स्वावलम्बन
Swavlamban

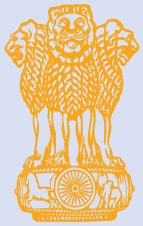
सत्यमेव जयते

EARLY INTERVENTION CENTRE
SHAPING STRONGER FUTURES

Handbook

on
Early Intervention Centres for Children with Disabilities

Department of Empowerment of Persons with Disabilities (Divyangjan)
Ministry of Social Justice and Empowerment
Government of India



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थावरचन्द गेहलोत
THAAWARCHAND GEHLOT
सामाजिक न्याय और अधिकारिता मंत्री
भारत सरकार
MINISTER OF
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MESSAGE

Research studies have shown that first 1000 days in the life of a newborn child are crucial for ensuring the wholesome growth. Capturing risk cases at an early stage and taking appropriate preventive measures help in eliminating disability or reducing severity of disability in most of the cases.

The Department of Empowerment of Persons with Disabilities has been striving to work out a module for early intervention of rehabilitation for Children with Disabilities in the age of 0-6 years. I am pleased to release the Handbook on Cross-disability Early Intervention Centre. It is a compilation of articles prepared by the Department on various components of early intervention. This Handbook envisages a plan for providing comprehensive early intervention therapies and services under one roof alongwith facilities of a preparatory school.

The Department has initiated the process of setting up of cross-disability Early Intervention Centres in all its National Institutes and Composite Regional Centres. I am sure that this Handbook will become a reference tool for researchers, academicians, professionals, parents and Persons with Disabilities on matters relating to early identification and intervention for rehabilitation for Children with Disabilities.

All the State Governments are requested to set up such EICs in all Districts for which this Handbook will be beneficial for the local health administrators. I commend the efforts of Ms. Shakuntala Doley Gamlin, Secretary, DEPwD, Joint Secretary - Ms. Tarika Roy, and Director - Shri K.V. S. Rao in taking this initiative of bringing out this handbook simultaneously with the inauguration of 14 EICs across different states in our National Institutes and Composite Regional Centres.

2.3.21

(Thaawarchand Gehlot)

कृष्ण पाल गुर्जर
KRISHAN PAL GURJAR

सत्यमेव जयते

सामाजिक न्याय और अधिकारिता राज्य मंत्री
भारत सरकार
MINISTER OF STATE FOR
SOCIAL JUSTICE & EMPOWERMENT
GOVERNMENT OF INDIA

MESSAGE

I am happy to learn that the Department of Empowerment of Persons with Disabilities under the Ministry of Social Justice and Empowerment has brought out a **Handbook on Early Intervention** for effective rehabilitation for Children with Disabilities.

This Handbook covers extensive areas relevant for the early identification and intervention through appropriate rehabilitative therapies so as to help children with disabilities live more secure and self-dependent life.

I am hopeful that the rehabilitation practitioners and other stakeholders will find this Handbook very useful.

(Krishan Pal Gurjar)

New Delhi

Dated: 05.03.2021

शकुन्ताला डौले गामलिन, भा.प्र.से.
सचिव
Shakuntala Doley Gamlin, IAS
Secretary

सत्यमेव जयते

भारत सरकार
सामाजिक न्याय और अधिकारिता मंत्रालय
दिव्यांगजन सशक्तिकरण विभाग
Government of India
Ministry of Social Justice & Empowerment
Department of Empowerment of Persons with Disabilities (Divyangjan)

26th February, 2021

FOREWORD

Disability among children is a matter of serious concern as it has wider implications. As per Census 2011, about 20.42 lakh children in the age group of 0 to 6 years suffer from some form of disability and 7.01 % of children in this age group have a disability that is either congenital or acquired.

Thus the period between 0 to 6 years of age in a child's life is considered vital for physical and psychological growth. This is also a period when early symptoms of any deformity or risk-cases can be captured and treatment/ therapeutic interventions for achieving necessary preventive, corrective or rehabilitative actions undertaken to prevent disability or lessen its severity.

Keeping this in mind and the mandate under the Rights of Persons with Disabilities Act , 2016, (RPwD Act) which emphasizes focus on mother and child at pre-natal, peri-natal and post natal stages, the Department of Empowerment of Persons with Disabilities has undertaken its first ever Pilot Project to set up 14 comprehensive cross-disability Early Intervention Centres (EICs) in its seven National Institutes and seven Composite Regional Centres in the first phase of its plan. These EarlyChildhood Identification / Intervention and Rehabilitation Centreshave been set up after due diligence with experts and professionals in the field to ensure that all the clients are treated and mentored with utmost care. The facilities, care services, the treatment plan, support provided to the children with disabilities and their parents must be evidentially demonstrated that they would in-turn become ambassadors of early intervention care and benefits of getting treatment by ensuring early identification/intervention and visits to the rehabilitation units within the State/District for making the child develop school-going habits; participate in inclusive pre-school and primary school education/ activities and in learning numeracy and literacy that will make her/him independent.

This Handbook provides a glimpse of Government's perspective on early rehabilitation and parent-centric approach in these Early Intervention Centres. It also brings out the features of early rehabilitative interventions including ensuring early and quality services in meeting the rehabilitation needs of all categories of disabilities recognised under the Rights of Persons with Disabilities Act, 2016.

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This Handbook will serve as a guidebook for all rehabilitation personnel and professionals - be it Occupational Therapists, Physiotherapists, Speech and Language Therapists, Paediatricians, Ophthalmologists, ENT Specialists, Audiologists, Neurologists, Orthopaedic Surgeons, Physical Medicine and Rehabilitation (PMR) Specialists , Dentists, Nutritionists, Psychiatrists, Rehabilitation Psychologists, Social Workers, or Special Educators, engaged in early intervention. The book would also help improve their understanding of the intrinsic principles and practices of early intervention which would translate into better rehabilitation services for the beneficiary children between the age group of 0-6 years. It will also enable parents to achieve better management of their children with disabilities at home as well.

It is expected that through these Early Intervention Centres providing cross-disability rehabilitative services, all-out efforts will be made to improve the sensory, motor and cognitive skills of the child optimally so as to cater to the demands of the children with disabilities in their daily living activities and prepare them for schooling. This would help reduce the overall disability burden of the country, as well as make children with disabilities more self-dependent through early rehabilitative intervention therapies and care provided by rehabilitation personnel and professionals.

(Shakuntala Doley Gamlin)
Secretary, DEPwD

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PREFACE

There is a good reason for this Handbook on early intervention for children with disabilities being conceived. It is an effort to express as to how the idea and concept of early intervention through rehabilitative therapies and treatment protocols for children in the age group of 0-6 years gained importance and momentum in this Department. The book was also conceptualized as a means to collate thoughts, perspectives and knowledge of basic principles and philosophies as well as best practices in this domain for sharing with stakeholders involved in this crucial sector for the critical care of small children with developmental delays or those at risk of disabilities.

It all began when Smt. Shakuntala D. Gamlin, Secretary, Department of Empowerment of Persons with Disabilities mooted the idea that there should be a National Programme on early screening, detection and intervention for children with disabilities in the age group of 0-6 years on the lines of the National Health Mission. While attempting to formulate such a scheme, it was realised that there was a lack of awareness with regard to the importance of rehabilitation therapies and interventions which are mainly non-medical in nature. Coupled with this, was the glaring fact of the acute shortage of rehabilitation professionals. As such, the gaping void identified in the early identification and intervention of disabilities found in the children in the age bracket of 0-6 years was sought to be bridged by this Department.

In order to demonstrate the necessity and feasibility of such a concept, the Department began introspection and took the decision for first implementing it in-house itself. For this purpose, it was decided to begin a pilot project for cross disability Early Interventions Centres by creating such facilities in seven of its National Institutes, together with seven Composite Regional Centres spread across different states of India. These 14 Centres to be taken up in the pilot phase were inspected to see the feasibility of setting up such cross disability centres, especially since most of our National Institutes currently have expertise mainly in one type of disability. However, since small children may have different types of disabilities including multiple disabilities, it was felt that all categories of disabilities need equal attention.

Thus, began several rounds of brainstorming sessions with the Directors of our National Institutes as well as other experts to carry out the framework and details and what all should these Early Intervention Centres be constituted of. The extensive deliberations and the learning gained therefrom resulted in conceiving and evolving these cross disability Early Intervention Centres as parent-centric, accessible and aesthetically appealing spaces for providing the much needed rehabilitative therapeutic interventions to children at risk or having disabilities.

This whole process of how the Department worked on this idea of creating Early Intervention Centres with a cross disability perspective, what would be requirements of manpower of medical and rehabilitation professionals and personnel, what equipments and furniture were necessary for such facilities, the financials, the protocols of case management, best practices, sensitization of staff to the needs of such parents and children with disabilities as also maintenance of database are attempted to be documented in this Handbook.

In a short span of time from October, 2020 onwards, all 7 National Institutes and 7 Composite Regional Centres plunged into action to set up the Early Intervention Centres to try and cater especially to the parents and children who suffer from lack of such facilities in their neighborhood. The professionals and staff in these National Institutes and CRCs teamed up well in time to create these useful units as an integral part of their organizations. Benefits are expected to follow through elimination of disabilities where possible, reduction in the severity of disabilities and handling every child with full focus in a scientific manner with the latest available technologies to help each of them manifest their innate potential. These centres have been conceived as services which will eventually bring relief to the parents, caregivers and the society at large.

It is expected that this Handbook will provide a strong rationale and guidance to the State and District authorities in setting up of such early intervention centres accessible to every family. It may also well pave the way to formulate and implement a National Programme on a mission mode in the years to come!

(Tarika Roy)

EARLY INTERVENTION CENTRES

About the Early Intervention Centres: Birth to 6 years of age is critical years for the physical growth, health as well as cognitive development and well-being of a child. These are also vital for the holistic development of children. A newborn's brain, which is merely a quarter of the size of that of the adult brain, is said to develop up to 90% by five years of age. Evidence also suggests that early stimulation is essential for all children for school and higher education and in case of children having impairments, it also averts further disabling conditions. Hence, Department of Empowerment of Persons with Disabilities (DEPwD) under Ministry of Social Justice and Empowerment (MSJE), Government of India has envisioned starting Early Intervention Centres (EICs) for shaping stronger futures for young children with impairments in the age group of 0-6 years. The aim is to provide a cross-disability, composite multi-functional facility for therapeutic interventions to help reduce the disability burden and also counsel the parents under one roof. It is also to prepare the children for school readiness which is crucial for inclusive education.

About the Logo: The small letters **'e'** and **'i'** in the logo depict **E**arly **I**ntervention, including identification of certain disabilities. Since the physical growth and cognitive development are crucial to 0 to 6 years of age, and happens due to the interaction of maturation and environment, the logo has a dot depicting the head or the brain. Emerging from the brain are green rays depicting its development for various cognitive skills, such as critical thinking, problem solving, etc. Further, environmental interactions are required to be provided by both the parents and the professionals. Accordingly, the logo has two green leaves symbolising the caring hands and equal partnership of both the parents and professionals that are essential for the child's sustained growth. The Early Intervention Centres (EICs) envisages providing all facilities of intervention for children with disabilities under one roof, so the logo has a blue half circle depicting the roof.

Since universally, blue colour symbolises boys and the pink depicts girls, the two colours are used for the letters **'e'** and **'i'** portraying 'gender equality'. Both these letters are also shown with tilts giving a subtle message of disability being beautiful. The yellow and orange solid sphere in the centre portrays the Sun's brightness which is actually the aim of the composite cross disability centres which have a tag line 'shaping stronger futures' of children with disabilities.

क्रॉस डिसेबिलिटी - शीघ्र हस्तक्षेप केंद्रों

क्रॉस डिसेबिलिटी शीघ्र हस्तक्षेप केंद्रों के बारे में : जन्म से लेकर 6 साल की उम्र एक बच्चे के शारीरिक विकास, स्वास्थ्य और संज्ञानात्मक/ बौद्धिक विकास के दृष्टिकोण से अत्यंत ही महत्वपूर्ण चरण होता है। ये बच्चों के समग्र विकास के लिए भी महत्वपूर्ण वर्ष होते हैं। ऐसा माना जाता है की एक नवजात शिशु का मस्तिष्क, जो वयस्क मस्तिष्क के आकार का केवल एक चौथाई होता है, वह पांच साल की उम्र तक 90% तक विकसित हो सकता है। प्रमाण यह भी बताते हैं कि शुरुआती प्रोतसाहन बच्चों के सभी स्कूल और उच्च शिक्षा के लिए आवश्यक है और बौद्धिक दिव्यांगता वाले बच्चों के लिए भी महत्वपूर्ण होता हैं; यह और भी अक्षम स्थितियों को टालने में सहायता प्रदान करती है। अत: दिव्यांगजन सशक्तिकरण विभाग, सामाजिक न्याय और अधिकारिता मंत्रालय, भारत सरकार द्वारा कम उम्र के दिव्यांग बच्चों (0-6) के सुदृढ़ भविष्य बनाने के लिए शीघ्र हस्तक्षेप केंद्र (EICs) शुरू करने की परिकल्पना की गई है। इन केंद्रों का उद्देश्य ऐसे क्रॉस-डिसेबिलिटी और समग्र बहु-कार्यात्मक सुविधायुक्त चिकित्सीय हस्तक्षेप प्रदान करना है जिसके द्वारा दिव्यांगता के बोझ को कम किया जा सके और माता-पिता के लिए एक ही छत के नीचे का उंसलिंग का सुविधा भी प्रदान किया जा सके। साथ ही साथ, समावेशी शिक्षा के लिए 'स्कूल सहजता' हेतु बच्चे को तैयार किया जा सके।

प्रतिकचिन्ह (logo) के बारे में: प्रतीकचिन्ह (logo) में अक्षर 'e' और 'i' अंग्रेजी शब्द 'Early Intervention' है जिसमे पहला दो अंग्रेजी छोटे अक्षर शीघ्र हस्तक्षेप को दर्शाता है और इसमें कई दिव्यांगता की पहचान भी शामिल है। चूंकि जन्म से लेकर 6 साल की उम्र बच्चों के शारीरिक और संज्ञानात्मक बौद्धिक विकास के लिए एक महत्वपूर्ण चरण होता है और यह परिपक्वता की प्रक्रिया और पर्यावरण के पारस्परिक क्रिया द्वारा होता है, इसलिए इस प्रतिक चिन्ह में बिंदु को सर या मस्तिष्क के स्वरुप में दर्शाया गया है। सर या मस्तिष्क से उभरनेवाली हरे रंग की किरणें को विभिन्न संज्ञानात्मक (ज्ञान सम्बन्धी) कौशल, जैसे कि आलोचनात्मक सोच, समस्या का समाधान, आदि के विकास को दर्शाती हैं। इसके अलावा, इन दिव्यांग बच्चों को उनके माता-पिता और प्रोफेशनल के द्व ारा उनके आसपास के परिस्थिति के बारे सजग कराते रहना हस्तक्षेप का एक महत्वपूर्ण पहलू है। तदनुसार, प्रतिक चिन्ह में दोहरे पत्तों के द्वारा देख भाल करने वाले हांथों तथा माता-पिता एवं प्रोफेशनल की सामान भागीदारी को दर्शाया गया है, जो दिव्यांग बच्चे के निरंतर विकास के लिए आवश्यक हैं। शीघ्र हस्त क्षेप केंद्रों/ अर्ली इंटरवेंशन सेंटर्स (EICs) की परिकल्पना एक छत के नीचे दिव्यांग बच्चों के लिए हस्तक्षेप की सभी सुविधाएं प्रदान करना है, इसलिए प्रतिक चिन्ह में नीले रंग का अर्धानृत जो की छत को दर्शाता है।

चूंकि सार्वभौमिक रूप से, नीला रंग लड़कों का और गुलाबी लड़कियों का प्रतिक है, इसलिए इन दोनों रंगों का उपयोग अक्षर 'e' और 'i' में लिंग समानता के चित्रण हेतु किया गया है। इन दोनों अक्षरों को झुकाव के साथ दिखाया गया है जो दिव्यांगता के सुंदर होने का सूक्ष्म संदेश देता है। केंद्र में पीला और नारंगी सूर्य की चमक को चित्रित करता है जो की समग्र क्रॉस दिव्यांगता केंद्रों के टैगलाइन 'shaping stronger futures' के अनुरूप है।

CONTENTS

1

Need for Early Intervention in Habilitation and Rehabilitation – A Government's Perspective

- K. Vikram Simha Rao
Director, DEPwD, MSJE, GoI

NIEPVD Dehradun: Early Intervention Centre

CRC Lucknow: Accessible Entrance to EIC

Background

Union Ministry of Health & Family Welfare, way back in February 2013, launched Child Health Screening and Early Intervention Services initiative under the umbrella of the then National Rural Health Mission (NRHM) to provide targeted, comprehensive care to children aged 0-18 years. The programme identified 30 health conditions for screening and management including birth defects like clubfoot, cleft lip, congenital heart disease, and deficiency conditions like anemia, goitre, rickets, developmental delays and certain childhood diseases like rheumatic heart disease, otitis media and dental caries.

The screening is implemented at various levels by facility-based screening for newborns at health facilities (public sector) and for home deliveries by Accredited Social Health Activists (ASHAs). Special teams undertake at least twice-yearly visits to anganwadi centres (centres in villages that provide basic health care) to screen children aged 6 weeks to 6 years, and, atleast once a year, they visit all Government and Government-aided schools to screen children in the age group of 06-18 years. The children identified as requiring further management are referred to District Early Intervention Centres (DEIC) for confirmation of their diagnosis and further care.

The programme depends on strengthening of three pillars:

i. Recruitment of human resources and their capacity building;

ii. Supply of logistics, training manually, equipment;

iii. Information, education and communication, including behavior – change communication.

This National Mission deserves appreciation for three reasons:

(a) A step in the right direction to focus on early life of children related to health conditions and possible interventions.

(b) Setting up of an institutional mechanism of DEIC.

(c) Mission-mode approach by both Centre and States to handle the issue.

Importance of Early Intervention

However, neither the aspects of disability reduction, prevention, and rehabilitation are dealt in the above national mission, nor is there any separate national programme to deal with the issue. Ignoring children with disabilities in the growing stage of life will result in higher costs in all forms including economically, physically, and socially for the individual, family and the community.

A number of disabilities can be prevented, eliminated and their degree of disability reduced if there is an institutional mechanism to screen, detect and intervene with possible solutions at the right time. 0-6 years of age is considered to be the crucial period of physical, sensory, cognitive and behavioral development. Timely support will also help them to acquire learning skills needed for inclusive educational set-up.

2. The awareness of importance of early intervention in children for habilitation and rehabilitation and the knowledge of various methods that are available in this regard have not yet seeped into the psyche of the general community and the Governmental agencies. United Nations Convention on the Rights of Persons with Disabilities to which India is a party has emphasised, *habilitation and rehabilitation* which enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life. Different disabilities have varying characteristics and require multiple types of interventions – medical and non-medical. Due to improving technologies and research, non-medical interventions are gaining ground. The focus is now on rehabilitative, therapeutic and psychological interventions. Now professional rehabilitation manpower is available to meet these demands.

3. 'Habilitation' refers to a process aimed at helping persons with disabilities attain, keep, or improve skills and functioning for daily living. Its services include physical, occupational and speech- language therapy, various treatments related to pain management and audiology, and other services that are offered in both hospital and outpatient locations. And 'Rehabilitation' refers to regaining skills, ability or knowledge that may have been lost or compromised as a result of acquiring a disability, or due to a change in one's disability orcircumstances.

Mandate of RPwD Act, 2016

4. The Department of Empowerment of Persons with Disabilities (DEPwD) in the Government of India is primarily focusing on the issues related to disability, rehabilitation and empowerment. It administers the principal disability law namely, the Rights of Persons with Disabilities Act, 2016 (RPwD Act). It guarantees several basic rights as are available to persons without disabilities, and also entitlements which help them in participating equally with others. Section 25 of the RPwD Act, 2016 deals with healthcare for persons with disabilities. It mandates the appropriate Government and the local authorities to take measures and make schemes or programmes to promote healthcare and prevent the occurrence of disabilities by the following ways:-

a) undertake or cause to be undertaken surveys, investigations and research concerning the cause of occurrence of disabilities;

b) promote various methods for preventing disabilities;

c) screen all the children at least once in a year for the purpose of identifying *at-risk cases*;

d) provide facilities for training to the staff at the primary health centres;

e) sponsor or cause to be sponsored awareness campaigns and disseminate or cause to be disseminated information for general hygiene, health and sanitation;

f) take measures for pre-natal, perinatal and post-natal care of mother andchild;

g) educate the public through the pre-schools, schools, primary health centres, village level workers and anganwadi workers;

h) create awareness amongst the masses through television, radio and other mass media on the causes of disabilities and the preventive measures to beadopted;

i) healthcare during the time of natural disasters and other situations of risk;

j) essential medical facilities for life saving emergency treatment and procedures; and

k) sexual and reproductive healthcare especially for women with disabilities.

Initial Steps Taken

5. As an initial step in this direction, on 4th June 2019, the Union Minister of Social Justice & Empowerment wrote a letter to the Union Minister of Women and Child Development highlighting the importance of identification of disabilities among children at the early growing stages which can result in timely treatment/rehabilitation and social inclusion. In response, the Union Ministry of Women and Child Development issued a directive on 2nd September 2019 to all its Directors in charge of Anganwadi Services in all States/UTs to take necessary steps in identifying the early cases of disabilities among children at the wide network of Anganwadi centres in coordination with the District Early Intervention Centres (DEICs) (**Annexure A**). DEPwD followed it up by writing to the Principal Secretaries relating to empowerment of persons with disabilities in the States/UTs on 11th November 2019 (**Annexure B**).

6. But the Department felt that a national level programme covering all States/UTs can be the best solution for providing early intervention services through an institutional mechanism supported by resources – human, financial and technical. Attempts were made to draft a national programme in the matter. While conceptualising the same, it was opined that if model Early Intervention Centres (EICs) are created encompassing all 21 disabilities with various types of therapies, interventions, manpower and protocols, then the State Government machineries at the State and District levels would appreciate its importance and learn as to how such services can be delivered.

Creating Model EICs

7. So, to begin with, the Department thought of creating such model EICs on its own home turf. On 30th October 2019, the Department wrote to the Directors of 7 National Institutes (NIs) and In-charges of Composite Regional Centres (CRCs) functioning under NIs to establish early identification and intervention unit alongwith preparatory school for cross-disabilities in their Institute/Centre by March, 2020 (**Annexure C**). Salient features of such proposed units are stated below:-

a) The unit should have enough space for providing facilities in separate rooms, including:
   - Physiotherapy
   - Occupational therapy
   - Speech and Language Therapy
   - Counselling/ Behavioural Support
   - Family Education & Training
   - Preparatory School
   - Waiting Hall and Paediatric Centre

b) The layout of the unit may be aligned at the ground floor (preferably) or first floor with accessible features so as to ensure seamless movement of children with disabilities availing different facilities mentioned at point (a) above.

c) The ambience of the unit should be designed with appropriate pictorial and aesthetic presentation to make the unit attractive for children, and

d) Proper sunlight and circulation of air needs to be ensured.

8. NIEPMD, Chennai has been designated as a mentor organisation for the project. It took some time for the NIs/CRCs to understand the proposal. Presently, each NI is specializing in a particular disability. It does not have any expertise in work relating to other disabilities. Though CRCs are involved in cross disabilities, overall the disabilities covered conventionally are physical disabilities like locomotor, hearing and visual. Services as to the intellectual and developmental disabilities are less in quantum in these Institutes/Centres.

9. As a part of sensitization, the officers of DEPwD visited various NIs, inspected the existing facilities and resources, and advised them how to initiate the process. They were also told to share knowledge and expertise with each other in respect to their disability domain. Interaction is facilitated through video-conferencing and WhatsApp mode. In order to create a uniform network, in December 2019, with the help of NIEPMD, Chennai, a "Model Project Proposal for establishment of Cross-disability Early Identification Centre in NIs and CRCs"

was prepared and circulated to them (**Annexure D**). It contains detailed requirements of manpower, infrastructure and equipment, and also various facilities that should be made available for the beneficiaries.

10. NIs and CRCs took this new assignment seriously, prepared their plans, and got funds sanctioned by their governing bodies. They have started implementing the project. Wherever there was civil works component in NIs/CRCs, DEPwD took up with DG, CPWD to ensure that such civil works are taken up on priority. Due to lockdown owing to COVID pandemic, the deadline of March, 2020 could not be adhered to. NIs/CRCs were requested to be cautious in restarting civil works by keeping in mind the health safety of construction workers and their family members during the lockdown.

11. During the lockdown period, NIs/CRCs continued planning, purchase of equipment and other activities. They focused on three important issues:

(a) Preparation of detailed protocol of client management from the stage of registration to evaluation, course of treatment and its completion

(b) Development of digital registration software and MIS and

(c) Finalisation of wall posters, background colour of the rooms, and overall ambience of the centres.

Way Forward

12. Present focus is on setting up of EIC in 7 NIs and 7 CRCs. In the next phase, remaining CRCs will be covered. This initiative of the Department is only a baby step and yet an important step towards undertaking a long journey. The aim is to make such facilities available at the doorstep of every family, every parent and every child. Following measures will help in achieving this larger goal:-

(a) Every Government District Hospital should have an EIC alongside DEICs.

(b) EIC must be set up in every primary health centre and community health centres.

(c) Anganwadis and ASHA workers must be trained about EIC- and their availability in the neighbourhood areas.

(d) All pediatricians (Government/Private) in the States must be trained regarding EIC-cum-Preparatory School.

(e) Health, Women and Child and Social Welfare Departments in the State and at District level should work together in this direction.

(f) Parent training in basic knowledge in early intervention will help in creating strong community awareness.

(g) A national programme in this area needs to be formulated to provide necessary support to the States to achieve their sustainability in a mission-mode.

13. Availability of rehabilitation professionals, special educators, various therapies at single point will be a boon to the parents, family and the children. Once the community witnesses the best results of the proposed EICs in the near future, there will be a growing demand for such services. Stigma and discrimination due to disability will fade away when process of early intervention gains momentum to find effective solutions to the vexing problems of children with disabilities. It is expected that the capacity and strength of persons with disabilities will expand immensely to add to the nation's socio- economic development.

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2

Cross-Disability Early Intervention Centres: A Parent-Centric Approach

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NIEPID Secunderabad: Parent-Centric Consultation

CRC Nellore: Parent- & Child-Centric Hydrotherapy Room

Background

The critical importance of the first six years of life for the overall growth and cognitive and physical development of every child cannot be stressed enough. Evidence bears out that an early identification of 'at risk' cases and timely early intervention for those with disability, including habilitation and rehabilitation, is the key in reducing the overall disability burden.

Unfortunately, the diagnosis of various disabilities among children has been increasing, including those of Autism Spectrum Disorders, Muscular Dystrophy, Cerebral Palsy, Specific Learning Disabilities among several others. Consequent to the diagnosis by medical authorities, there is an urgent need for such children to be given proper and regular habilitation and rehabilitative care and therapeutic interventions by professionals.

However, parents of Children with Disabilities (CwDs) find it difficult to provide the same owing to several factors, including the absence of rehabilitation facilities at a primary level in hospitals and scarcity of rehabilitation specialists to cater to such vital needs.

Thus, to identify this gap and to acknowledge the urgent need in this regard, the Department of Empowerment of Persons with Disabilities (DEPwD), Ministry of Social Justice and Empowerment, Government of India after doing due diligence with experts and professionals in the field, has decided that providing for and establishing Early Intervention Centres (EICs) across India is of critical and paramount importance and need of the hour.

Accordingly, DEPwD conceived the EICs with a cross-disability focus being established as contiguous units for providing rehabilitative services for children with various types of the disabilities. To begin with, seven National Institutes (NIs) were selected for establishing such cross-disability EICs. This was done, notwithstanding the fact that the NIs currently have mainly a single-disability focus, be it for locomotor disabilities at NILD (Kolkata), PDUNIPPD (New Delhi) and SVNIRTAR (Cuttack); for visual impairment at NIEPVD (Dehradun); speech and hearing impairment at AYJNISHD (Mumbai); intellectual disabilities at NIEPID (Secunderabad) and multiple disabilities at NIEPMD (Chennai).

A conscious decision was taken that being NIs of the Government of India, these institutions should be ready to take the lead in providing cross-disability care and rehab services for the 0- to 6-year age group. Simultaneously, seven Composite Regional Centres (CRCs) located at Lucknow, Sundernagar, Rajnandgaon, Patna, Kozhikode, Bhopal and Nellore were also shortlisted for setting up the EICs. Thus, in all, a total of 14 EICs were decided to be set up in Phase-I as a pilot before spreading similar Centres across other CRCs and eventually across all districts of India to be explored through DEPwD's District Disability Rehabilitation Centres (DDRCs).

A PARENT-CENTRIC APPROACH: THE PHILOSOPHY

The focus of this paper is to highlight how these EICs were conceived from a point of view of having a Parent-centric Approach. The reason for choosing this approach stem from the realisation that parents of infants born with disabilities or of children who are identified as 'at risk' for developmental delays experience several challenges. Such parents are often known to be gripped variously with emotional stresses and psychological trauma, mental issues related to depression, anger, guilt, distress, fear, denial, non-acceptance, sense of helplessness, self-isolation or seclusion, hiding the disability, and even suicidal tendencies among several other manifestations.

Apart from these facets, parents and the family of such children are often faced with other profound negative effects that may have a bearing on their lives and lifestyles. These include demands on their physical and emotional self, time and financial costs as well as issues of sheer logistical complexities depending on the type, condition and severity of the disability of their child.

Also, one should not forget the shattering of the dreams of parents (many being first-time parents) of how their lives would be post welcoming their new born "bundle of joy" which every child is to her/his parents. The relationships within the family, with siblings of the child have also been known to get affected due to the changed dynamics at home, including on account of giving more attention to the child with disability.

Coupled with such personal trauma faced by the family members, parents also have the added

responsibility of enhanced care and attention that needs to be given to the CwDs, their medical and therapeutic needs and regular check-ups, and extra financial burden in the form of medical expenses and employing care-givers. Besides, one of the parents may have to even give up their profession/economic engagement to take care of the child thereby sacrificing their own personal ambitions and financial independence, leading also to a reduction in the income of the household.

Such circumstances are naturally a cause of anxiety and deep anguish for parents who struggle to divide their time and attention, which is often already over-stretched, between the basic necessity of earning a living and looking after the requirements of the regular medical and rehabilitation protocols that CwDs need.

Sadly, harsh practical realities often push the parents to devote more time to earn a living – a decision that is often forced also on the account that medical and rehab services not being available as required. More often than not, parents do not even have access to information regarding the necessity of early identification of the disability, its early intervention thereafter, as well as of the knowledge about medical and rehabilitation facilities and their availability, especially in their close proximity. These factors often prove as obstacles in mitigating the damage that such disabilities may cause which could otherwise be addressed through appropriate and timely intervention by professionals.

PARENTS AS CUSTOMERS: THE CONCEPTUALISATION

Acknowledging and identifying such gaps that come in the way of early identification and intervention, as understood from experts as well as parents themselves, it was decided that the EICs that are being developed would be made with a parent-centric approach. Taking a terminology and concept from the world of management sciences, Team EIC was tasked to treat a PARENT AS A CUSTOMER, thereby focussing attention on parents - their needs, wants and expectations.

First and foremost, the parents had to know about the facility of an EIC and had to be convinced of its efficacy in terms of being able to help and benefit their child with disability or at risk of

disability. This would prompt the parents to start getting CwD to the EICs. Parents had to be told and shown how their child's future could become stronger once they came to these EICs, be it in terms of reduction of the disability burden or making the child more self-reliant or independent in doing activities.

Once that is achieved and parents, too, feel cared for at such EICs, the case-loads of those seeking early intervention for their children in the age group of 0-6 years is expected to increase through word-of-mouth or through other means. Team EIC at DEPwD, the NIs and CRCs are confident that once the parents decide to get their children to the EICs, the specialists, professionals and personnel providing the required rehabilitation care would be able to make a difference in the lives of such children by giving them the required interventions and rehabilitation protocols for different disabilities.

For this purpose, the new approach given to Team EIC was to be sensitive and to think from the point of view of what would parents like an EIC to be equipped with that would persuade, motivate and inspire them to willingly bring their child to these Centres. In fact, the focus was on what would parents look forward to their visit and not be pushed away or to give up on the therapy required for their child. It was felt that once the parents brought the CwDs to the EICs, the battle was already half won since it is persuasive enough that regular therapy is known to bring positive changes in the child's life and reduce the disability, depending on the type, nature and severity of the disability and their individual responses.

PARENT FOCUSSED INITIATIVES: A PRIORITY

In light of above considerations, the planning and conceptualisation of the EICs was done by keeping the parents and their needs as the primary focus. The initiatives taken towards this direction have been delineated below to give an idea of the nature and thought given to make these EICs sensitive to parents' requirements. For sake of convenience, these initiatives have been categorised under three broad headings, namely – Accessibility, Aesthetics and Empowerment:

I. Accessibility

1. The first and foremost essential component consciously decided and implemented was to have, as far as possible, **a single contiguous cross-disability EI Centre; one which was under a single roof and on one floor, preferably the ground floor**. The thought behind it was to ensure that the parents coming to the EICs with their CwD should not be inconvenienced when they are required to move across several rooms and floors in order to meet different specialists, be it for Occupational Therapy, Physiotherapy, Speech Therapy, for meeting the audiologist, ophthalmologist, clinical psychologist, paediatrician, etc., or for that matter even for drinking water or using the washrooms. Thus, keeping in view the specific needs and multi-disciplinary facilities required for early intervention, a separate unit was conceptualised. This aspect, in a large measure, proved a huge challenge given that these are mostly old buildings in NIs and CRCs where a lot of re-adjustments had to be made to shift old established sections/divisions/work-stations/spaces and to retrofit the same. However, given the crucial significance of such a parent-centric cross-disability approach at EICs, this was given priority by all Centres by making sincere efforts to try and accommodate this requirement.

2. It was decided to **make the place equipped with accessible features keeping in mind reasonable accommodation and, to the extent possible, undertake retro-fitment to provide accessible infrastructure at the EICs**. Provisions were accordingly made for features like accessible parking, accessible access routes, ramps, accessible reception counters and corridors, accessible toilets and drinking water points, staircases, elevators, tactile guiding and warning tiles as well as appropriate instructional and directional signage at all EICs. Providing features of accessibility in the buildings was crucial for facilitating ease of movement of parents accompanying the child with disability to move around the entire facility.

3. Given the fact that these EICs cater to infants, special care was given to spaces being prepared **to provide privacy to nursing mothers for feeding their infants**.

4. All NIs and CRCs have been asked to **spread information about the EICs at the paediatric**

wings in the hospitals as well as in the primary health units in the catchment area so that cases of CwDs can be referred to these new facilities being set up. This would help the parents being informed by ASHA and Anganwadi workers, nurses, paediatricians and doctors about the rehabilitation services that their child may be in need of.

5. For parents' sake, it has been designed to have **information boards** placed at the reception/ waiting hall areas for sharing of information with the parents. Efforts are to be made to make these accessible.

II. Aesthetics

1. In order to try and reduce any discomfort and distress that young parents might experience upon witnessing the condition of adult persons with disabilities (PwDs) who visit the NIs/ CRCs for their own treatment or for availing OPD services, it **was decided to try and retrofit the buildings and identity spaces for these EICs in such a way that they have a separate entrance wherever possible** and not to merge it with the common entrance catering to all other PwDs. This feature was conceived to take care of any avoidable stress being added on the parents.

2. The EICs were conceived of also having **aesthetically designed waiting halls with appropriate furniture** for parents who accompany CwDs so that they have **proper, well-ventilated, airy, well-lit spaces** to wait their turn. Besides, provisions are designed to be made, preferably near the waiting area itself, **for the appropriate potable drinking water as well as tea/coffee/snack points** or in close proximity within the EICs to reduce the movement of parents within the complexes. Possibility is to be eventually also explore for CSR funding for such facilities. These could also be spaces for parents to get an opportunity to interact and share their own experiences with and learn from other parents.

3. Special attention was devoted to the design and conceptualisation of the **aesthetics of these EICs in order to be pleasing to the eye and to keep a warm and welcoming ambience**. All NIs and CRCs were instructed to give attention-to-detailing aspects related to the selection of the colour schemes and themes so that they are not too jarring to the

eyes, while at the same time being vibrant, playful, educative and attractive for the small children as well, including having tactile features and surfaces, wherever possible.

III. Empowerment

1. **Parental counselling sessions in the privacy of confined spaces** have also been well thought out at the EICs. This is a important part of taking care of the sensitivities of the parents while they discussed about their child's or their own personal issues with the counsellors/specialists.

2. Provisions have been made to eventually have **help desks** in all EICs to get **the child's UDID card registered** and offer guidance and assistance related to it.

3. In order to smoothen the **process of registration**, all EICs have been asked to **prepare seamless software** which would capture details of the child, right from the stage of initial screening. The records would be updated by all Departments/Specialists who handled a particular patient and record their findings into the same software such that all rehab professionals/personnel would be aware about all aspects about a child's treatment and trace the developments, improvements and milestones reached. Significantly, this software is being been made compatible for sharing data across 14 EICs to gain from the knowledge bank and expertise of specialists available across all NIs and CRCs. This is a significant feature, since so far, NIs mostly have disability specific specialisation. Hence, it was felt that having such a system in place would enable pooling of resources and knowledge-sharing that would greatly enhance learning across NIs and CRCs for dealing with cross-disabilities, a first in many ways. This facility would also help the patients in having all data and reports related to their children available across all centres, should the need arise.

4. **Counselling and training of parents** has also been conceived of painstakingly and built into the protocols prudently such that **they can be trained in the rehabilitation care that can be provided at home for their children or within the community**. The setup in each of these EICs of the Family Education and Training Resource Units, it is felt, would go a long way in making the parents and families learn about aspects related to parenting,

child management, clinical aspects, etc. Training related to Activities of Daily Living (ADL) would also be provided through one-to-one sessions as well as through the conduct of workshops/online videos and tutorials.

5. These EICs are expected to **eventually become state-of-the-art facilities dealing with cross disabilities** so that the parents could find solutions to their child's issues. The holistic early intervention services provided at the EICs would include trans-disciplinary therapy units, multi-sensory integration units, OT and PT units, speech therapy and language intervention units, play areas and sensory parks, BM and Counselling units too, apart from preparatory school services as well. The EICs will also be looking at delivering the latest technologies and innovations in the field, beginning with virtual reality rooms. Each EIC has been conceived to have **all required clinicians and rehab specialists**.

6. In line with the requirements of the Rights of Persons with Disabilities Act, 2016, for moving towards inclusive education, the EICs have also been tasked for **making provisions for preparatory schools for school-readiness of the CwDs upto the age of 6 years**. The attention given to aspects of education and learning of such children by the Special Teachers at the EICs would also help the parent to identify and learn about the requirements of the special needs of their child.

7. Given that parents often tend to neglect their own mental and emotional anxieties/stresses amidst their whole-hearted focus and single-minded attention on their child's well-being, it was also decided that, wherever possible, arrangements should be made to have the **parents being attended to and counselled by psychiatrists/clinical psychologists** for their personal mental and emotional traumas/issues as well. Thus, providing such a facility at the EICs could prove beneficial for the personal wellbeing of parents who, in any case, would be visiting the EICs for their children's sake.

8. **Stress has been laid on staff/personnel to be adequately trained to deal with parents politely and to try and empathize with their state of mind**. The rationale behind this being that ultimately it is the human touch that defines the quality of services rendered and the impressions that people carry, no matter how good and state-of-the-art the infrastructure and facilities that one might provide for the rehab therapies.

9. Given the fact that parents might have to travel long distances from other states/cities/districts/towns/villages, with requirements of them having to even stay for long periods in the cities where the EICs are situated, **possibilities to be explored subsequently for CSR funding for travel grants and/or of transport facilities from relatively near-by places**. Such CSR funding could also be envisioned for **mess as well as boarding and lodging** since on many occasions, only the mothers accompany the child and they have to stay alone in the city. This makes their provisioning of foods and essentials not only inconvenient, cumbersome but also very difficult being a lone mother with a child with disability in a new unknown place. There could be, thus, tie-ups also explored also for **reasonable, affordable, healthy and nutritious meals through tiffin services, plus** certain basic essentials for such parents (both in-station and out-station) during their visits to the EICs, possibly also through the CSR route.

BUILDING STRONGER FUTURES

With the above conceptualisation of a parent-friendly approach at cross disability Early Intervention Centres, the basic endeavour is to ensure that children with disabilities who are brought to these Centres regularly by their parents for the required habitation and rehabilitation therapeutic interventions begin showing improvement. This is the children's right and our responsibility. These efforts are expected to ultimately help build stronger futures for not only the children with disabilities, but also for the parents, the family, the entire community, and thereby, of the nation as a whole.

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3

Ensuring Quality Control in an Early Intervention Centre

- Dr. Himangshu Das
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NIEPVD Dehradun: Standardised Occupational Therapy Room

NIEPVD Dehradun: Standardised Multi-Sensory Integration Room

NIEPVD Dehradun: Standardised Preparatory Classroom

NIEPVD Dehradun: Standardised Indoor Play Area

Early intervention is the essential foundation to the future health and well-being of children at risk, children with disabilities and their families; and its significance for the critical period of child's development can never be over-emphasized. The early years of child's life are key to predicting ultimate success in school and life; and exposure to positive, stimulating experiences develop their enhanced learning capabilities. Thus, it is vital to ensure quality control in an early intervention centre; which requires a detailed plunge into establishing a comprehensive value system in each organisation. This system must value that every child is precious and that early intervention is crucial to limit the impact of disability. Further, we must also acknowledge that each child has an economic impact on the family and the country; and in the long-run each Early Intervention Centre (EIC) must bring social and economic gains by reducing the burden of disability/diseases through awareness generation, improving professionalism in service delivery and empowering the parents and the community.

Creating an empathetic environment in the organisation, team building and development of faculty competence in early intervention is indispensable for success of any programme. Further, providing a nurturing and enriching atmosphere along with an infrastructure that is accessible to the child helps instil hope in the parents and the family. And, building a collective grit in the child, parent and the organisation as a triad towards optimal and holistic development in the child helps in inclusion.

To ensure the quality control at an early intervention centre, the work domains can primarily be distributed into the phases of (i) getting started; (ii) initiation of services; (iii) strengthening of services; (iv) continuing quality of service delivery; and (v) planning for transition. The article below details the areas and key considerations at each of these phases that will help an early intervention centre to maintain and ensure quality control of services. Readers may note that the article doesn't intend to cover details of discipline-specific SOPs and strategies in Early Intervention Centres.

Getting Started

For any early intervention to begin, it is critical that the service provider takes community-

based actions to increase social awareness about early intervention for children with disabilities. Promoting community awareness and non-discriminatory social attitudes is necessary for inclusion of children with disabilities and their families. Further, it also helps assist in the identification of resources for referrals in the community.

During the first appointment and initial consultation; it is necessary to maintain the client record that will provide both quantitative and qualitative data regarding the children and their enrolment. The family's appointment must be flexibly scheduled in order to facilitate parents' or caregivers' participation. The norms and policies for fee/charges, capping of individual session and ratio & parameters for group therapy must transparently be maintained at the organisation. Observing safety requirements, hygiene, fire, electricity,

housekeeping, security, CCTV monitoring and overall school environment conditions must be in accordance to the highest standard.

Promotion of least restrictive environment training of caregiving and support staff helps promote elimination of barriers and appropriate arrangements for the child. Additionally, enhancing morale, decreasing stress, helping parents to express their feelings and other support services to parents/family must also be kept in mind. In order to maintain an environment of dignity, respect and hope, it is important to ensure that everyone uses person-first language while addressing children with disabilities. Further, the understanding of disability etiquettes can help human resources, parents and family members to gain empathy and positive attitudes.

Moreover, the Early Intervention Centre must take responsibility to provide possible avenues for availing super-specialty services like genetic counselling, neurology, neuro-surgery, ortho-surgery, ENT, ophthalmic surgery, cochlear implant, syndrome-specific experts, etc.

Initiating Services

Admission or enrolment of a child to early intervention services must begin with a welcome interview, where the family's needs and demands are considered in their own words. Services must be fully respectful with family's beliefs, cultural practices or privacy requirements. And a

model of services that is broken down into sectors/domains of intervention and is decentralised must be supported. The case-work methodology for service provision may be customised as per the need of the child through approaches of inter-disciplinary, trans-disciplinary or early childhood special education.

The child's assessment aims to gather relevant information about personal history and relevant events (health & relations), main caregivers, risk factors, concerns shown in daily routines etc. Further, assessment of family must be aimed to gather relevant information about their needs and concerns, parenting and upbringing practices, family history, internal and external relations, etc. Additionally, environmental assessment of home must be done to gather relevant information about family habitat and circumstances, family members, resources available and involved in child development, risk factors, etc. Necessary undertakings and informed consent must be collected beforehand from the family for the purpose of emergency healthcare, outings, parental responsibilities, audio/video recording, use or records for print and media purposes, etc.

Assessment procedures must include relevant professionals to evaluate child's records, child observation and administration of criterion-referenced tools; alongwith identifying the needs of the child, the family and the environment, as it will help chalk out the Individual Family Support Plan (IFSP). The Early Intervention Centre must develop requisite formats and software for collecting and gathering information about the child and the inter-disciplinary and trans-disciplinary assessment as per the child's context of life.

Considering the news of diagnosis and prognosis of the child, providing unacceptable news to the parents, it becomes essential that the information is offered in an appropriate manner. It is essential to always address the child by her/his first name as it is the simplest

way of underlining the fact that the child is their daughter/son over and above any other consideration. Also, it is essential to provide them all possible professional opinions, address their queries and offer a chain of continuity for guidance/assistance.

Establishing an Advisory Board for Early Intervention Centres to lay out the protocols, norms and policies for services must be the first step towards establishment of services. A system and practices must be framed for guaranteeing confidentiality, systematization, teamwork dynamics, transferring of knowledge to stakeholders, evaluating programme outcomes, evaluation of family's satisfaction, promotion of early intervention training, encouraging research, etc. Also, procedures and practices for day-to-day record-keeping, case-history, meeting reports, case appointment scheduling/re-scheduling protocols, case transfer, homework for child, homework for parents, holiday work, etc. must be framed and made known to the concerned professionals.

Strengthening Services

Monitoring of current programmes as per the set targets and the evaluation of overall results by the experts to provide guidance, motivation and leadership is necessary for every Early Intervention Centre. It can help promote professional awareness regarding the mission, aims, programmes and teamwork in the early intervention services.

Instituting a Parent Advisory Board together relevant feedback and information about human and material resources, organisational charts, target population, parent satisfaction rating, and other aspects of service delivery is key to keep a check on quality control of the services. Further, it can assist in identifying areas for parent training, family involvement, facilitate home visits and help offer interventions needed for parental mental health-related issues. Having available a structure of directions and administration, a clear definition of roles and work procedures, staff with adequate training for facilitating slot adjustment (in case of session cancellation or ensuring activity engagement), evolving parents as therapy assistants, engaging parents in group/individual sessions during free time at the centre, temporary handing over of client, permanent handing over of client, or dealing with long-absence of client or other; buddy & peer support building etc. can improve the efficacy and impact of services offered to the clients.

Parent partnership and active family involvement helps not only in giving support through the coping and acceptance process, but also facilitates stability in upbringing practices; delivering

services in natural settings; reorganisation of family routines; providing resources; information and orientation as per need; sibling-training; assisting in home-based management of plans, positive behaviour support, monitoring child's screen time; and helps keep the focus on enhancing the transfer of learning by the child. This parent-professional partnership must also help facilitating resources to build up social relationships by means of self-help groups, parent associations, sibling networks, etc. that is targeted for empowerment and building esteem in the child and the parent.

Programmes and standardised practices for behaviour management at home and the Early Intervention Centre, administration of drugs, management of medical emergency, handling of fragile children, containing communicable diseases, management of children with high-support

need, increasing the sense of happiness and well-being of children and parents, process of identifying cases requiring urgent and immediate intervention etc. must be put in place to ensure efficient and transparent management of services.

Implementing trans-disciplinary intervention through a multi-disciplinary team that shares information and role-specific responsibilities can not only help offer understanding of the comprehensive needs of the child, the family and the environment, but also help determine a detailed educational, therapy plan and an IFSP customised to the needs of the child/family. Also, according to their needs, all children with disabilities or at-risk must receive developmentally appropriate aids (education, technical or therapeutic aids) in order to strengthen their autonomy. Furthermore, appropriate experiential learning opportunities and exposure for enhancement of skill generalization must be ensured during service delivery.

Preparation of an annual plan of action, specifying aims and methods for centre-based events/ activities, community activities, training and research must be practiced as it will ensure that the centre and those associated with it recognise and conceptualise the preciousness of the developmental period. It will also help facilitate and incorporate services for children at-risk of developmental delays/disabilities by means of awareness generation and early identification.

Continuing Quality of Service Delivery

Organisation of standards, good practices and maintaining simplicity within the evaluation procedures is essential for conducting and reporting evaluation of outcomes for the early intervention programme for each child. Further, designing a self-evaluation form to facilitate the monitoring/analysis of current practices and simultaneous reworking of new aims and action plans. Moreover, carrying out inspection and evaluation by external experts/authorities can help facilitate social audit, review of staff productivity and also monitoring quality of programmes and services.

Developing easy-to-use formats for documenting performances, for expressing or measuring the effect of intervention, for transferring practices of regular procedures, for observing the dynamics of child, for awareness of family's satisfaction or for gathering information to enable understanding by the team members, parents and the administration. Unifying case records from the trans-disciplinary team, and generation of individual, monthly, quarterly and annual reports for the client should be formalized with regular record-keeping system. Additionally, maintaining records of medical examination, health check-up reports, and other documents of the child like disability certificate, medical history, demographic data, etc. must be orderly stored.

Encouraging professional training through faculty development programmes and maintaining up-to-date records of staff qualification, curriculum vitae and professional development is of high significance. Having a long-term development plan for staff training should cover both specific and wide-ranging topics related to child development, family dynamics, teamwork, community-based activities, etc. Allocating time to train on plans and professional development must be considered during work hours of the professionals.

Developing protocols for intern and visitor management, grievance redressal, respite care, crèche services, discontinuation or transfer of client, management of child sickness at the centre, and routines & procedures for sanitisation/disinfecting toys/equipment along with ensuring avoidance of toy/chemical hazards to the children must be kept at a high priority.

Also, approaches to support parents/family in customisation of nutrition for the child and help in moving towards generalisation should be another area of primacy.

Providing quality early intervention and fostering a developmentally appropriate home environment can have long-lasting benefits for the child, the family and the community as a whole. Thus, it is imperative to transform the child's home environment to early childhood education and therapy centre. Simultaneously, it is equally essential to ensure that both the institution and parents are focused to ensure community participation of the child to ensure sensitisation and training of all stakeholders.

Integrating good and best practices of professionals and other service delivery agencies are essential in order to achieve a greater level standardisation in Early Intervention Centre. And accordingly setting objectives, procedures and organisational processes can create a culture of early intervention that has a collective vision for inclusion and reverse-inclusion possibilities along with the informed assistance/support reduction & using fading to ensure sustained efforts from the parents/family. Further, integrating technology, robotics, artificial intelligence, apps, etc., integrating art-based therapies like dance, theatre, music, painting, pottery, etc., and also integrating universal design of learning that offers multiple means of engagement, action, expression and representation can help ensure quality early intervention services to the beneficiaries.

Planning for Transition

Supporting transition to pre-primary or primary schools is the principal objective of an early intervention programme. Protecting and supporting the child and parents/family during the transition period via means of a comprehensive transition plan, referral agencies, capacity building, facilitating networking is necessary to ensure child-readiness for mainstream school. Likewise, linking of early-childhood special curriculum to early childhood curriculum; implementing motor-assisted training programme and enrolling child into Special Olympics programmes; developing specific individual aptitude, creativity and strength; and creating a child profile help facilitate a smooth transition process.

The IFSP of the child must summarise the procedures designed to support learning experiences and smooth phased transitions to home and pre-primary/primary schools as per the needs of the child. This process must be planned in coordination with the available educational resources and may be assisted through inclusion of ICDS early childhood centres. Further, it is essential to track the child during and post transition; provide continued support and graded fading of support; and connect parents to other parents, support networks, self- help groups, cooperatives, and other stakeholders. During transition we must also focus on development of resilience, advocacy and self-advocacy skills in the parents/family.

For efficient transition, one must ensure to facilitate requisite documentation needed by the child i.e. the disability certificate or the certificate of high-support-needs, detailed assessment and evaluation report of the child; along with facilitation of concessions and benefits to the family. It is equally important that the Early Intervention Centre helps arrange the financial, legal and referral support to the family. This process can be aided through quality record keeping that demonstrates and provides anecdotes and seemingly insignificant developments/ deterioration of the child's progress with qualitative analytical input. Such strengthened documentation must also lead to published work by the Early Intervention Centre.

In order to focus on qualitative research and mandating each professional for publishing best practices, it is essential that the centre must formalise individual and collective responsibility of all to ensure stress-less and work-friendly environment for manpower. Further, it must be ensured that proper induction and volunteer management is conducted to elicit support to human resources in day-to-day functioning. This will not only help reduce the attrition of manpower and limit the attrition damage, but also assist in identification of trends and best practices for work satisfaction of the professionals.

To conclude, it is a highly professional, scientific and yet artistic endeavour to ensure quality control in an early intervention and early childhood special education centre. A detailed study of best practices globally though can form a basis, but the traditionally rooted wisdom and Indian experiences in management of early intervention services have to be fused in order to develop Standard Operating Procedures (SOPs) indigenous to the Indian context. Further, customisation

of the SOPs to suit the particular early intervention centre in reference to availability of resources, locality, customs, and populace variables have to be integrated to ensure dynamism and quality control of the early intervention centres.

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"Disabled people are not only the most deprived human beings in the developing world, they also are the most neglected" – Amartya Sen

4

The Transition from Medical Model to Social Model of Disability– The Composite Regional Centre Preparedness

- Dr. Roshan Bijlee K N
Director, CRC-Kozhikode

NIEPVD Dehradun: Paediatric Consultation Room

NIEPID Secunderabad: Collaborative Intervention between Child, Therapist & Attendant

Introduction

The 2011 census identifies that every tenth household in India has a person with some kind of disability. The census also estimates that 78,64,636 children of India are having disability which accounts to 1.7 percent of the country's entire pediatric population. The UNESCO 2019 'State of the Education Report for India: Children with Disabilities' observes that around three-quarter of the children with disabilities up to the age of five years and one-quarter between 5-19 years are deprived of institutional education. It is noteworthy that these figures are from an era of Persons with Disabilities (PWD) Act 1995, where the disability types were 7, as against the 21 disabilities of the Rights of Persons with Disabilities (RPWD) Act 2016, which is currently in vogue.

As the number of persons with disabilities is staggeringly increasing and the dearth of rehabilitation professionals becomes overtly evident, the best and effective long-term solution for disabilities is early identification and early intervention. It is estimated that around 10 percent of children are having developmental delay (Ghai, Gupta, & Paul, 2000).

Medical to Social Model of Disability – The Philosophical Framework of EIC

In developing countries, the number of disabilities getting identified at an early age and the number of children receiving the right comprehensive habilitation-rehabilitation therapies are less compared to developed countries. Thus, a situation of social inclusion thrives. Many a time, those cases which are being identified in medical settings are unfortunately not always being guided properly to a trans-disciplinary rehabilitation setting due to multi-factorial reasons. This is even viewed by some experts in the field as the inherent deficit of the medical model of disability, which gives focus principally on the person's 'individual problems'. Whereas, the social model of disability identifies systemic barriers, belittling attitudes, and social exclusion (intentional or inadvertent), which make it difficult or impossible for individuals with impairments to attain their valued functioning. The social model of disability diverges from the dominant medical model of disability, which is a functional analysis of the body as a machine to be fixed in order to conform to normative values. (Paley, 2002).

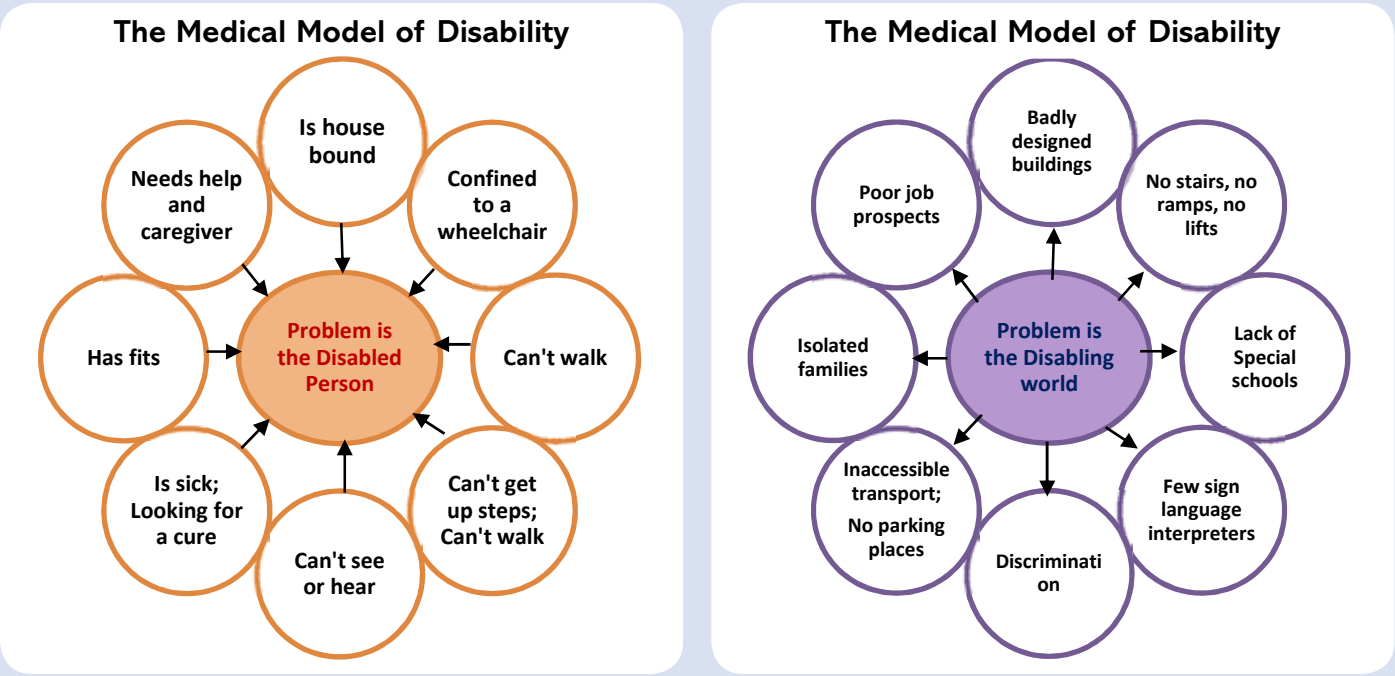


Figure 1- Medical and Social Models of Disability (Barbara Lisicki, 2015)

A system which facilitates the best of the model - a meticulous medical diagnostic approach in early identification and a well formulated social model approach in parent-centric rehabilitation therapies yields the ideal result. This exactly is what is envisaged through the Early Intervention Centres (EIC). The painstaking efforts at providing barrier-free access, caregiver-centric facilities, universal design and initiatives for attitudinal change are all indicators of the thrust given to the social model of disability.

The initial diagnosis and further therapies should be a continuum for which there should be a smooth passing of the baton between the medical and rehabilitation fraternities. Thus, the Child Health Screening and Early Intervention Services, under National Mission of Ministry of Health & Family Welfare need to be well fortified with the EIC component all across the nation to yield the best outcomes. The role of medical professionals becomes imperative here for initial assessment and diagnosis and to rule out any medical cause for the condition and to provide medical interventions, genetic counseling, etc. as required.

Early Intervention

As the saying goes – 'Catch them young'. A substantial number of disabilities can either be prevented, eradicated or the burden of disability reduced through early intervention. To define in simple terms, it is a process of integrated services which facilitates the kid's age-related growth and helps families in the vital initial years of development. Early intervention is done in children of up-to five years of age to facilitate their development, growth and learning who are having delayed developmental milestones or some form of such disabilities or children at risk owing to their environmental or biological causes. Early intervention focuses mainly on skills in these five areas: (1) Motor/Physical skills (2)Cognitive skills (3) Communication/language skills (4) Self-help/adaptive skills and (5) Social/emotional skills ("Physical Developmental Milestones by Age," n.d.).

The importance of early intervention:

In medical emergencies like heart attack and stroke, there is a dictum of 'golden hours'. It is the earliest timeframe by which a patient is to be taken up for an emergency medical intervention in order to salvage the organ fully. It is said that 'every second counts'. Similarly, a therapeutic intervention for a child with disability, if started at an early age, makes all the difference, especially for neuro-developmental disorders. The initial 3 years in the life of a child is very crucial for her/his overall development, growth and learning. The development of the brain influences the growth of a child in all domains.

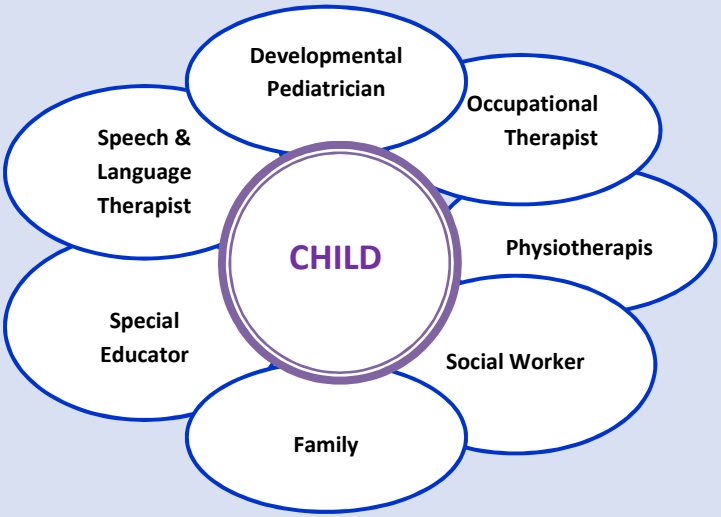
Researches indicate that size of a baby's brain, which is just about one fourth of a grown-up person, amazingly double in bulk in the initial 12 months. By around three years of age, the brain attains eighty percentage of size and by around five years, it becomes nearly fully grown – up to 90%. The neuronal circuitry and connections are growing at a very fast pace, compared to the entire lifespan - to the tune of up to a million novel neural circuitries per second. Hence, any effort at therapeutic intervention of such disabilities yields maximum result if started at a very early age, when the neurons are still pliable.

Trans-disciplinary approach:

Trans-disciplinary service is an accepted rehabilitation therapy system of our times. It is defined as "the sharing of roles across disciplinary boundaries so that communication, interaction, and cooperation are maximized among team members". This modality involves an obligation of each member in the team to learn teach and work jointly to impart harmonized services. A substantial result is the evolution of a shared goal or "shared meaning" between the members of the team and with members of family.

Trans-disciplinary team consists of professionals of different disciplines who are capable of influencing the developmental process of a child at risk through their respective professional expertise. This kind of service system has benefits in terms of service efficiency, cost-effectiveness, support to parents, more collaborative and coordinated intervention plans with a focus on overall development, and enhancement of therapists' knowledge and skills through structured team work.

Trans-disciplinary service



Here the child is addressed as a 'whole individual' and not as a 'particular disability'. It is akin to the folk tale of a group of visually impaired persons describing an elephant. Those who touched the tail said it is a broom stick, those who touched its leg told it is a pillar and so on, where as those who could see, said it is an elephant. Similarly, to cite an example, a child with autism might need the service of an occupational therapist to enhance his fine motor skills to improve hand writing or to enhance oro-motor muscles to assist in the deglutition problems. The same child would need physiotherapy to address gross motor skills to improve his balance issue. S/he may need speech therapy for improving the phonation problems and special education for curricular comprehension. Here these different therapists are not unrelated watertight entities.

Instead, all these multiple therapists are working in unison towards a single goal - the holistic improvement of the autism child.

Parents of Children with Special Needs (CwSN)– the unsung warriors:

"When I became a parent of a special needs child, nothing could prepare me for the emotional rollercoaster I would find myself on, a sea of ever changing emotions and quicksand I would step on every now and then that seemed to engulf me and I would feel like I was drowning. The worst part was I never knew if I should ask for help or just wish I would die" – This excerpt from the literature of Orla Kelly, a noted special needs parenting coach, enunciates the universal emotion of parents of children with special needs, across the globe irrespective of their nationality, caste, creed or socio demographics.

The presence of a child with disabilities changes the dynamics of a family forever. On the understanding of the diagnosis of their child, the parents pass through the initial psychological phases of denial, anger, fear, guilt, confusion, helplessness and disappointment. Further they arrive at a phase of acceptance. At times the long-term response can also be indifference or over-protection. Song et al. (2015) in their study indicated that parenting children with disabilities over a prolonged period of time affects cognitive functions, especially of the mothers. Bostrom and Broberg (2014) found in their study that mothers fail to strike a balance between their spousal duties and maternal responsibilities because of having to indulge in long periods of caretaking for a child with disability.

Many of the parents of CwSN are perplexed. They are in the dark as to how they can access the right therapeutic interventions for their child. It is here the primordial importance of the EIC emerges. EICs understand parents to the fullest. By providing the most welcoming ambience and the best therapeutic solutions, the EICs take the parents most comfortably along its stride. Thus, "the traditional service forms based on 'expert power' wielded by cohorts of unenlightened professionals", and compartmentalized consultant services, gives way to approaches based on facilitation and acknowledging the primacy and centrality of the service users – the parent's

requirements and necessities. The goal for the EIC team is to empathize with the parental perspective and thus to motivate them to avail regular services.

EICs – the CRC preparedness

Composite Regional Centre for Persons with Disabilities is serving persons with disabilities at various regions of the country, for more than two decades. As on date there are 21 CRCs.

Composite Regional Centres were established with the key objectives: to serve as the resource centre for rehabilitation; to undertake human resource development; to undertake public education programmes; to undertake services of education and skill development; to undertake research and development; to establish linkages to stimulate growth of services; to develop strategies for rehabilitation services; to undertake provision of aids and appliances, etc.

The nomenclature of CRCs was changed to 'Composite Regional Centre for Skill Development, Rehabilitation & Empowerment for Persons with Disabilities' in 2019.The basic structure of all CRCs comprises of the following departments / units:

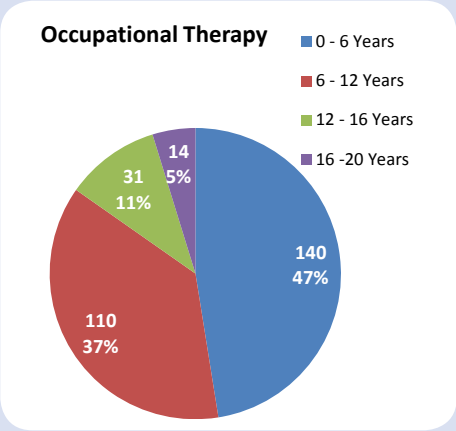
- Clinical Psychology
- Physiotherapy
- Speech & Language Pathology
- Prosthetic & Orthotic Unit
- Vocational Training & Rehabilitation Unit
- Occupational Therapy
- Physical Medicine & Rehabilitation
- Special Education
- Social Work & Placement Unit

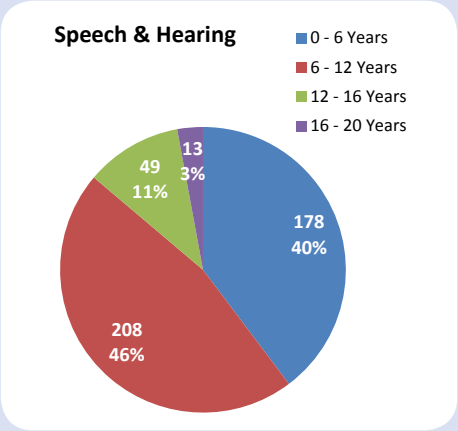
Hence the very basic infrastructure and human resource required to establish an elementary trans-disciplinary early intervention unit exists in CRCs. The scaling up of these resources with adequate provisions for exclusive space, accessibility, HR and infrastructure for child friendly ambience would enable CRCs to conductan ideal, full-fledged Early Intervention Centre, as envisaged by the project.

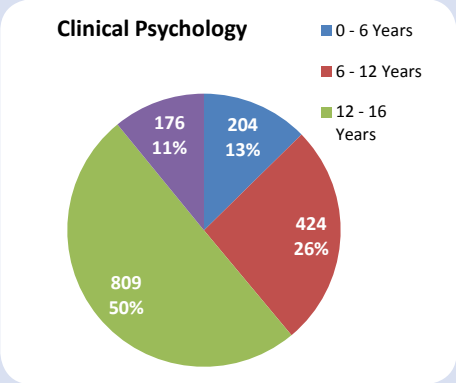
As the name indicates, CRCs are 'composite centres' catering to persons with disabilities of all ages and all disability types. One of the major components of activity of CRCs is clinical

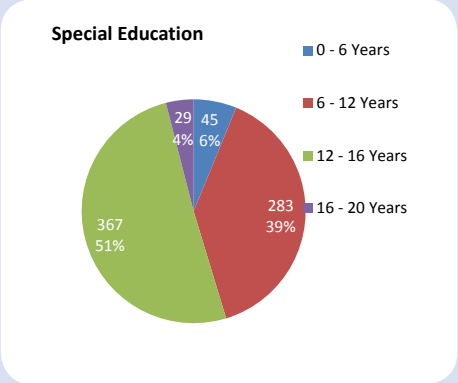
therapeutic services to persons with disabilities and children with special needs. Since CRCs are having departments like occupational therapy, speech therapy, special education, etc. whose beneficiaries are mainly children, majority of the clients attending CRCs, even otherwise belongs to the pediatric age group. For other departments as well, children form a sizable clientele. Hence, a considerable number of clients of CRCs by default are children belonging to the early intervention group.

The following are the age wise data of clients who availed therapy services from CRC Kozhikode, last year:







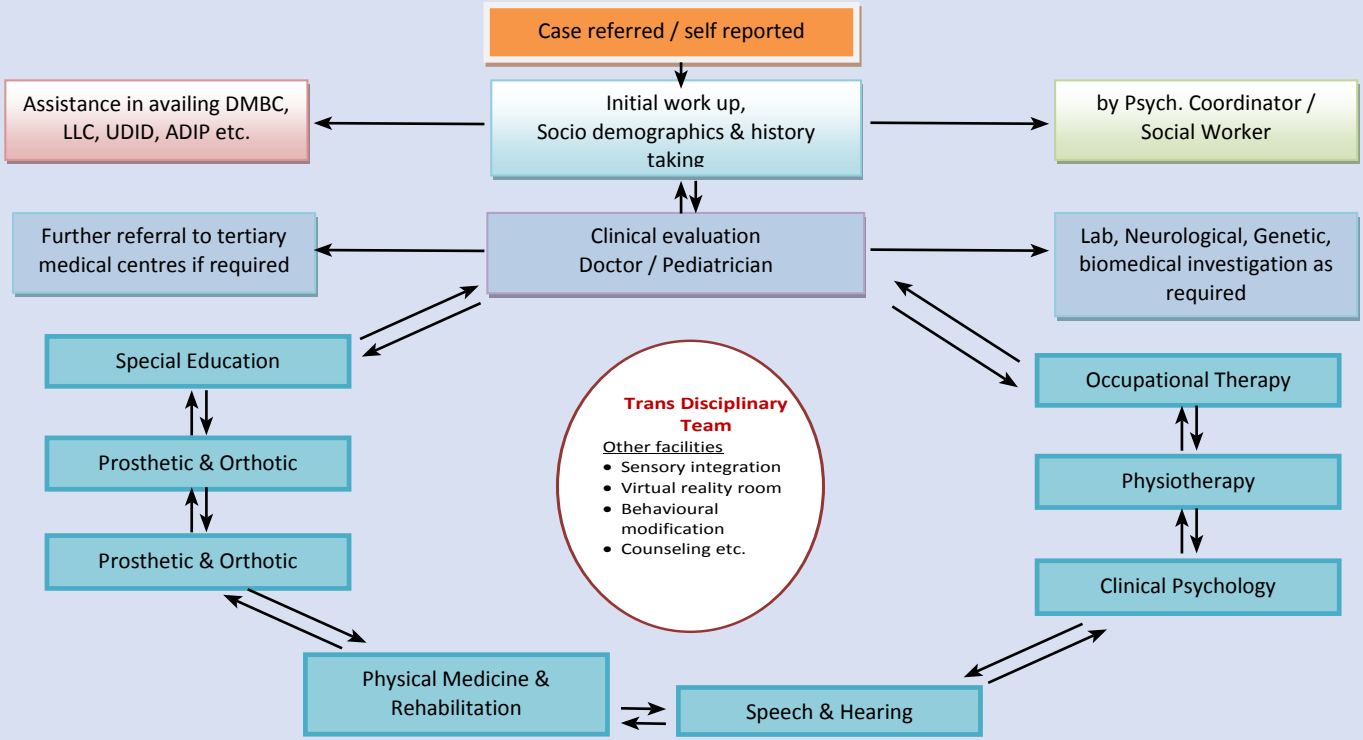


Thus, 47% clients of occupational therapy department were children of less than 6 years (84% upto 12 years). For speech and language pathology department it was 40% (86%

upto 12 years). These data may be generalized to other CRCs as well (with some variations). Hence, utilization of the facilities available at CRCs to the fullest without duplication of services and scaling up infrastructure, requisite manpower and offering exclusivity will equip CRCs to function as model Early Intervention Centers (EICs)

Services of the rehabilitation officer can be utilized for the assistance and guidance in disability related support systems like availing of Disability Medical Board Certificate (DMBC), Unique Disability Identity (UDID) cards, Local Level Committee (LLC: a district level committee to provide guardianship for persons with autism, cerebral palsy, mental retardation and multiple disabilities under National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act 1999), Assistance to Disabled Persons for Purchase / Fitting of Aids and Appliances (ADIP), disability pensions, State and Central Government schemes, etc.

MODUS OPERANDI OF EIC AT CRC



EICs and Disabilities under RPWD Act 2016 – way forward

The RPWD Act 2016 for the first time has incorporated diseases like haemophilia, thalassemia, sickle cell anaemia, etc, under its purview. Section 25 (2) b, c; Section 27 (1) etc. has vested upon the rehabilitation sector huge responsibilities with regard to the early identification and prevention of disabilities which includes these diseases as well. These hematological disorders are pediatric conditions which appears early in life.

Haemophilia: Registered hemophiliacs in India are only 16,000. Considering a frequency of one in 10,000 births for hemophilia, this is only 15% of the estimated figure. For India, an estimated 120,000 hemophiliacs are prevalent and around 1675 babies with hemophilia are born every year. These facts suggest that a majority of the patients are under-diagnosed in our country. Even if only a miniscule number of patients are diagnosed, just about 15% of the total receive some form of treatment. This poor access to treatment leads to the development of disabilities, as was seen in a study in 2007 where 94% of the PWH (People with Hemophilia) were suffering from disabilities and 76% of those in the productive age group of 18-26 years were unemployed.

Sickle cell disease: The defect here is that the red blood cell undergoes sickling when it is in a state of deoxygenation. The gene responsible for this condition is widely seen among many Indian tribal groups. The prevalence of the heterozygote type is upto 40%. High Performance Liquid Chromatography (HPLC) test is the widely usedscreening test in India. Solubility test is another cost effective test modality. Some states like Chhattisgarh, Maharashtra, Odisha, Gujarat, etc. have started newborn screening programmes for sickle cell disease. Scrutinizing the same will help in understanding the natural history of the disease in our country.

Thalassemia: This condition is considered the most common genetic disorder worldwide with approximately 3 percent of the population (about 150 million) carrying thalassemia genes. As of now, only few countries like Oman and Iran are maintaining thalassemia register for surveillance purposes.

If these conditions could be identified at a very early age and appropriate treatment/therapeutic/rehabilitation interventions administered without delay, the chances of these diseases leading to crippling disability conditions could be prevented to a great extent. Hence, efforts to liaison with comprehensive specialist medical care centers for the said diseases and specific programs to incorporate these diseases in the rehabilitation services, can also be taken up as the forthcoming plans of EIC.

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5

Sensitizing Stakeholders about Cross-Disability Early Intervention Centres

- Dr. Suni Mathew
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NIEPID Secunderabad: Sensitizing Stakeholders- Parents

Abstract

AYJNISHD (D) is in the process of establishing a cross-disability early identification and intervention centre for young Children with Disabilities (CwDs). It is a mammoth task requiring a collective effort of all its stakeholders, both internal and external. These valued collaborators need to be sensitized about their changing roles and responsibilities so as to realise the vision of the centre. The present article shares some of the efforts undertaken, especially in terms of capacity building of teachers and sensitising centres for a cross-disability approach with a broader aim to increase their accountability to ensure that 'No child with any disability is left behind'.

Every child has a right to be 'school readied'! Children born with severe-to-profound impairments or those who acquire it in their developmental stages also have a democratic right to learn and develop to their fullest potential. The first five years which are the sensitive years for the growth and development are also the most receptive years for children's cognitive growth and the socio-emotional foundations. The impairments in infants, if any, impede or create barriers resulting in developmental lags and, as a consequence, young children with disabilities do not get a chance to be readied for school.

Hence, early identification and intervention of disabilities holds the key for the holistic development of a young child with any type of impairment(s). While this gives the child a fair chance of to be 'included' in the mainstream school, the family and the society also reap the benefits as it helps to reduce the strain and demands on their resources.

The recently launched National Educational Policy (NEP) (2020) also envisions a cross-disability focus for children with disabilities and in fact, while emphasising foundational literacy, the policy is also suggestive that special teachers with a cross-disability focus must be engaged. The NEP (2020) also emphasises stakeholder involvement, especially the Aaganwadi workers and teachers, for Early Childhood Care and Education (ECCE) for addressing the needs of children at a young age in order to maximise the benefits.

AYJNISHD (D) while setting up the new cross-disability Early Intervention Centre (EIC) has initiated a number of activities that range from creating awareness to developing protocols and also pooling in evidence-based practices. Sensitising the stakeholders was also felt to be one of the crucial activities to ensure that no child with any type of disability or difficulty is left behind. This is because timely and informed communication across all disciplines and involving key stakeholders is the said to be the key to the successful project delivery.

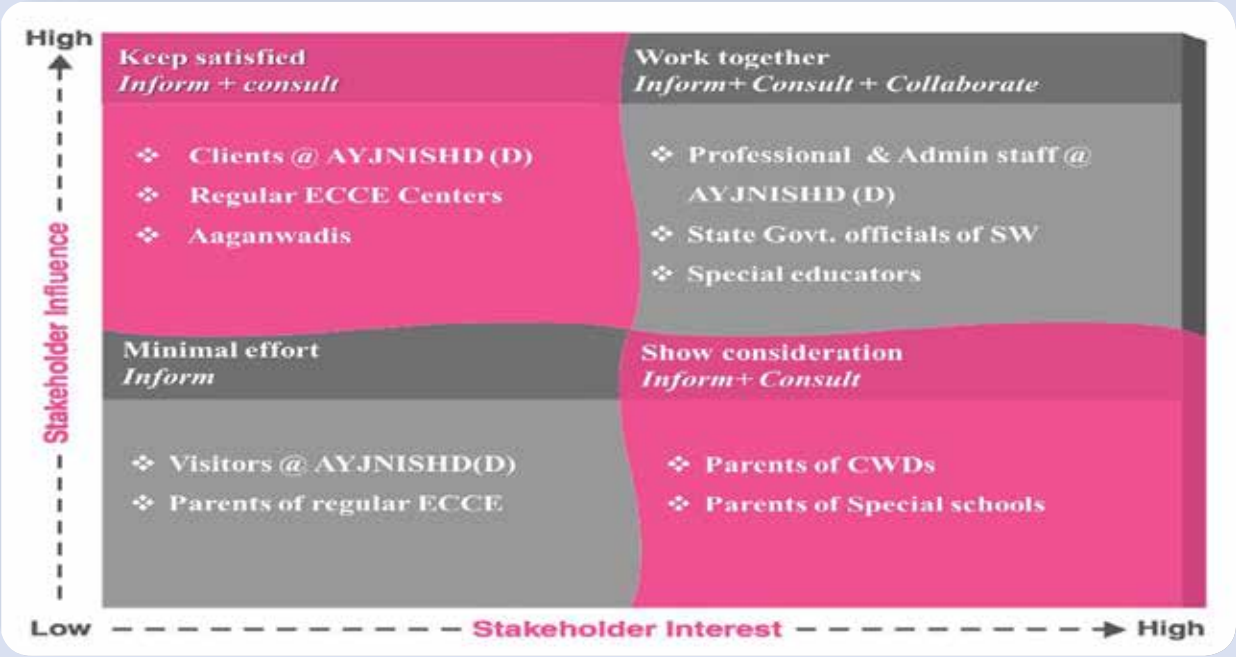
With this in view AYJNISHD (D) undertook a systematised effort for stakeholder sensitization with a mission to enhance their engagement for its new project of 'early identification and intervention of young children with disabilities with a cross-disability approach'. The key areas are depicted below:

Step 1: Identification of stakeholders:

The first step was to identify the internal and external stakeholders. A stakeholder by definition means the one who has a stake, i.e., who is a contributor for gaining through the outcomes of a planning, process or program. There are two categories of stakeholders – the internal and the external. The internal stakeholders are the ones who on a day-to-day basis directly participate in the co-ordination, funding, resourcing and publicity or building a strategy. In the present project of the cross-disability early identification and intervention centre, the internal stakeholders were the professionals comprising of special educators and other speech and hearing professional such as audiologists, speech and language therapist as well as the social workers and the psychologists working at AYJNISHD (D). The other staff members such as the admin and the registration staff were also the internal stakeholders who would assist in the budgeting, tendering and fundraising activities, plus the publicity work at the front desk and the website. The visitors and the clients who visit AYJNISHD (D) were also thought to be an important internal stakeholder who could publicise about the new project of early intervention.

The external stakeholders were the ones who were thought to be externally supporting. These included the special schools in different districts and special educators working in these schools. It also has the general ECCE centres and its parents and Aaganwadis, as well as, the state authorities of office of Commissioner of Persons with Disabilities (PwDs). The stakeholder's identification was followed by mapping their roles for conducting sensitising programs.

Step 2: Mapping the engagement of stakeholders:



A stakeholder analysis matrix was used as a technique to describe the extent to which their support and services would be required. This technique is generally known to be used in a particular strategic development such as the launch of a new service. The figure above depicts the quadrant which also gives the envisaged involvement of the stakeholders that AYJNISHD

(D) envisaged. This was done to plan the sensitisation activities for various internal and external stakeholders.

Work together: The stakeholders placed here have a high influence and their interests are also high, so they need to be first sensitised and fully engaged in the project.

Keep satisfied: The stakeholders mentioned here are highly important but having low influence or direct power and need to be kept informed through awareness campaigns and appropriate communication.

Minimal effort: Some stakeholders have low influence and low importance, but still need to be informed at least minimally to be kept on board.

Show consideration: These stakeholders have a high potential influence, but have a low say. So they need support from patrons or hand holders.

Step 3: Conducting sensitization programs

Internal stakeholders: Discussions by experts and on-site visits were arranged for the special educators and speech and hearing professionals of the institute for a cross-disability approach. The administration staff also accompanied them to get acquainted with the infrastructural and requirements of other disabilities. The various specialty disability centres also sensitised the staff about costs and others administrative details. For the parents of CwDs, a sensitization program on awareness was arranged.

External stakeholders: Aganwadis, General ECCE centres, especially in the slum pockets of Mumbai, were visited by the professionals of AYJNISHD (D) for generating need and building awareness about the launch of the cross-disability Early Intervention Centre and its services. It was realised that special schools and special teachers have been playing a pivotal role in early identification and intervention as well as in family empowerment. However, their new role calls for reaching newer horizons by providing support to any child in need and also out-reach for creating awareness about early supports and interventional facilities for children with disabilities.

With this mission, it was felt vital to orient and sensitise the special teachers who are trained and who specialise in a single disability towards identifying and intervening other disabilities. A five-day webinar series was hence planned for special educators to get first-hand information from experts towards newer trends of identification of impairments informally and formally and abreast them with evidence-based interventional strategies of sensory, intellectual and multiple disabilities. The program received an outstanding response with a viewership of more than 6,000 each day for each session and the inaugural program of the sensitisation program reaching its pinnacle of approximately 20,000 viewership. Each day the specialists in each disability informed about techniques of detecting disabilities in easiest possible ways so that the message could reach the ground level in a simplified manner. Developmental milestones of each domain and the curricular strategies were also presented using exemplars. The summing up had deliberations of how commonalities existed in identifying and intervening disabilities using home-based family-empowered techniques. This gave a much-needed impetus to the cross-disability approach.

Conclusion: Any new project reaches its desired outcomes if all the stakeholders are on board and feel engaged. However, given the paucity of resources, one needs to prioritise the process of engagement. An evidence-based practice that AYJNISHD (D) found most useful in creating a meaningful engagement was the sensitisation program that it undertook in partnerships with other stakeholders including the Central and the State Govt. authorities who were the most prominent and supportive stakeholders for the cause of establishing the cross-disability Early Intervention Centre.

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6

Sensitising the Staff/Officials about the Early Intervention Centre Approach

- Manjeet Singh Saini
Officer In-charge, CRC Sundernagar

NIEPID Secunderabad: Sensitizing Stakeholders- Staff and Medical Social Workers

"The greatest gift we can give our children are roots of responsibility & wings of independence"

.....Maria Montessori

This chapter presents the basic reasons for sensitisation of officers, administrators and staff members towards implementation, process of sensitisation and outcomes of early intervention approach towards developmentally delayed children in India. Through the process of sensitisation, these personnel may stand a better chance of becoming more socially competent individuals ready to benefit the community and society within their own environment.

According to the 2011 Census data, 7.01% of children in the age group of 0-6 years in India have a disability, either congenital or acquired. In this regard, multifaceted early identification and intervention services play a crucial role in prevention along with remediation strategies for the children lagging behind in their development. Early Intervention is a system of services for infants suffering from poor or delayed cognitive and physical development. Keeping in mind the complex needs of this underprivileged population with tardy growth, competent human resources and infrastructure are vital. Team-based collaborative approach is the backbone of early intervention services which is dispensed by qualified & skilled personnel like medical officers, therapists, nursing staff, anganwadi workers and other members of community. But many National Institutes (NIs) in India working in field of disability lack the qualified& trained professionals and staff members.

Officers & members of team working in field of disability require to be sensitised about Early Intervention Approach (EIC) approach and for successful implementation and output. All these personnel should be trained and sensitised adequately. A Multidisciplinary, Interdisciplinary & Transdisciplinary team-approach from professionals is required who can monitor the early intervention process as a guide to promote the caregivers' capacity to use everyday routine activities for child development.

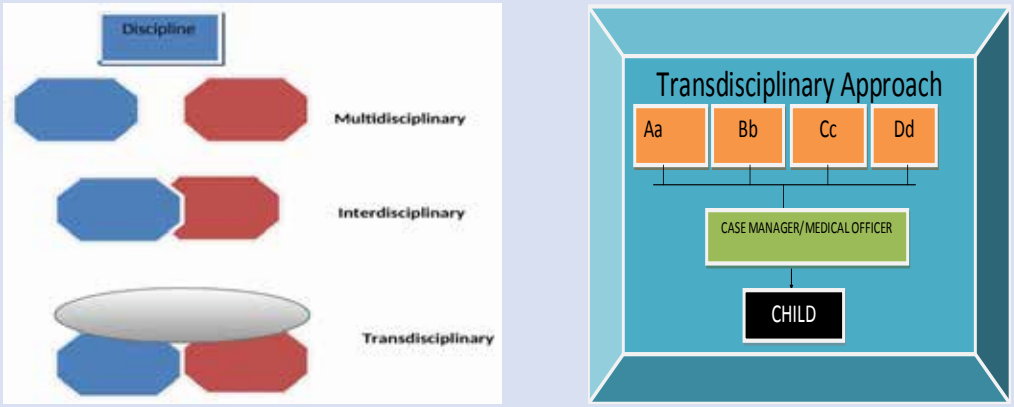


Figure 1 Approaches of Early Intervention & Transdisciplinary approach

There is a dire need to design high-quality sensitisation training process which can act as a bridge with EIC professionals to serve infants and toddlers during a critical period of their development, as well as to support their families to lay the groundwork of empowerment and advocacy for lifetime. Sensitisation process may include all staff members as representatives of community in implementation of services to sheath the culture variations. The process will create opportunities for family members, their children in removing barriers and biasness towards aesthetic & cultural values. The sensitisation process involves the following steps:

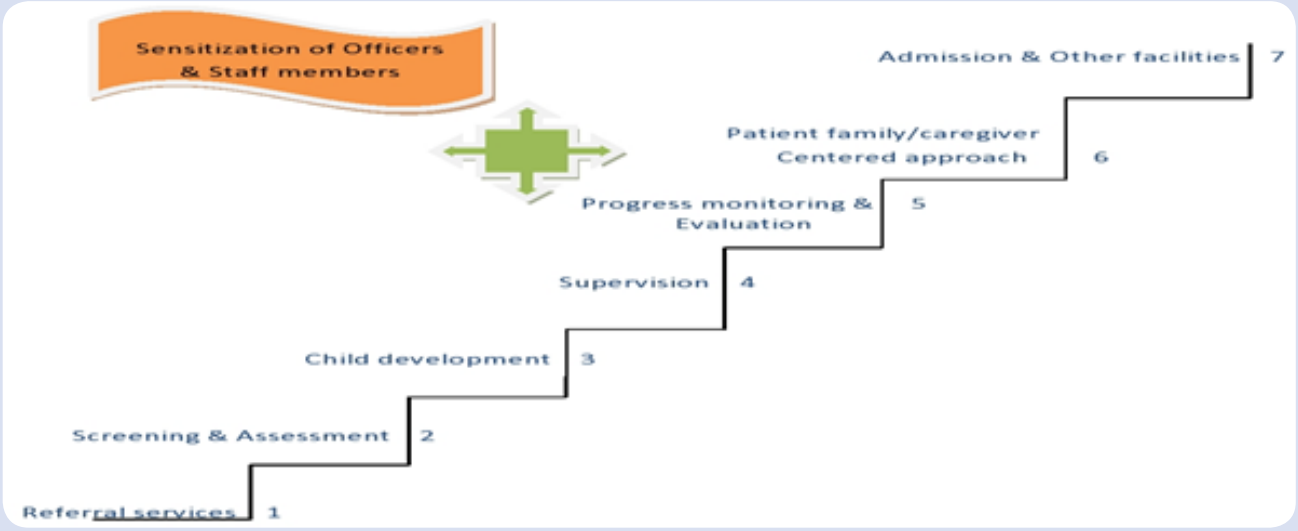


Figure 2- Sensitisation of Officers and staff members about EIC

1. Sensitisation towards referral services and their transition from one service to other-

The various departments of National Institutes (NIs) and Composite Regional Centres (CRCs) in India serving the Persons with Disabilities have established procedures ofreferring a child to proximate hospital for further evaluation and treatment. The parents and children can avail the advantage fromnumerous referral organizations such as district or civil hospitals, health care and educational agencies for absolute development of children. The flowchart of referral services from Cross Disability Early Intervention Centre is as below:

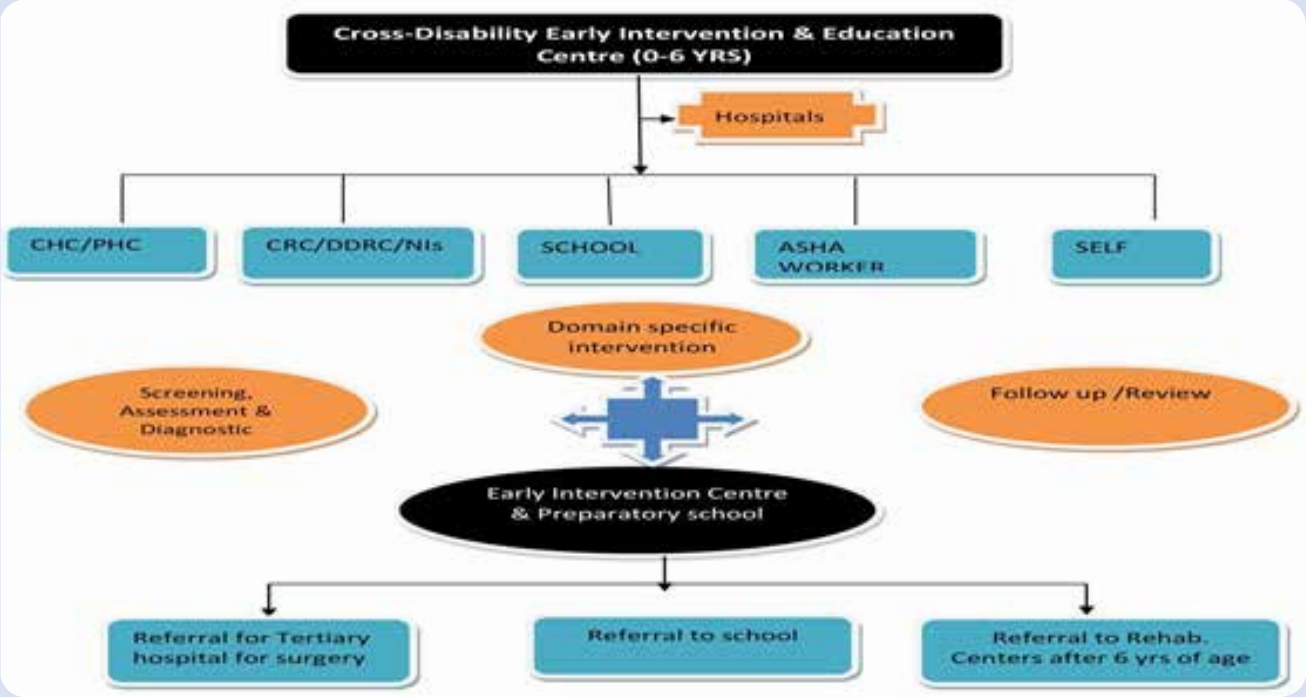


Figure 3- Flowchart of Referral Services from Early Intervention Centre

Information about cerebral palsy (CP) or developmentally delayed children should be disseminated from key referral source to the nodal officers serving the Cross-disability Early Intervention Centres. Passing of this information at right time help the officers and managers to develop individual strategies for infants to avoid unnecessary delay in rehabilitation.

2. Sensitising towards Screening and Assessment of child-

Child development and growth are an enduring affair by which child embraces diverse cognitive, physical, communication skills elaborately impacted by social, psychological, biological and hereditary factors. Sensitisation of professionals towards screening and assessment of toddlers or infants will keep check on marked developmental process and create guidance &awareness in parents.The screening and assessment process of infant imply planning, observation of infants, interviewing with parents and measuring progress based on particular screening tests. The staff and officers of early intervention centres can be sensitised by poster brochures, pamphlets and other modes like social media and short-term training programme by trained professionals. This sensitisation and proper counselling would save the time for parents and care taker in getting necessary information about their infants which will help in delineating the impairments in children and lifting the satisfaction level of parents.

3. Towards child development-

The personnel involved in early intervention process must be well versed with typical and atypical growth patterns of child in all domains like gross and fine motor development,cognitive issues,communication difficulties and social –emotional problems. Preliminary identification of child will help in well timed &prompt diagnosis and earlier interference preventing the disability.

4. Supervision-

Supervision takes place in one-on-one meetings after each activity as in child and family assessment and other related issues involved in delivering early intervention services. Supervision services exist at each important level of the administration, interdisciplinary team members of centre and at local community members. Supervisor collects information relevant to improvements in children and disseminates the information at higher level.

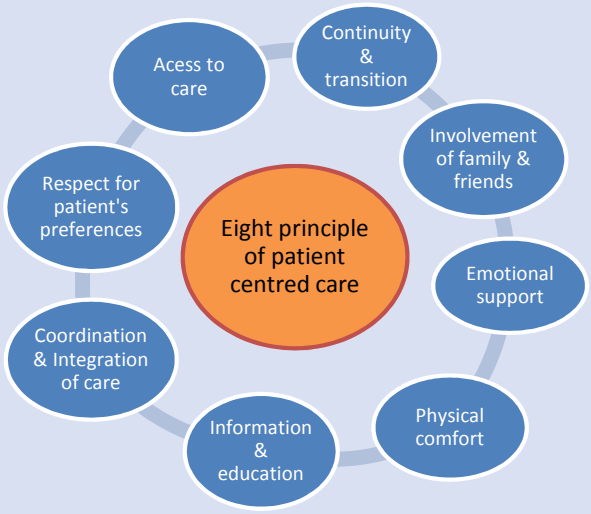
5. Progress monitoring -

The officers should monitor the progress of child by talking with care givers. The staff members

of early intervention centres should be meshed in advocacy at the regional, state and national level to increase and expatiate the community visits. This will assist in educating the parents and family and also to policy makers towards monitoring the developmental progression of child.

6. Patient Family /caregiver centered approach –

The patient focused care has captured central pivot stage in deliberation of quality allocation of early intervention services. The personnel should be sensitised and trained towards any requirement to family as family support in regards totoddler's growth, any related instructions, requirement of any material like therapeutic equipment or any support. All professionals must assist the families in getting the resources along with their utility to meet their demands. The eight principles of patient centralised care approach have been shown in figure:



7. Admission and other facilities –

Early intervention officials should be made aware about the requirements to furnish the parent's about admission/registration process or about eligible child's social security number for the purposes of the disability certification. Proper documentation of child assessment and treatment should be filed for further assessment and evaluation.

Conclusion

The thought behind the early intervention approach is to interfere at an early age to derogate the disabilities in new-born babies and children. It has been noticed that children who are lagging behind in their developmental milestones and acquiring permanent disabilities, the role of early intervention maximises the functional development and limit the further advancement of disabilities. A giant step is being taken for assessment, early identification of various diseases,

anomalies, impairments and disabilities through cross-disability early intervention centres in various National Institutes (NIs) and Composite Regional Centres (CRCs) in India. However, the lack of key professionals and manpower is a matter of serious consideration and staff members along with officials linked with early intervention centres should be motivated and sensitised to take up the rehabilitation process.

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7

Awareness Creation as a strategy to strengthen Early Intervention Centres

- Ms. P. Mercy Madhurima
Director, CRC Nellore

NIEPVD Dehradun: Awareness Drive

NIEPVD Dehradun: Awareness Drive with Different Stakeholders

Awareness is an essential component of prevention and early identification of childhood disabilities. Efforts in awareness creation can prove beneficial in the long run. Awareness needs to be created not only about the identification of disabilities but also about the facilities available at the centre, so that after the identification of children, they will avail the benefits of the services which aid in effective referral and rehabilitation.

Raising public awareness on early identification and intervention has various purposes like dissemination of information to expectant mothers, parents of high-risk babies/children born with congenital anomalies/ children with developmental delays, general public, employers who hire persons with disabilities regarding the importance of early identification, early intervention of the child's condition, facilities available at various government institutes, NGOs, rehabilitation centres.

Awareness creation amongst parents of children with disabilities/ developmental delays ought to focus on their child's abilities, rights, minimising negative attitudes, stereotypes and nullifying myths with facts. Awareness creation aids in transformation of mindsets in the long term.

Modes of Awareness Creation:

1. **Mass Media**: Broadcasting information via television, radio/FM announcements, newspaper articles, articles in magazines/ newsletters, providing information via brochures/pamphlets. This method can be effective by broadcasting interviews/ talk shows of panel of experts in early intervention and disability rehabilitation, articles showcasing excerpts from such interviews, giving out key contact information like websites, contact information of relevant organisations which enable the readers to approach the organisations at ease, and also for sure shot referrals.

2. **Social Media:** Displaying information about Early Intervention Centres (EICs) in the official websites of National Institutes (NIs)/ Composite Regional Centres (CRCs), and dissemination of information through regular tweets on Twitter, Facebook posts and photos via official Facebook accounts, posts in virtual communities like groups in Facebook / Whatsapp; compilation of informative videos specific to early identification and intervention of various

disabilities (21 disabilities specified in the Rights of Persons with Disabilities - RPWD Act, 2016) which can be uploaded in the official Youtube / Instagram channels or accounts; creative blogging. Online options like 'Tags', 'Hashtags' 'Threads' can work wonders when it comes to awareness creation.

3. **Exhibitions / Mela:** Disseminate informative material on early identification and intervention, showcase the facilities and resources available at the Early Intervention Centres.

4. **Networking with Other Organisations:** Networking with organisations working in the sectors such as development, health, social welfare is an effective method for awareness creation. The staff / professionals of these organisations can be enrolled for orientation sessions on early identification and intervention, discussion of Frequently Asked Questions (FAQs) pertaining to early intervention/ disability rehabilitation, and referral mechanism. These are potential organisations which aid in early referrals of children with disabilities and / or developmental delays.

5. **Training Programmes and Follow-Up Meets:** Short term training programmes, seminars, workshops can be conducted on a regular basis for health workers, grassroot workers, expectant mothers, parents/ guardians of children with disabilities. 'Follow-up meets' need to be organised for parents of children enrolled in the early intervention programme at respective NIs / CRCs so that the progress of children / clients can be tracked effectively. Guidance and group counseling sessions can be planned for the parents. Such meets also create opportunities for healthy interaction amongst parents of children enrolled in the early intervention programme which enhances motivation, boosts their morale and creates a support system amongst them. 'Follow-up meets' with staff of other organisations are crucial in the process of referral mechanism. The staff of the EICs should conduct follow-up meetings with the staff of local level organisations to ensure sure-shot referrals so that no child is deprived of the services provided at EICs. This is a collaborative effort which is highly beneficial to the organisation and the beneficiaries/parents.

6. **Internal Events:** Organise plenty of internal events for thematic awareness creation such as World Autism Awareness Day (2nd April), International Day of Persons with Disabilities

(3rd December), World Occupational Therapy Day (27th October), International Day of Yoga (21st June), World Mental Health Day (10th October), World Braille Day (4th January), etc. so that we create a safe platform where the parents of children with special needs are able to participate and contribute valuable insights in such events by sharing success stories and testimonials. An important factor to consider is informed consent.

7. **Create Infographics:** In this era of vast knowledge and variety of sources, we should be in a position to not only gain the attention of parents but also sustain their interest towards gathering relevant information and gaining knowledge which will aid in effective intervention of their child. This can be achieved by placement of few virtual kiosks inside the NIs/ CRCs campus. The kiosk will consist of a touch screen wherein anyone will be able to access key information in the form of interactive apps, videos, resource materials, and tutorials.

8. **Online Courses/ Webinars:** They should be conducted for parents/ caretakers, general public, and healthcare professionals.

Conclusion:

Awareness creation is a brilliant strategy for the development of Early Intervention Centres as well as sustainability of the same. This needs to be carried out not only in the initial phase but as a continual process for effective transmission of information and efficient functioning of the Early Intervention Centres.

8

Layout for Early Intervention Clinic

- Mr. Debi Prasad Mishra (OT)
Mrs. Sunita Kumari Sahoo (PT)
Dr. Narendra Behera In-charge, EIC
Dr. Sakti Prasad Das
Director, SVNIRTAR, Cuttack, Odisha

NIEPVD Dehradun: Brief Informational Layout for EIC Related Services

NIEPID Secunderabad: Accessible Passageway to EIC

An annual birth cohort in India is almost 27 million; India is expected to have the largest number of infants born with birth defect. Uniform surveillance of birth defects is still unavailable. As per NSSO 2002, the total number of disability population in India is approximately 1.8% of the population. As per the Census 2011 (Ministry of Statistic and Programme Implementation, Govt. of India), out of 121 Cr. population, about 2.68 Cr. persons are 'disabled' which is 2.21% of total population.

COMMON HEALTH PROBLEMS IN INFANCY

- Developmental delay
- Micro nutrient deficiency
- Hearing defect
- Congenital anomalies (defect at birth)
- Visual impaired
- Respiratory disorder

SCREENED FOR 4 'D' WITH NECESSARY FOR INTERVENTION

- Defect at birth
- Deficiency
- Disease
- Developmental delays – included disabilities (physical, mental, psycho-social).

AIM:

Aim is to have more accessible health facilities with infrastructure and resources for interdisciplinary evaluation and interventions to be delivered in one roof.

In the intervention setting, the need of the hour is to bring together trained professionals from different disciplines who had been working in silos so far to learn from one another in meeting the needs of the children, and training persons who have proper qualification and knowledge. There should be balance between supply side of these experts and the demand side.

CORE SERVICES OF EARLY INTERVENTION CLINIC

I. Medical services by paediatrician /medical officer. Diagnostic and evaluation processes, medical treatment of children for disease and deficiencies.

II. **Dental services – Dentist**

Services for problems of teeth, gums and oral hygiene in children from birth to 6 years. Treatment of 'early childhood caries'.

III. **Occupational therapy and physiotherapy services**

Assess the child with motor delay/disabilities and identify the need of the child. Formulate treatment goals on the basis of need of the child and provide services for sensory integration.

To counsel the parents on home therapy for child with focus on activities of daily living (ADL)

IV. **Speech – language pathologist and Audiologist**

Perform audiological assessment and advise on hearing aids depending upon severity of the child. Guide and counsel the parents about the auditory training.

Assess the level of receptive and expressive language deficit and to formulate treatment goals on the basis of needs of the child.

V. **Clinical psychologist:**

Perform the developmental assessment related to psychosocial, cognitive behaviour. Administer the scale/tools to diagnose developmental disability. Guide and counsel the family.

VI. **Optometrist:** Assess the vision problem and prescribe vision therapy and training or orthoptic treatment for children. Offer counselling services to the families on preventive vision care. Prescribe spectacle lenses.

VII. **Laboratory technologist**

Collection of blood or tissue sample, observing principles of asepsis to obtain blood sample. Conduct chemical analysis of body fluid such as blood and urine, using microscope or automatic analyser and conduct blood test to perform blood count.

VIII. **Data entry operator:**

Maintain all the data pertaining to the children to the EIC. Maintain computer, printer, and other instrument in proper running and safe condition.

IX. **Special educator:**

Focus on development of preschool children (3-6 years) with special needs. Employ special education strategies and techniques during instruction to improve the development of sensory and perceptual- motor skills, language, cognition, and memory. Monitoring and supporting supervision through information enabling system. Links with tertiary centre.

Linkage and convergence with Department Of Social Justice And Empowerment, Ministry of Women and Child Development and Ministry of Education.

TYPICAL DESIGN AND SECTIONS OF EARLY INTERVENTION CENTRE

EIC would comprise of following space / room (Ideal size EIC would be approx. 4900 – 5000 sq. feet):

- Waiting space
- Play/therapy area
- Reception space for registration including anthropometry
- Paediatrician/ medical officer room
- Dental examination room
- Vision testing room
- Hearing testing room and Soundproof room with rooms having two patients. One smaller room will be separated by an one-way looking glass with carpeted and double doors
- Speech room with looking mirror extending from almost the floor to one and half feet above the level of the table
- Early intervention room-cum-occupational therapy room
- Psychological testing room
- Laboratory (Lab tech)
- Nursing/nutrition room-cum-feeding room
- Sensory integration room
- ECG cum Echo room
- Computer room (manager) include store
- Pantry and space for drinking water and washing
- Toilets (male, female, staff – all equipped with accessible facilities for Persons with Disabilities)
- Open space/corridor
- Outer sensory garden (desirable)

SECTIONS OF EIC

I. AREA 1 – RECEPTION / WAITING

- Area – 12 feet × 16 feet
- REQUIRE EQUIPMENTS:
  - ⇒ Chairs for Patients and Attendants
  - ⇒ Speaker
  - ⇒ TV
  - ⇒ Low standing bookshelf (for illustrated children's book)

II. AREA 2 – REGISTRATION AND ANTHROPOMETRY:

- Area : 12 feet × 16 feet
- REQUIRE EQUIPMENTS:
  - ⇒ Reception table
  - ⇒ Desktop
  - ⇒ Registers
  - ⇒ 2 chair for staff
  - ⇒ Anthropometry related equipments
  - ⇒ Curtain
  - ⇒ Examination Table

III. AREA 3 – NURSING / NUTRITION CUM FEEDING ROOM:

- Area – 11.6 feet × 7.6 feet

REQUIRED EQUIPMENTS:

⇒ Chair

⇒ Table

⇒ Toys

⇒ Cupboard

IV. AREA 4 – SENSORY INTEGRATION UNIT

- Area – 15 feet × 8 feet

V. AREA 5 – EXAMINATION ROOM:

- Area – 12 feet × 16 feet
- REQUIRED EQUIPMENTS:

⇒ Examination Table

⇒ 4 chairs

⇒ Curtain

- MEDICAL EQUIPMENTS:-

⇒ Stethoscope

⇒ Ophthalmoscope

⇒ Height Scale

⇒ Torch

⇒ Sphygmomanometer

⇒ Weighing Machine/Infant meter

⇒ Measuring Tape

⇒ Knee Hammer

⇒ X- Ray viewer.

VI. **AREA 6 – DENTAL ROOM:**

- Area – 12 feet × 16 feet
- REQUIRED EQUIPMENTS:
  - ⇒ Dental chair
  - ⇒ Operator chair
  - ⇒ Assistant stool
  - ⇒ Specific dental equipment's
  - ⇒ Dental X-ray

VII. **AREA 7 – EEG cum ECHO cum EEG room:**

- Area – 11.10 feet × 7 feet
- REQUIRED EQUIPMENTS
  - ⇒ ECG machine and leads
  - ⇒ ECHO machine
  - ⇒ Resting table

VIII. **AREA 8 –LABORATORY:**

- Area – 12.3 feet × 7 feet
- REQUIRED EQUIPMENTS
  - ⇒ Automated blood cell counter
  - ⇒ Microscope
  - ⇒ Semi automated analyser
  - ⇒ Digital hemoglobinometer
  - ⇒ Lab reagents
  - ⇒ Testing kits
  - ⇒ Slides, beakers, test tube, etc

IX. **AREA 9 – PSYCHOLOGICAL TESTING ROOM**

- Area – length 8.6 feet × 8.6 feet wide

- REQURED EQUIPMENS:

⇒ Developmental Assessment for Indian Infants (DASSI)

⇒ Vineland Social Maturity Scale

⇒ Bayley- III Screening Test; complete kit includes Manual, Stim Book, Record Forms Book, Record Forms: 25 Packs

⇒ Developmental Screening Test(DST) by Bharat Raj

⇒ Developmental Screening Test (DST II)

⇒ Stanford Binet (Indian adaptation- Kulshreshtra)

⇒ Piaget's sensory- motor intelligence scale

⇒ Dyslexia early Screening Test 4-6 years (DEST) and Dyslexia Screening Test Junior (6 -11years)

⇒ Child hood behavioural checklist (CBCL).

X. **AREA 10 – SPEECH / LANGUAGE ASSESSMENT ROOM & HEARING ASSESSMENT ROOM**

- Area – length 12 feet × 16 feet wide

⇒ OAE screener

⇒ ABR screener

⇒ Audiometry

⇒ Portable Tympanometry instrument

⇒ BERA WITH ASSR with both insert phone and head phone

⇒ Otoscope

XI. **AREA 11 – VISION ASSESSMENT ROOM**

- Area – length 24.6 × 16.10 feet wide

- REQUIRED EQUIPMENTS
  - ⇒ Torch penlight
  - ⇒ Lea Symbol Visual Acuity test and conditioning flash card
  - ⇒ Lea puzzle
  - ⇒ Plastic colluder with lip
  - ⇒ Lea grating paddle
  - ⇒ Long fixation stick or lea
  - ⇒ Long mart chart or Snellen's chart
  - ⇒ Streak retinoscope
  - ⇒ Hiding Heidi
  - ⇒ Near vision Test with Lea symbol (Lea playing card set) and Near Vision Line Test
  - ⇒ Distance vision Test (Leas single symbols book).

XII. **AREA 12 – PLAY AREA**

- Area – length 36 feet × 16 feet
- REQUIRED EQUIPMENT
  - ⇒ Swings
  - ⇒ Slides
  - ⇒ See Saw
  - ⇒ Tunnel
  - ⇒ Tricycle
  - ⇒ Locally available toys.

XIII. **AREA 13 – PANTRY:**

- Area – length 9 feet × 7 feet
- Required equipments

⇒ Induction cooker

⇒ A set of utensil

⇒ Refrigerator

⇒ Microwave

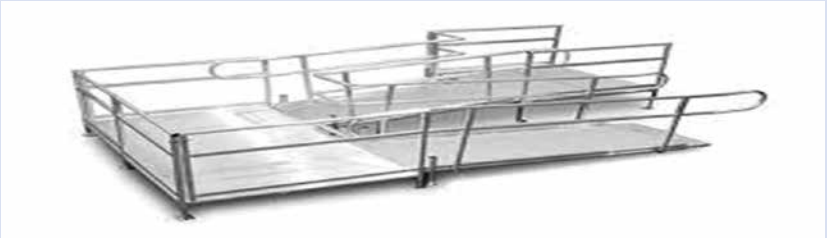
XIV. **AREA 14- TWO ADDITIONAL WAITING AREA**

- Area – length 12.6 × 6 feet wide
- REQUIRED EQUIPMENTS

⇒ chairs for each area

XV. **AREA 15: Gender specific and user friendly toilets**

XVI. **AREA 16- RAMP: Disability friendly Ramp**



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9

In Making Early Intervention Centres Accessible

- Tarika Roy
Joint Secretary, DEPwD
MSJE, GoI

CRC Nellore: Guiding Tactile and Handrails to Accessible Lift

CRC Patna: Ramp with Guiding Tactile and Handrails

NIEPVD Dehradun: Accessible Washroom with Grab Bars

NIEPVD Dehradun: Pictorial Signage in Hindi, English & in Braille

NIEPID Secunderabad: Dedicated Accessible Parking

Background

The Department of Empowerment of Persons with Disabilities (DEPwD) monitors the implementation of the Accessible India Campaign (AIC) launched in December 2015 with a vision of bringing accessibility in India across three main verticals, namely the built-up environment, the transportation sector and the ICT ecosystem. Accessibility has been mandated by the Rights of Persons with Disabilities Act, 2016; the United Nations Convention on the Rights of Persons with Disabilities that has been ratified by India, and in pursuance also of the Incheon Strategy.

While carrying out retro-fitments in buildings to make them accessible, it is imperative that the requirements and concerns of Persons with Disabilities (PwDs), the elderly, pregnant women, children, those infirm or injured and temporarily disabled are understood sensitively and addressed properly. However, in these years of the rolling out of the AIC across India, DEPwD has been privy to not just the practical difficulties being faced on ground, but also to the problems and issues witnessed with respect to the gaps in the level of understanding as well as in putting in place features of accessibility appropriately while retrofitting public buildings.

Accordingly, the Department has culled out **10 basic features of accessibility for the built-up environment** from the *Harmonized Guidelines and Space Standards for Barrier Free Environment for Persons with Disabilities and Elderly Persons* so as to simplify the process of providing at least the bare minimum requirements in all public buildings with a view to enhance accessibility. These 10 basic features were also ensured to be made available while planning and designing the Early Intervention Centres (EICs) at the 7 National Institutes (NIs) and the 7 Composite Regional Centres (CRCs).

The Ten Basic Features of Accessibility

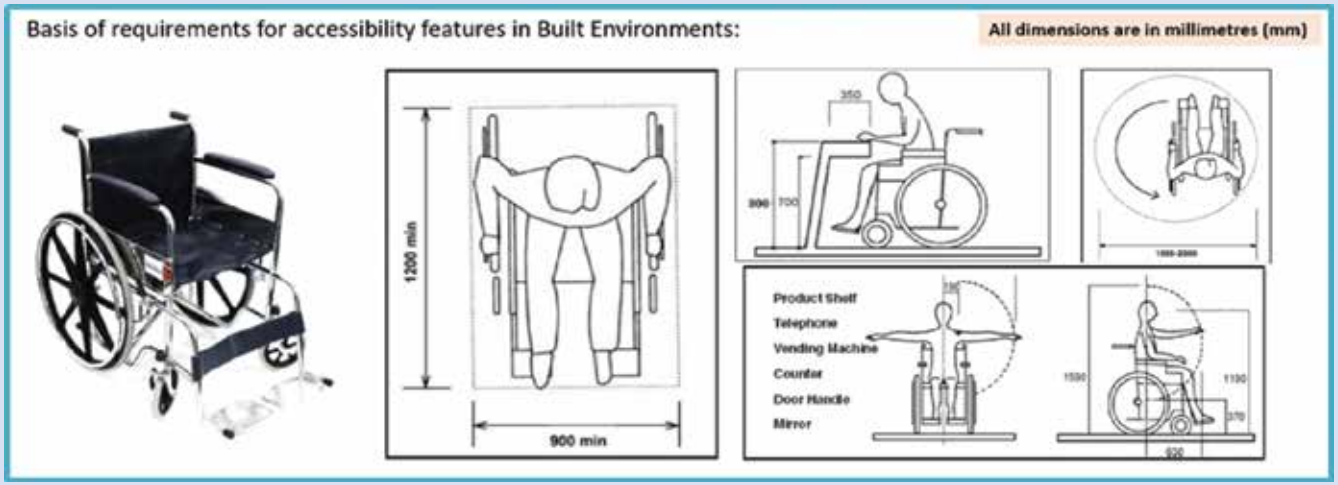
Based on the Harmonized guidelines and Space Standards for Barrier Free Environment for Persons with Disabilities and Elderly Persons issued by the Ministry of Housing and Urban Development in 2016, DEPwD has identified 10 basis features that were essential to be provided in all public buildings. These include 3 features that pertain to the area lying outside the main building and 7 features that are mainly found inside the buildings. These 10 features are tabulated as under:

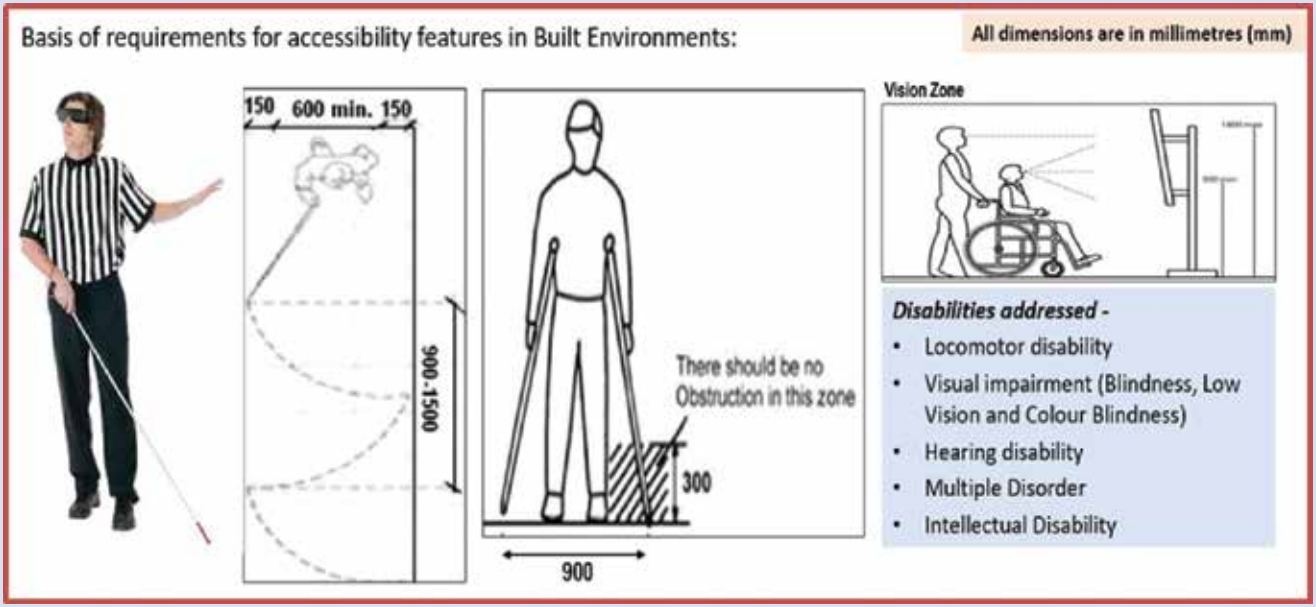
OUTDOOR FEATURES	INDOOR FEATURES
1. Accessible route/approach	6. Accessible lifts
2. Accessible Parking - Reserved near the entrance	7. Staircases with durable handrails
3. Accessible entrance to building – ramp	8. Accessible toilets
4. Accessible reception	9. Accessible drinking water provision
5. Accessible corridors and tactile flooring	10. Auditory and visual signage

Basic Principles of Design

In order to fully comprehend the subject and grasp the requirements of dimensions to be provided, it is essential to understand the basic principles of design on which to base these ten features of accessibility. It is important to understand and be sensitive to the needs of persons with different types of disabilities who may be of different age groups, gender and socio-economic levels. Accordingly, the basic principles of design take note of those who are wheelchair users or walk with the help of crutches; or those who are visually impaired – blind, with low vision or even having colour blindness and use canes/smart canes; have hearing impairment; or even those who cannot read instructions, be it on account of certain disabilities or otherwise.

These principles of designs can be understood with the help of the following basic diagrams:





Decoding Basic Features of Accessibility

This section would use photographs to decode the 10 basic features of accessibility and explain the dimensions required on grounds with the help of Dos and Don'ts. The proper implementation of these on the ground level in EICs would go a long way in providing ease of movement and comfort to the parents of small children with disabilities while visiting these centres.

I. OUTSIDE FEATURES OF ACCESSIBILITY

1. **Accessible Approach Route:** Right from the main outer gate till the entrance of the building per se, a colour contrasted accessible route with tactile path must be provided with the features including instructional and directional signage as under:

Dos

- **Minimum width for pathway should be 1500mm** (5) for one wheelchair and 1800mm (6) for two wheelchairs to cross simultaneously.
- Obstacles, projections or other protrusions should be avoided
- The route connecting the entire building **should be well lit and be provided with high contrast tactile floor guidance path**, connecting all public utilities, entrances and exits

Don'ts

- **Pathway/Route** created for wheelchair movement **is narrow**, less than 1500mm (5)
- **Path obstructed** by landscaping, manholes, potted plants, parking etc.
- **Tactile path provided is not continuous or not designed appropriately**, warning and guiding tiles not provided or wrongly placed
- Provision for lighting the pathway not considered

Specifications to be considered -

- Continuous and unobstructed path connecting all accessible elements and spaces in a building or facility. Width of 1800 mm for two wheelchairs/1500 mm for one wheelchair.
- Anti-skid flooring
- Tactile guiding path of at least 300 mm wide
- Colour contrasting surface
- Directional signage regarding accessibility features; e.g. directions towards the accessible parking, accessible entrance, ramps, etc.
- Well lit

2. **Accessible Parking:** A clearly marked and prominent accessible parking must be provided in close proximity to the main entrance with a transfer bay and a safe connecting access route to the main building.

Dos

- Parking must have **minimum dimensions of 5000 mm×3600 mm** (16.5'X12') **located nearest to an accessible entrance or lift lobby within 30m** (100')
- A **transfer bay 1200mm** (4') **wide** is required for transfer of wheelchair users, which **must be connected to the accessible route**
- **Accessible parking lot should be identifiable by the International Symbol of Accessibility, marked on ground and provided on a sign post**

Don'ts

- **No reserved parking provided for PwDs and if provided,not located near the entrance**
- **Signage not as per standard** – Missing ground marking, vertical post not provided, signage provided is not prominent
- **No transfer bay** provided for alighting and boarding of wheelchair users or **not connected to an unobstructed accessible route**

Specifications to be considered -

- Should be within 30m of the building entrance and connected to the accessible route
- Vertical and on floor signage
- Minimum dimensions of 5000 mm × 3600 mm (minimum 1200 mm wide transfer bay)

3. **Accessible Entrance:** The main entrance of the building should be accessible with a ramp provided with a gradual gradient and double height handrails and a wide door.

Dos

- Minimum **1200mm** (4') **wide unobstructed ramped entrance/approach of gradient 1:12, with stairs and minimum 1000mm** (3.3') wide door
- Ramp must have **continuous rounded double height handrails** (760mm(2.5') and 900mm(3')) on both sides; may also be provided with **Braille indicators** marking start and end of ramp, on the handrails.
- **Warning tiles at start and end, non-slippery flooring, landing and signage is mandatory**

Don'ts

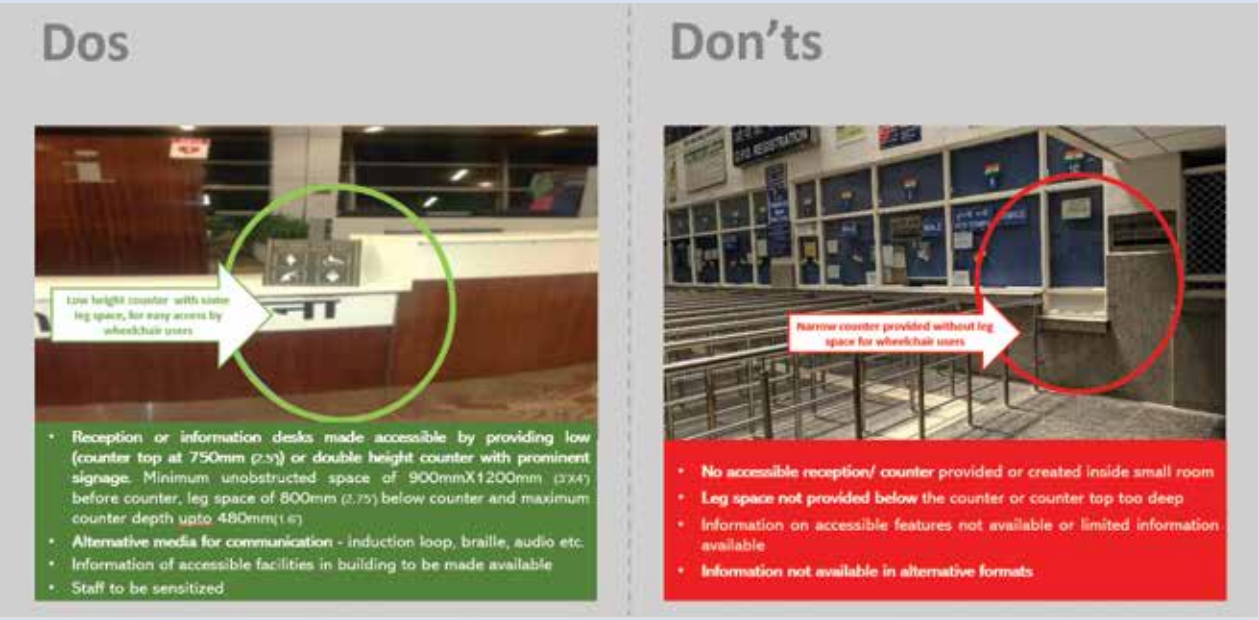
- **No ramp provided and if provided, designed very steep, narrow or slippery.**
- **Handrails not provided or not as per standard design**
- **Ramp not accentuated** with warning tiles, braille indicators or signage.
- **Ramp obstructed** by landscaping, protruding objects, parking etc.

Specifications to be considered -

- A **ramp of gradient of 1:12** to be provided next to the stairs.
- **Minimum width** of ramp should be **1200 mm**
- Provided with continuous **round handrails, on both sides, at a height of 760 mm and 900mm with rounded edges at the ends**, preferably with **Braille indicators**
- The **entrance door** should have **minimum clear width of 1000 mm**
- **Anti-skid flooring** with tactile tiles.
- **Signage** of the accessible ramp to be displayed prominently.

II. INSIDE FEATURES OF ACCESSIBILITY

4. **Accessible Reception:** The reception area must be provided with an accessible counter for wheelchair bound persons as well as make arrangement for providing information to those with visual or hearing impairment.



Specifications to be considered -

- **Low height counter** (counter top at **750 to 800 mm**); can have two different heights
- Minimum unobstructed space of **900 mm × 1200 mm** before the counter
- **Leg space (800 mm)** wide below counter
- Minimum **depth of 480 mm** for **closer reach to the counter**
- **Induction loop** may be provided for persons with hearing impairment
- **Information made available** regarding accessible features of the building (washrooms, drinking water etc.)
- **Tactile/Audio maps** for directions may be provided
- **Signage for easy identification.**

5. **Accessible Corridors:** The corridors of the building must be wide enough for wheelchair users to pass easily, be well lit, kept unobstructed, have handrails provided as also tactile guiding and marking tiles appropriately placed on anti-skid flooring and appropriate signage displayed prominently in accessible formats.

Specifications to be considered -

- Maintain unobstructed width of 2200 mm
- Anti-skid flooring, tactile path (at least 300mm wide), colour contrasting surface
- Should be kept free of any obstacles (plantation, seating arrangements etc.)
- Should be well lit (150 lux)
- Should be supported by directional and informational signage
- Handrails
- Room doors not to open outside on to the corridor

6. **Accessible Staircase:** The staircases in building must be marked with tactile tiles at the beginning and end for alerting persons with visual impairment. They should be provided with colour contrasting strips, rounded double height handrails, be well lit, and of appropriate height and thickness for comfortable climbing.

Specifications to be considered -

- **Warning tiles** (tiles with bold dots) **before and after the sloped surface**
- **Regular steps of tread** (width) **250 mm and rise(height) 150 mm**
- **Colour contrasting strips** (glow in the dark, retro-reflective kinds) at the edge of the nosing
- **Continuous round handrails, on both sides**, at a height of 760 mm and 900 mm with rounded edges at the ends
- **Braille indicator at both ends of the handrails**
- **Diameter of rounded handrail – 38 -45 mm**
- **Gap** of handrail from wall – **50 mm**

7. **Accessible Elevators:** The building must provide for accessible elevators that are wide enough for the wheelchair users to enter and manoeuvre comfortably. The elevators should have a mirror at the rear end, handrails on all three sides and the control panel having an alarm button and braille buttons, placed at an accessible height. The digital displays and audio-visual format of announcements to be ensured.

Specifications to be considered -

- **Minimum internal car dimensions of 1500 mm × 1500 mm** (if possible, 13 passenger lift)
- **Braille buttons and auditory announcement systems and digital display**
- **Alarm call button, emergency brake button and** other operating mechanisms **(control panels)** provided at an accessible height of 650mm to 800mm
- **Signage to be provided outside** the lifts
- **Handbars** at 900mm
- **Mirror** at the back
- **Warning Tactile tiles outside lift**

8. **Accessible washrooms:** This is one of the most critical features of accessibility since the persons with disability is alone inside the washrooms. Chaukhat-free wide doors for access of wheelchair users must be ensured, with adequate space for the wheelchair to turn around and manoeuvre comfortably. The floor must have anti-skid tiles and adequate

handbars and grab rails being provided near the wash-basins and the commodes. Alarms buttons/strings for pulling, should be provided prominently, preferably at more walls than one. Taps and door handles to be easy to operate.

Dos

- **Minimum toilet dimension should be 2000mm X 2200mm** (6.5'X7.3'), sufficient for wheelchair manoeuvrability
- **Floor Finish** - Toilet to be provided with well contrasted, anti skid flooring, with proper drainage and no threshold (*chaukhat)*
- Toilet door must be of minimum 900mm (3') wide. Latches to be placed at top, middle and bottom, with an easy-use mechanism which may be operated by foot also. The door handles must be of D-type or lever type, instead of knobs.
- Accessories/Fittings -
  - **Taps to be provided with sufficiently long necks and easy to use** lever type operating mechanism
  - WC top height should be at 450mm to 480mm (approx. 1.5')
  - Washbasin top height must be 750mm to 800mm (approx. 2.5')
  - **Grab bars/ door handles/ all fittings/ accessories/ operable items placed at approachable height of 300mm to 1000mm** from the floor and be easy to operate (Long/lever handles of taps)
  - **Enough grab bars must have adequate strength to bear weight upto 250 Kgs.**
  - **Emergency buttons at 300mm** (1') **from the floor on all 3 walls are mandatory**
- The toilet must be **well lit.**

Don'ts

- **Toilet dimension is not sufficient for wheelchair manoeuvrability**
- **Entry at door not levelled** or provided with Chaukhat
- **Door design make operating it difficult or the door opening is narrow for a wheelchair**
- **Grabs not provided** and if provided not as per standard design/ strength
- Latches and taps out of reach or difficult to use
- No emergency buttons and if provided not functional
- Dimly lit

Specifications to be considered -

- Minimum dimensions of 2000 mm × 2200 mm
- Outward-opening/ double door, double-swing doors, minimum 900 mm wide/level (no choukhat)
- WC top height - 450 mm to 480 mm
- Washbasin top height - 750 mm to 800 mm
- Grab bars/ door handles/ all fittings/ accessories/ operable items placed at approachable height of 300 mm to 1000 mm from the floor and be easy to operate/adequate strength (250 Kgs)/Easy operability)
- Anti-skid flooring
- Emergency button
- Height of latches also at base (foot operable/non-protruding) or mid height (750-800 mm)
- Long/lever handles of taps
- Door handles - D-type/ lever type (not knobs)
- Colour contrast

9. **Accessible drinking water facility:** Double height, preferable fountain type drinking water points to be provided which are easy to operate and have easy reach unhindered by open drains below.

Dos

- **Drinking water facility area should have clear space of 900mm X 1200mm** (3'X4') in front of the fountain for a wheelchair, **kept dry, anti skid and well drained by means of covered drainage**
- **Basin must have double heights** (750mm (2.5') to 900 mm(3')) with leg space of 300mm(1') to 680mm(2.1') below the counter
- **The taps must be lever or fountain type with easy to use operating systems** and long neck for maximum reach to wheelchair user

Don'ts

- **Conventional water coolers placed on platforms, kept inside cage or placed at end of narrow passages** without any leg room or turning space. Slippery surfaces to be avoided.
- **Taps niether provided at two levels** nor with fountain or lever type design making it difficult to be used
- Open drains, jaali over drains or *chaukhat* not to be provided as it causes hindrance to movement of wheelchair users and persons with visual impairment with or without canes.

Specifications to be considered -

- Area should have a clear space of 900 mm × 1200 mm
- Low height counter (counter top at 900 mm)
- Leg space of 680 mm below the counter which can extend maximum upto 300 mm from the wall
- Lever type tap systems (at two levels) with easy to use systems
- Non-skid surface with proper drainage should be created
- Fountain type taps

10. **Signage:** Appropriate easily understood and prominently displayed standard signage, both instructional and directional, must be made available with braille and pictograms.

Dos

- Signage to follow standard design, be well contrasted with background and have simple layout while being eye-catching.
- Positioning and viewing distances shall also be studied and planned to serve everyone.
- **Alternative formats** – Information should be given not just in text but as pictograms, symbols, infographics and, through alternative media such as braille, audio, digital display, tactile maps and model etc.
- **Lighting, material and finish to enhance visibility** and ease of viewing

Don'ts

- Signage design is not standardized and different themes are used all around a premise. Often size not maintained making it unreadable.
- Signage visibility either obstructed or affected due to distance
- Not well lit and material used is highly reflective causing glare and difficulty in reading
- Colour contrast is not provided as per standard hence doesnot serve the purpose

To make signage universally usable, components to be kept in mind, include-

- **Standardization**
- **Colour contrast (white on blue)**
- **Character, content and layout should be simple and eye-catching**
- **Pictograms and accessibility symbols for quick reference**
- **Positioning and Viewing Distance**
- **Lighting**
- **Material and surface finish to enhance visibility and ease of visibility,**
- **Alternative formats, etc. embossed letters with Braille (Audio/Visual information, Maps and models)**
- **Fonts-san serif family**
- **Mix of upper and lower case**

Features of Accessibility: At a glance

Based on the basic principles of design, the dimensions of the 10 basic features of accessibility can be summarized as under for quick reference:

Features	Specifications
OUTDOOR FEATURES	
Accessible Route	900 mm - 1800 mm, anti-skid surface, tactile path, signage (directional and informational)
Accessible Pathway	
Accessible Parking	5000 mm × 3600 mm, within 30m of entrance, transfer bay, accessible route, vertical and on floor signage
Accessible Entrance to the Building	900 - 1800 mm width, ramp with gradient 1:12 and double height handrail with proper grips, anti-skid flooring, colour contrast
INDOOR FEATURES	
Accessible Corridors	1200mm, anti skid surface, tactile path, well-lit, unobstructed (with chairs/plants)
Accessible Reception	Low height counter (750-800 mm), width (750-900 mm), leg space below counter (480mm), Information of accessible features, induction loop (audio enhancing technology)/tactile maps
Accessible Lifts	Braille and auditory information, 1500 mm × 1500 mm, grab bars, control panel (750-800 mm)
Accessible Toilets	Grab bars, 900 mm door (double or outside opening), anti skid floor, emergency button, latches (middle, base), easy to operate long lever taps, D-type/lever type door handles
Accessible Staircase	Colour contrasting strips, double height rounded handrails with proper grips, warning tactile tiles
Accessible Drinking Water Facility	Low height counter (750-800 mm), leg space below counter (300 mm), ramps, no drains/ holes below the water drinking point.
Signage	Directional and informational, high contrast, easy to understand, prominent locations, unobstructed, standardized

Conclusion

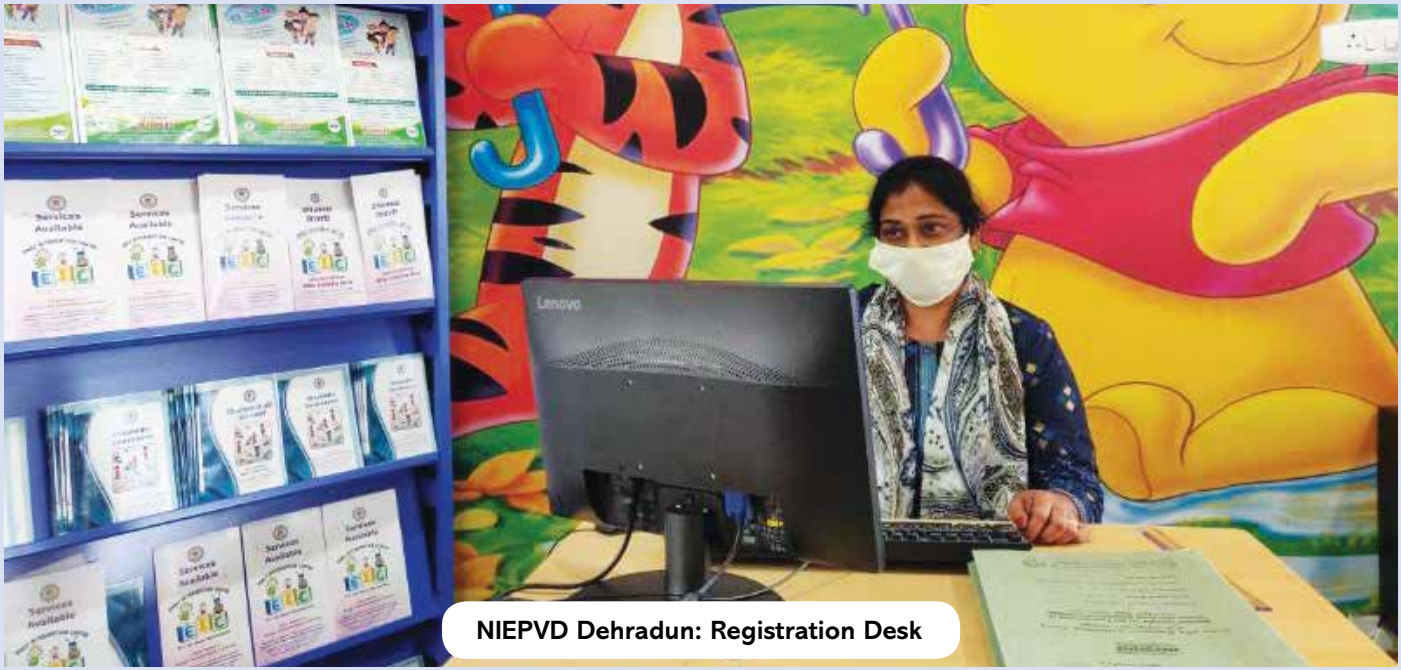
The Early Intervention Centres have been tasked with making provisions for these basic features of accessibility to ensure a safe, convenient and comfortable experience for the parents visiting these centres with their small children in the age groups of 0-6 years for the required counselling, care and therapeutic interventions. It is hoped that the parents would find the spaces not just aesthetically done up, but more importantly, accessible enough thereby making their visit to the Centres a comfortable one.

10

Web-Based Software for Data Management of Early Intervention Centres

- B. V. Ram Kumar, Deputy Director, (Admin)
Dr. Shilpa Manogna, Faculty in Special Education
NIEPID, Secunderabad

CRC Lucknow: Reception-cum-Registration Desk



NIEPVD Dehradun: Registration Desk

Early Intervention Centres (EICs) are special services for infants and toddlers at risk for developmental delays. Over a period of time, with advanced medical techniques and increased awareness on the benefits of early intervention, the number of parents and families availing the early intervention services has increased rapidly. Having a centralised data management has become essential with the increasing number of cases registering for disability rehabilitation services at the National Institutes (NIs) and its regional chapters. It is important to have access to centralised Software for Data Management of Early Intervention Centres.

With urbanisation taking place on a fast mode, it is often observed that parents and persons with disability move from one city to another either in search for better services or for job-related transfers. In such cases, it is difficult to carry all physical documents and medical/rehabilitation service records. It also often observed that parents from low socio-economic status and from rural background often misplace the important records unknowingly.

In disability rehabilitation and early intervention, clientele often have multiple conditions that require them to seek the help of different specialists and rehabilitation professionals such as Physiotherapist, Speech Therapist, Special Educator, Rehabilitation /Clinical Psychologist. It is of utmost importance that the different specialists maintain a constant stream of communication to design the overall best intervention plan for the person with disability. Digitisation of data and maintaining the records in centralised software helps the rehabilitation professionals be informed about the client's previous consultations and history in every situation.

Best Practices of Centralised Data Management across the Globe

Wisconsin's Early Childhood Integrated Data System (ECIDS) has established data linkages between the Department of Public Instruction (DPI), the Department of Health Services (DHS) and the Department of Children and Families (DCF). The use of the ECIDS has resulted in better outcomes for Wisconsin children, families and communities by providing the participating agencies' (currently DCF, DPI and DHS) internal researchers, content specialists and analysts with cross-departmental information to guide decisions about investing resources in effective, sustainable strategies while maintaining privacy, confidentiality and departmental accountability.

Early Childhood Data Collaborative (ECDC) linked child-level data to assess access to early care and education, early health social services, and children's school readiness. The integrated data helped how well the services were provided to promote positive school readiness or healthcare outcomes for children over a period of time.

Minnesota's Early Childhood Longitudinal Data System (ECLDS) Minnesota's ECLDS securely links data from the state departments of education, human services, and health. The ECLDS includes a web-based portal for the public to access de-identified, aggregate-level data to run standard reports and conduct analyses. Having access to these data enabled governmental organisations, NGOs, such as non-profit human service agencies to better serve the unique needs of their communities.

It was reported that using real data on the population of children and providers, the planning team was able to predict the annual encumbrances of various scenarios based on the number of current providers at each level and the number of subsidised children that each served. The state was able to direct more resources to the needy community and launch a special initiative for providing the services to young children. Data were critical in launching that initiative because the state would not have had the confidence to move forward with changes, without knowing that the changes would not affect the total cost and waitlist volume.

Early Intervention Services

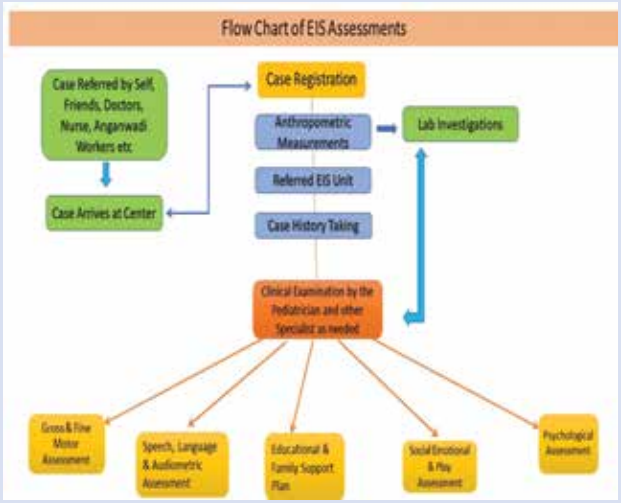
The importance of early intervention can never be over-emphasised. During the first two to three years, the growth and development of the child is at its greatest. It is during this first phase of cognitive development when the underpinnings of intelligence, motor movements and behaviour begin to evolve. Additionally, plasticity, the ability of the brain to affect structural and functional changes caused by external and internal influences is at its peak in the birth-to 2-year period. The malleability of the developing brain at this stage makes it possible to bring about these changes. If the child misses this opportunity, further learning will be slow or inadequate. Developmental intervention requires an interdisciplinary approach of a multidisciplinary team available under one roof who can assess and design a comprehensive intervention plan for the child.

The Department for Empowerment of Persons with Disabilities, MSJE has been striving to provide services with universal coverage and equitable distribution for Persons with Disabilities. To implement the Rights of Persons with Disabilities Act, 2016 which stresses on prevention and early detection of childhood disabilities, DEPWD has initiated establishment of 14 Early Intervention Centres in National Institutes (NIs) and Composite regional Centres (CRCs) which will provide comprehensive preventive, corrective and rehabilitation, and early intervention services under one roof. Although there are many non-governmental organisations offering services to young children, they are not reaching all the children.

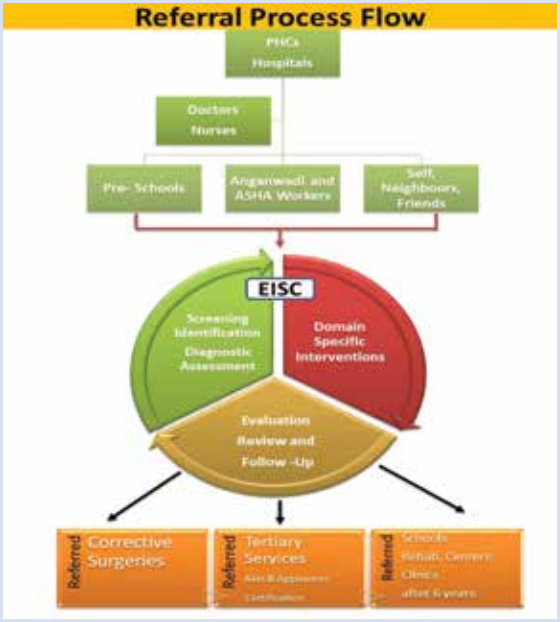
Early Intervention Centres (EICs) established by the DEPwD caters to children in the age range of 0-6 years who are at risk or have developmental delays. There is zero rejection for such children in the Early Intervention Centres. By zero rejection, it is implied that children with all kinds of disabilities such as visual impairment, hearing impairment, cerebral palsy, speech language and communication delay are offered early intervention services irrespective of the type of disability and degree of severity of the problem.

These services focus on prevention, remediation and treatment to foster holistic development of the child and the family. The services offered are child-centred and family-oriented and provided by a multi-disciplinary team of experts. The child receives individualised intervention consisting of physiotherapy, occupational therapy, speech and language intervention, medical, psycho-social and family intervention. EIC also offers parent training programmes, group therapy, play therapy, guidance and counselling. Many tertiary services such as referral to corrective surgeries, cochlear implantations, lab investigations, disability certification guidance, aids and appliances can also be provided based on the needs of the young child and the family.

The flowchart of the important assessments and interventions in EIC is explained in figure below.



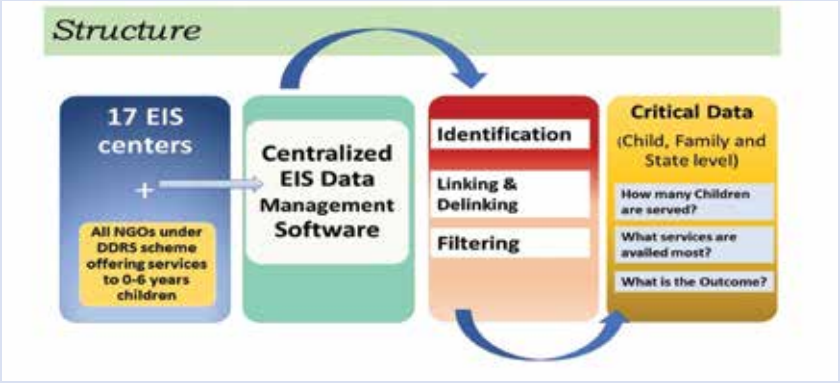
The child can come to EIC from various referral sources such as PHCs, hospitals, ASHA workers, friends and neighbours and so on. Irrespective of the referral points and sources, each child undergoes an initial screening and diagnosis. After comprehensive assessment based on the individual needs, domain-specific interventions are provided which will be periodically reviewed. The child will be referred to tertiary services to undergo cochlear implants and other corrective surgeries if required. The referral process flow is depicted in the figure below.



Why Data Management through Centralised Software?

Data management and governance through centralised software provides a means to establish a common vision for EIC services provided in different centres and states which will help in making key policy and programme decisions supporting the vision of giving quality and evidence-based services and training programme in EIC units. Further, when data management and governance is effectively established, the quality and security of data collected, reported, and used in EIC programs and agencies will improve data-driven decision-making, assist in the coordination of programmes and services, and improve research and ease of access for children and families.

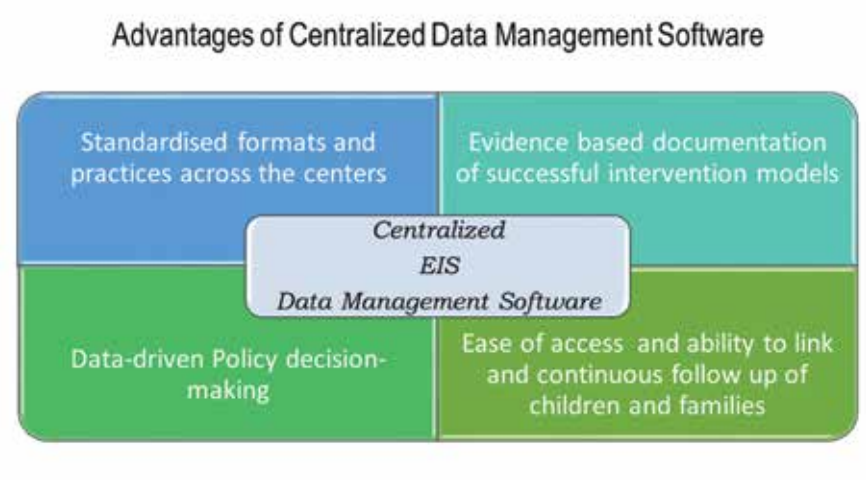
A simplified structure is depicted below with examples of what kind data can be obtained when a standard procedure is followed across the centres. Critical data right from Child's level (Eg: How many children have Motor delays, Iron deficiency, how many have Auditory



challenges, etc.?), from Family's level (Eg: Mothers' health history, Socio-economic profile, etc.) and from State's level (Which state has highest record of services availed; Any region with significant issues which needs to be addressed, etc.).

One of the most important advantages of a fully developed centralised data system standardised formats and practices which include: common terms and / or definitions for common data elements, ability to link assessment and intervention information for the same individual, family, or program setting across multiple data sourcesand procedures that safeguard data privacy. Also, as said earlier, this will be enable case data mobilisation between NIs and CRCs as and when any client moves from one location to other. The online data movement also ensures paperless data management and will be an eco-friendly measure. An added initiative is hygiene maintenance with no physical paper movement and contact, especially in times like the present pandemic.

Linking data collected across EICs units, NGOs offering early preschool education programmes can help programme leaders and policymakers better understand the needs of the children and families these programmes serve, as well as support continuous programme improvement, innovation, and research. Integrated early childhood data can help to answer important questions related to programme access, participation, quality, and their association with child outcomes. Initially, all the EICs under NIs and CRCs can be linked. Since NGOs who receive grant-in aid and financial assistance from DEPwD, MSJE are already aware of the importance of the early intervention and related services, they can be linked to get comprehensive coverage in the second phase.



Some of the important policy questions that linked and integrated data can help answer are:

⇒ How many children in the state are participating in EIC programmes and services?

⇒ What different combinations of EIC programmes and services do children receive?

⇒ Where are there gaps in accessing to and participation in high-quality EIS programs and services?

⇒ What other kinds of social and health services are families of young children accessing (e.g., Disability Certification, Schemes and Benefits offered by Govt. time-to-time. Supplementary Nutrition Assistance Program, Corrective Surgeries, Counselling support, Job training, etc.)?

⇒ Are there children and families that may qualify for EIC services, but are not currently availing them?

⇒ Are there children and families who discontinued the essential EIC services?

Reports:

Different type of reports can be obtained based on preloaded formats with click of a button. The reports can be generated anytime. Some of the reports which can be generated are given below. Apart from these, filters can be used to generate other details as per the requirement.

⇒ Case-wise Statistical Report (New / Follow Up, State-wise, Locality-wise reports)

⇒ Gender & State-wise Report

⇒ Registration Card

⇒ Registration Details

⇒ Case History Report

⇒ Medical Assessment with Individual Examination Report

⇒ Dental Assessment Report

⇒ Special Education Report

⇒ Psychological Assessment without IQ

⇒ IQ Report

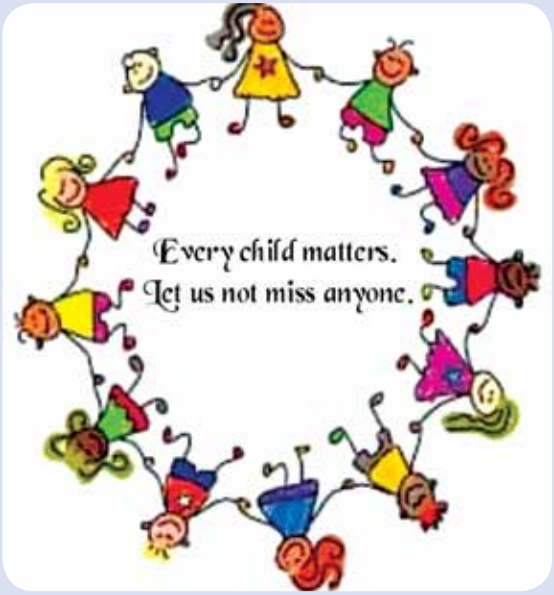
⇒ Speech and Language Assessment Report

⇒ Physiotherapy Report

⇒ Occupational Therapy

⇒ Provisional Diagnosis

⇒ Pharmacy Report



It is recognised that there are currently many gaps in information, assessment procedures used and inconsistencies in collection and reporting of data across different centres. Hence, the need for an integrated and comprehensive data management system to provide reliable and up-to-date data on all indicators involved in Early Intervention Centres. It will be a great source of MIS to better understand the full scope of services children receive in early childhood, learn what combinations of services are associated with positive outcomes for children, and identify service gaps. However, it deserves to be planned and carried out with consistent awareness to embrace its multilevel complexity, taking into account the patient needs, the clinical care pathways and the administrative requests.

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11

Preparedness for handling Cross-Disabilities

- Dr G. A. Joshi
Incharge, CRC, Bhopal

NIEPVD Dehradun: Cross-Disability Occupational Therapy

SVNIRTAR Cuttack: Cross-Disability Multi-Sensory Integration Therapy

Disability and Rehabilitation is an evolving concept that changes from hopeless and charitable condition to a condition with hope and resilience to achieve full human rights over a century. Rehabilitation is the process of re-training a person with disability to achieve his/her highest potential along with the highest possible environmental conditioning. When we refer to congenital and developmental conditions in children with disabilities (CwD), the intervention is called "Habilitation" because there is no premorbid status for reference for the particular child.

The Rights of Persons with Disabilities (RPwD) Act, 2016, explicitly mentions following points based on the mandate of United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) –

1. Respect for evolving capacities of children with disabilities and respect for the rights of children with disabilities to preserve their identities is the main principle.
2. 21 types of disabilities are defined in six broad categories with a scope to add many more.
3. Prevention, screening and care of child.
4. Inter-ministerial coordination to ensure continuum of habilitation.

The Department of Empowerment of Persons with Disabilities (DEPwD), Ministry of Social Justice and Empowerment (MSJE), Government of India as a Nodal Ministry has established 21 Composite Regional Centres (CRCs) for Skill Training, Rehabilitation and Empowerment of Persons with Disabilities till date since year 1999. The infrastructure of CRCs is a perfect model for handling cross-disabilities. CRCs have medical, paramedical, and rehabilitation staff to ensure continuum of habilitation for CwD which may be in any of the following categories defined in the RPWD Act, 2016:

1. Locomotor disability
2. Cerebral Palsy
3. Dwarfism
4. Muscular dystrophy
5. Acid attack victim
11. Intellectual disability
12. Specific learning disability
13. Autism spectrum disorder (ASD)
14. Mental behaviour
15. Hemophilia

6. Blindness
7. Low vision
8. Deaf
9. Hard of hearing
10. Speech and Language disability
16. Thalassemia
17. Sickle cell disease
18. Multiple disability like deaf-blind
19. Other

The developing capacities of younger children are well known. Hence, it is essential to start early to achieve the best potential in CwD. The strategy includes disability prevention and reduction in addition to core activity of rehabilitation of permanent disability. It needs to be stressed that TIME is unequivocally the crucial dimension in early intervention.

Disability prevention strategies include healthy lifestyle, diet, vaccination, genetic counselling, etc. These are taken care by the health services.To ensure timely services at fast tracking, it is the responsibility of Early Intervention Centre (EIC) to make it available for clients. Hence, a regular linkage with Ministry of Women and Child Development as well as Ministry of Health and Family Welfare is essential.

The clients of early intervention centre must have the diagnosis after thorough medical check-up. Paediatrician has the responsibility to work up on diagnoses and management of health issues as well as to arrange genetic counselling as appropriate. Physical Medicine And Rehabilitation (PMR) specialist is responsible for diagnosis of the disability and plan the habilitation along with prescription of medicine, therapy, assistive devices, etc. as well as carrying out surgical management.

While the paediatrician is the initial contact and shall be thorough with the diagnoses, PMR specialist provides regular fine tuning of rehabilitation during the life cycle of the child. In addition to these two core medical specialists, other specialists (otorhinolaryngologist, ophthalmologist, obstetrician & gynaecologist, psychiatrist) and super specialists (neurologist, haematologist, paediatric surgeon) are desired. Emergency first aid facility with a nursing professional is also required to manage situations like seizures. A visiting dentist is necessary to ensure the oral health.

The CwD with its definite plan of habilitation needs the care of paramedical and rehabilitation

professionals. Physio and Occupational therapists ensure development of capacities in the CwD while the rehabilitation professionals provide assistive devices and offer therapy services for development of the language, behaviour, educational capabilities, etc. Therapeutic nutritionist provides answers to nutritional needs of CwD with special diet modifications desired in clients having seizures or ASD.

The liaison between society, authorities, services, parents, etc. is the vehicle of change for CwD. A full-time medico-social worker at the early intervention centre shall take care of these needs. With addition of blood-related disorders among the defined disabilities, it has become necessary to link up to the blood banks and programmes dealing with blood borne diseases like AIDS and hepatitis. Linkup with donors and insurance agencies to fulfil financial needs of these CwD shall be ensured by the medico-social worker.

The professional shall link up with the district Early Intervention Centre to ensure provision of facility to CwD and also extend provision of assistive devices under the ADIP scheme including cochlear implant. The following stakeholders may be considered as core stakeholders in the activity:

Early Intervention Centre	AIIMS	Corporate partner (CSR)
Screening	Genetic Counselling	Vehicle
Early identification	Speciality care	Building
Early intervention	Research	Material

The early intervention centre shall be accessible via the cheapest modes of transport and also shall be linked up virtually through telehealth protocols to serve the remotest locations. Regarding space requirements, accessibility norms shall be followed for built-up environments and sufficient open spaces shall be provided to facilitate learning in nature as well as to ensure physical distancing in the times of COVID 19.

The tools for assessment and monitoring of developmental delays are the foremost requirement of early intervention centre. These include tools for screening and confirmation of various disabilities of vision, hearing, intellect, language, behaviour, learning, ASD, etc. One such device

"Sohum" http://www.sohumforall.com/hearing-screening/may be procured after due comments of audiologists for screening and early identification of deafness in neonates and infants.The records need to be maintained in computerised form with due privacy and access to the parent and professional at the time of need.

The programme shall be finely woven with the Women and Child Development Project at the level of Anganwadis. There shall be child visit at 0, 3, 6, 12, 18 and 30 months of age. This may be organised at the doorstep through the grassroot workers like ASHA and the data needs to be uploaded to the electronic health record. The high-risk children or CwD may be followed up by early intervention centre proactively.

At later stage, linkage with Sarva Shiksha Abhiyan (SSA) shall be done for preschool and school going CwD to ensure appropriate educational placement in special schools or an integrated setup.

Summary – Every child shall have a medical diagnosis and prescription. The plan of habilitation shall be carried out by the rehabilitation and paramedical professionals. Continuum of habilitation in society shall be ensured by medico-social worker. Health, WCD and education departments shall be involved at appropriate stages.

12

From ‘Pillar to Post’ to ‘All Under One Roof’: NILD, Kolkata Finds a Solution

- Dr Equebal A.,
Director

Mohapatra J. (OT)
NILD, Kolkata

NIEPVD Dehradun: Behaviour Modification and Family Training-cum-Counseling Room

NILD Kolkata: Consultation Room, Activities of Daily Living (ADL) and Feeding Room

NIEPID Secunderabad: Stairway with Handrails

THE STORY OF MRS X

Mrs X, a mother of two, who resides in a small village in rural Bengal, noticed that her 6-month-old child is not behaving as other children of her age. Not aware of the developmental milestones scientifically but a mother's instincts could tell her that something is not well with the child. Other family members and neighbours also agree with her observations. Her husband stays far off in Noida working as a construction worker and financially supporting his family back home. The neighbour aunty suggested that she should visit the nearest health centre and she did. The doctor at the PHC prescribed some medicines and assured that the child is a late bloomer and everything will be fine as she grows. Months pass by and the child remained as she was. Now the child is 10 months old and Mrs X is worried and discusses the issue with friends & family. She comes to know that a hospital in Kolkata caters to children with disabilities. One day, after a four-hour journey, she reaches at the National Institute for Locomotor Disabilities (NILD) Kolkata. There it is identified that the child has minimal problems with walking and hand functions but the main problem is communication, understanding and maybe some speech & hearing issues. She is assured that all these facilities are available in the same campus but not at one place and they will be taken care of by specialists from these places. She is referred to three different specialists and now the ordeal began.

PROBLEMS WITH THE CURRENT SYSTEM

She was able to meet only one specialist on that day who advised some tests. She could now realise that the same process of registration, waiting, consultation, tests and therapy is to be followed at all these three places. That too, coming to the place every day after a four-hour journey. But she was determined and took all the pain. Got the child examined with all specialists and started the therapy. The efforts started yielding some results. After some time she could notice a few things which are very common in a team-work. For instances:

⇒ Sometimes there is over-confidence of patient on the therapeutic team - replacement of patient goal by team goal which are at times unrealistic and inappropriate. In scientific parlance it is called 'paternalism'.

⇒ Arrogance of some specialists leading to the team taking the patient for granted.

⇒ In addition there was loss of clarity of roles, lack of communication among team members and conflict in decision making.

With limited financial resources and another child to look after, Mrs X started losing hope.

THE NEED FELT AND CONCEPT

The ordeal of Mrs X and many other people like her was also felt by the professionals at the Institute but the institute deals only with locomotor disability including Medical & Surgical services, Physiotherapy (PT), Occupational Therapy (OT), Prosthetics & Orthotics, Rehabilitation Nursing and Rehabilitation Engineering. Other facilities i.e. Intellectual, Visual, Speech & Hearing rehabilitation services are available in the same campus, albeit at a distance of half a kilometre. So, the system of parents & children moving from one professional to another continued.

To overcome the difficulties faced by all such parents, Department of Empowerment of Persons with Disabilities (DEPwD), Ministry of Social Justice and Empowerment (MSJE) came up with the idea and directed all its National Institutes (which were working in areas of single disability) and Composite Regional Centres to establish Early Intervention Centres (EIC) with a cross-disability focus. This idea was well taken by the Institute and the planning of the centre started. For NILD, Kolkata, it was easier to implement the concept of the Ministry as all the professionals are available in the same campus. The Institute utilised the academic and clinical experience available in-campus specialist professionals in designing, selecting and procurement of requisite materials and implementation of the project.

HON'BLE PRESIDENT OF INDIA VISITS NILD

Hon'ble President of India, **Shri Ram Nath Kovind** along with First Lady of India, **Smt. Savita Kovind** visited National Institute for Locomotor Disabilities (NILD), Kolkata on 1st October 2019. Hon'ble Governor of West Bengal, Shri Jagdeep Dhankhar; Hon'ble Minister of MSJE, Dr. Thaawarchand Gehlot; Secretary, DEPwD, Smt. Shakuntala D. Gamlin; Joint Secretary, DEPwD, Dr. Prabodh Seth; Shri K. V. S. Rao, Director, DEPwD and Shri Mrityunjay Jha, D. S., DEPwD were also present.

Hon'ble President visited the newly-established Multi-sensory Integrated Therapy Unit and complimented the Institute for setting up the unit for rehabilitation of children with various disabilities. Hon'ble President interacted with children with disabilities admitted for various rehabilitation services in the indoor ward and also spoke to rehabilitated patients, caregivers and professionals of the institute. He also visited an exhibition of arts and handicrafts made by Artisans with Disabilities. He took a lot of interest in them and praised their artworks. Hon'ble President also dedicated "e-rickshaw" to be used by the institute for ferrying Persons with Disabilities (PwDs) free of cost, from nearby bus stand to the NILD compound and to help the persons with physical disability with their parents and attendants to move inside the campus.

A child with disability welcoming Hon'ble President

Hon'ble President interacting with child and parent in indoor ward

Hon'ble President visiting Sensory Integration Unit at NILD

Hon'ble President interacting with artisans with disability

The visit of Hon'ble President along with other dignitaries was a great honour for the Institute and it paved the way for planning further facilities for rehabilitation of children with disabilities.

When the planning of the centre started, visits by senior-most officials from the Ministry and officials from NIEPID, Hyderabad were a driving force in planning and implementation.

SETTING - UP THE EARLY INTERVENTION CENTRE (EIC) AT NILD

As directed by DEPwD in the month of October 2019, the Institute began to plan the centre by immediately allocating a suitable area in the ground floor with separate entrance. A total of 1040 sq.ft., area was identified initially with 3 rooms. Later on, it was discussed in the meetings under the Chairpersonship of Secretary, DEPwD, Smt. Shakuntala D. Gamlin, and it was decided that the infrastructure and area need to be increased further with accessible features so as to ensure seamless movement of parents and children availing different facilities. Accordingly, another 880 sq. ft. area was added. It was also decided that the 12-feet wide corridor of around 480 sq.ft. may be used as registration / facilitation counter and for parents waiting areas. So, finally an approximate area of 2400 sq. ft. has been allocated on the ground floor for the centre. In addition, the open area just outside the centre is to be developed as a sensory park for children.

Getting things done in a limited time was a challenge which was coupled by the COVID-19 pandemic. The deadline for setting-up the centre in all NIs / CRCs was fixed within 31st March 2020. Things got delayed but senior officials of DEPwD regularly monitored the progress of work, interaction being facilitated through video-conferencing and other electronic modes regarding status of selection process of manpower, renovation of building and infrastructure allotted for services and procurement of equipment in setting up the centre. Emphasis has been laid that the centre should have has an aesthetic appeal and be comfortable and pleasant for parents and children, alike.

Teamwork helps solve problems and by working together as a team the Institute can find the solutions that work best to make the centre functional in stipulated time. Also, we ensured

that quality facilities, care, treatment and support is provided to the children with disabilities and their parents who in turn would become ambassadors of the centre. This will further the objective of establishing these centres to reach and include more and more such parents and their children.

MISSION AND GOALS OF EARLY INTERVENTION CENTRE (EIC)

The Early Intervention Centre at NILD, Kolkata is aimed to identify children with various disabilities as early as possible and to provide specialist intervention services under one roof, as a one-stop facility, to lessen the effects of the developmental delay or disability for children up to six years of age. The focus of the centre will be family centric to support parents in meeting their responsibilities to nurture and enhance their children's development with measurable functional outcomes and improve family life through delivery of effective, outcome-based, high-quality early intervention services. The overall goal of the centre is to have a cross-disability approach by creating opportunities for full participation of children with disabilities and their families by ensuring services are delivered in natural and aesthetic environments like another home in their community to the maximum extent appropriate.

ACCESSIBILITY: The most vital requirement

The EIC at NILD, Kolkata is situated at the ground floor with separate entry and exit only for parents and children with disabilities. The approach road to the centre is wide, cemented and can be easily accessed by wheel chair and vehicles. There is enough space for parking vehicles nearby. The entrance to the centre is built with a ramp and adjacent grab bar/rails in which two wheel-chairs can easily move at a time. The entrance leads to each room of centre for trans-disciplinary services. It is wide enough without any doorsill and each room has enough space for a wheel-chair to move and transfer. The toilet adjacent to centre is accessible for all with height adjusted commode, low height hand basins and with other disabled-friendly interiors.

The centre foresees to identify and meet a child's needs in core developmental areas that include physical development, cognitive development, communication, social or emotional development

and adaptive development. The following specialised services are envisaged:

1. **Centralised registration and data management** – The registration will be done in centralised data management software developed by National Institute of Empowerment of Persons with Intellectual Disabilties (NIEPID), Secunderabad for this purpose. This will connect all EIC units in the country which will enable us to maintain uniformity in functioning, decision making, management, analysis of results and further policy making for the benefit of parents & children. The software-based record-keeping will be used as a reliable source of further policy making decisions, research & development in the area.

2. **Occupational Therapy** – Occupational therapy enables a child to develop gross motor, fine motor and self-help skills using purposeful activity as a medium for fostering movement. Training in Activities of Daily Living caters to those aspects like feeding, bathing and dressing. These self-care skills are important to maximise the functioning and minimise the dependency of the child on parents. The Institute has a well-developed Occupational therapy set-up with experienced faculty the expertise of whom will be utilised to strengthen the functioning of the centre.

3. **Sensory Integration Therapy** – Sensory Integration Therapy is provided for children with sensory problems which are manifested due to early insult to the developing brain. Sensory Integration is useful in treating specific learning disabilities, emotional and behavioural disorders, attention deficit disorder, speech and language disorder, infants at risk, autism and hyperactivity. The centre plans to have a dedicated sensory integration therapy unit to cater to children with such needs.

4. **Physiotherapy** – Physiotherapy interventions takes care of motor development in the child using different neuro-developmental techniques. The emphasis of these techniques is on facilitating movement. Early physiotherapy in a child with cerebral palsy improves muscle strength and coordination, motor control and movement. These are required to meet the early intervention goal of maximising the child's learning potential. The institute has a well-established physiotherapy department with experienced faculty, the facilities and expertise of which will be utilised to strengthen the physiotherapy requirements of the centre.

5. **Prosthetics and Orthotics service** – The field of prosthetics and orthotics offers rehabilitation solutions to children with physical impairments of their limbs or spine to enable them to achieve physical developmental milestone and fulfil their potential for independence, inclusion and participation. Sometimes a simple support such as an ankle-foot orthosis or an ordinary prosthesis can be of great help in achieving mobility. The well-developed prosthetics and orthotics services in the Institute will be of great help in achieving these goals. The department will also be designing and fabricating customised equipment for sitting and activities of daily living for the children.

6. **Audiology testing and Speech intervention** – The critical phase of development of speech and language are the early years of life. The importance of interactions for facilitating speech and language development is an essential component of speech therapy. It also includes identifying and facilitating the specific speech and language deficits in children. Auditory training includes awareness, detection and discrimination (gross and fine discrimination). Auditory training is given in order to make the child aware of all the environmental and speech sounds which help in the development of speech and language.The centre will have a dedicated Speech & Audiology unit. In addition, the services of the regional centre of Ali Yavar Jung National Institute of Speech and Hearing Disabilities (Divyangjan) (AYJNISHD-D), Mumbai situated in the campus will be utilised, if required in specific cases.

7. **Behavioural Modification & Counselling** – Specific interventions like behaviour management and anticipatory guidance are important aspects of overall development of children. Family intervention is targeted for improving the care giving environment. Potential stressors like lack of motivation in mother, time management strategies and referrals for further assistance are the likely interventions. The centre will have segregated areas for counselling of parents so that they can understand the requirements and cope with the stress of juggling their lives between their child and other family responsibilities. If required, the services of the regional centre of NIEPID, Secunderabad situated in the campus will be utilised in select cases.

8. **Medical support** – Medical support is essential for the diagnosis and management of different conditions. As children with disabilities often have multiple problems which may

be a part of a symptom-complex or a syndrome; it is imperative that the child's condition must be diagnosed properly before embarking on a therapy programme. The Institute has a 50-bedded hospital with specialists in the area of Physical Medicine & Rehabilitation and Orthopaedics. Medical specialist in the fields- Paediatrics, ENT, Dental, Ophthalmology will also be empanelled as visiting consultants who will provide service when a child requires any support in Early Intervention Centre. This is in addition to service that is already available in institute like assessment and management of any locomotor disability including surgical intervention by Physical Medicine and Orthopaedics specialists.

9. **Medical Social Worker** – Medical social workers promote the development of hospital services and community healthcare. They will help to assess the socio-economic condition of the parents and provide appropriate counselling. They also help the parents find ways and means to financially manage with the illness/disability. Their services will be pivotal in making the family manage and tap resources for carrying out the rehabilitation and support the family, without which sustained rehabilitation is not possible.

10. **Virtual Reality Rehabilitation** – Virtual Reality (VR) rehabilitation is a promising intervention to improve balance and motor skills in children with developmental delay. The effectiveness of using VR applications has been studied for improvement of a variety of skills. The most intensively studied areas are arm and hand motor skills, control of posture, visual perceptual skills, social skills and pain management. The centre plans to have a VR unit to cater to children with Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorders (ASD) in particular.

11. **Preparatory School** – Preparatory School enables and helps parents to recognise and maximise the potential in their children. In case of children with special needs an Individualised Education Plan (IEP) is required that integrates cognitive, academic, social and behavioural strategies into a comprehensive program designed to instil the fundamental skills of learning. The centre has a preparatory school with two sections- one for toddlers and another for children of 3-6 years of age. The purpose is to recognise their potential, teach them basic skills in a playful and friendly manner and enable them to be ready for inclusive education.

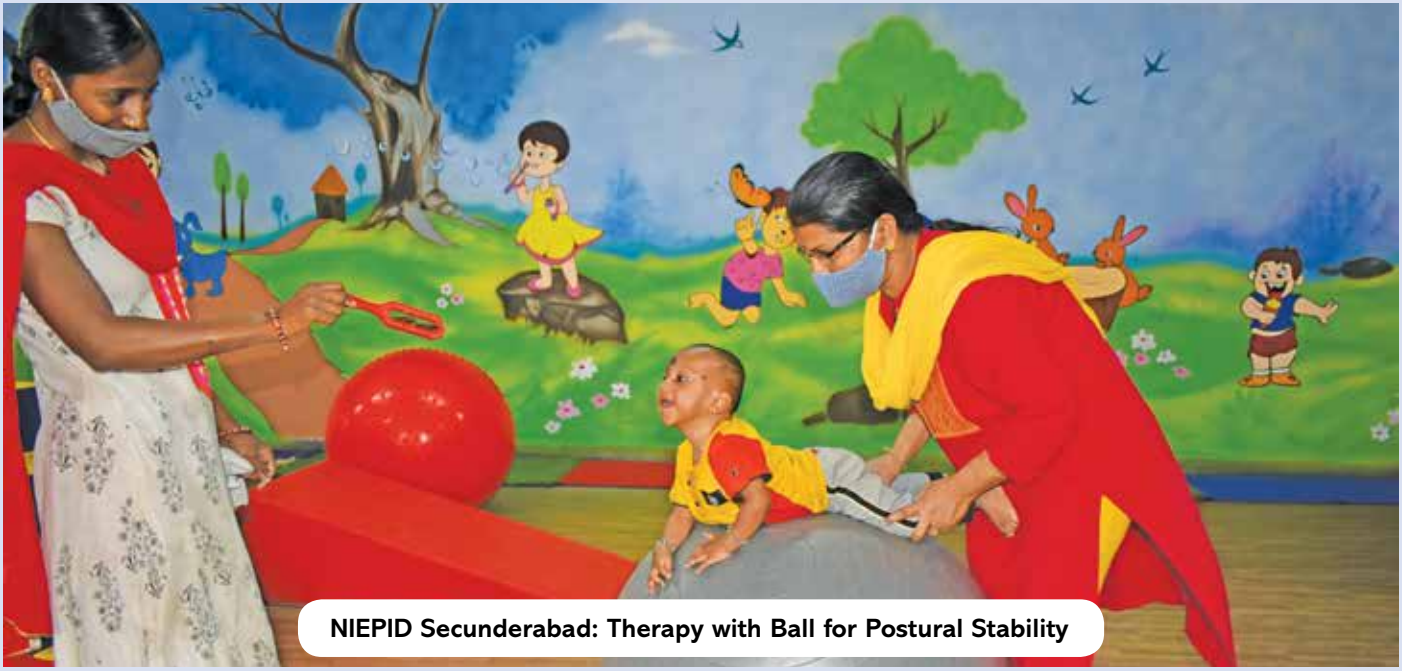
12. **Care of the baby** – As many of the mothers coming to the centre may need to nurse their babies, separate baby care area for mothers has been prepared with adequate seating comfort maintaining privacy.

Thus, the institute plans to have a centre that is aesthetic, parent and child friendly and caters to all requirements of the parents and children with disabilities in one place, within an accessible environment. It will help reduce the agony of parents of moving from one professional to another for various services. With all professionals at one place and coordinated habilitation /rehabilitation programme, the drawbacks of individualised and conflicting decision-making of different professionals will be eliminated and better results may be obtained. This will also instil a sense of confidence in the parents that even with their limited resources and time, they can achieve the possible improvements in their children which in turn will help in mainstreaming them in the society. Hope this centre reduces the burden of disability on parents and children and is successful in implementing the trans-disciplinary model of early intervention service delivery called “Team around the Child”.

13

EARLY IDENTIFICATION AND EARLY INTERVENTION

- Ms. Gunjan Wadhwa, Superintendent (OT)
Mr. Akhilesh Kumar Shukla, Assistant Professor (OT)
Mrs. Smita Jayavant
Director, PDUNIPPD, Delhi



NIEPID Secunderabad: Therapy with Ball for Postural Stability

NILD Kolkata: Physiotherapy

Background

The earliest years of a child's life are critical. These years determine child's survival and thriving in life, and lay the foundation for his/her learning and holistic development. It is during the early years that children develop the cognitive, physical, social and emotional skills that they need to succeed in life. The World Health Organization (WHO) states that early childhood is the most important phase for overall development. Factors like disability and malnutrition pose particularly difficult challenges. However, if these problems are solved at an early age, it minimises developmental risks and enhances child development.

Early identification of developmental disorders is critical to the well-being of children and their families. Delayed or disordered development can be caused by specific medical conditions and may indicate an increased risk of other medical complications and behavioural problems. Early identification should lead to further evaluation, diagnosis, and treatment. It is an integral responsibility of all paediatric healthcare professionals. The prompt early identification can spur specific and appropriate early therapeutic interventions.

'Early Intervention' means a wide range of support given to children during the pregnancy, infancy and early childhood period of development by parents, families and rehabilitation team. In other words, early intervention is giving support to the child as early as possible to enhance her/ his skills and overcome her/ his difficulties, thus leading to a holistic development of the child. It starts when parents are taught about sensory integration and motor dysfunction by the rehabilitation team so that they can develop strategies that help in the improvement of child's level of functioning and development. Thus, it gives support to the child as well as the family, thereby forming the base for the future years.

Since early identification and intervention can be critical for a child's prognosis, all children should undergo developmental screening.

Importance of services of Early Intervention Centres

Services of Early Intervention Centres include a range of healthcare, developmental, therapeutic,

social and cultural services for young children and their families. Children grow very rapidly in the early years and any stimulation at this stage helps to promote a child's optimum growth and development. Therefore, it is presumed that early intervention provides the brain a second chance to revisit some of the developmental stages which have once been incomplete. Parents are helped to become aware of the materials and activities that are suitable for children at each stage of development, and the community resources and services are made available to them as they work with their children.

Early Intervention Centre at the Pt. Deendayal Upadhyaya National Institute for Persons with Physical Disabilities (Divyangjan) PDUNIPPD, New Delhi

PDUNIPPD has been providing its services of early intervention centre to the Divyang children mainly through the Paediatric Unit, Sensory Integration Unit and Psychosocial Remediation Unit of the Department of Occupational Therapy. These services have been augmented by the services provided by the Doctors (Paediatrician and Orthopaedist), Psychologist, Speech therapist, the Department of Physiotherapy, and the Department of Prosthetics & Orthotics. The early intervention services in the institute have been focusing on the developmental screening and therapeutic intervention of the problems identified during screening.

Early Intervention Facility is available for the following categories of Disability:

- Locomotor Disability
- Cerebral Palsy
- Specific Learning Disabilities
- Muscular Dystrophy
- Autism Spectrum Disorder

Early Intervention focuses on the following areas of development of children:

- Motor development
- Sensory development
- Cognitive development
- Perceptual development
- Oral motor development
- Psychosocial development
- Play development

The Rehabilitation Team involved in the present Early Intervention services includes the following professionals:

- Pediatrician
- Occupational therapist
- Psychologist
- Speech therapist
- Orthopaedist
- Physiotherapist
- Prosthetist & Orthotist
- Nurse






Drawbacks of Early Intervention Centre as a Service Delivery System currently available at the PDUNIPPD

- The institute has a common reception / waiting area for adults as well as children.
- Doctors are available on consultancy basis only. Paediatrician is available only once a week and Orthopaedist is available for three days in a week. Other specialists like Neurologists, Ophthalmologists and ENT specialists are not visiting the institute to provide services to the children with disabilities.
- The professionals of the Rehabilitation team providing the early intervention services are not present in one confined area and under one roof. The parents of the child have to visit different rooms department wise.
- The academic activities of the child are not deeply looked into as the Rehabilitation team lacks a Special educator.
- The present Early Intervention services do not focus on the development of school readiness skills in the Divyang children.

- The present Early Intervention services are not able to cater the needs of the children with Deafness and Blindness.
- In the current scenario, the workshop in the Department of Prosthetics and Orthotics is common for both adult and paediatric cases. There is no separate workshop for paediatric cases only.

Motivating Factors contributing to the initiation of Early Intervention Centre

- The Honourable President of India, Shri Ram Nath Kovind, had graced the institute with his presence on 26th October, 2019 in order to celebrate the festival of Diwali with the Divyang children of the institute. The institute also had a privilege to honour Shri Thawar Chand Gehlot, the Minister of Social Justice and Empowerment, on this occasion. He was accompanied by the respected officials from the Ministry.

  The Director of the PDUNIPPD, Smt. Smita Jayavant, delivered a welcome address on the occasion. She gave a brief overview of the services provided by the institute to the Persons with Disabilities (Divyangjan).

  The Honourable President of India had interacted with the Divyang children, their parents and faculty members of the institute. He had presented assistive devices and other therapeutic equipment to the children diagnosed with cerebral palsy, autism, intellectual disability, spina bifida and other neurological disorders.

  The Honourable President of India appreciated the services provided by the institute to the Divyangjan. He also encouraged the staff of the institute to work selflessly in the field of disability. He motivated the staff to put in their extra sincere efforts in the therapeutic intervention of children especially as they are the pillars of building a strong nation.
- The respected Secretary Madam, Ms. Shakuntala Doley Gamlin, DEPwD, Ministry of Social Justice & Empowerment, emphasised her vision of creating an Early Intervention Centre (EIC) model based on Parent-centric Approach.

  We need to understand that if children with developmental delays or disabilities and their

families are not provided with timely and appropriate early intervention, support and protection, their difficulties can become more severe often leading to lifetime consequences, increased poverty and profound exclusion.

- Throughout the years, the institute has specialised and developed its services in the area dealing with the therapeutic intervention of persons with physical disabilities. Realising the fact that cross-disability approach is the need of the hour, the institute needs to expand its services to other disabilities, also.
- The early intervention centres need to be expanded by initiating the classroom learning program and by including the Special Educator in the Rehabilitation team so that the school readiness skills can be promoted in the children upto 6 years of age.

Guided by all the above factors, a separate Early Intervention Centre (EIC) was proposed for construction within the institute's premises that would provide a contiguous and composite complex to cater the therapeutic needs of the children with disabilities.

Efforts made to initiate Early Intervention Centre (EIC)

- The identification of space to start the Early Intervention Centre (EIC) posed a great hurdle in the beginning of this project. The proposed Centre had to be established on the ground floor so that it would have an easy approach and access for the children with disabilities and their parents. A contiguous and composite complex to cater the therapeutic needs of the children with disabilities was the ultimate objective behind establishing Early Intervention Centre. Unfortunately, the current OPD services were distributed in the premises in such a manner that there was no space with an adequate area which could be converted to a contiguous complex. After a series of meetings and discussions, it was decided that the Department of Physiotherapy would vacate 5 rooms and the Department of Occupational Therapy would vacate 1 room on the ground floor. Along with these rooms, two other rooms previously assigned to the Engineer and Research officer/in-charge were also vacated. The Department of Physiotherapy was given an equal space on the first and third floors of the institute's building. The Department of Occupational Therapy was allotted space on the second floor of the hostel building.
- Frequent visits to the institute and regular meetings with the CPWD Engineers were conducted by the respected Joint Secretary Madam, Ms.Tarika Roy, DEPwD, MSJE. She explained them the necessity of providing features of accessibility in such a centre. She gave her valuable suggestions of installing grab bars and tactile tiles in the corridors and the washrooms to be used by the children with visual impairments and other disabilities. In order to ensure a safe and accessible set-up, she had also advised to install an alarm system within the premises of the centre.

Facilities included in Early Intervention Centre

1. **Registration and Facilitation Counter**

Objective: To facilitate distribution of information to families for children "at-risk" and children with developmental delays.

Information boards would be placed at the reception area for sharing of information with the parents. Efforts would be made to make this area accessible to children with all types of disabilities and their families.

2. **Waiting and Resting area**

Objective: To provide a comfortable and congenial waiting room for parents of the children with disabilities.

Parents would be provided a comfortable, well-ventilated seating area and provision will be there for children's play facilities, both indoor and outdoor.

3. **Paediatric Unit**

Objective: To promote early identification of medical problems by a team of doctors.

The consultation services of doctors including ENT surgeons, Neurologist and Ophthalmologist would be provided for children from birth to 6 years of age so that any medical problem that could lead to functional deficits later in the child's life could be diagnosed at an early age.

4. Behavior Modification & Counseling

Objective: To promote psychological well-being of children and their families.

Mental well-being of the child and parents is as important as the physical well-being of the child. Behavioural problems may result in some children due to many reasons. In order to prevent behavioural problems and treat them, if present, a therapeutic approach will be designed to change a particular undesirable / maladaptive behaviour. The unit will provide individualized and group-based behaviour modification therapy sessions under the supervision of qualified clinical psychologists. It will also facilitate psychological intervention and support to the parents and family members of children at risk or with disabilities through counselling.

5. **Feeding and Activities of Daily Living (ADL) Room**

Objective: To facilitate family support by providing a comfortable, safe, and hygienic place for carrying out feeding and changing activities of the child.

The cross-disability early intervention centre at the institute will be catering the needs of children from birth to 6 years of age. It is, therefore, crucial that the therapeutic intervention of the child is carried out without disturbing the routines of the babies, infants and young children. The provision for a feeding and changing room would provide privacy to nursing mothers for feeding their infants and would also provide a comfortable, safe, and hygienic place for carrying out other ADL of the child.

6. **Trans-disciplinary Therapy Unit**

Objective: To promote coordination among various professionals of the Rehabilitation team.

The complex needs of children with disabilities usually require the expertise and knowledge of different professionals. The trans-disciplinary approach is a framework for allowing members of a Rehabilitation team to contribute knowledge and skills, collaborate with other members, and collectively determine the therapy that would benefit a child the most. This approach integrates a child's developmental needs across the major developmental domains and involves a greater degree of collaboration than other service delivery models. The primary purpose of this approach is to pool and integrate the expertise of team members so that more efficient and comprehensive assessment and intervention services may be provided.

7. **Physiotherapy Unit**

Objective: To help the children achieve their developmental milestones.

Physiotherapy is aimed at helping the children to develop and maintain their mobility skills, joint range of movement, muscle strength, and motor skills. It primarily involves the therapeutic activities that help them to restore the motor and physical milestones.

8. **Speech Therapy Unit**

Objective: To promote language development and communication skills of the children.

The ability to express one's self is paramount. Speech therapy can help the child to achieve a greater ability to use and understand language, to communicate with others and to express him or herself. Other benefits of Speech Therapy may include improved swallowing function and safety, achievement of school readiness skills, development of pre-literacy skills, improved vocal quality, fluent speech, greater self-esteem and increased independence. Speech therapist is a qualified professional who would provide the services in this unit.

9. **Occupational Therapy Unit**

Objective: To facilitate independence in daily living skills to the maximum possible extent.

This unit would provide occupational therapy services to help children with special needs develop their daily living skills. The use of purposeful activities and play activities would be an important medium for providing therapy to the children.

10. **Virtual Reality**

Objective: To provide therapeutic intervention using latest technologies and innovations in the field of Rehabilitation.

The Virtual Reality (VR) room would provide a stimulating environment to the children with disabilities. VR can be described as a simulation of real-world environments through a computer which a person can experience through a "human- machine interface". Children with various disabilities have a more limited play experience than healthy children. VR potentially offers children with disabilities the opportunity to participate in games which are usually inaccessible to them. It provides an experience of a three- dimensional spatial degree of movement between the real world and the computer. Children can receive positive visual, proprioceptive, tactile and auditory sensory feedbacks in VR. These sensory experiences facilitate motor learning, postural and motor control and improve sensorial,- perceptual, - motor,- cognitive,- communication skills in children with disabilities. This facilitates children to become more independent individuals in their daily lives.

11. **Visual Stimulation**

Objective: To provide visual stimulation activities to the children "at-risk" or with disabilities.

From birth through to early childhood, children use their senses to explore and try to make sense of the world around them. They do this by touching, tasting, smelling, seeing, moving and hearing. This unit would provide visual sensory experiences to the children. Children and even adults learn best and retain the most information when they engage their senses. Providing opportunities for children to actively use their senses as they explore their world through 'sensory play' is crucial to brain development – it helps to build nerve connections in the brain's pathways. This leads to a child's ability to complete more complex learning tasks and supports cognitive growth, language development, gross motor skills, social interaction and problem solving skills.

12. **Multisensory Unit**

Objective: To provide sensory stimulation in a structured environment.

This unit would provide sensory integration therapy to the children diagnosed with sensory processing issues, Specific Learning Disabilities and Autism Spectrum Disorder. The sensory experiences related to auditory, visual, tactile, olfactory, gustatory, proprioceptive and vestibular sensations would be provided in a structured manner using various therapeutic equipments.

13. **Prosthetics & Orthotics**

Objective: To promote functional independence of a child to the maximum possible extent.

An orthotic device is a simple device that is worn externally by a child. Orthotic devices pave the road towards strength, balance, comfort and independence. They help a child maintain his or her level of mobility, or correct physical issues that are preventing the child from being fully-ambulatory. Paediatric prosthetics are needed when a child has undergone a necessary amputation or is born with any type of congenital limb deficiency. This unit would deal with the fabrication of need-based orthoses and prostheses for the children with disabilities.

14. **Preparatory school (Junior) for 1-3 years**

Objective: To promote school readiness in the children with disabilities of the age group from 1 to 3 years.

The children in early intervention group of 1 to 3 years of age would be enrolled for group sessions in the preparatory classes for school readiness programme. The programme would be conducted by the Special educator.

15. **Preparatory school (Senior) for 3-6 years**

Objective: To promote academic skills and overall age-appropriate skill development in children with disabilities of the age group from 3 to 6 years.

The children in early intervention group 3 to 6 years of age would be enrolled for group sessions in the classroom learning programme. The programme would focus on the foundational literacy and numeracy skills. Besides this, the focus will also be on the development of other domains especially the development of socio-emotional skills. The program will help families in preparing themselves for transitioning and sustaining their children in inclusive schools.

Stepping forward to create opportunities

With the above concept of a family-centred and a parent-friendly approach at the Early Intervention Centres, the objective is to ensure that the children with disabilities who are brought to these Centres by their parents for the screening of the medical problems and the required therapeutic interventions are maximally benefited by the opportunities provided to them. Children are not only the future of a nation; they are the future of the world and humankind, also. Undoubtedly, the children of today will become the future of our country, India. So, we must train them for the future challenges. Providing them the opportunities to grow and develop in a manner so as to utilise their potential to the maximum extent, our efforts would ultimately help build a stronger nation.

14

A 3C Approach to Resource Mobilization for the Cross-Disability Early Identification Centre

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Abstract

The present article is an account of how Ali Yavar Jung National Institute for Speech and Hearing Disabilities (AYJNISHD) (D) mobilised resources for expansion of its early identification and intervention activities of hearing impairment for other disabilities. The article provides a 3C approach of Capacity building, Community involvement and Corporate support for resource mobilization for the said project

Margaret Wheatley's quote "There is no power for change greater than a community discovering what it cares about" was the driver for the team AYJNISHD (D) to revolutionize and expand their services of early intervention.

Early identification and intervention of young babies and infants with hearing loss had been the area of expertise of AYJNISHD (D) since its inception in 1983. The professionals at the headquarters in Mumbai and at its regional centres have been catering to the needs of children born in a silent world or those who acquired hearing loss at a young age. However, the professionals working at the institute always felt that their single super-specialty was not able to cater to the needs of many families whose young infants and toddlers had other developmental delays or disabilities. The plight of not being able to serve all children with disabilities under one roof was worrisome.

Thanks to the initiative of the 'Visionary Team' of DEPwD of MSJE. This gave the much needed impetus and directives for establishing the 'cross disability early identification and intervention centre'. AJNISHD (D), thus, took its baby steps in this direction – a 3C approach for resource mobilization for the cross-disability Early Intervention Centre.

Here is a short narration of the approach that AYJNISHD (D) initiated resource mobilization for Early Intervention Centre (EIC) with a mission of 'Shaping Stronger Futures' for the young infants with varying disabilities.

A small committed team was identified and entrusted the task to set up the centre and initiate its functioning. The team developed an action plan based on project management strategies for

resource mobilization. The activities of planning, estimating and resourcing went much beyond raising funds for the infrastructure. In fact, it helped AYJNISHD(D) to reach out to communities and create awareness about the 'early begun is half done' and 'catch the disabilities young' for giving the children a head start and equity for school readiness.

Space identification, information about other disabilities and estimating fund requirements were the significant essentials which the team decided to address first. The proposal from the DEPwD had very thoughtful and clear guidelines about 'an exclusive space preferably on the ground floor with a separate entrance'. To the team's great relief, a space of floor-area of approximately 4200 sq. ft. at the institutes' ground floor 'E Wing' was made available especially for EIC purposes. The space already had two exclusive and separate entrances. The pre-existing activities in this area before it were earmarked for EIC were relocated and rooms were vacated. This dedication for EIC is because of good-will of the staff members who were previously providing specialized intervention for speech and hearing disabilities, only.

Capacity building of the team:

"Human Resources isn't a thing we do. It's the thing that runs our business." - Steve Wynn.

Human resource is the first essential resource and hence capacity building of the professional team as well as the support of administration team for understanding the core requirements of other disabilities was undertaken. The team members undertook an 'Outside-In' approach by extensively using both inside and outside drivers. The team undertook literature review and browsed through relevant websites to know the global trends in each disability area. This was also coupled with visits to local centres catering to Cerebral palsy, ASD, Visual impairments and Multiple-disabilities in and around Mumbai.

Information received was collated into essentials and desirables. Lists of equipment, materials, learning aids, human resource and contacts details of vendors were amongst the most vital resources drawn together. Desirables for equipment as well as services such as aqua therapy, animal therapy, music and dance therapy were also enlisted, simultaneously.

The experts and practicing professionals from each disability area were approached for their inputs on curricular strategies. Later, a Focus Group Discussion (FGD) was undertaken for drafting a master plan for a centre catering to cross-disability approach. An important outcome of the FGD was a clear indication that the existing identified space and the rooms would have to be re-designed to meet the cross-disability requirements of young children of 0 to 6 year of age with disabilities. This was a huge challenge for which the team decided to tap-in and approach community resources.

Community involvement:

"We cannot live only for ourselves. A thousand fibers connect us with our fellow men." - Herman Melville

AYJNISHD (D) was fortunate to have IES College of Architecture and Design in the vicinity. The team approached the college authorities to explore the possibility for collaboration and for using their young, talented and budding architects for innovative ideas. The proposal was readily accepted and the college consented to undertake designing and reorganizing the rooms aesthetically by keeping in view the needs of young children.

AYJNISHD (D) arranged for a visit and a presentation for the students and faculty of IES College highlighting the 'Accessible India Campaign' as well as sensitized them about the needs of different disabilities. The importance of community service gave the much needed impetus to faculty members and students of IES College. They worked end to end for the project ranging from designing the floor plan, restructuring rooms and even detailing the walls, textures, customized furniture, workstations, window blinds, curtain colours, door hinges and other materials.

Corporate support:

"Contribution to the society is the rent we pay to stay on this planet." -Anonymous

The plans designed by IES College's faculty members and students were phenomenal and

unique. To realize this, fund mobilization became the next uphill task for the team. Fortunately, the Memorandum of Association (MoA) of AYJNISHD (D) had a clause that it could accept donations for its activities. So approaching corporate for CSR support became the mission thereafter for team AYJNISHD (D). A proposal highlighting the need and rationale of early identification and intervention of disabilities with the details of the project design and budget were drawn. The team browsed the websites of various corporate companies for their CSR policies and approached the ones which had education and health as its focus area. A presentation detailing the objectives, plan, the target beneficiaries and the social impact was developed on the following framework.

The steps undertaken for procuring the CSR support were as follows:

1. Establishing credibility: Information provided about achievements of AYJNISHD(D).
2. Alignment of corporate goals: Information on how the project goal matches the CSR policy of the corporate.
3. Bottom up approach: How employees of the corporate working at different levels could be involved in the project.
4. Establishing relationships: How AYJNISHD (D) will project the corporate and its support and also maintain transparency.
5. Emphasising social impact: The project outcomes will help the corporate in contributing for the SDG of 'Quality Education for All'.

Conclusion:

Resource mobilization is a social movement. It is the process of getting resources from the provider using different mechanisms to implement an organisation's predetermined goals. However, its impact is much more than fulfilment of needs between just two organisations. A systematised approach could help in generating a sense of belongingness among different resource providers which is crucial for a sustainable development.

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15

Early Intervention-cum-Preparatory School: Layout and Virtual Reality-Based Therapy

- Nagarjuna Narayanasetti
CRC, Patna

SVNIRTAR Cuttack: Visual Stimulation Therapy

NIPMR Kerala: Training through Virtual Reality-Based Technology

"Early intervention is a system of services that help infants and toddlers who are at risk with developmental delays or disabilities" 1. Early intervention helps infants and toddlers acquire skills that are cardinal in the early years of a child helping them in learning basic and new skills that develop during the first few years of life, such as:

- Physical (rolling, crawling, reaching and walking)
- Cognitive (thinking, solving problems)
- Communication (listening, talking, understanding)
- Social/emotional (Happy, jealous, play)
- Self-help (Activities of Daily Living- ADLs).

If an infant or a toddler shows delay in developmental milestones in one or more areas, they need early intervention. The services they may need are tailor-made to a specific child. Services may include:

A physiatry (Physical Medicine and Rehabilitation- PM&R), physiotherapy, occupational therapy, speech and language therapy, audiology, psychological service, nutrition service, counseling and training for family and preparatory school services, etc.

Early Integration Centre at CRC, Patna

The plan of setting up Early Intervention-cum-Preparatory School was initiated by the Department of Empowerment of Persons with Disabilities (Divyangjan) DEPwD, Ministry of Social Justice (MSJE), Govt. of India in the National Institutes (NIs) and Composite Regional Centres (CRCs) all over India in October 2019 with an aim of early screening, detection, and intervention of disability in children, especially in the age of 0 to 6 years.

The core idea of this concept is to provide all the services of Early Intervention Centre (EIC) under one roof. Barrier-free infrastructure and existing therapeutic facilities of CRC, Patna, made it easier to implement the concept of Early Intervention Centre. Visit by Joint secretary, Department of Empowerment of Persons with Disabilities helped in planning and implementation of the project at CRC, Patna.

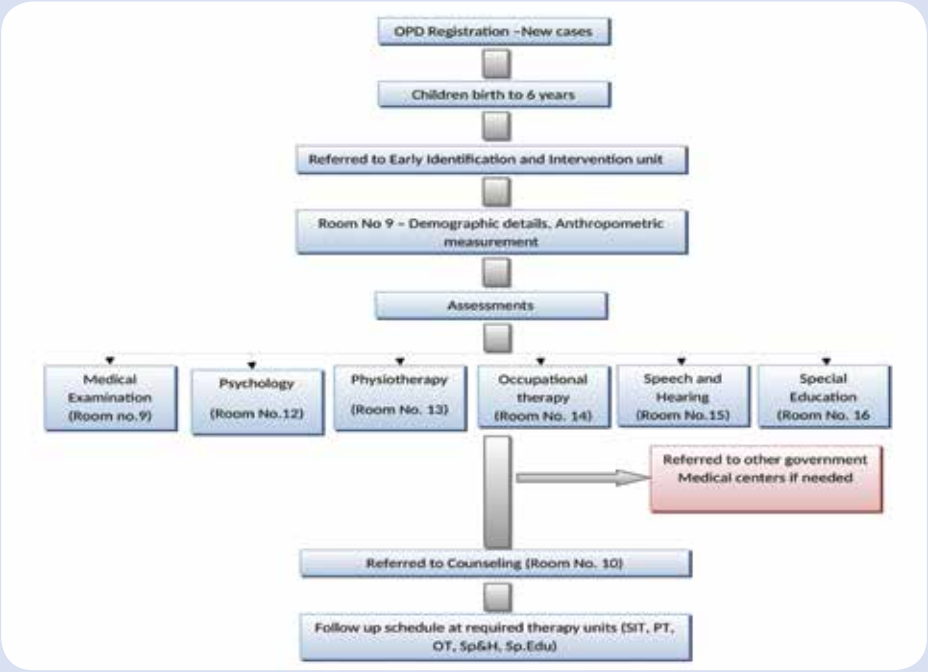
EIC unit is situated on the ground floor with accessible entry and exit with ramps and a corridor with grab bars. Each corner of CRC is barrier-free, accessible through a wheelchair, and with tactile paving to assist persons with visual impairment. The toilet adjacent to the centre is accessible for all with height adjusted commode, low height hand basins, and with other disabled-friendly interiors.

Consultation room, sensory integration room, visual stimulation and virtual reality therapy room, parent counseling, and training room, baby feeding and preparatory school rooms were painted aesthetically to attract children. New chambers of the EIC unit and the existing physiotherapy, occupational therapy, speech and language, and psychological services are equipped with the required equipment and resources to provide early intervention services to children with cross-disabilities.

ACCESS FOR PEOPLE WITH DISABILITIES

EIC unit is situated on the ground floor with accessible entry and exit, ramps, and a corridor with grab bars. Every corner of CRC is barrier-free, accessible through wheelchair, and with tactile paving to assist persons with visual impairment. Spacious parking area dedicated to PwDs and the parking is connected to the unit by ramp with grab bars. The toilet adjacent to the center is accessible for all with height adjusted commode, low height hand basins, and with other disabled-friendly interiors.

EIC Unit at CRC, Patna offers the following services under one roof:



1. **Parent waiting Area, Front Desk & Registration:**

The centre provides an accessible and friendly environment to parent and children with disabilities. Information about services and facilities, the enrolment process, referral services to children with disabilities, families will be provided in this area.

This area is spacious and contains comfortable sitting chairs for waiting, an LED monitor to display the services available at the center, awareness and educational information related to children with special needs, central & state level beneficiary schemes for persons with a disability, etc.

The registration will be done in a centralised data management software developed by National Institute

for the Empowerment of Persons with Intellectual Disabilities (NIEPID), Secunderabad for this purpose. This will connect all EIC units in the country which will enable us to maintain uniformity in functioning, decision making, management, analysis of results, and further policy making for the benefit of parents & children. The software-based record-keeping will be used as a reliable source of further research & development in the area.

2. **Consultation, Family education & Training room :**

Developmental delay causes functional disability and if it's not identified and intervened in the early ages, it makes children unable to perform any activities on their own and becomes dependent. Aiming for an early identification, physical and medical examination by a physiatrist or a pediatrician will be done in the consultation room. Interiors are designed aesthetically to gain maximal cooperation from the child.

Parents play a key role in intervention. Hence, intervention by educating and training parents by way of parent-centric approach is another strategy of intervention. This unit will be utilized for training, networking, and empowering parents of infants / young children at-risk or with disabilities.

This unit is provided with the required furniture, low height assessment couch, assessment equipment, computer for updating case history in the information system (software), and storage cabins to keep case history records.

Area: 350 Sq Ft (Approximately)

3. **Occupational Therapy and Sensory Integration Therapy:**

This unit provides an assessment and treatment plan to improve performance, independent living / daily living skills, play / leisure skills, and social skills. Occupational therapists participate in the in-patient and family education programmes. They provide the parent and the family with the necessary information and resources for independent living. The sensory integration unit will help to optimize the sensory imbalances present in children with developmental disabilities such as Autism Spectrum Disorders.

This unit is having a well-cushioned, safe, and non-slippery foam floor for therapeutic floor

activities for children with special needs. The unit is equipped with all required occupational therapy items like therapy balls, bolsters, prone wedge, wobbling boards, corner chair, multi-activity work station, rehab swing, tactile boards, and complete sensory integration unit, etc.

Area: 400 Sq Ft (Approximately)

4. **Physiotherapy:**

Physiotherapy is aimed at helping the children to develop and maintain their mobility skills, joint range of movement, muscle strength, and motor skills2. This is primarily aimed to undertake activities to help them to restore the motor and physical milestones.

This unit has a well-cushioned, safe, and non-slippery foam floor for therapeutic floor activities for children with special needs. The unit is equipped with all required physiotherapy items like therapy balls, Therabands, weight cuffs, bolsters, balance boards, CP walker and bicycle ergometer, etc.

Area: 400 Sq Ft (Approximately)

5. **Hearing & Speech, Language therapy :**

This unit aims to improve communication, enhancing language learning through language stimulation and the use of language through positive reinforcement, visual, and auditory aids. Speech therapists try to improve communication by helping a child learn an alternative way of communication. It helps in the achievement of school readiness skills.

This unit is equipped with an otoscope, Brainstem Auditory Evoked Responses (BERA), audiometer, hearing screener with automated Otoacoustic Emissions (OAE), audio system, musical box, tape recorder, noisemakers of various kinds, toys and puppets, etc.

Area: 400 Sq Ft (Approximately)

6. **Psychology and Behavioral Modification:**

The unit will provide an assessment of the psychological development of the child, behavioral characteristics of the child and family, intervention through individualised and group-based

behavior modification therapy, family counseling; under supervision of qualified clinical / rehabilitation psychologists. It will also facilitate psychological and interventional support to parents and family members of children at risk or with disabilities through counseling for the mental well-being of the children and their families.

Area: 400 Sq Ft (Approximately)

7. **Special Education:**

This unit focuses on the development of sensory and perceptualmotor skills, cognition, language, and memory of children with special needs. It creates an effective climate for learning and practicing.

8. **Preparatory School:**

The children in early intervention groups, i.e. 3 to 6 years of age, will be enrolled for group sessions in the preparatory classes for school readiness. The programme will focus on early and foundational literacy and numeracy skills. Besides these, the focus will also be on the development of other domains, most importantly on the socio-emotional aspects and dispositions to learning. The programme will help families in preparing themselves for transitioning and sustaining their children in inclusive schools.

Preparatory school's wall painting is designed aesthetically and consists of alphabets, numbers, etc. The school contains a well-cushioned, safe, and non-slippery foam floor, special chairs and C-table for safe and comfortable sitting, CP chairs for CP children, a complete set of Teaching Learning Materials (TLM), and audiovisual system, etc.

9. **Baby Care and Changing Room for Babies:**

The centre will be dealing with the children in the ages of 0–6 years. It's important to take care of the routines of the infants. The centre provides a dedicated, comfortable, safe, and hygienic area for feeding and baby care needs. The baby care area is furnished with a comfortable sofa, low height couch, platform for diaper change, and is well-ventilated. Parents are provided with the facility of safe lockers to keep their belongings during therapy sessions.

Area: 150 Sq Ft (Approximately)

10. **Gender-Specific Accessible Toilets:**

    The toilet adjacent to the centre is accessible for all with a wide entry, height-adjusted commode, low height hand basins, is well-illuminated, has SOS alarm and is equipped with other disabled-friendly interiors.

11. **Accessible Parking**

    Dedicated parking for persons with disabilities near to entry point to the EIC Unit. Parking connected to entry point with wide and low height ramp with grab bars and tactile paving.

The center plans to have an EIC Unit that is accessible, aesthetic, parent and children friendly, and caters as a one-stop solution for all therapeutic requirements for children with disabilities. The centre aims for awareness, treatment, and education on cross-disabilities to children with disabilities and their parents.

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Virtual Reality-Based Therapy

What is the best way to make children learn and practice a task? It's a Play! That's the best way to communicate with children. That's why any therapist dealing with children, especially below 6 years of age, plans therapy sessions in a playful atmosphere and methods. For example, to learn a task of overhead activities by upperlimb, we will encourage him to throw the ball to a marked height. The kid will actively participate and s/he may not feel bored even after many

repetitions. It applies to children with disabilities, too. In traditional rehabilitation, we follow the therapy which is repetitive in nature. These repetitive therapies reduce children's motivation to participate in the therapeutic activities overtime.

When a kid is trying to reach for an object, it seems like a simple process, but in reality, it's a complex act. This activity is a combination of motor acts that are processed from different levels in the brain and body. In children with disabilities, what looks to be an everyday task like eating, reading, writing can become a challenge. Their major goals of rehabilitation are learning functional activities and the application of learned activity in the community. This can be achieved by intensive intervention to improve sensory, motor, and cognitive functions followed by practice of everyday activities in the home and community setting. The activities learned in therapy sessions in a safe and supervised atmosphere sometimes may not be practical in the community. So, learning or practicing of activities in the community /home-simulated atmosphere with no compromise on the safety of children will be a great advantage.

So, children with disabilities should learn and practice in a safe community /home-simulated atmosphere in a playful way. But is it possible?

Virtual reality (VR) recently has emerged as a therapy incorporating rehabilitation strategies in a novel and can be tailor-made to patients' needs with imitation or video game- like activities. Virtual reality is a kind of computer game or virtual reality technique where the child can interact and play with virtual objects in a computer-generated environment (Sandlund, McDonough & Hager-Ross, 2009). Virtual reality-based therapy (VRBT) can provide a positive learning experience and can be engaging and motivating. Virtual environments can be tailor-made by designing tasks that fit the individual's cognitive and physical impairments, which is important in maximising brain reorganization and reactivating those brain areas involved in motor planning, learning, and execution, as well as in maintaining engagement1.

Children who are facing difficulty in walking in the community are benefited by practicing walking in customizable and simulated environments designed to expose dual/multi-tasks and unexpected situations. The child can learn to adapt to new environmental challenges while walking.

For children who are having trouble in reaching activities, VR provides a simulated atmosphere like flying butterflies and bubbles on the screen. Children are encouraged to catch the butterfly/ bubble.

Children can transfer the skills they are learning in the virtual environment to real life.

Children with cerebral palsy, autism, and other neuro-developmental disabilities benefit from VRBT.

Potential benefits of VRBT

- It allows the repeated and constant practice of the same task
- Enable to progress difficulty and challenge levels
- Provide a safe environment to perform activities which are unsafe or difficult in real day-to-day life
- Makes therapy more fun, engaging, and motivating, improves compliance
- Provide real-time feedback about performance

VRBT improves movement, cognitive, behavioral, and social skills in children with disabilities.

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16

Early Intervention and Developmental Disabilities: A Transdisciplinary Approach

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NIEPID Secunderabad: Consultation with Transdisciplinary Team

NIEPID Secunderabad: Transdisciplinary Group Therapy

In India two major acts concern the Persons with Multiple Disabilities (PwMD). The Rights of Persons with Disability Act, 2016 (RPwD Act, 2016) and The National Trust Act, 1999 (NTA, 1999) defines Multiple Disabilities (MD) as a "combination of two or more disabilities". The definition may need additions to decide the candidacy of PwMD and the approach for management because by this definition, a sixty-year-old person who has a limp due to post-polio paralysis and an acquired moderate hearing loss would also qualify to be a PwMD. If such combinations are included, then major disabilities like deaf-blindness, autism spectrum disorders with additional disabilities, and cerebral palsy and other developmental disabilities would fail to get the adequate consideration and resources.

A working definition for MD was evolved from a National Expert Committee Meet (NECM) during 2005 at The National Institute for Empowerment of persons with Multiple Disabilities (NIEPMD), Chennai which indicated that a person with MD in true sense is someone whose needs cannot be addressed by the available therapeutics for the persons with uni-disabilities. The need for evolving specific strategies was very much appreciated by the people who conceived NIEPMD, established at Chennai in 2005. One of the objectives of NIEPMD is to evolve a trans-disciplinary approach which is very distinct and different from the multi and inter-disciplinary approaches of work.

An example, with a pseudonym:

Rani is a five-year-old girl child diagnosed as having developmental delay due to spasticity of upper and lower limbs (diplegia), with minimal sensory neural hearing loss with autistic features like poor eye contact, self-stimulatory behaviors (body rocking, self-murmuring, finger fidgeting, hand flapping, smelling things, mouthing objects and self-biting) along with marked restlessness. She is yet to acquire independent walking, and has sensory issues pertaining to auditory, visual, vestibular and tactile integration. She is stubborn and exhibits challenging behaviors and lack of joint attention. She has not acquired true words and occasionally communicates about objects of interest using intentional communications like vocalizations along with gestures; idiomorph are yet to emerge. She has an adapted ability to grasp a pencil and scribble. Parents want her to be enrolled for formal education but are confused about the choice of school (regular or a

special school). The answer today is clear and loud that she should go to a regular school as inclusion is both the national and international mandate. The Government of India under Sarva Siksha Abhiyan (SSA) since 2001 and the United Nations declaration of Incheon Strategies (2012-2022) advocate inclusion and an inclusive society. Further, the special school is 20 kilometers away from Rani's home.

Rani was sent to the neighborhood school. Parents were happy that the school has a resource teacher available. The first day, Rani comes back from school crying, but she was unable to communicate. The second day, the parents meet the resource teacher who says, he is a special educator trained only for intellectual disabilities and Rani has hearing loss as well. So she belongs to MD and she needs input from another special educator as well. The second resource teacher of the Mandal is trained in hearing loss. The next day the other recourse teacher comes and assesses Rani. He checks the hearing aid and recommends activities to develop communication. He tries to get Rani's attention but Rani's cerebral palsy, ASD features and hearing loss could not be managed by both the resource teachers. Both the resource teachers have a discussion and recommend further consultation and therapy from five other therapists including occupational therapist, audiologist & speech therapist, clinical psychologist and physiotherapist.

Rani's mother accompanies Rani to the therapies and sends her to school as well. She meets the Speech Therapist / Speech Language Pathologist (SLP) to learn better communication skills; Occupational Therapist (OT) for sensory integration and to develop sitting tolerance; Psychologist for having challenging behaviors; Physiotherapist (PT) to develop gross motor skills; Audiologist for auditory training and ensuring that hearing aid is working. About forty-five minutes of bi-weekly sessions for each therapy was recommended for Rani. All the therapist and the special educators unanimously recommended; **"To have the real benefit of therapy, the suggestions from the therapists needs to be understood by Rani's mother and implemented at home. Because Rani spends most her time with the mother at home, while the therapists spend only about 45 minutes with the child**".

Rani's mother managed all therapies for six months. The speech therapist gets married and moves from the town. There are four other speech therapist & audiologists available in town,

three of them were experienced to work with individuals using hearing aids and adults with MD and located five kilometers away. Rani was finding the long journeys very tiresome. She has become irregular to school, she does not like going to school, and children do not accept her. Teacher shifts responsibility to resource teacher who shifts it to therapists and vice-a-versa.

To summarize, the prerequisites for Rani to begin formal inclusive education are:

1. Mother has to find at least five different types of therapists in her city who are accessible and have an experience in dealing children having MD.
2. She should be in a position to afford for the intervention i.e. a minimum of Rs. 300-400 per session. She needs to spend approximately Rs. 2400-3,200 per Week i.e. approximately Rs. 12,000 for therapy per month excluding transport, caregiver charges, medications, therapy materials, etc.
3. She has to manage the time, including travel time (usually double the therapy session); implement the recommendations of all the five professionals at home (on an average three hours per working day); co-ordinate with therapists, family members (she can't just dedicate all her time to the child, as 70% of Indian population live in a joint family). The nuclear families have no support and need to pay for engaging helping hand.
4. Rani needs to have the stamina to travel, adjust with therapist and cope up for formal education.
5. Above all, Rani's mother needs to understand physiotherapy, occupational therapy, speech therapy, special education, basic medications, and principles of psychology; she then has to simplify and implement all the therapy goals at home settings and prepare for the next day of therapy sessions.

After six months, Rani's mother becomes depressed. She has a free-floating anxiety and has picked up signs of apparent aging. She has developed frictions in the family for devoting excess of attention to Rani, remaining absent minded and neglecting other work. She has lost the self-assertive smile which was an integral part of her personality. She also has also been insisting her spouse to take up a rented house, and stay away from family, but near a rehabilitation

institution or clinic which has added to the family conflict. Attending a regular school has become the last priority and Rani is a school dropout. The purpose of SSA has failed and Rani is back to the exclusion model of education along with a lot of other associated issues of the family, mostly of the mother. When the mother is stressed, the child is uncomfortable, language therapy does not work, as it needs a lively environment and substantial joint attention. Even after five months of regular therapy, Rani is yet to be accepted at the school. When will Rani goes to school? There are so many questions left unanswered. But, **three queries for the professionals, keeping in view the need of a team & professional interactions in a team approach comes into picture:**

1. Can Rani's mother continue this daily routine for a few more years? Is it practically feasible?
2. Are we professionals putting up appropriate demands on the parents?
3. Is there a need to discover/follow any other team-work approach?

To answer these three queries:

There are three prevalent models of professional interaction & team work.

Figure 1: Three prevalent models of professional interaction & team work.

Multidisciplinary Team Work:

This is the model in which Rani was receiving therapy. She goes to each therapist separately, gets assessed and receives one-to-one therapy for 30-45 minutes. Recommendations by the therapist have to be implemented by the mother at home. In this model, the professionals do not interact amongst each other formally about Rani's condition and assume that they have a clear understanding about what Rani's condition is and Rani's mother can implement their recommendations at home. The example of the five blind men describing an elephant can be used as an analogy to appreciate the nature of team work in this case.

Interdisciplinary Team work:

In the interdisciplinary approach, the team interacts during the case conference; discuss Rani's condition and challenges. Based upon their individual assessments, together they plan the short-term goals (STG), a long-term goal (LTG) and the activities to be implemented. The goals are common and are agreed upon by the team. However, the therapy by the specialists is one-to-one. Such a model of work is practically possible only in an institutional setting or a multi-specialty clinic with all the therapists under one roof and all of them realizing the need for devoting extra time for a case conference, breaking "professional boundaries" and sharing.

Trans-disciplinary Team Work:

The therapist realises that the child needs to be addressed for multiple developmental domains like communication, cognition, motor and sensory integration, education and medical issues. If the therapy is not provided in an integrated manner, it would be challenging for the caregiver and the therapy may not have its impact. Any therapy method devised for uni-disability fails to work. Rather than putting the burden on the parent to understand, synthesizing and implementing the varieties of services would be easier and effective for the therapists to understand the basic requirements of the child and to train each other to execute therapy in a holistic way. The child needs to be handled by one therapist as a case manager, who assesses and delivers intervention by integrating all the therapy goals. The team trains each other and supervise each other as each one of the them is handling the client for assessment and then for therapy. The

parent needs to be a part of the team and needs to be trained as a co- therapist. This process of training and empowering each other is known as "role release". As and when required, the case manager obtains consultancies and further recommendations from the team members.

The trans-disciplinary model is described as a team approach that crosses and re-crosses disciplinary boundaries. The professionals systematically and stage wise empower each other through "role release" to the case managers and execute client management single-handedly. **Role release** is the **sum of six separate but related processes labelled role extension, role enrichment, role expansion, role exchange, role release, and role support.** Role release allows individual team members to carry out an intervention plan for the child and family backed by the authorisation and consultative support of team members from other disciplines (UCP National Collaborative Infant Project, 1978).

The Six Stages of Role Release:

1. Role Extension: The rehabilitation professional extends out his/her own knowledge and extensively understands all that has been prepared about the specific subject.
2. Role Enrichment: The professional begins to learn about the other disciplines through the processes of discussion and team meeting such as SLP, PT, OT, psychologists, special educators, etc., and gets information about the basic practice methods.
3. Role Expansion: The professional learns how to make observational and programmatic judgment outside of her/his own discipline, for instance learning how to hold a child, learning about muscular twitches and handling and positioning.
4. Role Exchange: In this stage, the professional under the supervision of other professionals such as OT, PT, SLP, psychologists implements the learned positioning and muscle handling skills for a few sessions.
5. Role Release: In this stage, the professional independently incorporates the learned skills.
6. Role Support: Backup to role exchange and role release will be constantly provided by the other team members for a constant living.

Implementing the transdisciplinary approach (Figure -2) in the below given example, Rani's goals were planned by a team after a case conference with reference to the Zone of Proximal Development (ZPD). As Rani had predominant sensory and fine motor issues, the team during the case management agreed to assign the occupational therapist to be the case manager. The case manager took the summary of goals planned by different professionals. The major five domains which were targeted apart from the parental counselling sessions are:

1. The receptive and expressive language;
2. Gross motor development;
3. Fine motor development;
4. Cognitive development;
5. Sensory integration;

All the professionals had undergone the process of role release which empowered them to carry out interventions in a holistic manner. The play way group therapy session was found to be effective in implementing therapy goals across disciplines.

Thus, games were categorised based on the seven senses along with other short-term goals. These activities were implemented and the progress report was reviewed every three months by the team to devise the next set of short-term and long-term goals for Rani (Figure 2). The therapy plan was executed both in group and in individual setting with the parent as a co-therapist. The parent now knows what is being done with the child and provides her inputs, too.

Described below are a set of six games used with Rani for a period of seven months. The speech language therapist was made the case manager. The activities which were found to be effective includes:

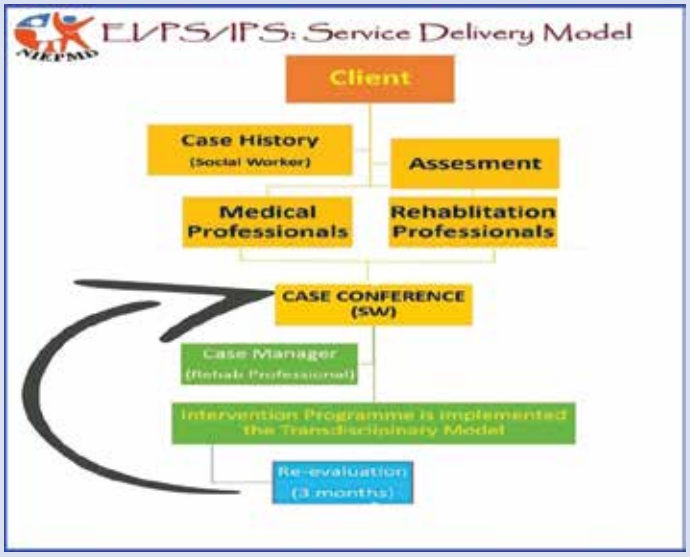

Figure 2: The Transdisciplinary Service Delivery model

Name of the activity: Human Tunnel
(**Focused:** Proprioceptive / Vestibular Integration)

Material used: Ball.

Procedure: Children have to stand with the wide based stand (open leg) in a line keeping some distance from each other. Each child has to pass the ball to the next person by bending forward and from below their legs by calling the next person's name.

Adaptation: Child with disability can stand with support. The size of the ball, the colour and texture of the ball can be varied. The children can be encouraged to crawl through the tunnel. Each child may be asked to say 'bow-bow', 'meow' or just 'aaa' as she/he pushes the ball through the tunnel.

Areas of Development:

Gross Motor skills: Standing with wide based legs, catching and throwing, dynamic balance to facilitate walking & running, increasing base of support for standing balance.

Sensory-based Motor Integration: Understanding beginning and end (motor praxis), adjusting one's body to spaces of different sizes, being part of a group, waiting for a turn, experiencing standing in queue behind others, awareness of others' bodies and allowing them into their space.

Cognitive skills: Enhances learning, boosts self-esteem and confidence, improves socialisation, Piaget's schematic development, adaptation, assimilation and accommodation. Gardener's **Intelligence:** Body kinaesthetic intelligence, naturalistic and visuo-spatial intelligence development.

Language (SLP): Preverbal: Eye contact, joint attention, imitation, turn taking, and socialization.

Receptive language: Action words like in /out / walk /start /stop; names of lexical items, simple commands, phrase level, daily activity.

Expressive language: Idiomorphs, single word, family member's names, simple action verbs, name call, call for the ball.

Literacy skills: Concept of ball, imitation, directions, naming, tracking of page, following instructions.

Name of the Activity: Facial Mask & Make up
(Focused on: Tactile Integration)

Materials used: Powder, plate, mirror, paint,and brush.

Procedure: Make it a group activity. Take the powder and put it on a plate, then apply the powder to the children's face one by one. Then make the children to apply the powder on their friends' faces. Then with the help of mirror show children their faces and how it looks.

Adaptation: Texture of powder and its colour can be modified based on the child's needs. Direction like 'put the powder on my cheek', 'see I made a moustache for Raju, you make one for me' can be given. A mirror can be used to get feedback. The child can be made to blow powder from different distances.

Areas of Development:

Gross Motor skills: Dynamic standing and sitting balance, and shoulder stability;

Fine Motor Skills: Dexterity, in-hand manipulation, Pincer grasp, eye-hand co-ordination

Sensory: Tactile integration, olfactory stimulation, visual stimulation

Psycho- Social skills: Maintain eye contact, attention & concentration, personal hygiene, visual stimulation, problem solving.

Play Skills: Onlooker play

Cognitive Skills: Enhances co-operation and socialisation, builds creativity, helps in emotional development & tolerance, builds self-confidence, Gardner's intelligence: Intra personal, visual spatial, bodily kinaesthetic.

Language (SLP): Preverbal: Joint attention, vocalisation, reaching, eye contact, turn taking.

Receptive language: Action words like in / out / walk / put / apply; names of different animals, body parts.

Expressive language: Expression of action verbs, body parts, colour, simple command

Literacy skill: Eye contact, colours, name of the object, visual perception, grasping of pencil & crayons

Name of the Activity: Wearing Mask
(**Focus:** Tactile Integration)

Materials: Animals/ Birds mask

Procedure: Clinician can wear a mask and children can identify the name of the animals or bird by touching the clinician's mask. Children will enjoy wearing the mask and can make sound of the animal while standing in the queue.

Adaptation: Texture of the mask can be modified for children with over sensitivity. The Mirror can be used for visual feedback.

Areas of Development:

Gross Motor Skills: Standing balance, improve proximal stability

Fine Motor Skills: Eye-hand co-ordination, grasping

Sensory Based Motor Integration: Tactile integration, vestibular & proprioception stimulation, spatial awareness, body kinesthetics.

Cognitive skills: Attention, concentration, self-esteem & confidence, focus and behavioural control, co-operation.

Psycho-social: Eye contact, ability to focus & control their behaviour, language skill, sitting tolerance & waiting tendency, peer group rapport & social interaction.

Language Skill: Pre-verbal: Joint attention, vocalization, reaching, eye contact, turn taking.

Receptive skills: Action words like come/ take/ show/ touch/ go; functional words, auditory integration

Expressive skills: Functional words, different textures of object, animal sounds, idiomorphs (bow bow, meow, etc.), animal names.

Literacy skills: Naming, line formation, imitation, identification of animals & birds, sequences, following instruction.

Name of the Activity: Swing & Ring
(**Focused:** Proprioceptive / Vestibular Integration)

Materials: Blanket, rings stands

Procedure: The child has to lie down on the swing (prone position), hands out. The persons holding the swing have to rock it in backward and forward movement. While rocking, the child has to reach and grasp one ring from the floor and put it in the ring stand one by one.

Adaptation: Speed of the rocking and the challenge level can be varied depending on the child's ability. The child can be given a pencil/ sketch pen/paint while the facilitator may hold a card and prompt the child to write, paint or complete a puzzle or putting a tail to an animal or beak to a bird.

Areas of Development:

Gross Motor Skills: Strengthens core muscles, pivot prone (trunk balance), spinal extension, neck contraction, promotes relaxation, inhibit Asymmetrical Tonic Neck Reflex (ATNR) as the child has mid line orientation.

Fine Motor Skills: Reaching the object, cylindrical grasp, release the object, hand-eye coordination.

Sensory-based Motor Integration: Calming & relaxing, vestibular and proprioceptive integration, gravitational insecurity, spatial awareness.

Cognitive skills: Enhances learning, boosts self-esteem and confidence, enhances spatial orientation, depth and size perception. schemata development, adaptation assimilation and accommodation. Gardener's Intelligence: body kinaesthetic, logical mathematical, verbal linguistics, visual spatial.

Psycho-social skills: Eye contact, improves their ability to focus and behavioural control, social Interaction.

Language (SLP): Preverbal: Joint attention, vocalization, eye contact.

Receptive language: Simple and phrase level commands, identification, discrimination, action verbs (in, out, reach, put), nominal.

Expressive language: Expression of requesting, functional communication (get, give, go, put, take), single word utterance, using some idiomorphs (hoo, hey).

Literacy skills: Following instructions, shapes, size, different colours, sequencing, identification of objects grasp and stroke, picture completions, eye-hand co-ordination.

Name of the Activity: 'Choo-Choo' Train Game
(Focus: Vestibular and Auditory Integration)

Materials used: Rope, red and green flag for the guard, whistle.

Procedure: The children stand in a line. The first child holds the rope, then places the rope in the middle of the open wide legs of other children. The first child may lead the activity with the help of an adult and make the sound of train and move around.

Adaptation: The child with disability can stand and walk with the support. The train may pass an imaginary station. Each child may be given a chance to be the engine and guard.

Areas of Development:

Gross Motor Skills: Dynamic standing balance to initiate walk, standing position.

Fine Motor Skills: Reaching the next child, holding, bilateral hand co-ordination.

Sensory-based Motor Integration: Vestibular stimulation, proprioceptive stimulation, motor praxis, listening skills, group play, auditory integration, rhythm, focusing, imitation, awareness of others.

Cognitive skills: Enhances co-operation, enhances spatial orientation, depth and size and their visual and tactile perception. Gardner's Intelligence: Body kinaesthetic, musical rhythmic, verbal linguistic.

Psycho-social skills: Joint attention, improve their ability to focus and behavioural control, social interaction, making friendship.

Language (SLP): Preverbal: Joint attention, vocalization, reaching, eye contact.

Receptive language: Action words like in / out /walk / go; names of different objects and lexical items, eye contact and attention, social interaction, functional words, auditory integration.

Expressive language: Expression of action verbs (go, come, move, slow, fast) name of the family members and objects (train, rope), single word utterance, imitation, using idiomorphs like 'chuk chuk kooooo'.

Literacy skills: Sequences, name of the child, direction, right & left discrimination, following instruction;

Name of the Activity: Blanket Ride

(**Focused**: Vestibular Integration)

Materials used: Blanket, a spacious area with smooth textured floor.

Procedure: Make it a group activity. Have two or more children sitting on the blanket and have two or more adult or older children pull the blanket. Do a role reversal ride or make the children

to do the activity with other peers.

Adaptation: The child with disability should be placed between two children who have good body balance. The blanket ride can go to different areas which need to be named as if they were stations. Pretend play like getting tickets, pressing horn, making vehicles noise can be used. A musical background or a drumbeat (slow and fast) can promote musical rhythmic intelligence.

Areas Development:

Gross Motor Skills: Dynamic sitting balance, core muscles strength, encouraging co-contraction of flexor, extensor of trunk.

Fine Motor Skills: Holding, bilateral hand co-ordination.

Sensory-based Motor Integration: Vestibular integration, awareness of others, proprioceptive input, awareness of cause and effect, understanding rules.

Cognitive Skills: Enhances co-operation, enhances spatial orientation, depth and size and their visual and tactile perception, pretend play activities. Gardner's Intelligence: Verbal linguistic, body kinaesthetic, musical rhythmic.

Psycho-social Skills: Improve their ability to focus and behavioural control, co-operative play, turn taking, social interaction, making friends;

Language (SLP): Preverbal: Joint attention, vocalization, reaching, eye contact;

Receptive language: Action words like in, out, sit, go, etc., names of children and other functional words.

Expressive language: Expression of action verbs (sit, stand, hold, start, stop), naming, idiomorphs (brrree…1, 2, 3) single-word utterance, stop in between and let the children request for the drag.

Literacy skills: Naming, pull, stop, go, hold, number concept, sound discrimination, rote counting, imitation, following instructions, attention, concentration, equilibrium, reaction.

17

Early Identification and Intervention of Childhood Locomotor Disability

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People around us have uniqueness in their appearances, personalities, thoughts, needs, occupations and interactions with others. For example, some people may have fair complexion, some have dark complexion; some may require headphones to listen to their mobile phones, some may be comfortable in using hearing aids. Among several types of activities, we may find ourselves not be fitting to participate in some of the activities. We all have various kinds of needs. We all have various kinds of skills and competencies. We all find limitations when we interact with our environment. We all try to adapt ourselves to our immediate environment to live a comfortable life.

A person with a disability also tries to adapt herself/himself as per the environmental demands, while interacting with her/his environment and experiences barriers that hinder her/his participation in some activities. But this is much difficult for a person having disabilities among several types (e.g., visual impairment, hearing impairment, locomotor impairment; cerebral palsy, mental retardation and mental illness, children with learning disabilities: i. dyslexia, ii. dysgraphia, iii. dyscalculia, iv. attention deficit and hyperactivity disorder- ADHD, autism spectrum disorder, sensory processing disorders, etc.) and each type have their specific nature and she/he may need extensive support. This can be best achieved by knowing the needs of these people at early age and plan intervention programmes to prepare them for a full and effective participation in school as well as society on an equal basis with others.

Early childhood intervention is the process of providing specialized support and services for infants and young children with developmental delays or disabilities and their families in order to promote development, well-being and community participation. Early intervention is undertaken to influence the development and learning of children from birth to 5 years who have a developmental disability/delay, or who are at risk due to biological or environmental factors1. There is evidence that effective early intervention can positively alter the child's longer term trajectory[2].

Early intervention for children with developmental disabilities involves timely provision of an optimal nurturing and learning environment that aims to maximise developmental and health outcomes and reduce the degree of functional limitations. It is a system of coordinated services

that promotes the child's growth than development and supports families during the critical early years. Early intervention can provide primary, secondary and tertiary prevention.

Early intervention ideally follows early identification of developmental problems. When developmental problems are identified, a comprehensive assessment and diagnosis must be carried out. It must examine the functional abilities, developmental diagnoses, health conditions and other factors likely to influence future outcomes and wellbeing. Identifying these factors enables parents and professionals to better match the intervention and support to the child and family's needs.

There is evidence that providing support and services for infants and young children with early developmental impairments and their families can alter the child's longer term developmental trajectory, and reduce the risk of secondary health and psycho-social complications. Early intervention programs are best delivered in a coordinated, planned, family-centered manner that reflects a life course approach to health and well-being outcomes. Supporting the family is a crucial component of early intervention programs, as the family has a key role in fostering their child's developmental potential and may experience additional stresses as they meet the special needs of their child

Positive early experiences are essential pre-requisites for later success in school, the workplace, and the community. Services to young children who have or are at-risk for developmental delays or disabilities have been shown to positively impact outcomes across developmental domains, including health3, language and communication[4,5,6,7], cognitive development[8,9] and social/emotional development[10,11].

Services from Early Intervention Centres are special services for infants and toddlers at-risk for developmental delays. These services are designed to identify and meet children's needs in five developmental areas. These are physical, cognitive, communication, social or emotional development, sensory and adaptive development.

Increased knowledge in the field of brain development highlighted the importance of early experiences in influencing the growth and development of neural pathways[12] Similarly, according

to Park & Peterson (2003),[13] research on brain development seems to prove that positive and rich experiences during early childhood can have positive effects on brain development, helping children to acquire language, to develop problem-solving skills, to form healthy relationships with peers and adults and to acquire different abilities that will be of importance throughout life.

For Shonkoff & Meisels (2000),[14] Early Intervention Centres (EICs) consists of multidisciplinary services provided to children from birth to six years of age. The main objectives are to: promote child health and well-being; enhance emerging competences; minimize developmental delays; remediate existing or emerging disabilities; prevent functional deterioration; promote adaptive parenting and overall family functioning.

This Early Intervention services improves outcomes, prevent secondary symptoms, reduces parental stress and it is cost effective. These centres will help to reduce the burden of disability by

- Early identification of infants at risk
- Early identification of developmental delays
- Enhancement of normal development
- Acceleration of rate of development
- Acquisition of new behaviour/skills
- Increase in independent functioning
- Early detection and prevention of advanced complications
- Minimizing the effects of disability
- Psychosocial support to families

These Early Intervention Centres will extend its services by

- **Prevention**
- **Early detection**
- **Surveillance**
- **Early treatment**

As per the Census 2011, in India out of the 121 Cr. population, 2.68 Cr. persons are 'differently-abled' which is 2.21% of the total population. Out of which 20.3% are under locomotor category.

There are 472 million children in India under the age of 18 years representing 39% of the country's total population. A large percentage, that is 29% of that figure, constitutes children between the ages of 0 to 6 years. We Indians love children and look to them as an extension of themselves. We feel they are our future.

According to 2011 census, 15 lakh children are having some or other form of disability. If in a country like ours so many numbers of children are having some form of disability, then what is the future and how will build a strong nation.

Common causes of locomotor disability in children's are:

1. **Clubfoot**
2. **Congenital dislocation of knee**
3. **Developmental dislocation of hip**
4. **Cerebral palsy**
5. **Perthe's disease**
6. **Congenital pseudo-arthrosis of tibia**
7. **Congenital skeletal limb deficiency**
8. **Post-traumatic deformity**
9. **Rickets and other childhood lower limb deformity**
10. **Post-infective limb deformity**
11. **Scoliosis**
12. **Dwarfism**
13. **Polio**

All of the above are some of the important causes of childhood locomotor disability. Early diagnosis and intervention will reduce the incidence of locomotor disability in society. Rickets, scurvy and polio are largely eliminated. Parents move from pillar to post to get a proper advice for these types of conditions and they get different advice in different medical set-ups.

There was no single-point entry for caregivers of childhood locomotor disability. Only in four percent cases, treatment was started immediately or within few hours, as perceived by the parents. In majority of the cases the treatment was started within one to six months (31%)15. Treatment gets delayed leading to major surgery and increased health care cost. Early identification and

intervention centers will provide awareness generation and updated information dissemination at all levels not only for parents but also the services providers for all categories of disability including locomotor type. Reduction of childhood trauma and infection will also reduce the burden of locomotor disability in the society.

1. CLUBFEET

Clubfoot is a range of foot abnormalities usually present at birth (congenital) in which a baby's foot is twisted out of shape or position. Clubfoot is a fairly common birth defect and is usually an isolated problem for an otherwise healthy newborn. Incidence of club feet is around 1.19 per 1000 live births. Its causes are multi-factorial. If clubfoot is not treated or managed successfully, it can progress to a severe deformity causing lifelong impairment affecting participation in activities of daily living. Treatment is expensive and time consuming in late presenters and results are also not satisfactory.

Clubfoot can be mild or severe. About half of the children with clubfoot have it in both feet. It can be diagnosed by ultrasound in mother's womb. This prenatal diagnosis helps in preparing parents to prepare them to manage the child just after birth. It can be easily and fully correctable by a plaster technique (Ponseti) in 85% of cases. Plaster has to be started in the first week of birth.

Fig. 1- Club foot at the age of one year

Fig. 2- Can be corrected by 6 weeks if managed early just after birth

Fig. 3- Ultrasound can detect club feet

2. Congenital Dislocation of Knee

Congenital Knee Dislocation (CKD) is a deformity of the knee with bone displacement, present at birth. It is often associated with muscle and ligament contracture. It is more

resistant to non-operative treatment. Early plaster treatment is a result-oriented approach. Plaster has to be started on first and second week after birth. Early surgery is indicated if plaster treatment fails.

Fig. 4- Congenital dislocation of both knee

3. DDH

Developmental Dysplasia of the Hip (DDH) is a condition where the "ball and socket" joint of the hip does not properly form in babies and young children. Risk factors are family history, breech presentation, foot anomalies, scoliosis (spine deformity), and torticollis. DDH is observed mostly to happen on a first-born female child. Screening procedure is an important tool for diagnosis in developed countries.

This congenital problem can be diagnosed by screening programs like Ortolani's and Barlow's test of which therapist are well aware of. Ultrasound of hip is a confirmatory diagnostic procedure. This dislocation of hip joint can be managed by a simple brace (Pavlik's) if diagnosed early. Expensive and time-consuming surgical procedure is necessary in late presenters with many complications. The child will be on bed for months together with plaster. Early identification by clinical tests has shown some chances of improvement and betterment.

Fig. 5. Developmental dislocation of hip

Fig. 6- Pavlik's harness

4. CEREBRAL PALSY

Cerebral palsy (CP) is a group of disorders that affects a person's ability to move and maintain balance and posture. CP is the most common motor disability in childhood. Cerebral means having to do with the brain. Palsy means weakness or problems with using the muscles. It's caused by damage that occurs to the immature brain while it develops, most often in perinatal period. Possible causes include:

- Poor brain development in the womb
- Maternal infections or medical conditions
- Disruption of blood flow to the developing brain
- Genetic conditions
- Ingestion of toxins or drugs during pregnancy
- Damage to the head or skull during delivery
- Complications related to premature delivery
- Meningitis and encephalitis
- Injury to brain

Cerebral palsy in an infant or toddler can be diagnosed by:

- Delays in movements and motor skills, such as holding head up, rolling over, sitting, crawling, and walking
- Body parts that are too stiff or floppy
- Scooting on the bottom instead of crawling
- Inability to stand, even with support

It may be associated with hearing deficits, vision impairment, seizures, cognitive disability, ADHD, behavioral and emotional issues, feeding problems and nutritional deficiencies, gastric reflux, constipation and sleep disorders. They also develop contractures, deformities of limbs, hip joint dislocations and spinal deformity (scoliosis).

Cerebral palsy can be suspected in uterus by ultrasound in some of the cases. Movements disorders in uterus can be detected by use of Ultrasonography (USG) and in Neonatal Intensive Care Unit (NICU) it can be diagnosed by conducting General Movement Assessment (GMA). These are the early diagnosing features of cerebral palsy. Once diagnosed, the child can be managed by early intervention. Developmental therapy, braces, medical management for spasticity and anti-convulsant therapy, Botulinum toxin injections and surgery are the various types of treatment protocols in a child affected with cerebral palsy. Anti-spastic treatment with medicines, botulinum toxin injection and surgery are important treatment for motor development. These children also develop hip-joint dislocation and spinal deformity (scoliosis). These deformities are preventable if detected early and managed early. Our centre will have a single entry and will follow a standard protocol throughout country which will benefit the children with neuro-motor disability.

Fig. 7- Scissoring walking pattern

Fig. 8- GMFCS V

Fig. 9- Hip dislocation in cerebral palsy

Fig. 10- Spine deformity in cerebral Palsy

5. **Congenital Pseudarthrosis of Tibia**

Congenital Pseudarthrosis of the Tibia (CPT) is a rare pathology. The natural history of the disease is extremely unfavorable and once a fracture occurs, there is a little or no tendency for the lesion to heal spontaneously. Early identification and management yields better result.

Fig. 11- Congenital Pseudarthrosis of Tibia

6. PERTHE'S DISEASE

Legg-Calve-Perthes (commonly known as Perthe's Disease) is a childhood condition that occurs when blood supply to the ball part (femoral head) of the hip joint is temporarily interrupted and the bone begins to die. This weakened bone gradually breaks apart and can lose its round shape resulting in hip joint pain and disability due to arthritis. Early signs are limping and not able to sit cross legged or squat. Age of occurrence is 5 to 15 years. This may be confused with sickle cell disease or tuberculosis. Key to diagnosis is suspicion, clinical examination and X-ray of hip joint. Management includes rest, exercise, brace and surgery. Early diagnosis can cure the disease with braces. So early identification and referral to tertiary centre will reduce the burden of disability

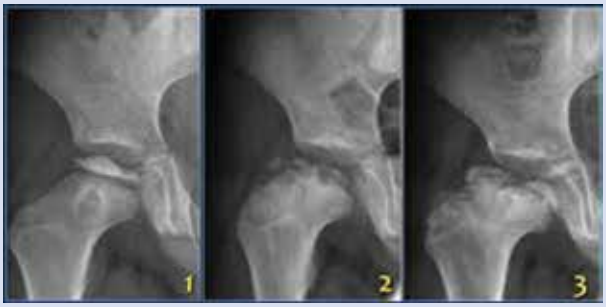

Fig. 12- Perthe's disease – Right Hip

7. SKELETAL LIMB DEFICIENCY

Skeletal limb deficiency (partial or total absence of a bone) needs a plan of treatment which is reassuring to the distraught parents. Causes are multi-factorial and early prosthetic and surgical management reduces the functional dependence of the child. It provides early, successful replacement of the involved extremity. Early acceptance of prosthesis by the family and patient afforded a high degree of reestablishment of function. Improved artificial-limb construction techniques and materials, advanced occupational and physical therapy training methods


Fig. 13- Congenital absence of Radius


Fig. 14- Both side congenital absence of fibula

and utilisation of basic surgical principles at an early age improves the functional status of children with skeletal limb deficiency.

Fig. 15- Both side congenital absence of tibia

Fig. 16- Phocomelia

Fig. 17- Congenital quadric amputee

8. POST TRAUMATIC DEFORMITY

Post-traumatic deformities in children and adolescents can result from a wide variety of traumatic injuries. Most commonly post-traumatic deformities result from mal-union of fracture. Overtime these injuries heal improperly, become more exaggerated and result in further complications. Prevention and proper treatment of trauma in children are very important to prevent post traumatic deformity and its related disability. It is a common belief that children fractures are not important and they heal perfectly whatever the treatment maybe. But in real sense, the bone of a child is a growing bone and improper management of growth plate leads to deformities. Opinion of orthpaedic surgeon having special interest in pediatric fractures should be taken in difficult pediatric fractures and deformities.

Fig.18- Deformity of right lower limb due to road accident.

Fig.19- Correction of deformity after multiple surgeries

9. RICKETS AND OTHER KNEE DEFORMITIES OF CHILDHOOD

The knee deformities area common problem reporting to rehabilitation institutes. Causes are physiological (corrected automatically), rickets, Blount's disease, bone infection (osteomyelitis) and of unknown origin. Cause and location of deformity are diagnosed by X-ray and blood examination. Management includes brace, exercise, medicine and surgery. If diagnosed early and treated at an appropriate time, the deformity can be corrected with minimum intervention. Major and expensive surgery can correct the deformity in late comers. Early identification, treatment and referral will prevent some of the major deformities in adult.

Fig. 20-Rickets-Vitamin D deficiency

Fig. 21-Deformity correct able by brace

10. POST SEPTIC DEFORMITY

Septic arthritis often affecting children is diagnosed late leading to irreversible damage to the articular cartilage, blood supply to the epiphysis and sometimes absorption of head and neck, resulting in severe shortening and disability. It affects hip, knee and other joints of body. It is a destructive arthropathy caused by an intra- articular infection that usually is related to severe symptoms such as pain and decreased range of motion. This condition requires prompt treatment aiming to avoid permanent damage to joint, which may result in chronic deformity or mechanical arthritis. They usually presents with pain and limping. If diagnosed early and managed at an appropriate time, then shortening and disability can be prevented.

Fig.22- Knee deformity due to bone infection during childhood

Fig.23- Childhood hip joint infection leading to disability

11. DWARFISM

Dwarfism is short stature that results from a genetic or medical condition. Dwarfism is generally defined as an adult height of 4 feet 10 inches (147 centimeters) or less. The average adult height among people with dwarfism is 4 feet (122cm). Rights of Persons with Disabilties Act (RPwD Act) 2016 includes dwarfism as a type of disability. All benefits and facilities for any other categories are now extended to dwarfism. Limb lengthening is an option and possible if they are advised in proper time. Limb lengthening not only reduce the disability, it can take care of some of the complications that one can develop during adulthood.

Fig. 24-Dwarfism-a category of disability in RPwD Act 2016

Fig. 25- Limb lengthening in childhood can prevent the burden

12. POLIO

Poliomyelitis, commonly shortened to polio, is an infectious disease caused by the poliovirus. It moves from the gut to affect the central nervous system which leads to muscle weakness resulting in paralysis. It is a highly infectious viral disease that largely affects children under 5 years of age. The last reported cases of wild polio in India were in West Bengal and Gujarat on 13 January 2011. On 27 March 2014, the World Health Organization (WHO) declared India a polio-free country, since no cases of wild polio had been reported in five years. The success of polio eradication goes to pulse polio vaccination programme conducted by Ministry of Health and Family Welfare with the help of NGOs. Today, despite a world wide effort to wipe out polio, polio virus continues to affect children and adults in parts of Asia and Africa. There is a risk for Post Polio Syndrome (PPS), a condition that strikes polio survivors decades after they've recovered from an attack of the poliomyelitis virus. Polio remains at here at in a number of countries. India needs to sustain its high quality efforts to prevent reintroduction of polio, and to ensure all children are protected from the disease.16 Finding children suffering from paralysis because of sudden onset or Acute Flaccid Paralysis (AFP) is a sensitive indicator of wild polio virus activity. Case detected by health workers is reported to local health authorities and to state and national bodies. This surveillance activity can be performed by our early intervention centre spreading throughout country.

Fig.26- Polio affects mainly lower limb

13. SCOLIOSIS

Scoliosis is a sideways curvature of the spine that occurs most often during the growth spurt just before puberty. While scoliosis can be caused by conditions such as cerebral palsy and muscular dystrophy, the cause of most scoliosis is unknown. There is no single factor that contributes to the development of the disease. Scoliosis affects the entire skeletal system including the spine, ribs, and pelvis. It impacts upon the brain and central nervous system and affects the body's hormonal and digestive systems. It can deplete the body's

nutritional resources and damage its major organs including heart and lungs. Moderate to severe scoliosis that is left untreated can lead to pain and increasing deformity, as well as potential heart and lung damage. Severe scoliosis typically progresses with time. Initial phase of treatment includes physiotherapy as well as bracing. If not corrected, surgery is advised to reduce the severity of the spinal curve and to prevent it from getting worse. Early diagnosis and early intervention with brace and therapy reduces the burden on the healthcare system and on the family.

Fig. 27-Spine deformity-Scoliosis

Fig. 28.-Brace prevents severity of deformity

So, it is the duties of all to reduce childhood disability, to make them stand, walk and see smile on their face and family. We are confident that the Early Intervention Centre coming up in the country will be able to achieve mission and vision.

Fig.29- A poor girl after getting treatment of polio is standing in front of her house.

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18

Virtual Reality in Rehabilitation

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NIPMR Kerala: Virtual Reality-Based Technology

NIPMR Kerala: Training through Virtual Reality-Based Technology

Introduction

Virtual Rehabilitation (VR) is a group of clinical intervention (physical, occupational, cognitive, or psychological) that are based on, or augmented by, the use of virtual reality simulation exercises, augmented reality and computing technology.

It provides an interactive and individualized environment in addition to increased motivation during motor tasks as well as facilitating motor learning through multimodal sensory information.

VR systems share three main features: immersion, interaction, and sense of being present in the environment.

The main objectives of the intervention for facilitating motor learning within this definition of Virtual Rehabilitation are to (1) provide repetitive and customised high-intensity training, (2) relay back information on patients' performance via multimodal feedback, and (3) improve motivation.[1]

VR therapies or interventions are based on real-time motion tracking and computer graphic technologies displaying the patients' behaviour during a task in a virtual environment. The VR user feels he or she is a part of the scene.

Types of Virtual reality techniques

Four forms of virtual environments:

1. Head-mounted display – Here subject sees only the computer-generated images and rest of the physical world is blocked from view.
2. Augmented – Both computer generated image and rest of the physical world is visible to the subject
3. Fish Tank VR – Stereo images are produced on a monitor in front of the subject.
4. Projection-based VR- Computer generated imagery is projected on a screen or wall in front of the user like that in a theatre, this has a wide field of view and can be multi-walled and floor systems.

Left: Rajesh Ramachandran (NIPMED) evaluating the head mount VR system in the VR unit in NIPMR Right: ED, NIPMR explaining the functioning of 360 degree camera used for creating virtual environment to honourable minister for health and social justice of Kerala Smt. K.K. Shailaja Teacher

Advantages of VR Rehabilitation

Virtual reality in rehabilitation offers several advantages as follows:

1. VR offers opportunity to bring the variety of complex physical world into the controlled environment.
2. VR allows control over variety of physical variables that influences human behaviour and allows us to record physiological and kinetic responses.
3. VR rehabilitation provides stimulus and response modification based on a person's physical abilities and real time performance feedback, independent practice by user, allows graduated exposure to stimuli, ability to augment user's attention, and most importantly motivation of the user.

4. There are studies demonstrating that transfer of training from virtual to physical environment is smoother and greater if the learner is immersed in the training environment [3]
5. Conventional form of rehabilitation is repetitive by nature, and these repetitions reduce patients' motivation over time. Additionally, it requires at least one therapist to work one-to-one with the patient, increasing the need for resources and, therefore, the costs for the healthcare system. Moreover, it doesn't provide objective data and the ability to monitor the portion of therapy patients complete at home. All of this and more is possible with Virtual reality Rehabilitation.

Comprehensive VR unit at NIPMR:

At VR unit in NIPMR, Irinjalakuda, Kerala, we have a dedicated Virtual Reality based Rehabilitation unit with the following:

1. A unique and customised four-walled virtual reality chamber with 4 projectors and 12 sensors provides an immersive therapy for innovation in all aspects of therapy and training in physical therapy, occupational therapy, speech and for special education.
2. Head-mounted VR system for individual-based skill development and progress monitoring.
3. A Fish Tank VR system-based on kinetic sensors and max box.

There are over 150 virtual reality environments, scenarios and games in these VR systems. This ranges from daily life scenarios, in-house situation, interactive playgrounds, interactive music band system, various interactive environment from deep sea to outer space, simulation of public transport, pedagogic games etc. More such environments are added to this using 360-degree camera and software. (See pictures below)

Legendary Australian cricketer Brett Lee trying Virtual football game at VR chamber at NIPMR`

An Autistic Child with a Therapist does a virtual vegetable shopping

A Child playing virtual musical instruments

Virtual metro (one among many such options)

A Special Child balancing in a virtual volcanic environment

Virtual Beach (one among many such environment and ambience settings)

Learning about moon and space while standing on "virtual moon"

Examples of studies showing effectiveness of VR in various conditions requiring Rehabilitation

1. In one meta-analysis of studies done on VR and motor functions, the difference in results were statistically significant for arm function based on seven studies with 205 participants [2]. They concluded that use of virtual reality and interactive video gaming may be beneficial in improving arm function and ADL function when compared with the same dose of conventional therapy in post stroke patients. [2]
2. Owing to deep learning and big data techniques, algorithms have been developed for diagnosis of autism spectrum that uses Machine Learning methods (ML) with adiagnostic accuracy rate of 96.7%.
3. In another randomised controlled study that examined the feasibility and acceptability of using an immersive Virtual Reality Environment (VRE) alongside Cognitive Behaviour Therapy (CBT) for young people with autism experiencing specific phobia, thirty-two participants were randomised to treatment or control[4]. They concluded that brief VRE exposure with CBT is feasible and acceptable to deliver through child clinical services and is effective for some participants.

Current research supports the clinical use of VR in treatment of physical disabilities, psychological conditions like anxiety disorders, pain management, and eating and weight disorders, psychosis, addictions, dementia, respiratory recovery, ADHD, autism.[5] VR rehabilitation is often combined with tele-rehabilitation where the user can access VR environment and perform prescribed personalised exercises remotely while the healthcare professional is provided objective feedback by the system and in turn makes the necessary modification to the plan of therapy.

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19

Role of Speech-Language Therapist and Strategies to be used in Early Intervention Centres

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Early Intervention Centre (EIC) offers therapeutic and educational services to children who have been diagnosed with hearing impairment, autism, cerebral palsy, global developmental delay and other disabilities.

The goal of Speech Language Therapy (SLT) in EI programme is to promote the development of social communication, speech, language, feeding and addressing the needs of the child.

The roles include:

- Initial screening and identification of the condition
- Assessment and treatment for:
  - Speech disorders (i.e., mis-articulation-articulation errors, fluency, voice problems which also include respiration, phonation, and resonance)
  - Language disorders (phonology, morphology, semantics and syntax)
  - Communication (verbal and nonverbal)
  - Cognitive aspects of communication
  - Pragmatic aspects of communication
  - Behaviour issues in collaboration with psychologist and occupational therapists.
  - Feeding &swallowing (mostly biting, chewing, cup and straw drinking, acceptance of different textured food and swallowing)
  - Maintenance of oral hygiene in children with nasogastric tubes and percutaneous endoscopic gastrostomy.
- Planning of therapeutic goals or programmes
- Coordinating and consultation with other professionals for framing Individualised Educational Plan (IEP)
- Training of parents, caregivers, family members and other professionals
- Educating, supervising, and mentoring new speech-language therapists

- Development of different learning materials for parents and caregivers

  Speech therapy in EI programme is provided mainly through group teaching and in classroom where speech therapist works together with teachers and other rehabilitation professionals to incorporate the IEP goals in classroom-based activities.

  Pull-out or individual speech therapy sessions may be provided to children with severe condition or as per the requirement of the child. Individual therapy sessions may be provided to the child for specific areas such as feeding, articulation and/or Sign Language Interpreter (SLI). The strategies used by the speech therapist in classroom or in individual session may also to be used at classroom setup or at home.

Some of the specific strategies to be used in the early intervention programme:

1. **Picture Exchange Communication System (PECS):** PECS is developed by Frost and Bondy, which is an alternative augmentative communication system, and is used for children with autism spectrum disorders and others with mostly nonverbal communication.

   PECS is not a way to speak but a way of communicating in a social context. This can be used for anyone having difficulty using speech or to communicate. PECS consists of six phases, in which the child learns to communicate from single word to complete sentences and then generalisation. In this child needs to use pictures for a desired item and go to communication partner for exchanging her/his desired item.

   Six phases of PECS are as follows:

   a. The Physical Exchange

   b. Distance & Persistence

   c. Picture Discrimination/Discrimination Training

   d. Sentence Structure

   e. "What do you want?"- Answering

   f. Commenting

The primary goal of PECS is to teach functional communication and can be used with all ages.

2. **More Than Words- The Hanen Programme:** This programme is designed for parents and caregivers of children up to five years of age with autism who are having difficulties in social communication. The objective of this programme is to empower parents as a facilitator of their child to communicate, develop language and communication skills (verbal and nonverbal) in day-to-day routine.

   The following are the strategies as taken from More Than Words:

   - Communication stages and goals
     - o Own agenda
     - o Early communicator
     - o Requester
     - o Partner
   - Strategies
     - o Follow your child's lead
     - o Keep the interaction going
     - o R.O.C.K in play or routine- Repeat what you do and say, Offer opportunities for your child to take turn, Cue your child to take her/his turn and Keep it fun
     - o Helping your child to learn with daily routines
     - o Take out the toys
     - o Expanding child play
     - o Bringing on the books

3. **It Takes Two to Talk (ITTT):** The programme is designed for parents and caregivers of children up to five years of age and who require extra support for their child's speech & language development.

   Some of the key learning points of this programme are:

   - Learning how and why children communicate.

- Different stages of child's communication.
- Strategies to develop communication skills:
  - Let your child lead
  - Take turns
  - Rewarding routines
  - Play
  - Follow your child's lead
  - Add language to the interaction
  - Sharing books, and

These strategies may be used for children with delayed development in day-to-day routine.

4. **Oral Placement Therapy (OPT) for Speech:** OPT for speech teaches oral structural placements to the clients who are unable to produce speech sounds by using auditory or visual input as in traditional therapy. It is a tactile-proprioceptive teaching technique which complements traditional therapy. As speech is a tactile-proprioceptive act, clients with motor or sensory impairments benefit from tactile and proprioceptive components.

   This is used to develop awareness, placement of articulators and stability as these components are important in the development of speech clarity.

   This is used for feeding and speech correction in children of all ages with speech disorders such as misarticulation, dysarthria, apraxia of speech and hearing impairment.

   Client's motor functioning for speech and feeding may be assessed before implementing the OPT and the implementer must be trained or certified to use this technique.

5. **PROMPT:** Prompts for Restructuring Oral Muscular Phonetic Targets, is a multidimensional approach which provides a structured way to examine various modalities such as visual, auditory and tactile across sensory motor areas to evaluate the reliability of oral-motor, sequencing, motor, language and speech characteristics.

   This approach also provides the assessment of dynamic interaction and the development status of speech sub-systems, speech support systems, limb and hand control and their combined effects in the development of communication and speech.

This programme may be used for:

- o Voicing cues
- o To construct an entire phoneme
- o To aid in co-articulation
- o Spontaneous production
- o To change articulator relationship and help to develop awareness at self-correction level.

This approach may be used with delayed development, autism spectrum, dyspraxia, dysarthria, phonological and fluency disorders.

6. **DIR® FloortimeTM:** Developmental, Individual Difference, Relationship-based (DIR®) / FloortimeTM. It is a developmental approach for the children with autism and other developmental delays or challenges. As per Greenspan and Wieder (1999), "DIR® is developmental form of psychotherapy, which works by assisting the child through different stages of socialization leading to higher level of communication."

   In this approach, interaction is done by the parents, teacher and/or therapist with the child in such a way that both child and parents create shared meaning towards the child actions, intent and emotions. The interaction between child and communication partner (parent, teacher, therapist) done through the reciprocal interaction in which communication partner is always respectful of the child's interaction. Through this process, child learns higher levels of communication, social relating and cognitive abilities.

   There are six stages of social-emotional development under DIR:

   - Attention and regulation
   - Engagement
   - Two way communication
   - Complex problem solving and communication
   - Forming emotional ideas
   - Building logical bridges between idea (Logical Reasoning)

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20

Efficacy of Early Intervention in Children with Autism Spectrum Disorder: Case Study

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CRC Lucknow: Sensory Integration (Coordination) Training

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ABSTRACT

Autism is the most common developmental disorder among the spectrum disorders. Children below 3 years suffer from abnormal and impaired development which can lead to autism spectrum disorder (ASD). Children with ASD experience a life-long neurodevelopmental condition that involves persistent challenges in three areas such as restricted/repetitive behaviours, communications, and social interactions. Early intervention with multidisciplinary approach can reduce difficulties in children with autism, particularly in their communication and social interactions and improve their behaviour pattern, which helps in independence and for a better quality of life of persons with autism.

Autistic children require sensory integration therapy, behaviour therapy, special education, group therapy, speech and language therapy for a better outcome. The present study is aimed to investigate the efficacy of early intervention in autistic children based on a case study method. The early intervention comprised of behaviour therapy, socialisation training, speech and language therapy, special education, sensory integration, group therapy and home-based management. The child was assessed using Indian Scale for Assessment of Autism (ISAA) and Short Sensory Profile (SSP) and both scales were used for pre and post assessment of intervention.

Results indicated that the child had improved eye contact, attention and concentration; sensory issues were reduced; hyperactivity was reduced; it was observed that there was an improved ability to recognise parents and socialisation skill improved. This study concluded that early intervention improved the synchronised functions of various sensory inputs in children with autism spectrum disorders to help them in adaptive, behavioural, educational, socialisation and activities of daily living.

Keywords: A Case Study, Autism Spectrum Disorder, and Early Intervention.

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INTRODUCTION

Children with autism spectrum disorder have deficits in mainly three areas – verbal and non-verbal communication, social interaction and problem behaviours. They have persistent deficits in social communication and social interaction across multiple contexts. They may also have restricted and repetitive behaviors and their receptive language skills (comprehension) are always impaired. The deficit in these children varies from mild-to-severe and non-verbal communication is abnormal in these children.

Stereotypic behaviours like patting to self and swaying restrict their range of activities. Eating behaviour is also affected by a limited food preference. The children with autism can be categorised into high functioning and low functioning depending upon the level of difficulties faced in the above-mentioned three key areas. High functioning children have difficulties in understanding facial expressions or some gesture but have normal or above normal intelligence and excellent language abilities. Whereas, on the other hand, children with low functioning autism will have moderate-to-severe intellectually disability, minimum communication skills and may be engaged in self injurious behaviours like repeatedly head banging on wall or floor, biting themselves or others.

These kinds of children with autism require constant support in their daily activities viz. dressing, bathing, feeding, toileting, etc. Furthermore, most of the children with autism have other associated condition like seizure disorder, psychiatric illness, sleep disorder, sensory abnormalities. These associated conditions further complicate the condition of children with autism and management is long drawn and complicated.

Children with autism are hypersensitive towards some particular sensory stimulus like sound, touch, light or smell. In 2016, it was reported that 1 in 68 children had prevalence of hypersensitivity. While, the prevalence rate of hypersensitivity in 2018 was approximately 1 in 59 children. When compared to 2018, in 2016 the prevalence increased to 15% (CDC, 2018). Ramey & Ramey, in 1998 highlighted the children at high risk including children with autism benefit from early intervention programme through professionals following comprehensive, individualized approaches. Lord (1995) found that children with ASD are being diagnosed in

the early 2 years of age. Behavioural modification, developmental therapy, speech therapy are the therapeutic interventional techniques for dealing with these category of children. Timely detection and appropriate treatment are the key factors in improving both the short as well as long term goals. Recent research undertaken in this field suggested that early intervention techniques are more effective than treatment at a later age.

Harris & Handleman, (2000); Sheinkopf & Siegel, (1998) also found that children receiving early intervention treatment as young preschoolers always have better improvements than children receiving intervention treatment as a school-aged children. Harris & Weiss, (1998) emphasises that importance of early intervention services has augmented as children with ASD shows greater improvements who received early intervention services prior to 48 months than those children who received services after 48 months of age. Some studies analysed a group of children with autism found that early intervention programme improves the developmental functioning and on the other side it also decreases the maladaptive behaviours and severity of symptoms of autism (Roger & Vismara, 2008; Sridevi & Sarojarya, 2014).

An investigation concluded that the parent-child interaction therapy is also helpful in improving the child's condition (Sridevi, et al., 2017). Mothers of children with disabilities are more active towards child's care and experience more burden compared to non-disabled children. It was seen that mothers of children with autism and intellectual impairment are more likely to use active coping, positive reframing and planning and acceptance as the coping strategies to cope with their child's disability as studied by Spandana et. al., (2013). On other hand when compared among parents having children with disabilities, Parents of children with autism have more psychiatric difficulties in relation to stress, burden, expressed emotions and it affects the quality of life of parents of children with autism (Sridevi, Debashis & Kumar Raju, 2020). Parents of children with intellectual disabilities experienced significant mental health problems than their counterparts (Sridevi, Sriveni, & Rangaswamy, 2013). McGee & Daly (1999) described about the Walden Toddlers Programme of toddlers with autism in the age group of 15 and 36 months, which focused to improve the incidental teaching and social inclusion. It was found that about 82% of toddlers learned to use meaningful word and about 71% improved in their proximity to other children after completion of the programme. It was also found that social

stories are very useful in modifying the target behaviour among high functioning children with autism as established in a study conducted by Md. Karkhaneh et. al.,(2010) and Gray (1994), where three children with high functioning autism were made to sit in front of a computer and presented with social stories. This type of intervention through video modelling helped in increased and improved rate of social communication which was useful for remediating social skills. Early Start Denver Model (ESDM), is a comprehensive developmental behavioural intervention technique imparted by trained professionals with active support of parents. This interventional method could improve cognitive and adaptive behaviour and help reduce the severity of ASD. It also enhances developmental outcome of young children with autism. One of the key therapeutic technique is Reciprocal Imitation Training (RIT), which is a "naturalistic imitation intervention" prepared to teach spontaneous imitation skill during play as children with autism have difficulties in imitating play action and descriptive gestures of other children. Ingersoll & Gergans (2007) evaluated the effectiveness of parent implemented RIT techniques using a multiple – baseline design among three young children with autism along with their mothers and found its effectiveness of imitation skill teaching to young children with autism satisfactory. It is also found that parents of newly diagnosed children with autism undergoing parent's education and skill training programme have greater positive improvements on their mental health and adjustments. Based on this, it has been recommended to add skill training programme for parents in early intervention programme (Tonge et. al., 2006). Furthermore, Jane Case-Smith and Teresa Bryan 1999, investigated the effect of occupational therapy intervention in a group of five preschool children and found that sensory integration therapy approach have great positive impact on improving children's problem behaviour. The multidisciplinary approaches of early intervention bring significant improvement in the progress of children with ASD specifically in the area of sensory integration, socialization and behavioural pattern (Sridevi & Rangaswamy 2013).

METHODOLOGY

In methodology, the aim was to study the effectiveness of treatment plan with multidisciplinary approach for younger children with autism spectrum disorder. In this study, early interventional

program was adopted in order to reduce the signs and symptoms of autistic children. There was a pre and post test conducted prior to start of this intervention program. This was again assessed after the targeted clients had received six months of multidisciplinary therapeutic program. A 3year old child with a pseudonym Master- 'M' was referred to Composite Regional Centre, Rajnandgaon, Chhattisgarh who underwent assessment with team of professionals and was diagnosed with Moderate Autism with Global Developmental Delay. He was given an all encompassing early interventional program and was provided various therapies for a period of 6 months. An informed consent was taken from the parents of M and they were informed about treatment procedure along with need of psycho-education, parental counselling and home based management.

The chief complaints of M were that he was unable to speak any word, inconsistent eye contact, could not recognize his mother, did not ask for mother when she was away from him, unable to relate with other people, not responding to name call, lack of attention, and was hyperactive. The child showed lack of social & emotional response. He prefered to play alone and not showing interest to play with peer group. He was not able to follow instructions. Also, he showed repetitive behaviors. He was not able to imitate verbal and non-verbal imitation, and was easily disturbed in new situations. His motor development skills were reported to be normal and he started to walk at the age of 1 year. But they also noticed that his symptoms were progressing with the increase of his age. M was self engaged and most of the time he liked to play with pink coloured objects, and tires of the toy cars. He used to carry four match sticks in his hand, and if one match stick was found missing, he used to vehemently search for that and would become restless and scream. He used to make non-contextual, meaningless sounds frequently. His parents noticed that their child's behaviour had increasingly become repetitive and his speech was not yet developed even at the age of 3 years. The birth history of M had no abnormality in pre, neo natal and post natal periods and there was no difficulty reported on motor development as he could walk within 1 year but his speech was delayed and he could not speak a single meaningful word.

In psychological and sensory evaluations, M was diagnosed with Moderate Autism with Global Developmental delay as he was administered under Indian Scale for Assessment of Autism

(ISAA) to understand the severity of autism and his score was 115. He was also assessed by using Denver Developmental Screening Test (DDST) which was used to assess his developmental progress and his score was 60 which also indicated global developmental delay. Short Sensory Profile (SSP) was also used to find out his level of sensory processing and his score was 85 which showed that M had sensory issues interfering his daily activity and developmental pattern. It was observed that in the clinical setting M was found to be restless and preferred to play alone and could not respond when his name was called out. He was not attentive and was very much distracted with external stimuli. M also had difficulty to understand and follow simple instructions. He was found with poor communication skills as he could not speak a single word and his parents helplessly provided for his basic needs.

Treatment Procedure:

Caregiver Counselling:

To deal with the issues of pressure and stress of parents having children with autism, we helped them to learn techniques of self coping in order to manage autistic children; parental counselling was carried out on such parents immediately after the diagnosis of their child. This was done once in a week. Parents were informed about the disorders and its consequences. Detailed information about the need and outcome of early intervention services were also briefed by multidisciplinary team of professionals which involved psychologist, Speech Therapist, Special Educator, Occupational Therapist and also the parents who are the primary care giver.

Sensory Integration:

M was assessed by Occupational Therapist on age-appropriate task-based activities. Accordingly, a goal was defined for M to improve his fine motor coordination skill. This was decided based on M's ability to hold a pencil, to catch a ball, to cut papers, to buttoning and unbuttoning clothing, etc. A detailed therapy plan was prepared to be carried out on daily basis and Mwas given a therapeutic session of 45 minute. After six months of regular and continuous therapy program, Mhe showed significant progress and presently he could write few alphabets and numbers. Mstarted to experience different types of sensations like smoothness, hardness, etc.

while gliding through various textures; he could react to bell's sound; play swing, etc. which supported to address his senses very effectively. He also got opportunity to mingle with other children, to interact and share things which helped him to accrue social skills.

Behaviour Therapy:

The department of clinical psychology provided behavior therapy for the period of six months to reduce his problem behavior such as hyperactivity, repetitive and stereotypic behaviour. In order to improve his attention; to develop eye-to-eye contact, etc. the therapy plan was carried out with the help of clinical psychologist for the duration of 45 min. in each session. The short-term and long term goals to attain the target skills was predefined in order to improve his functional, self help skills, communicational skills, social skills; it also was aimed to reduce his problem behavior, to mainstream him and help him become independent in future. Initially, the activities were shuffled within 2-3 minutes because Mgot distracted every now and then. Later the interval for change in different activities was increased with 7-8 min. M was pre occupied in a strange way with toys and was unable to understand the usual pattern of play with toys. Whenever the therapist observed a pre-occupied behavior in M, the therapist made him to get distracted from that behavior and engaged him by using different activities. The therapist would also signal warning to M, or call out by his name, or command to come and engage them with activities like take the ball, show pictures, or engage him in a talk or by giving toys to him, etc. Gradually, the frequency of pre-occupied behavior was seen to reduce; and after few sessions he started to get engaged in a proper manner. In 6 months of therapeutic approach, he was able to maintain his eye contact and paid attention which sustained for a while. His stereotypic and repetitive behaviors were reduced in a great way and he could follow simple single step instructions, as well.

Speech and Language Therapy

In order to evaluate M's ability in the area of communication; his parents were referred to Department of Speech & Audiology for complete evaluation of speech and communication. After complete assessment, a detailed therapeutic management plan had been developed to improve spontaneous language and maximize M's communication skills which are essential for

his development process for him to be independent. Speech and language therapy sessions were imparted to M on daily basis for around 45 minutes per session. Parents were also provided on Home-based management for continuation of therapy at home. Mother was trained to give language input to M in a natural environment involving natural teaching learning materials as a continuous therapy program.

Initially, M was unable to speak single word at all because of his poor attention and concentration and that lead his ability to speak get delayed and was not co-operative for initial therapy sessions, as well. After few sessions of behaviour modification and other multi-therapy approaches, M was found to be co-operative in speech therapy and his communication skills improved a bit after six month of regular therapy sessions. It was seen that he could speak few words clearly and started to communicate his needs by using initial letters of particular words.

Special Education:

M was evaluated for pre-academic skills by the Department of Special Education, Composite Regional Centre and special educator prepared individualized education program (IEP) on the basis of his educational needs and development of basic concepts. Every child needs pre-academic skills like concept of shape, size, colour and numbers based on their respective age related development. A detailed IEP program was introduced to child initially for 15 minutes per session and gradually increased up to 30 minutes per session. After six months of intensive therapy program, M could recognize various shapes and was able to discriminate between different sizes and was able to identify household articles. He also learned to write few alphabets and numbers.

Group Therapy:

Play is a wonderful tool for helping children to move beyond autism's self-absorption into real space and to interact. Play therapy can also allow youngsters to explore their feelings, their environment, and their relationships with parents, siblings and peers. Improving M's play skills, play therapy was implemented in three stages. The first stage was a starting point forM to get used to playing with another person. During this phase, prioritising M's likes was considered.

For instance, if Mliked to ride tricycle, then this engagement was child centred based on his wish. The focus was on building a rapport with the child. This was a good starting point for Mto accept another person's presence in his world. Parallel play is the second stage and in this stage, and Mdoes not play with another child but just plays alongside with that other child. In this activity, both the children would be involved in similar kind of play. The third stage is a group play. For this, M is evaluated and planned for long term goals. The role of parents was assigned where they had to follow M's play as mentioned above. Mwas involved in group therapy sessions along with his parents so as to initiate and interact with other children; to wish and greet others when asked to do so, and was trained to develop patience, group play etiquette and wait for his turn during the play. Parents were also suggested to continue these techniques in home for future development and to improve his social skills in group situations.

Social Skills Training:

Social Skill Training is one of the key areas where a child with autism needs specific interventions and is trained on learning how to act and react in a social situation. The training aims at teaching children with autism to maintain eye contact, to develop sense of self, to wait for their turn, to reply to questions; these children also explained the rules of address. Therapists along with M's parents attempts to develop M's own awareness, their strengths, limitation, interest, etc. Starting at a very basic level, M is taught to identify his image in the mirror. Therapist used the technique to point out M's reflection in the mirror and called out his name, and simultaneously, the therapist would mirror the same action on themselves. The same technique of pointing finger is replicated to identify a person in the photograph. For long term goals, the mother is asked to teach identification of body parts to M as tasks for him to do in home. She is also taught to use sorting techniques so that she can make M exercise in order to sort out his cloths and other belongings. The picture cards were introduced to teach him for answering the questions. Afterwards, Mwas trained to answer conversational questions, and taught to respond to small phrases like, 'I don't know', 'I like this', 'Yes', 'No', etc. These techniques were also used in a group situation along with other children as it helps to understand and observe other imitating children. M started to respond to questions at least with gestures and was motivated to use sounds for his needs as a conversational pattern.

Home based management

The mother of M showed interest to involve all these comprehensive therapy programs of different departments and she was actively involved in each session to train herself for replicating the same at home environment for her child with autism. The therapist provided training and suggestions along with clarifications, if any, to make her to understand and to prepare in order to help M. The mother was suggested to use all these techniques which were taught to her during these six months of intensive therapy program for the betterment of M's condition. She used to continue the intervention process at home and spent a lot of time with M, engaged him with different activities and new behavioural techniques. She followed the therapists' instructions and continued the therapy process at home which impacted M's condition positively.

RESULTS AND DISCUSSION

M was provided with six months of early intervention at an early stage and was provided different therapeutic interventions based on his physiological signs and symptoms of autism. He visited different departments of Composite Regional Centre for therapeutic interventional sessions and the professionals provided need-based therapies such as behavior therapy to reduce his hyperactivity, repetitive and stereotypic behaviors; speech and language therapy to improve his communication skills; group therapy to develop socialization skill and to encourage pretend and parallel play patterns; and sensory integration to regulate his sensory process. M was re-assessed with ISAA and SSP to find out improvement in all the areas of autistic behavior and sensory profile pattern. The result after six months of regular and continuous therapeutic program with different professional support system, M's hyperactivity was fairly reduced and he was co-operative with therapist for about 25-30 min per session without any distractions. He started to maintain eye contact and also started to reciprocate to smile. He became attentive and followed single step instructions without any difficulty. He started to communicate his needs with simple initial letters of words and could speak few words clearly. His concepts on shape and size developed a bit and he started to use pencil for writing few letters. He showed interest in coloring and could count single digit numbers. He initiated to interact and was involved in a parallel play pattern to some extent and used to greet therapist when asked to do so. His

emotional responsiveness improved with his parents and family members and his making of meaningless sounds significantly vanished. Parents were happy with his overall improvement and assured the centre for continuing his therapies regularly.

Table-1: Scores on Indian Scale for Assessment of Autism (ISSA) before and after therapy program

S. No.	ISSA Domains	Before therapy score	After therapy score
1.	Social relationship and reciprocity	29	19
2.	Emotional responsiveness	15	11
3.	Speech-language and communication	29	26
4.	Behaviour patterns	14	9
5.	Sensory aspects	18	11
6.	Cognitive component	10	5
	Total	**115**	**81**

Table 1: Scores on Indian Scale for Assessment of Autism (ISSA)

Table -1 present pre and post intervention scores on ISSA scale in each domain. The ISSA scores were reduced in almost all six areas such as Social relationship and reciprocity, Emotional responsiveness, Behaviour patterns, Speech-language and communication, Sensory aspects, Cognitive components but performance on Speech-language and verbal communication was comparatively less. Graphical representation given below is based on the scores as shown in Table 1.

Figure 1: Graphical representation on each domain of Indian Scale for Assessment of Autism (ISSA)

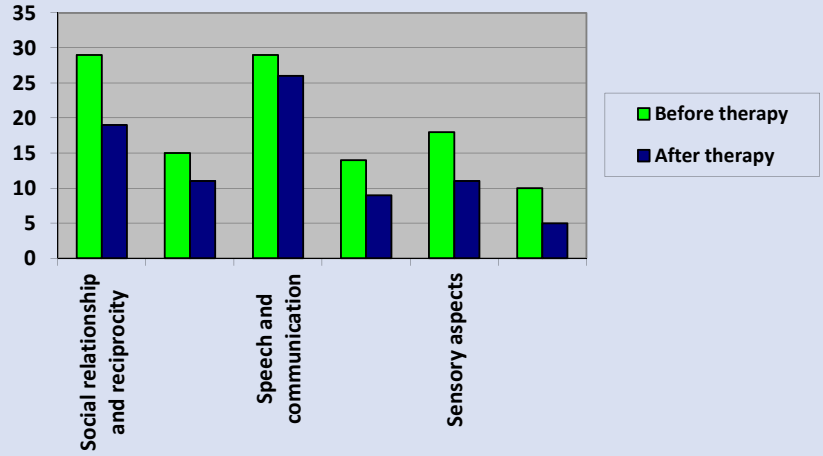

Figure 1: Graphical representation on each domain of Indian Scale for Assessment of Autism (ISSA)

Figure 2: Graphical representation on Indian Scale for Assessment of Autism (ISSA)

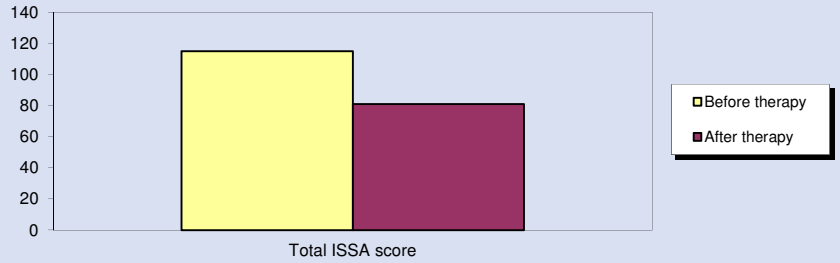

Figure 2: Graphical representation on Indian Scale for Assessment of Autism (ISSA)

The above figure-2 graphically presents the total scores of ISSA wherein the score after therapy was 81 while the score before therapy was 115. This indicates his reduced autistic features which ranges from moderate level to mild level. This shows that therapeutic intervention program in early stage helps to effectively improve in M's behaviour pattern.

Table-2: Scores on Short Sensory Profile (SSP)

S. No.	ISSA Domains	Before therapy score	After therapy score
1.	Tactile sensitivity	12	32
2.	Taste/smell sensitivity	10	17

3.	Movement sensitivity	7	12
4.	Under responsive/seeking sensation	11	23
5.	Auditory filtering	14	20
6.	Low energy	18	25
7.	Visual/ auditory sensitivity	12	16
	Total	**84**	**145**

Table 2: Score on Short Sensory Profile (SSP)

The above Table presents scores on Short Sensory Profile (SSP) in each domain. In SSP, greater improvement was seen in Tactile sensitivity, Under responsive/seeking, Movement sensitivity, Visual/auditory sensitivity, and Taste/smell sensitivity. While, there is need to improve in the domains of Auditory filtering and Low energy.

Figure 3: Graphical representation on each domain of Short Sensory Profile (SSP)

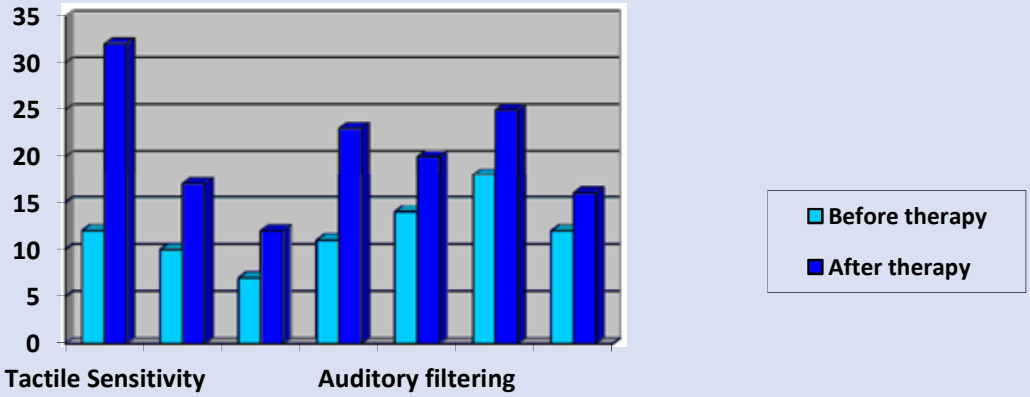

Figure-3 represents the pre and post intervention scores on Short Sensory Profile (SSP) in each domain. In SSP the greater improvement shown in tactile sensitivity, under responsive/seeking, movement sensitivity, visual/auditory sensitivity, taste/smell sensitivity and in the domains of auditory filtering and low energy need to be improved.

Figure 4: Scores on total score of Short Sensory Profile (SSP)

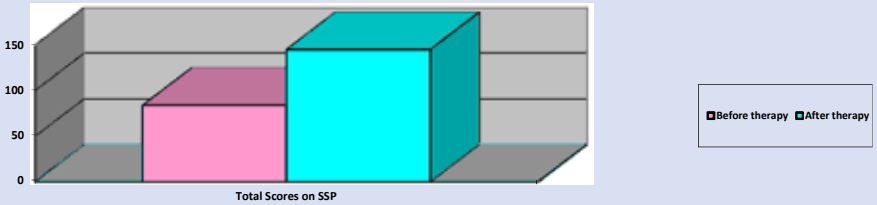

Figure 4: Scores on total score of Short Sensory Profile (SSP)

The above figure represents total scores of Short Sensory Profile (SSP) wherein his score before therapy was 84 which indicated that there is a definite sensory issue interfering with the daily activity and developmental pattern of the child. It was seen that after therapy, the total score improved to 145 as compared to 84 which indicated that there was a better probability of dealing with sensory issues. It proved that multidisciplinary approach of early intervention program using sensory integration therapy works effectively in autism spectrum disorder.

CONCLUSIONS

An approach to therapeutic intervention treatment in early stages could improve child's condition and through this case study, it attempted in indicating that the child improved in eye contact, attention and concentration; sensory issues were reduced; hyperactivity was reduced; and he was able to recognize parents and his socialization skill improved. It concludes that early intervention improved the synchronized functions of various sensory inputs in children with autism spectrum disorders to help them in adaptive, behavioural, sensory, educational, socialization and Activity of Daily Living.

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21

Early Intervention- Evidence-Based Activities: A Medical Officer's viewpoint

- Dr. J. Vijayalakshmy
Consultant, NIEPMD Chennai

NIEPID Secunderabad: Coordination Skill Training

NILD Kolkata: Occupational Therapy

A person with Intellectual and Developmental Disability (IDD) can be described as having difficulty in functioning related to cognition or physical condition originating from birth. It may be ranging from mild to severe and are generally regarded by limits in cognitive functioning and adaptive day-to-day actions and related skills.

There has been progress in catering to the needs of persons with IDD. With the vision of setting up of Early Intervention Centres (EICs) throughout India, undertaken by the Department of Empowerment of Persons with Disabilities (DEPwD), Ministry of Social Justice and Empowerment (MSJE), it is desired to catch them young where in a cross-disability setup, children from 0 to 6 years age can be identified at an initial stage and an early intervention can take place.

Reviewing the intervention from a medical care concept, simple procedures have to be followed for children in the early intervention group. A baseline assessment is conducted at a preliminary stage in each area like sensory, motor, cognition, language, social and emotional. After the baseline assessment, a plan centred on the child's need has to be written down. Prioritising the need of the child, simple activities which could be followed at home, too, needs to be given to the child. Even in the case of equipment and materials which would be in the form of toys should be age and need appropriate such that it is easy for the child to manipulate.

The activity for a child entering the centre for intervention begins with the ritualistic reception of the mother and child. If the child and the mother have travelled from a faraway place, they are allowed to freshen up before the intervention begins. Once fresh, they are attended by the professional who keeps a smiling face and greets the child with a loud 'Good Morning' while positioning the child by holding the child's hand and making the child feel the object of identity. The interventionist would sing a song and lead the child into the room, talk about the activities for the day with the mother of the child and simultaneously make the child feel the objects in the Timetable Box. Timetable box will have real objects representing the activity which could be given in the form of picture or a miniature object or a written word. Some children will be able to use large printed words or even in Braille.

Images showing examples of Timetable Box

Sensory activities could be started by introducing the day with a real vegetable. Monday can be represented using a potato where the child is made to touch, smell, and taste potato. Holding the potato in the hand will help the child to improve hand function. If the child progresses with these activities, then the child will be given an opportunity to trace the potato on a paper. If the child is visually compromised, the tracing could be done using a Velcro board with a thread. Cutting the potato and putting vegetable print could be a motor activity. This type of activity is used for stimulation of all areas of sensory development. Repeating the same activity will help the child to understand these nuances. Each day should be introduced with unique vegetables available. Depending on the severity of the disorders, the skill achievement time will vary, though the time period given for development of the skill is three months.

Relaxation is needed between the activities. So the child is made to lie down on a mattress and powder massage using talcum powder or herbal powder is given. Singing about body parts while massaging the body will enable the child to learn about body parts for those who do not have hearing issues. This activity improves tactile sensation, cognitive understanding, touch and smell, and movements will improve muscles. The child will also get speech and language stimulation.

Putting the child on a comfortable position and giving one or two textured toys that also produce sound can improve touch and hearing.

Structured exercises for the muscles will be given on the therapy ball or on the mattress by the physiotherapist for developing head steadiness, trunk control, sitting and standing and walking skills. When child is on therapy ball, make him look at the coloured objects in front, held by the mother. Mother has to talk to the child whenever possible during the activities. Facilitating the motor development is the aim of the therapist till the child cooperates. This might take around 15 to 20minutes.

Make the child feel relaxed inside the "Be active box". Multiple stimulation will be provided in the box for vision and hearing, vibration, touch, body image development, muscular coordination and spatial orientation.

Image- Be Active Box

Play activity is a must for skill and language development

Thumb printing using water colours helps the child to make thumbprint from left to right on a paper. Conversation on colours and numbers can be given by counting each thumb print. Play activities can alternate with water and sand play and a visit to sensory garden.

Occupational therapy and Speech therapy can be given on alternate days as the first activity for 20minutes followed with other activities.

Feeding has to be taught to parents based on the condition.

Mothers can write down the activity done in a diary. When the mother gets time, she will work with the child at home.

Behavioural modification is needed in children with Intellectual disability, autism and attention deficit hyperactivity disorder. Once in two weeks, a psychological intervention could be given in the first 30 to 40 minutes. An instance of chalking out daily therapy for a child and her/his parents are as follows:

Monday	S-M-I	Play	Feeding technique
Tuesday	OT	S-M-I	Toilet training
Wednesday	Speech	S-M-I	Relaxation
Thursday	Clinical psychology	OT	Behaviour Modification
Friday	Speech	Play	Parent as therapist

Table- 1

Abbreviations from Table- 1:

⇒ S-M-I: S- Sensory training; M- Motor development; I-Improving cognition;

⇒ OT- Occupational Therapy;

Time allotment for the above mentioned routine in Table- 1.

The total time allotted will be 45 minutes.

⇒ The Sensory training for 15 minutes;

⇒ Motor development- 20 minutes;

⇒ Play- 10minutes;

⇒ Occupational therapy- 20 to 30 minutes;

⇒ Clinical psychology intervention- 30 minutes;

⇒ Speech therapy- 20 minutes as speech stimulation is given even during all the other activity;

⇒ Once a week, 20 minutes could be allotted to mothers to work with children in presence of the therapist;

Certain guidelines to be followed during therapy in view of COIVD19 pandemic:

⇒ Care should be taken to wear mask and to maintain physical distancing until the present pandemic ends.

⇒ Therapist should wash their hands with soap and water, and direct face-to-face interaction should be restricted.

⇒ If the child cries for long time or if it develop fits, do not continue the therapy

22

Annexures

Annexure - A

No.14-6/2019-CD.I (e-69396)
Government of India
Ministry of Women & Child Development

Shastri Bhawan, New Delhi-1
Dated: 2nd September, 2019

To,

Principal Secretaries/Secretaries in-charge of WCD/Social Welfare (dealing with Anganwadi Services) in all States/UTs

Subject: Identification of early cases of disabilities among children - Regarding.

Sir/Madam,

I am directed to forward herewith a copy of the D.O. letter No. 22-18/2019-~~डीडी~~ III, dated 04.06.2019 received from Hon'ble Minister of Social Justice & Empowerment regarding identification of disabilities among children at the early growing stages at the wide network of Anganwadi Centres under this Ministry in coordination with District Early Intervention Centres (DEICs) under the Ministry of Health & Family Welfare.

2. The Right for Persons with Disabilities Act, 2016 provides for health check-up of children for any early signs of disability at an early age. Early diagnosis of disability can lower the level of disability and enable the family to treat the children medically and socially.

3. In the current scenario, for detecting the higher risk cases of disability, District Early Intervention Centres (DEICs) have been set up by the Ministry of Health & Family Welfare (MoH&FW). Most of the cases of disabilities among children in rural areas are ignored resulting in delayed treatment/rehabilitation. Early the disability is detected, early comes the treatment/rehabilitation and social inclusion.

4. Anganwadi Workers can prove to be a great help for early detection of disability among children. The Anganwadi Services functionaries in coordination with District Early Intervention Centres (DEICs) can identify the early cases of disabilities at Anganwadi Centres & DEICs.

5. It is, therefore, requested to issue necessary instructions to Anganwadi Services functionaries in the State/UT to take necessary steps in identifying the early cases of disabilities among children at the wide network of Anganwadi Centres in coordination with the District Early Intervention Centres (DEICs).

Yours faithfully,

Enclosure: As above

(Navendra Singh)
Director (Anganwadi Services)

Copy to:

Directors (Anganwadi Services) in all States/UTs

डॉ. थावरचन्द गेहलोत
DR. THAAWARCHAND GEHLOT
सामाजिक न्याय और अधिकारिता मंत्री
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अ.सा.स. 22–18/2019–डाडा–III

दिनांक 04 जून, 2019

आरणीया श्रीमती स्मृति जूबिन ईरानी जी,

जैसा कि आपको पता हैं कि सरकार ने दिव्यांगजन अधिकार अधिनियम, 2016 को अधिनियमित किया है जो दिनांक 19.04.2017 से प्रभावी हुआ। अधिनियम में अन्य बातों के साथ–साथ दिव्यांगता के निवारण की विभिन्न पद्धतियों को बढ़ावा देने के साथ–साथ 'जोखिम वाले' मामलों की पहचान करने के उद्देश्य से वर्ष में कम से कम एक बार सभी बच्चों की जांच करने पर ध्यान केंद्रित किया गया है। हमारी पार्टी के चुनावी घोषणापत्र 2019 में प्रारंभिक स्तर पर दिव्यांगता के मामलों का पता लगाने को सुनिश्चित करने के लिए आंगनबाड़ी और प्री–स्कूल प्रणाली को सशक्त बनाने पर जोर दिया गया है।

2. दिव्यांगता के मामलों की प्रारंभिक पहचान दिव्यांगजनों के प्रभावी पुनर्वास की कुंजी है। प्रारंभिक निदान से न केवल दिव्यांगता के प्रशमन और कमी करने में सहायता मिलती है बल्कि यह प्रारंभिक स्तर पर समुचित पुनर्वास दृष्टिकोण अपनाने में परिवार और प्राधिकारियों के लिए मार्ग प्रशस्त करता है। जो दिव्यांग बच्चे को एक स्वतंत्र और सम्मानजनक जीवन जीने के लिए सक्षम बनाता है।

3. जैसे आज स्थिति हैं, जोखिम वाले मामलों की पहचान अधिकांशतः स्वास्थ्य और परिवार कल्याण मंत्रालय के कार्यक्रमों के तहत गठित जिला प्रारंभिक पहचान केंद्र (डीईआईसी) पर केंद्रित है। आप मुझ से सहमत होंगी/होंगे कि ग्रामीण क्षेत्रों में ऐसी दिव्यांगताओं की पहचान होने से पहले दिव्यांगता के अधिकांश सूचित मामलों को प्रायः नजरअंदाज किया जाता है, और इस कारण पुनर्वास की प्रक्रिया में देरी होती है। यह एक तथ्य है कि जितनी जल्दी दिव्यांगता की पहचान होती है, पुनर्वास और सामाजिक समावेशन का परिणाम उतना ही अधिक होता है। हम महसूस करते है कि जोखिम वाले मामलों की प्रारंभिक पहचान के लिए ग्रामीण और दूरदराज के क्षेत्रों में हमारे नेटवर्क के विस्तार की सशक्त आवश्यकता है। महिला और बाल विकास मंत्रालय की एकीकृत बाल विकास योजना (आईसीडीएस) के आंगनवाड़ी कामगारों, स्वास्थ्य और परिवार कल्याण मंत्रालय के आशा **कामगारों** और अन्य प्री–स्कूल प्राधिकारियों को शामिल करने से यह अंतर दूर होगा। इसके साथ ही स्वास्थ्य और परिवार कल्याण मंत्रालय के डीईआईसी कार्यक्रम को महिला और बाल विकास मंत्रालय के साथ जोड़ने के लिए एक ठोस तंत्र विकसित करने की भी आवश्यकता है ताकि दिव्यांगता के मामलों की प्रारंभिक पहचान को सुनिश्चित किया जा सके।

क्रमशः 2/---------

सत्यमेव जयते

4. उपरोक्त के मद्देनजर, मैं आभारी रहूंगा यदि आप मामलें की जांच कराए और प्रारंभिक अवस्था पर दिव्यांगता के मामलों की पहचान के लिए आंगनवाड़ी कामगारों, आशा कामगारों को शामिल करने के लिए जांच अपने मंत्रालय में समुचित प्राधिकारियों को निर्देश देने के लिए कदम उठाएं। मेरा मंत्रालय इस प्रक्रिया में जुड़ा हो सकता है और आवश्यकता पड़ने पर हम तकनीकी सहायता प्रदान कर सकते हैं। **सादर,**

आपका,

4.6.19

(डॉ0 थावरचंद गेहलोत)

श्रीमती स्मृति जूबिन इरानी
महिला और विकास एवं कपडा मंत्री,
भारत सरकार,
शास्त्री भवन, नई दिल्ली ।

F. No. 16-02/2019 DD- III
Government of India
Ministry of Social Justice & Empowerment
Department of Empowerment of Persons with Disabilities

Dated: 11th November 2019

To,

Principal Secretaries/Secretaries of all States/UTs dealing with empowerment of persons with disabilities

Subject: Early identification and rehabilitation of children with disabilities – need for coordination with Health Department and grassroot level workers such as Anganawadi workers regarding

Sir/Madam,

I am directed to say that RPwD Act, 2016 lays emphasis on early detection of disabilities and appropriate rehabilitation so as to eliminate disability or minimize its severity in children especially in the age group of 0-6 years. This Department had taken up the matter with Union Ministry of Women and Child Development (WCD) requesting them to take steps to involve Anganawadi workers in the process of early identification of disabilities amongst children with disabilities so as to widen the coverage of the programme. Ministry of WCD has recently issued instructions vide letter no. 14-6/2019-CD.I (e-69396) dated 2nd September 2019 (Copy Enclosed) instructing Anganwadi Centres to work under the State Health Department for this purpose.

2. You are requested to follow up with both Women and Child Development and Health departments of your State to ensure early detection of disabilities amongst children especially in the age group of 0-6 years and also facilitate early therapeutic/rehabilitative interventions.

3. It may be noted that National Institutes (NIs) and Composite Rehabilitation Centres (CRCs), which are functioning under this Department have technical expertise in this area of rehabilitation and these organizations are being strengthened to meet the requirement of early detection. For any technical assistance you are requested to approach them.

4. It will be appreciated if you can inform Department of action taken in this regard.

Encl: As Above

(K.V.S Rao)
Director
Tel: 24369054

File No. 16-02/2019 DD- III
Government of India
Ministry of Social Justice & Empowerment
Department of Empowerment of Persons with Disabilities

Dated: 30th October 2019

To,

1. The Directors,
NIEPPD, Delhi, NIEPMD, Chennai, NIEPID, Secunderabad, AYJNISH, Mumbai
NIEVD, Dehradun, SVNIRTAR, Cuttack, NILD, Kolkata

2. In-charge of all CRCs (as per list attached)

Sir,

I am directed to say that early identification of disabilities and appropriate intervention immediate thereafter are vital for effective rehabilitation of persons with disabilities. The National Institutes of the Department though specifically address these issues with respect to a particular category of disability, comprehensive facility is not available to meet the requirement of addressing early identification and intervention in respect of all 21 types of disabilities as recognized under RPwD Act, 2016. This Department should create necessary facilities in our NIs/CRCs before the State Governments/ District Authorities are requested to do the same.

2. While the Department is working on developing a separate National Programme for early identification and intervention at district level, it will take some more time to implement such a programme. Meanwhile, it has been decided to strengthen all the NIs to enable them to have the facilities for early identification and intervention of all categories of disabilities. For this purpose it is suggested that NIs and CRCs functioning under them, may establish early identification and intervention unit alongwith preparatory school for cross cutting disabilities with the facility of multi sensory integration unit within a period of 3 months.

3. The following aspects may be taken into account while establishing early identification and intervention units for ensuring that comprehensive care is provided to all children at one location in an inviting and attractive environment:

a) The unit should have enough space for providing facilities in separate rooms, including:

- Physiotherapy
- Occupational therapy
- Speech and Language Therapy
- Counselling/ Behavioural Support
- Family Education & Training
- Preparatory School
- Waiting Hall and Paediatric Centre

b) The layout of the unit may be aligned at the ground floor (preferably) or first floor with accessible features so as to ensure seamless movement of children with disabilities availing different facilities mentioned at (a) above.

c) The ambience of the unit should be designed with appropriate pictorial and aesthetic presentation to make the unit attractive for children, and

d) Proper sunlight and circulation of air needs to be ensured.

4. Tentative human resource as well as infrastructure requirement for setting up of these units is at **Annexure 1**:

5. It is stated that NIEPMD, Chennai has such an unit which can be replicated by other NIs/CRCs. NIEPMD, Chennai will serve as the mentor organization. Other NIs/CRCs may seek technical advice from NIEPMD, Chennai for establishing such units. The expenditure in this regard should be met from the funds available with the NIs under appropriate head with the approval of EC/GC, as the case may be.

6. It is requested that immediate action may be taken for establishment of early identification and intervention units so as to make such units functional within current financial year. Special efforts may be taken to ensure that quality facilities, care, treatment and support is provided to the children with disabilities and their parents who in-turn would become ambassadors of such centres within the State/Districts for making the child develop school going habits, learning numeracy and literacy that will make him/her independent.

7. It is also requested that the facilities presently available at the institutes/ CRCs for early identification /intervention may be sent to this Department as per the enclosed proforma at **Annexure 2** within a week's time. It may be noted that while establishing the proposed unit, adequate care should be taken to optimize the facilities already available at present.

Encl: As Above

(K.V.S Rao)
Director
Tel: 24369054

ANNEXURE – 1

Features of a model Early Identification and Intervention Unit :-

A. Infrastructural facilities :

a) Electrical fittings and equipment – AC, Fans, Lights, Speaker System, T.V, Refrigerator, Hot Case, Projector and screen ,etc.)

b) Sanitary fittings and utilities - Accessible Toilets, WC, Water dispenser etc.

c) Other utilities – Internet fittings, computers, telephone bills, water bills, electricity bills, consumables like cotton, bandage, gels, electronic chips etc.

d) Upkeep of the building – building maintenance charge, cleaning cost etc.

e) Infrastructure cost – furniture, signage, tactile tiles, the emergency evacuation route, trolleys, examination table, stationary etc.

f) Annual Maintenance Cost

g) Equipment:

- Sensory Integration Unit
- Therapeutic units
- Visual stimulation room
- Speech and Language assessment room
- Special education unit
- Audiometry unit
- Paediatric splinting unit/Prosthesis Unit
- Assessment and therapy rooms
- Psychology tests, unit
- Prosthetic and Orthotic workshop

h) Pre-school Education Area and play/mobility training area

i) I.E.C. and Knowledge management

- Information booklets, Manuals, Modules tools, operational guidelines, S.O. Ps etc. (Content development, graphic designing and engineering and presentation cost)

B. Human resource

- Special Educators for Pre – Schools
- Coordinator/supervisor/H.O. D/ Early interventionist
- Clinical level
- Caregiver level
- Field officer
- Assistant/ housekeeping staff
- Optometrist
- Ear mold technician
- State Nodal officer

Annexure - 2

PROFORMA

(To be filled by all NIs/CRCs in response to Annexure - 1)

1. **Name of the Institute :**
2. **Early Intervention Facility available for (Indicate the category of Disability :**
3. **Whether Multi Sensory Unit is in place or not :**
4. **Details of Equipments available for early identification/rehabilitation units :**
5. **Special School Facility:**
6. **Special Educators, if any :**
7. **Preparatory School, if any :**
8. **Occupational Therapists, if any :**
9. **Social Workers, if any :**
10. **Availability of Physical infrastructure :**

Annexure - D

Model Project Proposal for Establishment of Cross-Disability Early Identification cum Intervention Centre & Preparatory School in NIs & CRCs

Prepared by:

Dr. Himangshu Das *(Director, NIEPMD)*

and

Submitted to:

Department of Empowerment of Persons with Disabilities (DEPwD) Ministry of Social Justice and Empowerment, Government of India.

December, 2019

Index of Content

The Concept

Early childhood is a time of remarkable brain development. It is a critical period that determines a person's ability to reach her/his lifelong health, social and economic potential; as Learning and Development is most rapid during the early childhood years. Providing quality early childhood intervention early in a child's life supports them to develop the skills needed to take part in everyday activities and to be included in family and community life; and can also reduce the amount of supports needed in later life.

Early Intervention provides specialized support and services for infants and young children at-risk or with disability and/or development delay and their families to help their development, well-being and participation in family and community life.

The single-window cross-disability early intervention center will be dedicated to serve children from birth to 6 years of age with a variety of special needs, including, but not limited to: children at-risk, with developmental delay and with disability. The center will provide comprehensive group and individual early intervention services, in parent participation groups, individual sessions and preschool programs; depending upon the child's individual needs; with key focus on developing parents as partners in process of rehabilitation.

Need

The rationale and need behind the establishment of this cross-disability early intervention and education centre, stems from the following facts:

- About 90% of brain development occurs before the age of 3 years.
- After age of 6 years, the brain development is highly restricted.
- Many children at-risk of developing disabilities can be prevented from developing disabilities, if intervened early.
- Early intervention can help reduce impact and severity of disability.
- Associated conditions and additional disabilities can be prevented or reduced with early intervention.
- Appropriate parental intervention can foster proper home-based intervention.
- Parent's coping stage could be facilitated with a quicker movement from shock, denial, anger, bargaining, frustration, and depression to acceptance and empowerment.
- Early intervention can promote inclusion by imparting requisite readiness skills.

Target Group

Primary Target: 0-6 years children at-risk

0-6 years children with developmental delay & disability (cross-disability) Parents/Families of children at-risk, developmental disability, with disabilities (cross-disability)

Project Components

1. **Early Intervention (Junior)**

   This component will provide family-centered services to support the development progress of infants at-risk & children with disability and/or developmental delay.

2. **Preparatory School (Senior)**

   The school will have early childhood special education programs designed to prepare the 0-6 years children with developmental delay & disability (cross-disability) for the regular school setting, help them meet developmental milestones and build skills for community life.

   In all the components, both the child and parent/family at large shall be the key intervention target and benefactors.

Disciplines / Services & Its Functions

[1] **Common Services - Indoor**

(a) Registration and Facilitation Counter:

To enable access to information about services and facilitate the enrolment process, referral services, UDID and Government benefits and concessions; databank of improvement and post-intervention life progress through software based client management system.

(b) Parent Waiting & Resting Area:

To allow parents to rest, engage in peer-group discussion, watch audios and videos for education & training of children with special needs; whilst waiting for their child. This shall dually function as an informal parent information center.

(c) Family Education and Training Unit

A training and education resource center for parents of infants/young children at-risk or with disabilities; to provide them information, support and assistance in their journey of

empowerment. Workshops on aspects of parenting, child-management, clinical aspects, coping, stress-management etc shall be organized.

(d) BM & Counseling Unit:

To facilitate psychological and intervention support to parents and family members of children at-risk or with disabilities. The unit will also provide individualized and group based Behaviour Modification (BM) therapy; under supervision of qualified clinical/ rehabilitation psychologist.

(e) Pediatric Centre:

This will offer comprehensive health services for the beneficiaries, and offer paediatric services, treatment and management of childhood illnesses, nutrition and growth, pediatric neurology and neurodevelopment facilities etc. The center will also offer weekly/fortnightly/ monthly super specialty medical services such as Ophthalmology, ENT, Psychiatry, Neurology, PMR, Orthopedic Surgery, Nutritionist, Pediatric Dentist etc

(f) Feeding & ADL Room:

To provide a comfortable, safe, hygienic and private space for the purpose of personal child care, nursing, feeding and attending other personal needs of the infants, toddlers and young children. Further, the unit will serve as a lab for training in skill for activities of daily living (ADL).

(g) Changing Room:

To provide a room for the use of the parents and/or caregivers, with accessible changing units for changing of diapers/dress etc., seating, sink, toileting and washing facilities & other related equipment.

[2] Common Services - Outdoor

(a) Outdoor Play Area:

A specifically designed play area to enable and provide a safe environment for children with recreational equipment such as seesaw, swing-set, slide, jungle gym, chin-up bars, play-houses, mazes etc.

(b) Sensory/Thera-Park:

This will provide an enclosed area with a range of fauna to touch and smell, and other therapeutically designed swings and activities like planting, den-building, channeling water, playing in mud-kitchen, sand-boxes etc. to enable children to engage in nature play, along with receiving sensorial and therapeutic input.

[3] Early Intervention Services (0-6 years)

(a) Trans-Disciplinary Therapy Unit (Group Therapy):

To provide group based interventions through special education teacher with an integrated input from different professional disciplines like physiotherapy, occupational therapy, speech therapy, psychology etc.

(b) Multi-Sensory Integration Unit:

To provide multi-sensory therapeutic intervention environment to enhance and stimulate sensory development and cognitive function. The unit will be equipped for sensory stimulation of the senses by using sensory modalities like sight, sound, touch, smell, self-motion, taste etc.; especially for vision, tactile and hearing.

(c) Multi-Purpose Activity Unit:

Group events and activities like assembly, yoga, drama, exercise, music, dance etc are key to improve outcomes in communication, language, physical skills, and literacy in the primary years. This unit will be dedicated for such miscellaneous activities.

(d) Virtual Reality Room:

It will feature interactive digital learning resources, that children can use to experience simulated real life situations; and additionally, explore technology for gaining pre- academic skills.

(e) Trans-Disciplinary Therapy Unit (Individual Session):

For individualized intervention with integrated inputs from different professional disciplines like early childhood special education, physiotherapy, occupational therapy, speech therapy, psychology etc. through parent, under the supervision of trained professionals.

(f) Occupational Therapy (OT) Unit:

To offer assessment and intervention for developing, recovering, or maintaining the meaningful activities among children; by use of self-care, play activities and assistive technology to promote and maintain health, prevent disability, increase independent function, and enhance development. The therapy to be provided both in individualized sessions and small groups.

(g) Physio Therapy (PT) Unit:

To restore, maintain and maximize the strength, function, movement, and overall well- being of children. The individualized or small group sessions to be given for optimal physical development by means of mobilization, stretching, therapeutic exercises, posture education etc.

(h) Speech Therapy (ST) & Language Intervention Unit

To help address speech, language problems and communication issues faced by the child due to her/his disability or developmental delay. Audiological evaluation based hearing aid will be provided, along with training for the use of hearing aid. Alongside in individual or small-group settings, as per requirement the strategies/techniques for drooling- control; feeding issues and oral-motor training; Auditory Verbal Therapy; Augmentative Alternative Communication; shall be used.

(i) Indoor Play Therapy Unit:

An extensive indoor play space to climb, jump, run and crawl through with therapeutically and aesthetically designed environment and activities.

[3] **Preparatory School Services (3-6 years)**

All the classrooms will feature key areas of learning and banks of accessible resources. Following classroom/groups are suggested:

(a) Preparatory Classroom 1 (Junior):

This unit will cater to 10 students with special needs (cross-disability). The interventions will be focused to lay an early year's foundation, through maintenance of good health and

wellbeing; encouraging effective communication; and providing opportunities to explore immediate environment.

(b) Preparatory Classroom 2 (Senior):

This classroom will also cater to 10 students with special needs (cross-disability). The education is focused on development of good habits, gross motor skills, body and special awareness; reading readiness; writing readiness; sensory development etc.

Possible merging of Units, in case sufficient space is not available.

[1] Common Services - Indoor

(a) Family Education and Training Unit & BM & Counseling Unit

(b) Feeding, ADL Room & Changing Room

[2] Common Services - Outdoor

(a) Outdoor Play Area & Sensory/Thera-Park

[3] Early Intervention Services

(a) Trans-Disciplinary Therapy Unit (Group Therapy) & Multi-Sensory Integration Unit

(b) Multi-Purpose Activity Unit & Indoor Play Therapy Unit

(c) OT Unit & PT Unit

[3] **Preparatory School Services**

Depending on number of students enrolled,

(a) Preparatory Classroom 1 (Junior) & Preparatory Classroom 2 (Senior): Class Capacity not exceeding 12.

Project Capacity

Early Intervention: Full-Time Enrolled Students: 16 (0-6 years)

Trans-Disciplinary Therapy Unit (Group): 08 students Trans-Disciplinary Therapy Unit (Individual): **08 students**

OPD services (New + Follow-up): **Total 400 per month** (Average of 20 per day)

(0-8 years) Session-basis/Part-time students

Preparatory School: Total 20 (Full-Time enrolled students)

(2 classrooms with 10 children with special needs each)

Impact Expected

Following is a list of expected impacts with the interventions based on this model:

- Early screening and early detection of children.
- Substantial number of infants and young children at-risk for developing disabilities will develop to be typical children.
- Reduction in severity and impact of disability in children.
- Substantial improvement in functioning level of children.
- Substantial reduction in additional and associated disabilities.
- Inclusion readiness skills will substantially improve.
- Parent coping skills will improve and they would become empowered.
- Enhanced participation of Parents as Partners in process of rehabilitation.
- Psychologically better equipped children to learn life skills.

Outcome Indicators

1. Boosted early screening and early detection of children.
2. Enhanced development of infants and toddlers at-risk and with disabilities.
3. Reduced educational costs by minimizing the need for special education through early intervention.
4. Minimized likelihood of institutionalization, and maximized independent living.
5. Enhanced capacity of parents/families to meet their child's needs.

Vertical Programme Link

- Expected to enroll maximum children into Samagra Shiksha Abhiyan schools or inclusive public school
- Students with High-Support Needs may get into home-based education/ schooling or enroll into special school, with better equipped skills
- These divyang children may later be a part of PM's skill training mission.

Salient Features

- Screening and Early Detection.
- Caters to all Range of Disability include Borderline and At-Risk Children.
- Caters to Cross-Disability (any positive or negative deviations including High-Support Need children).
- State-of-the-Art Protocol, Method, Strategies and Technology support.
- Referrals & Facilitation as single-window for Services, Investigation, Certification and Benefits & Concessions.
- Aesthetically Designed for Infant & Young Children.
- Caters to Parental Needs towards Empowerment.
- Inbuilt protocol to build Readiness towards Inclusion.
- Psychologically comforting for Child and the Parent.
- Caters to vertical programme for Schooling.
- Provision for Phased Development.

Operational Protocols

Curriculum:

The Early Years Foundation Stage will include 7 areas of learning. The three prime areas are:

- Communication and Language
- Physical Development
- Personal, Social and Emotional Development

In addition, children will be supported in four specific areas, including:

- Readiness for learning Literacy (Pre-Literacy)
- Readiness for learning Mathematics (Pre-Mathematics)
- Understanding the world
- Expressive arts and design

The above areas of learning are linked through an inter-disciplinary approach. And a balance between child-centered and adult-directed activities, with a differentiated curriculum to meet the needs of individual children at different stages of their development will be ensured.

Admission: To make it a model for early intervention and early education, it is desirable that the categories of disability and severity should be open and not restricted. Admissions to be provided primary target of 0-6 years at-risk children and 0-6 years children with developmental delay & disability.

Parent Committee: A parent body with representatives of parent of child with different special needs, including sensory disability, locomotor disability, developmental disability to be formed.

Parental involvement: This center will be a parent-centered model; where parents, with guidance and supervision of professionals will lead the intervention programs to help the children grow and develop into confident young people.

Software Management: The data of assessment, case-history, intervention program, evaluation and family history etc; to be digitally managed through software.

Classroom Safety: The children's physical safety is the prime responsibility; indoor safety requires careful planning, record keeping and maintenance of materials and equipment.

Classroom Adaptations: When the classroom environment doesn't meet the specific needs of a special child, adaptations must be made to accommodate that child's individual needs; with regard to the physical settings of the classroom and classroom processes. Changes in lighting,

noise level, visual and auditory input, physical arrangement of the room or equipment, and accessibility of materials are important considerations for adaptation.

Suggested Day's Schedule: Based on the selected pedagogical approach i.e. theme-based, activity-based, project/enquiry-based or the integrated approach; the teacher may plan activities and experiences using the given activity schedule

ACTIVITIES	METHOD OF TRANSACTION
Circle Time (Attendance, Conversation, Rhymes, Book reading, Calendar activity, Hygiene check, Prayer etc)	Teacher initiated large group activity
Environmental Awareness / Math Readiness	Teacher guided small group activity
Indoor Free Play in activity areas	Child initiated small group activities
BREAK / SNACK TIME	
Emergent and Early Literacy Activities (Story-Telling, Rhymes, Conversation, Dramatic/ Role Play)	Teacher initiated large/small group activity
Creative activities	Child initiated small group activity
Outdoor Play	Child/Teacher initiated
Good Bye Circle	Teacher initiated large group activity.

School Hours: 05 hours

(In view of the timings of the National Institutes and Composite Regional Centers, school timings from 09:00am to 02:00pm is suggested)

Holidays:

04 weeks of Summer Break02 weeks of Winter Break

As per State/Central Government holiday list

Project Requirements; Space
(SUGGESTIVE ONLY)

S#	Services	Quantity	Unit Size	Total Size	Remarks
COMMON SERVICES - INDOOR					
1	Registration & Facilitation Counter	01	200 Sq.Ft.	200 Sq.Ft.	-
2	Parent Waiting Area	01	200 Sq.Ft.	200 Sq.Ft.	May be increased
3	Family Education & Training Unit	01	350 Sq.Ft.	350 Sq.Ft.	Can be clubbed in case of lack of space
4	BM & Counseling Unit	01	200 Sq.Ft.	200 Sq.Ft.	
5	Pediatric Centre	01	150 Sq.Ft.	150 Sq.Ft.	
6	Feeding & ADL Room	01	250 Sq.Ft.	250 Sq.Ft.	Can be clubbed in case of lack of space
7	Changing Room	01	100 Sq.Ft.	100 Sq.Ft.	
COMMON SERVICES - OUTDOOR					
8	Outdoor Sports Arena	01	2,000 Sq.Ft.	2,000 Sq.Ft.	Can be clubbed in case of lack of space
9	Sensory/ Thera-Park	01	2,000 Sq.Ft.	2,000 Sq.Ft.	
EARLY INTERVENTION SERVICES					
10	Trans-Disciplinary Therapy Unit (Group)	01	800 Sq.Ft.	800 Sq.Ft.	Can be clubbed in case of lack of space
11	Multi-Sensory Integration Unit	01	800 Sq.Ft.	800 Sq.Ft.	
12	OT Unit	01	300 Sq.Ft.	300 Sq.Ft.	Can be increased/ clubbed as per availability of space
13	PT Unit	01	300 Sq.Ft.	300 Sq.Ft.	
14	ST & Language Intervention Unit	01	200 Sq.Ft.	200 Sq.Ft.	

15	Trans-Disciplinary Therapy Unit (1:1)	01 hall with 6 partitions	600 Sq.Ft.	600 Sq.Ft.	
16	Multi-Purpose Activity Unit	01	600 Sq.Ft.	600 Sq.Ft.	Can be clubbed in case of lack of space
17	Indoor Play Therapy Unit	01	600 Sq.Ft.	600 Sq.Ft.	
18	Virtual Reality Room	01	400 Sq.Ft.	400 Sq.Ft.	
PREPARATORY SCHOOL SERVICES					
19	Preparatory Classroom 1 (Junior)	01	500 Sq.Ft.	500 Sq.Ft.	Depending on number of student enrolled, these may be clubbed. Class Capacity not exceeding 12.
20	Preparatory Classroom 2 (Senior)	01	500 Sq.Ft.	500 Sq.Ft.	

Project Requirement; Human Resource: Full-Time
(SUGGESTIVE ONLY)

S#	Services	Staff Strength	Monthly	Total Size
COMMON SERVICES – INDOOR				
1	Project Coordinator	Clinical/Rehab. Psychologist to dually function as coordinator		-
2	Registration & Facilitation Counter	CBID Worker – 01	18,000	2,16,000
3	Parent Waiting Area	NIL	-	-
4	Family Education & Training Unit	NIL	-	-
5	BM & Counseling Unit	Clinical / Rehab. Psychologist – 01	60,000	7,20,000
6	Pediatric Centre	Nurse – 01	20,000	2,40,000

7	Feeding & ADL Room	Trained Caregiver -01	20,000	2,40,000
8	Changing Room	NIL	-	-
	COMMON SERVICES – OUTDOOR			
9	Outdoor Sports Arena	NIL	-	-
10	Sensory/ Thera-Park	NIL	-	-
EARLY INTERVENTION SERVICES				
11	Trans-Disciplinary Therapy Unit (Group)	ECSE Teacher – 01 Trained Caregiver:01	30000 20000	3,60,000 2,40,000
12	Multi-Sensory Integration Unit	ECSE Teacher – 01	30000	3,60,000
13	OT Unit	NIL	-	-
14	PT Unit	NIL	-	-
15	ST & Language Intervention Unit	NIL	-	-
16	Trans-Disciplinary Therapy Unit (1:1)	ECSE Teacher – 01	30000	3,60,000
17	Multi-Purpose Activity Unit	ECSE Teacher – 01	30000	3,60,000
18	Indoor Play Therapy Unit	Trained Caregiver:01	20000	2,40,000
19	Virtual Reality Room	NIL	-	-
PREPARATORY SCHOOL SERVICES				
20	Preparatory Classroom 1 (Junior)	ECSE Teacher – 01 Trained Caregiver – 01	30000 20000	3,60,000 2,40,000
21	Preparatory Classroom 2 (Senior)	ECSE Teacher – 01 Trained Caregiver – 01	30000 20000	3,60,000 2,40,000
TOTAL (FT):				

Human Resource: Part-Time & Guest/Visiting
(SUGGESTIVE ONLY)
May differ from Project-to-Project depending on No. of Children & Units

S#	Services	Staff Strength	Monthly	Total Size
COMMON SERVICES – INDOOR				
1	Project Coordinator	Clinical/Rehab. Psychologist to dually function as coordinator		-
2	Registration & Facilitation Counter	NIL	-	-
3	Parent Waiting Area	NIL	-	-
4	Family Education & Training Unit	CBID / Social Worker Staff – 01	1 visit of 3hrs per week @1,500/-	78,000 (52 weeks/ year approx.)
5	BM & Counseling Unit	NIL	-	-
6	Pediatric Centre	Pediatrician – 01 Visiting Consultants (Ophthalmology, E & T, Psychiatrist, Neurologist, PMR, Orthopedic Surgeon, Nutritionist, Pediatric Dentist)	2 visit of 3hrs per week @2,500/- 1 consultancy visit of 2 hrs per month @3,000/-	2,60,000/- 2,88,000/-
7	Feeding & ADL Room	NIL	-	-
8	Changing Room	NIL	-	-
COMMON SERVICES – OUTDOOR				
9	Outdoor Sports Arena	NIL	-	-
10	Sensory/ Thera-Park	NIL	-	-

EARLY INTERVENTION SERVICES				
11	Trans-Disciplinary Therapy Unit (Group)	NIL	-	-
12	Multi-Sensory Integration Unit	NIL	-	-
13	OT Unit	Occupational Therapist: 01	Daily 3hrs visit @900/-	18,000/mnth 2,16,000 p.a.
14	PT Unit	Physiotherapist: 01	Daily 3hrs visit @900/-	18,000/mnth 2,16,000 p.a.
15	ST & Language Intervention Unit	Speech Therapist: 01	Daily 3hrs visit @900/-	18,000/mnth 2,16,000 p.a.
16	Trans-Disciplinary Therapy Unit (1:1)	NIL	-	-
17	Multi-Purpose Activity Unit	NIL	-	-
18	Indoor Play Therapy Unit	NIL	-	-
19	Virtual Reality Room	NIL	-	-
PREPARATORY SCHOOL SERVICES				
20	Preparatory Classroom 1 (3-4 yrs)	Activity Teacher – 01 (Music, Dance, Drama, Art & Craft etc)	2 visit of 3hrs per week @1,000/-	1,04,000 (52 weeks/ year approx.)
21	Preparatory Classroom 2 (4-5 yrs)			
TOTAL (PT):				

Other Outsourced Jobs:
(SUGGESTIVE ONLY)

Job	Approx. Monthly Cost per person	Approx. Monthly Cost in Total	Annual Expense
MTS for Admin.	18,000	54,000	6,48,000
Security (1 x 3nos.)	18,000	54,000	6,48,000
Housekeeping (2 nos.)	18,000	36,000	4,32,000
Transport (3 nos.) - **Optional** In full capacity 3 vehicles (25seater) may be necessary to fly on 3 different routes	80,000 (per vehicle)	2,40,000	28,80,000
TOTAL (OS):			46,08,000

Budget could be worked out as under:
As per project size Recurring Expenses - Salaries

S#	Particulars	(Annual expenses in Rupees)
1	Staff: Full-Time	
2	Staff: Part-Time	
3	Guest / Visiting/ Consultants	
	Total Salaries:	

Recurring Expenditure - Other than Salaries

S#	Particulars
1	Maintenance of Machinery & Equipment
2	Journal, Magazine & Newspaper
3	Books
4	Contingency
5	TA/DA and Fuel

6	Students Books, Stationery and Uniform
7	TLM
8	Telephone/ Internet
9	Photocopy/Printing
10	Events for CWSN
11	Events for Parents
12	Other Miscellaneous
13	Admission of students
14	Staff training
15	Housekeeping
16	Security

Non-Recurring Expenses (SUGGESTIVE ONLY)

Budget may be worked out as per project size for each of the unit, under the heads of: **Wall décor, flooring, F&F, equipment, TLM**

S#	Domain/Area	Furniture & Fixture	Equipment	Wall Décor & Flooring	TLM
1	Registration & Facilitation Counter				
2	Parent Waiting Area				
3	Family Education & Training Unit				
4	BM & Counseling Unit				
5	Pediatric Centre				
6	Feeding and ADL Room				

7	Changing Room				
8	Accessible Lavatories				
9	Outdoor Sports Arena				
10	Sensory / Thera-Park				
11	Trans-Disciplinary Therapy Unit (Group)				
12	Multi-Sensory Integration Unit				
13	OT Unit				
14	PT Unit				
15	ST & Language Intervention Unit				
16	Trans-Disciplinary Therapy Unit (1:1)				
17	Multi-Purpose Activity Unit				
18	Indoor Play Therapy Unit				
19	Virtual Reality Room				
20	Preparatory Classroom 1 (3-4 yrs)				
21	Preparatory Classroom 2 (4-5 yrs)				
22	Preparatory Classroom 3 (5-6 yrs)				

Summary of Total Budget

Budget may be worked out as per project size under following heads.

Non-Recurring Expenses

(Rupees in Lakhs)		
S#	Particulars	Total
1	Equipment	
2	F & F	
3	Wall Décor & Flooring	
4	TLM	
	TOTAL:	

Recurring Expenses

(Rupees in Lakhs)		
S#	Particulars	Total
1	Salaries – Full Time	
2	Salaries – Part Time / Visiting	
3	Outsourced Jobs	
4	Other than salaries	
	TOTAL:	

Note:

(1) This is a suggestive project outline to be used for preparation of proposal by all NIs and CRCs. It is based on space and other resource availability. The annexure of lists is also suggestive only, and as per expertise of the NIs, it may please be edited, added, deleted, modified etc. and it may be implemented in a phased manner.

(2) Suggestive list of equipments etc will be provided by NIEPMD, Chennai, separately.

(3) The project may be submitted for EC's approval.

Notes

"….. All the State Governments are requested to set up such early intervention centres in all Districts…."

Dr. Thaawarchand Gehlot
Union Minister of Social Justice and Empowerment

I am hopeful that the rehabilitation practitioners and other stakeholders will find this Handbook very useful

Krishan Pal Gurjar
Union Minister of State of Social Justice and Empowerment.

"……Through these Early Intervention Centres providing cross- disabilities rehabilitative services, all-out efforts will be made to improve the sensory, motor and cognitive skills of the child optimally so as to cater to the demands of the children with disabilities in their daily living activities and prepare them for schooling……."

Shakuntala Doley Gamlin
Secretary, DEPwD, GoI

Leaving no one Behind