Sri Lanka.* Community based rehabilitation. (RHB/IR82.1) Geneva. WHO.

World Health Organisation (2001). Press release WHO/48. *WHO Publishes New guidelines to Measure Health.* www.who.inf-pr-2001/en/pr2001-48.html.

Zaman, S.S.; Khan, N.Z.; Islam, S.; Banu, S.; dixit, S.; Shrout, P. and Durkin, M. (1990). Validity of the 'Ten Questions' for screening serious childhood disability: results from urban Bangladesh. *International Journal of Epidemiology*, 19(3), 613 – 620.

Government publications and Western Cape Developmental Screening Programme support documentation

Department of Health (1997). *White Paper for the Transformation of the Health System in South Africa*. Government Gazette # 19710 Vol. 382.16 April 1997.

Department of Health (2000). *National Rehabilitation Policy: Rehabilitation for All.* November 2000. Pretoria: Department of Health, South Africa.

Department of Health (2001). *A Comprehensive Primary Health Care Package for South Africa*. Pretoria: Department of Health, South Africa.

Department of Health and Social Services Provincial Administration of the Western Cape (April 2000). *Report of the Bi-ministerial Task Team on the Implementation of a Municipality-Based District Health System.*

Department of Health (1999, 2000, 2001). *Reports on the implementation of the Integrated Management of Childhood Illnesses.*

Medical Research Council and Department of Health (1998). *Demographic Health Survey.*

Office of the Deputy President (1997). *White Paper on an Integrated National Disability Strategy*. November 1997.

PAWC Department of Health and Social Services (December 1999). *Provincial Directive, Superintendent General H159/99.*

PAWC Department of Health MCWH Sub-directorate (1998, 1999). *Developmental Screening Programme Training Packages.*

PAWC Department of Health MCWH Sub-directorate (December 1997). *Letter from Deputy Director to Regional Directors.*

PAWC Department of Health MCWH Sub-directorate (June 1998). *Letter from Deputy Director to Regional Directors.*

PAWC Department of Health MCWH Sub-directorate (May 1998). *Developmental Screening Programme Progress Report.*

Province of the Western Cape (July 2001). Integrated Provincial Disability Strategy.

Provincial Reference Group. *Initial goal, aims and objectives of Provincial Reference Group for Developmental Screening*. Draft, September, 1997.

Provincial Reference Group for Developmental Screening: *Letters to private company requesting funding*, December 1997, November 1998.

Provincial Reference Group for Developmental Screening: *Minutes of Meetings*: 7th meeting - 5 December 1997, 12th meeting - 9 October 1998, 20th meeting - 1 September 2000.

Verbal communication

Adnams, Dr. C., 2003.

Deputy Director MCWH, PAWC Department of Health, 2002.

Regional Developmental Screening Programme Co-ordinators, 2002.