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Evaluation of The Western Cape Province Screening Programme for Developmental Disabilities in Pre-School Children: *A Summary Report*

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iSebe lezeMpilo

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1. INTRODUCTION

What is the Developmental Screening Programme (DSP)?

The Western Cape Screening Programme for Developmental Disabilities in Pre-school Children, a standardised screening system to identify undiagnosed or unsuspected developmental problems in pre-school children, was introduced as formal policy in the Western Cape (WC) Province in December 1999. Since then, health workers at primary health care facilities have been delivering this programme, which involves the use of standardised screening tools to screen children for moderate and severe disability when they visit the health facility for their immunisations at 6 weeks, 9 months and 18 months.

2. BACKGROUND, DEVELOPMENT AND IMPLEMENTATION OF THE DSP

Prior to the implementation of the DSP, health workers often conducted screening for developmental disabilities in a random way, using instruments that were not necessarily standardised or scientifically sound. In addition, training packages and guidelines were frequently lacking, resulting in the poor management of developmental disability in children. As early as the 1970s, health care workers voiced the need for standardised developmental screening. *Figure 1 on the next two pages outlines the development and implementation processes of the DSP.*

Figure 1: Implementation process of the DSP and need for evaluation in Western Cape

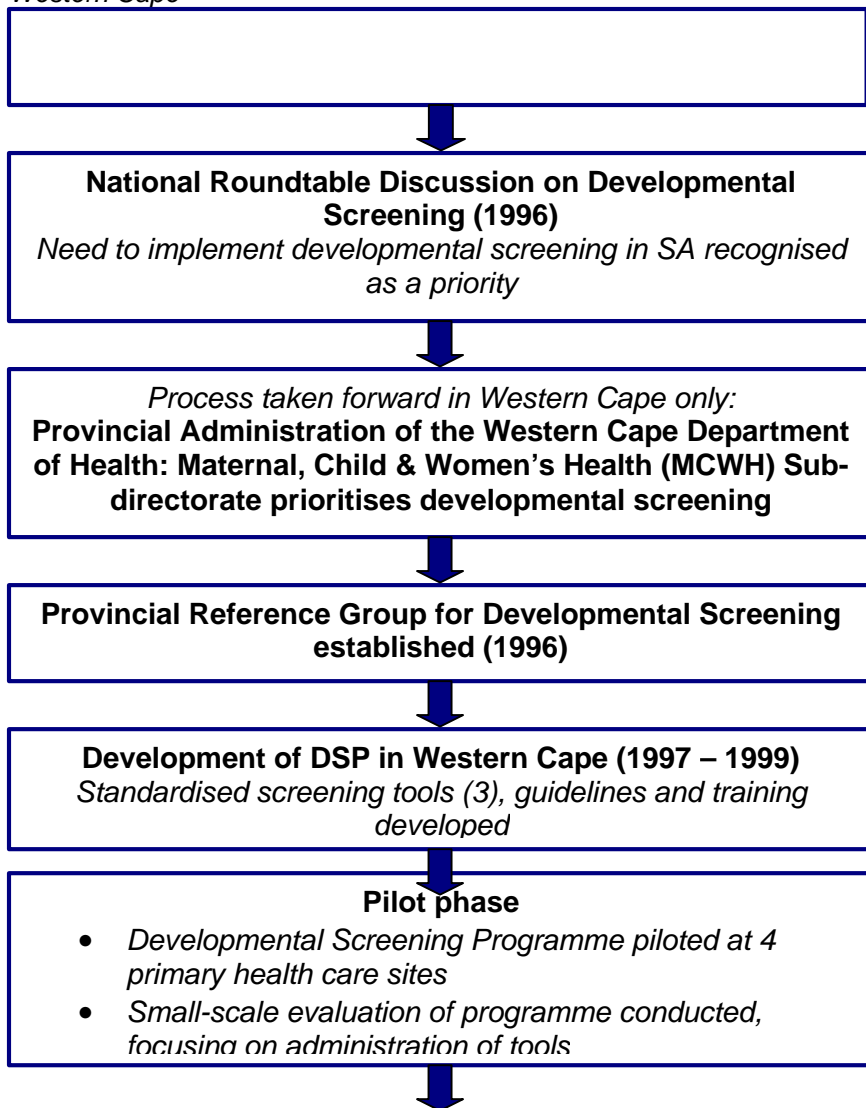
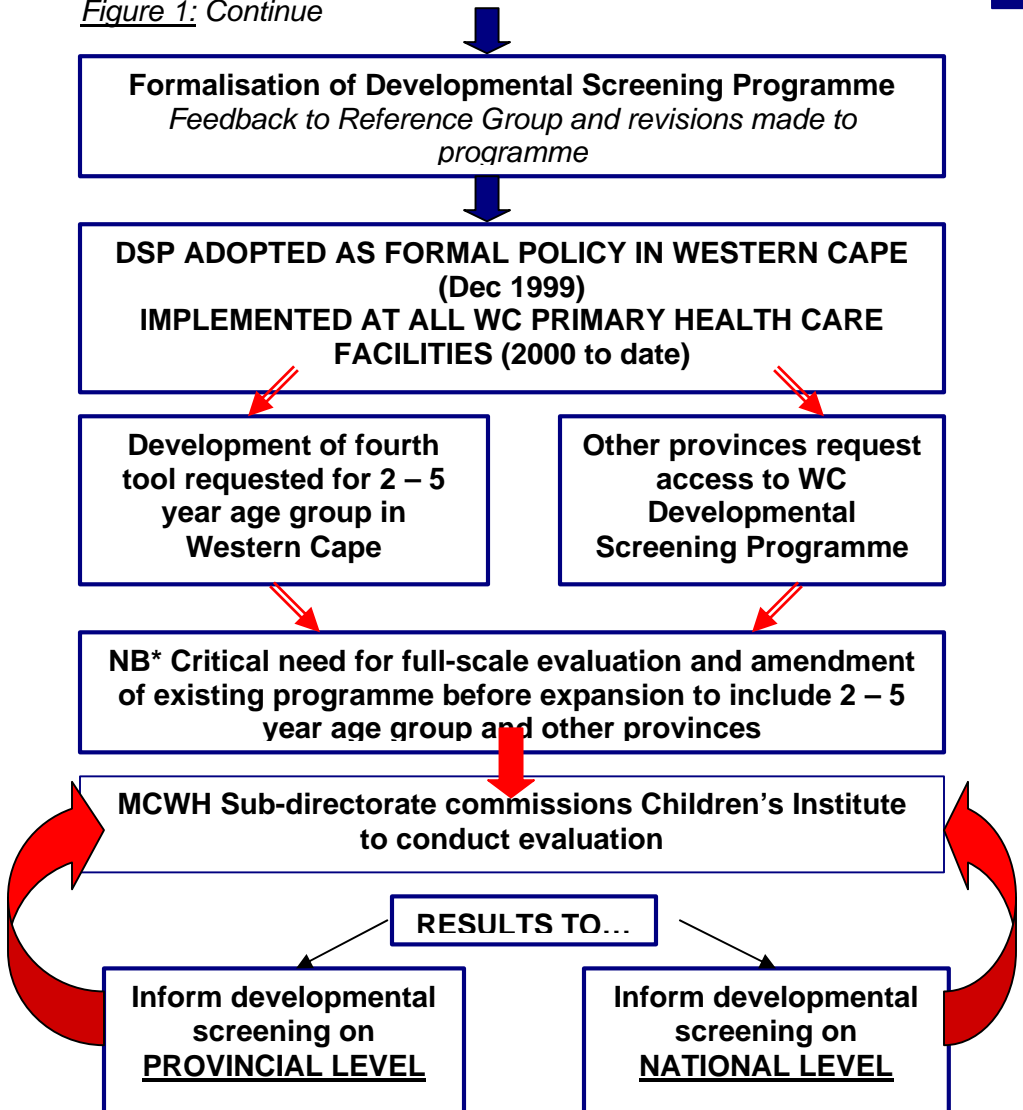


Figure 1: Continue



3. METHODOLOGY

Purpose

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

Scope

This evaluation focused on the input, process and output aspects of the DSP. Outcomes in terms of the developmentally delayed child were not evaluated, as this requires a cohort study of at least five years. The study did not examine the scientific validity and reliability of the three screening tools, as this requires a separate study.

Aim

The aim of this research was to evaluate the implementation of the WC 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 DSP.
2. To describe the current delivery of the programme.
3. To determine barriers and success factors within the implementation process.
4. To make recommendations regarding the DSP to the Western Cape Province Department of Health.

Stages of data collection and data analysis

The data collection for this study involved four stages, as outlined alongside the stages of data analysis in Figures 2 and 3 respectively.

Figure 2: Flow diagram indicating stages of data collection stages

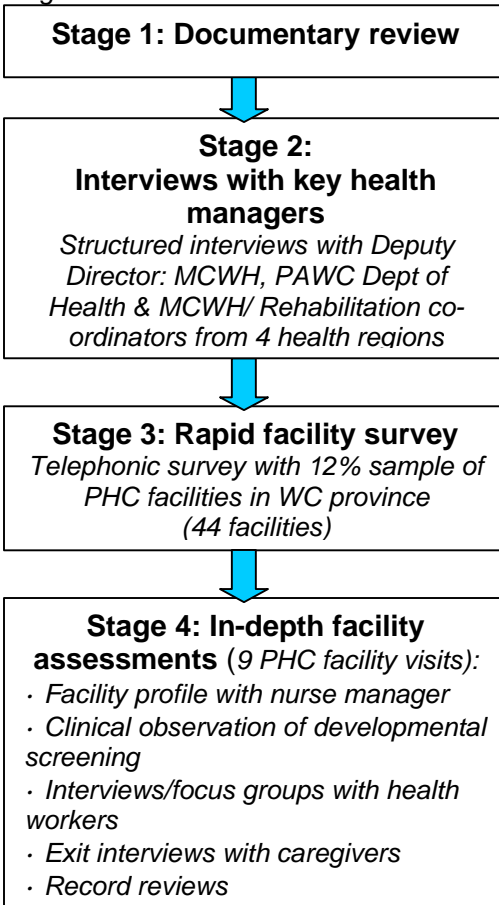
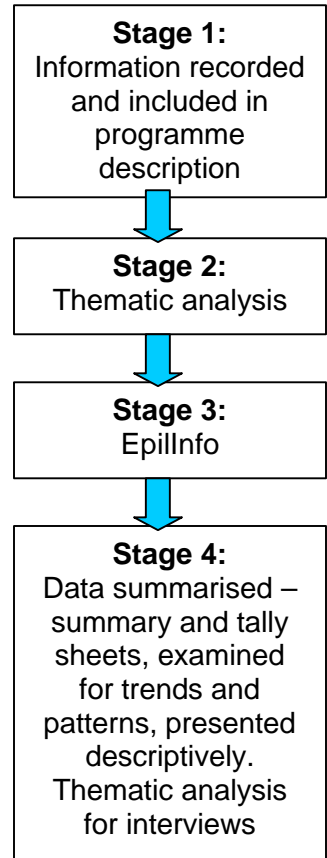


Figure 3: Flow diagram indicating data analysis stages



4. SUCCESSES IN THE CURRENT DELIVERY OF THE DSP

4.1 Awareness of the Developmental Screening Programme

Provincial and regional health managers interviewed for this study felt that a general awareness regarding the DSP exists across health facilities. These impressions were confirmed by both the rapid facility survey and the in-depth health facility visits. The telephonic survey revealed that 100% of the 44 health facilities interviewed were indeed aware of the DSP. Furthermore, all nine facilities visited for in-depth assessment indicated an awareness of the programme, with the extent of awareness varying from facility to facility.

4.2 Value of developmental screening and the DSP

Developmental screening receives little priority within the field of child health services at a national, provincial and regional level and has notably only been addressed within the WC Province. Similarly, at a local level, the implementation of curative services for children at primary health care facilities takes precedent over preventive and promotive services, including developmental screening. Despite this, the introduction of the DSP in the WC has been met extremely positively.

Health workers throughout the province who participated in this study unanimously voiced the need to conduct developmental screening, citing early detection as a strong motivation for this activity. Health workers expressed their gratitude for the development of standardised screening methods and lauded the DSP and its component tools and guidelines for their simplicity, ease of use, time-effectiveness and comprehensive content. Despite various constraints in delivering developmental screening, health workers insisted that it must continue. *“It is necessary because you may not know. It can be one 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.”

4.3 The successful development of the DSP and the key role of the Provincial Reference Group

In taking developmental screening forward in the province, the Maternal, Child & Women’s Health (MCWH) Sub-directorate of the Western Cape Provincial Department of Health (DoH) set up a multidisciplinary and inter-departmental Provincial Reference Group (PRG) for Developmental Screening in 1996. The PRG was chaired by the Deputy Director of MCWH and included representatives from the Chronic Care and Rehabilitation and Mental Health Sub-directorates of the DoH at a provincial level, regional managers and the WC Education Department. Teaching institutions and developmental services, other centres and non-governmental organisations (NGOs) involved with children with developmental disability, as well as health workers were also represented.

The multidisciplinary and inclusive nature of the PRG, specifically the high level of input from health workers “on the ground”, and professionals from academic institutions were acknowledged for facilitating the rapid and smooth implementation of the programme. The dedication and commitment of the Chairperson of the PRG and the core training task team were also highlighted.

5. CHALLENGES IN THE CURRENT DELIVERY OF THE DSP

Despite the need for developmental screening and the overall awareness of the DSP in the WC province, the delivery of developmental screening is taking place to a limited extent across the province. No distinct differences were seen between the delivery of the programme at pilot vs non-pilot sites, community

health centres vs primary health care clinics or between regions. Specific problem areas where delivery did not take place at all were identified in the study, and it is likely that many other such sites exist throughout the WC.

The evaluation revealed that:

- 78% of facilities are delivering some aspect of developmental screening, while almost a quarter of facilities (22%) are not delivering developmental screening at all.
- Of the facilities delivering some developmental screening, only 11% are delivering developmental screening according to protocol i.e. full tool used at the three prescribed ages according to the guidelines provided.

6. THE HEALTH SYSTEM AND ITS IMPACT ON THE DELIVERY OF THE DSP

A glaring finding of this research was that the majority of constraints identified in the delivery of the DSP were systemic (relating to the health system) rather than programme specific in nature. This means that implementation did not occur because of problems with the programme itself but because of multiple challenges and barriers within broader health care provision.

It should be noted that these findings are not unique to this particular evaluation. Recent studies evaluating other maternal and child health programmes within the WC reached similar conclusions. Various systemic factors have all been cited as constraints in the delivery of such programmes:

6.1 Transformation or restructuring of the health services

Like many other maternal and child health programmes introduced in the past five years, the context in which the DSP was

developed and implemented has been characterised by much restructuring and change within the health system. The introduction of the new district health system, including the decentralisation of services and the rationalisation - and in some instances the amalgamation - of facilities has caused much uncertainty for health workers. Free health care and more recently the introduction of a comprehensive, integrated “one stop service” has increased health workers’ workloads, while staffing levels have fallen. The “possibility of smooth implementation (of the DSP, like the downscaling of the outpatient services at Red Cross Children’s Hospital) has thus been marred by numerous other restructuring processes in the WC, that negatively impacted on the workload, staffing levels and available resources” (Child Health Policy Institute, 1998).

The quality of comprehensive primary health care provided has clearly deteriorated, with the delivery of curative services taking priority over other services. Due to time constraints, preventive services, including immunisations and developmental screening, do not receive adequate attention. According to one health worker, “...we do precious little preventive work. We try to prevent but I must say that the focus has actually shifted”. This was evident both in the fall in immunisation coverage in the province and the limited delivery of the DSP.

6.2 Organisation of service delivery at health care facilities

Health facility related factors also played a role in the efficient delivery of services, including developmental screening at a primary health care level. Although the provision of dedicated services at dedicated times by dedicated staff is contrary to the “one stop shop” philosophy of the DoH, these factors contributed positively to the delivery of (quality) services, including developmental screening. Similar to a study conducted by Ogilvy & Associates (2003) on the Policy and Guidelines for the

Management of Survivors of Rape and Sexual Assault, this study showed that developmental screening ran smoothly in an organised fashion where dedicated health workers carried out immunisations and developmental screening services at set times, rather than seeing well children while providing a range of other services at the same time. Children were more likely to be seen quicker and receive better attention from a focused health worker. It was clear from this evaluation that health workers were struggling to be “masters of all”.

In agreement with the interim Health System’s Trust study (2002) on the national Prevention of Mother To Child Transfer (PMTCT) pilot sites, this study found that strong sub-district, facility management and physical infrastructures (including a child friendly environment) had a positive affect on service delivery.

6.3 Staff and staff capacity

As highlighted by all previous evaluations of child health programmes, human resource constraints were identified as hindering the delivery of the DSP. Low staff levels and consequent work pressures impacted negatively on the quality of service delivery and staff morale. Health workers were highly dissatisfied with the quality of care they were able to provide and indicated that they just did not have the capacity and time to carry out preventive and promotive aspects of health care as in the past: *“I mean there is no way we can claim to have such a wonderful health service because we don’t.”*

6.4 Training

Like many other child health programmes, the need for training and ongoing support of health workers to sustain the positive impact of training is great (Health Systems Trust, 2002). Continued capacity development and support is especially important in view of the rapid staff turnover in many health facilities and the rotation of staff through the primary health care

services within many health facilities. It is thus a great concern that a large proportion of health care workers in the province do not have access to ongoing training and support on programmes such as the DSP. This is mainly attributed to gaps and inequities within the Human Resource Development (HRD) Sections of Regional Departments of Health and limited training provision by other district and local authorities, as highlighted in other programme evaluations such as the study by Ogilvy & Associates (2003).

6.5 Referral system

Similar to the findings of two evaluations conducted by the Child Health Policy Institute in 1998 and 1999 respectively, 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 restrained by the lack of resources for further assessment, intervention and transportation.

6.7 Intervention

One of the general principles for screening outlined by the World Health Organisation and one of the core principles of screening for developmental disability as set out by the 1996 national workshop, is that screening should only be conducted if linked to appropriate interventions. This evaluation revealed that although developmental and rehabilitation services were more readily available than in the past, in many cases the necessary interventions for children detected with developmental disability were still not always available or accessible. The government has committed to realising the rights of the disabled child and the delivery of rehabilitation services through the White Paper on an Integrated National Disability Strategy (1997) and the National Rehabilitation Policy (2000). However, the elements of the comprehensive PHC service package for the delivery of a

rehabilitative service to children with disability (DoH, 2001) are still largely not in place.

6.8 Monitoring and the role of health information

“Systems need to be in place to monitor on an ongoing basis the implementation of (health) interventions” (Children’s Institute, March 2002). This recommendation in the rapid appraisal of primary health care services for HIV-positive children is one that should be applied to all child health programmes but remains largely neglected. The lack of monitoring and structures for monitoring of the DSP emerged clearly from this evaluation.

7. ISSUES SPECIFIC TO THE PROGRAMME

While it is clear that the success of the DSP has been confounded by numerous broad health systems factors, the few noted programme specific challenges should also be mentioned. These challenges should not be considered in isolation but in the context of greater systemic challenges.

7.1 Training: Although the contribution of the Provincial Training Task Team (PTTT) in the initial training on the DSP was significant and exceptionally well received, major gaps were found in current training. HRD teams in each of the regions provide little or no continued training and support and there is inadequate training by other district or local authorities, or in-service training. The lack of delivery was seen to be directly linked to the lack of training. Table 1 on the next page sets out the percentage of health workers trained by various training bodies.

7.2 Recording of screening results: Results of developmental screening were found to not always be recorded according to protocol, and are most often not recorded on the Road to Health Card. In some facilities, old developmental screening tools still

formed part of paediatric clinic folders. This was believed to negatively effect the delivery of the “new” developmental screening tools. Where “new” screening tools formed part of patient folders, screening was more likely to occur.

Table 1: Training reported by facilities telephoned and visited

Source of information	% of health workers trained by each body				
	Prov. Training Task Team	Human Resource Dev. Sectors	Local/district Authority Training Depts.	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%	-

7.3 Referrals: Referrals of children identified through developmental screening are not always according to protocol. This study found that 30% of children were still referred directly to the tertiary level, bypassing the secondary level. This was often linked to transportation (ambulance) routes. Health workers showed some lack of confidence in referring children with developmental disability and often referred initially to medical doctors - medical officers or district surgeons - for confirmation of the “diagnosis”. Rehabilitation services remain underused. Most notable is that standard developmental screening referral forms are not being used.

7.4 Intervention: The availability of intervention was seen to be directly related to the delivery of developmental screening, as health workers were more motivated to screen children when they knew the child would receive intervention. The lack of uptake and regular attendance for intervention was also a key issue that emerged from this study. There is thus a clear need for health education around child development and disability in the community to highlight the importance of the early years for development and to dispel myths regarding development and disability.

7.5 Monitoring and evaluation: The only formal mechanism for monitoring the implementation of the DSP has been the health information data on developmental screening captured via routine monthly reports (RMRs). This data however is so inaccurate that it lacks both meaning and value.

8. RECOMMENDATIONS

Based on the findings of this evaluation study, a number of recommendations for the provincial health system and specific recommendations for the DSP are made.

8.1 Recommendations for the provincial health system

In view of the WC Department of Health's new Healthcare 2010 plan released by cabinet in March 2003, a number of serious health systems issues highlighted by this evaluation and in previous evaluations should be urgently addressed to ensure that existing and future programmes succeed. Table 2 outlines such issues.

Table 2: Recommendations for the provincial health system

Problems to be addressed	Action required	Directorate/ manager responsible for action
Delivery of comprehensive PHC package		
Failure of preventive/ promotive service provision	Recognise and fund at all levels of care	Top management
Failure of rehabilitation service provision	Recognise and fund at all levels of care; address gaps in service provision	Top management Rehabilitation Sub- directorate
Poor quality of comprehensive PHC to children	Re-organise services at PHC facilities to include fast-tracking of children; dedicate staff to specific services; booking system	Top management Programmes Directorate Regional, district & facility managers

Problems to be addressed	Action required	Directorate/ manager responsible for action
Staff		
Overload	Distribute staff equitably; dedicate staff to specific services; provide support for staff	Top management HRD Directorate HRM Sub-directorate
Poor morale	Facilitate restructuring; staff incentives	Top management HRD Directorate HRM Sub-directorate Regional, district & facility managers
Gaps in training	Clarify roles, responsibilities & capacity of HRD, ATD, FIST and training task teams	Top management HRD Directorate HRM Sub-directorate Regional, district & facility managers
Referral system		
Unclear referral pathways	Clarify child health referral pathways for each region and district; provide each facility with standardised referral guidelines	Programmes Directorate, regional programme managers, district managers and facility managers
Monitoring and evaluation		
Lack of objectives, targets and indicators for programmes	Set for all programmes	Health Information Directorate, Programmes Directorate

Problems to be addressed	Action required	Directorate/ manager responsible for action
Poor RMR data	Review all RMR data to ensure line items hold value and meaning	Health Information Directorate Programmes Directorate
Lack of programme evaluations	Regularly monitor and evaluate programmes to examine input, process, output and outcome boundaries	Research Directorate Health Information Directorate Programmes Directorate

8.2 Developmental Screening Programme specific recommendations

The programme specific recommendations are inextricably linked to those cited in Table 2 and will have little or no effect on the delivery of the DSP without improvements to the broader health system. The 2 – 5 year screening tool should not be developed until major health system reforms have taken place.

Table 3: Specific recommendations for the Developmental Screening Programme

Problems to be addressed	Action required	Directorate/manager responsible for action
Delivery of DSP		
Districts not delivering DSP	Send follow up provincial circular; meet with relevant district authorities	MCWH Sub-directorate Regional managers

Problems to be addressed	Action required	Directorate/ manager responsible for action
Lack/incorrect charting of developmental screening results	Send follow up provincial circular; highlight in future training and implementation	MCWH Sub-directorate Regional managers Relevant trainers
Lack of use of standard referral form	Send follow up provincial circular; highlight in future training and implementation	MCWH Sub-directorate Regional managers Relevant trainers
Unclear referral pathways for children identified with developmental disability	Clarify DSP referral pathways per region and district Provide each facility with set referral guidelines	MCWH Sub-directorate Rehabilitation Sub-directorate Regional managers District managers
Follow up of children who failed developmental screen	Institute a DSP register at PHC facilities of children who failed screening	MCWH Sub-directorate
Staff		
Failure of training	Clarify training mechanisms i.e. who should provide ongoing training and support on DSP and in what way	HRD Directorate
Response to DSP		
Unavailability and inaccessibility of rehabilitation services	Investigate current gaps and how to address. Look at transportation alternatives.	Rehabilitation Sub-directorate
Public awareness		
Lacking awareness of early identification, intervention and disability	Health education e.g. posters, talks in health facility waiting rooms	MCWH Sub-directorate Rehabilitation Sub-directorate, NGOs

Problems to be addressed	Action required	Directorate/ manager responsible for action
Lack awareness regarding DSP	Health education e.g. posters, talks in health facility waiting rooms	MCWH Sub-directorate Rehabilitation Sub-directorate, NGOs
Monitoring and evaluation		
Lack objectives, indicators and targets	Review objectives and set targets for DSP	Provincial Reference Group
Meaningless and valueless RMR data	Redefine DSP line items	Provincial Reference Group, Health Information Directorate

8.3 Recommendations for further evaluation and research

- An in-depth, cohort study of the referral, follow up and long term outcomes of children identified with developmental disability.
- An investigation of the scientific validity and reliability of the developmental screening tools.
- Re-evaluation of the DSP within 3 – 5 years once the recommendations of this evaluation have been addressed.

The Western Cape Department of Health, and in particular the MCWH Sub-directorate are acknowledged for their visionary step in commissioning this evaluation and for their commitment to the search for programme weaknesses, truths and realities.

To the participants in this evaluation...we hope that this study is a testament to your strong commitment to provide quality health care to all children in the Western Cape.