



CARE PATHWAYS FOR EARLY DETECTION OF COMMON CHILDHOOD DEVELOPMENTAL DISABILITIES

CHILD CARE, DEVELOPMENT & SPECIAL NEEDS UNIT
FAMILY HEALTH BUREAU
MINISTRY OF HEALTH - 2022



**World Health
Organization**
Sri Lanka



Care Pathways for Early Detection of Common Childhood Developmental Disabilities

Child care, Development and Special Needs Unit
Family Health Bureau
Ministry of Health
2022



**World Health
Organization**
Sri Lanka

Care pathways for early detection of common childhood developmental disabilities

ISBN (9 786245 990085)

ISBN (ISBN 978-624-5990-08-5)

© Family Health Bureau, Ministry of Health, Sri Lanka 2022

Compiled by;
Child Care Development and Special Needs
Unit Family Health Bureau

Printed by;
New Karunadhara Press
Colombo - 10.

Care pathways development committee

Resource team for the neonatal care pathway

- Dr. Pyara Rathnayake, Consultant Pediatric Neurologist, Lady Ridgeway Hospital for Children
- Dr. Gemunu Hewawitharana, Consultant Pediatric Neurologist, Teaching Hospital, Karapitiya
- Dr. Saraji Wijesekera, Consultant Pediatric Neurologist, Senior Lecturer, Faculty of Medicine, University of Sri Jayawardenapura
- Dr. Nishani Lucas, Consultant Neonatologist, Senior Lecturer, Faculty of Medicine, University of Colombo
- Dr. Nalin Gamaathige, Consultant Neonatologist, De Soyza Maternity Hospital
- Dr. Surantha Perera, Consultant Pediatrician, Castle Street Hospital for Women
- Dr. Saman Kumara, Consultant Neonatologist, Castle Street Hospital for Women
- Dr. Jayathri Jagoda, Consultant Rheumatologist, Lady Ridgeway Hospital for Children
- Dr. Hemali Jayakodi, Consultant Community Physician, Family Health Bureau
- Dr. Ayesh Fernando, Acting Consultant Community Pediatrician, Digana Rehabilitation Hospital
- Dr. Lakshika Kendaragama, Acting Consultant Community Pediatrician, Child Development Intervention Center, Maligawatta DH
- Dr. Chamara Jayathunga, Senior Registrar, Medical Rehabilitation, Lady Ridgeway Hospital for Children
- Dr. Rasika Aluthwalage, Medical Officer, Family Health Bureau
- Ms. Lakshika Udugama, Speech and Language Therapist, Teaching Hospital, Peradeniya

Resource team for the public health pathway

- Dr. Asiri Hewamalage, Consultant Community Physician, Family Health Bureau
- Dr. Suranga Fernando, Consultant Community Physician, Provincial Department of Health Services, Central province
- Dr. Hiranya Jayawickrama, Consultant Community Physician, Family Health Bureau
- Dr. Darshani Hettiarachchi, Consultant child and adolescent psychiatrist, Teaching Hospital, Karapitiya

- Prof. Samanmalee Sumanasena, Professor in Pediatric Disabilities, Ayati, Faculty of Medicine, University of Kelaniya
- Dr. Nimisha Muttiah, Speech and Language Therapist, Senior lecturer, Ayati, Faculty of Medicine, University of Kelaniya
- Ms. Thilini Madushika, Physiotherapist, Ayati, Faculty of Medicine, University of Kelaniya

Resource team for the primary care, general practitioner and other clinician's pathway

- Prof. Shyamali Samaranayake, Professor in Family medicine, University of Sri Jayewardenepura
- Dr. Aruni De Silva, Senior lecturer in Family medicine, University of Sri Jayewardenepura
- Dr. Hiranthini de Silva- Senior lecturer in Family Medicine, University of Sri Jayewardenepura
- Dr. Himali Jayaweera – Consultant paediatrician, Child Development Intervention Center, Maligawatta DH
- Dr. Rasika Gunapala, Consultant Pediatrician, Lady Ridgeway Hospital for Children
- Ms. Sakuni Hingurangala – Speech and language therapist, Child Development Intervention Center, Maligawatta DH
- Ms. Amandi Caldera- Psychologist, Ayati, Faculty of Medicine, University of Kelaniya
- Dr. Manjula Danansuriya - National Professional Officer, WHO

Coordinator:

Dr. Asiri Hewamalage

Consultant Community Physician, National Program Manager
Child Care, Development and Special Needs Unit
Family Health Bureau

Synopsis of IncluDe Logo

The IncluDe logo depicts the concept of 'embracing diversity'. All children are valuable for our motherland. Children are diverse and their diversity brings different strengths to the development of the country. Hence, as a country we include all the children in any health program. The different shape and coloured letters of the logo symbolizes the diversity. Some may be with disability but they too stand bold. The Inclusive Early Childhood Development program is about all children in Sri Lanka! All are INCLUDED!



Contents

	<i>Resource team for the neonatal care pathway.....</i>	<i>iii</i>
	<i>Resource team for the public health pathway.....</i>	<i>iii</i>
	<i>Resource team for the primary care, general practitioner and other clinician's pathway.....</i>	<i>iv</i>
1	Introduction	1
1.1	Care Pathways for early detection of developmental delays and disabilities of childhood	2
2	Neonatal Care Pathway	7
2.1	Graphical illustration	8
2.2	Neonatal Care package for all newborns	9
2.3	Risk profiling for developmental delays and disabilities	10
2.3.1	Identification of the neonates at high risk for developmental delays and disabilities.....	10
2.3.2	Identification of the neonates at intermediate risk for developmental delays and disabilities.....	11
2.4	Early generic developmental care package.....	12
2.4.1	Introduction	12
2.4.2	Developmentally conducive neonatal units.....	12
2.4.3	Screening for developmental delays and disabilities	15
2.4.4	Continuity of care.....	17
2.4.5	Monitoring & Evaluation	19
2.5	Referral of the high-risk neonates for developmental delays/disabilities to the multidisciplinary team at the CDIC.....	20
2.6	Follow-up of the intermediate-risk neonates for developmental delays/disabilities at the well-baby clinics	20
2.6.1	Screening for developmental delays and disabilities	21
2.6.2	Provide generic early childhood developmental interventions.....	24

3.	Public Health Pathway	27
3.1	Graphical illustration	27
3.2	Home-based care by the Public Health Midwife (PHM):	28
3.2.1	Provide information on early child development promotion and necessary parenting instructions.	28
3.2.2	Screen for developmental disabilities	28
3.3	MOH level clinic-based care	29
3.4	Screening by the Preschool teachers	29
3.5	Monitoring and Evaluation of the Public Health Pathway.....	30
3.5.1	Monthly by the PHM to the SPHM to PHNS	30
3.5.2	Quarterly by the MOH to the RDHS and FHB in two copies.....	31
4	Primary care, general practitioner and other clinician pathways	35
4.1	Graphical Illustration	35
4.2	IncluDe Package for primary care, general practitioner and other clinicians	36
5	Care pathway from the CDIC.....	37
6	Annexure	38

Message from the Director General of Health Services

The Sri Lankan health care system is striving to enhance the quality-of-service delivery. As a country which was successful in reducing child mortalities, now we are working towards services that would provide opportunities to achieve optimum developmental potential of the children.

Recently, with the advancement of neonatal care and novel therapies the survival of neonates with complications is rising around the world. Amidst this achievement, the country has to be ready to enhance the quality of life of the surviving children who will be facing many challenges including disabilities. The majority of children with disabilities all over the world live with a vast range of complications that disrupt their quality of life. This situation is more or less similar in Sri Lanka. Early detection and early childhood intervention is the evidence-based strategy to improve the quality of life of children with disabilities and developmental delays.

The Ministry of Health, along with the Family Health Bureau, the national focal point for maternal and child health had developed the Inclusive Early Childhood Development Program (IncluDe), to screen all the children in the country for the early recognition of the developmental delays and disabilities and to provide early childhood interventions via a multidisciplinary team. This is one of the cost-effective approaches of furnishing services to children with developmental delays and disabilities in Sri Lanka.

I would like to extend my gratitude to all those who contributed in countless ways to make this task a success. Furthermore, I hope this book would provide guidance for all the health care personnel to deliver inclusive care for children with disabilities and developmental delays.

Dr. Asela Gunawardena,
Director General of Health Services,
Ministry of Health, Sri Lanka

Message from the Director, Maternal and Child Health

The Family Health Bureau is the national focal point for maternal and child health in Sri Lanka. With consideration to child health, the aim is to acquire the highest possible levels of health in all the children through provision of comprehensive, sustainable, equitable and quality child health services in a nurturing, culturally sustainable and child friendly setting.

Many of the programs that are developed focusing on child health promotion, generally line up the children who are accessed through the routinely available services. However, there is an important group of children, who are not generally infiltrated through the health services and who demand special attention. This group embraces children who are physically, mentally and socially disabled and developmentally delayed.

Equivalent to the developmentally normal children, disable and developmentally delayed children with special needs should also be assisted in such a way that empower them to optimally flourish their mental, physical and social capacities to be independent and function as a fruitful representer of the society.

Therefore, along with the assistance of the Ministry of Health and World Health Organization, the Inclusive Early Childhood Development Program (IncluDe) was developed. Through this program three child-care pathways have been introduced to identify those children with special needs (Public health pathway, neonatal care pathway and primary care, general practitioner and other clinicians' pathway). I hope by utilizing this program we will be able to achieve the expected outcome along with the contribution of other sectors.

Finally, I would like to appreciate the effort of all the contributors of this great endeavour.

Dr. Chithramalee de Silva,
Director Maternal and Child Health,
Family Health Bureau,
Ministry of Health

Message from the WHO Country Representative

Global estimates show that 52.9 million children under 5 years old had developmental disabilities and 95% of them live in low- and middle-income countries.

The Sustainable Development Goals (SDGs) mandate systematic monitoring of the health and wellbeing of all children to achieve optimal early childhood development (ECD). The Nurturing Care Framework (NCF) for ECD launched by WHO, UNICEF and World Bank, at the 71st World Health Assembly in 2018, reiterates the importance of early childhood interventions, as an opportunity to construct the foundation for child's lifetime learning and engagement.

Conventionally child health services in Sri Lanka, has been focusing more on improving nutritional status, providing vaccinations and preventing childhood morbidity and mortality. Child development and care for children with developmental disabilities has been a low priority. However, with the availability of new scientific evidence on the importance of early interventions with a very high return of investment coupled with SDG 2030 agenda, Sri Lanka has considered revamping child developmental services prioritizing the marginalized and vulnerable groups.

While taking steps to ensure that all children in the country are subjected to developmental screening, three pathways namely "Public Health", "Neonatal Care" and "Primary Care", have been introduced to identify and refer children with developmental disabilities for early interventions. These multiple pathways are expected to have a synergistic effect, minimizing leakages.

WHO is happy to be a partner in this health system development initiative and in implementing the inclusive childhood development program to provide support for children with developmental delays. I congratulate the Ministry of Health on introducing the guideline on Care Pathways for early detection and management of developmental delays and disabilities, to facilitate uniform and quality health service for needy children.

Dr. Alaka Singh

WHO Country Representative for Sri Lanka

List of Abbreviations

B/L CP	-	Bilateral Cerebral Palsy
CDC	-	Child Development Clinic
CDIC	-	Child Development Intervention Clinic
CDIC-Reg	-	Regional Child Development Intervention Clinic
CHDR	-	Child Health and Development Record
CNS	-	Central Nervous System
CP	-	Cerebral Palsy
CWC	-	Child Welfare Clinic
ECI	-	early childhood interventions
eNIMS	-	Electronic Neonatal Information Management System
ENT	-	Ear, Nose, Throat
ET	-	Educational Therapist
FHB	-	Family Health Bureau
GMA	-	General Movement Assessment
GMFCS	-	Gross Motor Function Classification System
GP	-	General Practitioner
HIV	-	Human Immunodeficiency Virus
HINE	-	Hammersmith Infant Neurological Examination
IIP	-	Individualized intervention plans
IncluDe	-	Inclusive Early Childhood Development Program
LMIC	-	Low Middle-Income Countries
MCH review	-	Maternal and Child Health Review
MDT	-	Multidisciplinary team
MOH	-	Medical Officer of Health
MOH CDC	-	Medical Officer of Health Child Development Clinic
NICU	-	Neonatal Intensive Care Unit
NO	-	Nitric Oxide
OT	-	Occupational Therapists
PBU	-	Premature Baby Unit
PHM	-	Public Health Midwife

PHNS	-	Public Health Nursing Sister
PT	-	Physio Therapist
RDHS office	-	Regional Director of Health Services office
SCBU	-	Special Care Baby Unit
SD	-	Standard Deviation
SGA	-	Small for Gestational Age
SLT	-	Speech and Language Therapists
SPHM	-	Supervising Public Health Midwife
WBC	-	Well Baby Clinic

List of figures

Figure 1:	Overview of the care pathways	3
Figure 2:	Graphical illustration of the neonatal care pathway	8
Figure 3:	Overview of the early generic developmental care package for Neonatal Units	12
Figure 4:	Screening for developmental delays and disabilities at the well-baby clinics by the neonatal teams	21
Figure 5:	Graphical illustration of the public health pathway	27
Figure 6:	Graphical Illustration of the primary care, general practitioner and other clinician pathway	35
Figure 7:	The link of service delivery between the field services, CDIC and the Tertiary level clinical services	37

1 Introduction

The child health program of Sri Lanka traditionally had been focusing on child survival and nutrition. Hence, most of the activities targeted enhancing the nutrition of children and preventing childhood morbidities and mortalities. Although some services targeting early child development were included in the MCH programme for the past two decades, services for children with disabilities was not a priority until recently.

However, with recent scientific evidence on brain plasticity and brain development, it was evident that early child development and early interventions for developmental concerns have a very high return of investment. In addition, the sustainable development goals 2030 agenda, urges the countries to provide equitable services prioritizing the marginalized and vulnerable populations.

Even though there are no prevalence data in Sri Lanka, globally it is estimated that about 15% of the world's population and approximately 5% of children live with some form of disability. In the Low Middle-Income Countries (LMICs) this prevalence rate amongst children aged 0-18 years is as high as 12.7%.

Most childhood developmental disabilities are caused by an insult to the developing brain during the antenatal or perinatal period. Cerebral palsy, autism spectrum disorder, dyslexia and intellectual impairment are examples of some of the developmental disabilities that are commonly seen.

Recently, with the advancement of neonatal care and novel therapies, the survival of neonates with complications is rising around the world. Sri Lanka is not an exception with a remarkable achievement in the Millennium Development Goals on child mortality by halving preterm deaths. Amidst this achievement, the country has to be ready to enhance the quality of life of the survived children who will be facing many challenges including disabilities.

Identifying this need, the Ministry of Health focal point for maternal and child health, the Family Health Bureau developed the Inclusive Early Childhood Development Program (IncluDe) with many discussions with the stakeholders.

IncluDe program targets to systematically screen all children of Sri Lanka to identify the developmental delays and disabilities as early as possible and to provide early childhood intervention via a multidisciplinary team. We have identified this as the most cost-effective way to provide services for children with developmental delays and disabilities in Sri Lanka.

1.1 Care Pathways for early detection of developmental delays and disabilities of childhood

The development of this book was mandated as a process of the system development to provide services for children with disabilities. The target of the Sri Lankan Government is to detect developmental disabilities as early as possible and provide early interventions, which would significantly improve the quality of life of the affected children.

For this purpose, the systematic screening of all children born in the country is necessary. This duty is assigned to the public health staff. The public health midwife is trained to screen the children for developmental delays and disabilities and the systematic screening process commences from the age of 2 months. The children are screened until they are 5 years of age at ten different screening points; 2, 4, 6, 9, 12, 18, 24, 36, 48 and 60 months. Any child who becomes screen positive will be referred to the Medical Officer of Health (MOH), who will do a comprehensive assessment and refer the child to the multidisciplinary team (MDT) at the Child Development Intervention Clinic (CDIC) of the District. This is the main pathway for early detection of developmental disabilities and this is known as the 'Public Health Pathway'.

In addition, there is another group of high-risk infants who are more vulnerable to developmental delays and disabilities. These are the children graduating from neonatal units, who are either premature, low birth weight or subjected to perinatal insults to the developing brain. This category of children needs closer scrutinization and follow-up. They will be screened and followed up by the neonatal care teams through the 'Neonatal Care Pathway'. Simultaneously they will receive the services from the public health pathway as well, enabling a rigorous screening process.

Some of the children born in the country may miss the screening from the above two pathways. To capture those children and to screen them for developmental delays and disabilities the 'Primary care, general practitioner and other clinician pathways' was identified as an opportunistic screening pathway to supplement the public health and neonatal pathways.

From any of the above pathways, the screening positive children will be directly referred to the CDIC of the district.

The CDIC will function with the multi-disciplinary team (MDT) who are trained in many disciplines to manage children with developmental delays and disabilities. The MDT is headed by a Consultant Community Pediatrician/General Pediatrician and comprises Medical Officer Child Development, Nursing Officers, Speech and Language Therapists (SLT), Physio Therapist (PT), Occupational therapists (OT), Psychologist and Educational Therapist (ET). They will be responsible to evaluate each child, develop individualized intervention plans (IIP), link with social services, educational services, counselling and other necessary services and refer the child to the MOH CDC for home-based follow-up and community management.

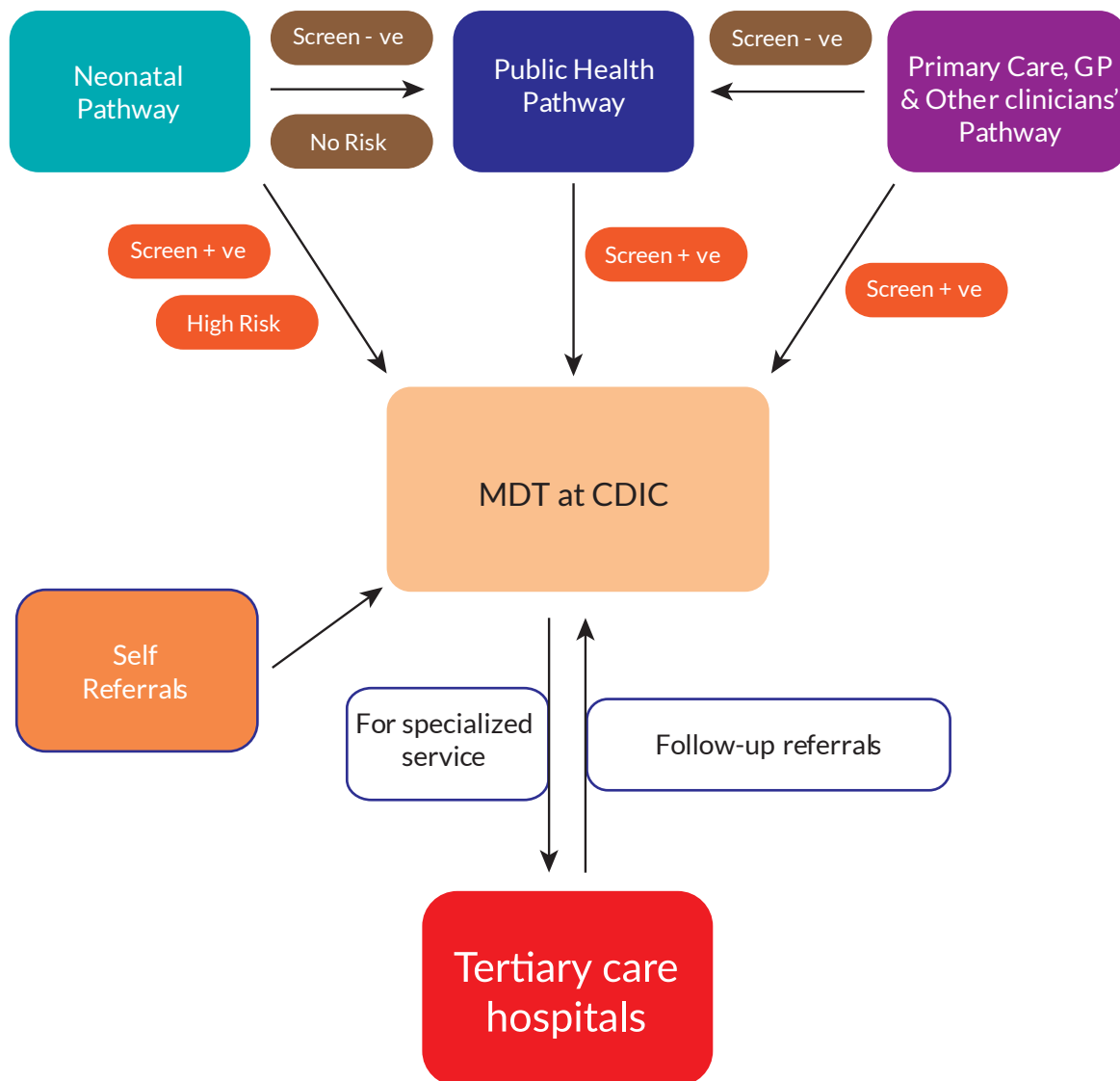


Figure 1: Overview of the care pathways

The CDIC is a specialized center that links with the community level services as well as the tertiary care level clinical institutions. They will be providing early child interventions, rehabilitation services for children and organizing community follow-up plans for children with chronic conditions.

This care pathway guideline focuses on the early detection and provision of early interventions for children with developmental delays and disabilities. The pathways are designed to match the available services in Sri Lanka and to meet the local needs, circumstances and expectations. The next chapters will describe the three different care pathways in detail and the minimum operational standards.

NEONATAL CARE PATHWAY

2 Neonatal Care Pathway

This pathway outlines the processes and standard operation procedures promoting early child development at the curative sector hospitals where childbirth takes place. The clinical team who undertakes the neonatal care upon delivery is responsible to provide the necessary developmental support for the newborn and the family. In hospitals where there are neonatal units, in addition to the above, the clinical team is responsible to provide developmentally conducive environments and stimulations during the hospital stay and to screen the infants for developmental delays and disabilities at the follow-up well baby clinics.

The whole process is outlined graphically in the following section and each activity is described in detail.

2.1 Graphical illustration

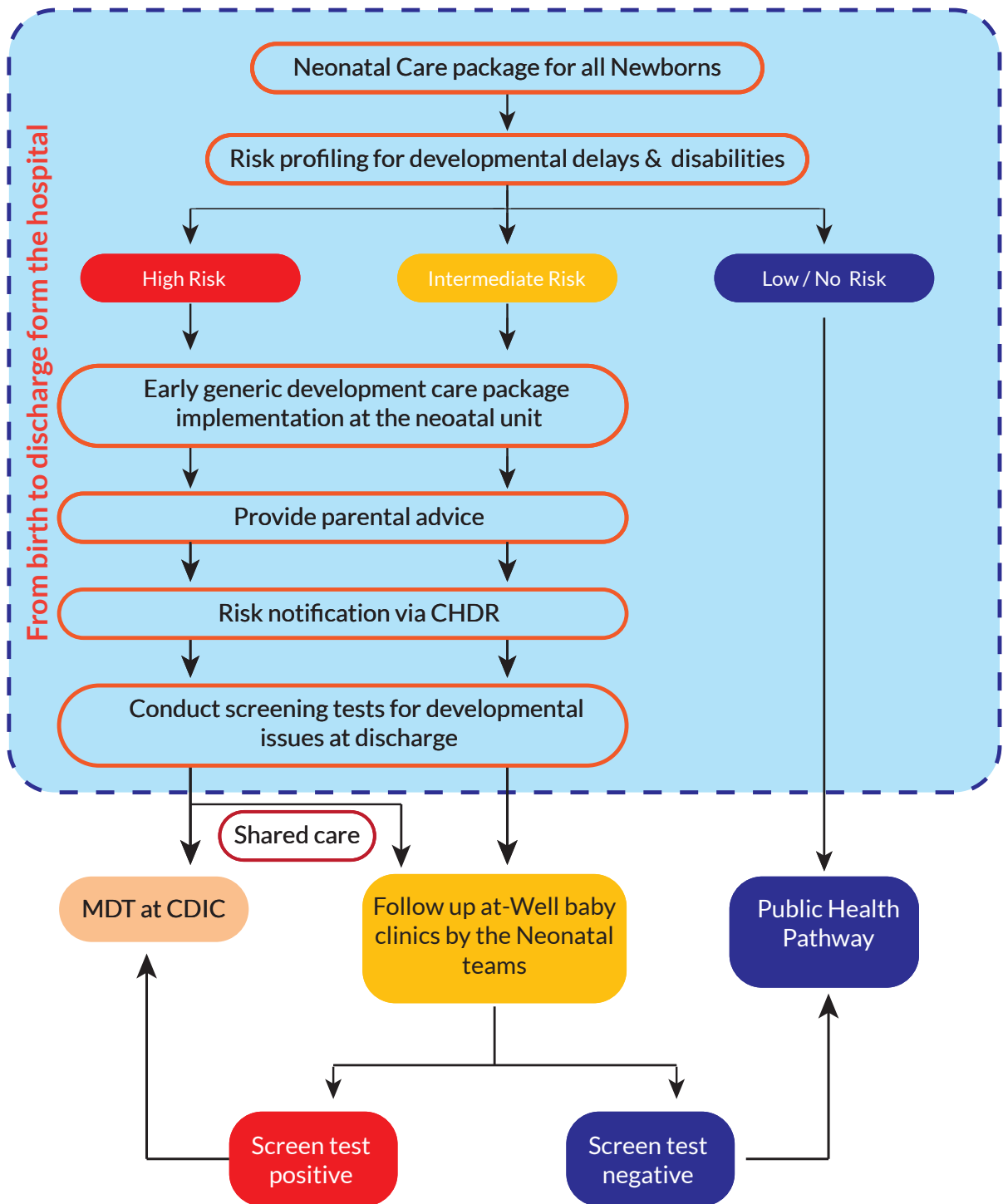


Figure 2: Graphical illustration of the neonatal care pathway

2.2 Neonatal Care package for all newborns

Birth and the neonatal period (first 28 days of life) are very crucial as they consist of many physiological changes required for the transition from in utero to ex utero life. All neonates, whether they are born healthy, small or unwell, require essential newborn care to ensure their survival, optimal growth and development. It includes appropriate preventive care, routine care, transition and the care needed by sick and small babies. This also discusses the preterm growth charts and the need for the measurement of head circumference which are very important aspects. However, those aspects are not discussed here as they are covered in detail in the "National Guidelines for Newborn care" Volume I, II, and III.

The essential services are listed below;

1. Care during labour and childbirth
 - Promote and support skilled care at birth
 - Infection prevention
 - Promote female companion of choice at birth
 - Monitoring progress of labour, maternal and fetal wellbeing with partograph
 - Antenatal corticosteroids in preterm labour
 - Magnesium sulphate for neuroprotection in pre-term deliveries
 - Antibiotics for premature rupture of membranes
2. Essential Newborn Care
 - Skin to skin care
 - Prevention of hypothermia
 - Delayed cord clamping
 - Hygienic cord care
 - Early initiation of breastfeeding within one hour
 - Exclusive breastfeeding
 - Newborn resuscitation if required
3. Care of sick and small newborn
 - Recognition of danger signs and prompt treatment
 - Identification and initial management of newborn complications and appropriate referral
 - Management of newborn complications
 - Extra thermal care
 - Support for feeding small and preterm babies
 - Kangaroo Mother Care
 - Antibiotic treatment for infections
 - Full supportive facility care

- Infection prevention and management
 - Safe oxygen therapy
 - Case management of jaundice
 - Surfactant therapy
 - Respiratory support
4. Care beyond newborn survival
- Newborn screening
 - Management of birth defects
 - Follow up of high-risk newborns (Pre-term, SGA, SCBU discharges)

2.3 Risk profiling for developmental delays and disabilities

According to recent evidence, providing high-quality early interventions to vulnerable infants can positively change their development trajectory. To achieve the maximum potential benefits to children, families and communities, Intervention should be delivered when the developing brain is most capable to change and it is likely to be more effective and less costly when it is provided earlier in life rather than later.

To achieve the above target, all neonates born in the hospitals should be subjected to a risk profiling for developmental delays and disabilities. Based on this the neonates can be categorized as high risk, intermediate risk and low/no risk for developmental delays and disabilities. The neonates who are identified as 'low/no risk' will be discharged from the hospital and will be followed up via the public health pathway through MOH and the PHM (this will be further discussed under Public Health Pathway). As early risk profiling would not have an absolute sensitivity and furthermore there could be acquired disorders, the public health pathway would incorporate intermittent screening to further strengthen early intervention. The high risk and intermediate-risk category neonates should receive the 'early generic developmental care package' while they are staying within the hospital.

2.3.1 Identification of the neonates at high risk for developmental delays and disabilities

Neonates with the following conditions should be categorized as high risk for developmental delays and disabilities. The definitions/diagnosis of the below-mentioned conditions is available in the "National Guidelines for Newborn care" Volume I, II, and III.

1. Hypoxic Ischemic Encephalopathy (HIE) grade 2, 3
2. Neonatal convulsions
3. Symptomatic neonatal hypoglycemia
4. 32 weeks or less Extreme prematurity (before 28 weeks) and very preterm babies (28 -32 weeks)
5. Post Haemorrhagic ventricular dilatation/ hydrocephalus
6. Chronic lung disease
7. Neonatal stroke
8. Abnormal neurological examination ex: hypotonia/hypertonia/manifestations of neuro-cutaneous disorders/ hand preference etc.
9. Severe neonatal hyperbilirubinemia requiring exchange transfusion
10. Neonatal meningitis
11. Structural central nervous system abnormalities (CNS abnormalities including spinal dysraphism)
12. Congenital infections (neonatal rubella, toxoplasmosis, cytomegalovirus, Zika, HIV, congenital syphilis etc)
13. Neonatal septicemia
14. Circulatory instability requiring NO support
15. Invasive respiratory support > 24 hours

2.3.2 Identification of the neonates at intermediate risk for developmental delays and disabilities

Neonates with the following conditions should be categorized as the intermediate risk for developmental delays and disabilities. The definitions/diagnosis of the below-mentioned conditions is available in the "National Guidelines for Newborn care" Volume I, II, and III.

1. HIE grade 1
2. Late preterm >32 weeks
3. Asymptomatic Hypoglycaemia
4. Dysmorphic new-borns
5. Severe failure to thrive (birth weight < -3SD)
6. Birth trauma leading to neurological injury
7. Non-invasive respiratory support > 24 hours
8. Hyperbilirubinemia
9. Family history of developmental delay or disorder

One baby may have many conditions that may enlist a single baby under different categories. In this instance, this baby should be followed up under the higher risk category.

2.4 Early generic developmental care package

2.4.1 Introduction

The early generic developmental care package is provided for intermediate and high-risk neonates for developmental delays and disabilities. This package is delivered by the neonatal teams at the hospital, during the hospital stay of the neonates after delivery.

This package consists of five key areas eight activity areas within that, which should be carried out by the neonatal teams. The consultant neonatologist or the paediatrician of the neonatal unit should ensure that these activities are carried out and periodic audits should be implemented to assess the quality of developmental services delivered.

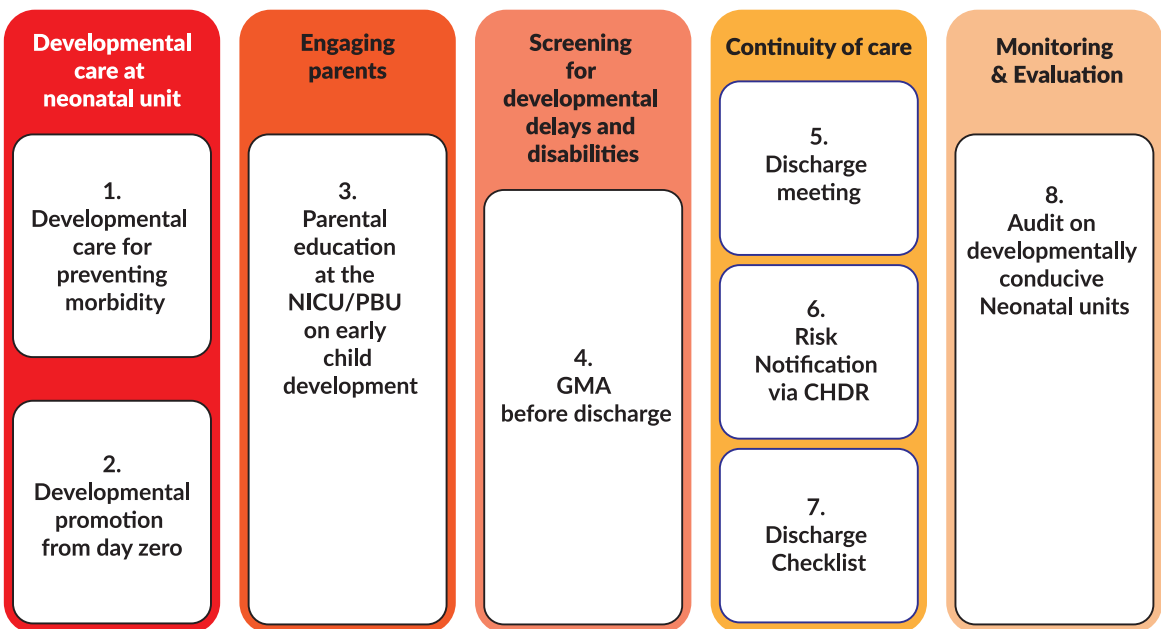


Figure 3: Overview of the early generic developmental care package for Neonatal Units

2.4.2 Developmentally conducive neonatal units

2.4.2.1 Developmental care for preventing morbidity and promoting development in the neonatal unit

The goal of developmental care is to provide individualized care with a structured care environment that supports, encourages and guides the developmental organization of each premature and/or critically ill baby. These adaptations encompass the physical environment

and its components, as well as the care and treatment provided for the infant and their family.

There is increasing evidence that early life stress is harmful to the developing central nervous system and brain. The concept of developmental care is based on the evidence that early life stressors will impact the developing brain and that each caregiving act has the potential to be a nurturing or stressful event.

The neonatal unit's staff will be trained and necessary resources for implementation and monitoring will be provided in order to create a developmentally conducive environment in the neonatal units.

Following are included under the umbrella of developmental care for preventing morbidity in neonates.

- Control of external stimuli that are potentially noxious (visual, auditory, tactile, smell etc.) by light and noise reduction
- Pain – prevention and detection
- Minimizing oral aversion and promoting suckling
- Tactile stimulation
- Minimal handling
- Sleep protection
- Clustering of nursery care activities
- Positioning of the baby to provide a sense of containment similar to the intrauterine experience
- Involving parents in the care of their baby
- Understanding the stress signals of the baby and using appropriate consoling strategies

2.4.2.1.1 Developmental care for promoting development promotion in the neonatal unit

Following are included under the umbrella of developmental care for promoting development in neonates.

- Kangaroo mother care (Skin to Skin Contact)
- Provision of age-appropriate visual stimulation from 32- 34 weeks onwards starting with the human face,
- Enhancing the development of circadian rhythms by dimming lights at night
- Encouraging parents and neonatal unit staff to talk softly to their babies while following their cues, whilst gradually leading on to normal conversation with time

- Familiarizing babies with the smell of their mother's breast milk by using milk- soaked gauze during tube feeds
- Positioning of the baby to provide a sense of containment similar to the intrauterine experience
- Encouraging hand to mouth contact via positioning
- Encouraging baby to nuzzle on the empty breast
- Gradual introduction to tactile stimulation with stroking or patting from 32 weeks onwards Engaging parents

2.4.2.2 Parental education at the neonatal units on early child development

Parent education goes hand-in-hand with all other aspects of parental involvement in the care of their neonate. It is important to provide them with the skills and knowledge they need to confidently and safely care for their infant not only in the practices in the neonatal units but also at home after discharge from the hospital. Child development is one of the most vital areas to be covered comprehensively as it is a major deciding factor of a child's future outcome. Providing ample opportunities to positively stimulate brain development through responsive parenting is particularly important for infants who start their lives with admission to the neonatal units. As most of them already have some insult to the brain, their parents must have the attitudes, knowledge and skills on proper developmental stimulation to reach the maximum potential as an individual. This empowerment can also contribute positively to the follow-up process and early detection of developmental delays or concerns.

- Parent education on child development must be done at least once before the baby is discharged and ideally both parents have to be involved in this session.
- A PowerPoint presentation ("Nurturing your baby") is developed to serve the purpose of educating parents on early child development and is available for the neonatal teams. A summary of this presentation will be available as a leaflet to distribute among caregivers.
- As this slide show is self-explanatory, the staff member attending the session has to provide clarifications and answer questions only.
- It can be organized as a group session or individualized according to the situation of the neonatal units, staff and each child.
- A nursing officer/ therapist or suitable staff member/s should be identified to deliver this task according to the requirement of neonatal care units.
- Mothers can also be allowed to watch this slide show during their leisure time in the neonatal units.
- The staff of the unit can schedule the education session as appropriate.
- Include the participation for a parent education session as a checklist item in the discharge checklist to ensure delivery of the session.

The line-up of the PowerPoint presentation

- 1. Why is early childhood important?**
- 2. Why do we have to start early?**
- 3. How do we optimize brain growth?**
 - a. making the baby feel that he/she is safe and loved
 - b. enriched learning
 - c. building trust and social relationships
- 4. What can be done at home?**
 - a. “Serve & return” - how interactions promote development
 - b. Sleep protection
 - c. Exogenous (environmental) stimulation
- 5. Important factors for brain development at different ages**
 - a. Sleep
 - b. Environment
 - c. Making memories:
 - d. Communication
 - e. Minimizing screen time
 - f. Handling and positioning the baby
 - g. Consoling the baby
- 6. Concept of “Family” and father’s involvement**
- 7. Take-home messages**

The main objective of this presentation is to let parents realize the important role they can play in influencing the developmental outcome of their baby and empower the parents to provide as many opportunities for their child's early development based on responsive parenting and the latest available evidence.

2.4.3 Screening for developmental delays and disabilities

Before discharge from the neonatal units, all intermediate and high-risk neonates should be screened for hearing, vision and probable developmental delays and disabilities. The “National Newborn screening program for congenital deafness” has been introduced and currently functioning to identify children with hearing disabilities. Screening

assessments for vision before discharge are complete examination of the skin and external eye structures as well as the conjunctiva, cornea, iris and pupils as an integral part of the physical examination of all newborns, the red reflex inspection, and corneal light reflex. The recommended screening test for probable development delay before discharge is the General Movement Assessment (GMA) which is described below in detail.

2.4.3.1 General Movement Assessment

2.4.3.1.1 What are General Movements?

Infants have typical and distinct spontaneous movements with rich and complex repertoire which can be detected from early fetal life onwards up to 5 months post term age which are known as “General movements”.

There are two main time periods that general movements occur:

- Writhing period -from birth to eight weeks corrected age.
- fidgety period- at twelve to twenty weeks corrected age

2.4.3.1.2 Significance of GMA

- It has a sensitivity of 97-98% and specificity of 89-91%
- Infants whose general movements are absent or abnormal have a high predictive value of their neurodevelopment outcome (Cerebral palsy, minor neurological deficits, and cognitive impairment and autism spectrum disorders) when assessed in preterm and term infants with risk factors.
- Enables early commencement of interventions and minimization of sequel.

2.4.3.1.3 On whom GMA are done?

- Infants under 20/52 post term (corrected age) with identified risk factors.
- Infants who are not developing typically for their corrected age.

2.4.3.1.4 Who can do the GMA?

GMA are done by medical staff that is specifically trained in assessing general movements in infants and best-done video based. The team consists of trained Paediatrician, medical officer, Physiotherapist/occupational therapist. The videos will be viewed and assessed by a trained health care team. When in doubt the videos will be sent to another trained Paediatrician to get a second opinion.

2.4.3.1.5 How is the assessment done?

The assessment can be completed from birth up to 20 weeks of age (corrected age).

- It is non-invasive and non-disruptive.
- The video can be taken by clinicians with appropriate consent.
- The video may be recorded by the team whilst the baby is an in-patient or an outpatient at WBC or CDIC.
- Video will be assessed by a GMA trained health care personal.
- The videos should be stored in a secure place and need to keep confidentially.

Instructions for the video:

The video should be taken when the infant is lying on his/her back, in a calm, alert state and lightly dressed. Baby's spontaneous movements should be captured without the baby interacting with the parents or playing with toys.

Position:

- Place the baby on their back on a plain colored flat surface
- Baby should be lightly dressed
- Take the video when they are awake and calm
- Avoid catching their eye or talking to them as this can suppress fidgety movements

Video:

- The baby should be seen in the video (including their hands and feet)
- Can use a phone or video camera
- Hold it about 2m above the baby
- Film for 3-5 minutes
- Return the video to the GMA team via secure way, E-mail etc.

2.4.4 Continuity of care

It is very important to establish continuity of care for intermediate and high-risk neonates by the time they are discharged from the hospital. Parents should be made aware of the importance of taking care of the baby as well as the follow-up at the neonatal unit clinics and/or child development intervention centers to ensure the optimum development of the child.

The following three activities are identified to establish the continuity of care by empowering the parents and linking with the public health teams.

2.4.4.1 Discharge meeting

Babies discharged from Neonatal Intensive Care Units (NICU)/PBU require special attention to prevent morbidity and mortality at home. In addition, the transition from hospital to home can be very stressful for most of the parents and results in experiencing anxiety about providing proper care for the baby. Therefore, the discharge process should be properly planned and the baby, parents, family and even the home environment has to be prepared well in advance to make this transition smooth and uneventful.

Ideally, the discharge preparedness plan should be started from admission with updating continuously and individualized throughout the child's stay in the NICU. Discharge meeting is one important point in this process of discharge planning. This has to be taken as an opportunity to review all the aspects of the discharge plan, discuss the concerns of the parents, check their understanding of child's intervention, follow up, care at home etc. and to confirm whether all the steps and arrangements before discharge have been properly addressed. (Also refer pages 48 & 49 of National Guidelines of Newborn care- volume III)

- **Timing of the meeting:** No less than 24 hours before the proposed discharge and ideally 48 hours ahead of the proposed discharge (48 hours -24 hours before discharge)
- **Venue of the meeting:** within hospital premises
- **Coordinator/organizer:** Nursing officer looking after the child/nursing sister or nursing officer in charge of NICU
- **Participants:** mother and father of the baby, any other caregiver involved in looking after the baby at home, consultant neonatologists in charge of the child, nursing officer, midwives looking after the child, social worker, medical officer/ registrar/ senior registrar, therapists involved in the care of baby, field Public Health Midwife (PHM) and/or the medical officer of Health (MOH).
- **Conduct of the meeting:** ideally the social worker or even the nursing officer/ nursing sister can conduct the meeting
- **Recording:** one member from the team should be allocated to take minutes which should be ideally circulated among participants within 5 days of the meeting.
- **Duration:** ideally 1 hour

A detailed guide on how to conduct the discharge meeting is available with the training module

2.4.4.2 Risk notification via CHDR

If a newborn is identified as high risk or moderate risk for developmental delays or disorders (refer to page 7 for risk conditions) it is important to communicate it with all the parties involved in his/her medical care including the field PHM. "Child Health and Development Record (CHDR)" is the most appropriate document to include this risk notification and it is

decided to include the phrase "developmentally challenged" under 'reasons for special care'. Until this is incorporated into the current CHDR, the risk could be written and notified under 'other' row of the 'reasons for special care' section.

2.4.4.3 Checklist at the discharge

A discharge checklist is an essential component of the discharge plan to ensure all the steps required to continue the holistic care of babies have been carried out before their discharge from the neonatal units. The responsibility of marking the checklist can be given to the nursing officer caring for the child with the help of the medical officers and therapists involved to plan the care of the child. This can be prepared according to the needs of neonatal units and the neonatologists in a way that the child and families are ensured the best possible care. Checklists can be used throughout the discharge planning process including the discharge meeting. The nursing officer discharging the child must re-check this list before they send the baby home to ensure that any important step is not missed out.

2.4.5 Monitoring & Evaluation

2.4.5.1 Audit on developmentally conducive neonatal unit

A developmentally conducive neonatal unit is a place where the four thematic areas developmental care at neonatal unit, engaging parents, screening for developmental delays and disabilities and continuity of care are operating systematically. It is the responsibility of the Nursing sister or the nurse in charge of the neonatal unit to conduct periodic audits and review the implementation of the above practices. Upon review, the positive activities should be further strengthened and the deficiencies should be rectified. This will enhance the quality of care delivered from the neonatal unit.

2.4.5.2 NICU data System

Having a well-functioning health information management system enables collection, analysis and use of data to ensure early appropriate action to improve the care of every small and sick newborn managed in NICUs. In order to address these, an electronic neonatal information management system [eNIMS] was developed by the FHB. This online system has the capacity of capturing all relevant clinical data of all NICU admissions, printing a uniform discharge summary across the NICUs in the country and data sharing capabilities if the treating consultants need to do so.

This system can be linked with the grass root level healthcare workers to follow up these newborns to assess the outcome in the long run.

The staff of the NICU is expected to use this data system and add all the relevant data including the developmental concerns. At the discharge meeting it should be evaluated that the data entry to the system had been completed.

2.5 Referral of the high-risk neonates for developmental delays/disabilities to the multidisciplinary team at the CDIC

From the risk profiling, neonates who are categorized as high risk for developmental disabilities should be directly referred to the Consultant Community Pediatrician/ General Paediatrician and the MDT at the CDIC of the District. These children will receive shared care by the neonatal teams and the MDT at CDIC. The MDT at CDIC will screen and follow up for the developmental delays/disabilities and provide early interventions. The neonatal teams will manage the other neonatal issues.

Steps to follow for the referral:

1. Write the referral note in the 'referrals' section of the CHDR
2. Get down the name of the mother, address and contact number to a register maintained at the NICU/PBU (High-risk for developmental delays/disabilities referral register)
3. Send the above details to the CDIC team by contacting the nursing officer of the CDIC. The team at the CDIC will schedule an appointment to assess the child.
4. Give the contact number of the CDIC for the parents as well, to schedule an appointment
5. Both the CDIC and Neonatal clinic are responsible to follow up the infant.

2.6 Follow-up of the intermediate-risk neonates for developmental delays/disabilities at the well-baby clinics

The responsibility to screen for developmental delays/disabilities for the neonates categorized as 'intermediate-risk falls to the neonatal teams. In addition, they will be subjected to routine screening via the Public Health Pathway. In an ideal situation, before discharge from the neonatal units, they must have undergone the first GMA WRITHING assessment. Ideally this is the video that had been obtained to assess later. At the follow-up well-baby clinics, the neonatal teams are expected to;

1. Screen for developmental delays/disabilities
2. Provide generic early childhood developmental interventions
3. Do the necessary referrals

2.6.1 Screening for developmental delays and disabilities

The screening test is recommended to use at the well-baby clinics for early identification of motor impairments;

1. General Movement Assessment (GMA)- Described in section 2.4.3.1

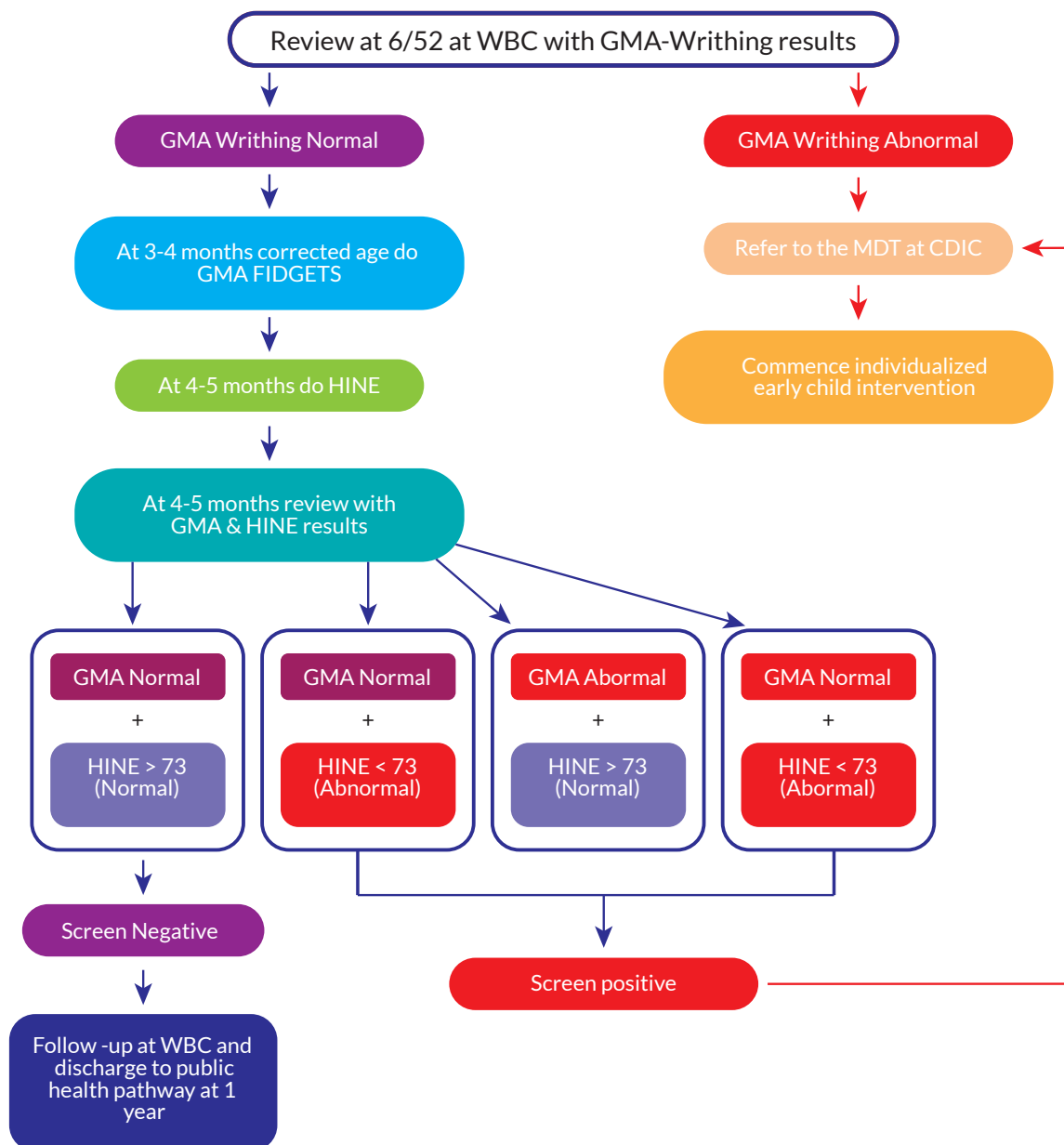


Figure 4: Screening for developmental delays and disabilities at the well-baby clinics by the neonatal teams

2. Hammersmith Infant Neurological Examination (HINE) – Described below 2.6.1.1
3. Age specific developmental assessment for Visual and communication impairments– Described below 2.6.1.

2.6.1.1 Hammersmith Infant Neurological Examination

2.6.1.1.1 What is HINE?

It's a standardized neurological examination for infants between 2 and 24 months, composed of 26 items assessing cranial nerve functions, posture, quality and quantity of movements, muscle tone, reflexes and protective reactions and behaviors as well some age dependent items reflecting the gross and fine motor functions. Each item is scored individually with a sum score of all individual items.

2.6.1.1.2 Significance of HINE and its scores

- Enables early detection of infants with high risk of cerebral palsy and other motor disorders
- Predicts severity and topography of CP
- HINE sensitivity at 3 months 96%, specificity 85%

HINE scores at:-

- 3/12- <57 is 96% predictive of CP
- 6,9,12 months 90% is predictive of CP
- <73 predictive of CP
- <40 almost always indicative of CP

Severity and topography: -

HINE at 3-6months- 40-60 indicates GMFCS 1-11

<40 indicate GMFCS 111-v

HHINE at 3, 6, 9,12months- 50-73 indicates unilateral CP (95-99% will walk)

<50 indicate B/L CP

2.6.1.1.3 Who can perform the HINE?

Can be easily performed by any trained clinician (Medical Officer, Physiotherapist) and no certified training required

2.6.1.3.4 How long does the HINE take to perform?

The examination takes 10–15 minutes to perform

2.6.1.2 Age specific developmental assessment for visual and communication impairments

2 Months

- Observe general response to various stimuli
- Vision- fixing and following
- Response to sound – localizing
- Look for cooing vocalizations

4 Months

- Response to voice and faces
- Observe babbling sounds
- Flash a light across face
 - ❖ Gazes directly into bright light or fail to close their eyes in response to direct intense light (light gazing)
 - ❖ Or may close eyes
- Whether the child blinks when touched at the bridge of the nose (visual reflex differences)
- Whether the child looks at the face with eye-to-eye contact (visual complexity)

6 Months

- Response to familiar and unfamiliar face and sounds
- Response to mirror
- Observe babbling sounds- vowels and consonants

9 Months

- Observe bonding with caregiver and response to assessor
- Assess object permanence- response to fallen or hidden object
- Assess cause and effect play with a rattle or bell
- Engagement of social game – ‘peek a boo’ or wave ‘bye’, imitating ‘Sadhu’
- Observe exploration of toys- banging
- Picture book reading

- Response to name
- Perform crude distraction test for localization of sounds
- Observe poly syllable babbling

12 Months

- Observe imitative actions, playing social game and bonding with caregiver
- Observe child play with cup, spoon, doll and car
- Check understanding of use of common objects
- Check response to 'name', 'no' and simple command
- Observe nonverbal gestures and joint engagement
- Observe speech- complex babbling and variation of sound

Checklist for the above assessment is annexed (Annex 1).

2.6.2 Provide generic early childhood developmental interventions

For the neonates categorized as “intermediate risk” if they are screen positive for developmental delays and disabilities, they should be referred for shared care with the MDT at the CDIC. All the other screen test negative neonates should receive generic early childhood development interventions with the assistance of a therapist at their well-baby clinic visits. The age-appropriate generic developmental promotion interventions and parent education material are made available for the neonatal teams.

After the 4 months screening if the child is screen negative at 6, 9 and 12 months the CHDR based developmental screening and the developmental assessment for non-motor neurodevelopmental disorders can be carried out at the well-baby clinic. After 12 months if there are no developmental concerns, the child can be directed to be followed up at the public health pathway.

Public Health Pathway

3. Public Health Pathway

The systematic screening of ***all children*** born in the country to detect developmental delays and disabilities is carried out via the '***Public Health Pathway***'.

The services of the public health pathway will be delivered in two settings; home-based and MOH level clinic-based care with community management.

The main screening and health education tool used in the public health pathway is the Child Health and Development Record (CHDR)

3.1 Graphical illustration

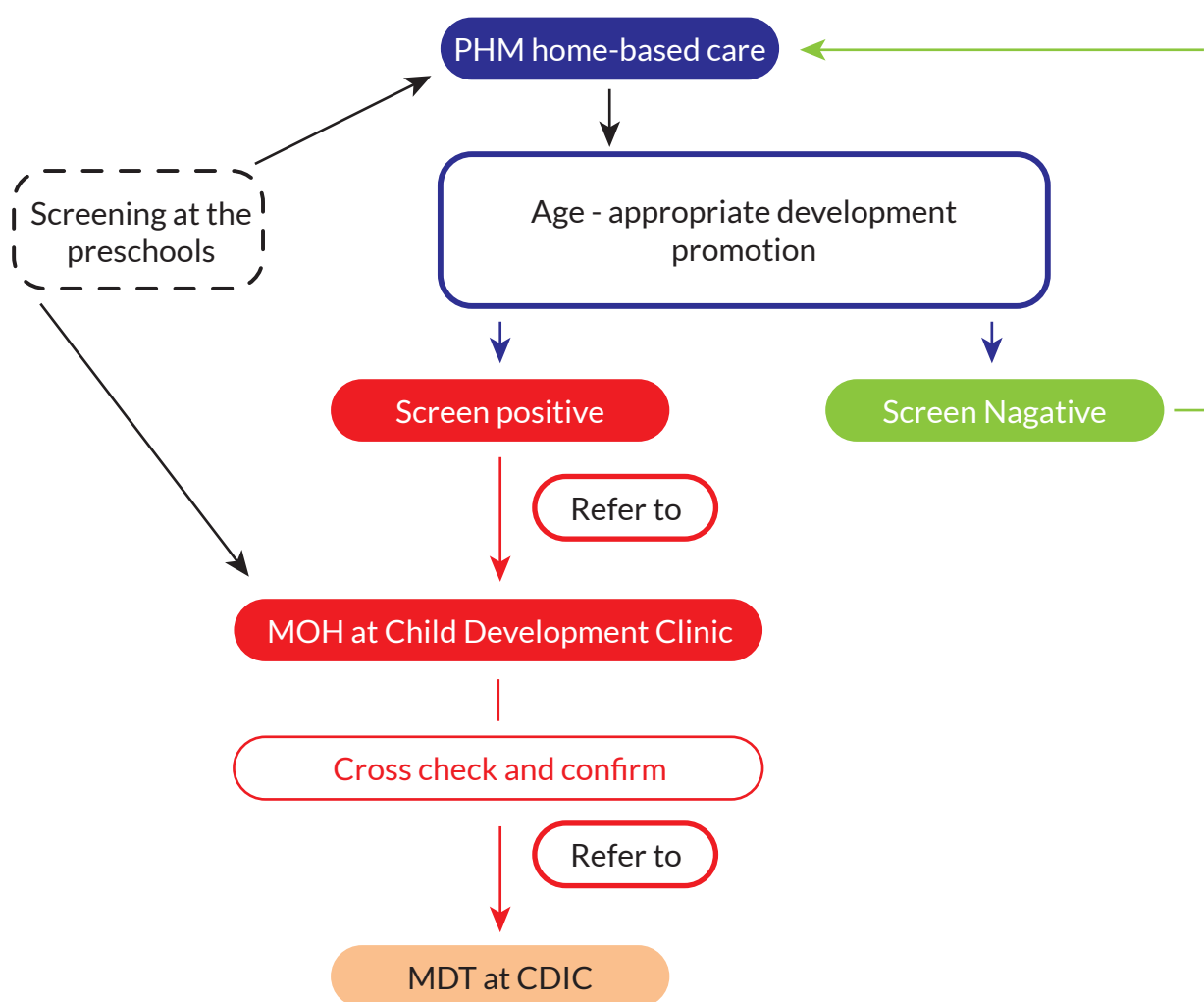


Figure 5: Graphical illustration of the public health pathway

3.2 Home-based care by the Public Health Midwife (PHM):

The main service provider of home-based care is the Public Health Midwife (PHM). They are supposed to visit the homes of children in the following manner;

- During the first year of life – Home visit once a month by the PHM
- During the second year of life – Home visit once in two months by the PHM
- During the third year of life – Home visits once in three months by the PHM

The PHM is supposed to do two main activities under this project during home visits.

1. Provide information on early child development promotion and necessary parenting instructions.
2. Screen for developmental disabilities at 2, 4, 6, 9, 12, 18, 24, 36, 48 and 60 months

3.2.1 Provide information on early child development promotion and necessary parenting instructions.

The PHMs are trained on early child development and development promotion. The training manual on "Child development: Concepts, Interventions, Assessment and Problems-Manual for Primary Health care workers in Sri Lanka" and the training guide published by the Family Health Bureau is used for the training. In addition, the general circular issued by the Ministry of Health 01-12/2020, on "guideline on child development promotion and development screening for primary health care workers" gives detailed instructions for the PHMs and the public health staff.

The child development promotion and parenting information are based on the “responsive caregiving”, “safety and security” and “early learning opportunities” components of the nurturing care framework. Thus, PHMs are supposed to;

- Educate parents about the child development and the importance of early stimulation and the need for creating a developmentally conducive home environment.
- Inform parents about age-specific development milestones and educate them on developmental stimulation activities that promote normal development.
- Assess parenting skills of mothers and advise accordingly
- Educate mothers on using CHDR as a tool to monitor child development

3.2.2 Screen for developmental disabilities

The PHM is expected to conduct a development screening assessment at 2nd, 4th, 6th, 9th, 12th, 18th, 24th, 36th, 48th and 60th months of age. The CHDR Screening tool is utilized for this purpose. PHMs have to assess children with the given indicators in CHDR

at relevant age points and put their signature to confirm what parents/caregivers have marked. If the answer is 'yes' to any of the screening questions the PHM should refer the child to the developmental clinic at the MOH office for further assessment.

3.3 MOH level clinic-based care

Each MOH is supposed to conduct a child development clinic (CDC) once in two weeks at the MOH (However, the MOH teams may decide to conduct this as one activity of the Polyclinic/CWC depending on the resource availability). The screen-positive children, by the PHM's home-based screening, will be referred to the CDC. The MOH has to do a developmental assessment and confirm the positive indicator in the screening tool and refer the child to the regional level child development intervention center (CDIC). When referring the child;

1. Write the referral note in the 'referrals' section of the CHDR
2. Mark the positive indicator/indicators number and the age of the child in the reasons for referral column.
3. If the child has any home risk factors, identify the Z code of home risk assessment from the CHDR B portion and write the Z code in the reasons for referral column.
4. Maintain a register at the MOH office as well as the PHM office with the name of the mother, address, contact number, and the PHM area (High-risk for developmental delays/disabilities referral register)
5. Send the above details to the CDIC team by contacting the nursing officer of the CDIC. The team at the CDIC will schedule an appointment to assess the child.
6. Give the contact number of the CDIC to the parents as well, to schedule an appointment
7. Instruct the SPHM/PHNS to follow up on the referral and mark the outcome of the referral in the 'High-risk for developmental delays/disabilities referral register' at the MOH office.
8. Instruct the PHM to follow-up on the referral and mark the outcome of the referral in the 'High-risk for developmental delays/disabilities referral register' at the PHM office

3.4 Screening by the Preschool teachers

The children between the ages of 3-5 years may be screened for developmental status by the preschool teachers. In addition, during preschool, some teachers may identify developmental delays and disabilities. If such children are detected by the preschool, the teachers can refer them to the PHM or directly to the relevant MOH office. Then those children will be incorporated into the public health pathway and will be referred to the CDIC accordingly.

3.5 Monitoring and Evaluation of the Public Health Pathway

The following five process indicators are monitored and evaluated in the IncluDe program at PHM, MOH, Regional, and National level. PHM level monitoring is done at the monthly MOH conference, MOH level monitoring is done at monthly MOH review at RDHS office and National level monitoring is done at National MCH reviews.

1. Percentage of infants (0-11 months) screened for developmental delays and disabilities
2. Percentage of young children (12-23 months) screened for developmental delays and disabilities
3. Percentage of preschoolers (24-59 months) screened for developmental delays and disabilities
4. Percentage of Infants referred to the CDIC
5. Percentage of Young children referred to the CDIC
6. Percentage of Pre-schoolers referred to the CDIC
7. Percentage of children under 5 years of age with a developmental delay/disability

3.5.1 Monthly by the PHM to the SPHM to PHNS

Age category (months)	Number of children under care	Number of children screened	Number of children needed referral to MOH	Number of children referred by the MOH to the CDICreg	Number of children diagnosed as having a developmental delay/ disability by the CDICreg

3.5.2 Quarterly by the MOH to the RDHS and FHB in two copies

For each MOH area

Indicator	Number
Infants under care	
Young children under care	
Pre-schoolers under care	
Infants screened for developmental disabilities	
Young children screened for developmental disabilities	
Pre-schoolers screened for developmental disabilities	
Infants referred to the CDIC	
Young children referred to the CDIC	
Pre-schoolers referred to the CDIC	
Children under 5 years of age with a developmental delay/disability	

Primary care, general practitioner and other clinician pathways

4 Primary care, general practitioner and other clinician pathways

This pathway was identified as an opportunistic screening pathway to supplement the public health and neonatal pathways. At present, there is a considerable proportion of the population who obtain services solely from the private sector. In addition, due to internal migration and various other socio-cultural reasons some families may miss the services from the public health pathway. The 'primary care, general practitioners and other clinician pathways', provides an opportunity to include such missed children in the IncluDe program. Hence, this is an opportunistic screening, whenever these children visit the primary care physicians, GPs and any other clinician the children will be screened for developmental delays and disabilities and refer to the CDIC or back to the public health pathway.

In addition, the 'primary care, general practitioner and other clinician pathways' supports the other two pathways by providing necessary supportive advice through a familiar clinician.

4.1 Graphical Illustration

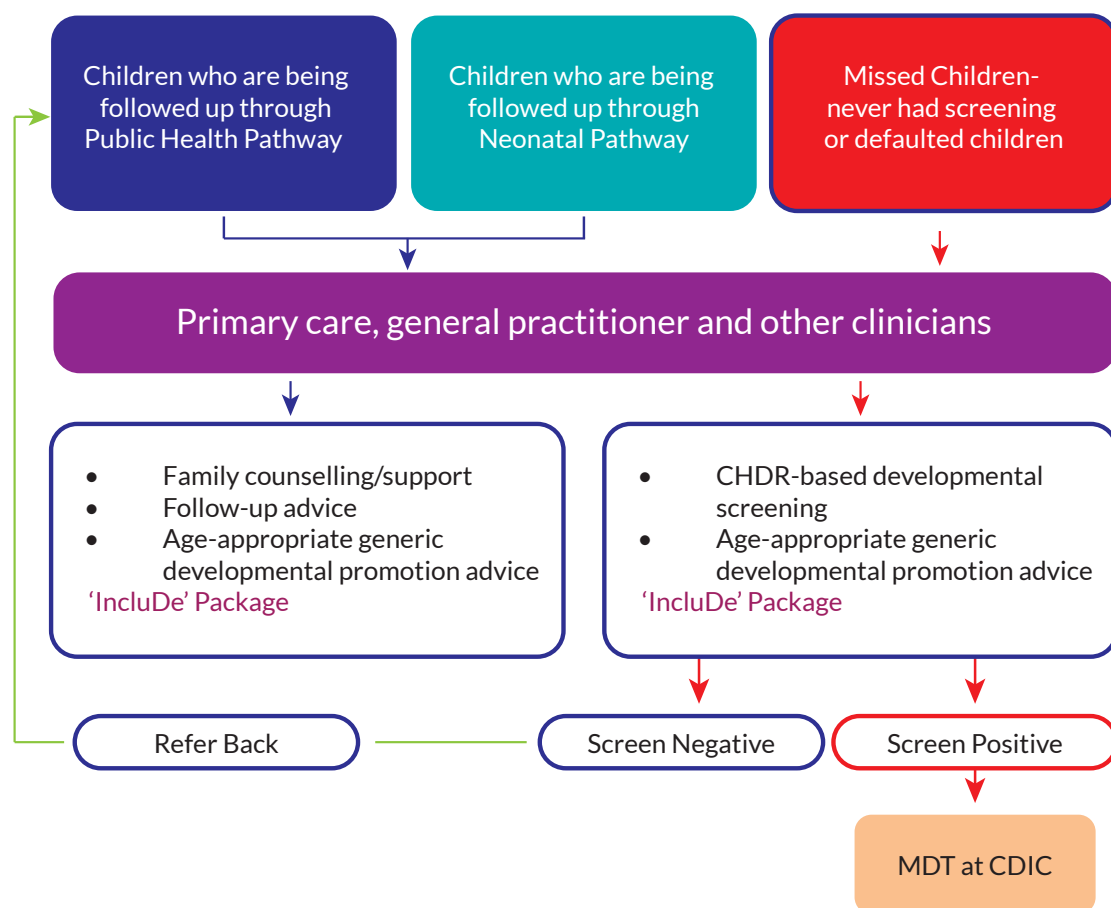


Figure 6: Graphical Illustration of the primary care, general practitioner and other clinician pathway

4.2 IncluDe package for primary care, general practitioner and other clinicians

The primary care, general practitioner and other clinicians who are involved in the health care for a child less than five years of age are expected to provide developmental promotion advice and development screening at any encounter they get with the child and the family. Some of the children are followed-up at the public health or neonatal care pathway. That means they have undergone age-appropriate development screening, had been referred to an MDT team at a CDIC if indicated and parents are aware of the developmental promotion. In such situations, the primary care physician, general practitioner or any other clinician is expected to reinforce already commenced activities, provide family counselling/support and age-appropriate development promotion advice if necessary.

However, if they find a child who has missed age-appropriate development screening or defaulted services, it is expected to;

1. Conduct CHDR-based development screening
 - a. If the child is screen positive to refer to the CDIC
 - b. If the child is screen negative to refer to the PHM/MOH for the public health pathway follow-up
2. Provide age-appropriate development promotion advice using the CHDR
3. Attempt to elicit reason for default or being missed and communicate this to CDIC as well as public health team. Thereby Primary care physician has to remove the barriers for intervention. Further he/she has to inform details to CDIC/Public health team as the risk of default is high and follow up frequently.

The training module for primary care physicians, GPs and any other clinician on IncluDe package will be made freely available, and will consist of the following modules;

- CHDR-based developmental screening
- Red flag signs to identify developmental disabilities
- CHDR based age-appropriate development promotion advice
- Caregiver/ Family support for children with disabilities
- Common developmental disabilities
- Importance of ECI and a brief introduction to ECI for children with disabilities
- Referral pathways and available services
- Medications/drug interactions – must-known facts
- Identifying barriers and resources available to overcome such developmental disabilities

5 Care pathway from the CDIC

The CDIC is the referral center for children who become positive for the screening for developmental disabilities. The MDT at the CDIC has the responsibility of initial assessment of the child, arriving at a diagnosis (may be probable) and devise an individualized management plan with early childhood interventions (ECIs). They may have to refer the child for further evaluations for a tertiary care hospital for subspecialties such as pediatric neurology, child and adolescent psychiatry, pediatric rheumatology, ENT and pediatric cardiology.

The CDIC collaborates closely with the public health team in the community management of the child with a developmental delay/disability. In addition, the CDIC plays a collaborative role with the non-health sectors in long-term management of the child.

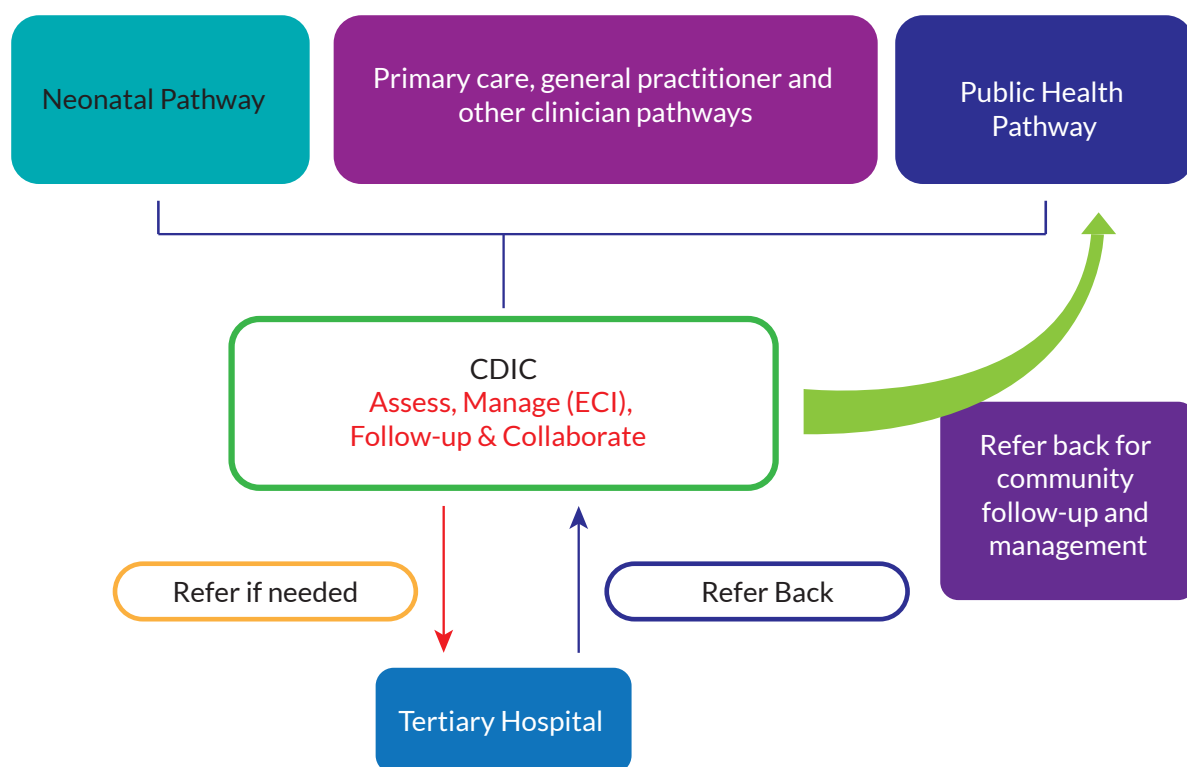


Figure 7: The link of service delivery between the field services, CDIC and the Tertiary level clinical services

6 Annexure

Developmental assessment checklist for visual and communication impairments

- ❖ To be administered at every developmental center clinic visit
- ❖ To be filled by a Nursing officer with Direct questioning of parent/s
- ❖ Age should be taken as corrected for Gestational age in preterm babies

2 Months

- Social/Emotional
 - o Begins to smile at people
 - o Can briefly calm himself (may bring hands to mouth and suck on hand)
 - o Tries to look at parent
- Language/Communication
 - o Coos, makes gurgling sounds
 - o Turns head toward sounds
- Cognitive (learning, thinking, problem-solving)
 - o Pays attention to faces
 - o Begins to follow things with eyes and recognize people at a distance
 - o Begins to act bored (cries, fussy) if activity doesn't change
- Movement/Physical Development
 - o Can hold head up and begins to push up when lying on tummy
 - o Makes smoother movements with arms and legs

4 months

- Social/Emotional
 - o Smiles spontaneously, especially at people
 - o Likes to play with people and might cry when playing stops
 - o Copies some movements and facial expressions, like smiling or frowning
- Language/Communication

- o Begins to babble
- o Babbles with expression and copies sounds he hears
- o Cries in different ways to show hunger, pain, or being tired
- Cognitive (learning, thinking, problem-solving)
 - o Lets you know if she is happy or sad
 - o Responds to affection
 - o Reaches for toy with one hand
 - o Uses hands and eyes together, such as seeing a toy and reaching for it
 - o Follows moving things with eyes from side to side
 - o Watches faces closely
 - o Recognizes familiar people and things at a distance
- Movement/Physical Development
 - o Holds head steady, unsupported
 - o Pushes down on legs when feet are on a hard surface
 - o May be able to roll over from tummy to back
 - o Can hold a toy and shake it and swing at dangling toys
 - o Brings hands to mouth
 - o When lying on stomach, pushes up to elbows

6 months

- Social/Emotional
 - o Knows familiar faces and begins to know if someone is a stranger
 - o Likes to play with others, especially parents
 - o Responds to other people's emotions and often seems happy
 - o Likes to look at self in a mirror
- Language/Communication
 - o Responds to sounds by making sounds
 - o Strings vowels together when babbling ("ah," "eh," "oh") and likes taking turns with parent while making sounds
 - o Responds to own name
 - o Makes sounds to show joy and displeasure
 - o Begins to say consonant sounds (jabbering with "m," "b")

- Cognitive (learning, thinking, problem-solving)
 - o Looks around at things nearby
 - o Brings things to mouth
 - o Shows curiosity about things and tries to get things that are out of reach
 - o Begins to pass things from one hand to the other
- Movement/Physical Development
 - o Rolls over in both directions (front to back, back to front)
 - o Begins to sit without support
 - o When standing, supports weight on legs and might bounce
 - o Rocks back and forth, sometimes crawling backward before moving forward

9 months

- Social/Emotional
 - o May be afraid of strangers
 - o May be clingy with familiar adults
 - o Has favorite toys
- Language/Communication
 - o Understands “no”
 - o Makes a lot of different sounds like “mamamama” and “bababababa”
 - o Copies sounds and gestures of others
 - o Uses fingers to point at thing
- Cognitive (learning, thinking, problem-solving)
 - o Watches the path of something as it falls
 - o Looks for things he sees you hide
 - o Plays “peek-a-boo”
 - o Puts things in her mouth
 - o Moves things smoothly from one hand to the other
 - o Picks up things like cereal o’s between thumb and index finger
- Movement/Physical Development
 - o Stands, holding on
 - o Can get into sitting position

- o Sits without support
- o Pulls to stand
- o Crawls

12 months

- Social/Emotional
 - o Is shy or nervous with strangers
 - o Cries when mom or dad leaves
 - o Has favorite things and people
 - o Shows fear in some situations
 - o Hands you a book when he wants to hear a story
 - o Repeats sounds or actions to get attention
 - o Puts out arm or leg to help with dressing
 - o Plays games such as “peek-a-boo” and “pat-a-cake”
- Language/Communication
 - o Responds to simple spoken requests
 - o Uses simple gestures, like shaking head “no” or waving “bye-bye”
 - o Makes sounds with changes in tone (sounds more like speech)
 - o Says “amma” and “thatha” and exclamations like “uh-oh!”
 - o Tries to say words you say
- Cognitive (learning, thinking, problem-solving)
 - o Explores things in different ways, like shaking, banging, throwing
 - o Finds hidden things easily
 - o Looks at the right picture or thing when it’s named
 - o Copies gestures
 - o Starts to use things correctly; for ex., drinks from a cup, brushes hair
 - o Bangs two things together
 - o Puts things in a container, takes things out of a container
 - o Lets things go without help
 - o Pokes with index (pointer) finger
 - o Follows simple directions like “pick up the toy”
- Movement/Physical Development
 - o Gets to a sitting position without help

- o Pulls up to stand, walks holding on to furniture (“cruising”)
- o May take a few steps without holding on
- o May stand alone

Red flags for visual development

The visual milestones may not be achieved due to motor cognitive or other difficulties.

The milestones in bold letters are mostly independent of above.

At Any age

- No response to visual threat
- No blink response to tap on forehead
- Gazing at lights/ no objections to a bright light shone in the eye
- Closing eyes in an environment with normal background light/ rubbing eyes after looking at an object observed repetitively
- Constant absence of fixing at a bright object at 8-12 inches
- Looks only at objects with 1 or 2 favourite colours
- Abnormal head posture when looking
- Abnormal eye movements/ nystagmus
- Squint/ dysconjugate eye movements beyond 5 months

Age	Sign
Birth to -1 month	☐ Infant blink or close eyes in response to bright light or touching eye ☐ Able to stare at object if held 8 to 12 inches away ☐ Fixes eyes on a face or light ☐ May follow a moving object

1 -2 months	☐ Looks at faces and pictures with contrasting black and white images ☐ Can follow an object up to 90 degrees ☐ Watches parent closely ☐ Smiles at caregiver consistently as a response to seeing (when silently approached) by 2 months
2 to 3 months	☐ (Hand regard) Is baby aware of his/her hands ☐ Look directly at parent's or caregiver's eyes ☐ Follows beyond 90 degrees ☐ Smiling at his/her parent or caregiver without need for attracting with sound
4 to 5 months	☐ Beginning to reach hands to objects, faces ☐ Recognizes familiar objects such as toy/ bottle (gets excited) ☐ Shifts eyes from one person to another ☐ Looks with eyes together by 5 months
5 to 7 months	☐ Consistently reach for objects ☐ Will turn head to see an object ☐ Follows objects when placed near (< 1 foot) and far (> 6 feet) by 7 months
7 to 11 months	☐ Recognize family members and/or caregivers and have a welcoming smile before hearing voices or seeing his/her smiles? ☐ look at small objects, such as rice grains /moving insects cereal or a raisin ☐ Plays peek-a-boo

12 to 14 months	☐ Able to place shapes in proper holes ☐ Becomes interested in pictures ☐ Recognizes familiar objects and pictures in books, may point to some objects when asked, "Where is the ...?" ☐ Points and gestures for objects ☐ Copies actions
-----------------	---

Red Flags of Autism in Infants

Age	Social Communication and interaction	Restricted repetitive behaviors
By six months	Few or no big smiles or other warm, joyful and engaging expressions	Very difficult to console, requires rocking and unusual movements in excessive amounts to console
	Limited or no eye contact	
By 9 months	Does not respond to name	Unusual repetitive movements of limbs and body.
	Does not show facial expressions like happy, sad, angry, and surprised	Prefers to stare at rotating objects such as fans for prolonged periods
	Little or no back and forth sharing of sounds, smiles or other expressions	
By 12 months	Little or no babbling	Obsessed with parts of toys or clings on to same toys
	Little or no back-and-forth gestures such as pointing, showing, reaching or waving	Spins toys or objects frequently
	Does not play simple interactive games like 'athuru-mithuru' – or hand games involving clapping with each other by 12 months of age	



9 786245 990085