

# An assessment of the inclusive early childhood development program (IncluDe) in Kandy district, Sri Lanka a case study

## Abstract

Sri Lanka has identified the importance of providing quality and effective health care to all women, children, and families. In 1968, the Ministry of Health established the Family Health Bureau (FHB) to conduct the Maternal and Child Health (MCH) program nationally. The FHB's Inclusive Early Childhood Development Program (IncluDe), which will be phased across all districts, aims to systematically screen all Sri Lankan children to detect developmental delays and disabilities as early as possible and intervene through a multidisciplinary team approach to improve their quality of life. The purpose of this study is to evaluate the IncluDe program in the Kandy district and to prioritize the issues that need to be addressed to establish a comprehensive, sustainable program to serve the district's children with disabilities. Data collection was done by Key Informant Interviews, Focus Group Discussions, Team discussions, Observation visits to study settings, and review of secondary data. Numerous issues were identified across the program's service settings (Screening program of the children, Services of Child Development Intervention Center (CDIC), and specialized referrals at Tertiary Care Hospitals). Improving the comprehensiveness of care given at CDIC at rehabilitation hospital Digana, addressing the training needs of health staff, fulfilling the human resource requirement, and establishing a monitoring and evaluation mechanism of the program were among the priority problems. After conducting an in-depth analysis, recommendations were made to enhance the comprehensiveness of care provided at CDIC. The study reveals the importance of parallel development of all facets of the IncluDe program to provide adequate care to children with developmental delays and disabilities in the Kandy district. In conclusion, the Inclusive Early Childhood Development Program in Kandy District, Sri Lanka needs urgent attention in implementing measures to achieve its objectives successfully.

**Keywords:** early childhood development program, Kandy district, Sri Lanka

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Jayasundara KMPD,<sup>1</sup> Hewamalage A<sup>2</sup>

<sup>1</sup>Senior Registrar (Medical Administration), Office of DDG Laboratory Services, Ministry of Health

<sup>2</sup>National Program Manager, Child Development and Special Needs - Family Health Bureau, Ministry of Health

**Correspondence:** Jayasundara KMPD, Senior Registrar (Medical Administration), Office of DDG Laboratory Services, Ministry of Health, Sri Lanka, Email [dinukap@yahoo.com](mailto:dinukap@yahoo.com)

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## Introduction

### Inclusive early childhood development program (IncluDe)

#### Background

The Sri Lankan child health program focuses on activities to enhance the growth and prevent morbidities and mortalities of children. Until recently, the services for early child development and services for children with disabilities were not a priority. Around 15% of the world's population is estimated to have some form of disability.<sup>1</sup> Also, it is estimated that among 52.9 million children with disabilities under 5 years worldwide, 95% live in Low Middle-Income Countries.<sup>2</sup> There is no data on the prevalence of disabled children in Sri Lanka. Recent scientific evidence justifies that the insult to the developing brain during the antenatal or perinatal period causes most of the developmental disabilities in children.<sup>3,4</sup> Among them, Cerebral Palsy, Autism Spectrum Disorder, Dyslexia, and Intellectual Impairment are common. Early detection and intervention in managing these children through a multidisciplinary approach is the key to successfully addressing the developmental issues. Thus, identifying the importance of managing children with disabilities, the Family Health Bureau (FHB) of the Ministry of Health developed the Inclusive Early Childhood Development Program (IncluDe) with multi-stakeholder concurrence. The Child Care Development and Special Needs Unit (CDSNU) of the FHB is the focal point leading this program.<sup>5</sup> IncluDe program targets to systematically screen all children of Sri Lanka to identify developmental delays and

disabilities as early as possible and to provide early intervention via a multidisciplinary team led by a Consultant Community Pediatrician or a Consultant Pediatrician.

## Overview

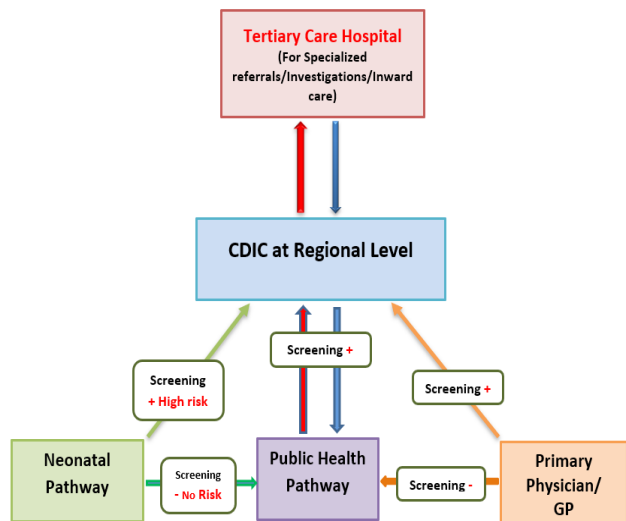
There are three service delivery settings of the IncluDe program.

	Setting	Health staff	Activities
01	Home-based care	Public Health Midwife (PHM)	<ul style="list-style-type: none"> <li>Provide information on child development and instructions to parents</li> <li>Assess developmental milestones</li> <li>Screening for disabilities</li> <li>Follow-up</li> </ul>
02	Divisional level clinic-based care (MOH – Child Development Clinic)	Medical Officer of Health (MOH)	<ul style="list-style-type: none"> <li>Conducts a clinic for children with developmental disabilities referred by PHM</li> <li>Comprehensive assessment and second screening of referred children</li> <li>Identify and refer necessary children to regional level CDIC for multidisciplinary care</li> </ul>
03	Regional level hospital-based care (Regional level-Child Development Intervention Center (CDIC))	<b>Multidisciplinary Team</b> <ol style="list-style-type: none"> <li>1. Consultant Community Pediatrician / Consultant Pediatrician</li> <li>2. Medical officers</li> <li>3. Nursing Officer</li> <li>4. Speech and Language therapist (SLT)</li> <li>5. Occupational therapist (OT)</li> <li>6. Physiotherapist (PT)</li> <li>7. Child psychologist</li> <li>8. others</li> </ol>	<ul style="list-style-type: none"> <li>Evaluate each referred child, Develop individualized intervention plans (IIP),</li> <li>link with social services, educational services, counseling, and other necessary services</li> <li>Back refer the child to the MOH CDC and home-based follow-up.</li> <li>Managing data and reporting</li> <li>Conducting outreach clinics.</li> </ul>

The three screening pathways are as follows,

- I. Systematic screening of all children by PHM
- II. Screening of high-risk neonates by institute base neonatal teams
- III. Screening by primary care physicians and general practitioners.

### Referral pathways of the program



The program intends to establish a CDIC in a selected apex hospital in every district phase-wise. Currently, the program is functioning in the Colombo and Kandy districts.

### IncluDe program in the Kandy District

The IncluDe program in the Kandy district was launched in March 2021, establishing the CDIC at Rehabilitation Hospital Digana (RHD) with the existing resources. This 60-bed health facility is located 15 kilometers from Kandy and is directly administered by the PDHS central province. It provides a range of rehabilitation services for patients, including Inward care, Outpatient care, Physiotherapy, Occupational therapy, Speech and Language Therapy, Counselling services, Vocational Training, Supply of disabled appliances (free of charge), and Training of relatives of disabled care. In addition, it provides medical, dental clinic services and, Emergency treatment services, and general OPD. RHD provides a conducive environment for disabled patients and has high accessibility. The dedicated administrative and clinical staff offers essential rehabilitation services to manage children with disabilities. PHMs of the district were trained online. All MOHs have commenced referring patients. Currently, the CDIC is caring for 153 disabled children under two consultant pediatricians.

### The objective of the study

This study aims to assess the IncluDe program of the FHB in the Kandy district to identify the critical problems to be addressed and suggest practical recommendations to improve the quality of service delivery.

### Data collection

Methods of data collection,

- I. Conducting Key Informant Interviews (KIIs) with the,

- II. The National Focal Point of the program, Central Provincial and Kandy Regional Directors of Health, Institutional Heads (National Hospital Kandy, Rehabilitation Hospital- Digana), Consultant Community Physician – Kandy, Consultant Community Pediatrician – Rehabilitation Hospital Digana, MOH
- III. Focus Group Discussions (FGDs)
- IV. Discussions with Therapists at Rehabilitation Hospital Digana
- V. Observation visits
- VI. Secondary data
- VII. Literature Review – (Journal articles/Publications).

### Problem analysis

The main problems were identified through a situational analysis that focused on three primary areas:

- A. Screening program of the children
- B. Comprehensive care at CDIC at Rehabilitation Hospital – Digana
- C. Provision of specialized services at Tertiary Care Hospital.

The following issues have been identified:

### Screening program of the children

#### At the community level

- 1.1 Inadequate and insufficient Training for PHMs/MOHs

*For PHMs*

Due to the prevailing COVID-19 situation, only an online training session has been held on screening, documentation (Filling the Child Health Development Record and Maintaining a register), and referral. However, no proper review has been done. In addition, no follow-up continuous training was conducted.

*For MOHs*

No formal training on a comprehensive assessment of referred children was provided to MOHs and staff.

- 1.2. Deficiencies in conducting Child Development Clinics at MOH offices and referring patients to CDIC

All MOH areas have started the screening though some have detected comparatively low cases. Since the staff was mobilized to participate in COVID-19 programs, they could not conduct regular child development clinics.

- 1.3. Deficiencies in parental awareness of the program
- 1.4. Low sensitivity of the screening

- I. Most patients referred already had significant developmental issues, with only a few new cases detected.
- II. The detection rate of young infants with disabilities was very low.

#### At tertiary Care Level – The Neonatal Screening

It is yet to commence at a tertiary care institute in the Kandy district.

**At the Primary care Physician/General Practitioner** – screening has not commenced yet

### Lack of comprehensive care at CDIC at Rehabilitation Hospital – Digana

The analysis revealed multiple issues at RHD in providing continuous quality care to children referred by the community-based screening program.

- I. Deficiencies in the management processes at CDIC
- II. The waiting list for the first visit till the end of December 2021
- III. Due to COVID-19 staff regulations, the staff is attending to work in rotations. Specialized therapists (OT/PT/SLT) are allocated two days per week to manage pediatric patients, limiting the exposure time.
- IV. Gaps in parental training and providing continuous guidance
- V. Gaps in arranging specialized referrals and investigations from tertiary care hospitals
- VI. Transport issues of patients causing lapses in follow-up visits

#### Deficiencies in Infrastructure

There is no sufficient place to conduct the multidisciplinary clinical assessment. At the moment, the hospital Montessori building’s limited space is being utilized. The toys and tools available are deficient and outdated.

#### Issues related to Human Resources.

#### Details of cadres

	Staff Category	Approved Cadre	Existing Cadre	Remarks
1	Consultant Community Pediatrician/ Consultant Pediatrician	02	02	One Acting CCP – awaiting overseas training, and the other has already submitted retirement documents
2	Other Specialties – Consultant Rheumatologist	01	01	
3	Medical Officers	09	07	
4	Nursing Officers	25	20	
3	Physiotherapists	04	08	
4	Occupational Therapists	03	04	
5	Speech and Language Therapist	-	03	No approved cadre
	Orthotist	02	00	
6	Health Assistants	33	26	

(Source: Cadre information- Central provincial council 2021)

The main issues are,

- I. No designated trained medical officer to the CDIC
- II. There is no permanent therapist staff dedicated to the CDIC. Therefore, different therapists attend the multidisciplinary assessment, which affects the quality of developing individualized management plans and subsequent patient assessments and management.
- III. Lack of a proper training program to update the knowledge and skills of therapist staff in managing children with disabilities.

#### Inadequate Investigation Facilities

Only basic laboratory tests are available at RHD. Many patients needing Thyroid and Bone profiles have to be referred to National Hospital Kandy, or patients have to do them from the private sector.

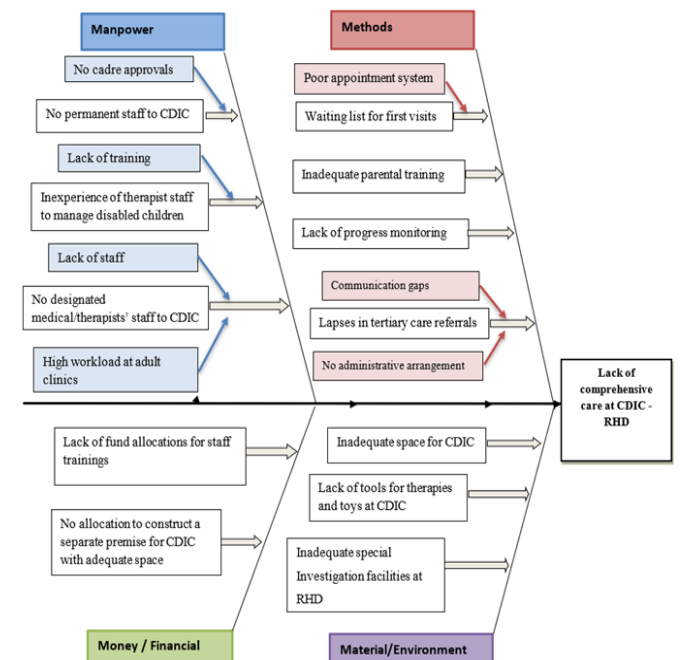
X-Ray facilities are not available. Patients are referred to BH-Theldeniya, or they get it done from the private sector.

### Provision of specialized services at Tertiary Care Hospital

Sirimavo Bandaranayke Specialized Children Hospital (SBSCH) Peradeniya, National Hospital Kandy (NHK), and Teaching Hospital Peradeniya (THP) are the Tertiary Care Referral centers for CDIC at DRH. Children who need Pediatric Neurology, ENT, Eye, and Child Psychiatric assessments are referred to SBSCH, and the orthopedic opinions are obtained from NHK or THP. However, the following gaps were identified in getting specialized services from these referral centers.

- I. There is no administratively agreed-upon system for appropriately referring children with disabilities detected through the program to tertiary care hospitals.
- II. Referrals are done in a conventional paper-based method where case discussions among clinical specialists are lacking between institutes
- III. No priority is given to these children with disabilities at the Tertiary care level
- IV. The children are being assessed in the general clinics at tertiary settings most of the time, which may affect practical assessment due to inadequate time and a non-conducive environment for these referred children.
- V. Children who need multiple specialists’ opinions had to visit different intervals to tertiary settings as the clinics were held on other days of the week.

Based on the findings, prioritization of the problems was done with discussions of RDHS-Kandy, Consultant Community Physicians in the PDHS office, and RDHS office Kandy and Matale.



Impact on the program, Practical feasibility, Financial feasibility, and Administrative leadership were the elements considered in selecting the “Lack of comprehensive care at CDIC” as the priority problem for further analysis using an Ishikawa diagram.

## Proposal

The CDIC is where most IncluDe program activities occur, including developing and implementing individualized management plans, progress monitoring, and intersectoral collaboration to deliver effective care. Thus, it is proposed to strengthen the CDIC at RHD, which is essential to provide comprehensive care to children with disabilities identified by the screening program.

## Recommendations

Based on the findings of the in-depth analysis, the following suggestions are made for early implementation to strengthen the services provided at CDIC

- I. To discuss with the Regional, Institute administration and the clinical team conducting the intervention clinic at more spacious and convenient pediatric ward premises until a permanent place is provided. The other options are,
  - Request to acquire the adjacent building of RHD, which belongs to Mahaweli Authority (This is a single-story, underutilized building that can be renovated with minimal financial resources to an ideal CDIC setting)
  - Request donor support to construct a separate CDIC building
- II. Provision of adequate tools and toys to CDIC
- III. Assigned a medical officer to CDIC and arranged a two-week training at AYATHI center, Ragama, on managing disabled children
- IV. Conduct a structured training program for therapists to update their knowledge and skills in managing children with disabilities
- V. Discuss with the therapist staff to arrange a practical roster for attending services at CDIC regularly
- VI. The management team of CDIC to implement a system to achieve the program objectives focusing on,
  - Developing a communication channel with screening teams and curative sector teams in preventive and tertiary care settings
  - Appointment systems, registration, and follow-up plan of referred patients at CDIC
  - Parental education and training on home base care
  - Management of patient data
  - Intersectoral collaboration – special education, social services
  - Arranging outreach programs
  - Research
- VII. To provide a point-of-care analyzer to the medical laboratory to perform specialized onsite investigations (Thyroid profile)
- VIII. Form a monitoring and evaluation mechanism of the CDIC services by establishing an oversight committee with national and regional representatives.
- IX. Request a permanent cadre of health staff for CDIC from the Human Resource Division of the Ministry of Health.

## Plan of implementation

	Activity	Responsibility	Expected Time frame
01	Stakeholder discussion on shifting the CDIC to Pediatric ward premises / Negotiation to acquire Mahaweli authority building	PDHS, RDHS, MOIC-RHD, and Clinical Team	November/December 2021
02	Implementing a system at CDIC to achieve program objectives	Clinical Team, MOIC-RHD, PDHS/RDHS, CCPs	November/December 2021
03	Assign a Medical officer to CDIC and arrange training at the AYATHI center	MOIC-RHD/Consultant Community Pediatrician	December 2021
04	Make available adequate tools & toys at CDIC	FHB, Health Administrators	November/December 2021
05	Arranging a practical work roster for therapists	MOIC-RHD/Consultant Community Pediatrician/Senior Therapists	November/December 2021
06	Arranging training program for therapists	FHB, Health Administrators Consultant Community Pediatricians	December / January 2021
07	Strengthening Laboratory Facilities	PDHS, RDHS, MOIC-RHD	2022 Procurement
08	Administrative initiatives to get approval for new cadres and increase existing cadres	MOIC-RHD, RDHS, PDHS, FHB	To justify the requirement and get the approval in the following cadre revision
09	Formation of a program monitoring and evaluation team	FHB, CCPs of PDHS/RDHS offices	December 2021

## Discussion

Detecting developmental delays is essential for early intervention in low to middle-income countries.<sup>6</sup> Sri Lanka has a well-organized preventive healthcare system focusing on delivering equitable care for all ages. The FHB of the Ministry of Health, Sri Lanka is the focal point of delivering community-level childcare comprehensively. However, it was identified that the detection of children with developmental defects at a very early age was not addressed sufficiently through the FHBs child development program. Thus, the Inclusive Early Childhood Development Program (IncluDe) was introduced by the Childcare Development and Special Needs unit of the FHB.<sup>5</sup> In India, the Integrated Child Development Service (ICDS) is a government program that provides nutritional meals, preschool education, primary healthcare, immunization, health check-ups, and referral services to children under 6 years of age and their mothers. However, it has been revealed that this program has been largely ineffective and needs major refurbishing.<sup>7</sup>

Having a well-trained professional health staff is essential to conducting early childhood developmental screening programs, and managing and referring to other specialties. Thus, Primary care physicians play a significant role in the early identification of developmental delays, both through developmental screening and routine developmental surveillance. Hence, they must have the knowledge and skills to identify developmental delays and provide an appropriate management plan to the family, including counseling the parents if necessary.<sup>8</sup> Establishing and maintaining a Child Development Intervention Centre (CDIC) is the greatest challenge as the community-level specialists in pediatrics, physiotherapists, speech therapists, occupational therapists, etc., and other necessary services such as Radiological and laboratory services are incomplete in this case.

Data and evidence on Early Childhood Development are essential to identifying the children at greatest risk of not achieving their full



potential, improving and targeting services, and making the case for adequate investments in young children and their families.<sup>9</sup> This study reveals the necessity of having appropriate infrastructure, human resources, and training and coordination among different levels of healthcare facilities to sustain the IncluDe program in the Kandy District.

## Conclusion

The Family Health Bureau has identified the importance of a comprehensive program (IncluDe) to detect children with disabilities at a very early age. The objective is to implement a structured multidisciplinary approach to intervene early in management and arrange regular follow-ups. This program is a timely initiative to improve the quality of life of children with disabilities. To achieve an effective outcome, it is essential to strengthen all facets of the IncluDe program in the Kandy district (screening, CDIC facilities, and tertiary care referrals). Since CDIC is the center point of care, priority should be given to improving the facilities of CDIC at the rehabilitation hospital Digana.

## Acknowledgments

None.

## Conflicts of interest

The author declares there is no conflict of interest.

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