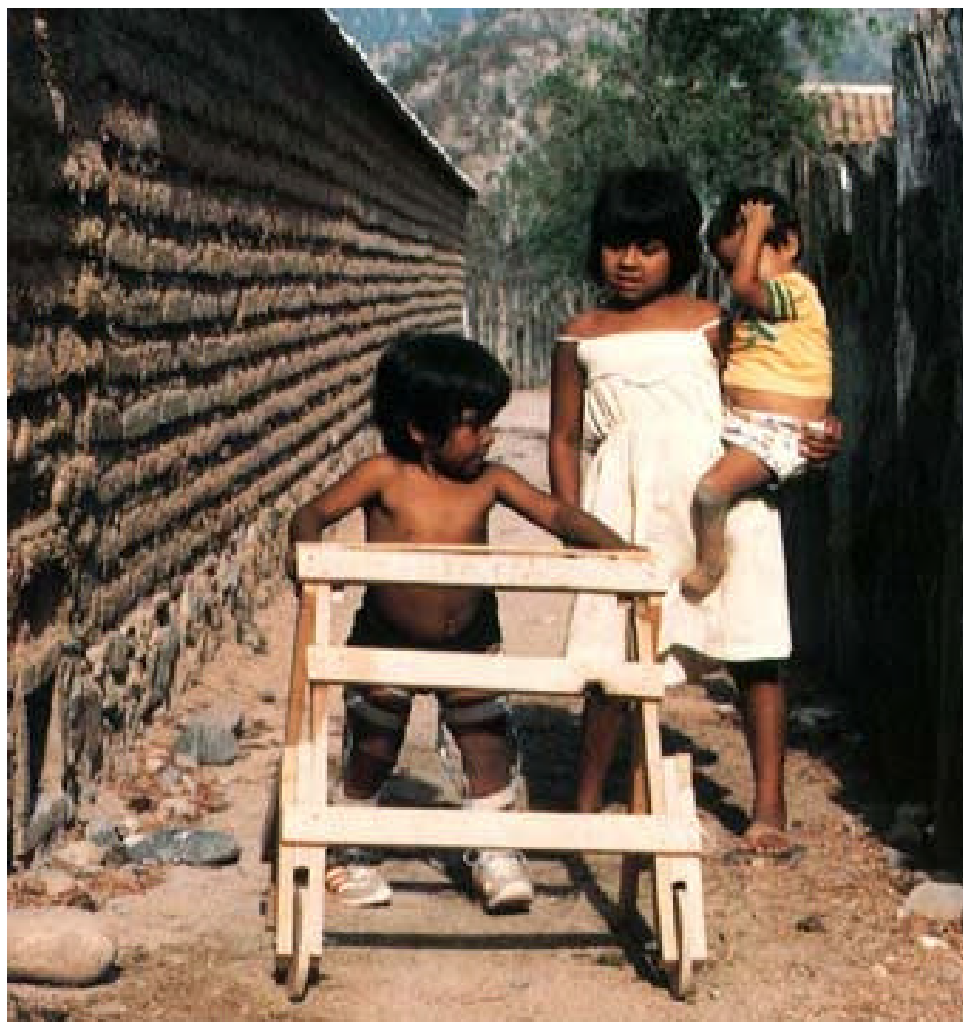


# **National Programme for the Children with Special Needs**

## **Role of the Health Sector**



### **CONCEPT NOTE AND PROGRAMME PLAN**

**Child Health Unit: 2, Family Health Bureau, Ministry of Health**

## **Introduction**

Children vary in their growth, development, biological functions and degree of socialization. For majority of children, these variations fall within permissible ranges so that their capacities to function are comparable to each other. A smaller proportion of children fail to function as their peers and most often they need additional or special forms of care for maintaining their growth, development, health and overall quality of life. They are called children with special needs (CSN). Presence of special need in a child could impart enormous burden on family members and caregivers. They often require continuous health care; have special educational needs and a wide range of other welfare services.

Children with special needs (CSN) have been a concern of the National Child Health programme for considerable years. Monitoring of developmental mile stones to screen for the children with developmental problems and referring them to specialist care were among the very early intervention packages of the child health programme. However, the capacity and readiness of the child health programme for catering for the comprehensive needs of CSN is not optimal. The Maternal and Child Health Policy 2007 recognizes this service gap and focuses a separate goal to address the health care needs of the children with special needs. In response to this policy thrust the Family Health Bureau has embarked on developing and implementing a comprehensive programme for the CSN. This document provides the conceptual framework and the long term action plan of the “National Programme for the Children with Special Needs”..

### ***Definition: Children with Special Needs***

Children with special needs are defined in many different forms. There is no single internationally agreed-up on definition. In the Protection of the Rights of Persons with Disabilities Act of Sri Lanka, a disabled person is defined as “Any person who, as a result of any deficiency in his physical or mental capabilities, whether congenital or not, is unable by himself to ensure for himself, wholly or partly, the necessities of life”. This definition takes in to account both medical and socio-economic parameters of disability.

The following definition constructed by the Maternal and Child Health Bureau- USA and adapted by many other centers could be viewed as one of the most comprehensive ones that could be adopted by health sector programmes.

*CSN: Children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions who require health and related services of a type or amount beyond that required by children generally.*

This definition would encompass a large number of disability conditions. For instance it includes birth defects or injuries that make them permanently dependent on equipment such as feeding tubes and breathing machines; and disorders that hinder their physical and mental development (visual, hearing and speech problems, cerebral palsy, Autism Spectrum Disorders (ASD), attention deficit hyperactivity disorders (ADHD), learning and behavioral disorders; cancer, thalassaemia, sickle cell anemia, and other debilitating diseases. The concept of at risk children would make the level of inclusiveness of CSN to almost unwieldy capacity. Therefore, any programme aimed at children with special needs has to demarcate a manageable area of work; clearly considering the priorities, resources and feasibility. Such a clear cut boundary is necessary to determine the burden of diseases within the selected areas of concern, resource needs, and service requirements. Hence, at the initial stage, The National Programme for CSN will focus on the following conditions:

Table -1 Condition identified to be focused by the National Programme for the children with special needs.

1. Autism spectrum disorders
2. Disruptive behavior disorders (Attention-deficit/Hyperactivity Disorder, conduct disorders and other behavioral problems)
3. Specific learning disorders
4. Cerebral Palsy, other neural problems and physical disabilities related to illnesses, developmental problems and trauma

### ***Extent of the problem***

A wide variation is seen in the reported prevalence of children with special needs around the world that ranges from 11 to 23.5 %. Much of this variation is due to the use of different definitions and research methodologies in estimation, rather than for population characteristics.

Not much information is available on the burden of disease and disabilities due to special needs in children in Sri Lanka. The Census of Population and Housing 2001 – Sri Lanka has tried to enumerate prevalence of disabled persons. According to that 0.27 % of children under 19 are reported to have some form of disabilities (Total disabled = 16746, Total 0-19 children – 6,095,853). The census defined a disabled child as “a person who is unable or limited in carrying out activities that he or she can do due to congenital or long term physical/mental disabilities”. However this estimate should be interpreted with caution as many shortcomings are seen in the methodology used to identify these persons and it is heavily deviated from the prevalence reported from other parts of the world where preconditions for health are much satisfactory.

About 25,700 children with special education needs are currently enrolled in schools and 1382 teachers are involved in providing their education (Teachers to student ratio = 1: 19).

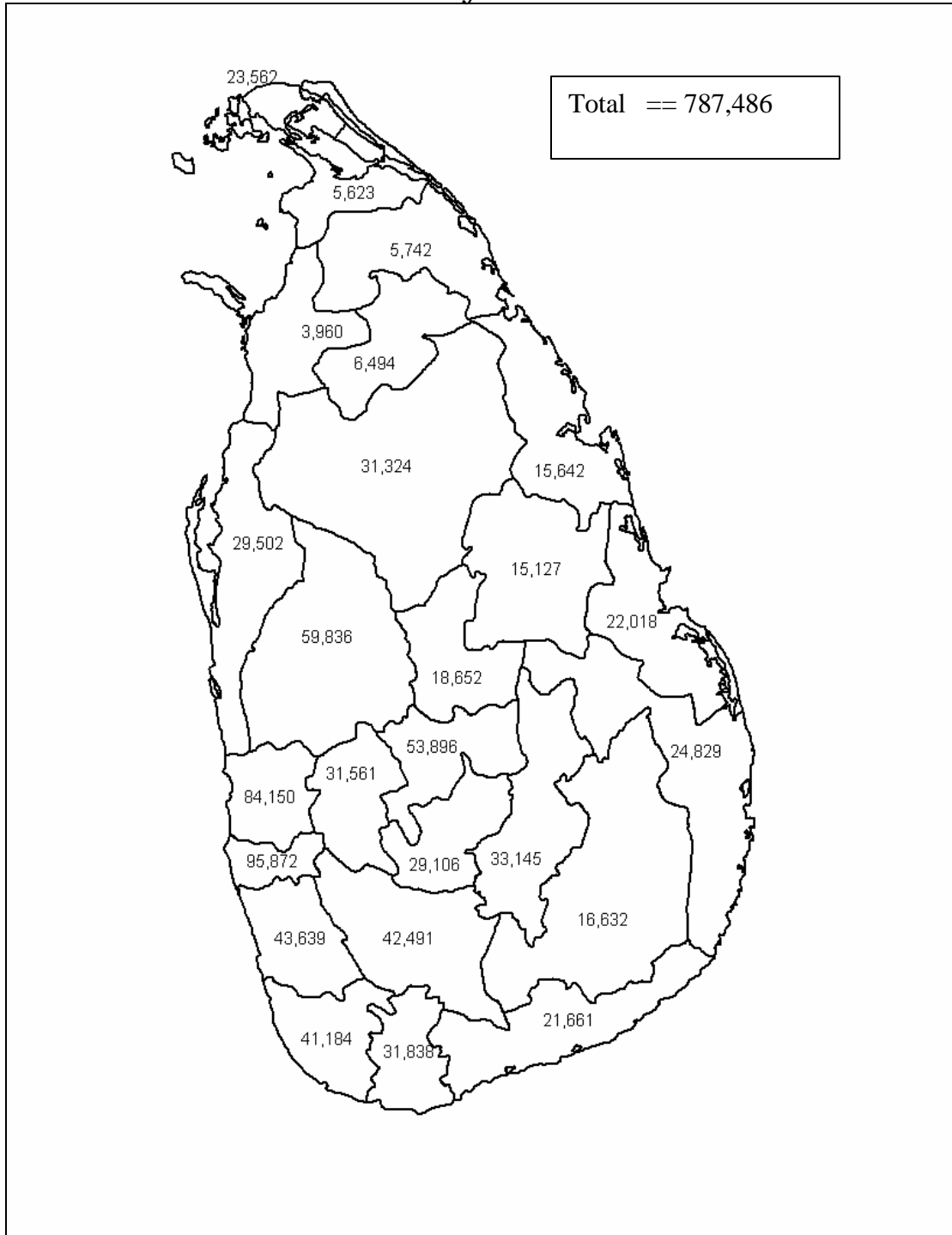
As there was no country specific prevalence rates, the following estimates of the number of children with special needs in different districts were determined by applying a prevalence rate of 11% ( lowest international prevalence) to the estimated number of under 19 population in different districts ( Table 2; Figure 1) . According to these estimates nearly 800000 children with special needs are estimated to present around the country.

**Table 2**  
**Estimated numbers of children with special needs by district**

<b>District</b>	<b>Number</b>	<b>District</b>	<b>Number</b>
Amparai	24829	Kurunegale	59836
Anuradapura	31324	Mannar	3960
Badulla	33145	Matale	18652
Batticaloa	22018	Matara	31838
Colombo	95872	Moneragale	16632
Galle	41184	Mullaitivu	5742
Gampaha	84150	Nuwara Eliya	29106
Hambantota	21661	Polonnaruwa	15127
Jaffna	23562	Puttalam	29502
Kalutara	43639	Ratnapura	42491
Kandy	53896	Trincomalee	15642
Kegalle	31561	Vavuniya	6494
Kilinochchi	5623	<b>Total</b>	<b>787,486</b>

**Figure -1**

**Map of Sri Lanka indicating the estimated number of children with special needs by districts**

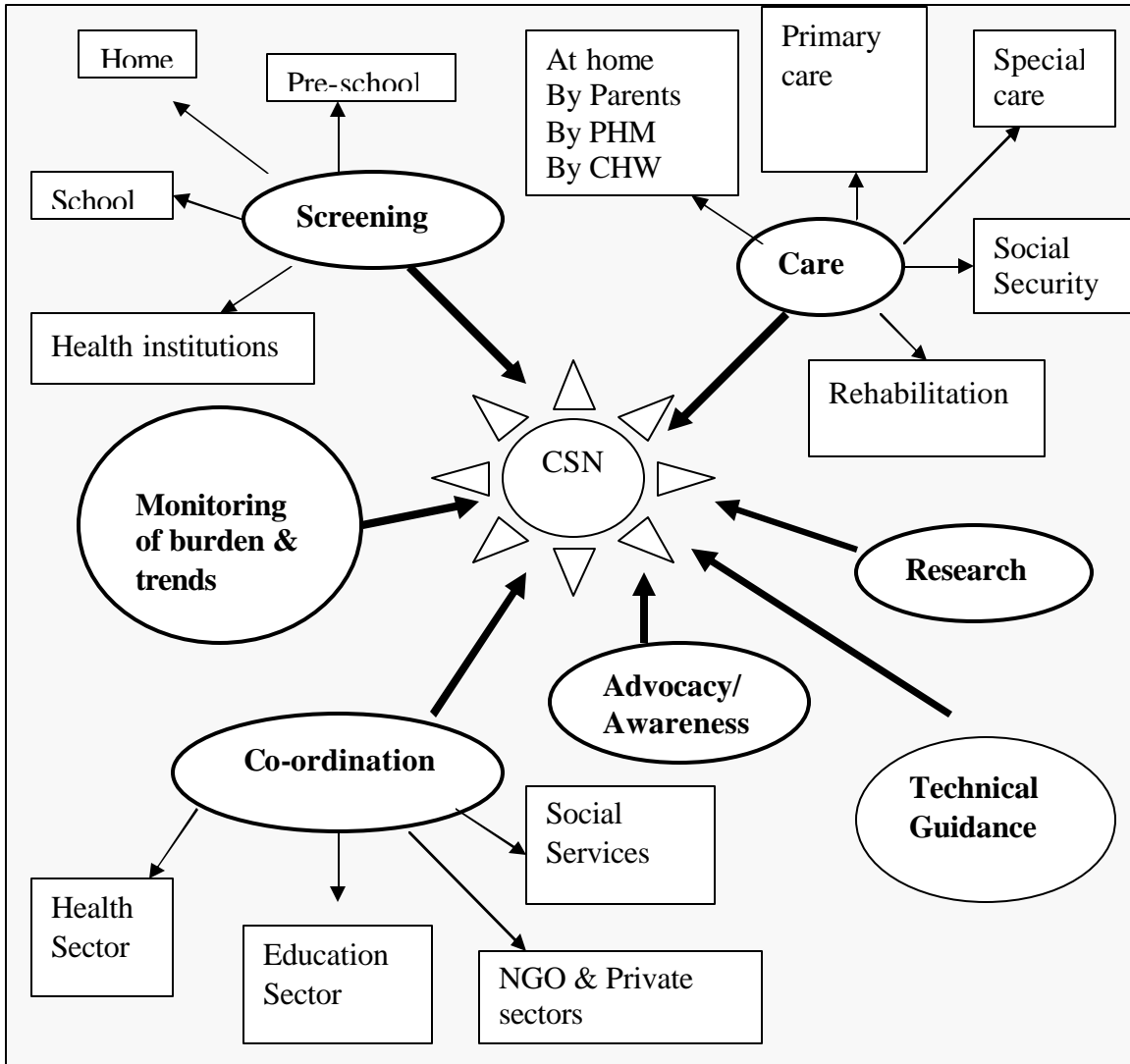


## ***Frame work for action***

As indicated above a large number of children with special health care needs live in the country. Even though many institutions and persons are working for the benefit of these children a well planned programme that covers all the districts and target children is yet to be organized. Needs of these children are extensive and include a broad spectrum of services that are not always covered in uniform benefit packages. These services include; home and hospital care, durable medical equipment, special education, psychosocial services, nutrition interventions, and family support. These needs also vary depending on whether the child's condition can be improved in terms of function and life expectancy. Children with special needs require a broad range of services, from primary to specialized medical care, equipment support and special educational services. In addition to the needs of the child, families of CSHCN may need additional services, such as awareness & training, respite care, family counseling, or genetic counseling. The multiple requirements require careful and joint programming with the involvement of all types of stakeholders. The following framework was conceptualized as the basis for formulating the National Programme for the Children with Special needs.

Interventions from different disciplines are mandatory for the provision of complete care for children with special needs. Hence, it is very important to define the respective roles of the different partners in the process to ensure meaningful outcome. Each partner should have a well demarcated and agreed up on roles and the activities should be coordinated adequately. The following conceptual framework describes the proposed main areas of focus of the National Health Programme for the Children with Special Health Care Need. The framework identifies key areas of concern; viz: assessment of the extent of problem that would be necessary for advocacy, programme planning and monitoring and evaluations, provision of care at home, field, hospitals, preschools and schools, rehabilitation and referral systems. Coordination of the programme activities between different partners viz:, Directorate of Disabled Persons, education sector, Social Services Department, Professional Organizations, NGO and private sector.

**Figure 2:**  
**Conceptual frame describing the focus of the National Health Care Programme for the Children with Special Needs**



## **NATIONAL PROGRAMME**

Considering the above context Family Health Bureau of the Ministry of Health will embark on designing of a comprehensive strategic plan on the CSHCN. It is expected that this programme is initially pilot tested in selected areas and later be expanded and integrated in to the national child health programme.

### **Objectives of the national programme for CSHCN**

1. To quantify the burden of illness among children resulting from special needs
2. To ensure early identification of children with special needs at different levels, viz: field, pre-schools, schools, health institutions.
3. To establish comprehensive holistic care for the children with special needs at different levels of health system, viz: at field, primary, secondary and tertiary care institutions
4. To develop standardized guidelines for the management of children with special needs at different levels of care, viz: field, primary, secondary and tertiary care institutions.
5. To empower capacity of health workers on managing problems of and providing care for children with special needs
6. To empower the capacity of pre- school and school teachers on the identification and caring for the children with special needs.
7. To empower the parents of children with special needs on the caring for such children and provide psychosocial support
8. To build up a network of multidisciplinary partners who work for the benefit of children with special needs
9. To provide the context specific evidence based information on the special needs during childhood
10. To create awareness, provide advocacy and technical guidance on the problem of special need to relevant personnel and institutions.



# Strategies and major activities of the programme for the (CSHCN)

<b>OBJECTIVE-1</b>	
<b>To quantify the burden of problems due to children with special needs</b>	
<b>Strategies</b>	<b>Major Activities</b>
1. Synthesize the available data	List out sources
	Compile information
	Identify information gaps
	Prepare a report
2. Conduct an epidemiological survey	Develop a proposal
	Review the proposal with a participation of a multidisciplinary group
	Solicit funding
	Development and validation of study tools
	Pilot study
	Study proper- Field data collection
	Data Management
	Analysis and report writing
	Dissmination of findings-link with advocacy actions...
3. Conduct advocacy/awareness based on burden analysis	Identify advocacy needs, awareness gaps
	Prepare advocacy/awareness plan
	Conduct advocacy /awareness
	Key Policy Makers
	Media
	Health educational workers
	General population

<b>OBJECTIVE-2</b>	
<b>To ensure early identification of children with special needs at different levels, viz: field. Pre-school, school, health institutions.</b>	
<b>Strategies</b>	<b>Major Activities</b>
1. Identify suitable screening tools	Explore available screening tools (local /international)
	Selection / modification / validation
	Pilot testing
2. Integrate adapted tools in to existing services	Identify relevant screening personnel
	Advocate high level programme managers
	System orientation- Preparation of circulars/guidelines
	Train the relevant staff on "the conditions giving rise to Special Needs" and screening tools
3. Establish referral systems	Provide guidelines to first contact personnel on course of actions to be taken
	Work out a referral system in consultation with all stake holders

<b>OBJECTIVE-3</b>	
<b>To establish services for children with special needs at hospitals, MOH level and through field service workers</b>	
<b>Strategies</b>	<b>Major Activities</b>
1. Define locally adapted service packages for different conditions that need special care	Literature search, Expert consultations
2. Define service requirements at different levels of care	Identify the service personnel at the lowest levels of care who will be competent to deliver particular service requirements
3. Capacity building of service personnel	<b>Linked with Objective 5 &amp; 6</b>
4. Make system reorientations required for (Policies/guidelines/ resource) establishment of services at different levels	Identify resource needs and assess the gaps
	Advocacy missions to make required system changes
	Revise, establish policies and guidelines, reorient systems to facilitate the establishment of services at different institutional settings
	Provide material support
5. Establish services	Help with raising grants and providing equipments
	Provide technical guidance
	Involve primary care staff, integrate referral mechanisms

<b>OBJECTIVE-4</b>	
<b>To develop standardized guidelines for the management of children with special needs. (At field, primary care institutions, and specialized institutions)</b>	
<b>Strategies</b>	<b>Major Activities</b>
1. Formulate diagnostic and management guidelines for different conditions (ex: Autism, CP, ADHD etc...) at different levels ( DMO, 2secondary/tiatiary care hospitals) and health workers ( MO, Specialists, Paramedical staff)	Study and acquire skills on standard guidelines through literature search and expert opinion
	Adapt such guidelines to suit local conditions
	validate the adapted guidelines
	train the relevant staff
<b>OBJECTIVE-5</b>	
<b>To empower capacity of health workers on managing problems of and providing care for children with special needs</b>	
<b>Strategies</b>	<b>Major Activities</b>
1. Establish training needs	Determine the knowledge, skills and attitudinal changes necessary for health care workers at different level
2. Provide in-service training	Design training programmes, develop training materials
	Organize and conduct pilot training programmes aimed at different staff.
	Pre/post evaluation
3. Integrate special need training packages to relevant basic training programmes	Identify relevant basic training programmes
	Advocate D/Training institutes and Ministry of Health

<b>OBJECTIVE-6</b>	
<b>To empower the capacity of pre- school and school teachers on the identification and caring for the children with special needs.</b>	
<b>Strategies</b>	<b>Major Activities</b>
1. Establish training needs of the pre-school and Scholl teachers on the caring for the children with special health care needs	Define the potential roles of pre-school and school teachers in catering for the needs of CSHCN
	Identify the information, tools and skills required by them to cater for the needs of CSHCN
2. Provide in service training	Design training/ otherwise programme of empowering teachers on the subject
3. Establish a referral system that is receptive to the requirements of teachers in providing care for the CSHCN	Review current referral system for its practicality & efficiency & modify it if needed
	Develop a referral system for pre-school teachers
	Specify guidelines that should be adapted when referring
4. Integrate special need training packages to relevant basic training programmes	Identify relevant basic training programmes
	Advocate D/Training institutes and Ministry of Education

<b>OBJECTIVE-7</b>	
<b>To empower the parents of children with special needs on the caring for such children and provide psychosocial support</b>	
<b>Strategies</b>	<b>Major Activities</b>
5. Provide information on the relevant conditions	Identify the problems encountered by the parents' of CSHCN
	Identify the information needs, of the parents/caregivers of CSHCN based on the above problems
	Develop and disseminate relevant IEC materials
	Conduct awareness programmes for the parents/caregivers of CSHCN
6. Provide psycho social support	Establish counseling services through relevant PHC staff
7. Improve the skills of parents on the care of the CSHCN	Identify the information skills required by the parents/caregivers of CSHCN
	Develop training programmes and materials
8. Provide material support	

<b>OBJECTIVE-8</b>	
<b>To build up a network of multidisciplinary partners who work for the benefit of children</b>	
<b>Strategies</b>	<b>Major Activities</b>
1. To set up a national level steering committee to monitor the progress of national level actions on the special need programme	Establish a focal points
	Mapping of partners
	To convene a seminar to share the programme experiences of different stakeholders and to identify the avenues for mutual support mechanisms
	To establish a network of partners and set up a profile data base at FHB
<b>OBJECTIVE-9</b>	
<b>To provide the context specific evidence based information on the special needs during childhood</b>	
<b>Strategies</b>	<b>Major Activities</b>
1. To conduct research	Identify priority research questions
2. To establish a collaborative relationship with international centers of excellence	Solicit funds
	Conduct research

## **Proposed Service Model**

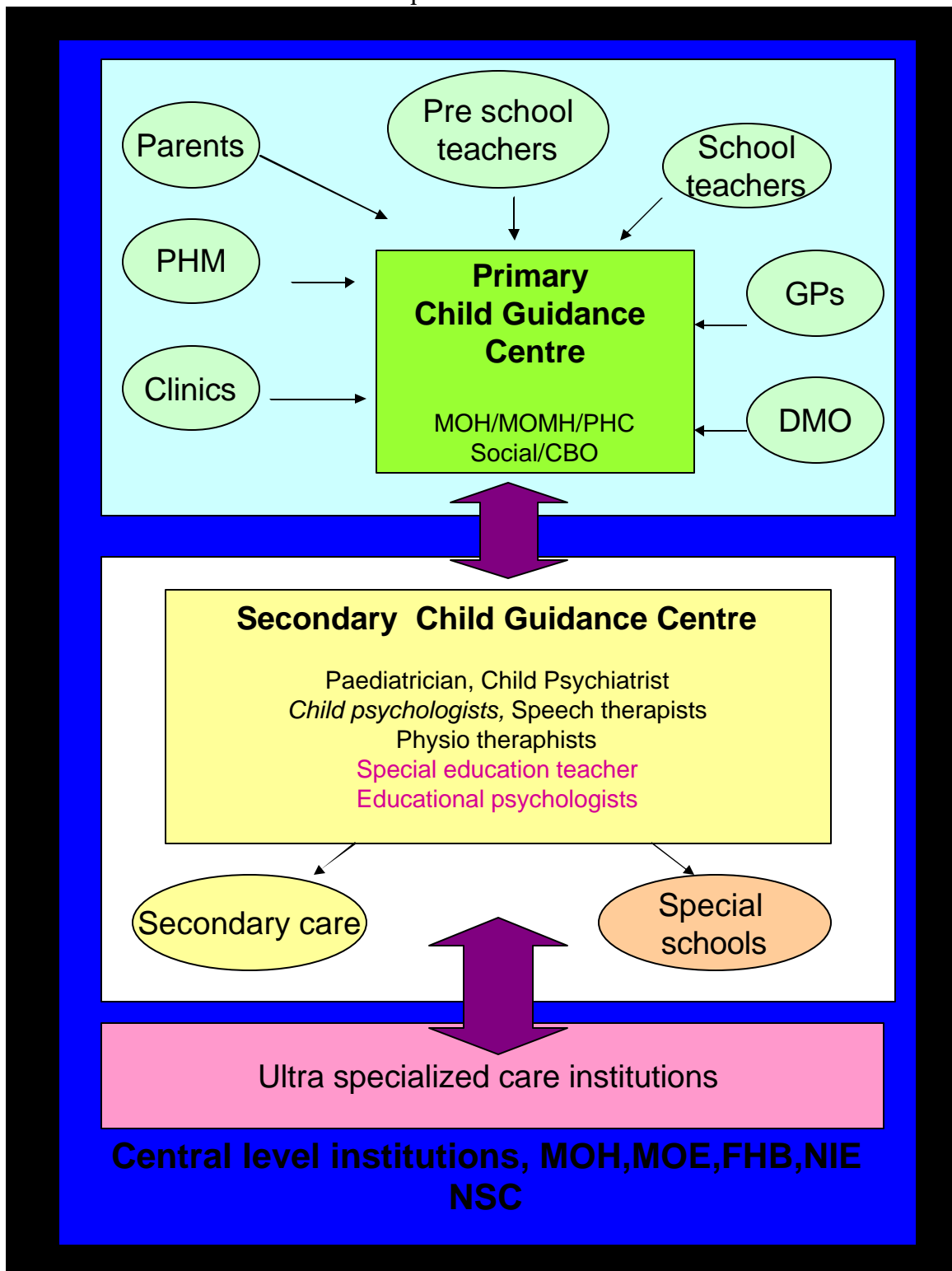
It is expected that the activities pertaining to the above framework will be packaged in to a pilot project to be implemented in a rural and urban settings. The experience gained in the pilot project will be used to establish the National Health Programme for the CSN. The basic structure of the pilot programme will comprise of a 2 staged referral structure (Figure 3) that is streamlined to suit the local health system, the available resources and the already existing health related practices in the community.

According to the model a Primary Child Guidance Centre is established in each MOH area. This center is considered as the primary level focal point for the activities of the programme for the CSN. A secondary Child Guidance Centre will also be established for a district. The Secondary Child Guidance Centre will be the specialist referral agent that provides specialist care and management plans for the children referred by the Primary Child Guidance centers. The Secondary Child Guidance Center is managed by a paediatrician supported by other specialist staff ( Child Psychiatrists, Speech Therapists, Occupational Therapists, Physiotherapists, Educational Psychologists etc..)

**Primary Child Guidance Centre:** The MOH of the area will be assigned the responsibility of functioning of Primary Child Guidance Centre. The main responsibilities of the centre will include screening, assessment, management and referral of CSN who will be identified by the service providers and those who will be brought by the parents. In addition the functions such as parent education, counseling, and provision of follow up care recommended by the secondary child guidance centre will also be among the functions of the centre. The field level care providers (Public Health Midwives, Medical officers, GPs, Pre school teachers, and School teachers) are expected to be able to identify and refer the CSN to the Primary Child Guidance Centres. They are also expected to be able to provide the field level follow up care and parent education. These service personnel have to be trained for these purposes and provided with necessary screening tools and other IEC materials. They will be provided with simple guidelines needed of screening and follow up care. Proper awareness campaign among parents is expected to encourage the self referrals by the parents themselves. Public Health Nursing Sisters, Medical Officers of Mental Health will support the MOH to carry out the functions of the Primary Child Guidance Centers. It is expected to integrate the services of social service workers and other community based activities to this center.



Figure 3 Proposed Service Model for the National Programme for the Children with special needs



**Secondary Child Guidance Centers:** At least one Secondary Child Guidance Centre will be established per district at the initial stage. Final aim is to establish a referral service facility for catering for the needs of CSN who will be referred from the Primary Child Guidance Centers. A specialist panel comprised of a paediatrician, a child psychiatrist, Speech Therapists, Occupational Therapists, Physio therapists Educational psychologists are expected to provide coordinated management for the referred children. The paediatrician is expected to be the team leader of the specialist panel. The panel is expected to review each referred child and develop a management plan and attend accordingly. Once the assessment is completed and management plans are finalized the children are expected to be referred back to the Primary Child Guidance Clinics along with follow up instructions. The Secondary Child Guidance Centers are expected to be supplied with standard management protocols and necessary equipment and other relevant logistical support.

**Figure 3 Roles of different levels of care**

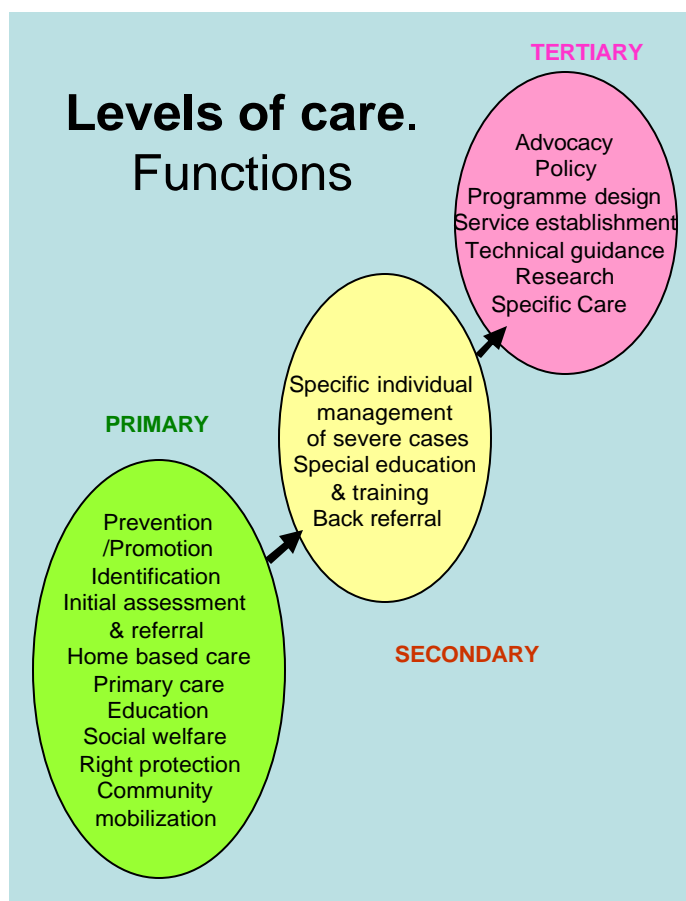


Figure 3 depicts the types and the nature of care that should be aimed by the National programme for the CSN. The primary level care will be provided by the

Primary Child Guidance Centers while the Secondary Child Guidance Centers will be provided by the Secondary Child Guidance Centers. The tertiary level care is expected to be provided by the central level organizations such as Family Health Bureau, Professional Colleges, and Ministries of Health and Education.